MoPAct

Mobilising the Potential of Active Ageing in Europe

## WP8 Overview Report

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# Social support and long-term care in EU care regimes

Framework conditions and initiatives of social innovation in an active ageing perspective

**Final draft**
**August 2014**

Funded by the European Commission's Seventh Framework Programme FP7-SSH-2012-1/No 320333
www.mopact.group.shef.ac.uk

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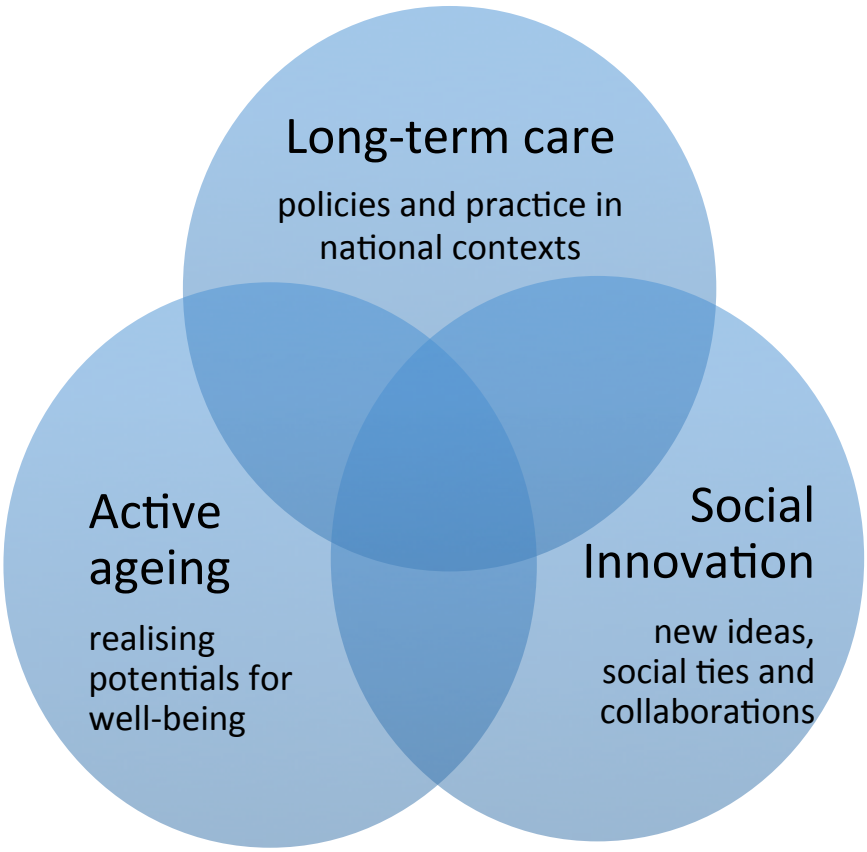
# 1 Introduction

The countries of Europe are ageing, yet at a different pace and with huge differences in political, cultural, social and economic framework conditions. This is particularly true, when it comes to address the needs of older people who are suffering from chronic and often multiple diseases, with physical, mental and/or cognitive impairments. Although this group of the population is steadily rising, services, facilities and related policies with respect to their social and health support are only slowly developing. Indeed, neither the rhetoric of active ageing nor the current discourse on social innovation are considering the area of social support and long-term care as a major source for new ideas and positive change in the social construction of old age. This report contributes to the MOPACT project and sets out to correct this image and will therefore fulfil two main tasks:

- Firstly, the different approaches to fund, organise and regulate long-term care regimes across Europe will be described, compared and analysed.
- Secondly, opportunities for and on-going practice of social innovation will be identified and analysed in the context of different national realities.

Figure 1.1 depicts the area of concern, where active ageing, social innovation and long-term care should theoretically meet to realise enhanced policies and practice in long-term care through new ideas and related change processes. Given the on-going debates on definitions and approaches that are characterising each of these notions it is initially necessary to outline our understanding of emerging LTC systems across Europe as well as of 'active ageing', 'social innovation' and 'care regimes'.

**Figure 1.1 Searching for opportunities of social innovation and active ageing in long-term care**



### 1.1 Defining long-term care

Long-term care (LTC) as a system at the interface between health and social care, and between formal and informal care, is only just emerging as a specific area of social protection and support (Leichsenring et al., 2013). This becomes most visible by the fact that the majority of all LTC activities (on average around 80%) are carried out by informal carers, mainly by women as partners or daughters. While residential care facilities in Europe are hosting an average of not even 5% of older people over 65 years, all other formal LTC services – from home care in the community to intermediate facilities and service housing – are reaching between 20% of this age group in the Netherlands and no more than 4% in Portugal (Rodrigues et al., 2012: 86).

Specific criteria to delineate LTC from pure social and/or health care entail, among others, the following characteristics:

- continuity of care and mechanisms to overcome barriers at the interfaces between social and health care are addressed
- clients' needs are at the centre of all interventions
- multidisciplinary work is a value and principle
- incentives to improve cooperation between health and social care facilities or services (e.g. financial, contractual advantages) are in place
- relevant information is efficiently transferred between services or agencies, e.g. by means of a joint care plan based on a dialogue with users/patients and their informal network
- individual care needs are assessed by a multidisciplinary team (with multidisciplinary methods)
- individual capacities of users/patients are enabled and strengthened
- quality assurance is guaranteed, at best across health and social care services and/or facilities
- agreements between services and/or organisations are based on contracts
- IT and communication technology are used to facilitate the communication between services and between different professional groups (e-health, e-care, ambient assisted living)
- conditions for the involvement and participation of users/patients and carers are ensured (e.g. shared decision-making)
- multi-disciplinary teams are established, supported and continuously trained
- an integrated access point (e.g. concerning referral, financial issues, payment regulation, one-stop-shops) is available
- integrated discharge and follow-up planning is fostered (mainly for residential and/or hospital-based facilities)
- case management is carried out by trained and specialised staff with relevant job-profiles

In addition to these specific characteristics, the following general issues concerning organisation and management should be addressed by LTC organisations:

- equal access (considering culture, gender and class) is guaranteed to all citizens
- leadership and management capacities are enhanced through appropriate training
- funding is ensured by defined budgets
- involved staff is participating regularly in advanced and further training
- IT and communication technology are used to make administration more efficient

- evaluation studies concerning structures, processes and outcomes are carried out and available
- outcome indicators are used to measure and further develop the initiative
- quality management serves to implement continuous improvements

Based on this definition of LTC, this report aims at investigating opportunities for active ageing (1.2) and social innovation (1.3) in selected EU Member States representing different types of 'care regimes' (1.4).

## 1.2 Linking 'Active Ageing' and long-term care

The general WHO-definition defines 'Active Ageing' as "the process of optimizing opportunities for health, participation and security in order to enhance quality of life as people age. It allows people to realise their potential for wellbeing throughout their lives and to participate in society according to their needs, desires and capabilities, while providing them with adequate protection, security and care when they need assistance" (WHO, 2002: 12). People in need of LTC are, by definition and particularly in the case of heavy physical, mental or cognitive constraints, challenging the active ageing paradigm, even if empowerment and enabling strategies that help older people (and their relatives) and make the most out of their respective situation are enshrined in this framework. Active ageing approaches must therefore include strategies to extend healthy life expectancy and quality of life for all people as they age including those who are frail, disabled and in need of care, and promoters of 'Active (and Healthy) Ageing' have conspicuously taken on board the issues of 'cure and care' (see for instance the European Year 2012, but also the European Innovation Partnership on Active and Healthy Ageing). Still, it should be avoided that 'Active Ageing' turns into a prescriptive norm that discriminates against those who, for whatever reason, are not able to age in an active and healthy manner (Ruppe, 2011). As a corollary, the potential of active ageing will have to be assessed in a slightly distinct way when it comes to LTC as against, for instance, activation strategies in employment, active citizenship and health promotion (see also Walker and Foster, 2013):

- First, a large number of older people are already very active in caring for a partner with LTC needs. This activity is in many cases endangering health and well-being of carers themselves – active and healthy ageing in this case means to provide respite, counselling and proactive strategies to support carers and avoid care-related stress.
- Secondly, access to prevention, rehabilitation and other formal care services is most unevenly distributed – eligibility criteria often leave ample margins of discretion, and the fragmented schemes and service provisions are frequently unknown to potential beneficiaries– also in this case multi-stakeholder collaboration and client-centred interventions are necessary to prevent a deterioration of living conditions by supporting different needs and preferences in the respective national and cultural context.
- Thirdly, active ageing in the context of LTC is, perhaps more than in other areas, dependent on social investment strategies across a range of policy fields. For instance, there are ample margins for organisational improvements in terms of coordination with health systems, for promoting 'carer-friendly' employment policies and for designing user-friendly ICT applications to enable social participation and solidarity. Apart from obligations to take advantage of these opportunities and remain active, these strategies have to be based on rights to social protection and other forms of social welfare, thus combining top-down and bottom-up initiatives that enable people to develop their own forms of activity.

- Finally, active ageing should involve inter-generational solidarity and fairness between generations with an emphasis on activities that span across generations.

It should be clear by this point that active ageing involves a life-course perspective and must be seen as a lifelong process, rather than as mere participation in the labour market and production processes. Indeed, active ageing is intrinsically linked to re-production processes in the economic sense of the term, on an individual, community and societal level.

### 1.3 Conceptualising 'Social Innovation' in the context of long-term care

In general, social innovations are "new ideas (products, services and models) that simultaneously meet social needs (more effectively than alternatives) and create new social relationships or collaborations" (European Commission, 2011; see also Murray et al., 2010). Social innovation is needed because societies are in a period of transformative innovation due to the role of technology (particularly ICT), the influence of culture and values (putting people first with a greater democratic choice) and the disjunction between current institutions and the requirements of new ones (Murray et al., 2010). It is therefore necessary to find "acceptable progressive solutions for a whole range of problems of exclusion, deprivation, alienation, lack of wellbeing" (Moulaert et al., 2013: 16) that have come about as a result of fast-evolving social dynamics, though at a very different pace in individual jurisdictions.

Given the nascent state of its development, LTC is an area with a wide range of opportunities for such processes, in particular with respect to 'new types of public services', 'new business models', 'new forms of organisation in the public, not-for-profit and in the private sectors' as well as in creating 'novel interactions between the public sector, third sector, social enterprises, the social economy, economic operators and civil society'. Indeed, 'changes in rules and regulations (e.g. concerning the access to financial benefits) and in governance (forms of democracy and decision making on priorities in welfare and cohesion politics) are likewise important fields for social innovations that should not be neglected' (Evers and Ewert, 2013: 7).

This report will highlight and analyse a number of initiatives in LTC that realise such opportunities for social innovation in the LTC sector as they meet (at least two of) the following conditions (cf. Heinze and Naegele, 2012):

- *They are oriented towards exceptional societal challenges/social issues:* if an initiative is addressing LTC needs this condition is almost automatically fulfilled because there is no doubt that LTC is and will remain an exceptional societal challenge.
- *They suggest new solutions in the respective societal, cultural and economic context*: given the different developmental stages, resources and pathways that characterise LTC policies in Europe, the process of social innovation may be put in practice in various ways according to social, cultural and economic preconditions.
- *They create new patterns of social practices to overcome shortcomings of traditional arrangements*: To fulfil this condition, innovative initiatives in LTC must be able to show their ability to address traditional bottlenecks and to implement new solutions (products or services).
- *They tend to overcome the traditional dichotomy between technological and social innovations*: The use of information and communication technologies (ICT) per se is not sufficient to qualify

initiatives in LTC as socially innovative. LTC is not just a new 'market' for ICT applications, but technology must be embedded into the social context, they must be compatible with users' skills and expectations, and they need to involve users in the development and deployment of ICT solutions.

- *They promote the integration and/or collaboration of heterogeneous stakeholders that have hitherto not co-operated*: LTC is an area of complex relationships between various stakeholders, where everybody is 'doing his/her best', but often with counterproductive results as the people involved do not communicate sufficiently. Opportunities for social innovation in LTC are therefore manifold if initiatives can be identified that bring together representatives of organisations, groups or sectors that have hitherto not been considered as relevant co-producers of LTC.
- *They include reflective and multidisciplinary approaches towards the key goal of societal usefulness*: This condition is closely linked to the above as it can be assumed that initiatives in LTC with the aim to improve shortcomings will be based on reflection and the cooperation of people from different disciplines.
- *They create structures and processes that are sustainable and realise new growth potentials in terms of regular employment*: This is one of the most difficult conditions to be realised by social innovations in LTC as their realisation does not only depend on the individual initiative. However, it should be considered whether stakeholders involved are or are not in the position to have developed strategies to carry the initiative beyond a piloting (project) phase.
- *It involves end-users as co-producers of services or products*: This condition is crucial for an initiative to qualify as social innovation. As one of the characteristics of LTC services consists in the fact that beneficiaries (and their carers) are almost by definition co-producers of such services, initiatives should also show their ability to really involve these end-users in the quality development (planning, implementation, monitoring, improving) of services and products.

Finally, social innovation may take place on different scales and scopes. Initiatives may focus on a micro-scale development, e.g. changing relations between individuals and small groups, or they may be designed on a macro-scale (relations between groups) leading to systemic change (Garcia et al., 2010). This implies considering differences between countries or 'care regimes' not only in their approach to LTC, but also in the degree to which they support the circumstances necessary to nurture social innovation in LTC specifically. These issues will be addressed in the ensuing section.

### 1.4 'Care regimes' as an analytical tool to compare different approaches to long-term care

It has already been mentioned that societal, cultural and economic preconditions as well as political legacies and pathways are shaping the state of this sector, namely how LTC and related societal needs are being addressed, regulated and served in individual countries. International comparisons therefore need to describe and analyse differences and commonalities, respectively, in order to identify typologies and their meaning in terms of outcomes and, as in the case of this paper, opportunities for active ageing and social innovation. Related exercises have often relied on Esping-Andersen's seminal work *The three worlds of welfare capitalism* (Esping-Andersen, 1990) as a starting point. Although the area of long-term care was not mentioned in this context, the distinction between Liberal, Conservative and Social Democratic ideal types of welfare states provides a first orientation of the general characteristics of welfare states in terms of decommodification, social stratification and the public-private mix in welfare provision. Following a number of criticisms and

further development, new ideal types were added, e.g. the 'Mediterranean' or 'Southern' welfare regimes (Ferrera, 1996;Bonoli, 1997) as well as the 'Transition countries' of Central and Eastern Europe (Fenger, 2007).

In addition, particularly in reaction to the feminist critique new analytical categories were added such as the degree of defamilisation[1] and the relationship between benefits in kind and in cash (Bambra, 2007; Kautto, 2002). Related policy domains were also eventually included, in particular health policies (Bambra, 2005) and care policies (Bettio and Plantenga, 2004). The latter resulted in a new debate about typologies of 'care regimes' with different clusters of countries depending on the categories chosen. For instance, Lamura et al. (2007) identified five typologies – by considering both care demand elements (such as its quantity and the role of poverty-driven factors) and factors affecting the supply of (formal and informal) care – which Nies and colleagues (2013) adapted to reach a four-regime typology (Table 1.1). Similarly, Kraus et al. (2010) distinguished four clusters that, however, embrace very different groups of countries, as a focus is put on private funding and access or coverage, respectively (Table 1.2).

***Table 1.1*** **A typology of European long-term care regimes**

| | *Demand for care* | *Provision of informal care* | *Provision of formal care* | *Countries* |
|---|---|---|---|---|
| *Standard-care mix* | Medium/high | Medium/low | Medium | Germany, Austria, France, UK |
| *Universal-Nordic* | Medium | Low | High | Sweden, Denmark, The Netherlands |
| *Family based* | High | Low | Low | Spain, Italy, Portugal, Ireland, Greece |
| *Transition* | Low | High | Medium/low | Hungary, Poland, Czech Republic, Slovakia, Romania, Bulgaria, Estonia, Latvia, Lithuania |

*Source:* adapted from Lamura,2007; Nies et al., 2013.

***Table 1.2*** **A new typology of European long-term care regimes**

| | *Nature of the system* | *Characteristics* | *Countries* |
|---|---|---|---|
| *Cluster 1* | Informal care oriented, low private financing | Low spending, low private, high informal care use, high informal care support, cash benefits modest | Czech Republic, Germany, Slovakia, (Belgium) |
| *Cluster 2* | Generous, accessible and formalised | High spending, low private, low informal care use, high informal care support, cash benefits modest | Denmark, The Netherlands, Sweden |
| *Cluster 3* | Informal care oriented, high private financing | Medium spending, high private, high informal care use, high informal care support, cash benefits high | Austria, England, Finland, France, Spain |
| *Cluster 4* | High private financing, informal care seems a necessity | Low spending, high private, high informal care use, low informal care support, cash benefits medium | Hungary, Italy |

*Source:* Kraus et al. 2011.

[1] Analogous to 'de-commodification', Esping-Andersen's central category to distinguish the performance of different welfare regimes, 'de-familisation' describes the degree to which social and family policies help reduce responsibilities of families, in particular women, to provide care and support to other family members.

While the characteristics of care regimes are constantly changing and depend on the social, economic and health care systems in individual countries, recent studies highlight the presence of converging trends in Europe. Beside existing variations related to specific contextual, institutional and cultural settings of care, it has been observed that European care regimes are undergoing a process of convergence towards commodification, with the consequent rise of a more market-driven care provision (Williams, 2012). For instance, many countries across Europe have acknowledged long-term care as a social risk by specific legislation, e.g. with respect to informal carers or the introduction of cash benefits (OECD, 2011b), and notwithstanding increasing constraints on public budgets, employment in health and social care has steadily grown. In the context of market-oriented governance, these new approaches also triggered the extension of the care mix, promoting a greater role for the private sector and for market mechanisms in care provision and organisation (Salis, 2013).

However, the specific 'care culture' and legacies – as well as contingent factors such as, for instance, the relative vicinity of lower-income economies – contributed to new types of care provision by migrant care workers who are directly employed by families, often in a 'grey' area of labour or straightforwardly under 'illegal' conditions. This applies not only to Mediterranean countries – where a large number of migrant care workers are directly employed by families - but also to an increasing number of Western European countries (e.g. Austria, Germany). This tendency can only partially be explained by the presence of (flat-rate) cash benefits. It is mainly derived from the specific 'culture of care' prevailing in each country, as reflected by the main political strategies, be they implicit or explicit. This add-on to the traditional care mix in several countries has driven some scholars to hypothesise the rise of a new type of care regime, i.e. that of the 'migrant-in-the-family' model (Da Roit, 2010; van Hooren, 2011).

Furthermore, migrants are also playing an increasingly important role in the formal care workforce, where they are often overrepresented in agency-based care due to financial constraints and low wages paid in this sector. Migration issues thus have become an additional factor to be considered when it comes to future strategies in the area of active ageing and long-term care both with respect to the supply of labour and with respect to patterns of demand, e.g. by migrants of the first and second generation ageing as pensioners in their host countries.

Given the liveliness of the debate described above, the attempt to find common ground for one, comprehensive typology of care regimes reveals a number of issues. To begin with, long-term care is an emerging area of social protection and the sector remains subject to continuous changes, both on a national level and indirectly influenced by supra-national (EU) regulations. In addition, the methodology by which countries are grouped together depends on the dimensions and criteria that have been chosen to describe and compare national long-term care systems (see Table 1.2). Though there may be notable similarities between the countries of each cluster, especially in terms of national-level policy approaches and the general balance between levels of (de)familisation versus commodification, even countries within the same cluster diverge from one another when elements of their care systems are looked at in greater depth. For example, though informal care by family members is the most prevalent model in all countries, the Family-based care regime has been thus named precisely because of the perception that care provided by family members is not only widespread, but that its LTC systems revolve around a reliance on and implicit or explicit expectation of family care. However, closer examination of the precise mix of services reveals that, while for instance Italy has comparatively high levels of public expenditure and that informal carers are

increasingly being supported by formal services/benefits (mainly cash benefits), and supplanted by migrant carers. Other examples include the Transition countries which show a large variance in patterns of expenditure for LTC, and Germany and Austria of the Care-mix regime which have very different funding mechanisms. This is all to say that no one typology of care regimes can fully capture the variation in LTC systems across countries, but rather that it can be a useful tool with which to begin to disentangle and analyse complex care mechanisms. To carry out the analyses addressed in this paper we use a mixed approach, which defines care regimes not only according to tradition.

For organisational purposes and to provide a point of departure from which to discuss similarities and differences between LTC systems, the typology developed by Lamura et al. (2007) and adapted by Nies and colleagues (2013) will be adopted with slight modifications due to the country sources available. This typology has been chosen as a starting point for it takes both the factors influencing need for care as well as provision of services into account, factors which may also prove to be drivers of social innovation in the sector. The countries covered in this paper are therefore loosely grouped into four care regimes: Universal, Care-mix, Family-based, and Transition (see section 1.5 Structure and methods). This paper will test existing typologies and add more information, in particular in relation to Central and East European countries (CZ, SK, HU, EE, LT, LV, BG, RO), to better show convergences and differences between (and within) care regimes. In particular, the following indicators will be used:

**Governance and financing**

- Percentage of LTC public (private) expenditures (as a share of GDP)
- Percentage of expenditure for cash benefits, home care services (in kind) and residential care
- Share of public/non-profit/for-profit providers -> index: complex provider mix vs. monopsonic providers

**Needs and coverage**

- Degree of service provision (coverage of people with LTC needs by formal – residential and home care – services) = family vs. service based (de-familisation)
- Percentage of home care beneficiaries as against residents in residential care facilities
- Percentage of older people with care needs relying on migrant carers
- Employment rate of women
- Percentage of older people living alone

**Agency**

- Centralised policy-making vs. multi-level governance
- Degree of user choice (index)
- (Optional) ICT skills and usage

## 1.5 Structure and methods

Following this introduction, Chapter 2 will draw on secondary data analysis to provide basic information for comparison in the areas of governance and financing of LTC systems, and Chapter 3

will explore patterns of care needs and coverage. As explained above (see section 1.4 Care regimes), the following (preliminary) care regimes and countries are represented:

- Care mix (Western): AT, DE, FR, UK
- Universal (Nordic): DK, FI, SE, NL
- Family-based (Mediterranean): EL, ES, IT, PT
- Transition (Central and East Europe, New Member States): BG, CZ, EE, HU, LT, LV, SK, RO

Chapter 4 will then explore opportunities for active ageing and social innovation in LTC based on information provided by the country teams, in particular through the identification of initiatives, programmes and policies that promote social innovation and active ageing in the national LTC context (detailed descriptions of case studies will be gathered in the Annex).

The concluding Chapter 5 will serve to combine the quantitative and qualitative analysis in order to identify (a) new patterns (profiles) of LTC provision with respect to opportunities for active ageing and social innovation, and (b) potential drivers and obstacles for active ageing and social innovation that will be analysed more in depth during the next phase of research.

# 2 Description and Analysis of LTC regimes

## 2.1 Socio-political principles driving LTC policies

The policies determining LTC policies as well as the contribution of public provisions, market forces, the third sector and households are driven by particular political choices, legacies and cultural traditions that are important to consider. This section describes the tension between the role of the family and the role of the state and the degree to which family members are valued and indeed relied upon in respective countries in terms of care provision, and presents some consequences and explanations for specific patterns across care regimes.

### *Familisation vs. commodification*

LTC is a relatively new sector that has emerged in most European countries somewhere between the domains of health and social care, and while some country LTC systems have a longer history and more developed infrastructure and public sector involvement than others, the current provision of LTC has come about in all countries with the purpose of complementing, supporting, and in some cases, substituting for care that would otherwise be provided in the home by family and friends. This professionalisation process has often been used as an indicator for the comparison of care regimes in terms of defamilisation and commodification (Le Bihan, 2012; Leitner, 2003; Rostgaard and Pfau-Effinger, 2011; Simonazzi, 2009).

Among the countries represented here, there is a division between those in which caring has firmly remained the responsibility of family members, and those in which the state has taken an active role in financing and providing services. In a few countries in the Family-based and Transition care regimes (IT, EL, HU, SK, RO), the legislation concerning LTC of older people explicitly stipulates that care is legally the responsibility of family members. In Latvia, for each person who applies for public home care services, their family's ability to take care of the person in need is first assessed (European Commission, 2014). While LTC has traditionally been undertaken within the domain of the family in

Hungary also, the obligation of families to care for older kin was greatly reinforced recently when it was enshrined in the constitution adopted in 2011. This recent legislation contradicts the Social Welfare Act III of 1993 which declared that LTC provided in the home (home care/assistance, meal delivery) is a basic, mandatory service to be provided by local governments. Everyone 60 years and older is eligible to apply for this basic level of care; in practice, however, approximately 40% of local governments are unable to finance the services and many older people are unaware of their rights and eligibility. In the Transition countries of Hungary and Slovakia, this type of legislation emphasising the role of the family reflects both the more socially conservative political ideologies that predominate in these countries, as well as the restricted availability of financial resources when compared to other, wealthier countries in Europe. In particular the Universalist care regimes have strengthened the individualisation of benefits and the socialisation of risks. In terms of de-familisation, marked differences between care regimes continue to exist. As the legal responsibilities of intra-family care have remained constrictive as well, it can be argued that family ethics and traditions often prevail over economic considerations in LTC. In fact, these cultural and economic realities compound each other and result in limited resources being allocated to formal LTC provision and a strong reliance on family care. The strong reliance on family provided are is also reflected in the fact that across many countries and care regimes to this day, the male breadwinner model predominates, despite an overall rise in the labour market participation rates of women. The increasing employment rate of women (see Table 2.1) and the gradual shift towards greater employment equality between genders in many countries, while undoubtedly a positive development from an economic and equal rights perspective, is nonetheless also contributing to a gap between demand and available supply of informal carers. Ideally, formal services would be expanded in order to fill this void, and a number of countries where LTC services have played a more important role since the 1980s clearly show a connection between the professionalisation of care and the participation of women in the labour market. In fact, the countries representing the Universal/Nordic care regime rank highest in terms of female employment rates, while countries representing Family-oriented care regimes are the lowest-ranking.

In the context of the difficult economic climate of recent years, public resources to fund the expansion of LTC services have not been forthcoming. A notable exception is legislation establishing the System for Autonomy and Care for Dependency (SAAD) in Spain. Passed in 2006 and gradually rolled out since, the law sought to create a more universal, decentralised system of care, with joint funding from the central government and the Autonomous Region administration. Funding levels have suffered as a result of the crisis, however, and successful implementation has been fraught with administrative and coordination challenges (Patxot et al., 2012; Spanish Economic and Social Council, 2012). The migration of informal carers, mostly women, from their home countries to other European countries for economic reasons exacerbates the shortage of (formal and informal) carers in the sending country, even as it provides a solution in the receiving one. The most visible examples of this care migration are Slovakia, which sends large numbers of informal carers to neighbouring Austria in particular (European Commission, 2013c), and Romania, which has sent more than 150,000 citizens to Italy and Spain where they have found employment providing household and care activities (OECD, 2013). In most Transition countries national-level strategies for governing LTC are only now in the process of being developed (BG, RO), as their starting point has been a strong reliance on informal care by family members. Nonetheless, in Estonia and Lithuania for instance, emphasis is now being placed on formal home care, the role of family carers in the provision of LTC remains crucial. In general, the 'welfare mix' in LTC is characterised across care regimes by the

important role of the third sector (non-profit organisations and charities) in providing care services, both in the home as well as in residential homes and day-care settings.

**Table 2.1 LTC Labour force and employment rate of women**

| Country | Employment rate of women (% of total women) | LTC labour force (% of total labour force) |
|---|---|---|
| *Sweden* | 71.8 | 3.6 |
| *Netherlands* | 70.4 | 3.4 |
| *Estonia* | 69.3 | 0.5 |
| *Finland* | 68.1 | 2.1 |
| *Germany* | 68.0 | 2.3 |
| *Austria* | 67.3 | 3.0 |
| *Latvia* | 66.4 | (6.1) |
| *Lithuania* | 65.7 | 0.41 |
| *United Kingdom* | 65.7 | |
| *Czech Rep.* | 62.5 | 0.35 |
| *Bulgaria* | 60.2 | (4.8) |
| *Portugal* | 58.7 | (3.0) |
| *Slovak Rep.* | 57.3 | 0.27 |
| *Hungary* | 56.4 | 0.49 |
| *Romania* | 56.3 | (4.4) |
| *Spain* | 50.6 | 0.9 |
| *Italy* | 47.1 | 0.4 |
| *Greece* | 41.9 | 0.3 |

Sources: National sources; OECD Health for All Database, latest available year. Note: Data in brackets are for the total health care workforce (Eurostat, NACE.R2)

In addition, multigenerational living is prominent in some countries, while increasing numbers of older persons are living alone in others (See Table 2.2).

These new forms of care responsibilities are changing the way familisation itself is understood and defined. Women of middle-age still constitute the greatest share of informal carers across most care regimes (of the countries included here, Romania, Hungary, and Lithuania are exceptions in that nearly half of all informal carers in these countries belong to younger age groups (European Commission, 2013c), yet in some cases their role, along with that of other family members, has extended to the 'outsourcing' of care which involves making arrangements for care provided by non-family members (European Commission, 2013; EQLS, 2012). The delegation of caring responsibilities and the coordination of care among multiple care providers are responsibilities that are increasingly falling to family members in the absence of one family member taking on full time caring duties. Finally, as women of working age are employed in greater numbers, the share of informal care provided by spouses/partners has increased, leading to an 'ageing' of the informal care workforce.

**Table 2.2 Share of the population 65+ living alone**

| Country | Total persons 65+ living alone (% of total persons 65+) | Females 65+ living alone (% total 65+ females) | Males 65+ living alone (% total 65+ males) |
|---|---|---|---|
| *Lithuania* | 44.3 | 51.8 | 29.6 |
| *Estonia* | 40.8 | 48.9 | 24.4 |
| *Finland* | 39.6 | 50.5 | 24.8 |
| *Sweden* | 38.0 | 49.9 | 22.8 |
| *Latvia* | 35.5 | 42.6 | 20.7 |
| *Austria* | 33.8 | 45.3 | 18.7 |
| *Czech Rep.* | 33.8 | 43.7 | 20.1 |
| *Netherlands* | 32.5 | 44.1 | 18.3 |
| *Slovak Rep.* | 32.5 | 42.0 | 17.1 |
| *Romania* | 31.9 | 41.0 | 20.0 |
| *United Kingdom* | 31.9 | 40.4 | 21.6 |
| *Germany* | 31.5 | 39.2 | 23.0 |
| *Italy* | 30.7 | 41.0 | 16.8 |
| *Hungary* | 27.2 | 36.9 | 10.8 |
| *Bulgaria* | 25.0 | 31.5 | 15.5 |
| *Portugal* | 23.1 | 31.3 | 11.7 |
| *Spain* | 22.4 | 28.4 | 14.4 |
| *Greece* | 19.1 | 28.8 | 7.1 |

Sources: *Eurostat Data Explorer*: EU-SILC data, 2012.

While the traits of familisation continue to characterise most care regimes, even countries that traditionally adhere to the Family-based care regime model are being challenged by contradictions between traditional arrangements and social realities that have evolved over the past decades. In a number of countries the search for alternatives to informal home care provided by family members has created new types of arrangements that fall into a grey area between formal and informal care. This includes personal care provided by migrant carers from third countries characterised by low wages and high unemployment. In order to make up for the growing care gap, especially in so-called 'Family-based' care regimes, but also in Austria, Germany and the UK this type of 'social innovation' has spread at an impressive pace. For instance, there are an estimated 700,000 migrant care workers in Italy (Di Santo and Ceruzzi, 2010), but they play an increasingly significant role in Greece and Spain as well. It has been argued that cash benefits have often fuelled this development. This argument is only partly sustained by the correlation between the presence of live-in migrant carers and the existence of such non-earmarked cash benefit schemes (e.g. in Austria and Italy) as these benefits may cover the costs of migrant carers to a limited extent only. Other factors such as the general level of family income and the necessity of appropriate housing facilities as well as geographic vicinity also play an important role. Indeed, even Germany and Austria, two countries that usually represent the Care-mix care regime, differ considerably in the actual organisation of care, be it with respect to migrant carers, or in the formal care sector and the specific mix of services. Austria is unique in passing legislation formalising the role of '24-hour assistants', mostly female migrant carers from neighbouring Slovakia who previously could only be employed informally, and often illegally. In Germany, where significant numbers of migrant carers from Poland, the Czech Republic and Romania are present, such policies are not being debated (Schmidt et al., 2014).

This section has shown that de-familisation does not seem to be a priority across welfare regimes. With the exception of the Nordic/Universal care regime, family care is still perceived as the cheapest type of care arrangement, even if general public policies – and EU growth strategies – explicitly aim to extend (female) labour market participation. The debate is open, however, on whether active labour market development drives LTC policies – as seems to have been the case in France and Spain before the crisis – or whether general cultural legacies and family ethics are driving labour market and LTC policies in the respective care regimes. It is likely, though, that a combination of these different factors might help to explain differences.

## 2.2 Financing and Governance

### 2.2.1 Public expenditure on LTC

This section will expose and analyse the current structure of expenditures in LTC in selected countries, providing data first on total public expenditure on LTC as a whole, and then by expenditure disaggregated by type of LTC service.

- Total public expenditure on LTC
- Total public expenditure on LTC by type of service (home care-services; home care-cash benefits; residential care)

Data on the level of state investment in care services across care regimes provides a good, albeit limited, picture on the degree to which care is considered the responsibility of the state or the private user. Public investment is measured here by public expenditure on LTC as a percentage of GDP, and Table 2.1 reveals that figures vary considerably across countries, both between the different care regime clusters as well as among individual countries. On the higher end, the countries included in the Universal care regimes (SE, NL) spend definitely the most on LTC, but already within the alleged cluster of Care Mix regimes (DE, AT, UK) as well as within the cluster of Family-based care regimes (IT, EL, ES) there is a wide variety of expenditure patterns that can only partially be explained by purely demographic differences (OECD, 2011; European Commission, 2012: Graph 3.4). Similarly diverging patterns can be observed, albeit on a generally much lower level (around 0.5% of GDP), within the cluster of Transition countries. While Bulgaria reports almost no public expenditure at all on LTC (0.02% of GDP in 2007, the latest year for which data is available; Eurostat, 2013), neighbouring Romania reports expenditures of 0.75% of GDP in 2009 (Eurostat, 2013). Hungary and the Czech Republic report expenditure close to 1%, while public spending in the majority of the other Transition countries, including Estonia, Latvia and Lithuania hovers around 0.5% of GDP. One reason for this divide is a general lag in economic development among the Transition countries, but this alone does not explain the low *proportion* of public spending allocated to care services in many of these countries. Instead, consistent low prioritisation of LTC and the entrenched belief that care for older people belongs in the realm of the family are important factors behind the numbers.

Public spending can be further broken down for many countries by type of service, and in comparing the distribution across care regimes, a number of patterns emerge (see Table 2.1). For one, in most countries a significant portion of overall spending goes to each of the three types of formal care services: (1) in-kind home care services, (2) cash benefits for home care services, and (3) residential care. However, this typology of care services is less than perfect as depending on the country context, the operationalisation of benefits can be very different. In some countries (e.g. Austria) cash

benefits are granted to eligible persons who then decide for themselves whether to use the money to pay for care at home (whether formal or informal home care services) or for residential care. In other countries (e.g. France), cash benefits take the form of vouchers that are restricted to funding formal care services. In some cases (e.g. Germany), a further wrinkle is that beneficiaries may choose between such vouchers to engage formal services and 'pure' cash benefits that may be used, for instance, to compensate family members/friends who provide informal care.

**Table 2.3 Public expenditure on LTC for older people (+65)**

| Country | Public expenditure on LTC (% GDP) | Share of public expenditure by type of service (%) | | |
|---|---|---|---|---|
| | | Home care (Services) | Home care (Cash) | Residential care |
| *Sweden* | 3.60 | 41.0 | 0.0 | 59.0 |
| *Netherlands* | 3.50 | 31.0 | 11.0 | 58.0 |
| *Italy* | 1.90 | 19.4 | 49.6 | 31.0 |
| *Austria* | 1.40 | 8.5 | 62.1 | 29.4 |
| *Greece* | 1.40 | 64.7 | 25.7 | 9.6 |
| *United Kingdom* | 1.20 | 25.0 | 25.0 | 50.0 |
| *Finland* | 1.20 | 24.0 | 5.0 | 71.0 |
| *Germany* | 1.00 | 19.5 | 27.3 | 53.2 |
| *Czech Rep.* | 0.81 | 7.4 | 65.4 | 28.4 |
| *Hungary* | 0.80 | 17.0 | 0 | 83.0 |
| *Spain* | 0.80 | 26.8 | 17.1 | 56.1 |
| *Romania* | 0.75 | 85.5 | 0.9 | 3.9 |
| *Lithuania* | 1.22 | 39.3 | 41.8 | 18.9 |
| *Estonia* | 0.53 | 1.8 | 62.3 | 35.8 |
| *Portugal* | 0.30 | 30.5 | 41.7 | 27.8 |
| *Slovak Rep.* | 0.30 | 4.9 | 26.1 | 69.0 |
| *Latvia* | 0.27 | 16.7 | 8.3 | 75.0 |
| *Bulgaria* | 0.02 | 18.5 | 44.5 | 37.0 |

Sources: National sources; OECD Health for All Database, latest available year; own calculations and estimates; http://ec.europa.eu/economy_finance/publications/economic_paper/2012/pdf/ecp469_en.pdf table 3 (p 15).

The intricacies of LTC systems make comparability a challenge and need to be kept in mind. Due to a lack of availability of other data, we include information here on expenditure by type of service according to the typology described above, with the caveat that calculating cash benefits only for home care provides a distorted picture of the actual amount spent on cash benefits by the public sector. For instance, data on cash benefits for home care in the Netherlands and a range of other countries often also include expenditures for people with disabilities below 65 years of age. Still, the general tendencies with respect to generosity of individual countries' LTC financing can be retrieved. In any case, of the selected countries only Hungary and Sweden have yet not yet introduced cash benefits for older people in need of LTC, notwithstanding their rather contrasting care regimes.

Differences across the care regimes can also be found in the list of countries, in which cash benefits constitute the largest chunk of spending (e.g. AT, BG, EE, LT, IT, PT). Indeed, cash benefits are often 'hidden' as they might be reported under schemes for people of working age with disabilities. This is the case in Romania and partly in Bulgaria, where these benefits are not only needs tested, but also means tested. It is interesting to note that cash benefits play only a minor, if not negligible role in the Universal/Nordic care regimes too (e.g. FI) where the provision of services in kind has always been a central characteristic. Although cash-for-care schemes and vouchers (personal budgets, direct

payments) have spread in countries such as Sweden, Finland, the Netherlands and the UK, they remain a complementary feature, restricted to a smaller group of older people with LTC needs. However, they may also be interpreted as a sign of further convergence across care regimes.

A special scheme to support care at home has been introduced in Romania, where people with severe disabilities of any age may choose between cash benefits and assistance from a 'personal assistant'. The personal assistant may even be a family member who receives basic training in order to be employed by the local council equivalent to that of a junior social worker. In Latvia, though cash benefits specifically for LTC are not offered, older people may be eligible for cash benefits for other reasons depending on the disposable budget of the municipalities, and in direct correlation with their degree of dependency and income level. This shows the still unformed identity of LTC particularly in Transition countries, with social assistance schemes whose primary purpose are to compensate for a lack of household income, rather than for needs and costs that occur due to LTC needs.

Another feature that runs counter to any attempt to cluster countries by 'care regimes' concerns the allocation of funds and their distribution between home care and residential care. Although policy papers across Europe maintain that care at home should be facilitated and residential care should be avoided as long as possible, expenditures for residential care outpace those for home care in most countries, irrespective of care regime. For instance, in Hungary (83%) and Latvia (75%), but also in Finland (71%) the vast majority of total public expenditure on LTC goes to residential care facilities, while a different pattern, sometimes at a lower level of general expenditure on LTC, can be observed in countries such as Portugal, Lithuania or Greece, where funding for in-kind care services at home prevails over expenditures on residential care. This distinction is blurred, however, by the fact that for countries with a widespread take-up of cash benefits it is difficult to calculate the extent to which these resources are used to pay for care services at home (AT, BG, DE, EE, IT, PT). In each of these cases except Portugal, cash benefits for home care are followed by residential care in terms of proportion of public spending, and only then by home care services. This may indicate that in these countries, cash benefits for home care have to a certain degree alleviated the demand for formal home care services, even as the examples of Germany, Austria, as well as Estonia, show that home care services have been expanded in parallel to the implementation of cash benefits in order to keep pace with demand. It is difficult to say, however, how much home care services would have to be expanded if cash benefits were not an option for LTC recipients.

As was addressed above, in certain countries cash benefits for residential care are not necessarily included in the calculations of total cash benefits awarded and may skew the overall picture. Cash benefits are prominent in Germany, Slovakia and Greece as well, though in these countries in-kind services, either home or residential care, dominate. Residential services receive the majority of public expenditure in Germany and in a number of the Transition countries reporting data (LV, ES, HU, SK). It should be noted, however, that these figures only refer to public funding, i.e. to services and benefits financed by the public sector, and excludes care provided informally by family members, or care paid for privately by the user and provided by migrant carers hired outside the formal sector. This reality renders publicly financed services a small piece of the overall pie in most countries, as according to some estimates, the informal care workforce is up to ten times the size of the formal care workforce (OECD, 2011, p. 44).

### 2.2.2 Governance

Due to its relative novelty the governance of LTC is spread between different sectors, various government levels and across a wide range of stakeholders. Over the past two decades the resulting multi-level and multi-stakeholder networks that have influenced the emerging LTC systems have been conditioned, apart from national specificities, by three 'mega-trends' of public governance:

A first general trend in governance was coined 'New Public Management' and led to the introduction of market-mechanisms that reduced the allegedly inefficient social planning processes and the public provision of services. While some countries such as the UK or the Nordic countries thus markedly reduced monopolies in public provision, the existing 'welfare mix' changed in other care regimes also with the appearance of new types of stakeholders such as for-profit providers or new types of organisations representing the 'social economy'. This applies even more drastically to the Transition countries where new stakeholders had to be partially 'invented' both in the public and in the private spheres. This so-called 'horizontal re-scaling' of governance increased the complexity of stakeholder relations in particular in LTC, with related consequences for steering mechanisms (quality regulation and prices).

- A second trend concerns 'vertical re-scaling', i.e. shifts of responsibilities within multi-level governance frameworks from the central to regional and/or local levels, and vice versa. Centralisation of responsibilities for LTC took place in terms of funding, for instance in Austria and Germany (LTC insurance), or in terms of quality assurance mechanisms, while the more salient decentralisation trend could be observed across care regimes, in particular related to the organisation of services and facilities. Together with the introduction of quasi-markets this resulted in widening differences between jurisdictions in terms of access, choice and prices in all care regimes.
- The third trend, and the one that actually conditioned all other endeavours of developing and governing LTC, consisted in the eternal search to reduce public spending. This mentality is particularly challenging in an area that had hardly taken its first steps to becoming acknowledged and visible in the realm of social protection. The difficulty in defining and unpacking public accounts for LTC reported to Eurostat, OECD or WHO in any given year, as outlined above, makes it even more difficult to compare developments over time. Notwithstanding these caveats it can be stated that a slow but steady rise in the proportion of GDP that was spent on LTC can be observed over the past decade in most Member States. While expenditure started out at a very low level in Transition countries and most Family-based care regimes in the Mediterranean, countries with traditionally high proportions of LTC expenditure have reported relatively low growth rates or even a slight decline recently, as for instance, the Netherlands and Sweden. This is partly due to demographic idiosyncrasies but also to tangible policy reforms.

In the following paragraphs, this section highlights the key trends in selected countries concerning the way in which these general trends were shaped by established structures and how these impacted on the development of LTC policies, thus promoting or hampering active ageing and social innovation processes.

A fundamental precondition for LTC policies is the distribution of responsibilities between health and social care. In most countries responsibility is shared by two ministries with specifically health-related elements of LTC falling under the governance of the health ministry, and the social care

aspects of LTC under the ministry of social affairs. This division is often repeated at the different levels of government.

Related difficulties in coordination of policies are apparent in all countries, but perhaps particularly articulated in the countries of the Transition care regime where the concept of LTC as a distinct sector is especially novel. Unclear responsibilities are certainly one cause for a lack of adequate services available, particularly in rural areas in Bulgaria (Mincheva and Kanazireva, 2010), Romania and Hungary as well as the Slovak and Czech Republics. First steps towards public recognition of LTC as a social risk and related public policies could be observed over the past decade, but in many countries even the term 'long-term care' was mentioned and defined in legal documents only recently, e.g. in 2011 in Romania. In Hungary, home care is under the umbrella of social care and is therefore funded not through health insurance but from the budget. In terms of 'vertical rescaling' some re-centralisation has taken place recently, when the central government took over responsibility both for financing and organising specific components of LTC (e.g. home emergency care), stripping local authorities of their prior capacity to determine how these services should be operated. Also in the Czech Republic, where most formal long-term care services are provided in residential settings, central government is most influential. However, while nursing homes (exclusively for older persons) are wholly funded by health insurance, social care homes are supported by a combination of state subsidies and out-of-pocket user fees. Both types of services have experienced a decline in funding during the recent years of crisis, when subsidies for social care homes have been cut back by the public health insurance fund. As a result, stagnation in the number of care homes and in their capacity has taken place, despite the fact that demand, in particular for places in nursing homes, has increased.

An opposite trend can be observed in social care for older people in the Baltic countries, where decentralisation has been a guiding principle, though health care remains mostly centralised. The division between the health and welfare systems is thus further extended, for instance in Estonia, where local municipalities organise and fund (based on local taxes) domestic services, caregiver allowances, transport, day care centres and residential care, whereas nursing care, physician services, rehabilitation, nursing care hospitals, specialist care hospitals and acute care hospitals are governed through the national health insurance scheme. For all services, hardly regulated quasi-markets have emerged as both public and private providers (both for-profit and not-for-profit) have spread (OECD, 2011c), thus increasing the fragmentation of the Estonian care system with important costs for both users' and public budgets. The various sources of funding (e.g., Health Insurance Fund, local taxes, Social Insurance Board and users' contributions) are producing different incentives (e.g., activity-based financing, per diem or global budgets), in particular as regulatory framework are lacking. As a result, a 'race to the bottom' is taking place because both public (municipal) and private care providers seek to serve those persons with the greatest ability to pay (either directly or through co-payments), while providing lower-quality services to those least able to pay (OECD, 2011c). Similar patterns are prevailing in Lithuania. Another common trait of the Transition care regime is the importance of EU structural funds and the important role of NGOs as providers and advocacy organisations. The latter are often supported by international organisations and foundations, thus amending the lack of equal national funding opportunities through donations and charities. It remains to be seen in a mid-term perspective, whether these external incentives will serve to achieve the general objectives formulated in related policy papers, e.g. to shift LTC from institutional care towards home-based care (Marcinkowska, 2010).

In Family-oriented care regimes such as Italy and Spain a general tendency towards decentralisation can be observed. In both countries, regional autonomies have been strengthened over the past decades, resulting in a highly fragmented system with an important degree of variation in regulation of LTC services from region to region. Both countries are characterised by a legalistic tradition and therefore provide insight into interesting legislation concerning health and social care coordination, albeit with difficulties in the implementation of related objectives and intentions. While Spanish regions have started to implement an important national framework law on LTC ('Ley de dependencia') in 2007, the Italian framework legislation on integrated service provision passed in 2000 ('Legge quadro per la realizzazione del sistema integrato di interventi e servizi sociali', L. 328/2000) has a broader scope concerning the governance of all types of social services towards user-orientation, involvement and activation of all stakeholders. In the context of on-going decentralisation both of these Acts have been implemented to different degrees and with various interpretations at the regional levels, resulting in further differentiation, in particular between Northern and Southern regions. This is also due to rising problems of funding. Spain's central government only provides 50% of funding, and in Italy a reduction in dedicated funds has continued as the 'Long-term care fund' (*Fondo per la non autosufficienza*), established as recently as 2007 to support LTC service provision with about €400 million per year, was eventually cancelled in 2011. In Greece as well, the reliance on regional authorities to fund and set up community care centres (KAPIs) has led to financial and organisational difficulties, exacerbated by the financial crisis since 2008. In Portugal, policy-makers have sought to overcome the challenge of coordination by creating the National Network for Integrated Continuous Care, a network based on the cooperation between the Ministry of Labour and Social Solidarity and the Ministry of Health. Given the nascent state of LTC in Portugal, this initiative might help to overcome the usual pattern of development, which has been to expand residential facilities before starting to develop community care services.

In the Care-mix countries also, responsibility for funding and provision of different LTC benefits is situated between health and social ministries at the federal level, but all other levels of government are also in charge, partly with considerable autonomy to fund, organise and deliver services. For instance, in Austria, where funding of LTC was centralised to a large degree, regional governments are responsible for planning and organising residential facilities and community care services that are provided chiefly by large welfare organisations and private for-profit organisations. A similar type of welfare mix has developed in Germany, although funding is mainly ensured by LTC insurance (public or private) that is supervised by the Ministry of Health due to the fact that the distinct LTC insurance fund is affiliated with the health insurance fund. While this may contribute to a more medicalised model of long-term care, regional governments and their social assistance departments still have some supervisory and funding responsibilities, in particular for users whose income and LTC insurance benefits are not sufficient to cover costs of residential care and services (so-called Support for Care – *Hilfe zur Pflege*). A more centralised structure characterises health care related LTC issues in England, where the divide between health and social care seems to be even more marked than in other Care-mix countries, notwithstanding continuous and on-going attempts to improve structural and functional coordination between the sectors. England and Germany are the countries where market-oriented governance is most clearly shaped and where free market access for all accredited providers has been promoted in a more explicit manner than in other countries since the 1990s.Furthermore, England is yet another example of the historical and persisting divide between health and social care, with the tax-funded NHS providing services (almost) free of charge at the

point of delivery, while 'social care' implies means-testing and important private out-of-pocket contributions, including personal assets.

Market-oriented governance has also affected the Universal-Nordic care regimes, where monopolistic public provision was predominant until the 1980s. The significantly longer tradition of social rights concerning social services, rather than cash benefits, in the Nordic countries (and in the Netherlands) was certainly one reason for the establishment of joint Ministries of Health and Social Affairs. However, coordination problems and fragmentation between health and social care with different legal and financial frameworks, geographical boundaries, accountability mechanisms and cultures can also be observed in tax-funded welfare states such as Sweden (Ahgren and Axelsson, 2007) and Finland for instance. In particular, the distinct decentralisation (including fiscal decentralisation) of responsibilities continues to produce different levels of service provision at municipal levels. A number of mechanisms have been introduced to overcome mal-incentives. In Sweden for instance, where county councils are responsible for acute care in hospitals, and municipalities for LTC (also the case in Denmark), case management and financial incentives have been installed to avoid prolonged hospital-stays of people with long-term care needs by coordinating municipalities' home care services with county council's hospitals (Emilsson, 2011). In spite of structural preconditions, including important funding sources for LTC that would suggest improved cooperation between health and social care, issues of standardisation and regulation have outweighed social innovations in long-term care in the Nordic countries over the past decade. This has been accompanied by pronounced 'targeting' in particular in Sweden where the number of service hours provided remained stable while the number of users steadily declined (Sundström et al. 2011; Szebehely and Trydegard, 2012). Attempts to increase choice and the marketization of the sector (Meagher and Szebehely, 2013), e.g. by introducing service vouchers and opening the market up to for-profit providers in a large number of municipalities have contributed to new types of 'horizontal re-scaling' and related new challenges of cooperation.

## 2.3 Latest policy reforms to support active ageing and social innovation in long-term care

This section presents recent and relevant reforms that have been undertaken in the selected countries in the area of LTC. These reforms generally concern the expansion and improvement of service provision, support for informal carers, coordination of care and financing. They are therefore important preconditions for providing appropriate support to older people in need of LTC.

Several countries have undergone reforms to their LTC systems in the past few years. Reforms in countries with less developed LTC infrastructures have focused attention on initiating national strategies and plans to clearly define LTC services and beneficiaries and to expand service provision. This has been the case in several of the Transition countries such as the Czech Republic, Romania and Bulgaria. There is on-going debate in Bulgaria surrounding the precise mix of services that should be offered as well as the financing and delivery of said services. For the near future, policymakers are focused on passing stronger regulatory legislation and enacting a national plan for LTC to guide future development of the sector (Government of Bulgaria, 2013). In Latvia, expansion of LTC services involves the creation of a network of public hospitals offering LTC services by the end of 2014 (Latvia Ministry of Health, 2011). The Romanian government recently took steps in a new framework legislation to define LTC distinctly from other health and social care services, and proposed quality assurance measures for publicly provided services in the context of a New Social

Assistance Act in 2011.These reforms have taken place in the broader context of policies promoting 'ageing in place', rather than residential care, although the level of supply both in community care and in residential care remains perspicuously low.

Reforms to the LTC system in Hungary have followed a broader pattern of centralisation of governing authority taking place across sectors. The financing and organisation of certain policies that were previously the responsibility of regional and local governments have come under the mandate of national-level institutions, however with the consequence that services such as home care – which remains under regional operational control – have seen their state funding reduced. This development towards an exoneration of public policies concerning LTC has been accompanied by the above-mentioned new Hungarian constitution which explicitly places legal responsibility for the care of older persons on family members and a recent bid to more firmly shift the care burden to the private sector. In the Czech Republic, the most important development in LTC in recent years has been the attempt by the Ministry of Health and the Ministry of Labour and Social Affairs to pass legislation devoted to defining and setting guidelines for the financing and provision of services within the framework of long-term care. Unfortunately, the process of passing this legislation has not been transparent and has been stalled several times by political infighting (Horecky, 2013). There is reason to hope that steps will be taken toward a national strategy for LTC, however, as the topic has spurred lively debate across a wide range of stakeholders in both the public and private sectors (Horecky, 2013). In Slovakia, where previously users could only elect to use private services when the publicly provided services were insufficient or lacking entirely, recent legislation enacted in 2011 has enabled patients to freely choose between public and private providers of care (Vagac et al., 2012). In conjunction with this regulation the financing mechanism was also modified in a 2012 amendment to the Act on Social Services which introduced a combination of means-tested co-payments (up to 50% of the cost of the service) and a special state subsidy to fund social care, including LTC services. The legislation raised heated political debate at the time due to the increased cost burden the co-payment would mean for patients (Vagac et al., 2012).

While there is little to report in the way of reforms to the LTC system in Estonia – despite the urging and publication of recommendations by the OECD in particular (OECD, 2011c) – Lithuania has taken definite steps in the past few years to develop an integrated system of care for older persons and the disabled. Funding provided by the European Social Fund made the 2012 implementation of the Integrated Development Assistance Programme possible. This programme seeks to provide integrated health (primarily nursing) and social care assistance to the target groups, as well as consulting services for informal carers providing care to family members. A pilot project consisting of 21 municipalities is being carried out in the 2013-2015 period.[2]

Germany and Austria in the Care-mix regime have both passed legislation in the last few years, which acknowledges and seeks to address the important role of informal caregivers in their respective LTC systems. In Austria in 2007, the formalisation of the employment status of migrants working as '24-hour carers' was undertaken and has led to the regularisation of many formerly illegally employed migrant carers(Schmidt et al., 2013). While similar developments in the informal care-markets of

[2] Order No A1-353 of the Minister of Social Security and Labour of the Republic of Lithuania of 20 July 2012 "On the Approval of the Integrated Assistance Development Programme" (Official Gazette Valstybėsžinios, 2012, No 89-4663).

other countries (IT, DE) have occurred (Bednárik et al., 2013), serious attempts to regulate these arrangements at the interface between formal and informal care were not undertaken. In Germany, the challenges facing reconciliation of work and caring duties for informal, family caregivers were addressed by increasing (unremunerated) care leave. German legislators also took steps to increase the quality and efficacy of services by promoting rehabilitation, case management and counselling as part of LTC practices (Rothgang, 2010). New legislation is also planned for 2015 and will be implemented in two steps through 2017. Beginning in January, 2015, the first step will consist of increasing most LTC insurance benefits by 4 per cent. This will include expansion of available support services, measures to improve individuals' living environments, technical and other nursing aids, as well as increasing the number of auxiliary care staff in residential facilities in an attempt to improve the relationship between professionals and those in need of care. Home care benefits will also be increased in order to ease the burden on caring relatives; part-time residential care (day and night) will be available in addition to benefits in cash and in kind (previously, use of day care reduced the amount of in-cash and in-kind benefits granted by approx. 50 per cent). In addition, dementia patients will be eligible to receive part-time institutional care and respite care and short-term care will be made more flexible and comprehensive. Furthermore, benefit amounts will be adjusted to factor in annual price increases (Council of the European Union, 2014).

The supplementary benefits provided for 'low-threshold' care offers will be updated as well. New additional relief benefits will be introduced. Moreover, these additional supplementary care and relief benefits will be accessible to all persons with care needs and are intended to facilitate greater use of home care and support family caregivers. To date, only people with a high level of care need due to severe ADL and IADL impairments were eligible. Taken together, these adjustments to LTC benefits will work to ensure that people with care needs can remain longer in their home environment (Council for the European Union, 2014).

In the second step of the upcoming reform package, LTC services will be fundamentally transformed beginning in 2016. The current 3 levels of care will become 5 levels of care and will include implementation of a new term: 'in need of care.' This designation will take into consideration the individual situation of the person in need of care, focusing on his/her 'level of independence' without just referring to physical or mental impairments. To finance this, the premium for LTC insurance will increase by 0.3 % beginning 2015 and by a further 0.2 % in 2017, raising an additional 6 billion Euros per year for the LTC budget. 1.2 billion Euros will be spent each year on the newly established 'LTC provision fund' (*Pflegevorsorgefonds*) to stabilize the LTC insurance premiums within 20 years (German Federal Ministry of Health, 2014).

In the UK (England) there is an on-going debate about decent funding of social care as well as possibilities for 'integrated commissioning' of long-term care services (Fernandez and Forder, 2012; Barker et al., 2014).

Countries in the Family-based care regime have undertaken reforms in multiple areas of LTC. Both Italy and Portugal have sought to increase coordination between different types and levels of service provision by emphasizing integrated care as an important goal. A national fund to meet this objective in part was created in Italy in 2007, with funds distributed among regions depending on the numbers of persons requiring LTC in each (Tediosi and Gabriele, 2010). This initiative was short-lived, however, as the funds were not structurally secured from the beginning and could therefore be arbitrarily suspended, as indeed they were following 2010.Since that time no specific policy initiatives have

been undertaken in the area of long-term care at the national level, while regional governments are struggling with further budget cuts and selective local projects focusing on family care and migrant carers. In Portugal the implementation of the National Network for Integrated Continuous Care in 2006 and initiatives by regional authorities to promote quality of service provision were important policy initiatives to frame the expansion of services at both the national and regional levels(São José and Wall, 2006).Spain also took steps towards an integrated, home care-oriented model by introducing a nation-wide programme to oversee LTC provision in 2007 (Sistema para la Autonomía y Atención a la Dependencia, SAAD). This programme constitutes a marked shift towards a universal care regime as it was intended to ensure a minimum level of public LTC services, but its implementation, depending on additional tax-based funding by the autonomous regions, was partly halted, in particular as a result of budget cuts in the context of the financial crisis (Patxot et al., 2012). Both Spain and Portugal also made provisions for more market-oriented governance with the aim of expanding service provision through the private sector. For instance, Spanish legislation stipulates that should there be a shortage of supply of publicly provided services they can be purchased from accredited private providers (Casanova, 2010). Since the reforms of 2003 in Greece, all LTC services are directly supervised by 'Peripheral Health and Welfare Systems' that act as autonomous, regional, decentralised units of health and social care.

In Universal/Nordic care regimes with a relatively stable tradition and defined rights for people in need of long-term care, recent reforms have been concentrating on procedural improvements (quality assurance), including ICT, enhanced choice for users, and financial amendments to ensure sustainability, e.g. by more restricted targeting of the most needy target groups (Sweden) and by experimentation with personal budgets (The Netherlands, but also England and Germany). Finland has remained one of very few countries where public policies have engaged in a broad debate and the definition of transparent and measurable national objectives for LTC have ensued. The Netherlands (but also Germany) have implemented important investments in improvement measures and quality assurance (Leichsenring, 2010). Two commissions in Denmark have been looking at how to adjust LTC services in view of population ageing and the rise in the number of people at risk of developing LTC dependency. The main recommendations of the commissions relate to home care. The commissions call for a paradigmatic shift in focus from service provision to a) prevention of chronic conditions in the case of older people without functional limitations, b) rehabilitation for older people with minimal to moderate limitations, and c) more compensatory and nursing care services for persons with significant and complex care needs. A large-scale programme to train and re-train staff in home care is envisaged to ensure that the workforce is prepared to assume rehabilitation of people who are frail and who have functional limitations. The commissions recommend that early detection and addressing frailty become core components of prevention (Council of the European Union, 2014).

This section has shown that, in spite of a number of policy papers, distinct debates about reforms and even targeted legislation, LTC issues remain a 'poor cousin' of social protection and health policies. This has been made evident once more during the recent financial crisis, when budget cuts, rather than investments in LTC were high on the agenda (see also Waldhausen, 2014).

## 2.4 Labour force: Education and training

In this section, information is provided on the educational profile of LTC workers across countries, the qualifications required (if any) by country for employment in the formal care sector, and the kinds of training/professional development opportunities that are available.

- Overall level of qualification of carers
- Required qualifications
- Training/professional development
- Migrant carers

Adequate education is important to ensure that professionals are equipped with the necessary skills to allow them to deliver a high quality of care. Education and training are also important for the professional integrity and recognition of care work. Changing demographics and the increased participation of women in the labour market has led to a larger demand for formal care services across regimes; in many countries there exists a shortage of trained staff to fill this gap. This is of greatest concern in the Mediterranean countries of the Family-based regime in which informal care has historically played an even more essential role within LTC provision than in the other care regimes. These countries are characterized by a low-skilled LTC labour force in comparison with other regimes (Rodrigues et al., 2012, Table 6.2), with the exception perhaps of the Transition countries. Among the Mediterranean countries LTC is recognised as a profession in its own right, and in most cases there are basic qualification requirements for those people providing formal care services; these are generally divided into qualifications for 1) LTC health professionals and for 2) social carers.

Across regimes there is need for greater numbers of qualified professionals working in the LTC sector. Beyond calling for more trained personnel, only a few of the Transition countries have reported concrete steps in this direction. In 2012, Romania established the National College of Social Workers, a membership organisation promoting social work professionals through training programs and granting of certifications. Also in 2012, a training programme to develop the professional competencies of people working in social care was implemented by the Romanian Ministry of Labour, Family, Social Protection and the Elderly (MMFPSVP). Despite the clear need for additional training programmes, there is cause for concern that as long as wages in the field remain low, trained care personnel will seek employment abroad, either as live-in carers in private households or in formal care settings. This has proven to be the case among nurses, with more than 20% of trained nurses expressing an intention to leave the country (Vladescu and Olsavsky, 2009), and a large number of semi-skilled carers working in Italy and Spain. Nevertheless it is important to continue qualification measures that have to be complemented by improvements in working conditions and remuneration.

In Lithuania in 2011, the Ministry of Social Security and Labour required that social service professionals must have tertiary-level education in social work. Explicit requirements for the LTC labour force, however, are not so strictly regulated. Vocational education is considered sufficient to provide care-giving services in Lithuania. There are at least 8 institutions that provide vocational training yet there is a shortage of LTC workers to meet the demand. Therefore, the Lithuanian Red Cross Society actively participates in social programmes geared towards recruiting volunteers to train them for social and nursing work. The Red Cross provides a 12 hour training programme for LTC volunteers. In Latvia, the Social Workers Association which also promotes the interests of professionals and cooperates with the Ministry of Welfare and national institutions of higher

education has been operating since 2006. Although there are several LTC-related training courses and degree programs available to students at the tertiary level, one of the consequences of Estonia's weak regulation of its LTC system is that the qualifications required for providing formal care are not standardised and vary from region to region. Tertiary level education for social workers, for example, is expected only by employers in the capital city, and in more populous municipalities. In smaller municipalities, secondary level education is generally considered acceptable.

In Hungary, regulations require that 50% of carers providing basic home care services (care/assistance, meal delivery), and 80% of those working in residential services must have vocational training after secondary school. Vocational training is offered for social assistant, auxiliary social carer/nurse, and skilled social carer positions and takes a maximum of 2 years to complete. Exceptions to these requirements include: a) the hiring of an employee without vocational training for up to 5 years, provided there is no other skilled carer available, and that s/he is prepared to participate in the requisite training; b) if the employee participates in other vocational training. Directors of residential care facilities must have a tertiary-level education. If a person in this position has not completed the necessary education, s/he must pass the professional re-training examination within 2 years of occupying their role as director.[3]

In the Care-mix and Universal regimes, the education requirements for formal carers are more clearly regulated and a wide range of vocational qualifications are offered for working in LTC. Nonetheless, there is growing concern about a care shortage in these countries as well, and the need for more and better-trained personnel has been recognised. In Germany, most employees working in residential care are geriatric nurses, while most working in home care are general nurses. Since 2008 in Austria, based on a national reform to streamline regionally fragmented education in social care, accredited centres for social professions have started to offer training programmes for the Professional Social Carers certification and the Social Carers diploma, based on a modular training design.

As a consequence of the shortage of caretakers and enabled by the expansion of the EU to include several new Transition countries, migrant carers have proliferated in the LTC labour markets in many countries. The education and qualifications held by migrant carers is of growing concern in all care regimes given that migrant carers make up increasing numbers of both the formal and informal workforce in the Care-mix, Universal and Family-based regimes, with many of the Transition countries serve as sending countries, though Hungary for example has also reported increasing numbers of migrant carers from Romania (Széman, 2012, p. 97). According to the EUROFAMCARE project, which involved a Europe-wide study of family care, families reported employing migrant carers to provide informal care in 17 out of 23 surveyed countries, at least from time to time (Mesthenos and Triantafillou, 2005). Particularly in the cases of migrants working informally, it is nearly impossible to monitor or regulate qualifications. Equally important from a rights perspective is the fact that many migrant carers are overqualified for caring tasks and are underpaid because the qualifications they receive in their home countries are not recognised in the countries in which they work (Bednárik et al., 2013).

[3] Order 1/2000 (I.7) Hungarian Ministry of Health, Social and Family Affairs unabrogated (2014.VII.19. and Order 5. of Hungarian Ministry of Health, Social and Family Affairs 9/2000). (VIII.4). Based on the Social Welfare Act, 1993.

## 2.5 Labour force: Gendered division of labour

Information on the varying degrees to which the LTC labour force is divided along gender lines is provided in this section. Although briefly noted in the 'policy approaches' section above, more detailed data is presented here on the proportion of females vs. males occupying certain roles within LTC.

In all care regimes, female carers comprise the vast majority of the LTC labour force, both in formal and informal care. What these isolated data do not show, however, is that in most countries and across care regimes, more women in general are entering the formal labour market, leaving a widening gap between care needs and available informal care provision.

Though the measures reported are not equivalent across countries, the overall picture that emerges is the same. Of German workers employed in formal home care services, recent data shows that 88% are women. Similarly, 85% of nursing home employees are female (German Federal Statistical Office, 2013). In Austria, 86% of individuals working in care-related professions were female according to 2007 Labour Force Survey (LFS) data (Bettio and Verashchagina, 2010).

Of the countries in the Family-based care regime, LFS data for Greece and Spain show that women make up just under 80% and just over 90% of those employed in care-related professionals, respectively (Bettio and Verashchagina, 2010). Data from Italy shows that 83% of women's working time was devoted to domestic/family tasks in 2008 (Servidori, 2008), and personal care is largely provided by women, both as family members or as paid caregivers. In Portugal and Greece, despite considerable advancements with regard to gender equality – a 3.4 and 4.9 hour difference between men and women in the number of hours spent in paid work, respectively, compared to the European mean of 6.8 (European Quality of Life Survey, 2011) – women still dedicate more hours than men to unpaid work (a difference of 7 and 8 hours of difference, respectively, compared to the European mean of 5) and women make up the majority of both formal and informal LTC workers. In Portugal, almost 94% of the total personal care workforce consists of women (Bettio and Verashchagina, 2010). A recent study on the gendered division of labour in Spain shows that as in the other Mediterranean countries, the labour market confers the major role in family care to women. This fact persists in influencing the career paths and trajectories of women in Spain (Torns, 2013).

Employment in LTC is also highly gendered in the countries of the Transition care regime. In Hungary, the Czech Republic and Slovakia, the share of female carers as a per cent of total persons working in care-related professions[4] was well over 80% in according the 2007 LFS, with Slovakia exhibiting the highest share at almost 88% (Bettio and Verashchagina, 2010). In Bulgaria, the employment rate for women in the formal health and social care sector was 78.6% in 2012 (Eurostat, 2012) and women are considered the primary providers of care in the informal sector as well. In Latvia, the figure for this same measure is 85.4% (Eurostat, 2012) while Romania provides data on the employment rate of women in the LTC sector, citing 78.5% (Eurostat, 2012). In Latvia, 99% of the personal care workforce is made up of women (Bettio and Verashchagina, 2010).

[4] Calculations based on Labour Force Survey 2007 data; personal care and related workers (isco_513).

# 3 Needs and coverage

## 3.1 Access and eligibility

### 3.1.1 Need for care

This section provides an overview of the level of demand for LTC by care regime by presenting data and trends on the share of the older and disabled populations:

- Share of the population aged 65+
- Disability rate in the 65+ population

The countries represented here report a 65+ population that makes up anywhere between 12% and 21% of the total population (See Table 3.1).

**Table 3.1 Number and share of persons aged 65+**

| Country | No. of persons 65+ | | | Share of population 65+ (%) |
|---|---|---|---|---|
| | Male | Female | Total | |
| *Germany* | 7,247,6977 | 9,632,853 | 16,880,550 | 20.63 |
| *Italy* | 5,322,080 | 7,233,964 | 12,556,044 | 20.6 |
| *Greece* | 970,215 | 1,220,959 | 2,191,174 | 19.7 |
| *Lithuania* | 179,235 | 355,314 | 534,549 | 19.7 |
| *Sweden* | 830,358 | 997,925 | 1,828,283 | 19.1 |
| *Finland* | 431,769 | 586,424 | 1,018,193 | 18.8 |
| *Portugal* | 835,997 | 1,184,131 | 2,020,128 | 18.7 |
| *Estonia* | 77,253 | 155, 288 | 232,541 | 18.0 |
| *Bulgaria* | 539,095 | 786,796 | 1,325,891 | 17.5 |
| *Latvia* | 127,228 | 262,981 | 390,209 | 17.4 |
| *Spain* | 3,475,407 | 4,652,634 | 8,128,041 | 17.4 |
| *United Kingdom* | 4,917,238 | 6,068,452 | 10,985,690 | 17.2 |
| *Austria* | 591,036 | 827,301 | 1,418,337 | 16.8 |
| *Netherlands* | 1,263,536 | 1,560,809 | 2,824,345 | 16.8 |
| *Hungary* | 611,466 | 1,059,669 | 1,671,135 | 16.7 |
| *Czech Rep.* | 640,301 | 996,668 | 1,636,969 | 15.6 |
| *Romania* | 1,297,969 | 1,908,439 | 3,206,408 | 14.9 |
| *Slovak Rep.* | 254,474 | 423,974 | 678,448 | 12.6 |

Sources: National sources; Eurostat database, EU-SILC data, 2013.

The majority fall between 15% and 20%, with the Slovak Republic and Romania pulling down the average, where persons 65 years of age and older make up only 12.6% and 14.9% of the population, respectively. On the higher end are Germany and Italy, both recording 20.6%. On the whole, the Family-based countries have the highest rates of people aged 65+, and the Transition countries the lowest, but variation between countries in each of the regimes is considerable. Across care regimes, and indeed in each of the selected countries, women make up a larger portion of the 65+ population than men. In several Transition countries (EE, LT, LV, SK, HU) the number of women is double that of

men. The disability rates of the 65+ populations in each of the countries are also considerably varied, though these differences only partly reflect actual country-level differences in disability due to differences in how disability is defined and reported as well as to cultural variations in self-reported perceptions of disability. The Family-based countries had relatively high rates of disability, with three of the countries (EL, ES, IT) reporting a disability rate of around 30% for the 65+ population. On the lower end are Bulgaria and Hungary with disability rates just over 11% for persons aged 65 and older. Despite having one of the lowest shares of the population 65 and older, Romania has one of the highest disability rates (25.4%). The remaining countries for which data is available reported rates between 15% and 25%.

These figures provide important context when considering the resources that need to be directed to the sector to ensure that appropriate care is accessible for everyone in need of it. In those countries in which the share of the older population is particularly high, the numbers may also serve to reveal an existing or impending gap or shortage in care providers, due to the large proportion of potential persons in need of and eligible for care.

**Table 3.2 Disability rate among persons 65+, 2011**

| Country | Disability rate among 65+ (%) | | |
|---|---|---|---|
| | **Male** | **Female** | **Total** |
| *Slovak Republic* | 26.8 | 35.4 | 32.1 |
| *Romania* | 19.2 | 29.6 | 25.4 |
| *Portugal* | 21.3 | 26.8 | 24.5 |
| *Greece* | 22.44 | 26.0 | 24.4 |
| *Estonia* | 20.8 | 25.2 | 23.8 |
| *Austria* | 20.7 | 26.0 | 23.7 |
| *Italy* | 19.1 | 25.9 | 23.0 |
| *Hungary* | 17.8 | 23.0 | 21.1 |
| *Lithuania* | 17.5 | 22.8 | 20.9 |
| *Germany* | 17.9 | 20.1 | 19.1 |
| *Latvia* | 16.6 | 20.1 | 19.0 |
| *United Kingdom* | 18.5 | 19.4 | 19.0 |
| *Finland* | 16.0 | 19.1 | 17.8 |
| *Spain* | 11.5 | 16.1 | 14.1 |
| *Czech Republic* | 11.5 | 15.5 | 13.9 |
| *Bulgaria* | 10.4 | 12.0 | 11.3 |
| *Sweden* | 9.0 | 13.1 | 11.3 |
| *Netherlands* | 8.8 | 11.6 | 10.3 |

Sources: Eurostat Data Explorer, data collected by EU-SILC data, 2011.
Note: Disability rate is calculated based on self-perceived, long-standing limitations in usual activities due to health problems. Only persons with 'severe' activity limitations are included here.

### 3.1.2 Eligibility

This section presents issues related to eligibility for services and evaluation of LTC needs across the five care regimes.

- Eligibility and access
- Evaluation of LTC needs

Eligibility criteria for LTC services vary by care regime and by country. In general, citizens of the Care-mix and Universal regimes and registered residents of have a right specifically to LTC benefits, regardless of their age or income. In other words, eligibility is not means tested, though in some cases means testing may be used for specific types of benefits. LTC in these countries is also not only reserved for older persons, but rather is a distinct form of care available to persons of all ages in need of care over an extended period of time. In Germany, one requirement for eligibility is that the individual be insured for a certain amount of time prior to submitting a request for services.

Conversely, of the Family-based countries, LTC is guaranteed only in Spain, while Italy, Greece and Portugal all incorporate means testing into certain components of care provision (e.g. cash benefits are determined in part by income level in PT). These kinds of regulations related to eligibility are closely tied to the socio-political principles governing care provision in these countries. Approximately 80 per cent of older persons receive care informally from family members in these countries, with only the remaining 20 per cent of the older population receiving formal care services, formal care is geared toward those who have limited financial resources and those with little to no family available to assist them. Italy is unique within the Family-based care regime due to the regional variation that exists in eligibility criteria for LTC and in evaluation of care needs. This variation at the regional level is consistent with the fragmented nature of Italy's LTC system as a whole, and may lead to regional inequality in access, an issue that will be addressed in the following section.

The picture is also mixed in the Transition regime, though care is generally not guaranteed to all. Romania and Bulgaria both guarantee care for older persons and for the disabled (although Bulgaria does take income into consideration in calculating the fee-for-service amount), while Lithuania and Latvia (unlike Estonia), use means testing to determine eligibility for care services that are free at point of use (and for the amount of cash benefits). It should also be noted, that in countries in which legislation stipulating LTC as a form of care distinct from health and social care does not exist, eligibility for long-term care is assessed within the frameworks of either health care or social care provision, or both. This is true for all of the countries included in the Transition care regime. For example, in Bulgaria, legislation explicitly addressing LTC does not exist and as a result care needs are assessed within the framework of illness and disability. On the other hand, in Romania, LTC is defined as care that is provided for longer than 60 consecutive days and which consists of care tasks intended to provide support to the beneficiary in carrying out basic and instrumental activities of daily living (ADL/IADL). Because LTC needs are incorporated into general illness and disability needs in Bulgaria, age is not a factor in determining eligibility. In Romania and Hungary, however, in order to be eligible for public LTC services, a basic requirement is that the individual be of standard retirement age or older. Home care in Hungary is regulated by Social Welfare Act III, 1993 and its amendments (see Section 2.1). Older people 60 years and older, and disabled people of all ages, have the right to receive basic home care as part of social care services. Local governments are obliged to provide these LTC services (home care/assistance, meal delivery, etc.), and though means testing is generally

conducted, local governments decide the scales of fees. Typically, persons with minimum or low pensions receive the services free of charge. The level of need is assessed by home carers. Despite eligibility being guaranteed for the target group, many local governments do not have sufficient financial resources to provide home care free of charge. As a result, administrators have been known to increase fees leading many older people to cancel services. Home nursing care, on the other hand, is evaluated within the health system (by GP's and nurses) and is financed by the Health Insurance Fund. Lithuania's eligibility criteria are comparable to that of Bulgaria's. As care is means tested, once a person's income and level of self-sufficiency has been evaluated, s/he is eligible to receive either long-term medical care through the health sector and provided by nursing services, or, if the person meets disability criteria, social care at home, in a day-care centre, or in an institution. Similarly, in Latvia, LTC is integrated within health and social services for the elderly, children and the disabled and eligibility is granted to all permanent residents of the country. As payment for services are means-tested, however, an individual may end up having to pay a substantial fee out-of-pocket.

Particularly in those countries where LTC services (and cash transfers) are means tested, access to care is a fundamental issue. This is true in the Transition countries of Lithuania and Latvia, and in Portugal and Greece within the Family-based regime. In Lithuania, persons who are eligible for residential care based on evaluation of their care need are often unable to pay for services which range from 430-740 EUR per month, while the median income of persons aged 65+ living alone was 194.08 EUR per month in 2009 (European Commission, 2012b). In an effort to increase affordability and thereby access, special compensation for nursing and care (assistance) expenses are granted to persons of retirement age if a need for long-term nursing or assistance is determined. Whereas cash benefits are not means tested in the case of long-term care in an institution, eligibility for the special compensation does depend on the person's ability to pay for the long-term social care. If the person spends at least one-third of the set fee on long-term social care, a certain part of the benefit is paid to the institution (European Commission, 2013b). In Latvia, the private user is responsible for paying for all social care services out-of-pocket, unless their income is insufficient in which case services are fully or partly covered by municipalities. In Portugal, recent reforms to cash benefits amounts and eligibility have been undertaken in an effort to ease the burden on private users. Nonetheless, eligibility and access to in-kind services is relatively restricted. Publicly subsidized home care services and day-care centres are means tested which means that only very low income families are entitled to services free at point-of-use.

An assessment of care needs is generally required before provision of services or granting of cash benefits is approved. In all the selected countries, assessments are carried out by a qualified professional in the health and/or the social care field, and in many cases by multidisciplinary teams of specialised medical doctors, psychologists, nurses, and social workers. Again, in those countries in which LTC is under the auspices of health and/or social care, multiple assessments by professionals from both sectors may be necessary. This is most often the case in the Transition countries. On the other hand, the need for social services is evaluated by social workers using a different rubric. This is also the case in Latvia and Lithuania. In Estonia, access to social benefits is determined by the severity of disability, which is assessed by the Social Insurance Board based on the medical records and the patient's self-reported condition (state of health, functional capacity and living environment, available help, the need for supervision). Romania is an exception, however, in that assessment of LTC need is conducted by medical doctors and social workers working together and using an integrated methodology. Within the family-based regime, Italy is a unique case in that the needs assessments for LTC services are carried out by a multidisciplinary team specialising in geriatrics

whereas the assessment for cash benefits – which are provided directly to the user by the national-level social security fund – is carried out at the regional level by way of a geriatric and disability assessment unit, with variance in the composition of the commission by region.

Recent reforms in Spain have introduced a classification system with three levels of support according to the intensity of help needed to perform the activities of daily living (ADL): moderate, severe and major dependency (Gutiérrez et al., 2010). The uniformity of the assessment criteria is guaranteed by use of a 'scorecard' which is standardised across the country by the national coordinating body (i.e. the Territorial Council). The board takes into account the ADL scale, personal care items (bathing, feeding, etc.), mobility (inside and outside the home) and mental status (e.g. ability to make decisions). The assessment of individual cases is made by local committees, and the information collected is subsequently used to define the individualised care plan. Each case is evaluated and assigned a rating. To be eligible, a minimum score of 25 is required out of a possible score of 100. The three categories of dependence are each divided into two sub-categories defined by the values of the disability scores (Gutiérrez et al., 2010). In Portugal, the process of evaluating a person's long-term care need is undertaken either by a hospital discharge management team or by a health centre's multidisciplinary team of professionals. The final certification of the degree of dependency and the amount of the dependency allowance is provided by a team of two or three medical experts affiliated with the country's social security institution.[5] In Greece, the level of incapacity (50%, 67% or 80%), which determines the level of care provision, is evaluated by the Centres for Certifying Incapacity (KEPA). Since 2011, the certification process is the responsibility of the Social insurance Organization (IKA).

In almost all cases, physical disability (assessed according the individual's ability to complete daily activities independently) and level of autonomy/dependency are the primary considerations in determining the level of care need. Definitions of disability and dependency can vary, however. In Germany, for example, the definition of dependency is quite restrictive, with the result that people with dementia may not qualify for LTC benefits because they do not necessarily require assistance with activities of daily living, though they may require supervision (Rothgang, 2010). Consequently, Germany is taking steps to incorporate dementia further into its assessment of LTC need (see Section 2.2 above on implementation of the LTC reform starting in 2015). In most countries across the five care regimes, a person qualifying for LTC is assigned to one of multiple levels of care depending on the intensity and type of care they require. This is true both for services and for cash benefits. As was discussed above, countries in which LTC is means tested, persons who submit a request for care are evaluated not only based on their physical and psychological condition, but also on the financial resources at their disposal.

[5] Portuguese Ministry of Solidarity and Social Security, Law Decree n. 360/97: http://www.igf.min-financas.pt/Leggeraldocs/DL_360_97.htm

## 3.2 Coverage of care needs

This section addresses the coverage of care needs, or the extent to which the need for care in the selected countries is met by formal care services and cash benefits. The proportion of LTC beneficiaries over the age of 65 will be discussed, as will the proportion of beneficiaries broken down by type of LTC benefits. Lastly, issues related to unmet LTC needs will be noted.

- Proportion of LTC beneficiaries aged 65 and older
- Proportion of beneficiaries by type of service

### 3.2.1 Proportion of LTC beneficiaries

As can be seen in Table 3.3, the proportion of older people over 65 years of age who are beneficiaries of formal, publicly subsidised LTC services and facilities is relatively small. There is clearly a connection between expenditure and the number of beneficiaries in that Universal and Care-mix regime countries generally cover a higher share of older people. However, neither the correlation between public expenditure and the number of beneficiaries, nor between these numbers and self-perceived limitations (see Table 3.2 on disability rates) may be attributed to specific care regimes. Due to the different national schemes that are linked to various eligibility criteria and assessment procedures mentioned above, coverage rates show diverse patterns that cut across care regimes.

**Table 3.3 Number of beneficiaries of LTC services**

| Country | N 65+ beneficiaries of LTC | | | N beneficiaries of LTC 65+ as proportion of total population 65+ (%) | | |
|---|---|---|---|---|---|---|
| | Male | Female | Total | Male | Female | Total |
| *Austria (2012, 60+)* | 107,482 | 253,662 | 361,144 | 12.2 | 22.4 | 17.9 |
| *Germany (2011)* | 634,222 | 1,445,052 | 2,079,274 | 8.8 | 15.0 | 12.3 |
| *Netherlands (2009)* | 146,370 | 336,320 | 482,680 | 13.6 | 24.0 | 19.5 |
| *Estonia (2009)* | 5,825 | 12,044 | 17,869 | 7.6 | 7.8 | 7.8 |
| *Spain (2012)* | 175,955 | 489,379 | 665,334 | 5.0 | 10.5 | 8.1 |
| *Portugal (2012)* | 10,852 | 15,803 | 26,655 | 1.3 | 1.3 | 1.3 |
| *Hungary (2009)* | 43,982 | 120,906 | 164,888 | 7.3 | 11.6 | 10.1 |
| *Czech Republic (2009)* | 53,483 | 152,259 | 205,742 | 8.8 | 16.5 | 13.5 |
| *Slovak Republic (2008)* | n/a | n/a | 43,288 | - | - | 6.7 |
| *Finland (2009)* | 30,808 | 77,116 | 107,924 | 8.3 | 14.6 | 12.0 |
| *Sweden (2007/08)* | 76,616 | 172,259 | 248,875 | 10.6 | 18.9 | 15.2 |
| *Bulgaria (2007/08)* | n/a | n/a | 50,908 | - | - | 3.9 |
| *Romania (2010)* | n/a | n/a | 38,477 | - | - | 1.2 |
| *Italy (2010)* | n/a | n/a | 1,751,005 | - | - | 14.3 |
| *Greece* | n/a | n/a | n/a | - | - | - |
| *Lithuania (2008)* | 2,322 | 6,121 | 8,443 | 1.3 | 1.7 | 1.6 |
| *Latvia (2010)* | n/a | n/a | 20,681 | - | - | 5.3 |
| *United Kingdom* | | | | | | 17.5 |

Sources: National sources; OECD Health Data 2009, Eurostat; own calculations.

For instance, according to OECD Health data, in the Czech Republic a higher share of the older population is eligible for LTC benefits than in Germany. The same is true for Austria in relation to the Netherlands and Sweden or for Italy in relation to Finland. Although some of these variations may be

explained by obvious flaws in existing data, it can be deduced that some countries – in particular those representing the Universal care-regime – are targeting their resources to restricted groups, mainly ones with the most intense care needs, and on services rather than cash benefits. While some countries are covering a larger number of beneficiaries with 'low-cost' benefits, others invest larger amounts in more costly services and facilities. For instance, Italy reports the highest figures of all Family-based care regime countries with 14.3% of people aged 65 and older receiving public support, though in the majority of cases by means of cash benefits. While this indicator moves Italy close to the Care-mix regime countries, with 17.9% of people aged 60 and over receiving benefits in Austria (again, with a focus on cash benefits), Spain too has increased its coverage rate to more than 8%. Considering that persons 65 and older make up a significant portion of the total population in most countries (see section 3.1.1 on *Need for care* above), the low levels of coverage in most of the selected countries indicate a potential lack in formal services and a strong reliance on informal care. This is particularly true in the case of the Family-based care regime where a proportionally large older population reporting limitations is contrasted with very low levels of formal care provision.

It should be noted once more, however, that national sources collecting data in this area varied considerably in their parameters and methodology – particularly in the selected age range of beneficiaries — making comparability of information difficult.

### 3.2.2 Proportion of beneficiaries by type of service

Building on the above considerations it is important to take account of the different types of benefits in cash and in kind that are provided. Countries with the highest coverage rates are often those representing Care-mix regimes in which beneficiaries of cash benefits occupy the largest share of LTC beneficiaries. While Universal care regime countries have, in general, successfully decreased the share of people in residential care over the past two decades, the Netherlands, Sweden and Finland still rank high in their provision of residential care, but they are also leading in the provision of home care services. Still, considering that, for instance, Sweden spends more than 60% of its LTC expenditures on about 38% beneficiaries (Rodrigues et al., 2012), there is still some way to go to realise the objectives of 'ageing in place'.

The low rate of older people living in residential care hints once more to the importance of informal care in Family-based care regimes and in the Transition countries. While in some countries the basic infrastructure is still scarce, this could also be seen as an opportunity to further develop alternative pathways, e.g. by expanding community care services rather than residential facilities. As a general tendency it can be observed that governments – generally declaring community care as a priority against residential care – are still 'muddling through' rather than designing strategies towards a coordinated mix between various types of long-term care.

Currently, the vacuum between family care and formal care services that may be observed in a number of countries, is often filled by 'migrant carers', e.g. in Italy, Spain and Austria, mainly from the Transition countries. In a European perspective this phenomenon is of major importance, as it is likely that human resources to develop LTC delivery in the sending countries will be missing in a mid-term perspective (see also section 3.3.3 on *Provisions for migrant carers*).

**Table 3.4 Proportion of beneficiaries of LTC by type of benefit and service (in %), selected countries**

| Country | Home care | Cash benefits | Residential Care |
|---|---|---|---|
| *Germany* | 47.3 | 23.0 | 29.7 |
| *Portugal* | 68.4 | | 31.6 |
| *Hungary* | 69.9 | | 30.1 |
| *Czech Republic* | 83.3 | | 16.7 |
| *Slovak Republic* | 51.9 | | 48.1 |
| *Finland* | 60.2 | | 39.8 |
| *Sweden* | 61.6 | | 38.4 |
| *Bulgaria* | 77.0 | | 23.0 |
| *Italy* | 27.6 | 57.7 | 14.7 |
| *Lithuania* | 35.3 | | 64.7 |
| *Latvia* | 47.2 | | 52.8 |

Sources: OECD Health Data 2009; National data.

## 3.3 Care Leave

The different types of leave available to carers across the selected countries are addressed in this section. Specifically the following forms of care will be covered:

- Paid and unpaid leave
- Other provisions to support informal carers
- Provisions for migrant carers

### 3.3.1 Paid and unpaid leave

There is considerable variation between countries and regimes in terms of the leave that is guaranteed to carers, and in the degree to which governments seek to support persons juggling both employment and informal care. Austria offers the most generous benefits in this regard; since 2014 up to three months per year of paid leave may be agreed between employee and employer, if the former cares for a person with severe care needs (also part-time arrangements are possible). The employee remains covered by social insurance and receives a benefit replacing 55% of his/her last income during that period. In Germany, the allowance for unpaid leave is the same as in Austria, but paid leave is more restricted, available for up to ten days on short notice in the event that a family member suddenly falls ill. Only employers with 15 or more employees are obligated to provide paid leave, and the continuation of remuneration past the first 10 days is only required of the employer if they are bound by some other statutory provision or by a prior agreement between them and the employee.[6] In 2012, new legislation for employees with caring responsibilities at home came into effect. Employees with a family member in need of care at home are allowed to reduce their working hours to a minimum of 15 hours per week during a maximum period of two years, to be agreed upon with their employer. Employers can increase an employee's reduced salary by up to half of the difference between the old and new salaries with an interest free credit from the Federal Office for Family and Social Responsibilities (*Bundesamt für Familie und gesellschaftliche Aufgaben)*. Returning to work post-leave, the employee must work full-time until the credit is paid back. The government has indicated its intention to further promote reconciliation of work and informal care

[6] More details on care leave legislation available here: http://www.gesetze-im-internet.de/pflegezg/index.html

responsibilities (Council of the European Union, 2014). The legislation also states that employees are protected from dismissal before and after taking care leave.

In the Family-based countries, a distinction is made in the cases of Spain and Portugal between care leave for public sector workers and those working in the private sector. In practice, this means that in the private sector the employer has the power to accept or reject the employee's request for care leave. For those working in the private sector in Spain, unpaid leave, which is available for up to two years, is more often than not conditional on the approval of the employer. In Portugal, public sector workers receive partial remuneration of their salary for up to fifteen days of leave, while employees of private companies receive this same amount of days unpaid. An additional fifteen days per year of unpaid leave are available in Portugal for all employees looking after a relative suffering from a chronic condition. In Italy, employees are eligible for three days per month of paid leave, but only if the family member they are caring for is disabled. Since 2011, paid leave is available to parents of children with disabilities, and in 2013 a law was passed expanding the target beneficiaries: in special cases, a child living with a disabled parent may obtain paid leave in the event that the care cannot be provided by the spouse of the disabled person. Unpaid leave is available for a longer period of time; again however, this is often conditional on approval by the employer. Eligibility for paid leave in Greece is also contingent on the family member being certified disabled. Employees are allowed to work one hour less per day in these cases. Also, if an employee has a child who requires routine therapy/medical attention, they may take up to twenty-two days per year in paid leave. Six days of unpaid leave per year are guaranteed in the case of illness of a family member.

The Transition countries have minimal provisions at the national level for employees in terms of care leave. Slovakia offers neither paid nor unpaid leave for employees providing informal long-term care to family members. In Hungary, paid leave is not guaranteed. Under the provisions of Act 1 of the 2012 Constitution, however, persons with an older relative are entitled to 2 years of unpaid leave, whether the employee has a fixed-term or indefinite contract. The employee is asked to indicate the approximate length of their absence so that the employer can hire a replacement for that period of time. In the Czech Republic employees may work with their employers to adapt their working time to accommodate caring responsibilities in cases of children and/or other dependent family members. While the Czech Republic guarantees neither paid nor unpaid care leave to employees, Czech legislation concerning sickness insurance enables insured employees to collect Attendance Allowance (i.e. care allowance). This law provides something of a loophole whereby the attendance allowance can, in practice, be considered 'paid care leave' if the caregiver and person receiving sickness leave reside in one household. In Bulgaria and Romania, legislation exists governing both paid and unpaid leave, though the duration of leave is sometimes conditional on a variety of factors. In Romania, paid leave to care for a spouse or another dependent relative is guaranteed. Leave is granted on a part-time working basis and remuneration is the equivalent of the base salary of a social worker. Paid leave is funded by local authorities and the duration is not specified in advance as this depends on the availability of funds at the local level. The length of the unpaid leave is specified in collective labour agreements or in the rules of procedure. In Bulgaria, paid leave up to 40 days per year is granted in the event of illness of a family member, including an older person in need of care. Unpaid leave of up to thirty days per year is available, though it is conditional on the approval of the employer.

In Lithuania, the labour laws only specify the right to unpaid leave for caring for older persons and the disabled. Employees can take up to fourteen days per year of unpaid care leave, and up to thirty

days to take care of a family member with disabilities. Annual paid leave is implicit in certain legislation, however, and is available to all employees based on their length of employment. Estonia and Latvia both guarantee employees paid short-term care leave to care for an ill family member. In Latvia, the remuneration amount must be agreed to by both the employee and the employer. In Estonia, doctor certified paid care leave is available for 7 days, with 70 per cent of the salary guaranteed to the employees by the Health Insurance Fund. In Latvia on the other hand, unpaid leave is granted for an unspecified amount of time, conditional on the approval of the employer. In Estonia, from the 8$^{th}$ day unpaid leave is guaranteed for an unlimited period conditional on the provision of a doctor's certificate to the employer. Legislation governing employment also allows employees short leave from work for family reasons.

### 3.3.2 Other provisions to support informal carers

Other forms of leave are provided in some of the countries represented here, both for employees attempting to reconcile work and care, as well as support for informal carers who do not participate in the labour market. Bulgaria and Romania both offer flexible working times to employees who have family members requiring care, as does Latvia, however flexible work schemes must be negotiated between the employer and the employee. Similarly, in Estonia, no other provisions exist to support informal carers, but employers and employees may agree on flexible working times on a case by case basis. Furthermore, Romania has introduced a specific scheme titled 'Personal Assistance' that allows people with severe disabilities at any age to employ a personal assistant who may also be a family member. The personal assistant is then employed by the local council with a wage at the level of a junior social worker.

Austria and Germany both provide respite care for informal carers for a certain number of weeks per year, and Portugal offers ninety days per year of residential care services to take over from informal carers in need of respite from their care responsibilities. Slovakia also guarantees respite care of up to thirty days per year, though only for those carers looking after someone with a severe disability. Slovakia, as well as Hungary and the Czech Republic all offer a carer's allowance to support informal carers.

A number of the Family-based countries also allow for flexible working time for informal carers. In Greece, civil servants who are also informal carers have the option to work one hour less per day without a reduction in salary (Kazassi and Karamessini, 2013). In Italy, most of the support measures for informal caregivers exist not at the national level but rather are defined by the individual regions. In general, they promote education and support groups for relatives, economic contributions to the payment of taxes in residential homes, vouchers and other social and health initiatives (Triantafillou et al., 2010). The same is true in Spain, where, however, the national system provides insurance coverage for carers (Casanova, 2010).

### 3.3.3 Provisions for migrant carers

Only Austria and Germany in the Care-mix regime make special provisions for migrant carers working in LTC. There has been considerable effort in recent years in Germany and particularly Austria[7] to regularise or 'legalise' those migrant carers who are undocumented in their host country, due to the

[7] Personal Carer's Act, 2007 (BGBl. I Nr. 33/2007)

fact that migrant carers constitute a significant share of the informal care workforce in both countries (Schmidt et al., 2013). In Germany, as of May 2011 legislation governing the "free movement of workers" from the central and eastern EU member states came into force (excluding citizens of Romania and Bulgaria who remain subject to employment restrictions). The law enables foreign workers to be employed in a German household for up to three years as providers of nursing care and domestic tasks (German Federal Labour Office, 2013). At present, Germany actively recruits carers primarily from Spain, Portugal and Italy (Merda, 2013). In Austria, migrant carers were incentivised to register as self-employed in order to receive social insurance benefits. In the remaining countries, the same rules and provisions apply to migrant carers as to other informal carers, thus often remaining in an unregulated situation.

### 3.4 ICT use

The use of information and communication technologies has only recently started in the LTC sector in Austria, mainly via the use of smart phones and personal computers to improve administration and coordination. Still, the use of Internet and PCs in private households is widespread also in households of the 'younger' pensioner, so it can be assumed that informal carers will increasingly use the Internet and social networks for searching and exchanging experiences. The Ministry of Transport, Innovation and Technology initiated a programme called the 'benefit programme' to support projects that develop ICT for innovative products and services for older people.

In Germany, 18 pilot projects with a focus on Ambient Assisted Living (AAL) and 12 assisted care pilot projects receive funding from the Federal Ministry of Education and Research (Fachinger et al., 2012). Unfortunately most of these projects do not make it beyond the pilot phase due to poor integration of relevant stakeholders (a commonplace problem in the German Social insurance system), according to certain experts. A lack of communication and coordination between care service providers and the housing industry has proven to be a major obstacle in implementing AAL-Technologies, both in existing households and in new construction projects (Heinze, 2013). An added obstacle is that some older people are sceptical of and intimidated by technical innovations, as these systems can seem impersonal and too technical (ibid). It is expected that this attitude will change with subsequent generations, not only because of a greater familiarity with technical devices, but also due to the fact that as the pool of informal carers grows smaller, older persons may increasingly have to rely on technical support to enable them to retain a level of independence and remain at home (Fachinger et al., 2012). A concept known as Networked Living, whereby ICT systems are built into residences intended for older persons, is gaining popularity in Germany. The collaboration of different stakeholders and technology firms is an important feature of these programmes, and as a result some projects have encountered the same coordination challenges as were mentioned above. Many Networked Living initiatives have not developed beyond the pilot phase. Strong political support and action on several levels of government would be needed in order to successfully implement integrated, neighbourhood-based care structures (Heinze, 2013, p. 141).

Romania, Bulgaria and Hungary also developed several AAL projects with the declared objectives to develop the ICT skills of older people and of professionals working in health and social care. According to self-reported measures reported by people in several of the Transition countries and

collected by Eurostat, Internet/computer skill levels and frequency of use of ICT are relatively low, particularly among the 65-74 age group.[8] The lowest levels are reported in Romania, where in 2011 only 4% of individuals aged 65-74 years old judged their computer or Internet skills to be sufficient to communicate over the Internet below the European average of 26%, and 93% of individuals in the same age group had never used a computer, almost double the European average of 58%. Looking at the total population in Romania – which provides a basic if incomplete picture of the skill level of informal carers – 40% thought their Internet/computer skills were sufficient to communicate with over the Internet, again well below the European average of 66%. And 50% of respondents, regardless of age, had never used a computer, well above the European average of 21%.[9]

Bulgaria's numbers are only a slight improvement: in 2011, 6% of respondents in the 65-74 age bracket judged their computer or Internet skills to be sufficient to communicate over the internet and 89% of individuals between 65-74 years of age had never used a computer. Of the total population, 46% thought their Internet/computer skills were sufficient to communicate, and 45% had never used a computer.[10] In Latvia, according to the same survey in 2011, 13% of individuals aged between 65-74 years rated their computer or Internet skills to be sufficient to communicate over the Internet, and 79% of individuals aged between 65-74 years had never used a computer. Of the general population, 66% reported having sufficient skills to communicate, and 26% had never used a computer. Using different measures, Estonia reports that 68% of 65-74 year olds did not use computers and 69% did not use the Internet. In general, older persons living in rural areas were less likely to have developed Internet/computer skills and to engage with ICT devices than their counterparts living in more urban municipalities.

Information on ICT skill level and use is more limited from the other countries in the Transition care regime. Interviews conducted in Hungary as part of the EU-wide INNOVAGE project asked respondents questions about their ICT use (basic computer functions and programmes, and Internet) and about the ICT skill-level of informal carers and care professionals. The study proved to be a challenge in the Hungarian context because often neither the carers (informal and formal) nor the care recipients interviewed understood the questions that were posed to them, presumably because their ICT skill is very low. These findings imply that the level of use as well as the skill-level is basic or non-existent in the majority of cases, though the small sample surveyed is by no means representative of a particular age group or of the general population. A number of computer and internet literacy programmes targeted to senior citizens are trying to improve skill level, however, including 'Kattints rá nagyi!' (Click on it Granny!) 'Folytassa nagyi' (Carry on Granny), and 'nagyinet' (Grannynet).

In the Family-based care regime, the use of ICT by LTC professionals, informal carers and care recipients is low, though there is variation among the four countries both in terms of use and skill-level. Mobile phones are used to varying degrees by people between 65 and 75 years of age (42% in

[8] Eurostat, online data code for computer or Internet skills: isoc_sk_cskl_i; on-line data code regarding computer usage: isoc_ci_cfp_cu, extracted on 26.09.2013. In the absence of statistical data, respondents aged between 65-74 years were selected, considering that due to age they are potential LTC beneficiaries.

[9] In the absence of statistical data, all individuals were selected, regardless of age, considering that among them there are both informal/formal carers and potential informal/formal carers.

[10] Idem 9.

Greece, 51% in Portugal, 70% in Italy, and 58% in Spain)[11], opening up opportunities for mobile-based initiatives such as telecare, particularly in Spain where a number of telecare projects have already been developed. In all four countries there is still a strong divide in ICT use and skill-level between the younger and older generations, with Greece reporting the lowest rates of ICT use in the 65+ age group. To date, the primary achievements in integration of ICT in LTC services have been telecare initiatives that have been implemented or planned at the national (in Spain and Portugal) or local (Italy and Greece) level. A few publicly funded programmes to increase ICT use among older people have been designed in Portugal and Spain, while in Italy monitoring programmes such as the eCare network (Carretero et al., 2012) represent an initial attempt to overcome the fragmentation of activities developed at the local level, and to set up a national framework for ICT in LTC. In Greece, the tele-medicine unit of a public hospital provides comprehensive care to older persons living in a residential care facility with the use of equipment that files and transmits medical bio-signals, enables tele-consultations with physicians, and real-time communication among health professionals and patients (Mastroyiannakis and Kagialaris, 2010).

## 3.5 Agency

### 3.5.1 Key stakeholders

In Germany, key stakeholders include professional home care service providers (576,000 home care services in 2011), nursing homes (12,400 nursing homes in 2011), family members (in their capacity as informal carers and/or decision-makers) and national associations of the long-term care funds. Contracts regarding the provision and compensation of care services take place between the respective national associations and the responsible institutions of the nursing homes/ the home care service providers. Through these contract negotiations it is possible to regulate the type, quantity, costs and quality of benefits (Bäcker et al., 2010). Representation of professional interests (primarily geriatric nursing) is comparatively weak. A mere 10% of formal carers belong to a professional organisation. To strengthen the position of professional carers and to improve the situation in (geriatric) nursing the introduction of 'chambers of nursing' has been proposed by several bodies, including the Nursing Council (Deutscher Pflegerat) – the umbrella organisation for key professional organisations of nursing and midwifery in Germany – which advocates for the chambers of nursing (Pflegekammern) acting as independent, self-governing bodies.

The provider mix has changed significantly in Austria in recent years, bringing new stakeholders to the table and diminishing the role of others. This is particularly true in the area of residential care where private commercial groups have increased their influence. Furthermore, welfare organizations affiliated with religious institutions and political parties have joined forces and founded The Federation of Non-profit Organisations Providing Social Care (Bundesarbeitsgemeinschaft Freie Wohlfahrt). The federation developed quality criteria for community-based care – such as, for instance, a service charter, documentation and monitoring of professional processes, further training of staff, user orientation etc. – and has been involved in care reforms. In the context of the Austrian system of social partnership it is also important to mention that a voluntary federation of employers in social and health care (Berufsvereinigung von Arbeitgebern für Gesundheits- und Sozialberufe) was founded in 1997 with the main aim to establish a commonly agreed collective bargaining process for

[11] Eurostat, online computer code for mobile phone use: isoc_cias_ mph, extracted on 30.07.2014.

social care workers, with respective standards and levels of payment (www.bags-kv.at). Finally, since the 1990s, the Austrian Federation of Care Homes has contributed to quality improvement by introducing a special training for managers of care homes, and by promoting quality management resulting in the introduction of the voluntary National Quality Certificate for care homes in 2012.

In Denmark, the election of Senior Citizens Councils is a legal requirement in all Danish local authorities since 1996. This interest group was set up to function as a link between older persons and the local and national (then within the 'National Association of Senior Citizens Councils') stakeholders. The institution represents all Danish citizens aged 60+, including all persons in need of long-term care (Campbell and Wagner, 2009). The organisation must be consulted in all matters that affect persons over the age of 60.

In the countries of the Transition regime, long-term care has multiple actors and stakeholders. In all countries the state is an important stakeholder despite the fact that it typically passes the burden of LTC provision and financing to families. None of the countries offer long-term support for informal carers, although certain benefits do exist in rudimentary form, often incorporated into legislation targeting other types of carers and care recipients (the disabled, children). As a result, in many of these countries, NGOs and charity organisations have stepped in as crucial providers of care and have established themselves as key stakeholders in the LTC system. In the case of Hungary in particular a striking withdrawal of the state from social service provision, combined with a centralisation in the organisation of surviving public services can be observed. The Hungarian Maltese Charity Service and Zivot 90 in the Czech Republic – two of the largest charity organisations in their respective countries – have been active for a long time and have worked to develop important innovative solutions in LTC. The Hungarian Maltese Charity Services' latest innovation has focused exclusively on informal family carers. In addition, the Hungarian Jewish Social Support Foundation (JOINT) designed a home care model in 1994, which was later incorporated into home care services provided by the healthcare system.[12] One non-profit umbrella organisations promoting productive retirement, 'Életet az éveknek' (Life to Years), has almost 1,200 member organisations. The National Association of Hungarian Pensioners, also a large umbrella organisation, has 1,200 member associations and undertakes a wide range of activities to advance the interests of its target group, though it does not operate any programmes in the area of LTC. Another organisation in the Czech Republic, the Alzheimer Society, has an important role in identifying challenges related to dementia and Alzheimer's disease in the older population and in raising public and political awareness. Slovakia's LTC system demonstrates a pattern in which the presence of both the state and NGOs is limited, and responsibility for care is laid even more fully on family members.

In Bulgaria, there are very few participative bodies that directly target older people and address the issue of LTC (AGE Platform Europe, 2010). Instead, there exist public councils that bring together all citizens to facilitate their participation in policy-making. These public councils are voluntary and independent and exist at national, regional, municipal and community levels. The community level councils implement the widest range of initiatives, including initiatives that address problems faced by particular population groups such as older people. One example is the Public Council for Older

[12] The home care model described here was incorporated into the *Elderly-friendly Housing Model* which was implemented as a pilot programme between 2003-2005 with the support of the Ministry of Social and Labour Affairs. For more information, see the full description of the *Elderly-friendly Housing Model* in Annex I.

People established in the municipality of Russe (chaired by the mayor) where various organisations working with and for older people jointly discuss possible actions. In 2010, representatives of more than 20 civil society organisations from all over the country, working with and for older people, set up an informal network to strengthen the social inclusion of older persons. An important part of its activities concerns the promotion of older people's participation in the process of policy development. The network is open to every organisation working on behalf of senior citizens that is interested in sharing information and cooperating with peer organisations across the country. The network empowers its members to participate actively in lobbying policymakers i.e. promoting their positions and lobbying national and local authorities and institutions. Another important stakeholder is the Civil Participation Forum, an independent and informal platform for nongovernmental organisations seeking to influence government policy. The Forum also acts as a watchdog and puts pressure on government authorities to involve citizens in the development and implementation of its policies (including LTC for older persons).

In Latvia, the Federation of Pensioners is one of the organisations most frequently consulted by the government and the parliament on policy and legislation related to pensioners and older people. It was established in 1992 to defend the right of elderly to a dignified life and unites 82 pensioners' organizations to defend the interests of this group. Latvia is also a member of the European Association for Directors and Providers of Long-Term Care Services for the Elderly. In Romania, the Ministry of Labour, Family, Social Protection and the Elderly is a specialized body of the central public administration that coordinates strategy and government policies in the areas of work, family, and social protection for older people. Older persons are represented by the National Council of the Elderly, a public autonomous body for consultation and social dialogue in order to ensure that central and local authorities protect the rights and freedoms of older persons. Councils of older persons exist in all counties, as well as in Bucharest. As in many other countries, the non-profit sector plays an important role. Within the framework of the project 'For Our Seniors – network of NGOs providing social services for the elderly' a network of NGOs involved in assistance programmes for older persons was created in order to develop common action at the national level with the aim of improving quality of life and promoting the rights of older people. Romania is also member of the European Association for Directors and Providers of Long-Term Care Services for the Elderly. The Estonian health system has developed with the strong participation of professional organizations and, increasingly, patient organizations which have gained more influence in recent years. Estonia has received international acclaim for its energetic health reforms and the efficiency gains it has made, but major challenges persist regarding patient empowerment issues, among others (Koppel et al., 2008).

In Lithuania, in addition to stakeholders at the central government level, the local municipalities are key actors as they have the right to delegate LTC organisational functions to local providers of nursing and social care.[13]

The provision of LTC services to older people in the Family-based care regime countries is fragmented and involves a plurality of actors and stakeholders. The predominant mode of

[13] According to legislation in chapter IV, section 19; http://sena.sam.lt/lt/main/teisine_informacija/ministro_isakymai?id=45223.

governance is the traditional state or public sector coordination based on a hierarchy of command and a division of responsibilities between central and local authorities. Nevertheless civil society organizations have a presence in all four countries represented, including the non-profit sector as well as networks and partnerships between different institutional bodies within the public, and both the private for-profit and non-profit sectors (Vabo, 2010). In Italy, governance of the LTC system is divided between the National Health Service and municipalities. The stakeholders involved are the central government, regional governments, local health authorities, municipalities and provinces, but the regional governments have a great deal of autonomy and are perhaps the single most important stakeholder. Similarly in Spain, LTC provision revolves around collaboration between the state and the autonomous communities. Two bodies, the Territorial Council and the Consultative Advisory Committee bring together policymakers, trade unions and professional and patient organisations in the sector. The organizational structure of the Portuguese LTC system combines the responsibility of the Ministry of Health and the Ministry of Labour and Social Solidarity, as well as the municipalities and the private sector. Therefore, it articulates a hierarchical mode of governance with elements of self-organization (Jessop, 1999; Vabo, 2010) involving several stakeholders. In Greece, health and social care are integrated under the leadership of one Ministry, which acts as the central stakeholder. Nevertheless, the Greek system also involves the Peripheral Health and Welfare Systems (PESYO), which are state bodies that act as autonomous, regional, de-centralised units of health and social care provision (Kagialiaris et al., 2010); and the municipalities which are responsible for providing and managing public social care services as well as services from the private and the voluntary sectors (Mastroyiannakis et al., 2010).

### 3.5.2 Decision-making responsibility

In Austria, long-term care has challenged the traditional patterns of multi-level governance in Austria over the past twenty years. To begin with, the introduction of the long-term care allowance has created a new hybrid form of tax-funded social benefit had been created (rather than a 'fifth' pillar in the social insurance system). Secondly, the instrument of 'state contracts' between the federal government and the regional administrations had to be used to re-regulate an area that had hitherto been an exclusive responsibility of the latter. In Denmark, the central government is responsible for dictating the principles that underpin the long-term care system. Local authorities are responsible for the delivery of LTC services, for making and implementing LTC policy and deciding how LTC resources are allocated. Due to the fact that formal care is emphasised over informal care by Denmark's agency for Long-Term Care Services, public authorities play a significant role in the provision of all kinds of LTC. Despite the emphasis on formal LTC, informal carers are also supported by the local authorities in that they can claim compensation for lost wages due to care obligations in the form of a cash allowance. The local council is ultimately responsible for determining whether or not an applicant qualifies for the care allowance. Finland's LTC decision-making framework is similar to Denmark's in that the organization and provision of long-term care is the responsibility of local authorities. There are currently about 320 municipalities with a median size of about 6,000 inhabitants. Municipal services for the elderly include home care, support for informal care, serviced housing, institutional care, preventive care services and rehabilitation. A municipality can provide the services independently, together with other municipalities or purchase services from private sector providers. Due to the decision-making autonomy granted to municipalities, policies related to long-term care vary considerably across municipalities, particularly regarding the balance between home care and institutional services. Local government also sets the means-tested fees for certain services, e.g. service housing, as well as the level of subsidies for informal family care. In order to maintain a

degree of oversight and ensure a certain standard of care, the central government passed legislation to guarantee a minimum level of service in 2013.[14] In addition, the law includes a set of good practices that municipalities are required to follow.

In both Bulgaria and Latvia, central and regional and local government levels are responsible for decision-making regarding long term care for older persons (Riedel and Kraus, 2011). As was mentioned in the previous section concerning stakeholders, in addition to government authorities at the national, regional, and municipal level, the public councils are important bodies in the decision-making process. Long-term care management and organisation in Latvia is managed by the state, municipalities and the social service providers on three levels. The first level involves the Ministry of Welfare and the Ministry of Health in terms of legislation, policies and standards as well as monitoring. Social service initiatives, special programmes and proposals for new services are developed at the second level by municipalities. In Romania, long-term care is centrally organized and central levels are responsible for decision-making, but most formal LTC responsibilities have been transferred to local authorities; the financing mechanism combines central and local resources with NGOs playing an important role in the delivery of services. The government ensures the provision of LTC in Romania through the Ministry of Labour, Family, Social Protection and Elderly in cooperation with the Ministry of Public Health, which are represented at the county levels by the county councils and local councils, respectively. Similarly in Hungary, legislation at the central level provides the framework for public service provision in the form of the Social Welfare Act of 1993 stipulating that home care is mandatory responsibility of local governments. Though the mandate is handed down from the central authorities, local governments have autonomy in determining financial scales.

In Estonia, stewardship and supervision as well as health policy development are the duties of the Ministry of Social Affairs and its affiliate agencies. The financing of health care is mainly organized through the independent health insurance fund. The Ministry of Social Affairs and its agencies are responsible for the financing and management of public health services, that is, the share paid by the state budget. Local municipalities have a minor, rather voluntary, role in organizing and financing health services. The organisation of LTC is generally managed by the local municipalities, which means that the organization of the services range and quality is highly dependent on the capability of the local municipality. The Ministry of Social Affairs has drafted recommended guidelines concerning LTC for the local municipalities to follow, but this does not guarantee that all the services are available in every municipality. The main pitfall of the Estonian LTC system is that service provision depends on the financial capacity of the local municipalities. This results in an uneven quality of services and differences in the level of cost-sharing. The major decision-makers in the organization of LTC in Lithuania include the Ministry of Health, the Ministry of Social Security and Labour and its Department of Supervision of Social Services. The latter is directly responsible for administering social services, designing and implementing various governmental social programs and projects, as well as policy-making. The goal of the department in relation to older persons is to ensure their successful integration into society and to help protect their rights. The department is also responsible

[14] Act No. 980/2012 on Supporting the Functional Capacity of the Older Population and on Social and Health Care Services for Older Persons.

for the monitoring, assessment and supervision of social services provided at the state and local self-governance levels.

Despite the hierarchical structure of governance that is common to all, the Family-based countries vary in the degree to which decision-making is centralized, i.e. in terms of the variety of institutions and organisations with responsibilities for LTC coordination and service delivery (Allen et al., 2011). In Italy, decision-making regarding service management and provision is highly decentralized, resulting in a transfer of authority and funding responsibility for LTC from a national to a sub-national level. This governance strategy is intended to respond to region-specific care needs and to bring the service provision process closer to users in order to reduce logistical and bureaucratic obstacles. By contrast, in Spain, Portugal and Greece, decision-making authority is largely left to national-level bodies based on a framework that seeks to standardise care practices and maintain a certain level of quality. Nevertheless, the degree of centralisation varies across these latter three countries also, with the greatest variation occurring between Spain and the remaining two countries. Controlled and supervised by a territorial council, the decision-making process in Spain regarding LTC is characterised by a high degree of regional autonomy, though the central organising body, the Ministry of Health, Social Services and Equality has ultimate responsibility for managing the care system. This kind of mixed system is evident when we look at the Spanish system's three care levels: the first is defined by the central government and is implemented across the whole country. The second level is proposed by each autonomous community (AC) and is implemented jointly by the regional and national authorities only within the jurisdiction of the AC. The third care level is optional and is defined, managed and implemented solely by the AC. The second and third levels of care are considered regional care levels, while the first is a basic level of care and is guaranteed throughout Spain.

While each autonomous community defines its own system in Italy's decentralised system, in both Portugal and Greece a national entity exists which enforces a degree of homogeneity/standardization in social care regulation by requiring and evaluating minimum standards of quality in care provision throughout the country. In addition to differences in the level of government at which decision-making takes place, there are also differences regarding the number of levels of government involved and the level of health and social care integration in the country. The number of levels of government involved is directly related to the level of centralization; the more decentralised the country, the more levels are included in the vertical structure. Therefore, Italy has the largest number of stakeholders (5), followed by Spain (4) and finally Portugal and Greece (both with 3 levels).

The organizational structure of the Italian LTC system is split between the National Health Service (SSN) and the municipalities. The stakeholders involved are the central government, regional governments, local health authorities, municipalities and provinces. At the managerial level, Spain chooses the path of inter-institutional collaboration between the State and the Autonomous Communities (such as the Italian Regions) identifying two coordination bodies:

- The Territorial Council is tasked with managing inter-institutional coordination. It defines the performance and services, access policy and co-payment, control instruments (monitoring and evaluation) and carries out the overall action plan.
- The Comité Consultative advisory body aims to make institutional participation of representative organisations real and permanent. Consisting of government agencies, trade unions and

organisations operating within the sector, the committee discusses and makes proposals to the Territorial Council.

The organisational structure of the Portuguese LTC system combines responsibilities of both the Ministry of Health and the Ministry of Labour and Social Solidarity, as well as of municipalities and the third sector. Therefore, it articulates a hierarchical mode of governance with elements of self-organization (Jessop, 1999; Vabo, 2010), involving several stakeholders. In Greece, health and social care are both integrated under the leadership of one Ministry, which is the central point for decision-making. It involves, nevertheless, different stakeholders at three main levels:

- The Ministry of Health and Social Solidarity is responsible for the development of policies, service planning, as well as for the provision and financing of the National Health System and health and social services for the poor, elderly and disabled.
- Peripheral Health and Welfare systems (PESYO) are state bodies that act as autonomous, regional, de-centralised units of health and social care provision. They also monitor and regulate the legality and quality of services provided by NGOs, which have a significant role covering welfare system inadequacies and as state partners in the provision of some social services (Kagialiaris et al., 2010).
- Municipalities are responsible for providing and managing public social care services as well as services from the private and voluntary sectors (private non-profit sector). The new law enables authorities to design and develop LTC services, however these services come under the direct supervision of the PESYO and the Ministry of Health and Social Solidarity (Mastroyiannalis et al., 2010).

Finally, the degree of integration of health and social care also varies across the Family-based countries. In Italy and Greece, these two areas of care are highly integrated due to the fact that they are coordinated by a single government ministry; in Spain and Portugal each is governed by a different ministry. Nevertheless, while in Portugal coordination between the social and health care ministries is facilitated by a national network for integrated LTC (RNCCI), health and social care services are largely separate and uncoordinated in Spain.

### 3.5.3 Role of beneficiaries and informal carers

In Germany, relatives and beneficiaries have not taken an active part in professional and institutional discussion, though they are represented through several patient associations (see wir pflegen – Interessenvertretung begleitender Angehöriger und Freunde in Deutschland e.V., or the campaign Alliance for Good Care). The position of informal carers has been strengthened with the latest reforms, including legislation requiring that LTC insurance funds provide counselling to beneficiaries within two weeks after receipt of the application for care (at home, if requested). In Austria, beneficiaries of LTC and informal carers remain poorly organized and have not played an important role historically in decision-making related to LTC due to the fact that since the 1990s, people of working age with disabilities and their representative associations were the ones campaigning for the introduction of an LTC allowance in 1993, while the influential seniors' and pensioners' organisations only played a marginal role in the area of LTC. This division of interests continues as organisations representing seniors are focusing mainly on issues related to pensions rather than long-term care. This reasoning may provide one explanation for why informal and family carers have limited agency, with the exception of some self-help groups for carers of people with Alzheimers' disease.

Influential interest groups representing LTC beneficiaries and informal carers are not characteristic in most of the Transition countries reporting on this area. In Estonia, however, a non-profit NGO called Estonian Carers is an increasingly influential advocacy group on LTC issues, and the public discourse is led by recognized public figures. Although interest organisations such as Alzheimer's disease societies do exist in other Transition countries, their activities are rather limited, and larger pensioner unions focus mainly on pensions rather than on LTC services. In Romania, the importance of informal care is recognised by authorities but no official estimation exists on the extent of the informal care need for older persons. At the central government level, informal care is mainly supported through subsidies granted to NGOs by the Ministry of Labour, Family, Social Protection and Elderly (MMFPSPV). In Bulgaria and Latvia informal care provided by family members is also widespread, yet official statistics from both countries do not include informal care providers (European Commission, 2014). For this reason informal caregivers are not organized into associations.

The role of beneficiaries is relatively strong in Denmark and older persons are able to design their own individualised care plans. Legislation passed in 2002 and 2003 stipulated that they can also choose between a variety of housing options and personal and practical help providers, respectively. Furthermore, in 2009, a care home guarantee was introduced ensuring that citizens eligible for residential nursing facilities would not have to wait more than two months for a placement. In terms of home care services, Danish law states that persons needing LTC (including the disabled and chronically ill older people) are entitled to a cash allowance with which to pay the service provider of their choice (Campbell and Wagner, 2010).[15]

## 4 Opportunities for social innovation and active ageing

European welfare states have been subject to a series of pressures over the past decades, in particular with respect to the emerging endeavours to address the area of LTC and related need for social support. This situation has been exacerbated by the economic and financial crisis of recent years. The first pressure is related to the ageing of the population, the increase in life expectancy and related rapid changes in the structure of social needs and the emergence of 'new risks' throughout the life cycle: the difficulty in reconciling work and family responsibilities (in particular women), job insecurity, increase in digital inequalities, an increasing number of (older) people living alone, long-term care-needs and social exclusion. The second pressure is related to the countries' financial (in)ability to adequately respond to those social changes and needs. The prevailing trend has been to contain public expenditure. As the present economic and financial crisis has been almost exclusively addressed by policies of austerity, cuts in salaries and pensions as well as the growing unemployment rate will further increase the number of older people and families with restricted financial resources to cover their daily living, not to speak of (co-)payments for LTC services.

However, from a more optimistic perspective, these current social and financial challenges may be considered as a catalyst for social innovation in LTC, i.e. as an opportunity for the development of "new ideas (products, services and models) that simultaneously meet social needs (more effectively than alternatives) and create new social relationships or collaborations (…) that are both good for

[15] Danish Consolidation Act No. 979 on Social Services, §95 and §96 (2008).

society and enhance society's capacity to act" (European Union and Young Foundation, 2010). In the absence of sufficient public resources to fully meet LTC demands, ideas for innovative practices are being generated, developed and implemented by multiple actors and stakeholders, often in collaboration with one another.

The subsequent sections seek to describe the opportunities for social innovation and active ageing in LTC that are present in selected countries across the four care regimes. Opportunities (and a lack of opportunities) for innovation are presented according to several elements of long-term care systems at the macro-, meso-, and micro-levels. While we include LTC reforms and policy-changes towards active ageing at the macro-level, 'social innovation' initiatives have been identified exclusively at the meso- and micro-levels.

### 4.1 Family-based countries

In the four countries of the Family-based care regime a number of initiatives at the macro-, meso- and micro-levels with regard to social innovation in LTC can be identified. It is not surprising that these initiatives are generally influenced by the hitherto family-based pattern of care. There is a tendency towards a greater acknowledgement of informal care and the need for supporting and complementing family care through public policies and community solidarity.

*Macro-level*

- **Identity and value building**: As the need for care has been rising and families are becoming less well-equipped to fulfil these growing needs – caused in part by increasing employment rates of women, and financial insecurity due to the crisis – the expectation that the state should take on more responsibility for the care of older persons is also growing. In general terms, all countries in this care regime have adopted policies that promote integrated services to support informal carers and home-based care in particular. The most explicit approach to making long-term care an area of job-creation and more service-oriented support has been undertaken in Spain, where a legal framework was passed in 2007. While the financial crisis partly hampered its implementation and contributed to a reduction of assigned budgets, first steps to structural improvements have been undertaken and could be a basis for future growth of the sector.
- **Policy and governance:** Trends at the macro level include the implementation of more integrated LTC services, promotion of a diversification of services, in particular those for the support of older people living at home (including their families), and the development of initiatives that foster partnerships between the multiple stakeholders involved in LTC funding and delivery.
- **Processes and pathways:** Implementation of national initiatives working towards an integrated LTC care system, as is the case in both Spain and Portugal where networks seeking to manage and promote quality, equity and coverage of service provision have been set up. In Italy, funds at both the regional and national level were set up with the intention of increasing coverage of care needs, especially for the most dire of cases. In Portugal, another set of national programs was implemented with the intention of promoting and supporting investments in coverage and institutional human resources, as well as in social entrepreneurship at the micro-level through national funding and partnerships with private non-profit and for-profit institutions (*Banco de Inovação Social* - BIS).
- **Management and leadership**: In all four Mediterranean countries examples can be found of efforts to promote quality of care both in the community and in residential facilities. In Italy,

specific national and regional funds have been implemented to promote improvements related to the coverage of needs, in particular targeting people with severe needs of care. Furthermore, national and regional programmes/initiatives have been introduced, namely training for family carers and low qualified migrant caregivers (National Programme for the Work of the Caregiver) to improve the quality of care and to enhance the role of informal caregivers (Casanova, 2010). In Portugal, multiple national programmes include innovative measures to ensure a better quality of care and enhanced quality of life for older people living at home. These programmes stipulate the adaptation of older people's homes, home-help services, free public transportation and access to thermal health treatments.

- **Education, resources and means:** In Spain and Greece, post-secondary non-tertiary level qualification for formal and informal carers and migrant care workers has been promoted, in particular by means of a free web-based e-learning initiative ('ECV Certificate'). Other national programmes in Portugal aim at investment in human resources, as well as in new micro-level social business ideas through national funding and partnerships with private non-profit and for-profit institutions (Social Innovation Bank - BIS).

*Meso- and Micro-level*

- **Organisational structures**: Social innovation is particularly noticeable in the multiplicity of actors involved and also in some of the characteristics of the services provided. One example is the growing number of private enterprises and foundations that are promoting the development of innovative social services for older people in Portugal with regard to LTC and active ageing (e.g. Calouste Gulbenkian Foundation and António Manuel da Mota Foundation). Also in Italy there is growing collaboration between the public and private sectors in the management of the LTC system. There are numerous collaborations with social enterprises in the delivery of services at home or in managing hospital discharge. Another example of new types of partnerships can be found in the 'Consultative Committees' in Spain. These inform the 'Territorial Councils' and consist not only of members of the government, but also representatives of trade unions and other organisations at the meso-level.
- **People, Organisational structures and leadership**: There is evidence that new partnerships between regional and local authorities and other stakeholders are being formed. A programme funded by Italy's Piedmont Region but carried out by local governments and their partners promotes the professional recognition and development of informal carers. The Piedmont Region's Recognition of Informal Skills programme empowers family members and migrant carers by assessing their LTC skills and setting them on the path to attain specific qualifications and certifications through training.
- **People**: The Consultative Committees in Spain referred to above are also an example of a new type of interest representation in that they bring together stakeholders from all corners of the LTC system, including policymakers, representatives of caregivers as well as care recipients. Volunteer-based organisations and initiatives that rely on the work of volunteers in the area of LTC are also on the rise in all family-based countries. One example of this is the Care for the Carers programme operating in Portugal, in which volunteers support and assist informal carers of persons with dementia or stroke. Other examples include local training initiatives and a number of EU-funded projects to design and provide training for both professional and informal carers.

To sum up, it can be stated that in the Family-based countries social innovation and active ageing are promoted at all levels, but a prevailing role is being played by the local stakeholders. This entails relevant incentives that are often developed by local authorities (municipalities) but first and foremost by private organisations and the third sector. The initiatives are largely grounded in partnerships between public and private local services, e.g. health, social and cultural institutions, and often involve higher education institutions and/or research units. These initiatives address mainly specific local needs and are generally characterised by the following three features of social innovation: they involve new stakeholders (e.g. concerning the role of volunteers); they create new types of social relations (e.g. intergenerational activities or public-private partnerships); and they utilise new methods and tools (e.g. ICT and related applications). These initiatives represent good opportunities for further development, notwithstanding the visible budget cuts in health and social care that have been implemented over the past few years.

### 4.2 Transition Countries

Given the nascent state of LTC in the diverse countries of the Transition care regime, opportunities for social innovation and active ageing are theoretically vast. This includes the opportunity to learn from other countries and to place particular emphasis on the development of community care, rather than expanding residential care only. In practice, however, LTC does not seem to be a priority area of current reforms. Despite considerable socio-political differences, the countries are facing similar challenges, especially with regard to human and financial resources.

*Macro level*

- **Identity and value building**: LTC is very much a nascent area within broader social care services in the Transition countries, to the extent that in most countries, national legislation does not exist governing LTC, and if it does, the role of the state is limited. In most cases, care for older persons is considered the responsibility of family members. There are signs, however, that the identity of LTC is shifting. In Romania, LTC was recently defined and associated with a distinct group of beneficiaries, i.e. older persons, by law for the first time. In part, this shift is likely the result in part of the EU accession process and both the policy pressure as well as the availability of funding that has come with membership in the European Community. At the beginning of 2014, Bulgaria adopted a National Strategy of LTC, while in Romania a new reform of the health care system— including the LTC component—was initiated (European Commission, 2014). In Latvia, the recently proposed Concept Paper on the Development of Social Services for 2014 – 2020 formulated several objectives to increase the territorial coverage of home care services for older and disabled people (Zilvere, 2013). In Estonia, the Active Ageing Plan 2013-2020 prepared by the Ministry of Social Affairs (2013), addresses a number of bottlenecks in LTC. However, no sustainable plan to respond to these challenges is offered for the timeframe covered by the policy paper. In Lithuania, the 'Resolution on Long-term Care of Older People' put forward by the country's self-government board pointed out a number of shortcomings in the implementation of LTC policy and highlighted the need to fall in line with EU policy objectives concerning healthy and active ageing. A distinct trend can be observed in Hungary, where the responsibility of families for LTC was reinforced by constitutional law.
- **Policy and governance:** On the one hand, retrenchment of public services and a lack of support for innovative third sector and grassroots initiatives have been characteristic of policies in countries like Hungary, Czech Republic and Slovakia, though there have been instances in which

the public sector has provided funding and organisational support to mainstream and subsidise projects initiated by NGOs. In Romania, secured funding at the national-level for social assistance programmes, including LTC, was renewed in recent years, while at the same time a push toward decentralisation of service provision in LTC has been a policy priority. A trend that is visible in several countries, including Bulgaria and Lithuania, is the collaboration of public sector actors at the national and sub-national level, with input from NGOs and funding from EU institutions and international foundations. In Estonia, despite the publication of a strategy to integrate health and social care in the provision of LTC, the objectives have not been reached.

- **Processes and pathways:** In many cases, NGOs are acting as a coordinating bridge between public authorities and beneficiaries of LTC services, as well as advocating for and organising training programmes for LTC professionals, as is evidenced by the Lithuanian Red Cross' programme to train volunteers in the basics of social work and provide vocational training for social workers. In Bulgaria, the European Charter for Family Carers developed by COFACE – Disability was created as a reference document for organisations representing care recipients and their families (Neykov and Salchev, 2013). There are also many instances of innovative pilot programmes initiated by NGOs and other third sector actors, and implemented with the cooperation of regional and municipal authorities receiving joint funding from national and international/EU sources. These include the EU- and nationally-funded Bulgarian programme 'Care in family environment for the independent and decent living of people with different types of disabilities and people living alone', and the Lithuanian government's project 'Integrated Help at Home', which seeks to provide professional consultation and support for informal carers of older people in the home, which was also made possible by funding from the European Social Fund.
- **Management and leadership:** There is little evidence that opportunities for innovation in LTC in this area have been realised in the Transition countries. In a number of countries, legislation at the national-level has focused on improving the quality of care services, but these regulations have only recently been passed, e.g. in Lithuania and Romania, so that their implications for standard practice remain to be seen.
- **Education, resources and means:** NGO's often fill the gap both in mapping the need for and in providing training for LTC-related professions in many of the Transition countries. In Bulgaria, municipalities and NGOs registered as providers of social services received co-financing from EU and national funds with which to train people for two new positions: social assistants and domestic assistants as part of the 'Care in family environment' programme. In Lithuania, the Red Cross has trained over 4,000 social work professionals, as well as volunteers in social care. NGOs have also been at the forefront of innovations in the field that make use of ICT solutions, e.g. WebNurse in Hungary, an online compendium of tutorial videos for carers; VIRTU, a virtual elderly care service in Estonia; AREION, an emergency alarm system in the Czech Republic; and Carer+, a project to develop digital competencies of Care Workers to improve the quality of life of older people in Romania and Latvia. In Romania, the development of residential units for older people (primarily those living alone) in need of care is supported by the national programme 'Development of the national network of residential units for older people.' Carried out by the MMFPSVP, the programme was approved in 2011 and will run through 2015. Designed to reduce the hospitalisation period for older people suffering from chronic diseases, evaluations to capture changes in quality of life must be conducted in the future.

*Meso- and Micro-levels*

- **Organisational structures:** Cooperation between NGOs, other stakeholders and regional and local government authorities is occurring in several countries. This extends to the development and implementation of training programmes, as well as care provision and consultation services carried out at the local level. A move toward decentralisation of service organisation and provision can also be observed, as in the case of Romania, where from February 2010 to August 2012, the national government carried out a project called 'Strengthening the implementation of social services legislation at the local level within the context of the decentralisation process'.
- **People:** The most visible trend in this area is the growing recruitment and involvement of volunteers in the management of initiatives and in the actual provision of LTC, mainly in an informal, assistant capacity. This phenomenon is closely related to the important role that is being played by NGO's in LTC throughout the Transition countries, with the exception perhaps of Estonia and Latvia, where little such activity has been reported.

It is apparent that a lack of public funding and incentives at the macro-level is a barrier not only to traditional LTC services, but also to socially innovative practices. Countries in the Transition care regime are very much in the process of developing their LTC systems, and national governments are focusing on increasing investment and securing funding for the sector – which has been made somewhat easier by membership in the EU – and in outlining more clearly, and often for the first time, their vision for LTC. This has meant that NGOs and other for- and non-profit organisations are finding new ways of providing unfulfilled needs for care and professional development, often in partnership with government at the regional and local levels. It is interesting to note that projects involving ICT seem to be a major driver of innovation in Transition countries. Still, individual projects are seldom scaled up at national level due to a lack of sustainable funding.

### 4.3 Care-mix

With a wider range of stakeholders and more established structures of LTC, countries representing the Care-mix care regimes are starting from a different point in terms of opportunities for social innovation and a more proactive and preventive approach to and within the realm of LTC. Compared to the previous two groups of countries described, both policies at the macro-level and initiatives at the micro-level in the Care-mix regimes have started to 'mainstream' LTC as an area to support the reconciliation of care and employment and as an area for social investment in ageing societies.

*Macro-level*

- **Identity and value building**: Reforms in LTC, while already fairly decentralised in most countries in the Care-mix regime, have in recent years moved towards a more integrated and community-based model that is referred to as the 'caring communities' model in Germany. This model for LTC is characterised by local infrastructure (network) and integration of local stakeholders with the aim of achieving an environment that increases the possibilities of home care and consequently of independence and autonomy not only for older people in need of care (Klie, 2013). LTC in these countries is being redefined in what were previously regarded as purely physical/medical needs are now being considered through a more social and inclusive lens. In the UK (England) the 'Big Care Debate' promoted by the previous government was a national initiative to raise awareness of the current LTC system, involving a wide range of stakeholders in

debates about future funding options. There is an on-going political debate about alternative funding of 'social care' in the UK, with opportunities for better and more equal access to care services.

- **Policy and governance:** In Germany, the 'Long-Term Care Further Development Act' passed in 2008 opened the door to a number of innovative practices both in terms of care and consultation provision, as well as support for informal carers. The Act's emphasis on rehabilitation for older persons with injuries or chronic conditions, as well as the inclusion of case management and consultation in its provisions, led to the establishment of 16 pilot Nursing Care Bases in several municipalities. Both in Austria and in Germany, legislation concerning 'care leave' was recently passed and can be seen as a first step to improved reconciliation of care and employment for older workers with family members needing LTC, in particular at the end of life. The implementation of the 'Care Fund' (2011-2014) to further promote community care and innovation (alternative housing, case management) in Austria has to be monitored in terms of results and outcomes, in particular as this solutions has been prolonged till 2016 and tends to replace a major reform. It has to be evaluated, whether the funds have really been used to finance innovation, rather than to cover costs of 'traditional' provisions only. Also in Austria, the 'legalisation' (2007) of migrant personal carers, mainly self-employed, has to be further analysed in terms of sustainability and the question, whether this 'solution' is a positive development for care at home and active ageing (Schmidt et al., 2014). The explicit market-orientation of governance of LTC in Germany and the UK (England) has led to an increase in the number of stakeholders and should be considered a crucial determinant in assessing opportunities and/or obstacles for social innovation.
- **Management and leadership:** In Germany, the national Society for the Aged (Kuratorium Deutsche Altershilfe) generated a conceptual framework to guide the development of neighbourhoods and communities ("Quartiersentwicklung") in a way that takes into consideration the needs of older persons and intergenerational harmony. The guidelines serve as a template of good practices for local governments (Michell-Auli and Kremer-Preiß, 2013). Since 2012, care homes with an accredited quality management system in Austria may apply for the voluntary 'National Quality Certificate', which is an external audit to certify the introduction of continual improvement in care homes. It remains to be evaluated, which outcomes will be reported from this process and to what extent residents and their families have been involved. The constantly changing regulatory framework for health and social care in the UK (England) has hampered the linear development of LTC services and facilities. While further integration of health and social care remains a defined objective, quality improvement and monitoring have undergone a series of reforms over the past decade so that providers are struggling with their implementation.
- **Education, resources and means:** In Austria, the development of ICT in social support and long-term care has been driven over the past five years by the so-called 'benefit Programme', promoted by the Ministry of Transport, Innovation and Technology. The programme supports projects to develop ICT for innovative products and services for older people (http://www.ffg.at/benefit). Research would be needed to investigate on the outcomes of individual projects and their further utilisation. The implementation of 'Professional Social Carers' (with or without diploma) in Austria in existing structures and services of care provision is an on-going process that would need to be monitored for signs of new types of multi-professional exchange and potential changes in formal care delivery.

*Meso- and Micro-levels*

- **Organisational structures:** At the regional and municipal level, a number of cooperative initiatives have been developed that focus on creating environments in which the needs of older persons are looked after without isolating them from the rest of the community. These include the Austrian Region of Vorarlberg's decision to promote dementia-friendly environments to enable people with dementia to participate in public life in the community by awareness-raising, information and counselling activities (www.aktion-demenz.at). Similar initiatives can be observed in other Care-mix countries (e.g. UK, France, Germany). Research would be needed to show the innovative character of these activities and tangible outcomes related to new partnerships, changing patterns of social relationships and the visibility of people with dementia (and their carers) in public life. In Germany, a housing model known as the Bielefelder model, a cooperation between a non-profit housing association and the Bielefeld regional authority. It ensures the care of the whole population in a designated area, regardless of the level of need, and includes as residents younger persons with no care needs.
- **People, organisational structures, and leadership:** Community development projects with a larger focus on ageing populations and related needs of social support and care are another trend and opportunity to enhance innovation in this sector in Austria. One challenge to be addressed in particular in rural areas is the lack of professionals and the need for strategies to recruit professional carers. This has been taken up by an INTERREG-Project, coordinated by the Upper Austrian Chamber of Work, aiming at developing competencies of relevant stakeholders in the area of long-term care and health services, in particular those of managers and staff, (local) policy-makers and other change agents. The activities include the development of innovative concepts for the future of long-term care together with four pilot municipalities (http://www.zukunft-pflegen.info; see below). Another aspect concerns 'barrier-free' building and inclusive design for all – an Austrian agency has shown how this area can become a profitable activity by networking with local authorities and other relevant stakeholders (http://www.cedos.at).
- **Management and leadership:** Issues about reconciling work and care in the context of corporate social responsibility have been discussed widely not only in Austria. Many organisations are facing an ageing labour force with a related higher probability of staff caring for an older relative. A number of initiatives by individual firms, including organisations providing care (Volkshilfe, 2009), have addressed this challenge, but with respect to social innovation and active ageing a critical view on these measures will be necessary, e.g. concerning the perpetuation of women's caring roles (see also Di Santo and Villante, 2013).
- **Processes and pathways:** In the context of the 2005 health reform, so-called 'health platforms' were installed in all Austrian regions, gathering all relevant stakeholders involved in health care, with some links to social care. Among other things, these 'health platforms' were also to fund 'reform pool projects' to reduce in-patient care and improve coordination with primary care and home care. Although the instrument was used only scarcely (and was thus abandoned in 2013), a number of projects focused on disease management and improved care pathways. Research would be needed to document and analyse the individual projects and their outcomes.
- **People:** Enabling volunteer work in the community is another widely discussed issue with an important impact on active ageing and social innovation. One of the most important challenges in the area of long-term care is to strike a balance between the necessity to invest in formal care services and opportunities for voluntary work. Interesting projects could be identified in

Carinthia ("Dorfservice") and other regions with similar initiatives. For instance, though still very small-scale, some initiatives have emerged using 'time-banking' (see e.g. http://www.zeitbank-altjung.at) as a way to allocate and distribute care – a concept that would be much more adapted to social support and long-term care than the futile quest for increased productivity in this sector. Similar initiatives have been established in Germany and the UK. For instance, a social network called 'Tyze' enables users in the UK to build online personal networks where caregivers can coordinate, share, and contribute within a circle of support – making it easy for the individual, their family, friends and care professionals to work together to ensure an individual's needs are met (http://giving.nesta.org.uk/project/tyze/).

Despite the existence of a relatively supportive environment for social innovation in both the public, private and third sector, the sustainability of successful initiatives is often threatened due to a lack of regular funding by the public sector. As a positive feature in this context it should be underlined that, although the financial and economic crises had an impact on public policies in general, some reform efforts and even investments in LTC could be identified even during the past few years. The emphasis in these countries appears to be on action to improve quality and efficiency of services provided at the community-level, involving stakeholders from multiple sectors and interest groups, also with support from ICT applications.

### 4.4 Universal

The most important factor distinguishing the countries grouped in the Universal care regime consists in their established high level of structural public funding in LTC. However, the relatively stable pool of funding reserves to draw on in these countries cannot hide the fact that they are also haunted by the spectre of demographic change and face challenges in the recruitment and retention of qualified personnel. Other issues concern cost effectiveness and tensions between the different levels of public administration levels (regions, municipalities, etc.). There has been, therefore, an emphasis at the macro-level in national legislation promoting new governance mechanisms (marketisation, decentralisation, quality assurance) and targeting of formal care interventions. These framework conditions have nevertheless been conducive to the emergence of new processes, new stakeholder relationships and new types of service provision in LTC in these countries.

*Macro-level*

- **Identity and value building:** Universal care regimes are characterised by a relatively well-established LTC identity, in particular in terms of 'elderly care'. Two of the key principles at the core of the Universal care regime are enabling older persons to determine the kind of care they want for themselves, and providing community-based services that support older people in living independent lives as long as is possible and desirable. Increasingly over the past two decades market-oriented governance and a more mixed economy of care provision have underpinned the formerly mentioned principle in the Nordic countries. The latter principle has been realised via a radical downsizing and re-structuring of the residential care sector towards service housing as well as community care targeting the most vulnerable older age groups. Though similar in their approach, the Netherlands started from a different tradition– with chiefly private non-profit organisations providing residential facilities and services, and LTC as a part of a centralised social security system – yet the country also achieved a reduction in residential care with the goal of better integration between social and health care systems. Finland has been a forerunner in developing tangible strategies for LTC with its publicly debated 'Framework

for High-Quality Services for Older People' (Ministry of Social Affairs and Health, 2008) that set out measurable targets at the macro-level. For instance, by 2012 92% of people over 75 years of age should have been living at home independently, with appropriate health and welfare services granted to them (up from 90% in 2008).

- **Policy and governance:** Mainstream policies in LTC have adopted the New Public Management approach in the area of LTC by complementing the hitherto monopsonic public provision of services with an increasing share of for-profit providers in quasi-markets of care, in particular in Sweden (Szebehely and Meagher, 2013), though with important differences according to individual municipalities. Market-oriented governance mechanisms also played an important role in extending user choice by means of voucher systems (Finland, Sweden) and 'personal budgets' (The Netherlands), but also by classical New Public Management instruments (e.g. competitive tendering, purchaser-provider split). The search for strategies to reduce the constant rise of expenditures has also led to a 're-discovery' of family care, albeit in the tradition of supportive welfare policies. For instance, Denmark's National Report on Strategies for Social Protection and Social Inclusion 2008 – 2010 underlined, among other things, the importance of relative networks in LTC, and the role played by family members in representing the interests of their loved ones. This national-level policy put pressure on local authorities to involve relatives in individual and community care decisions. Also in Sweden, since 2010 municipalities have been obliged to support informal carers, resulting in different forms of personal support, counselling, family groups and incentive funds (Emilsson, 2011). In the Netherlands, there is on-going debate about a major reform of responsibility for LTC that is likely to result in a more decentralised governance, a reduction of 'personal budgets' and new types of fragmentation between LTC insurance and the municipalities.
- **Management and leadership**: Major efforts have been invested in large improvement programmes (The Netherlands) and quality assurance mechanisms (Sweden, the Netherlands) in combination with public reporting (Schols et al., 2014).
- **Resources and means:** Although it has been around since 2000, the voucher scheme for health and social care services in Finland has proven to be a popular way for municipalities to subsidise care services without being responsible for their organisation or delivery. With the voucher funding method, beneficiaries receive a set amount from the municipality with which they can then procure services from the private provider of their choice, including both formal and informal services.

*Meso- and Micro-levels*

While it is difficult to calculate the exact trade-off between higher expenditures for LTC and for health care, both sectors have been subject to attempts by policymakers to reduce further growth in expenditures and to improve effectiveness. These reforms at the macro-level were, however, partly backed by large-scale reform programmes and transformed into improvement processes at the meso- and micro-levels, mainly driven by professionals, rather than by users and carers.

# 5 Conclusions

The objectives of this report were, first, to describe, compare and analyse the different approaches to fund, organise and regulate long-term care in the various 'care regimes' across Europe and, secondly, to identify and analyse opportunities for and on-going practices of social innovation in the field of LTC. Notwithstanding the academic debate surrounding the relevance and applicability of a 'regime' approach to drawing comparisons across Europe, the clustering and grouping of countries helps to understand differences and commonalities as well as tendencies towards converging approaches and policy objectives. At the same time it is important to underline that differences and variations in organisation and funding of LTC continue to exist not only between and within 'care regimes', but even within individual countries.

## 5.1 General framework conditions

In terms of the first objective, a number of key points emerge across both the 'governance and financing' and the 'needs and coverage' dimensions.

Firstly, there remains a fundamental division between those care regimes and those countries that have well-established, publicly-financed LTC systems with dedicated funding, and those for which LTC is a new and developing (or stagnating) sector with insecure and often insufficient resources. This country division adheres fairly well to the lines drawn by the classic welfare regime typology in that the Transition countries lag particularly behind the countries of the Universal and the Care-mix regimes in terms of the adequacy of formal services, as well as in the public sector's structural and political support for innovative organisational frameworks, partnerships and practices in LTC. The Family-based care regime countries, in particular Spain and to a certain extent Italy and Portugal, have taken first steps towards more 'Care-mix' oriented regimes. In any case and across care regimes, the vast majority of care is provided and funded privately, outside or complementary to the public service infrastructure.

Secondly, while supporting older people through formal home care services (in-kind or in-cash) rather than residential care is being emphasised across Europe, two distinct patterns of support for people in need of LTC continue to persist. On the one hand, countries clustered around the Universal care regime are emphasising services in kind with some success in reducing residential care. On the other hand, countries in the Care-mix cluster have increased the provision of services in kind, but have not abandoned their tradition of cash-benefits, both because they provide beneficiaries with a greater degree of choice in the type and provider of care, and in certain cases because they enable the beneficiary to pay family members – and increasingly migrant carers – for care services rendered, thereby relieving the public sector of the need to procure more staff and services to meet demand. Transition countries are still struggling to develop clearly defined strategies, with no distinct patterns – at still very low levels – neither between residential and home care nor between cash- and service-based approaches. In general, LTC is still a policy area of 'muddling-through' in most countries – with clear strategies and objectives missing and policy-makers paying lip-service to the concept of 'ageing in place'. This concept appeals not only to older people's desire for independence, but also to policy-makers who still do not acknowledge that building on informal care only to close the gaps in service provision may endanger a number of social and economic goals of individual states and EU strategies, namely to increase (female) participation in the labour market and to increase disability-free life-expectancy.

Thirdly, latest reforms reflect the rather fragile status of LTC between health care and social care. The often still-missing structural roots are making the sector also vulnerable during the on-going financial crisis. As provisions in many countries are based on discretionary regulations they are convenient subjects to cuts (see for instance the discontinuation of the Italian 'Fund for long-term care' or cuts during the implementation of the Spanish 'Dependency Act') and/or to silent deflation, e.g. in the case of cash-benefits not being adapted to general price indices (Austria, Germany, Italy). In countertendency to a generally enhanced acknowledgement of LTC as a social risk that needs solidaristic support, Hungary has recently even strengthened the responsibilities of families to care for their relatives. However, financial pressures have also contributed in some countries to improve the existing infrastructure, to invest in initiatives to ensure quality, to improve access, to better integrate health care and social care, and to support informal carers.

## 5.2 Opportunities for social innovation

These general framework conditions certainly have an impact on opportunities for social innovation, that usually takes place at the meso- and micro-levels of societies. As we have seen, there is a great need in all care regimes to adopt political and organisational structures in the area of LTC to new societal challenges. However, the lack of resources and social investment are certainly key obstacles to social innovation in many countries. Having said this it is however possible to identify certain endeavours for change, initiatives that create new social ties, adapt new technologies to needs or develop new types of processes, products and markets. It will be the task of further research in this work package to elaborate on the drivers and/or inhibitors of such endeavours, in particular as, at first sight, there are great variations across the care regimes and indeed across countries.

While in some countries opportunities for innovation are promoted or made possible by the public sector, in other countries, charity organisations, NGO's and private enterprises partner with local communities and individuals to create new channels and modes of service delivery. Again, one explanation for this variation is the level of policy priority given to LTC by the public sector at the national level, and the existence of established networks and partnerships across sectors.

It goes without saying that opportunities for innovation are again closely tied to national policy, or the lack of it. In countries in which the public sector is retrenching, opportunities for innovation are made possible largely by the third sector, in some cases in cooperation with government actors and, among the Transition countries in particular, supported by EU-level funding. In Germany and Austria, decentralised, community-based services have led to several innovative initiatives that focus on neighbourhood/housing development and localised units of care provision. In some of the Family-based countries, integrated services are being made possible by the creation of national and regional networks and close collaboration between health and social care institutions. In terms of the gendered division of labour in long-term care, however, opportunities for a more equal distribution of both formal and informal care responsibilities remain scarcely addressed.

In their report on innovation in welfare services, Evers and Ewert (2013) devise a framework for analysing innovative practices, grouping them in the following way: Innovations in services and their ways to address users; Innovations in regulations and rights; Innovations in governance; Innovations in operation and financing; and Innovations concerning the entity of (local) welfare systems consisting of the public sector (municipality), the third sector, the market sector, and the community/family sector.

The initiatives identified by our network focused mainly on innovations that fall into the first category (*innovations in services and their ways to address users*) and that in many cases it very much depends on the contextual framework conditions, whether an initiative may be characterised as innovative. It will therefore be useful in the ensuing stages of research to look at recent reforms in operations/financing, in governance, and in regulations at local or regional levels because 'changes in rules and regulations (e.g. concerning the access to financial benefits) and in governance (forms of democracy and decision making on priorities in welfare and cohesion politics) are likewise important fields for social innovations that should not be neglected' (Evers and Ewert, 2013: 7). Tracing the pathway between the innovative, services-focused initiatives we collected and the regulatory and operational structures that made them possible (in the public, private and third sectors) will be a starting point for identifying drivers of change.

In any case, further research is needed to compile data and make these more comparable across countries, as such data was not available for a large number of chosen indicators. In this respect, the authors can only support the recommendations of the recent report jointly prepared by the Social Protection Committee and the European Commission services (European Commission, 2014), in particular with respect to information needs and data gaps.

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## I. Ageing Geo-Information System—Portugal

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| 1. Abstract | The Ageing Geo-Information System *(AGS)* is a new tool developed by the biggest and oldest social institution in Portugal – Santa Casa da Misericórdia de Lisboa (SCML). SCML is under state authority, yet it is private and self-financed. As the entity responsible for the management and delivery of public formal social services in the city of Lisbon, one of the main social issues/challenges it addresses is the ageing of Lisbon's population and the growing poverty and social isolation of older people, many of whom have a medium- to high-level of dependency. Since 2008, a protocol between the Ministry of Internal Administration and SCML, co-financed by the communitarian initiative EQUAL, has enabled the development of this initiative. The initiative revolves around a geo-information system on ageing that allows for the spatial representation of multiple dimensions of Lisbon's elderly population, including vulnerability factors (age group, type of family, level of dependency and housing conditions), as well as information about services (day-centres, home-help, residential, etc.) and the multiple agencies that provide them throughout the city. This geo-information system not only constitutes a powerful tool both in terms of organizational decision-making at the meso-level and for intervention and services management at the micro-level, but also allows for better inter-institutional collaboration. |
| 2. Target group and number of population covered (region/s) | At the moment 12,581 older persons are registered in the Geo-System. All of them live in the city of Lisbon and use at least one of SCML's services. At the moment, information being collected not only on those who have requested services (more or less 8,000 people), but also based on the sample group of a study undertaken in Lisbon that included nearly 100% of Lisbon's senior population. |
| 3. Qualification as social innovation and/or social innovation potential (please highlight): | **a. <u>It is oriented towards exceptional societal challenges/social issues</u>**<br>**b. <u>It suggests new solutions in the respective societal, cultural and economic context</u>**<br>**c. <u>It creates new patterns of social practices to overcome shortcomings of traditional arrangements</u>**<br>**d. <u>It tends to overcome the traditional dichotomy between technological and social innovations</u>**<br>**e. <u>It promotes the integration and/or collaboration/partnership of heterogeneous stakeholders that have hitherto not co-operated</u>**<br>f. It includes reflective and multidisciplinary approaches towards the key goal of societal usefulness<br>g. It creates structures and processes that are sustainable and realise new growth potentials in terms of regular employment<br>**h.** It involves end-users as co-producers of services or products<br>**i. <u>It creates new roles and partnerships</u>** |
| 4. The initiative is clearly addressing LTC challenges as it is characterised by the | a. multidisciplinary work is a value and principle<br>**b. <u>clients' needs are at the centre of all interventions</u>** |

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| following key-issues (please highlight): | **c. continuity of care and mechanisms to overcome barriers at the interfaces between social and health care are addressed**<br>d. continuity of care and mechanisms to overcome barriers at the interfaces between formal and informal care are addressed<br>e. it is supported by legislation which explicitly addresses the coordination/integration between health and social care<br>**f.** incentives to improve cooperation between health and social care facilities or services (e.g. financial, contractual advantages) are in place<br>**g. relevant information is efficiently transferred between services or agencies**<br>h. equal access (considering culture, gender and class) is guaranteed to all citizens<br>i. individual care needs are assessed by a multidisciplinary team<br>j. individual capacities of users/patients are enabled and strengthened<br>k. leadership and management capacities are enhanced through appropriate training<br>l. quality assurance is guaranteed across health and social care services and/or facilities<br>**m. agreements between services and/or organisations are based on contracts**<br>**n. IT and communication technology are used to make administration more efficient**<br>o. **IT and communication technology are used to facilitate theservice**<br>**p.** conditions for the involvement and participation of users/patients and carers are ensured<br>q. multidisciplinary teams are established, supported and continuously trained<br>**r. an integrated access point (e.g. concerning referral, financial issues, payment regulation, one-stop-shops) is available**<br>s. integrated discharge and follow-up planning is fostered (mainly for residential and/or hospital-based facilities)<br>t. case management is carried out by trained and specialised staff with relevant job-profiles<br>**u. funding is ensured by defined budgets**<br>**v. involved staff is participating regularly in advanced and further training**<br>**w. evaluation studies concerning structures, processes and outcomes are carried out and available**<br>**x. outcome indicators are used to measure and further develop the initiative** |

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| | **y. <u>quality management serves to implement continuous improvements</u>**<br>z. the initiative is controlled for costs and cost-advantages |
| 5. Status of the initiative | a. National or regional project (terminated)<br>b. **<u>European/international project (terminated)</u>**<br>c. National or regional project (ongoing)<br>d. European/international project (ongoing)<br>e. **<u>Implemented practice (at least in restricted areas)</u>**<br>f. Widely spread practice/rolled out |
| 6. Type of the initiative | a. **New product**<br>b. New service<br>c. New platform (new legal framework and platform)<br>d. New organisational form<br>e. New process<br>f. New market<br>g. New business model |
| 7. Rationale and objectives: *Why was the initiative implemented? What social needs does it satisfy? Which societal challenges were addressed (context conditions)? For which target groups? With which objectives?* | The initiative came about as the result of two factors. First, there was the will and objective of SCML's Ageing observatory to look for new work methodologies/tools through national and international partnerships in order to overcome the lack of rigorous and expedited information solutions to support institutional research and prospective planning. Second was the opportunity for partnership in an international project (CAIM) that intended, 1) to build and test a geo-information system for the issue of human trafficking; and 2) to evaluate the applicability of a geo-information system (SIG) in a new context/area of interest. The project CAIM, promoted by the Ministry of Internal Administration and the Portuguese Commission for Citizenship and Gender Equality (CIG) and co-financed by the communitarian initiative EQUAL from the Seventh Framework, proposed a partnership with SCML for the implementation of the Ageing Geo-Information System (AGS). In addition to testing the applicability of SIG in the social intervention/action domain, the implementation of the tool sought to guide and support strategic and immediate operational decision-making, as well as social intervention services and resource management (e.g. services distribution and differentiation based on the population's specific needs). |
| 8. Description: *What? How was change made possible? Who is involved? How many users are served per year? What is the role of users?* | The AGS system creates a map at the parish level of: 1) the exact home address of the 65+ population living in Lisbon and links each point on the map to individual and family socio-demographic information, vulnerability level and needs (e.g. level of dependency, housing conditions), and types of services used, as well as 2) the multiple services provided (e.g. day-care centre, home-care services) by SCML and by other private, public and publicly-subsidized institutions. The implementation of this new tool involved five main phases: |

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| | 1. Project design and team formation (1 sociologist and 5 geographers);<br>2. Construction of the geo-information database – the starting point for which were pre-existing institutional databases, and involving the standardisation and quality-checking of data through cross analysis. During this phase one geographer was allocated to each one of the four territorial social intervention units of SCML;<br>3. Partnership development – project evaluation was undertaken by an external entity; consultation by the national commission for data protection; geographic databases. Other partnerships were undertaken to enable information overlap with official national data and data from other entities (e.g. National Institute of Statistics – INE);<br>4. Development of a manual to help professionals in their client registration process in order to ensure information collection, standardisation and quality;<br>5. External and internal dissemination of the new tool among professionals providing services in the community (e.g. day-care centres, home-care services) intended to clarify doubts and demonstrate AGS's applicability and utility in day-to-day practice and decision-making. |
| 9. Impact: *Have objectives been realised? How was it measured, shown, evaluated? What are the demonstrated or potential impacts on users, informal carers, staff, inter-organisational collaboration, costs? What is the systemic impact (extent to which the initiative changes the way that LTC is provided across systems or services)? Has the example proven to be sustainable, or mainstreamed? Has the example been implemented elsewhere?* | The project CAIM, of which AGS is one component, was evaluated by a research team from the external research institute CESIS, but the evaluation is not publicly available. The dimensions evaluated have not been clarified but seem to be concerned mainly with the level of applicability of the IT tool to the social context. Outputs of the project include the Geo-System Implementation Manual and a Technical Geo-system Procedure Guide for the Ageing Observatory.<br>Other outputs of the project are the Atlas on Ageing in the City of Lisbon and a territorial study of ageing in the city of Lisbon, providing a global and geo-referenced image of existing and essential data to support the work of Santa Casa da Misericórdia in accomplishing its social intervention objectives in Lisbon.<br>Although the evaluation has not focused on the impact of this new tool at the macro, institutional and individual level, the new tool is seen as a major contribution to an increase in the perception of quality of services delivered to older persons because it allows for the development and provision of services targeted to the specific needs of the population. Also, it allows for territorial analysis of overlaps in services, both in terms of different institutions providing the same service (SCML services and private and publicly-subsidized services) and in the types of services available in each part of the region, as well as in terms of the service type, number and location of services used by every older person. The AGS is therefore considered an innovative tool for institutional strategic planning and decision-making, especially decisions regarding type of service(s) needed in each territorial area (parish) and ideal positioning of services in order to cover population needs and promote resource optimization. |

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| | The use of this type of IT tool by the institution responsible for the management and delivery of public formal social services in the city of Lisbon allows for the systematisation, organisation and mobilisation of a large quantity of social knowledge. The tool contributes to a better understanding of the social reality of ageing, its geographic representation as well as the evolution of the social dynamics of ageing and the needs of older persons in Lisbon. This information is crucial for intervention planning, especially in terms of interventions targeted to poor and/or socially isolated older people.<br><br>Although professionals in the field initially resisted recognising the utility of the tool, that resistance was gradually replaced by curiosity about the tool and its potential for day-to-day field intervention and operational decisions. For example, professionals responsible for home-care services find it very useful to determine the number of teams needed, the number of users each team can support and to determine the most efficient and least time-consuming route each team should take to reach users.<br><br>The positive evaluation of the tool is also evident in the creation of an online platform (WebSIG) where geographical representation of ageing-related content could be directly available for professional use. Because of the technical and IT infrastructure needed for such a platform, this is not yet possible. At the moment, although every month each unit receives a map with the geographic representation of their service users, more specific analyses and representations considering other information in the database involves a formal request to the department responsible for the geo-information system.<br><br>Another potential of the geo-information system is the fact that it concentrates a significant amount of information about older persons (e.g. the address of the most vulnerable seniors, the number of people living in the house, etc.) which can be of great use for emergency civil authorities in case of catastrophic events (e.g. cold wave) and subsequent evacuation procedures.<br><br>The successful evaluation of the geo-information system for ageing has led the institution to consider it as the basis in terms of software for building up a network of partners to support older people living alone. This would not only promote institutional cooperation but would also avoid institutional overlap and waste of resources.<br><br>Finally, the success of this tool has motivated SCML to apply it to other institutional domains (e.g. homelessness, building patrimony management).<br><br>The implementation costs are sizeable, especially as no technological infrastructure (hardware) existed previously in the institution. |
| 10. SWOT Analysis | *Strengths: What solutions were found to overcome key-challenges? What facilitated problem-solving?*<br>- Development of an AGS Implementation Manual<br>- Territorial representation of services for older persons with information on socio-demographic, family, health and vulnerability |

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| | variables<br>- Development of a new tool and process to support decision-making and management of services for older persons<br>- The system allows for an optimisation of resources and a better fit between population needs and services available<br>- Recognition by professionals and incorporation of SIG's potential for daily operational work decisions<br><br>*Weaknesses: Which gaps/obstacles have been witnessed/experienced?*<br>- Need for continuous information standardisation and control in order to ensure geo-system information quality<br>- The amount and kind of technical resources and structure involved in the project (e.g. hardware)<br><br>*Opportunities: Which improvements could be implemented? What additional activities will be needed to deliver on targets? How could the initiative be scaled up or rolled out?*<br>- Application to address other social issues (e.g. homelessness)<br>- Mapping of the entire older population in Lisbon (service clients, service users, non-service clients/users)<br>- Creation of an online platform (WebSIG) for the geographical representation of SCML's ageing-related content to be used directly by professionals<br>- Building up a network of partners to support identified older persons living alone. The support and institutional collaboration based on WebSIG would promote institutional cooperation and avoid institutional overlap and waste of resources<br><br>*Threats: What pressures does the initiative currently experience that could threaten its existence?*<br>- Field professionals' initial resistance and difficulty to assimilate standardised information gathering and to register criteria and rules |
| Website | NA |
| Sources | Santa Casa da Misericórdia de Lisboa (2008) Testemunho de um Futuro Incorporador. IN Direcção-Geral da Administração Interna. *Roteiro para a Construção de um Sistema de Monitorização sobre o Tráfico de Mulheres para Fins de Exploração Sexual.*pp. 91-95.Available online: http://www.cig.gov.pt/wp-content/uploads/2013/12/roteiroconstrucao.pdf. (Portuguese only)<br><br>Santa Casa da Misericórdia de Lisboa (2008). Estudo de Caracterização do Envelhecimento na Cidade de Lisboa. (Portuguese only)<br><br>Expert interviews were conducted with Filomena Gerardo, who was responsible for project definition, development and implementation, and Luís Conceição, the coordinator of Geo-Information System at Santa Casa da Misericórdia de Lisboa. |

## II. AREÍON Emergency care—Czech Republic

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| 1. Abstract | In 1990, the non-profit organisation Život 90 was founded with the goal of supporting frail older people by providing new services with the help of volunteers. In 1991, the proportion of persons aged 60 years or over living alone in the Czech Republic was already high at 33.5%; higher than in Hungary at 24.3%, Romania at 20.3% and Bulgaria at 19% (Gavrilova & Gavrilov, 2009). To ensure a safe home environment for frail older people a telephone service for seniors launched in 1992 was followed by other services such as consultation services for healthcare. The AREÍON Emergency Care Service—the alarm system created by ŽIVOT 90—was designed to reduce health and social risks for older and disabled people. Although the roots of AREÍON go back to the 1990s, it can be considered an innovative service due to the fact that thanks to persistent lobbying, AREÍON emergency care was finally recognized at the macro level in 2006 when it was incorporated into the Social Service Act enacted that same year (care services category).[16] The service is now one of the standard care services provided by the NGO (care service, daily care centre, respite residential and rehabilitation centre). It is installed in the homes of clients of the social service. ŽIVOT 90 was awarded the Makropoulos Prize by the Ministry of Health. |
| 2. Target group and number of population covered (region) | Target groups: frail older and disabled persons at health and social risk.<br><br>Specific criteria: health, psychosomatic problems, impaired mobility or age 60 years and over; living alone (or disabled persons younger than 60 years); remote place of residence (exposing a senior to social isolation and possible mental stress).<br><br>The AREÍON Emergency Care Service is provided to almost 1,300 clients in 34 towns in six Czech regions through its headquarters in Prague and regional control rooms in Hradec Králové, Kutná Hora and Jihlava.The population of persons 60 years and over in the Czech Republic in 2012 was 2,419,000, 23% of the total population. The number of persons reached with this service represents a small portion of the target population. |
| 3. Qualification as social innovation and/or social innovation potential: | **a. <u>It is oriented towards exceptional societal challenges/social issues</u>**<br>**b. <u>It suggests new solutions in the respective societal, cultural and economic context</u>**<br>**c. <u>It creates new patterns of social practices to overcome shortcomings of traditional arrangements</u>**<br>**d. <u>It tends to overcome the traditional dichotomy between technological and social innovations</u>**<br>e. It promotes the integration and/or collaboration of heterogeneous |

[16] Act No. 108/2006, Coll., on Social Services, and by the Ministry of Labour and Social Affairs Decree, No. 505/2006 Coll., implementing certain provisions of the Social Services Act.

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| | stakeholders that have hitherto not co-operated<br>f. It includes reflective and multidisciplinary approaches towards the key goal of societal usefulness<br>g. It creates structures and processes that are sustainable and realise new growth potentials in terms of regular employment<br>h. It involves end-users as co-producers of services or products |
| 4. The initiative is clearly addressing LTC challenges as it is characterised by the following key-issues: | **a. multidisciplinary work is a value and principle**<br>**b. clients' needs are at the centre of all interventions**<br>**c. continuity of care and mechanisms to overcome barriers at the interfaces between social and health care are addressed**<br>d. continuity of care and mechanisms to overcome barriers at the interfaces between formal and informal care are addressed<br>**e. it is supported by legislation which explicitly addresses the coordination/integration between health and social care**<br>f. incentives to improve cooperation between health and social care facilities or services (e.g. financial, contractual advantages) are in place<br>g. relevant information is efficiently transferred between services or agencies, e.g. by means of a joint care plan based on a dialogue with users/patients and their informal network<br>h. equal access (considering culture, gender and class) is guaranteed to all citizens<br>i. individual care needs are assessed by a multidisciplinary team (with multidisciplinary methods)<br>j. individual capacities of users/patients are enabled and strengthened<br>k. leadership and management capacities are enhanced through appropriate training<br>l. quality assurance is guaranteed across health and social care services and/or facilities<br>m. agreements between services and/or organisations are based on contracts<br>n. IT and communication technology are used to make administration more efficient<br>**o. IT and communication technology are used to facilitate the service (e-health, e-care, ambient assisted living)**<br>p. conditions for the involvement and participation of users/patients and carers are ensured (e.g. shared decision-making)<br>q. multi-disciplinary teams are established, supported and continuously trained<br>r. an integrated access point (eg concerning referral, financial issues, payment regulation, one-stop-shops) is available |

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| | s. integrated discharge and follow-up planning is fostered (mainly for residential and/or hospital-based facilities)<br>t. case management is carried out by trained and specialised staff with relevant job-profiles<br>u. funding is ensured by defined budgets<br>v. involved staff is participating regularly in advanced and further training<br>w. evaluation studies concerning structures, processes and outcomes are carried out and available<br>x. outcome indicators are used to measure and further develop the initiative<br>y. quality management serves to implement continuous improvements<br>z. the initiative is controlled for costs and cost-advantages |
| 5. Status of the initiative | a. pilot project (terminated)<br>b. pilot project (ongoing)<br>c. project (terminated)<br>d. project (ongoing)<br>e. **implemented practice (restricted areas)**<br>f. widely spread practice/rolled out |
| 6. Type of initiative | a. New product<br>b. **New service**<br>c. New platform (new legal framework and platform)<br>d. New organisational form<br>e. New process<br>f. New market<br>g. New business model |
| 7. Rationale and objectives: *Why was the initiative implemented? Which societal challenges were addressed (context conditions)? For which target groups? With which objectives?* | Emergency care is a comprehensive social service providing quick help in emergency situations. Emergency care can be a critical service for older and disabled people living at home for the following reasons:<br>- to preserve their self-sufficiency and independence,<br>- to ease social exclusion of older people,<br>- to reduce the number of personal risks (health, social and criminal),<br>- to reduce the rate of admission to healthcare institutions,<br>- to reduce the number of persons waiting to be admitted to social care institutions,<br>- to support families in taking care of their elderly or disabled family members (respite care).<br>The main purpose is to reduce health and social risks for older persons and disabled people. The provider of the AREÍON emergency alarm service is Život 90. |

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| 8. Description: *What? How? Who is involved? How many users are served per year? What is the role of users?* | A telephone service for seniors—the first such helpline of its kind—was launched in 1991. By the end of 1992, ŽIVOT 90's headquarters were connected to the first in a series of user terminal stations, which were installed in the homes of clients. Its creators decided to call the service AREÍON – Rapid Assistance Messenger.[17] AREÍON emergency care is provided under the following circumstances:<br><br>- unexpected situations (injury, fall etc.),<br>- emergency situations (assault or threat by another person),<br>- unforeseen critical situations (sudden deterioration of health etc.),<br>- social service consultation,<br>- therapeutic services,<br>- arranging appointments/social contacts,<br>- assistance in understanding and accessing benefits/rights.<br><br>User's technical conditions for provision of service are: SIM card from cell phone operator and a fixed telephone line. In order to provide emergency care, coordination of different parties (sometimes several) is needed. These different actors include integrated rescue teams (Czech Police, fire brigade, rescue service); ambulance service; town police; contact person (family, friend, neighbour, etc.) specified in each applicant's request for service; general practitioner or attending physician; community care service, personal assistant and any social service indicated by the application; another person or entity, vital for quality provision of emergency care service to the user in conjunction with providers of telecommunication services; boroughs and municipalities of the provider of social services (subsidized organizations, NGO's, public benefit organizations etc.).<br><br>The most important steps in recognizing ŽIVOT 90's activities were as follows:<br>- 1996: Václav Havel presented a personal gift to ŽIVOT 90,<br>- 1999: first issue of Generace magazine was published,<br>- ŽIVOT 90 organised European seniors' conference EURAG,<br>- 2001: first annual Seniors' Mile run from Kampa to Žofín was organized,<br>- 2005: ŽIVOT 90 was awarded the Makropoulos Prize by the Ministry of Health as the first provider of emergency care in the Czech Republic for carrying out the emergency alarm system,<br>- 2006: ŽIVOT 90 joins other international organisations and individuals in appealing for increased awareness about violence against seniors, issued by INPEA (International Network for the Prevention of Elder Abuse).<br><br>Through successful lobbying by ŽIVOT 90, AREÍON emergency care was incorporated into the Social Services Act in 2006 (108/2006 Coll.) in the |

[17] ŽIVOT 90 was invited to participate in theEastern European Network of the COST A5 Action "Ageing and Technology". COST A5 is an intergovernmental framework for European Cooperation in Science and Technology and dissemination and exchange of innovative practices between the Eastern European countries of the Network (Slovakia, Slovenia and Hungary as the network coordinator were participants) that might have contributed to gaining "up-to-date" knowledge of the 90s to develop innovation based on ICT. Hungary started to implement the Emergency Alarm System also in 1992.

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| | care services category.<br><br>As mentioned above, 1,300 clients receive AREÍON emergency care. It is paid for by clients (a monthly fee of about 10 EUR). Because it is defined in the Act on Social Services, clients can claim a state subsidy to help fund the service. |
| 9. Impact: *Have objectives been realised? How was it measured, shown, evaluated? What are the demonstrated or potential impacts on users, informal carers, staff, inter-organisational collaboration, costs? What is the systemic impact (extent to which the initiative changes the way that LTC is provided across systems or services)? Has the example proved to be sustainable, or mainstreamed? Has the example been implemented elsewhere?* | The objective has been realised as is evidenced by the fact that the service was incorporated into the Social Services Act in 2006 (as mentioned in point 10) and has been gradually implemented in many regions across the country (mentioned in point 4). While the main provider of the alarm system remains Život 90, there are also other smaller providers offering the service, totalling 18 providers in all. The incorporation of the system into law ensures that it is recognised as a standard social service. Although the initiative's origins date back to the 1990s, the public care system considers it to be a new and innovative development (Horecky, 2013). |
| 10. SWOT Analysis | *Strengths: What solutions were found to overcome key-challenges? What facilitated problem-solving?*<br><br>The most important solution was the dissemination and lobbying activities of ŽIVOT 90 which led to incorporation of the innovation into law (detailed description in point 10).<br><br>*Weaknesses: Which gaps/obstacles have been witnessed/experienced?*<br><br>Low-income persons could be excluded from the system if they cannot afford the monthly service charge.<br><br>*Opportunities: Which improvements could be implemented? What additional activities will be needed to deliver on targets? How could the initiative be scaled up or rolled out?*<br><br>To continue former activity: lobbying, network activity, dissemination and communication in the media.<br><br>*Threats: What pressure does the initiative currently experience that could threaten its existence?*<br><br>Its existence is not threatened; exclusion of low-income persons (because of the fee) could be a problem. |
| Website | http://eng.zivot90.cz/4-social-services/10-areion-emergency-care |
| Sources | Gavrilova, N.S. & Gavrilov, L.A. (2009) Rapidly Aging Populations: Russia/Eastern Europe. In, *International Handbook of Population Ageing,* ed. Peter Uhlenberg, Springer. International Handbooks of Population 1, |

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| | pp. 113-132.<br><br>Horecky, J. (2013) *Dignity first – priorities in reform of care services*. Comment paper – Czech Republic, Prepared for the Peer Review in Social Protection and Social Inclusion programme coordinated by ÖSB Consulting, the Institute for Employment Studies (IES) and Applica, and funded by the European Commission.<br><br>Expert interview conducted with Petr Wija, Institute of Health Information and Statistics, Centre of Expertise in Longevity and Long-term Care, International Longevity Centre of the Czech Republic at the Faculty of Humanities of the Charles University.<br><br>http://www.un.org/esa/population/publications/2012WorldPopAgeingDev_Chart/2012PopAgeingandDev_WallChart.pdf (Accessed on 02 05 2014). |

## III. Active Ageing with Dementia—Portugal

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| 1. Abstract | 'Active Ageing with Dementia' is a nation-wide project developed by a private non-profit association – Alzheimer Portugal. It intends to promote the active ageing of people with dementia by overcoming the lack of general information on dementia, the lack of formal and informal carers' knowledge on the topic, as well as the lack of services, especially public (and affordable) ones specifically targeted to people with dementia (more than 153,000 in 2012). Therefore, its main goals are 1) to raise awareness and to promote attitude change of the general population towards dementia patients by building an online free-access information platform with reliable and updated content on dementia; 2) to promote and increase carers' skills by implementing training courses for carers of dementia patients through e-learning, and thus to support carers and to reduce their stress, depression and anxiety; and 3) to offer free or low-cost community-based and individual or group cognitive and sensorial stimulation activities that maintain and promote dementia patients' cognitive and social skills, and thus promote the prolongation of their autonomy in everyday tasks and social participation and inclusion. In order to accomplish its goals and to develop and implement its multiple actions and activities, the project relies on partnerships with both public and private institutions, as well as on the voluntary work of specialized professionals (e.g. doctors). The project is both self- and externally-financed and was awarded the private Manuel António da Mota's Foundation prize in 2012 for initiatives in Active Ageing and Intergenerational Solidarity. |
| 2. Target group and number of population covered (region/s) | It is a nation-wide project developed throughout Alzheimer's Portugal's 4 delegations. For the one-year duration of the project, 3,935 people participated in its different training and information activities. Of these, the great majority participated in workshops and information sessions for the general public; 190 were formal carers and 57 were informal carers that participated in formative actions and workshops on care for dementia patients. |

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| 3. Qualification as social innovation and/or social innovation potential (please highlight): | **a. It is oriented towards exceptional societal challenges/social issues**<br>**b. It suggests new solutions in the respective societal, cultural and economic context**<br>**c. It creates new patterns of social practices to overcome shortcomings of traditional arrangements**<br>**d. It tends to overcome the traditional dichotomy between technological and social innovations**<br>**e. It promotes the integration and/or collaboration/partnership of heterogeneous stakeholders that have hitherto not co-operated**<br>f. It includes reflective and multidisciplinary approaches towards the key goal of societal usefulness<br>g. It creates structures and processes that are sustainable and realise new growth potentials in terms of regular employment<br>**h. It involves end-users as co-producers of services or products**<br>**i. It creates new roles and partnerships** |
| 4. The initiative is clearly addressing LTC challenges as it is characterised by the following key-issues (please highlight): | **a. multidisciplinary work is a value and principle**<br>**b. clients' needs are at the centre of all interventions**<br>c. continuity of care and mechanisms to overcome barriers at the interfaces between social and health care are addressed<br>d. continuity of care and mechanisms to overcome barriers at the interfaces between formal and informal care are addressed<br>e. it is supported by legislation which explicitly addresses the coordination/integration between health and social care<br>**f.** incentives to improve cooperation between health and social care facilities or services (e.g. financial, contractual advantages) are in place<br>g. relevant information is efficiently transferred between services or agencies<br>**h. equal access (considering culture, gender and class) is guaranteed to all citizens**<br>**i. individual care needs are assessed by a multidisciplinary team**<br>**j. individual capacities of users/patients are enabled and strengthened**<br>k. leadership and management capacities are enhanced through appropriate training<br>l. quality assurance is guaranteed across health and social care services and/or facilities<br>**m. agreements between services and/or organisations are based on contracts**<br>**n.** IT and communication technology are used to make administration more efficient |

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| | o. IT and communication technology are used to facilitate the service<br>**p. conditions for the involvement and participation of users/patients and carers are ensured**<br>**q. multidisciplinary teams are established, supported and continuously trained**<br>r. an integrated access point (e.g. concerning referral, financial issues, payment regulation, one-stop-shops) is available<br>**s. integrated discharge and follow-up planning is fostered (mainly for residential and/or hospital-based facilities)**<br>**t. case management is carried out by trained and specialised staff with relevant job-profiles**<br>u. funding is ensured by defined budgets<br>**v.** involved staff is participating regularly in advanced and further training<br>w. evaluation studies concerning structures, processes and outcomes are carried out and available<br>x. outcome indicators are used to measure and further develop the initiative<br>**y. quality management serves to implement continuous improvements**<br>**z. the initiative is controlled for costs and cost-advantages** |
| 5. Status of the initiative | a. **National or regional project (terminated and then transformed into new smaller projects that are ongoing)**<br>b. European/international project (terminated)<br>c. National or regional project (ongoing)<br>d. European/international project (ongoing)<br>e. Implemented practice (at least in restricted areas)<br>f. Widely spread practice/rolled out |
| 6. Type of the initiative | a. **National or regional project (terminated and then transformed into new smaller projectsthat are ongoing)**<br>b. **European/international project (terminated)**<br>c. **National or regional project (ongoing)**<br>d. **European/international project (ongoing)**<br>e. **Implemented practice (at least in restricted areas)**<br>f. **Widely spread practice/rolled out** |
| | a. **New product**<br>b. **New service**<br>c. **New platform (new legal framework and platform)** |

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| | d. **New organisational form**<br>e. **New process**<br>f. **New market**<br>g. **New business model** |
| 7. Rationale and objectives: *Why was the initiative implemented? What social needs does it satisfy? Which societal challenges were addressed (context conditions)? For which target groups? With which objectives?* | Active Ageing on Dementia was implemented to overcome the general lack of information and awareness concerning dementia and the lack of formal and informal carers' knowledge on the topic. Also, it intended to overcome the lack of services, especially public (and affordable) ones, specifically targeted for people with dementia (more than 153,000 in PT in 2012). Furthermore, there was a need to define a broader, integrated and long-standing strategy for the support of dementia patients and their carers in order to perpetuate and continuously implement and promote active ageing for old persons with dementia. Therefore, the project's goal was to develop an integrated response for the promotion of dementia patients' active ageing and for a more inclusive society where this vulnerable group may be fully integrated. More specifically three main goals were defined:<br>1. Community information - to raise awareness and to promote attitudinal change in the general population and among politicians towards dementia and its impact on society;<br>2. Carers training - to promote and increase formal and informal carers' skills; to support carers in their caring responsibilities and to reduce their stress, depression and anxiety levels. In turn, these strategies are expected to contribute to the delay of dementia symptoms and patients' dependency.<br>3. Dementia patients' stimulation and social integration - to offer free or low-cost community-based and individual or group cognitive and sensorial stimulation activities that allow for the maintenance and promotion of dementia patients' cognitive and social skills, and thus for the prolongation of their autonomy in everyday tasks and an increasing social participation and inclusion in society. |
| 8. Description: *What? How was change made possible? Who is involved? How many users are served per year? What is the role of users?* | To accomplish its goals, a variety of initiatives were undertaken. In terms of the community information goal, multiple information sessions that aimed to build public awareness for dementia disease and its impacts and to disseminate knowledge about its diagnosis and prevention were implemented; also, an online free-access information platform - Alzheimer Portugal Website - as well as periodic bulletins with reliable and updated content on dementia was created. Large-scale events intended for general population awareness were also initiated, such as the 'Memory Walkway' which took place in several cities and consisted of a one-day walk to draw attention to the issue and provide information on dementia.<br><br>Regarding the carers' training goal, training courses on dementia were made available for formal and informal carers. The courses were carried out both in-person and via an e-learning programme, and covered a range of topics organized into different modules/workshops (e.g. The Bio-psycho-social needs of dementia patients; The person-centred |

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| | approach in caring for dementia patients).<br><br>Finally, the goal related to services for dementia patients' mental stimulation and social integration involved the promotion of frequent social events for dementia patients and their carers (e.g. Alzheimer's Coffee) and the implementation of multiple recreational, sports, cultural, and social activities for dementia patients (e.g. intergenerational activity; cooking atelier, reality orientation therapy, individual cognitive stimulation, memory group). The improvement of services delivered to dementia patients also involved the use of the Snoezelen sensory stimulation technique which has been shown to contribute to a decrease in anxiety levels of dementia patients and increase of quality of life.<br><br>The project implementation was carried out at the national level by Alzheimer Portugal's delegations. It involved the establishment of a number of partnerships with small local entities and both private enterprises (e.g. Bial) and public institutions like the Portuguese Institute of Social Security which co-financed dementia patients' paid activities. The project funding was partly provided by Alzheimer Portugal's own funds and partly funded by the prize received from the Manuel António da Mota Foundation.<br><br>Participant opinions and needs were constantly considered during the project development and improvement phases, namely in terms of the kinds of activities developed with dementia patients and their carers; the type of content presented on the website and bulletins; and themes presented and discussed in the training sessions for formal and informal carers. Also, part of the training sessions for informal carers were largely self-managed as each one of the participants had the time and the opportunity to share their personal cases, experiences and problems. Thus, specific topics chosen by participants were collectively discussed. |
| 9. Impact: *Have objectives been realised? How was it measured, shown, evaluated? What are the demonstrated or potential impacts on users, informal carers, staff, inter-organisational collaboration, costs? What is the systemic impact (extent to which the initiative changes the way that LTC is provided across systems or services)? Has the example proven to be sustainable, or mainstreamed? Has the example been implemented elsewhere?* | This initiative is particularly innovative in terms of the broader approach used to address the impact of active ageing on dementia. Instead of focusing only on activities with dementia patients, the intervention was designed to reach both formal and informal carers, as well as the broader society.<br><br>During the one year of the programme, 73,414 people visited Alzheimer Portugal's website and were able to easily access online information on dementia topics. Of those, 80% visited the site more than once. During the year 2012, 132 training and information actions have taken place, reaching more than 3,935 people. 17 of the training actions were specially developed for formal carers and 6 for informal carers. Initiative promoters believe that the training sessions contributed to a better quality of care and to the dissemination of strategies for the development of a sense of self-efficacy and self-achievement on the part of carers, and to a decreased burden on carers, lower levels of anxiety and stress as well as social isolation. These were made possible through acquisition of new knowledge and skills, broadening of the carers' support network and sharing of their experiences, problems and feelings.<br><br>Another innovative feature was the fact that the programme's activities broke with the traditional model in which stimulation activities are |

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| | mainly performed in closed groups and in a controlled environment. In the framework of this project, learning, social knowledge/experiences-sharing, relaxation and therapeutic activities were implemented in open and social environments that fostered the social inclusion of dementia patients and their carers.<br><br>Although the plan for project evaluation included various quantitative indicators (e.g. number of website visitors and bulletin readers; number of formative activities; participant level of satisfaction; periodic evaluation of patients' conditions; carer anxiety and stress levels), the indicators do not seem to have been systematically recorded, or at least data was neither systematically analysed nor reported. Therefore, it is hard to understand the impact of the initiative. It is especially difficult to understand its impact on dementia patients, not only in terms of the number of patients covered by the initiative activities, but also in terms of the evaluation of their condition. |
| 10. SWOT Analysis | *Strengths: What solutions were found to overcome key-challenges? What facilitated problem-solving?*<br>- Broader perspective on the impact of active ageing on dementia patients;<br>- Providing information and raising awareness for dementia disease at the society-level;<br>- Training for formal and informal carers on how to care for a dementia patient and on strategies to decrease the negative consequences of caregiving;<br>- Website and bulletins with pertinent information on dementia diseases;<br>- Social inclusion of dementia patients and their carers through participation in stimulation activities implemented in different social contexts and in an inclusive, open environment.<br><br>*Weaknesses: Which gaps/obstacles have been witnessed/experienced?*<br>- Lack of systematic evaluation and outputs report;<br>- Only reaches a small number of dementia patients.<br><br>*Opportunities: Which improvements could be implemented? What additional activities will be needed to deliver on targets? How could the initiative be scaled up or rolled out?*<br>- Need to create a phone helpline service that provides immediate and individualized support for carers;<br>- Greater level of general population participation in events like 'Memory Walkway.'<br><br>*Threats: What pressures does the initiative currently experience that could threaten its existence?*<br>- Informal carers' difficulty to leave their dementia patients in order to participate in training workshops and actions;<br>- Lack of funding, especially from private enterprises;<br>- Needs continuity. |
| Website | http://alzheimerportugal.org/pt/ |

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| Sources | Alzheimer's Portugal (2011) Proposta ao Prémio Manuel António da Mota: Envelhecimento Activo nas Demências.<br><br>Alzheimer's Portugal (2012) Relatório de Actividades 2012.<br><br>Expert interview conducted with Ana Margarida Cavaleiro, part of the project's technical team and Coordinator of Projects and Research Department at Alzheimer's Portugal. |

## IV. Bielefelder Model—Germany

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| 1. Abstract | In 1996 the "Verein Alt und Jung e.V." in cooperation with the "Bielefelder Gemeinnützige Wohnungsbaugesellschaft (BGW, a non-profit housing association) developed the "Bielefelder Modell," or the Bielefelder Model, which is currently being implemented by seven nursing services and five housing associations in 40 residential districts across the region. The cooperation between the partners is fixed through a cooperation agreement. The aim of the model is to ensure the care of the whole population in each district regardless of the actual level of help needed. The focal point of the district is a housing project of the respective housing association, where barrier-free dwellings are provided and a bureau of the association as well as a neighbourhood café as a central meeting place are located. The model can also be recommended for persons with dementia in need of care, as persons suffering from this condition are able to stay in their established living quarters and are socially integrated into the surrounding environment (cf. Ehlers et al. 2011).<br><br>The model enables autonomous living with security of care without raising a "lump-sum". Instead of a flat rate, tenants only have to pay for care services they use.<br><br>The Bielefelder Model adheres to the "outpatient rather than in-patient care" model. The organisation of the different district projects in responsibility of the community includes all the different stakeholders: professionals of the health system, volunteers, people in need of help/care and citizens of the quarter (cf. Köhler/ Goldmann 2010). People in need of help or care which cannot afford professional care according to their needs find support in the community. |
| 2. Target group and number of population covered (region) | Older persons and other people in need of long-term care in the region of Bielefeld. Bielefeld has about 328,000 inhabitants (Statistische Kurzinformation Bielefeld, 2013). 65,874 of the inhabitants are aged 65+ and are therefore the main target group of the Bielefelder Model. In 2013, the initiative covered 442 households in 12 housing areas (cf. INTERROGARE/ GEO, 2014). |
| 3. Qualification as social innovation and/or social innovation potential (please | **a. <u>It is oriented towards exceptional societal challenges/social issues</u>**<br>**b. <u>It suggests new solutions in the respective societal, cultural and</u>** |

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| highlight): | **economic context**<br>**c. It creates new patterns of social practices to overcome shortcomings of traditional arrangements**<br>d. It tends to overcome the traditional dichotomy between technological and social innovations<br>**e. It promotes the integration and/or collaboration of heterogeneous stakeholders that have hitherto not co-operated**<br>**f. It includes reflective and multidisciplinary approaches towards the key goal of societal usefulness**<br>g. It creates structures and processes that are sustainable and realise new growth potentials in terms of regular employment<br>**h. It involves end-users as co-producers of services or products** |
| 4. The initiative is clearly addressing LTC challenges as it is characterised by the following key-issues (please highlight): | **a. multidisciplinary work is a value and principle**<br>**b. clients' needs are at the centre of all interventions**<br>c. continuity of care and mechanisms to overcome barriers at the interfaces between social and health care are addressed<br>**d. continuity of care and mechanisms to overcome barriers at the interfaces between formal and informal care are addressed**<br>e. it is supported by legislation which explicitly addresses the coordination/integration between health and social care<br>f. incentives to improve cooperation between health and social care facilities or services (e.g. financial, contractual advantages) are in place<br>g. relevant information is efficiently transferred between services or agencies, e.g. by means of a joint care plan based on a dialogue with users/patients and their informal network<br>**h. equal access (considering culture, gender and class) is guaranteed to all citizens**<br>**i. individual care needs are assessed by a multidisciplinary team (with multidisciplinary methods)**<br>**j. individual capacities of users/patients are enabled and strengthened**<br>k. leadership and management capacities are enhanced through appropriate training<br>**l. quality assurance is guaranteed across health and social care services and/or facilities**<br>**m. agreements between services and/or organisations are based on contracts**<br>n. IT and communication technology are used to make administration more efficient |

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| | o. IT and communication technology are used to facilitate the service (e-health, e-care, ambient assisted living)<br>p. conditions for the involvement and participation of users/patients and carers are ensured (e.g. shared decision-making)<br>**q. multi-disciplinary teams are established, supported and continuously trained**<br>**r. an integrated access point (eg concerning referral, financial issues, payment regulation, one-stop-shops) is available**<br>s. integrated discharge and follow-up planning is fostered (mainly for residential and/or hospital-based facilities)<br>t. case management is carried out by trained and specialised staff with relevant job-profiles<br>u. funding is ensured by defined budgets<br>**v. involved staff is participating regularly in advanced and further training**<br>**w. evaluation studies concerning structures, processes and outcomes are carried out and available**<br>x. outcome indicators are used to measure and further develop the initiative<br>y. quality management serves to implement continuous improvements<br>z. the initiative is controlled for costs and cost-advantages |
| 5. Status of the initiative | a. pilot project (terminated)<br>b. pilot project (ongoing)<br>c. project (terminated)<br>d. project (ongoing)<br>e. **implemented practice (restricted areas)**<br>f. widely spread practice/rolled out |
| 6. Type of the initiative | a. New product<br>b. **New service**<br>c. **New platform (new legal framework and platform)**<br>d. New organisational form<br>e. New process<br>f. New market<br>g. New business model |
| 7. Rationale and objectives: *Why was the initiative implemented? Which societal challenges were addressed* | In Germany – as in most of the other countries – older people tend to prefer to stay in their own homes and live independently for as long as possible. For several reasons the realization of this wish becomes more and more difficult as the person ages. These reasons include the fact that |

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| *(context conditions)? For which target groups? With which objectives?* | more and more older people do not have children, that the distances between the residences of parents and children have increased, that the labour market participation of women is rising—leading to a decline in family care potential, and the share of single households has increased. The aim of the Bielefelder Model is to provide housing arrangements that enable older people (in need of help or care or not) to live autonomously alongside their neighbours in a barrier-free surrounding with the opportunity to call for assistance 24 hours if it becomes necessary, but without having to pay a lump-sum for care services. The housing arrangements revolve around the needs of potential tenants. On the one hand, multi-disciplinary teams of professionals (consisting of nurses, geriatric nurses, social care workers, social workers, educators, skilled workers, craftsmen, housekeepers and numerous volunteers) offer services for a range of care needs, and on the other hand people who do not need services can also afford to live in a barrier-free, safe and familiar surrounding (cf. Köhler and Goldmann, 2010). By incorporating characteristics of different kinds of housing projects under the umbrella of the Bielefelder Model—with regard to care-services but especially community services—it appeals to the whole population. For this reason, not only people in need of care live in the project housing. The model encourages integrated living: tenants are healthy persons of all ages, young and old physically and mentally ill persons and/or persons in need of care with varying levels of needs of assistance (ibid.).<br><br>By connecting different relevant stakeholders and engaging citizens in volunteering in their neighbourhood the above-mentioned challenges should be met. |
| 8. Description: *What? How? Who is involved? How many users are served per year? What is the role of users?* | The model "living with security of care" is organised through a huge network of different stakeholders (as mentioned above). Involved are the associations 'Alt und Jung Süd-West e.V.' , the 'Alt und Jung Nord-Ost e.V.', the 'Bielefelder Gemeinnützige Wohnungsbaugesellschaft' (BGW), 'Wohnprojektberatung e.V.', 'Freie Scholle Wohnungsbaugenossen-schaft', the City of Bielefeld, the 'Landschaftsverband Westfalen-Lippe', the 'Landesentwicklungsgesellschaft NRW GmbH (LEG)', 'Gemeinnützige Siedlungs- und Wohnungsbaugenossenschaft Senne eG (GSWG)', 'Generationentreff' and the Wohlfahrtsverband 'der Paritätische'. Furthermore the association 'Alt und Jung Süd-West e.V.' cooperates with outpatient service providers, Kindergärten, schools, church communities and other associations (http://www.altundjung.eu/partner). In 2010 "Alt und Jung e.V." had signed more than 400 supply contracts with different service providers, including services that arise from the social code books V, IX, XI, XII of the German social legislation (http://www.altundjung.eu/leistungen).<br><br>The aims of the model are:<br><br>- To ensure living in modern and comfortable own apartments for older people in a familiar surrounding despite growing need of help or care.<br>- Enable integrative living for young and old people, for people with and without disabilities, for people with different care needs – in the |

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| | housing arrangements and in the quarter.<br>- To guarantee a 24-hour care for tenants and the living environment without raising a lump-sum.<br>- To improve the possibilities of (health) prevention through early support in the form of strengthening the abilities of self-help of the people in need of care and their surroundings.<br><br>Key components of the model are:<br><br>- Barrier-free apartments with good infrastructural links. Residential café for tenants and the neighbourhood serving as a meeting place and a locus for communication.<br>- Guest-apartments and other functional spaces (e.g. for short-term care, night service ready room, counselling office).<br>- 24-hour local presence of a social service provider (with a service centre in the neighbourhood).<br>- Maintenance service.<br>- Integration of the whole living quarter.<br>- Close cooperation and regular exchange between the 'Bielefelder Gemeinnützige Wohnungsbaugesellschaft' as the lessor and the cooperation partners of the social service field.<br><br>The special characteristic of the Bielefelder Model – the 24-hour care service without the required payment of a lump-sum – Is made possible by offering the cooperation partner (outpatient care service provider) a right of proposal regarding the renting of four to six apartments. In this way a minimum number of tenants in need of care and who ask for the services of the provider are guaranteed. The cooperation partner is able to ensure a 24-hour presence via matching periods of service and on-call duties of the employees.<br><br>The tenants have freedom of choice regarding the care service provider and do not have to use the services of the cooperation partner of the project. This implies that there is no coupling between the rental agreement and the supply contract.<br><br>Further components of the housing project are offers for special target groups:<br><br>- Since 2010 in Bielefeld a housing project especially for people with a migration background exists.<br>- Dementia care: estimated a quarter of the tenants in the projects of the Bielefelder Model are demented people. To enable a "normal" living with dementia in the quarters, volunteers are trained to be able to support demented people during their everyday life. Moreover resource-oriented assistance-offers are made (legally supported by the social code book XI, §45, which fosters so called "low-threshold assistance"). These are for example: memory training, cooking, singing, sports and exercises.<br><br>Examples for volunteering and intergenerational exchange are:<br><br>- Cooking for and with children in cooperation with the evangelical youth |

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| | centre Bielefeld.<br>- Organized mother-child activities in cooperation with the association 'Leben-Wohnen-Begegnen e.V.'<br>- Story times for young and old people<br>- Reading coaches in the day care centres for children in cooperation with the church district, the public library, primary schools and the City of Bielefeld.<br>- Cooperation with the comprehensive school to convey 'media competence' to older tenants.<br><br>The users – or the tenants – are integrated into the activities of the housing quarter and have the possibility to comment on the needs and problems to the service teams of the 'Bielefelder Gemeinnützige Wohnungsbaugesellschaft'. Once or twice a year the 'Bielefelder Gemeinnützige Wohnungsbaugesellschaft' organises meetings with for the tenants where it is possible to exchange among themselves and with the lessor (cf. presentation of the Bielefelder Model).[18] |
| 9. Impact: *Have objectives been realised? How was it measured, shown, evaluated? What are the demonstrated or potential impacts on users, informal carers, staff, inter-organisational collaboration, costs? What is the systemic impact (extent to which the initiative changes the way that LTC is provided across systems or services)? Has the example proved to be sustainable, or mainstreamed? Has the example been implemented elsewhere?* | The fact that the Bielefelder Model is being adopted in many regions throughout Germany points to the quality and transferability of the model. The possibility of choosing a very individual way of caring (without being forced to pay a monthly lump-sum for care services) and the network of different service providers and professionals enable users to stay in their own homes longer. Furthermore, the staff does not work as employees but as self-employed persons. This leads to a lean administration which ensures the high quality, further education and social security of the members of the association. 20 decentralised service teams function as contact persons for the members (cf. Köhler and Goldmann, 2010).<br><br>Neighbourhood development and "caring communities" is very topical in Germany. The city of Bielefeld has a long tradition in implementing alternative living arrangements and community-oriented service concepts. Already in the 1980s the city started with the construction of such living concepts for old and young people. For that reason the relevant actors were able to draw on their collective experiences when embarking on the Bielefelder Model in 1996. As the concept was very successful (underlined by the rising demand in Bielefeld) it acted as an exemplary model for similar projects in Germany at large and has therefore been influential in changing the strategy for planning senior living arrangements.<br><br>Users/tenants and their relatives are integrated into the community via planned leisure time activities and targeted cooperation between different stakeholders. Tenants and their relatives are able to participate |

[18] http://www.rehacare.de/cipp/md_rehacare/lib/all/lob/return_download,ticket,g_u_e_s_t/bid,1887/no_mime_type,0/~/Vortragsreihe_8_V4_Oliver_Klingelberg.pdf; http://www.rueckenwind-fuer-buerger.de/media/Bielefelder%20Modell.pdf

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| | in the arrangement of everyday activities.<br><br>The involvement of the municipality is a necessary precondition for the implementation of such a project. In Bielefeld the municipality forms the basis for a successful project by creating favourable framework conditions, for example by co-financing community services or by providing general support to community-oriented city planning. Cooperation with other professional service providers is often organised informally (cf. Stolarz, 2010) – the resulting networks are a further development in the pillared care system in Germany and foster an orientation towards the needs of the people in need of care. The organisation of personnel leads to a lean administration effort - the staff of the association do not work as employees but as self-employed persons – and as a consequence to more resources in the fields of quality assurance, further education and social security of the members of the association 'Alt und Jung e.V.'.<br><br>The model was adopted in more or less 18 cities and communities and was set up in 10 municipalities (cf. Köhler and Goldmann, 2010). As is the case in the other innovative initiative from Germany—the nursing care bases—the Bielefelder Model profits from the large, established networks in place in helping to overcome systemic barriers and solve problems via short communication paths. From 1996, when the first project was realized to 2014, 12 districts (14 projects) in Bielefeld have been adapted in accordance with the Bielefelder Model.<br><br>The innovative aspect of the model is summed up by the responsible employee of the housing association (BGW):<br><br>"In particular at the start of the project – in 1996 – the change in perspective from singular care-services to a "care in the neighbourhood" was innovative. In addition, the concept of *inclusion* (or an integration of disabled and non-disabled people) was taken up very early (long before the UN Disability Rights Convention). The third core characteristic is the [previously mentioned] 24-hour care service for tenants and the living environment without raising a lump-sum for this service. This service is always connected to the idea of a "caring community," which implies volunteers and staff and the help of the whole neighbourhood."<br><br>To achieve large-scale participation within the neighbourhood, the housing association (BGW) informs residents about the Bielefelder Model and opportunities for volunteering before implementing the model in a residential district. Furthermore, a district manager is named responsible for the construction and the coordination of the project and the different participants (volunteers). To enable easy communication and interaction, every residential district implementing the Bielefelder Model has a residential café where events are organized – among other things the offer of communal meals and self-organised cooking events are of particular importance. It is estimated that more than 200 volunteers are regularly engaged in the projects. |

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| 10. SWOT Analysis | *Strengths: What solutions were found to overcome key-challenges?*<br>The city of Bielefeld has a long tradition in implementing alternative living arrangements and community-oriented service concepts. Already in the 1980s the city started with the construction of such living concepts for old and young people. Cooperation between non-profit housing associations and outpatient care service providers (as the mentioned BGW and the "Alt und Jung e.V.") are common since that time. Because of this history, the relevant stakeholders were able to build their initiative on existing networks and collaborations. Concerning the neighbourhood development the project bears huge potentials. Consciously limiting the care services to a small radius around the housing project as well as involving only two main partners allows the projects to be carried out with relatively little organisational effort. This is even the case for locations where residential area concepts have never before taken place. All necessary building blocks of the model have been achieved on a small scale (housing, social support and nursing care), this also includes other implementation methods such as cooperation and participation. In other words the model works as an 'area concept within a wider area' and is particularly ideal for sparking further development in the area. If other providers acted in a similar way then an integrated service offering could be implemented throughout the whole area with little coordination effort (cf. Stolarz 2010). The project supports older people and people in need of care by extending the period of time spent living autonomously and independently at home.<br><br>Moreover, the model supports the cooperation of inhabitants as to the care provided in the residences. Voluntary work and self help are actively encouraged by the care service team. This is done by offering courses for helpers and relatives, assistance with tasks, events, but also with compensation and insurance coverage (ibid.).<br><br>Framework conditions in Bielefeld are as follows: Three actors support the project, share aims and cooperate with each other. The housing association is not only involved in financing and running the housing project, but also invests in adapting the houses/flats in the surrounding area. The care service provides comprehensive services across a small area. It is organised in such a way as to be flexible and to master the very complicated financing system, by involving a variety of cost-carriers. The municipality supports the financing of community-based services in terms of social benefits and other financial carriers sign appropriate performance agreements (ibid.).<br><br>The designated employee of the housing association (BGW) is responsible for arranging networking with the other partners, for the continuous coordination with additional stakeholders (in particular the municipality and administration) and for building and maintaining the relationship with the people living in the residential quarter. These tasks are considered among the most important factors for successful implementation of the Bielefelder Model. According to the model, existing structures in the neighbourhood are taken up and informal |

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| | networks are strengthened.<br><br>It should also be mentioned that socially disadvantaged groups and people in need of care living alone are also reached with this model. Through a guaranteed 50%-share of state-subsidized apartments within the barrier-free apartments, qualifying persons have access to affordable housing within the Bielefelder Model. By establishing proactive management of the district, existing needs of tenants (living alone) are recognized at an early stage so that appropriate help and care can be arranged.<br><br>Young people are also included in the project – either through voluntary work (integration in joint activities, family support services such as child care or after-school homework supervision), or through individual support and care due to care needs (personal assistance or integration assistance).<br><br>People requiring a high level of care are also to live in apartments as part of the Bielefelder Model. There are no exclusion criteria – even for people with advanced dementia or patients on ventilation machines, care services are possible.<br><br>The main reasons why people choose to move into housing provided by the Bielefelder Model are:<br>- To be able to live in a self-determined way<br>- To be able to stay in their own home as long as possible<br>- Barrier-free apartments<br>- 24-hour care service<br><br>This shows that the concept meets the demands especially of older people who may be in need of care in the future.<br><br>*Weaknesses: Which gaps have been witnessed/experienced?*<br>At one point, there was an attempt to involve another large care provider in the implementation of this model. This cooperation (in 'Heinrich Street') ended after three years due to differences in opinion as to how the care work should be organised. Since then, this same care provider has implemented the model (with some alterations) in conjunction with another housing venture (cf. Stolarz, 2010).<br><br>Evaluation of the Bielefelder Model has shown that households involved in the project do not rate the offer of community activities or the existence of a residential café as important for their decision to move in an apartment of the Bielefelder Model (cf. INTERROGARE/ GEO 2014). This may be because the offerings are not very well-known or the households are not interested in community activities. This shows a potential for improvements regarding the fostering of community involvement and better dissemination of information about community activities.<br><br>The designated employee of the housing association (BGW) mentioned |

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| | that the increasing size of the network and the increasing number of project partners has led to a necessity to further develop the quality management system in order to maintain networking between the partners. Measures to address this issue are currently being developed.<br><br>*Opportunities: Which improvements could be implemented? What additional activities will be needed to deliver on targets? How could the initiative be scaled up or rolled out?*<br><br>As was mentioned above, community activities may suffer from low-visibility and information about opportunities should be more widespread. This is underlined by answers provided by households regarding whether or not they participate in the community activities on offer (45.3% do participate, 46.1% do not participate). Reasons for not participating included health restrictions, no appropriate offer of activities or lack of knowledge of the existing options. This presents an opportunity to better circulate information on activities and to reconcile what is offered with the demand for activities.<br><br>Similarly, the share of households surveyed that provide assistance for other persons living in the residential district is low. 75% of households are not engaged in activities on behalf of other persons, mainly because of restrictions to their health. Of the 105 households who do not provide assistance/care to others but are medically able to do so, 21 households could imagine doing so. Furthermore, it is important to mention that many households do not want support–52 of 182 households that do not receive support do not want it. 54 households affirm the question of possible help from volunteers (cf. INTERROGARE/ GEO 2014). Maybe more focused intergenerational interaction would foster volunteering within the project (to date, the average age of surveyed residents was 74.6 for men and 77.2 for women (ibid.). Or perhaps an explicit discussion involving (potential) residents regarding possible volunteering would increase the rate of volunteering.<br><br>As mentioned above, the further development of the quality management system in order to maintain strong networking ties between partners would be an opportunity for improvement.<br><br>*Threats: What pressures does the initiative currently experience that could threaten its existence?*<br><br>Asked what possible threats exist to the Bielefelder Model, the designated employee of the BGW answered that securing sustainable financing is a challenge as the initiative must be able to pay for itself. There are no public subsidies or other financial allocations from the BGW/social agencies (e.g. Alt und Jung e.V.). This requires a diverse range of social services which need to be provided in a qualified way and have to be deducted with the respective funding bodies. Simultaneously, tenants have freedom of choice as to which care provider they choose, meaning that the cooperation partner does not necessarily provide the main share of the services. If an imbalance developed in the way the service provider (as the cooperation partner and the partner in charge of the 24-hour service) is able to cover all services, refinance services, serve all services in an adequate quality the central pillar of the Bielefelder |

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| | Model – the 24-hour care service – would not be sustainable.<br><br>Furthermore all partners have to be aware of the fact that the concept focuses on "living" rather than on "care and support". |
| Website | http://www.bgw-bielefeld.de/bielefelder-modell.html |
| Sources | Bielefelder Gemeinnützige Wohnungsgesellschaft mbH (o.J.): Seniorenbroschüre. „Das Bielefelder Modell". Selbstbestimmt Wohnen mit Versorgungssicherheit. http://www.bgw-bielefeld.de/bielefelder-modell.html<br><br>Ehlers, Anja; Köhler, Kerstin; Leve, Verena; Meschkutat, Bärbel; Zimmer, Barbara; Goldmann, Monika; Reichert, Monika (2011): Vernetzte Demenzversorgung. Empfehlungen für die Praxis. Evaluation vernetzter Versorgungsstrukturen für Demenzkranke und ihre Angehörigen: Ermittlung des Innovationspotenzials und Handlungsempfehlungen für den Transfer (EVIDENT), Dortmund. http://www.ffg.tu dortmund.de/cms/de/Startseite/Meldungen/Broschuere_zur_vernetzten_Demenzv ersorgung_erschienen_/index.html<br><br>INTERROGARE und GEO (2014): Evaluation BGW Bielefelder Modell. Unveröffentlichtes Dokument.<br><br>Köhler, Kerstin; Goldmann, Monika (2010): Soziale Innovation in der Pflege: Vernetzung und Transfer im Fokus einer Zukunftsbranche, in: Howaldt, Jürgen; Jacobsen, Heike (Hrsg.): Soziale Innovation: auf dem Weg zu einem postindustriellen Innovationsparadigma, Wiesbaden, S. 253-270. http://www.sfs.tu dortmund.de/odb/Repository/Publication/Doc/1326/goldmann_k%C3%B6hler.pdf<br><br>Stadt Bielefeld, Amt für Demographie und Statistik (2013): Statistische Kurzinformation Bielefeld 2013.<br><br>Stolarz, Holger (2010): Bielefelder Modell. Wohnen mit Versorgungssicherheit, in: Integrated Service Areas 7/2010. http://www.isa-platform.eu/best-practice/bielefelder-modell-de.html<br><br>Expert interview was carried out with Mr. Oliver Klingelberg, employee in the social management of the Bielefelder Gemeinnützige Wohnungsbaugesellschaft (BGW). |

## V. Buurtzorg (Care in the neighbourhood)—Netherlands

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| 1. Abstract | The development of home care services by increasingly 'taylorised' organisation has been an important attempt to allegedly improve efficiency to the detriment of user satisfaction and working conditions of professionals. In order to overcome this situation a group of community nurses in the Netherlands started to revolutionise the organisation of home care by putting the users their self-care potentials and local resources at the centre of formal care interventions. In the context of a well-funded LTC system this approach, together with participative leadership and the efficient use of information and communication technology (ICT) triggered a most innovative, sustainable and user-centred organisation of home care. Not only improved user and staff satisfaction, but also care quality and continuous growth from 100 to |

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| | more than 7,000 employees between 2007 and 2014 speak for themselves, in particular as this growth was facilitated by community nurses themselves, rather than by a centrally coordinated strategy. The innovation also spread to other home care organisations, thus increasing integrated work in autonomous teams that are able to provide more proactive and comprehensive care to older people living at home. By reducing overhead costs through a small and efficiently working back-office, average costs per client could be reduced by about 40%. If applied to the entire home care market, the model has the potential to reduce forecast additional workforce needed in home care by up to 7,000 full time employees nationwide. In 2011, 'Buurtzorg' received an award as 'Employer of the Year' in the Netherlands, and was ranked second and third in the ensuing years. |
| 2. Target group and number of population covered (region/s) | All older people with assessed needs of long-term care and their families, neighbours and other stakeholders across the Netherlands.<br><br>On average, 'Buurtzorg' is now catering for about 50,000 clients. |
| 3. Qualification as social innovation and/or social innovation potential (please highlight): | **a. <u>It is oriented towards exceptional societal challenges/social issues</u>**<br>**b. <u>It suggests new solutions in the respective societal, cultural and economic context</u>**<br>**c. <u>It creates new patterns of social practices to overcome shortcomings of traditional arrangements</u>**<br>**d. <u>It tends to overcome the traditional dichotomy between technological and social innovations</u>**<br>**e. <u>It promotes the integration and/or collaboration/partnership of heterogeneous stakeholders that have hitherto not co-operated</u>**<br>**f. <u>It includes reflective and multidisciplinary approaches towards the key goal of societal usefulness</u>**<br>**g. <u>It creates structures and processes that are sustainable and realise new growth potentials in terms of regular employment</u>**<br>**h. <u>It involves end-users as co-producers of services or products</u>**<br>**i. <u>It creates new roles and partnerships</u>** |
| 4. The initiative is clearly addressing LTC challenges as it is characterised by the following key-issues (please highlight): | **a. <u>multidisciplinary work is a value and principle</u>**<br>**b. <u>clients' needs are at the centre of all interventions</u>**<br>**c. <u>continuity of care and mechanisms to overcome barriers at the interfaces between social and health care are addressed</u>**<br>**d. <u>continuity of care and mechanisms to overcome barriers at the interfaces between formal and informal care are addressed</u>**<br>**e. <u>it is supported by legislation which explicitly addresses the coordination/integration between health and social care</u>**<br>f. incentives to improve cooperation between health and social care |

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| | facilities or services (e.g. financial, contractual advantages) are in place<br>**g. relevant information is efficiently transferred between services or agencies,**<br>**h. equal access (considering culture, gender and class) is guaranteed to all citizens**<br>**i. individual care needs are assessed by a multidisciplinary team (with multidisciplinary methods)**<br>**j. individual capacities of users/patients are enabled and strengthened**<br>**k. leadership and management capacities are enhanced through appropriate training**<br>**l. quality assurance is guaranteed**<br>**m. agreements between the services and the funding organisations are based on contracts**<br>**n. IT and communication technology are used to make administration more efficient**<br>**o. IT and communication technology are used to facilitate the service (e-health, e-care, ambient assisted living)**<br>**p. conditions for the involvement and participation of users/patients and carers are ensured (e.g. shared decision-making)**<br>q. multi-disciplinary teams are established, supported and continuously trained<br>r. an integrated access point (e.g. concerning referral, financial issues, payment regulation, one-stop-shops) is available<br>s. integrated discharge and follow-up planning is fostered (mainly for residential and/or hospital-based facilities)<br>**t. case management is carried out by trained and specialised staff with relevant job-profiles**<br>**u. funding is ensured by defined budgets**<br>**v. involved staff is participating regularly in advanced and further training**<br>**w. evaluation studies concerning structures, processes and outcomes are carried out and available**<br>**x. outcome indicators are used to measure and further develop the initiative**<br>**y. quality management serves to implement continuous improvements**<br>z. **the initiative is controlled for costs and cost-advantages** |
| 5. Status of the initiative | a. National or regional project (terminated)<br>b. European/international project (terminated) |

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| | c. National or regional project (ongoing)<br>d. European/international project (ongoing)<br>e. Implemented practice (at least in restricted areas)<br>f. **Widely spread practice/rolled out** |
| 6. Type of the initiative | a. New product<br>b. **New service**<br>c. New platform (new legal framework and platform)<br>d. **New organisational form**<br>e. **New process**<br>f. New market<br>g. **New business model** |
| 7. Rationale and objectives: *Why was the initiative implemented? What social needs does it satisfy? Which societal challenges were addressed (context conditions)? For which target groups? With which objectives?* | The usual organisation of home care tends to be progressively fragmented with respect to individual care tasks carried out by different professionals. In addition, different tasks are often funded from different sources, e.g. home nursing care by the LTC insurance (AWBZ) and home help by the municipality. This 'taylorised' organisational setting creates frictions and coordination problems, and it runs counter to integrated and 'holistic' care approaches that are promoted, for instance, in community nursing. In the Netherlands, community nursing is a special education programme for nurses who want to work in the community, rather than in hospitals or residential care facilities. A group of well-trained and experienced community nurses started to develop a new approach in 2005 as they had been particularly dissatisfied with the common organisation of home care. In the framework of a large national investment programme in LTC 'Buurtzorg' was founded as a pilot project with a successful business plan that allowed to roll out the approach beyond the project period. |
| 8. Description: *What? How was change made possible? Who is involved? How many users are served per year? What is the role of users?* | In order to overcome fragmented and reactive care delivery the Buurtzorg approach was twofold: on the one hand, trained community nurses work pro-actively with users to improve their self-care capacities and to prevent further loss of autonomy, also by involving carers and other resources in the neighbourhood, including specialists and therapists. This is realised during comprehensive visits, rather than by several home care workers calling in for a defined time to do their allocated tasks. On the other hand, community nurses and nursing assistants are organised in small teams of about 10 to 12 professionals who are responsible for an area of about 10,000 inhabitants. They are autonomous in the way to organise and distribute their individual workload, working-time and further training. New teams are not founded by a central office but by team-members themselves. These flat hierarchies are complemented by a central back office that is seconding each team by means of coaches and by accomplishing all administrative |

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| | work, supported by customised software.<br><br>Buurtzorg care comprises six components, which are delivered as a coherent package. Starting from individual needs assessment, a care plan will be compiled including a mapping of informal care networks and their potential involvement. Furthermore, additional formal care professionals needed (specialists) will be identified and included. The delivery of care is monitored by means of a specialised quality management system (Omaha model). Clients are then supported in their social roles to promote self-care and autonomy.<br><br>Buurtzorg has expanded its services in the context of the strictly regulated quasi-market of home care in the Netherlands, competing with traditional providers. This means that, apart from an initial subsidy during the pilot phase, costs are covered by the LTC insurance (AWBZ) and by municipal funding, but also by projects and private clients who are not entitled to AMBZ funding.<br><br>Up till today, these funding sources can be used in a quite flexible way from which the Buurtzorg model can draw advantage. Individual users' long-term care needs are administratively assessed according to the regulations of the AWBZ. A beneficiary will then be entitled to a certain amount of services in kind, e.g. three hours of care per day. Buurtzorg community nurses will take in charge this beneficiary and will work towards reducing his/her care needs, for instance by providing a special remobilisation programme in one week and reducing the actual number of hours provided during the following week(s) as this user might get more autonomous. Thus the budget of Buurtzorg, which is a non-profit organisation, will remain on balance, while users' are satisfied to have regained more autonomy and need less formal care. If a client needs acute health care in a hospital, community nurses will remain in contact and prepare the discharge process and follow-up support. Buurtzorg community nurses carry out individual needs assessment regularly and report these to the regional AWBZ office to adapt to the needs of a client.<br><br>If one of the neighbourhood teams has the impression that their workload is exhausted, usually this is the case when they have more than about 50 clients, the team will split up and a new team will be established in the next neighbourhood to better match staff hours and client hours. Only in these cases it might be necessary to actively search for staff on the local level.<br><br>This strategy triggered an on-going expansion across the Netherlands from one team in 2007 to more than 600 teams employing about 7,000 professionals by 2014. In the meantime, Buurtzorg serves more than 50,000 clients per year.<br><br>The financial revenue of this non-profit organisation has increased from €1 million (2007) to €50 million (2013). |
| 9. Impact: *Have objectives been realised? How was it* | The general idea of Buurtzorg is to provide comprehensive care by a well-trained specialist, who is also better paid than low-skilled home helpers, |

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| *measured, shown, evaluated?What are the demonstrated or potential impacts on users, informal carers, staff, inter-organisational collaboration, costs? What is the systemic impact (extent to which the initiative changes the way that LTC is provided across systems or services)? Has the example proven to be sustainable, or mainstreamed? Has the example been implemented elsewhere?* | in order to provide better quality of care and at the same time to reduce costs per individual user over time. Indeed, this preventative and 'activating' approach has proven to produce reduced care cycles, significantly higher times of face-to-face care, lower overhead costs as well as higher user and staff satisfaction. In the framework of the Netherlands' 'transition programme' (www.transitieprogramma.nl) the 'social business case' of Buurtzorg was evaluated, showing that their users consume only 40% of the care that they are entitled to (according to the administrative AWBZ assessment) and half of the patients receive care for less than three months (Buurtzorg Nederland, 2009). In patient satisfaction surveys that are carried out yearly covering all home care providers in the Netherlands, Buurtzorg users report scores that are 30% above the national average. Furthermore, the number of unplanned (crisis) interventions as well as rates of absence due to illness have dropped, while the number of users' complaints is close to zero (KPMG, 2014). In 2011, Buurtzorg received an award as 'Employer of the Year' for organisations of more than 1,000 employees, based on indicators such as staff involvement, employee turnover rates and staff satisfaction (Huijbers, 2011), and continued to be ranked second and third over the past few years.<br><br>The Buurtzorg approach to home care delivery has also led to higher workforce productivity and lower overhead (8% as against an average of 12% of other home care providers). In 2010, the company achieved a 58% time actually spent with patients, versus a national average of only 51%. With about 45 million hours of home care that were provided in total in the Netherlands (2010), the higher productivity level represented by Buurtzorg has the potential to reduce forecast additional workforce needed in home care by up to 7,000 full time employees nationwide (KPMG, 2014).<br><br>With more than 70% of all community nurses in the Netherlands, who are now working for Buurtzorg it is logical that many other home care providers have partially adopted the Buurtzorg approach in order to recruit and retain staff in a contested sector of the labour market.<br><br>There is ample interest in the Buurtzorg approach to other countries, in particular the US (Monsen & de Blok, 2013), Sweden and Belgium, but such a transfer is hampered mainly by funding issues, the lack of a professional profile such as the 'community nurse' and prevailing traditions in home care. |
| 10. SWOT Analysis | *Strengths: What solutions were found to overcome key-challenges? What facilitated problem-solving?*<br>- Engaged community nurses established a nurse-led holistic approach to home care, oriented towards prevention, self-care and the use of formal and informal resources in the neighbourhood of users<br>- High user and staff satisfaction<br>- Amazing growth in terms of employment, revenue and coverage within the given quasi-market of home care in the Netherlands<br>- Reduction of overhead costs, increasing productivity rates and high |

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| | quality home care<br>- Efficient use of ICT<br>- Creation of new social ties and relations in the neighbourhood<br><br>*Weaknesses: Which gaps/obstacles have been witnessed/experienced?*<br>- High demand on skills and personal engagement of staff<br><br>*Opportunities: Which improvements could be implemented? What additional activities will be needed to deliver on targets? How could the initiative be scaled up or rolled out?*<br>- The transfer to other countries is a great opportunity, but it is hampered by existing framework conditions, in particular with respect to funding, organisational and professional cultures<br><br>*Threats: What pressures does the initiative currently experience that could threaten its existence?*<br>- There is an on-going discussion and new legislation in the Netherlands about long-term care funding that might result in less proficient framework conditions and regulations in the future |
| Website | www.buurtzorg.nl<br><br>http://journal.aarpinternational.org/a/b/2013/06/Buurtzorg-Nederland-Nurses-Leading-the-Way |
| Sources | Buurtzorg Nederland (2009) *maatschappelijke Business Case (mBC)* [Social Business Case], available at http://www.invoorzorg.nl/docs/ivz/professionals/Maatschappelijke_business_case_Buurtzorg.pdf<br><br>Huijbers, P. (2011) Care in the neighbourhood: better home care at reduced cost, available at http://interlinks.euro.centre.org<br><br>Monsen, K. and J. de Blok, J. (2013) Buurtzorg Nederland, *American Journal of Nursing*, 113(8): 55-59.<br><br>KPMG International (2014) 'Netherlands: Buurtzorg empowered nurses focus on patient value' in:KPMG International(ed.) *Value walks. Successful habits for improving workforce motivation and productivity*, pp. 20-24, available at www.kpmg.com/healthcare |

## VI. Carer+, Developing Digital Competencies of Care Workers to Improve the Quality of Life of Older People—Romania and Latvia (ES, IT, FR, AT, UK, HU, BE)

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| 1. Abstract | Several changes across Europe have led to an increased demand for home care services: demographic changes, a constant decline in welfare provision (mainly in the last years due to economic crisis); the increased participation of women in the labour force; the challenges of balancing working life with family life; and the increase in the number of older persons in rural areas. In the near future, the demand for competent, qualified and trusted domestic workers in the area of long-term care is expected to grow dramatically. At the European level, programmes for ageing well that support the use of ICT are generating projects that support innovative solutions for active ageing.<br><br>The purpose of the CARER+ project is to link together and build on a range of activities aimed at improving the lives of older people in their homes and local communities, using new ICT and AAL (Ambient Assisted Living) technologies. The project also promotes the key role of professional social carers through the development of digital competencies. |
| 2. Target group and number of population covered (region/s) | The main target group consisted of 250 care workers and caregivers. In addition, 250 care recipients (older persons) received support in their use of ICTs and AAL technologies.<br><br>25 trainers (5 per country) were trained to be prepared to support the social workers, caregivers, and care recipients.<br><br>100 local and national policy-makers will conduct visits in 2014. |
| 3. Qualification as social innovation and/or social innovation potential (please highlight): | **a. <u>It is oriented towards exceptional societal challenges/social issues</u>**<br>b. It suggests new solutions in the respective societal, cultural and economic context<br>c. It creates new patterns of social practices to overcome shortcomings of traditional arrangements<br>**d. <u>It tends to overcome the traditional dichotomy between technological and social innovations</u>**<br>e. It promotes the integration and/or collaboration/partnership of heterogeneous stakeholders that have hitherto not co-operated<br>**f. <u>It includes reflective and multidisciplinary approaches towards the key goal of societal usefulness</u>**<br>g. It creates structures and processes that are sustainable and realise new growth potentials in terms of regular employment<br>**h. <u>It involves end-users as co-producers of services or products</u>**<br>i. It creates new roles and partnerships |
| 4. The initiative is clearly | **a. <u>multidisciplinary work is a value and principle</u>** |

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| addressing LTC challenges as it is characterised by the following key-issues (please highlight): | **b. clients' needs are at the centre of all interventions**<br>c. continuity of care and mechanisms to overcome barriers at the interfaces between social and health care are addressed<br>d. continuity of care and mechanisms to overcome barriers at the interfaces between formal and informal care are addressed<br>e. it is supported by legislation which explicitly addresses the coordination/integration between health and social care<br>f. incentives to improve cooperation between health and social care facilities or services (e.g. financial, contractual advantages) are in place<br>g. relevant information is efficiently transferred between services or agencies, e.g. by means of a joint care plan based on a dialogue with users/patients and their informal network<br>**h. equal access (considering culture, gender and class) is guaranteed to all citizens**<br>i. individual care needs are assessed by a multidisciplinary team (with multidisciplinary methods)<br>**j. individual capacities of users/patients are enabled and strengthened**<br>k. leadership and management capacities are enhanced through appropriate training<br>l. quality assurance is guaranteed across health and social care services and/or facilities<br>m. agreements between services and/or organisations are based on contracts<br>n. IT and communication technology are used to make administration more efficient<br>**o. IT and communication technology are used to facilitate the service (e-health, e-care, ambient assisted living)**<br>**p. conditions for the involvement and participation of users/patients and carers are ensured (e.g. shared decision-making)**<br>**q. multi-disciplinary teams are established, supported and continuously trained**<br>r. an integrated access point (eg concerning referral, financial issues, payment regulation, one-stop-shops) is available<br>s. integrated discharge and follow-up planning is fostered (mainly for residential and/or hospital-based facilities)<br>t. case management is carried out by trained and specialised staff with relevant job-profiles<br>u. funding is ensured by defined budgets<br>**v. involved staff is participating regularly in advanced and further** |

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| | **training**<br>**w. evaluation studies concerning structures, processes and outcomes are carried out and available**<br>x. outcome indicators are used to measure and further develop the initiative<br>y. quality management serves to implement continuous improvements<br>z. the initiative is controlled for costs and cost-advantages |
| 5. Status of the initiative | a. National or regional project (terminated)<br>b. European/international project (terminated)<br>c. National or regional project (ongoing)<br>d. **European/international project (ongoing)**<br>e. Implemented practice (at least in restricted areas)<br>f. Widely spread practice/rolled out |
| 6. Type of the initiative | a. New product<br>b. **New service**<br>c. New platform (new legal framework and platform)<br>d. New organisational form<br>e. New process<br>f. New market<br>g. New business model |
| 7. Rationale and objectives: *Why was the initiative implemented? What social needs does it satisfy? Which societal challenges were addressed (context conditions)? For which target groups? With which objectives?* | Several changes across Europe have led to an increased demand for home care services: demographic changes, a steady decline in welfare provision (mainly in the last years due to economic crisis); the increased participation of women in the labour force; the challenges of balancing working life with family life; and the increase in the number of older persons in rural areas. According to European projections the number of persons aged 65 years and over will rise to 28.7% by 2050. At the same time the economic dependency ratio will reach 69.8% in EU27 countries (European Commission/Ageing Report, 2012). These scenarios will result not only in greater pressure on budgetary expenditures, but also in an increased demand for competent and qualified caregivers in the area of LTC. Current technological advances allow the integration of monitoring and therapeutic systems, provide educational content, and enable communication and data flow between patients and professional health care providers.<br><br>From the provider and professional (caregiver) side, such tech solutions support the care delivery process. They enable caregivers to deepen their competencies and to achieve personal development and career progression. At present, care workers are under-skilled and need |

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| | specialized education and competencies (CEDEFOP, 2010). Regarding informal carers, ICT's support professionalisation (development of new competencies), peer learning and support. ICT and AAL solutions enable older persons to avoid institutionalisation and to self-manage their own situation with the assistance of formal or informal caregivers, depending on their needs. For frail older persons, the use of ICT may have a positive impact on their quality of life, autonomy and safety. The literature in this domain emphasises the positive impact of ICT usage on the social life of older persons (Malanowsky, 2009; Lindberg et al, 2013).<br><br>In response to these realities and in line with the European initiatives and actions to support active ageing (eHealth initiative, Ambient Assisted Living Programme), the purpose of the CARER+ project is to improve the lives of older persons in their home environment and local communities using new ICT and AAL technologies in the framework of a new model of care service. The project also promotes the key role of professional social carers through the development of digital competencies. The key mediators between ICT-based opportunities and their integration into the lives of older persons are the care workers and the set of competencies they possess. Based on the European realities in the LTC sector (in terms of supply-demand, available labour force, informal caregiver involvement), the following objectives were set forth:<br><br>- to develop, host and administer the Carer+ web portal with a Content Management System and Application for providing information, resources and social networking facilities to the European stakeholders of the home care-sector;<br>- to develop a list of ICT knowledge and skill-based competencies for informal caregivers and care workers;<br>- to develop a certification process for digital competencies of social carers linked to the competence framework;<br>- to develop the learning environment, learning pathways and associated resources so that informal hard and soft skills are integrated with the attainment of formally accredited competencies within the defined digital competence framework within the two key strands of 'employability' and 'social care with ICT';<br>- to deliver guidelines to enable transfer of the Carer+ processes and tools to promote the development of digital competencies in care sector, for sustainability and transferability purposes in Europe. |
| 8. Description: *What? How was change made possible? Who is involved? How many users are served per year? What is the role of users?* | With funding from the European Commission (Competitiveness and Innovation Framework Programme; ICT Policy Support Programme), the consortium embarked on the project in 2012 with a coordinator specialised in vocational training for family employment and 14 organisations from 8 EU countries specialised in the care sector, research and digital inclusion.<br><br>The project began with the development of a European portal for care workers. A Carer+ e-learning platform provides ICT enhanced blended learning for carers in each country.<br><br>The virtual learning environment (VLE) covers: |

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| | - a profiling tool to baseline participant skills and knowledge and to assess their readiness to study and their attitudes to ICT use;<br>- micro-certification delivered through a badge system that rewards skills acquisition and promotes positive learning behaviours and community activity in the VLE;<br>- a specific course on professionalisation that supports personal development planning and enhancement of individual professional status and social capital.<br><br>VLE consists of three tools: a social network, a learning platform and a competency wiki. The social network integrates or gives access to the learning platform and the competency wiki. In each piloting country participants will access these tools in their national language.<br><br>In the second phase the competence framework of digital skills and competencies (DCF) for care workers was defined. For the competence framework to be both conceptually robust and practically relevant and functional, original research collected evidence on the use of digital skills in 8 European countries: 57 competence-related documents were analyzed (curricula, qualifications standards, occupations standards, etc.), 8 expert focus groups were organized, 46 expert interviews were conducted, 156 questionnaires were returned by care workers and caregivers. The DCF structural elements are organized according to five dimensions: 3 competence domains, 12 competence areas, 48 competencies, 2 application levels (see figure 1). DCF is a reference tool that helps caregivers and care workers to assess their digital competence and plan their further development in an organised and outcome-oriented way. The framework allows caregivers to assess the knowledge and skills they possess, their level of mastery, and where best to target further learning. The DGF was finalised in the first quarter of 2013 and published in a wiki environment in the Carer+ portal for all interested stakeholders to use, review and comment on. The review phase ended in June, 2013.<br><br>The third step will be to certify the competence framework. DGF pilot testing began in September 2013 in France, Latvia, Italy and Spain. Pilot testing the new technologies and approaches include the assessment of the Li1 and Webnapperon devices - supported by Internet Tablets and other Smart Networked Objects. During this phase 500 care workers and caregivers (family members or any other informal caregiver) in the CARER+ project have free access to modern ICT tools and can attend a 200 hours training for free (40 hours of face-to-face learning, complemented by 160 hours of distance learning). Of these, 200 care workers and 50 informal caregivers will participate in training sessions and 250 care recipients will receive smart devices. A 'train the trainers' programme has been developed to train trainers who support care workers. The training programme offers advanced care workers the opportunity to become mentors/trainers for the programme. Trainers support care workers throughout the entire training programme. The training sessions will develop the care worker's digital competencies and help establish new working practices. At the end of the training |

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| | programme care workers can apply and try out their new skills providing home care services to older people. The carers will also be equipped with an Internet tablet or a smart phone that will aid personal communication with care recipients. Care recipients will benefit from a six-month period of home care provided by a qualified care worker or an informal caregiver/family member free of charge. Care recipients will also have free access to ICT devices (equipped with a 3G connection that permit wireless access to the Internet) that can be used during the period they receive home care services.<br><br>At the end of the pilot phase, the consortium will promote national campaigns in order to facilitate the effective involvement and participation of the target groups, local cooperation and transparent implementation. Also, carers will take part in the research phase which will help the consortium to learn about the impacts and the effectiveness of the project, and about benefits that can potentially be provided to care workers in the future.<br><br>Policy-makers will conduct visits in order to be able to build a common European strategy addressing the potential of ICT use for social care, social workers and active ageing. |
| 9. Impact: *Have objectives been realised? How was it measured, shown, evaluated? What are the demonstrated or potential impacts on users, informal carers, staff, inter-organisational collaboration, costs? What is the systemic impact (extent to which the initiative changes the way that LTC is provided across systems or services)? Has the example proven to be sustainable, or mainstreamed? Has the example been implemented elsewhere?* | The CARER+ project runs until Autumn, 2015, but the objectives undertaken so far have already been realised. The piloting and related validation processes are currently running. Analysis of impact will be done after the completion of the piloting phase.<br><br>*Expected impact*<br>It is envisaged that the development of the digital competencies of the care-working labour force will serve two purposes:<br>For care workers:<br>- Increased professionalization through access to skills and accreditation in the use of ICT for improving the quality of life of care recipients;<br>- Enhancement in the personal use of ICT allowing greater mobility, and access to learning and professional opportunities including peer support within communities of practice and social networks, train the trainer activities.<br>For older people:<br>- Improvement in quality of life, which can result in empowerment, encompassing a greater and extended participation in society.<br>- Contribution to active ageing and wellbeing of older people at home.<br><br>*Sustainability and transferability issues*<br>Through a 'train the trainers' pathway that offers advanced participants an opportunity to become mentors for the programme, an important element of sustainability has been assured. The CARER + project create many opportunities for collaboration with the stakeholders of the social care sector and those concerned by the development of digital competences of care workers and caregivers. Transferability of technologies is ongoing.<br><br>The methodology and the training programme have attracted |

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| | considerable interest in social care. A programme in Scotland is currently being developed. More information on this will be published when the development process is finished (end of May, 2014).<br><br>The CARER+ project has been nominated for the "Trophées du grand âge et du Bien vieillir" which rewards the best initiatives that seek to improve the quality of life of older people. |
| 10. SWOT Analysis | *Strengths: What solutions were found to overcome key-challenges? What facilitated problem-solving?*<br>- The project enables the development of certified digital competences and digitally-supported professional skills for both domiciliary care workers (formal)/ and caregivers (informal) and older people (care recipients);<br>- The development of a certification process for the digital competencies linked to the competence framework of social carers;<br>- The involvement of a wide range of stakeholders from the fields of digital literacy, social inclusion, social care, ambient assisted living (AAL) and eHealth;<br>- Contribution to active ageing and wellbeing of older people at home, as technological advances facilitate care management in the home environment, thereby avoiding or postponing institutionalisation;<br>- Carer+ promotes consensus building through the involvement of local, regional and national actors working in the sector of LTC;<br><br>*Weaknesses: Which gaps/obstacles have been witnessed/experienced?*<br><br>- The project is still ongoing; no gaps/obstacles have been identified so far.<br><br>*Opportunities: Which improvements could be implemented? What additional activities will be needed to deliver on targets? How could the initiative be scaled up or rolled out?*<br><br>- The project exploits the new role of the care worker in a digital society, demonstrating that increased professionalisation of the care sector through access to skills and accreditation in the use of ICT translates into the improvement of the quality of life of care recipients;<br><br>- The use of migrant care assistants as mediators or facilitators for the diffusion of ICT-based tools and services among older care recipients;<br><br>- The methodology and the training programme are transferable to other countries from Europe.<br><br>*Threats: What pressures does the initiative currently experience that could threaten its existence?*<br><br>- Funding (e.g. lack of funds for equipment that can be used by care workers in their caring tasks, devices that can meet their training needs in ICT–especially in the case of Romania);<br>The lack of policies supporting the adoption of care-related technological innovation and a high reliance on informal (and often undocumented), poorly trained and ill-supported caregivers from certain countries (Spain and Italy); |

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| | - The lack of interest in ICT usage among caregivers due to age, gender, material resources, etc. |
| Website | http://www.carerplus.eu/ |
| Sources | European Centre for the Developmentof Vocational Training (CEDEFOP)(2010) *Quality assurance in the social care sector. The role of training.*<br><br>European Commission (2012) *The 2012 Ageing Report. Economic and budgetary projections for the 27EU Member States (2010-2060*).<br><br>Lindeberg, B., Nilsson, C., Zotterman, D., Söderberg, S., Skär, L. (2013) Using Information and Communication Technology in Home Care for Communication between Patients, Family Members, and Healthcare Professionals: A Systematic Review, *International Journal of Telemedicine and Applications*, vol. 2013, Article ID 461829, doi:10.1155/2013/461829.<br><br>Malanowsky, N. (2009) ICT-based application for active ageing: challenges and opportunities, In Cabrera, M. and Malanowski, N., *Information and Communication Technologies for Active Ageing: Opportunities and Challenges for European Union*, IOS Press Publishing, pp. 107-207.<br><br>Valenta, L., Suba, E., Warburton, S., Ziegler, P. (2013) Carer+: Towards a digital competence framework for care workers in domiciliary care, *The Joy of Learning Enhancing Learning Experience - Improving Learning Quality Proceedings of the European Distance and E-Learning Network 2013 Annual Conference,*pp. 589-602, Oslo, 12-15 June 2013.<br><br>Email consultation was provided by Eva Suba of the Communication and Networking, EDEN – European Distance and E-Learning Network Secretariat, http://www.carerplusproject.eu/,http://www.carerplus.eu. |

## VII. Care for Carers—Portugal

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| 1. Abstract | Care for the Carers (I) is a local project for the support of informal carers of dependent elderly persons with dementia or limitations caused by a stroke. It provides several diversified services: informal carer psycho-educational intervention groups, pool of trained professionals, pool of trained volunteers, diagnosis of the carers' need for rest, promotion of discussion and awareness of the community. The project is promoted by a local association (CASTIIS), municipal authorities (Santa Maria da Feira city hall) and by a higher education institute research unit (UNIFAI – Abel Salazar Institute, Oporto University), which also evaluates the program. It was financially supported by Calouste Gulbenkian Foundation and by the Portuguese Health High Commissioner. The project involved inter-municipal, multidisciplinary and public partnerships, as well as an articulation between health and social services and professionals. |

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| 2. Target group and number of population covered (region/s) | Informal Carers of senior persons with Alzheimer in a post-stroke situation from 5municipalities in the northwest part of the country. A total of 288 informal carers participated in psycho-educative intervention groups. |
| 3. Qualification as social innovation and/or social innovation potential (please highlight): | **a. It is oriented towards exceptional societal challenges/social issues**<br>**b. It suggests new solutions in the respective societal, cultural and economic context**<br>**c. It creates new patterns of social practices to overcome shortcomings of traditional arrangements**<br>d. It tends to overcome the traditional dichotomy between technological and social innovations<br>**e. It promotes the integration and/or collaboration/partnership of heterogeneous stakeholders that have hitherto not co-operated**<br>**f. It includes reflective and multidisciplinary approaches towards the key goal of societal usefulness**<br>**g. It creates structures and processes that are sustainable and realise new growth potentials in terms of regular employment**<br>**h. It involves end-users as co-producers of services or products**<br>**i. It creates new roles and partnerships** |
| 4. The initiative is clearly addressing LTC challenges as it is characterised by the following key-issues (please highlight): | **a. multidisciplinary work is a value and principle**<br>**b. clients' needs are at the centre of all interventions**<br>**c. continuity of care and mechanisms to overcome barriers at the interfaces between social and health care are addressed**<br>**d. continuity of care and mechanisms to overcome barriers at the interfaces between formal and informal care are addressed**<br>e. it is supported by legislation which explicitly addresses the coordination/integration between health and social care<br>**f. incentives to improve cooperation between health and social care facilities or services (e.g. financial, contractual advantages) are in place**<br>**g. relevant information is efficiently transferred between services or agencies**<br>**h. equal access (considering culture, gender and class) is guaranteed to all citizens**<br>**i. individual care needs are assessed by a multidisciplinary team**<br>**j. individual capacities of users/patients are enabled and strengthened**<br>**k. leadership and management capacities are enhanced through appropriate training**<br>l. quality assurance is guaranteed across health and social care services and/or facilities |

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| | **m. agreements between services and/or organisations are based on contracts**<br>**n. IT and communication technology are used to make administration more efficient**<br>**o. IT and communication technology are used to facilitate the service**<br>**p. conditions for the involvement and participation of users/patients and carers are ensured**<br>**q. multidisciplinary teams are established, supported and continuously trained**<br>r. an integrated access point (e.g. concerning referral, financial issues, payment regulation, one-stop-shops) is available<br>s. integrated discharge and follow-up planning is fostered (mainly for residential and/or hospital-based facilities)<br>t. case management is carried out by trained and specialised staff with relevant job-profiles<br>**u. funding is ensured by defined budgets**<br>v. involved staff is participating regularly in advanced and further training<br>**w. evaluation studies concerning structures, processes and outcomes are carried out and available**<br>**x. outcome indicators are used to measure and further develop the initiative**<br>**y. quality management serves to implement continuous improvements**<br>**z. the initiative is controlled for costs and cost-advantages** |
| 5. Status of the initiative | a. **National or regional project (terminated and then transformed into a new project of 4more years)**<br>b. European/international project (terminated)<br>c. National or regional project (ongoing)<br>d. European/international project (ongoing)<br>e. Implemented practice (at least in restricted areas)<br>f. Widely spread practice/rolled out |
| 6. Type of the initiative | a. **New product**<br>b. **New service**<br>c. New platform (new legal framework and platform)<br>d. New organisational form<br>e. **New process**<br>f. New market<br>g. New business model |

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| 7. Rationale and objectives: *Why was the initiative implemented? What social needs does it satisfy? Which societal challenges were addressed (context conditions)? For which target groups? With which objectives?* | The Care for the Carers(I) was designed to address an aspect previously identified in a study carried out by social and health institutions from a group of municipalities in the northwest of the country: the absence of social and health support services for informal carers of LTC patients.<br><br>The project was specifically targeted to promote and develop new, community-based and sustainable services for informal carers of senior persons with Alzheimer or in a post-stroke situation. More specifically its main goals were:<br><br>- to create and implement a multidisciplinary psycho-educational intervention program for informal carers of senior persons with Alzheimer and another one for informal carers of senior persons in a post-stroke situation;<br><br>- to constitute a group of professionals specifically trained for the care of elderly persons with Alzheimer or in a post-stroke situation;<br><br>- to boost local volunteering and to sensitize and train volunteers for the issues and problems related to the informal care of senior persons with Alzheimer or in a post-stroke situation;<br><br>- to study informal carers' profile and to identify and describe the respite services available in the municipalities.<br><br>- to sensitize the community as a whole and professionals of senior related services for the specific issues and problems of informal care, as well as for the needs of both informal carers and dependent senior persons. |
| 8. Description: *What? How was change made possible? Who is involved? How many users are served per year? What is the role of users?* | Care for the Carers (I) involves five lines of action for the accomplishment of each of the goals mentioned above. Nevertheless, the core activity is the one related to the first goal – i.e. implementation of a psycho-educational intervention program in groups of informal carers of senior persons with Alzheimer and in groups of informal carers of senior persons in a post-stroke situation. The program was designed to foster informal carers' skills and knowledge, as well as to potentiate the development of informal carers' coping and self-care strategies.<br><br>The project was promoted by three entities – municipal authority, a public-subsidized institution for senior persons (CASTIIS) and higher education institute research unit (UNIFAI) - that brought together their different skill sets and strengths to design and implement the project, as well as to find and monopolize the required financial resources and partnerships. In terms of project funding, it was supported both by public programs (Portuguese Health High Commissioner and Santa Maria da Feira City Hall) and by a national private non-profit institution (Calouste Gulbenkian Foundation).<br><br>In what refers to partnerships, a set of diverse, municipal and interdisciplinary public institutions actively participated in the project conception, implementation and evaluation. The partners of each municipality formed a local team responsible for the project divulgation, as well as for the development/execution/implementation of project activities within their municipality. Local teams had two coordinators, |

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| | one partner from the social field and another from the health field. Inter-municipal articulation and communication was coordinated by the project's technical team.<br><br>During the 4 years of the project, 288 informal carers participated, 81.6% of them were informal carers of Alzheimer patients. The profile of the informal carer that participated in the project is: married or civil union (96.1%) women (81.2%), aged between 23 and 82 years old (mean=56.5; SD=13.3), with primary education (31%), unemployed or retired (81.9%) and with an income lower than the national minimum wage (60.6%).<br><br>Besides the active role of the project partners, there was also the active participation of informal carers, namely through their feedback on the psycho-educational program's sessions, mainly, during its implementation and pilot test. Participant's opinions and needs were considered on program adaptation and adjustment – e.g. after the terminus of the psycho-educational intervention groups, mutual aid groups, previously not considered, were created as a way to maintain the support to informal carers and, therefore, to respond to their needs continuously in time/in a long term time range. |
| 9. Impact: *Have objectives been realised? How was it measured, shown, evaluated? What are the demonstrated or potential impacts on users, informal carers, staff, inter-organisational collaboration, costs? What is the systemic impact (extent to which the initiative changes the way that LTC is provided across systems or services)? Has the example proven to be sustainable, or mainstreamed? Has the example been implemented elsewhere?* | The project evaluation was conducted by the research unit that co-promoted it– UNIFAI. For each line of action a specific set of indicators was evaluated.<br><br>Regarding the psycho-educational intervention groups, each participant was evaluated before and immediately after the intervention, as well as in a face-to-face/phone follow-up interview done 2-3 months, 5-6 months and 8-9 months after the intervention. The dimensions evaluated were: informal carers' physical and mental health, psychological distress, positive features of care and carer over-burden.<br><br>The psycho-educational intervention program had a positive impact in the informal carer's mental health, perception of positive aspects of care, psychological distress and overburden. Also, 98.4% of the informal carers mentioned being "satisfied" or "very satisfied" for participating in the psycho-educational intervention groups, mainly because 'it made me understand that I'm also important and that I also have to take care of myself' and 'the sole fact of knowing that I'm not alone, have the opportunity to speak freely, listen and share ideas with other carers'.<br><br>In terms of the lines of action related to the creation of a pool of trained professionals and a pool of trained volunteers, the indicators used were mainly the number of professionals/volunteers participating on the training sessions and the number of professionals /volunteers that actually gave support to informal carers in caring for a dependent senior person. There were 43 professionals and 12 volunteers that received training, and from those, respectively, 82% and 91%indicatedbeing very satisfied with it. Only one of the professionals was hired and none of the volunteers was asked to give support.<br><br>After the end of the project a qualitative analysis was undertaken involving: 1) interviews to the technical team and to the local coordinators and 2) focus group with each of the local teams. A |

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| | documental analysis of project's records, like minutes of partnerships and coordination meetings, was also carried out.<br><br>Another evidence of the positive impact on informal carers was the need – after the end of the program – to create mutual aid groups as a way to maintain support to informal carers and, therefore, to continue responding to their needs in a broader time range. This mutual aid groups are still active and are financially supported by municipal partnerships established during the project and that keep on going after its terminus. This is an evidence of both project continuity and sustainability.<br><br>From this project a new one was created (Care for the carers (II)). In this new project different social/health institutions of 16 municipalities (the same 5 municipalities + 11 new ones from the Oporto district) will receive training to implement the psycho-educational intervention program for informal carers. Also, as a response for an informal carers' need identified in the Care for the Carers project, an Informal Carer's Cabinet will be created to provide individualized and personalized support. |
| 10. SWOT Analysis | *Strengths: What solutions were found to overcome key-challenges? What facilitated problem-solving?*<br><br>- Creation, implementation and test of a multidisciplinary psycho-educational intervention program for informal carers<br>- Project co-promoted by three different institutions, namely a research centre that ensured program evaluation and validation.<br>- High-level of participation and involvement of social and health municipal institutions as partners of the project with key formally-defined responsibilities;<br>- Continuous monitoring of and adjustment to informal carers needs;<br>- Diversified lines of action – support, knowledge and sensitization for informal carers' specific needs and problems.<br>- Availability of a pool of professional and volunteer-based support for informal carers<br>- Scientific knowledge and analysis supported program development, project evaluation and validation.<br>- Sustainability commitment made possible by collaboration and involvement of all partners.<br><br>*Weaknesses: Which gaps/obstacles have been witnessed/experienced?*<br><br>- Low adherence of informal carers of senior persons in a post-stroke situation.<br>- Initial resistance of informal carers to participate in the group sessions as it involved leaving their care receiver unattended.<br>- Lack of public transportation made it difficult for informal carers to go to the intervention groups |

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| | - Informal carers' reluctance to let strangers come into their home and to accept help from volunteers.<br>- Unwillingness of public institutions to make partnerships with private institutions;<br>- Lack of family financial resources to pay for at-home professional support.<br>- Evaluation did not include a control group<br><br>*Opportunities: Which improvements could be implemented? What additional activities will be needed to deliver on targets? How could the initiative be scaled up or rolled out?*<br>- Make use of and give training to existent municipal institutions' pools of volunteers;<br>- Develop personalized and individualized support for informal carers<br>- Extend the number of municipalities involved<br>- Capacitate local institutions to apply the psycho-educational intervention programme<br><br>*Threats: What pressures does the initiative currently experience that could threaten its existence?*<br>- Management of partnerships network is not easy, as well as ensuring their cooperation and communication<br>- Continuous need of a technical team to work as catalyst and motivation source. |
| Website | http://www.cuidardequemcuida.com |
| Sources | Ribeiro, O., Pires, C., Brandão, D., Teixeira, L., Martín, I.&Paúl, C.(2013) Cuidar de Quem Cuida entre Douro e Vouga: Relatório de Avaliação Final.<br><br>Expert interview was carried out with Dr. Cátia Pires, who was part of the Care for Carers' (I) evaluation team (higher education institute research unit - UNIFAI) and is now part of the technical team for Care for Carers (II). |

## VIII. CarEIn, Emotional intelligence care in health and social assistance —Bulgaria (ES, CZ, IT, PL, UK, CH, DK)

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| 1. Abstract | CarEIn improves the qualification of workers through the promotion of EI; it improves the quality of their work and services provided; facilitates the adaptation of workers in the health and care sector to changes in the sector; increases the motivation and satisfaction of workers of health and care sector; improves the quality of life of the beneficiaries of the health and care sector. |
| 2. Target group and number of population covered (region/s) | Target group consisted of 200 professionals:<br>- Social care professionals: social assistants, psychologists, occupational therapists, carers, etc.;<br>- Health and medical care professionals (doctors, nurses, physiotherapists, etc.), working in social care centres such as rehabilitation centres, day-care centres or social institutions.<br><br>The indirect users/beneficiaries:<br>- Groups suffering a progressive loss of their physical functions and therefore needing social care in addition to medical treatment;<br>- People suffering from degenerative illnesses that affect their functional abilities, including older persons. |
| 3. Qualification as social innovation and/or social innovation potential (please highlight): | **a. It is oriented towards exceptional societal challenges/social issues**<br>b. It suggests new solutions in the respective societal, cultural and economic context<br>c. It creates new patterns of social practices to overcome shortcomings of traditional arrangements<br>**d. It tends to overcome the traditional dichotomy between technological and social innovations**<br>**e. It promotes the integration and/or collaboration/partnership of heterogeneous stakeholders that have hitherto not co-operated**<br>**f. It includes reflective and multidisciplinary approaches towards the key goal of societal usefulness**<br>g. It creates structures and processes that are sustainable and realise new growth potentials in terms of regular employment<br>**h. It involves end-users as co-producers of services or products**<br>i. It creates new roles and partnerships |
| 4. The initiative is clearly addressing LTC challenges as it is characterised by the following key-issues (please highlight): | **a. multidisciplinary work is a value and principle**<br>**b. clients' needs are at the centre of all interventions**<br>c. continuity of care and mechanisms to overcome barriers at the interfaces between social and health care are addressed<br>d. continuity of care and mechanisms to overcome barriers at the interfaces between formal and informal care are addressed |

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| | e. it is supported by legislation which explicitly addresses the coordination/integration between health and social care<br>**f. incentives to improve cooperation between health and social care facilities or services (e.g. financial, contractual advantages) are in place**<br>g. relevant information is efficiently transferred between services or agencies, e.g. by means of a joint care plan based on a dialogue with users/patients and their informal network<br>**h. equal access (considering culture, gender and class) is guaranteed to all citizens**<br>i. individual care needs are assessed by a multidisciplinary team (with multidisciplinary methods)<br>j. individual capacities of users/patients are enabled and strengthened<br>**k. leadership and management capacities are enhanced through appropriate training**<br>l. quality assurance is guaranteed across health and social care services and/or facilities<br>m. agreements between services and/or organisations are based on contracts<br>**n. IT and communication technology are used to make administration more efficient**<br>o. IT and communication technology are used to facilitate the service (e-health, e-care, ambient assisted living)<br>p. conditions for the involvement and participation of users/patients and carers are ensured (e.g. shared decision-making)<br>**q. multi-disciplinary teams are established, supported and continuously trained**<br>r. an integrated access point (e.g. concerning referral, financial issues, payment regulation, one-stop-shops) is available<br>s. integrated discharge and follow-up planning is fostered (mainly for residential and/or hospital-based facilities)<br>t. case management is carried out by trained and specialised staff with relevant job-profiles<br>u. funding is ensured by defined budgets<br>v. involved staff is participating regularly in advanced and further training<br>**w. evaluation studies concerning structures, processes and outcomes are carried out and available**<br>x. outcome indicators are used to measure and further develop the initiative<br>**y. quality management serves to implement continuous** |

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| | **improvements**<br>z. the initiative is controlled for costs and cost-advantages |
| 5. Status of the initiative | a. National or regional project (terminated)<br>b. **European/international project (terminated)**<br>c. National or regional project (ongoing)<br>d. European/international project (ongoing)<br>e. Implemented practice (at least in restricted areas)<br>f. Widely spread practice/rolled out |
| 6. Type of the initiative | a. **New product**<br>b. New service<br>c. New platform (new legal framework and platform)<br>d. New organisational form<br>e. New process<br>f. New market<br>g. New business model |
| 7. Rationale and objectives: *Why was the initiative implemented? What social needs does it satisfy? Which societal challenges were addressed (context conditions)? For which target groups? With which objectives?* | The health and social care sectors are characterised by important flows of emotions between the patient/care recipients and care givers. The management of emotions by professionals facilitates a better performance in social work field. For these particular sectors, the ability of caregivers to manage their emotions and the emotional responses of patients is crucial to accomplishing necessary tasks. It has been acknowledged that the social sector is an important component of national economies and that often the most demanding issues faced by states are and will continue to be social in nature.<br><br>Education and training for practitioners in healthcare related to LTC (doctors and nurses) needs to be improved. In countries like Bulgaria, the actual level of training of health care workers in LTC is not in line with national standards and requirements (Neykov and Salchev, 2012). With regard to the social care side of LTC, salaries are low and career prospects are limited for those working in the field and as a result, it is difficult to recruit, motivate and retain workers in the sector (Beleva, 2010). Relatives provide informal care, but this has consequences for the quality of services provided, as this part of the labour force needs intensive qualification and training, as well as regulation of employment conditions, health and security.<br><br>Several changes in the healthcare and social care sectors in the last years (e.g. progressive ageing of population, an increased focus on illness prevention, and increased demand for integrated services covering specific needs of patients) require - from a workers' point of view – an adaptation of skills to meet the challenges of the changing situation in order to be able to match the market's demand. |

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| | CarEIn addressed one of the needs for social innovation in LTC by building up the skills of professionals (European Commission/BEPA, 2011) and at the same time it offered a creative way to cope with the societal challenges generated by an ageing population. The product fostered the well-being at once of professionals, users, and carers. The initiative also aimed to better develop the social innovation in training programmes at the national level with the goal of improving the quality of life of patients receiving health and social care services. The CarEIn solution involved the partner states through their respective health care and social care systems.<br><br>CarEIn pursued the following objectives:<br>- Making a useful curriculum available that improves the quality of work and services provided for health and social assistance workers.<br>- Improving the skills of workers through the promotion of a series of cross-cutting competencies, resulting from the use of Emotional Intelligence (self-knowledge, emotional management, self-motivation, empathy and social ability).<br>- Fostering a higher professional flexibility, enabling professionals to quickly adapt to changes that can occur in the health and care sector.<br>- Increasing the motivation and satisfaction of health and care sector workers, by enabling them to manage their work in an emotionally intelligent way.<br>- Promoting continuous training for workers in the health and care sector.<br>- Improving quality of life among beneficiaries of services. |
| 8. Description: *What? How was change made possible? Who is involved? How many users are served per year? What is the role of users?* | The CarEIn project is a Leonardo da Vinci Transfer of Innovation project approved in 2009 through the European Commission (DG Education and Culture) Lifelong Learning Programme. It ran from October 2009 until September 2011.<br><br>The CarEIn Project was the response of the consortium to the present realities that characterize the health and care sectors and to the empirical research conducted by social workers providing daily long-term services. The project sought to identify the determinants of a person's psychological state and its effects on their work satisfaction (Czerw and Borkowska, 2009). Most innovative solutions in LTC mainly target users/patients or carers, whereas the CarEIn project chose to find a solution to ease the work of professionals providing daily care to LTC recipients. These workers face not only low wages and insufficient professional recognition, but also a high level of emotional stress and pressure generated by the demands of patients and of caregiving. It has been shown that care professionals are at high risk for developing burnout syndrome (Felton, 1998; Howe, 2008; Czerw and Borkowska, 2009). Most of the times these workers learn to develop an emotional resilience based on their 'personal optimism and emotional intelligence' (Czerw and Borkowska, 2009).<br><br>The CarEIn team proposed a solution to address a challenge faced by health and social care professionals. It considered that to ensure an optimum performance of the specific tasks in the health and care |

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| | sector it is important that workers be aware of their own emotions. In addition, the technical knowledge, material resources and improved technologies were not considered effective enough if the influence of the emotions involved in the health and care sector's care worker—patient relationship is not being taken into consideration.<br><br>The CarEIn partnership was promoted by ABDEM Spain, a non-profit organization aimed at improving personal autonomy and quality of life of people who suffer from multiple sclerosis) and coordinated by INVESLAN Spain (company specialised in social research in different fields such as employment, gender equality, social inclusion and training). The partnership consisted of nine partners from different countries with diverse backgrounds and experiences in long-term care services. These institutions, with experience in working and delivering different types of services to the beneficiaries of long-term services, were:<br>- An association with experience in working with disabled persons;<br>- A private organisation specialised in social and market research;<br>- A private developer of information technology applications;<br>- 3 NGO's specialised in training, consultancy, preparation of e-learning materials;<br>- A state-funded organisation specialised in short cycle vocational and health care continuing training;<br>- A sole proprietorship with abilities in mentoring, relaxation techniques and motivation;<br>- An organisation specialised in mediation plans.<br><br>The solution aimed and succeeded in elaborating a web 2.0 learning environment for the promotion and development of EI competencies among health and social assistance workers in order to contribute to a qualitative improvement of their daily activities. The web 2.0 learning environment consists of material on EI and it promotes EI competencies among health and social assistance sector workers in order to foster higher responsibility, team working, trust and self-confidence, better organisation of work, conflict solving, the capacity to learn how to learn, better communication, etc.<br><br>The main product was developed by all partners and the training contents were elaborated with the collaboration of all project partners. The learning environment was designed with specific consideration of the characteristics of health and care sectors in each partner country and of the competencies of the workers. The analysis of the specific needs of professionals was based on a mixed methodology: qualitative methodology and desk-research. Each project partner carried out *qualitative data gathering* in its respective country through primary (interviews) and secondary sources (bibliographical research, databases, Internet).<br><br>Different experts with higher education qualifications (trainers, psychologists, etc.) and health and social workers (with or without university degrees) were interviewed (via telephone or internet): |

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| | - Bulgaria: 4 experts and 4 health and social workers;<br>- Czech Republic: 4 experts and 6 health and social workers;<br>- Denmark: 4 experts and 4 health and social workers;<br>- Italy: 4 experts and 4 health and social workers;<br>- Poland: 4 experts and 3 health and social workers;<br>- Spain: 4 experts and 4 health and social workers;<br>- United Kingdom: 4 experts and 5 health and social workers.<br><br>Based on the observations collected and analysed (between May and June 2011), the product was adjusted and improved. The final version of this product is currently available and includes updated content and additional resources in the languages of all partner countries.<br><br>Other products were also designed and carried out:<br>- an analysis of the specific needs of workers from health and care sector.<br>- a compilation of practices for the promotion of the use of EI in the health and care sector (a specific methodology was designed for the search and selection for practices promoting EI).<br><br>After the conclusion of the project, 800 persons accessed and used CarEIn materials: an annual average of 400 users. |
| 9. Impact: *Have objectives been realised? How was it measured, shown, evaluated? What are the demonstrated or potential impacts on users, informal carers, staff, inter-organisational collaboration, costs? What is the systemic impact (extent to which the initiative changes the way that LTC is provided across systems or services)? Has the example proven to be sustainable, or mainstreamed? Has the example been implemented elsewhere?* | All objectives of the CarEIn project have been realised.<br><br>*CarEIn impact on target groups and VET systems*<br><br>Taking into account the feedback received from the stakeholders and members of the target group, it is possible to state that the CarEIn products achieved an increase of awareness regarding EI competencies in terms of personal and professional growth and development of the health and social care professionals. At the same time, the project introduced the need to develop ICT competencies. Most of the members of the target group were not users of ICT and technological methodologies, and in this sense, the CarEIn project offered them a new perspective. It is also important to highlight that the improvement of competencies of the target groups, also turned into positive benefits for the organizations (health centres, care centres, hospital, residential facilities, etc.) and the indirect beneficiaries (disabled people, dependent people, etc.). Concerning the healthcare and educational sector, the CarEIn materials were used by different kinds of training institutions and vocational schools in educational processes for personal development. They were adapted to workplaces due to the applied learning methodology. The CarEIn project extended the catalogue of educational services and methods addressed to health and welfare sector by promoting the web 2.0 platform as a good example of personal development.<br><br>*Sustainability Issues*<br><br>The CarEIn project was based on TREIN – Training in Emotional Intelligence LdV Pilot Project, the main objective of which was the elaboration of a training tool for the promotion of the use of EI skills in continuing education methodologies. The main reasons for adopting the |

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| | TREIN Project were that the training content could be applied to other target groups, as EI is a cross-cutting issue which can be applied to all sectors and beneficiaries with some adaptations, and that it could contribute to improving the quality of health and social services, and the quality of life of people receiving such services. Through its objectives, the CarEIn project improved the skills of workers, improved the quality of their work and the services provided, facilitated the adaptation of workers from the health and care sector to changes in the sector, increased the motivation and satisfaction of workers in health and care sector, and improved the quality of life of the beneficiaries of health and care sector. The project Emotional Intelligence and Social Sensitivity in Health Care – CarES (http://www.car-es.eu/training.html) – is the successor of the project Emotional Intelligence Care in Health and Social Assistance Project (CarEIn).<br><br>The CarEIn project ended, but interested persons can access the results and products through the Web page of the project (www.carein.eu).<br><br>*Transferability issues*<br><br>The project was transferred to additional countries under the LLP-TOI CALL (CarES project- Emotional Intelligence and Social Sensitivity in the Healthcare Sector). The CarEIn products were used in other EU member and non-EU member countries such as Portugal, Romania, Morocco, Germany, Turkey and Russia. Interest in the project was expressed by many relevant training and educational entities at the European level: Silesian University of Opava and University in Ostrava (Czech Republic), PREDIF 8 (Spain), REHACER (Spain), ASPAYM (Spain), EMBAT (Spain), Hospital St Joan de Déu (Spain), University of Balearic Islands (Spain), Regional Centre for Social Welfare (Poland). |
| 10. SWOT Analysis | *Strengths: What solutions were found to overcome key-challenges?*<br><br>- The project CarEIn contributed to the improvement of the skills and qualification of health and social care workers and to the improvement of their daily activities, by helping them to develop EI competencies (cross-cutting competencies): self-knowledge, emotional management, self-motivation, empathy and social ability. Acquired EI competencies helped health and social care workers to foster higher responsibility, team work, trust and self-confidence, better organisation of work, conflict management and problem-solving, the capacity to learn how to learn, better communication, etc.<br><br>- CarEIn raised awareness about the importance of applying EI in the health and care sector, as the subject of EI competencies is scarcely regarded in social care and health training.<br><br>- The use of ICT (training contents were available on a web 2.0 learning platform developed within the project) in training activities held a series of advantages for the people trained, as a good example of personal development: self-management occasion for learning time and time saving. The virtual nature of the training saves time that would otherwise be consumed with travel and allows participants to |

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| | design their own learning schedule.<br><br>*Weaknesses: Which gaps have been witnessed /experienced?*<br><br>- The learning methodology developed and applied within the project required at least basic knowledge in WEB 2.0 and in computer use. Not all the workers from the social and health care sector have the necessary skills.<br><br>- To better exploit the e-learning possibilities it's important to have the occasion to access to Web 2.0 learning platform not only from work, but also from home, which implies the need for hardware, software and Internet connection.<br><br>- Learning about Emotional Intelligence based on Web 2.0 is not entirely suited to ICT. The perception of some of the people trained during the project was that technology-based tools could not teach everything: It's impossible to learn how to manage a conflict, how to relate with a person or how to manage the stress through the e-learning, in a virtual space, without face-to-face contact.<br><br>*Opportunities: Which improvements could be implemented? What additional activities will be needed to deliver on targets? How could the initiative be scaled up or rolled out?*<br><br>- During the course of the project continuous improvements of the product were implemented (new modules/information to the training curricula were adjusted or added).<br><br>- Taking into account the feedback received from the stakeholders and members of the target group, the CarEIn products achieved an increase of awareness regarding Emotional Intelligence competencies in terms of personal and professional growth and development of the healthcare professionals.<br><br>- The project introduced the need to develop ICT competencies. Most of the members of the target group were not users of ICT and technological methodologies as training opportunities. In this sense, the CarEIn project offered them a new perspective.<br><br>- Concerning the health care and education sector, the CarEIn results were used by different kind of training institutions and vocational schools in educational processes for personal development, due to the applied learning methodology. Furthermore, the project was also transferred into new countries under the LLP-TOI CALL.<br><br>*Threats: What pressures does the initiative currently experience that could threaten its existence?*<br><br>- People trained as part of the CarEIn project declared that the training on Emotional Intelligence based on new technologies was a good and interesting initiative but such training tools provide only a theoretical framework. So, a complementary training tool is needed in order to give the professionals the opportunity to interact, to play roles, to exchange experiences.<br><br>- Before implementing a learning methodology such as the one used |

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| | within the CarEIn project, intensive awareness-raising is needed among people targeted for training. There are countries where a link between EI, Web 2.0 and social and health sector is still missing (more information on Web 2.0 and its opportunities, information about EI, attention on the link between EI and the social and health sectors are needed). Moreover, EI is a not a very well-known term among social and health care professionals, who tend to divide EI into many skills that are considered independent of one another (conflict management, communication, stress management, teamwork, etc.).<br>- In order to use a single training methodology for different countries with different cultures and care systems, a common point has to be found to manage such complex situations. The social and care sectors are not always comparable. In some countries, the two fields of activity are separated and workers perceive their training needs differently. Moreover, there are cultural differences from one country to another, which raises difficulties regarding the use of the terminology. For example, there are countries in which terms such as empathy, communication, etc. are often used in training courses addressed to workers from the social and health care sector, but there are countries where people have not been exposed to the same terms. |
| Website | www.carein.eu |
| Sources | Beleva, I. (2010) *Thematic Report 2010: Care for dependent elderly and gender equality in the EU: Dependent Elderly and Gender Equality in Bulgaria.*<br><br>Czerw, A., Borkowska, A. (2010) The Role of Optimism and Emotional Intelligence in Achieving Job Satisfaction. Implications for Employee Development Programs, *Contemporary Management Quarterly: the Journal of scientific community and business leaders,* 9(1), pp.69-82<br><br>European Commission (2013) *Guide to social innovation.*<br><br>European Commission/Bureau of European Policy Advisers (2010) *Empowering people, driving change: Social innovation in the European Union,* Luxembourg: Publications Office of the European Union.<br><br>Felton, J. *(*1998) Burnout as a clinical entity: its importance in health care workers, *Occupational Medicine*, Vol. 48, No. 4, pp. 237-250.<br><br>Howe, D. (2008) *The Emotionally Intelligent Social Worker*, Palgrave Macmillan.<br><br>Neykov, I., Salchev, P. (2012) *Annual National Report 2012 Pensions, Health Care and Long-term Care Bulgaria*. [on-line]: http://socialprotection.eu/files_db/1206/asisp_ANR12_BULGARIA.pdf<br><br>Projects and Product Portal for Leonardo da Vinci, [on-line]: http://www.adameurope.eu/adam/project/view.htm?prj=5843#.UvIKqFhWEVF<br><br>Email consultations were conducted with Jaione Santos Miguel, coordinator of the CarEIn Project. |

## IX. Care Support Centres in Mönchengladbach—Germany

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| 1. Abstract | With the introduction of the Long-Term Care Further Development Act (Pflegeweiterentwicklungsgesetz) in July 2008, the basis for the so-called Pflegestützpunkte (care support centres) was created. These centres tend to overcome the problem of overprovision/ under-provision/mal-provision of social services via bundling and targeting distribution of all relevant information regarding long-term care. The extreme division of the German care landscape hampers the transparency and – from the perspective of caring relatives – the appropriate combination of existing services.<br><br>The main (legal) objectives of the nursing care bases are:<br><br>- Information and counselling for the beneficiaries regarding the whole spectrum of care matters.<br>- Coordination of all regional demands of support and service.<br>- Networking among the coordinated care demands.<br><br>Nursing care bases are facilities established and coordinated by the health insurance and long-term care insurance funds or by municipalities with the opportunity for private insurance funds and funding institutions of social and geriatric care to participate. The personnel is specially trained and oftentimes supported by "Care consultants" (Pflegeberater) who are basically employees of the long-term care insurance funds. The concentration of all of the information in the field of long-term care in combination with high accessibility intends to ease the burden of caring relatives to get in contact with each of the service providers. To avoid duplication regionally existing care information centres should be enlarged according to the objectives of the legal nursing care bases.<br><br>The nursing care base Mönchengladbach is one of 16 pilot projects that were evaluated during their implementation. It was implemented in 2008. Up to now there is one central nursing care base of the municipality and one central nursing care base of the health insurance companies. 13 'satellite centres' – belonging to the central nursing care base of the municipality – ensure information through short distances in the single neighbourhoods. The satellite centres are occupied by the hour by aforementioned care consultants. Office hours of the central nursing care base of the municipality (service hotline) are from Monday-Thursday: 8.30 – 11.00 am. Furthermore it is possible to arrange individual appointments. The provider of one nursing care base (including its aforementioned 13 satellite centres) is the Department for Elderly Care of Mönchengladbach; cooperation partners are AOK Rheinland/ Hamburg – die Gesundheitskasse (health insurance fund), Barmer GEK (health insurance fund), Innungskrankenkasse (health insurance fund) and community facilities: social welfare office, public health department, assistance centre and hospital social services. The other nursing care base is provided by the AOK Rheinland and the Techniker Krankenkasse (health insurance funds). |

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| 2. Target group and number of population covered (region/s) | Target group is essentially the population of Mönchengladbach as a whole (255,087 inhabitants), but with a focus on the growing share of the population aged 65+ (53,995 inhabitants). With 15 service bases in total (2 main bases and 13 satellite stations belonging to the nursing care base of the municipality), all of the population is covered. |
| 3. Qualification as social innovation and/or social innovation potential (please highlight): | **a. It is oriented towards exceptional societal challenges/social issues**<br>b. It suggests new solutions in the respective societal, cultural and economic context<br>**c. It creates new patterns of social practices to overcome shortcomings of traditional arrangements**<br>d. It tends to overcome the traditional dichotomy between technological and social innovations<br>**e. It promotes the integration and/or collaboration/partnership of heterogeneous stakeholders that have hitherto not co-operated**<br>f. It includes reflective and multidisciplinary approaches towards the key goal of societal usefulness<br>g. It creates structures and processes that are sustainable and realise new growth potentials in terms of regular employment<br>h. It involves end-users as co-producers of services or products<br>**i. It creates new roles and partnerships** |
| 4. The initiative is clearly addressing LTC challenges as it is characterised by the following key-issues (please highlight): | **a. multidisciplinary work is a value and principle**<br>**b. clients' needs are at the centre of all interventions**<br>**c. continuity of care and mechanisms to overcome barriers at the interfaces between social and health care are addressed**<br>**d. continuity of care and mechanisms to overcome barriers at the interfaces between formal and informal care are addressed**<br>**e. it is supported by legislation which explicitly addresses the coordination/integration between health and social care**<br>**f. incentives to improve cooperation between health and social care facilities or services (e.g. financial, contractual advantages) are in place**<br>**g. relevant information is efficiently transferred between services or agencies, e.g. by means of a joint care plan based on a dialogue with users/patients and their informal network**<br>**h. equal access (considering culture, gender and class) is guaranteed to all citizens**<br>**i. individual care needs are assessed by a multidisciplinary team (with multidisciplinary methods)**<br>**j. individual capacities of users/patients are enabled and strengthened** |

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| | **k. leadership and management capacities are enhanced through appropriate training**<br>**l. quality assurance is guaranteed across health and social care services and/or facilities**<br>**m. agreements between services and/or organisations are based on contracts**<br>**n. IT and communication technology are used to make administration more efficient**<br>**o. IT and communication technology are used to facilitate the service (e-health, e-care, ambient assisted living)**<br>**p. conditions for the involvement and participation of users/patients and carers are ensured (e.g. shared decision-making)**<br>**q. multi-disciplinary teams are established, supported and continuously trained**<br>**r. an integrated access point (e.g. concerning referral, financial issues, payment regulation, one-stop-shops) is available**<br>**s. integrated discharge and follow-up planning is fostered (mainly for residential and/or hospital-based facilities)**<br>**t. case management is carried out by trained and specialised staff with relevant job-profiles**<br>**u. funding is ensured by defined budgets**<br>**v. involved staff is participating regularly in advanced and further training**<br>**w. evaluation studies concerning structures, processes and outcomes are carried out and available**<br>**x. outcome indicators are used to measure and further develop the initiative**<br>**y. quality management serves to implement continuous improvements**<br>**z. the initiative is controlled for costs and cost-advantages** |
| 5. Status of the initiative | a. **National or regional project (terminated)**<br>b. **European/international project (terminated)**<br>c. **National or regional project (ongoing)**<br>d. **European/international project (ongoing)**<br>e. **Implemented practice (at least in restricted areas)**<br>f. **Widely spread practice/rolled out** |
| 6. Type of the initiative | a. New product<br>b. **New service** |

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| | c. **New platform (new legal framework and platform)**<br>d. **New organisational form**<br>e. **New process**<br>f. New market<br>g. New business model |
| 7. Rationale and objectives: *Why was the initiative implemented? What social needs does it satisfy? Which societal challenges were addressed (context conditions)? For which target groups? With which objectives?* | The implementation of the care bases intervenes at a serious problem of the German care system. Existing coverage deficiencies – what means problems with costs and quality – result from different weaknesses (vgl. Michell-Auli et al., 2010):<br>- Disincentives in the area of prevention and rehabilitation: social services, which are based on the Social Security Code, are offered within a divided benefit system. This leads to insufficient incentives for prevention and rehabilitation, because the various funding organisations and service providers solely act for their interests.<br>- Variety of uncoordinated benefits and lack of benefits: in the field of long-term care a variety of different contact persons and providers exist – e.g. family doctors, specialist doctors, geriatric hospitals, ambulant or outpatient care services, advice centres (e.g. regarding housing situation), low threshold assistance, household-related services, mobile prevention programs and gerontological psychiatry. Most of the time benefits are rendered uncoordinated. Furthermore a nationwide provision of services is lacking. This leads in case of doubt to overprovision/under-provision/mal-provision and to an early moving of people in need of care into a stationary institution. What is (or was) required is a consulting structure, which enables the single person to find the right balance and the right form of benefits. In cases where it is necessary to claim for various benefits, the confusing legal situation and the complex structure of supply require a case management besides the consultancy, to ensure a useful utilisation of benefits.<br>- Lack of organisation of benefits directed to the neighbourhood: to ensure a long-term independent life for people in need of help and/or care an equivalent adaption of the surrounding/neighbourhood is necessary. Social services should be organised in relation to the demands in the respective area. Furthermore remaining in one's own home obviously increases the quality of life of older persons – with a quality controlled consulting and attendance possibilities of supporting an autonomous life should be identified and help to overcome the prior lack of comprehensive reorganisation of benefits linked to the neighbourhood.<br><br>With the care bases the social need of an 'all-inclusive-consulting' or 'care management' in the field of long-term care is met. Via building up a network which includes all relevant stakeholders and themes (e.g. benefits of the insurance companies, housing counselling, dementia) and which works within the neighbourhood (ideally), interested persons and people in need of care and their relatives have a contact point where all |

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| | relevant information is bundled. Here they get an individual consulting which takes all relevant offers in the neighbourhood into account (Case management). The care consultants have an overview of the existing market and through their knowledge overprovision/under-provision/mal-provision may be avoided. The nursing care bases ensure an increasing transparency in the system of long-term care.<br><br>Furthermore the care consultants are in charge of comparing the needs of the clients of the nursing care bases with the respective supply in the local regions. This procedure uncovers existing gaps within the supply system and cooperation problems between the different actors and service providers and may lead to initiation of new services. |
| 8. Description: *What? How was change made possible? Who is involved? How many users are served per year? What is the role of users?* | With the adoption of the Long-Term Care Further Development Act (Pflegeweiterentwicklungsgesetz) 'Case Management' and 'Counselling' were two major topics of the content of this law. To improve the sharing of information regarding how to arrange a suitable care arrangement, so-called 'Pflegestützpunkte', i.e. information centres, were founded. Care advisers (Pflegeberater) help relatives to systematically analyse needs, inform about legal claims against LTCI but also other social security systems, and inform about available services in order to finally draw up an individual needs plan. The federal government made about €60 million available to support the introduction of such information centres. The federal states are responsible for the introduction of the structure.<br><br>In North-Rhine Westphalia the legal equivalent was set within the State Nursing Law (Landespflegegesetz). Article 4 (§4 counselling agencies) refers directly to how counselling should be organised:[19]<br>(1) People in need of care, people at risk of needing care and their relatives should be advised independent of the provider and should be informed about the necessary outpatient, day patient, inpatient and complementary services available.<br>(2) The counselling has to take place in conjunction with the municipalities, long-term care insurance funds and other stakeholders involved in care provision. During care-conferences (Pflegekonferenzen), stakeholders should discuss the appropriate procedure and design of the counselling support. The aim should be to implement joint and independent counselling points as well as case management structures.<br><br>The nursing care base Mönchengladbach implemented all the mentioned requirements. The city benefited from the existing structures and networks when starting with the care base. The cooperation partners are: AOK Rheinland/Hamburg – die Gesundheitskasse (health insurance fund), Barmer GEK (health insurance fund), Innungskrankenkasse (health insurance fund) and community facilities: social welfare office, public health department, and assistance centre and hospital social services. |

[19] https://recht.nrw.de/lmi/owa/br_bes_text?anw_nr=2&gld_nr=8&ugl_nr=820&bes_id=3867&aufgehoben=N#det149187

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| | As a pilot care base its implementation was evaluated by the KDA (Kuratorium Deutsche Altershilfe). From April 2009 to March 2010 the care base recorded 10,410 contacts (vgl. Michell-Auli et al., 2010).<br><br>Via single interviews and workshops the clients of the care bases were involved in the development of the operational concept where the available services were defined (ibid.). |
| 9. Impact: *Have objectives been realised? How was it measured, shown, evaluated? What are the demonstrated or potential impacts on users, informal carers, staff, inter-organisational collaboration, costs? What is the systemic impact (extent to which the initiative changes the way that LTC is provided across systems or services)? Has the example proven to be sustainable, or mainstreamed? Has the example been implemented elsewhere?* | With the nursing care bases the counselling situation regarding long-term care improved. In Möchengladbach the development of the nursing care base from a pilot care base to an established advice centre was successful. As mentioned above this nursing care base profited from the already existing network structures. It is a follow-up to the Care and Housing municipal advice centre implemented in 1996.<br><br>The aim of providing an all-inclusive-consulting centre has been realised. The central nursing care base offers mainly consulting in the fields of long-term care and housing. A multidisciplinary team existing of five social workers, one geriatric nurse and one building technician are in charge of the consulting. In the satellite-stations social workers serve as contact persons and offer mainly psycho-social counselling and care. All of the employees work part-time. The respective focus of counselling in the satellite-stations depends on the needs and requirements of the population in the neighbourhood. If there are any consulting requirements which cannot be fulfilled directly in the nursing care base respectively in one of the satellite stations, employees of the nursing care base are contacted (in case of the satellite stations) or contact will be established to external advice centres. In those cases, it is up to the client if he or she contacts the external centres on his/her own or with support of the nursing care base. Also it is possible to arrange common appointments with the client, his or her social environment and the external advice centre. To guarantee a comprehensive overview of existing support services all employees have access to a care information system provided online. As of 2010, two-thirds of all care-providers were registered. Also, another nursing care point on behalf of two health insurance companies exists in Mönchengladbach – this ensures consulting reserves regarding the field of the Social Code V and XI.<br><br>The 16 German pilot nursing care bases were evaluated within the project “Workshop nursing care bases” of the KDA (Kuratorium Deutsche Altershilfe) from 2007 to 2010. Via different evaluation tools the implementation and effectiveness were assessed. These instruments are:<br>- Regular visits of all pilot nursing care bases<br>- Regular regional and nationwide workshops<br>- Internal and external information centre (for the nursing care bases)<br>- Two customer surveys<br>- Two surveys of nursing care base related data<br>- Survey of client-related data<br>- Qualitative case studies |

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| | This comprehensive evaluation shows the effectiveness of the nursing care bases especially when focussing on the customer related data. All of the interviewed clients signalized a high satisfaction with the counselling of the nursing care points. In 54 cases of the evaluation study employees of the nursing care bases recommended a endangering of the home care. In 51 of these cases the KDA rates the counselling as completely fulfilled. This means all relevant topics were addressed: housing counselling, types of housing, 24-hour-care, inpatient care, outpatient care, day care, partial inpatient care, medical aid, complementary offers, volunteering, low-threshold offers, and financing. After receiving counselling from the nursing care bases the respective persons were interviewed once again. 46% of counselled clients still lived in their own homes, only 7.4% had had to move to an inpatient care institution. This is one reference for the realization of the guiding principle of the care system in Germany "outpatient rather than inpatient care" which is also a guiding principle of the implementation of the nursing care bases. Obviously the counselling enables people in need for care or help to strengthen their ability for an independent living. Since it could be proved that on many first contacts follow-up contacts follow, a broad acceptance of the nursing care bases can be assumed.<br><br>In some cases the networking efforts were not successful from the outset. Other outpatient service providers saw the centres as competitors and were for this reason not interested in cooperation. Here patience and persistence paid off, however, and networking structures were eventually established. Similarly, many nursing care bases described the networking with physicians as being problematic. Frequently networking failed at the first contact. In Mönchengladbach 19 physicians sent patients to the nursing care base for a counselling. In contrast, networking with regional hospitals was successful. In some cases nursing care bases were involved in the transition management of patients (from hospital to rehabilitation or home, inpatient-care), or employees of one nursing care base interviewed patients for their requirements after their hospitalization. In Mönchengladbach 103 of the nursing care base contacts came from hospitals. Networking is done with all local hospitals.<br><br>Furthermore, there are networking activities with local volunteering. The inclusion of this group was part of the legal requirements when establishing a nursing care base. Therefore all of the pilots nursing care bases are linked to voluntary organisations. In Mönchengladbach the integration of volunteers is organised through meeting places (Begegnungsstätten) in which the satellite stations of the nursing care bases are integrated. These meetings places are owned by the churches and voluntary organisations which are responsible for the coordination of the volunteers. The cooperation works very well, especially because volunteers consider the relationship as a means to reaching more people in need of care or help. Volunteers support the nursing care bases with several services. These include: visiting services to keep company with socially isolated people, leading self-help groups with different topics, transport services to enable participation in different events or to keep |

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| | medical appointments, visiting the physician or other important appointments or organising leisure events, e.g. seniors' afternoons with coffee and cake, computer courses or fitness programmes.<br><br>Lastly, the nursing care bases cooperate with the benefit permission departments of the long-term care insurance companies, the health insurance companies and the municipalities. As providing counselling services in the area of application for benefits is one of the main activities of the nursing care bases, this cooperation is very important. According to the results of the surveys these networking activities are very constructive.<br><br>The implementation has an impact on how long-term care is provided and how the different stakeholders of the system work together. Interface problems regarding the different responsibilities of the service providers (long-term care insurance funds/ health insurance funds, SGB V/ SGB XII/ SGB XI) can be reduced when fostering cooperation. Evidence, that this is a new way of working, is given by the aforementioned difficulties of networking with physicians, outpatient care providers and hospitals. For the clients this "one-stop-shopping" principle eases the burden and reduces the invested time needed for organising care. Moreover the comparison of the needs of the clients with the supply of the regional services uncovers existing gaps within the supply system and cooperation problems between the different actors and service providers and may lead to initiation of new services. In this way the existing care landscape will be enlarged and the quality of services will be increased. Nursing care bases in this way can help to prolong the time older people (in need of care or not) spend in their own home and therefore may reduce the costs for inpatient-care.<br><br>Up to august 2010, 312 nursing care bases were established in Germany. Actually, almost 400 nursing care bases in 14 federal states exist[20]. In Germany the difference between implemented and planned nursing care bases is very different. Evaluation studies which evaluated the customer satisfaction came to mainly positive results. Therefore a further expansion of implementing nursing care bases is expected (cf. Schmidt/ Luderer 2013: 10ff). |
| 10. SWOT Analysis | *Strengths: What solutions were found to overcome key-challenges? What facilitated problem-solving?*<br><br>- The legally supported fostering of networking between all of the relevant stakeholders of the long-term care system and the client-oriented counselling helps to overcome the lack of transparency in the system. Via connecting information about client's needs and regional supply service gaps can be identified. The appropriate combination of care services prevents overprovision/ under-provision/ mal-provision. A prolonged stay in the own housing is supported. |

[20] http://www.zqp.de/index.php?pn=care&id=9&page_id=1 [07.03.2014]

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| | - Mönchengladbach profited from the existing network structure, which facilitated the networking activities and the acceptance of potential clients. In former times the nursing care base in Mönchengladbach was an advice centre (Care and Housing) of the municipality and therefore already known among residents and among potential network partners. The network concept of the nursing care base is sustainable because of a written agreement which was signed by all relevant stakeholders. Simultaneously the agreement is the base of the contract between the nursing care base and the federal government.<br>- Since 1994 in Mönchengladbach, the so called care conference is an established platform where all stakeholders in charge of care have the opportunity to meet and exchange. This is a regular date and therefore it has been a facilitator for networking as well.<br>- In order to provide consultation services that are accessible for all residents, Mönchengladbach implemented so-called satellite stations of the central nursing care base. These satellite stations are located in the different neighbourhoods of Mönchengladbach and are integrated with community centres (Begegnungsstätten) funded by the city.<br>- Financing is ensured by the municipality.<br>- This continuation and expansion of the existing structures was described as the innovative element of the project by the manager of the nursing care base of Mönchengladbach.<br>- The fact that the nursing care point in Mönchengladbach combines care and housing counselling is assessed as very useful. For that reason counselling usually takes place at clients' homes so that general advice related to long-term care and housing can be addressed at the same time.<br>*Weaknesses: Which gaps/obstacles have been witnessed/experienced?*<br>- It is possible that, in the future, the misguided incentives inherent to legislation governing social services (no standard qualifications/multiple funding organisations and service providers for inpatient and outpatient care, only minor incentives for prevention and rehabilitation) may affect the quality of counselling. To date, this has not been the case.<br>- The nursing care base run by the municipality is not connected with many physicians. They likely do not associate municipal work with counselling in the field of long-term care. The nursing care base run by the health insurance companies do have more contact with physicians, but not to a large extent.<br>*Opportunities: Which improvements could be implemented? What additional activities will be needed to deliver on targets? How could the initiative be scaled up or rolled out?*<br>I. General opportunities for improvements are: 1) fostering the integration of physicians, 2) the need for research exists in the field of networking management to develop patterns for the implementation |

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| | and efficient operation of nursing care bases, 3) the name "Pflegestützpunkt" is not very clear, and many people do not understand what this term stands for and associate it with tangible care service provision. In Mönchengladbach people do not know the nursing care base under the term "Pflegestützpunkt" but under the term 'Department for Elderly Care' (Amt für Altenhilfe). For this reason the information regarding nursing care bases should be better disseminated.<br><br>II. Opportunities for improvement specifically in the case of Mönchengladbach: 1) also fostering the integration of physicians, 2) increase human resources (especially concerning the growing share of population aged 65+).<br><br>- The care base in Mönchengladbach does not offer multilingual consulting. Most of the migrant clients are accompanied by a German-speaking relative or friend when seeking consultation. This is an opportunity for improvement – to meet the needs of migrant people who are in need of care (which currently is the responsibility of other departments). Regarding the organisation of the nursing care base no opportunities for improvements are named. The fact that the nursing care base is integrated into a municipal or local authority is an asset. This entails short ways of decision-making.<br><br>*Threats: What pressures does the initiative currently experience that could threaten its existence?*<br><br>Actually the nursing care base does not experience any pressures that could threaten its existence. If any, necessary financial savings could threaten the existence. But this is very implausible, because the municipality appreciates the importance of such a consulting in times of demographic change. |
| Website | http://www.werkstatt-pflegestuetzpunkte.de/nordrhein-westfalen-moenchengladbach.html |
| Sources | Michell-Auli, P., Strunk-Richter, G., Tebest, R. (2010) *Was leisten Pflegestützpunkte? Konzeption und Umsetzung. Ergebnisse aus der 'Werkstatt Pflegestützpunkte'*, Köln.<br><br>Schmidt, S. & Luderer, C. (2013) 'Da fühlte ich mich gut aufgehoben' – Eine Studie zum Erleben der Arbeit von Pflegestützpunkten aus der Perspektive von Nutzerinnen und Nutzern, *Informationsdienst Altersfragen*, 40(1): 10-17.<br><br>An expert interview was conducted with Angelika Noll, director of the care-conference Mönchengladbach and head of the care support centre in Mönchengladbach. |

## X. Elderly-friendly Housing—Hungary

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| 1. Abstract | The initiative enables older persons in need of care to continue living in their own homes by removing obstacles. It prevents fractures, avoids or postpones admission to a residential home. The Elderly-friendly Housing as a pilot programme (included 60 homes (300,000 HUF/home; 1172 EUR) ran from 2003 to 2005 with the support of the Ministry of Social and Labour Affairs. In order to scale up the programme and provide wider access, in 2009 the Government provided funding of 270 million HUF (92,000 EUR). The housing programme targets persons over 65 already receiving care as a basic social service (at least one from the basic care services such as social meals, home help, home help with alarm system, day care for the older persons, caretaker service for isolated farms, 1993 Social Welfare Act No. III). The central government entrusted the operation of the Elderly-friendly Housing project to the Hungarian Maltese Charity Service Association. Linking the environment factor and care was an innovative element in the program and thereby created the possibility for the development of a more complex long-term care. 746 elderly persons (706 home alterations) received non-refundable financial support (max. 400,000 HUF/1355 EUR per home) without an own contribution requirement; most of the recipients lived in a disadvantaged region of northern Hungary. The primary criterion in judging applications was that the alterations should have the effect of making life easier. In order to avoid abuses the successful applications did not receive a cash payment; instead the organisation signed contracts directly with 250 entrepreneurs. From 2011 Elderly-friendly Housing was incorporated in the system of care of a town in the developed western part of Hungary, while there was no continuation of the solution in the less-developed northern and north-eastern regions, resulting in inequalities in quality of life between the disadvantaged and the well-off settlements. |
| 2. Target group and number of population covered (region) | *I. Elderly-friendly Housing pilot programme*. From 2003 to 2005 (pilot period) the target group included persons aged 75+ who received at least one of the following services: a) home help, b) home care with alarm system, c) older persons cared for by a family. The central government provided 270 million HUF (92,000 EUR) in funding.<br><br>Persons living together with one other person (Social Welfare Act No. III of 1993) were included. Altogether, this amounted to 60 persons.<br><br>*II. Elderly-friendly Housing Programme*. In 2009, the age bracket of the target group was reduced to 65 years as the figures for HLY in Hungary are very low. Also, only those receiving formal care could apply and family carers with a nursing allowance were excluded (decision of the Ministry of Labour and Social Affairs). Altogether 746 older persons (706 households) representing approximately 2% of all recipients of care, received support through this initiative.<br><br>Implementation regions:<br><br>I. During pilot period 2003-2005: the capital, a large town, rural settlements |

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| | II. During the scaled-up version of the programme in 2009: several settlements in all 19 counties, but mainly those in remote parts of eastern and northern Hungary, in under-developed settlements.<br><br>The proportion of successful applications for support was highest in three rural counties in the north and north-east at 59% (Szabolcs-Szatmár 29%, Borsod-Abaúj-Zemplén 12%, Hajdú-Bihar 11%, 7%) and one impoverished county in the south, while in the western region and in some of the wealthier southern counties it varied between 0.6%-5%.<br><br>III. Since 2011, the model has been implemented in a large town in western Hungary (5-11 homes per year). |
| 3. Qualification as social innovation and/or social innovation potential (please highlight): | **a. <u>It is oriented towards exceptional societal challenges/social issues</u>**<br>**b. <u>It suggests new solutions in the respective societal, cultural and economic context</u>**<br>**c. <u>It creates new patterns of social practices to overcome shortcomings of traditional arrangements</u>**<br>**d. <u>It tends to overcome the traditional dichotomy between technological and social innovations</u>**<br>**e. <u>It promotes the integration and/or collaboration of heterogeneous stakeholders that have hitherto not co-operated</u>**<br>f. It includes reflective and multidisciplinary approaches towards the key goal of societal usefulness<br>g. It creates structures and processes that are sustainable and realise new growth potentials in terms of regular employment<br>h. It involves end-users as co-producers of services or products |
| 4. The initiative is clearly addressing LTC challenges as it is characterised by the following key-issues (please highlight): | **a. <u>multidisciplinary work is a value and principle</u>**<br>**b. <u>clients' needs are at the centre of all interventions</u>**<br>c. continuity of care and mechanisms to overcome barriers at the interfaces between social and health care are addressed<br>d. continuity of care and mechanisms to overcome barriers at the interfaces between formal and informal care are addressed<br>e. it is supported by legislation which explicitly addresses the coordination/integration between health and social care<br>f. incentives to improve cooperation between health and social care facilities or services (e.g. financial, contractual advantages) are in place<br>g. relevant information is efficiently transferred between services or agencies, e.g. by means of a joint care plan based on a dialogue with users/patients and their informal network<br>h. equal access (considering culture, gender and class) is guaranteed to all citizens |

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| | i. individual care needs are assessed by a multidisciplinary team (with multidisciplinary methods)<br>j. individual capacities of users/patients are enabled and strengthened<br>k. leadership and management capacities are enhanced through appropriate training<br>l. quality assurance is guaranteed across health and social care services and/or facilities<br>**m. <u>agreements between services and/or organisations are based on contracts</u>**<br>n. IT and communication technology are used to make administration more efficient<br>o. IT and communication technology are used to facilitate the service (e-health, e-care, ambient assisted living)<br>p. conditions for the involvement and participation of users/patients and carers are ensured (e.g. shared decision-making)<br>q. multi-disciplinary teams are established, supported and continuously trained<br>r. an integrated access point (e.g. concerning referral, financial issues, payment regulation, one-stop-shops) is available<br>s. integrated discharge and follow-up planning is fostered (mainly for residential and/or hospital-based facilities)<br>t. case management is carried out by trained and specialised staff with relevant job-profiles<br>u. funding is ensured by defined budgets<br>v. involved staff is participating regularly in advanced and further training<br>**w. <u>evaluation studies concerning structures, processes and outcomes are carried out and available</u>**<br>x. outcome indicators are used to measure and further develop the initiative<br>y. quality management serves to implement continuous improvements<br>z. the initiative is controlled for costs and cost-advantages |
| 5. Status of the initiative | a. pilot project (terminated)<br>b. pilot project (ongoing)<br>c. project (terminated)<br>d. project (ongoing)<br>e. **<u>implemented practice (restricted areas)</u>**<br>f. widely spread practice/rolled out |
| 6. Type of the initiative | a. New product |

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| | b. **New service**<br>c. New platform (new legal framework and platform)<br>d. New organisational form<br>e. New process<br>f. New market<br>g. New business model |
| 7. Rationale and objectives: *Why was the initiative implemented? Which societal challenges were addressed (context conditions)? For which target groups? With which objectives?* | From 2003-2005 the objective of the programme was to help frail older people with LTC needs to continue living at home safely and independently despite their changed functional abilities and the deterioration in their health status, and to prevent falls by adapting their home environment. The survey conducted before implementation of the project found that 40% of falls are caused by obstacles in the home. The evaluation of the pilot programme found that elimination of the obstacles resulted in a great reduction in the number of falls. It became obvious that eliminating obstacles should help to avoid placement in a nursing/residential home or spending lengthy periods in hospital.<br><br>*The Elderly-friendly Housing programme* launched in 2009 made funding support for the elimination of obstacles available on an application basis to persons already receiving some form of basic service (social meals, home help, home help with alarm system, persons living on isolated farms and in small settlements covered by the caretaker service (Social Welfare Act No. III of 1993)). Instead of 75+, the project extended eligibility for support to persons 65+ as health status among this group is relatively poor. |
| 8. Description: *What? How? Who is involved? How many users are served per year? What is the role of users?* | At the beginning of the project's implementation (2003-2005), the outdoor mobility of older people in the programme (average age of 80+) was low, more than 10% were bedridden, almost all saw their doctor several times a month, they took an average of 7.5 medicines daily and in the year prior to the interview they spent an average of 16 days in hospital, 15% on two occasions and close to 20% on three or more. In addition to formal care (home help), 40% received care from family members and 10% from neighbours). An obstacle-free home enabled them to remain safely at home. The programme was designed by a multidisciplinary team (engineer, sociologist, home helper) and implemented as a pilot program by the Hungarian Maltese Charity Service (MMSZ). In the first year 20 older persons were selected in the capital city (Budapest), and 20 in a smaller city in the countryside (Debrecen). In the second year, 2004, an additional 10 persons were included in the sample in each of the two original sites and in a new settlement type, a micro-region with villages (Tiszavasvári region) and an additional 10 selected by the Maltese in the capital and the villages.<br><br>The model included different flat/housing types: pre-fabricated housing estate flats, flats in multi-story city buildings, individual family homes.<br><br>Based on the positive results of the pilot programme, in 2009 the ministry entrusted the handling of applications for a scaled up version of |

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| | the programme to the Hungarian Maltese Charity Service Association. 746 elderly persons over 65 (representing around 2% of the total number of recipients of home care in the country) received non-refundable financial support requirement (max. 400,000 HUF/1,355 € per home) without an own contribution. Typical alterations in the home environment involved eliminating differences in level (e.g. removing a step), eliminating slippery surfaces, installing safety grips, adjusting the height of the work surface in the kitchen as well as numerous other solutions not restricted to a single room. The alterations to the homes were made in three different ways always taking into consideration the request of the elderly person, with a solution adapted to the knowledge and earlier demands of the elderly person or with a modern technical solution after it had been explained to the elderly person concerned.<br><br>In order to avoid abuses no cash payments were made to the successful applicants, instead the organisation signed contracts directly with 250 entrepreneurs.<br><br>Since 2011, a relatively prosperous city in the western part of Hungary included home alterations to remove obstacles in its policy for care for older persons (yearly 5-9 older persons). |
| 9. Impact: *Have objectives been realised? How was it measured, shown, evaluated?What are the demonstrated or potential impacts on users, informal carers, staff, inter-organisational collaboration, costs? What is the systemic impact (extent to which the initiative changes the way that LTC is provided across systems or services)? Has the example proved to be sustainable, or mainstreamed? Has the example been implemented elsewhere?* | During the pilot programme the removal of obstacles in the homes was linked to a follow-up study. A comparison of the number of falls before and after the removal of obstacles showed that falls on one or two occasions ceased entirely, and multiple falls were reduced to single falls. Cost of alteration (300,000 HUF/home; 1,172 €) was less than half of a one-year stay in a residential home. Both results have had a positive impact at the macro-level. The success of the pilot programme, combined with lobbying by the Hungarian Maltese Charity Service contributed to the decision of the Ministry of Social and Labour Affairs to fund the scaled-up version of the programme to support housing alterations for older persons.<br><br>In 2009, the Government provided funding of 270 million HUF (92,000 €) to start the scaled-up version of the programme. Despite the short deadline set for online applications to be submitted (February 2009), 2,700 applications were received, 2421 of these were valid and close to one third, 706 were accepted. The judging of the applications found the removal of obstacles to be necessary in the great majority of applications submitted, indicating the high level of demand, but due to limited funds only applicants with multiple disadvantages and those most in need of care were accepted. Most of those accepted were in northern and north-eastern counties and one poorer southern county (see above). In 2011 a relatively prosperous city in the developed western part of Hungary implemented the programme and incorporated it into its LTC policy. |
| 10. SWOT Analysis | *Strengths: What solutions were found to overcome key-challenges? What facilitated problem-solving?*<br>- The pilot programme elaborated appropriate methods and guidelines which were presented in a book: “Idősek otthon. Megszokott környezetben nagyobb biztonsággal” (Elderly at Home. Greater Security |

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| | in the Accustomed Environment) (Széman & Potthyondy, 2006). Written in a readily understandable style, this offered solutions to the problems that arise in removing obstacles in various types of settlements and homes and also explained the cost-efficiency of the solution compared to care in a residential home. The positive impact of the pilot programme helped to convince political decision-makers of the need to make the homes of the elderly obstacle-free.<br>- In 2009 the methodology was extended with strict evaluation consideration of applications and strict monitoring of entrepreneurs. http://www.szmm.gov.hu/idosbaratlakas/index3.html<br><br>*Weaknesses: Which gaps/obstacles have been witnessed/experienced?*<br><br>- Lack of public funds: although eligibility criteria to apply for an alteration grant are the same everywhere, in remote settlements the demand is especially high as local governments have limited financial resources and the financial situation of many older people does not allow them to finance alterations themselves. There was no continuation of the programme in the less-developed northern and north-eastern regions, resulting in inequalities in quality of life between higher- and lower-income residential settlements.<br><br>*Opportunities: Which improvements could be implemented? What additional activities will be needed to deliver on targets? How could the initiative be scaled up or rolled out?*<br><br>- One of the most important opportunities would be to convince local decision-makers of the importance of removing obstacles, and encourage them to secure the required funds. The best way of achieving this is to stress the combined benefits of cost effectiveness and improved quality of life. Communication in the media and strong dissemination can play a large role in this. Incorporation into the curriculum of higher education (e.g. social work) could help to bring about a change in attitude and priority afforded to the home environment in LTC.<br><br>*Threats: What pressures does the initiative currently experience that could threaten its existence?*<br><br>The big challenges include the following:<br><br>- The economic crisis (lack of funds in the public sector).<br><br>- Withdrawal of the state from LTC, lack of political interest, shifting responsibility for LTC to local governments and families.<br><br>- Dwindling financial resources of families/older persons. |
| Website | http://www.maltai.hu/?action=program&programid=18 |
| Sources | Széman, Z. & Pottyondy, P. (2006) Idősek otthon. Megszokott környezetben nagyobb biztonsággal (Elderly at Home. Greater Security in the Accustomed Environment), Szociális és Münkaügyi Minisztérium, Magyar Máltai Szeretetszolgálat, MTA Szociológiai Kutatóintézet: Budapest.<br><br>Széman, Z. (2013) Elder-friendly Housing Model: Results of an Action Research. In: Zsuzsa Széman (ed.) Challenges of Ageing Societies in the Visegrad Countries, |

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| | pp. 130-137, Hungarian Charity Service of the Order of Malta, Budapest.<br><br>Expert interview conducted with Zoltán Tarnai, head of the Hungarian Maltese Charity Service's Methodology Centre |

## XI. Family Nurse Programme—Italy

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| 1. Abstract | The private company Finisterre consortium provides health care services in many local health districts (LHD's) in the Lombardia Region (in northern Italy). In May 2013, the district of Saronno (a city in the Lombardy province of Varese) was chosen as the site for a pilot project called the Family Nurse Programme. The idea was to create a group of LTC professionals able to more effectively respond to the various care needs related to chronic health conditions.<br><br>Recent years have witnessed a reduction in residential care services and this has resulted in an increasing need for alternative care settings. When properly trained, the family nurse is able to meet the growing need for care management. The focus of this project is the case management of vulnerable and chronically ill subjects.<br><br>The main activities of the family nurse are: direct hands-on assistance to the patient in his/her home through technical nursing interventions and rehabilitation; health education and provision of information to raise the awareness of the patient and his/her primary care network about specific requirements and options pertaining to the patient's case; and technical support to help family members manage the patient independently. The family nurse takes charge of a patient's case, evaluates which care interventions to be implemented, arranges any specialist medical consultations, coordinates the activities of health workers and advises family members concerning their own health and that of the patient. In particular, the family nurse plays a key role in case management. The family nurse collaborates with municipal social services and with primary care physicians, thereby creating a network of interdisciplinary care. The initiative is particularly innovative in the Italian context (where the role of the case manager is one of the central themes in the current LTC debate), as it promotes both a model of integration between health and social care and a local network of services by strengthening collaboration with various other stakeholders. |
| 2. Target group and number of population covered (region/s) | The project seeks to arm family nurses with the skills to handle the case management of vulnerable and chronically ill patients, especially older patients. The project operates in the province of Saronno and neighbouring communities, serving a total population of 100,000 inhabitants, of which 21.5% are over 65 years of age. The total number of households is 44,000, which means that almost one out of every two families includes an older person. |
| 3. Qualification as social innovation and/or social innovation potential (please highlight): | a. **It is oriented towards exceptional societal challenges/social issues**<br><br>b. **It suggests new solutions in the respective societal, cultural and economic context**<br><br>c. **It creates new patterns of social practices to overcome** |

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| | **shortcomings of traditional arrangements**<br>d. It tends to overcome the traditional dichotomy between technological and social innovations<br>e. **It promotes the integration and/or collaboration/partnership of heterogeneous stakeholders that have hitherto not co-operated**<br>f. It includes reflective and multidisciplinary approaches towards the key goal of societal usefulness.<br>g. It creates structures and processes that are sustainable and realise new growth potentials in terms of regular employment<br>h. It involves end-users as co-producers of services or products<br>i. It creates new roles and partnerships |
| 4. The initiative is clearly addressing LTC challenges as it is characterised by the following key-issues (please highlight): | a. multidisciplinary work is a value and principle<br>b. **clients' needs are at the centre of all interventions**<br>c. **continuity of care and mechanisms to overcome barriers at the interfaces between social and health care are addressed**<br>d. continuity of care and mechanisms to overcome barriers at the interfaces between formal and informal care are addressed<br>e. it is supported by legislation which explicitly addresses the coordination/integration between health and social care<br>f. incentives to improve cooperation between health and social care facilities or services (e.g. financial, contractual advantages) are in place<br>g. relevant information is efficiently transferred between services or agencies<br>h. **equal access (considering culture, gender and class) is guaranteed to all citizens**<br>i. individual care needs are assessed by a multidisciplinary team<br>j. individual capacities of users/patients are enabled and strengthened<br>k. leadership and management capacities are enhanced through appropriate training<br>l. quality assurance is guaranteed across health and social care services and/or facilities<br>m. agreements between services and/or organisations are based on contracts<br>n. IT and communication technology are used to make administration more efficient<br>o. IT and communication technology are used to facilitate the service<br>p. conditions for the involvement and participation of users/patients and carers are ensured<br>q. multidisciplinary teams are established, supported and continuously |

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| | trained<br>r. an integrated access point (e.g. concerning referral, financial issues, payment regulation, one-stop-shops) is available<br>s. integrated discharge and follow-up planning is fostered (mainly for residential and/or hospital-based facilities)<br>t. **case management is carried out by trained and specialised staff with relevant job-profiles**<br>u. funding is ensured by defined budgets<br>v. involved staff is participating regularly in advanced and further training<br>w. evaluation studies concerning structures, processes and outcomes are carried out and available<br>x. outcome indicators are used to measure and further develop the initiative<br>y. quality management serves to implement continuous improvements<br>z. the initiative is controlled for costs and cost-advantages |
| 5. Status of the initiative | a. National or regional project (terminated)<br>b. European/international project (terminated)<br>c. National or regional project (ongoing)<br>d. European/international project (ongoing)<br>e. **Implemented practice (at least in restricted areas)**<br>f. Widely spread practice/rolled out |
| 6. Type of the initiative | a. New product<br>b. **New service**<br>c. New platform (new legal framework and platform)<br>d. **New organisational form**<br>e. New process<br>f. **New market**<br>g. **New business model** |
| 7. Rationale and objectives: *Why was the initiative implemented? What social needs does it satisfy? Which societal challenges were addressed (context conditions)? For which target groups? With which objectives?* | *Why was the initiative implemented?*<br>Within the framework of the Lombardy region's new healthcare reforms (as established by Regional Law No. 1746 of 18/05/2011), one of the main priorities identified was the need to overcome the fragmentation of care pathways. From this perspective, one of the key issues is the shift from hospital to community care. Accordingly, the strategy has been to look for alternative care settings in which more effective and appropriate interventions can be achieved, both from an economic and a societal perspective. The focus is on mobilising the local community to promote |

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| | prevention and on the management and personalisation of care. Hence there is a need to review the role and function of health authorities in order to achieve a welfare system that is capable of providing an efficient and appropriate response to multidimensional needs by combining different forms of specialised assistance (hi-tech intensive) with an extensive care system implemented at the local level. The Family Nurse initiative has originated precisely to satisfy the need for health care and regular monitoring at home.<br><br>*What social needs does it satisfy? Which societal challenges were addressed*<br><br>The growing need for long-term care, the management of chronically ill and frail persons at home, especially older persons.<br><br>*For which target groups? With what objectives?*<br><br>The objective of this project is to handle the case management of vulnerable and chronically ill patients, with one family nurse per 1,000 inhabitants in the province of Saronno, which has about 100,000 citizens in total. During the first pilot year, the Finisterre consortium will limit the intervention to three categories of users: users of home help provided by the municipality (social care, e.g. cleaning); Integrated Home Service users (a combination of health and social home care); and those people in need of care who do not yet receive public services (potential users). The main objectives of this service are:<br><br>- to care for the user at home and reduce the number of hospital beds;<br>- to reduce costs incurred by the regional health system;<br>- to provide social care training to caregivers, ensuring them direct access to a welfare professional 24 hours a day. |
| 8. Description: *What? How was change made possible? Who is involved? How many users are served per year? What is the role of users?* | *Description: What?*<br><br>The main activities carried out are as follows:<br><br>1. Direct assistance to the patient at home by means of technical nursing interventions and rehabilitation;<br><br>2. Health education and provision of information to raise the awareness of the patient and his/her primary care network aware regarding the specific needs of the patient;<br><br>3. Technical support aimed at increasing the independence of family caregivers in managing the person suffering from a chronic disease.<br><br>It is expected that the family nurse will manage the case, evaluate which care interventions need to be implemented, arrange any necessary specialist medical consultations, coordinate the activities of health care workers and provide health information to the patient and his/her family, and that he/she will personalise the interventions according to the patient's specific condition and the care pathways outlined by medical authorities.<br><br>*How was change made possible? Who is involved?*<br><br>Change was made possible through the creation of a network of local |

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| | stakeholders, including:<br>a) primary care physicians<br>b) social services;<br>c) family nurses.<br>*How many people are served each year?*<br>From May 2013 to April 2014, 110 users accessed the nursing services. Of these:<br>- 89 were aged 65 and over;<br>- 21 were under the age of 65.<br>*What is the role of the users?*<br>Users can either request direct nursing services from the Finesterre, or they may be referred by their primary care physician or the municipal social services agency. Users can also call a telephone hotline active 24 hours a day which provides advice and information, and which can book a service/appointment or activate emergency services in case of emergency. |
| 9. Impact: *Have objectives been realised? How was it measured, shown, evaluated? What are the demonstrated or potential impacts on users, informal carers, staff, inter-organisational collaboration, costs? What is the systemic impact (extent to which the initiative changes the way that LTC is provided across systems or services)? Has the example proven to be sustainable, or mainstreamed? Has the example been implemented elsewhere?* | *Were the objectives achieved? How has this been measured, displayed, evaluated?*<br>- Feedback-based self-assessment (in which the impacts are assessed based on feedback from the target group without the use of strict methods),<br>- Self-evaluation (qualitative and/or quantitative methods to assess impacts),<br>- External evaluation of impacts based on qualitative methods (interviews, focus groups, etc.).]<br>Finisterre has addressed the issue of quality measurement by incorporating the following two features of quality evaluation into its evaluation process:<br>- service quality standards;<br>- assessment tools to measure quality as perceived by the user and by the care professional.<br>In order to evaluate both elements, assessment tools had to be capable of detecting the specific characteristics of each of the two areas of research. The Finesterre quality assessement measured and analyzed the following aspects:<br>- issues related to the characteristics of the service;<br>- structural aspects;<br>- relational aspects.<br>To this end, Finesterre has constructed a series of indicators and indices. While the sections on 'issues related to the characteristics of the service' and 'structural aspects' contain objective data, 'relational aspects' are |

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| | expressed through results obtained from a customer satisfaction survey and the average of results obtained from the operator satisfaction survey.<br><br>As the identification of an 'average' level of quality requires a comparison between multiple measurements repeated over time, the usefulness of the method can only be validated in the medium and long terms.<br><br>*What are the impacts demonstrated on potential users, informal carers, staff, inter-organisational collaboration, costs?*<br><br>Users expressed their satisfaction with the initiative; the collaboration among physicians, nurses and social services is perceived to be very positive.<br><br>*What is the systemic impact (the extent to which the initiative will change the way in which LTC is provided for all systems or services)?*<br><br>It is changing the way the health care system operates in that users are becoming familiar with the family nurse service, and are starting to ask for its services. Other service providers are learning about the initiative and have expressed interest in joining the Family Nurse network.<br><br>*Has this an example proven to be sustainable, or integrated?*<br><br>The initiative is integrated. |
| 10. SWOT Analysis | *Strengths: What solutions have been found to overcome the key challenges?*<br><br>The experience gained in delivering integrated home care services, which is composed of 90% nursing, 7% physiotherapy and 3% social care (such as ADL care) interventions has been crucial to overcoming key challenges. This, combined with daily contacts with users and their families, as well as continuous collaboration with LHD's, social services and primary care physicians;<br><br>*What has facilitated problem-solving?*<br><br>The collaborative activities carried out in cooperation with physicians and workshops with members of the LHD's where problems and solutions could be openly discussed and resolved.<br><br>Importantly, nurses have shown a strong interest in the project as they see it as an improvement in working conditions due to the fact that it allows them to independently organise their work time (as opposed to working conditions in health and social care facilities where shifts are fixed).<br><br>*Weaknesses: What gaps/barriers have been witnessed/experienced?*<br><br>The organisation of the service model because some nursing services are concentrated in (though not limited to) specific times of day. For example, blood samples can only be collected in a patient's home from 7:00 to 9:00 in the morning. It follows that a substantial increase in the demand for this service involves the organisation of a large number of nurses working at approximately the same time. |

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| | Lack of information or poor dissemination of the service; misconceptions held by older people and the difficulty of establishing a trusting relationship (which is fundamental in home care).<br><br>*Opportunity: what improvements could be implemented? What additional activities are needed to achieve the objectives? How could the initiative be scaled up or rolled out?*<br><br>Public sector contribution to the costs of the services which are currently being fully paid for privately by users.<br><br>Improving the information provided to users and families (both in terms of quantity and quality).<br><br>*Threats: What pressures does the initiative currently experience that could threaten its existence?*<br><br>The economic crisis has had a negative effect on this project because the funding of the services rests entirely on the user's shoulders as available public funding is limited. |
| Website | http://www.gruppofinisterre.org/assistenzadomiciliarebadanti.html |
| Sources | Finisterre activity monitoring reports.<br><br>Expert interview conducted with Davide Peri, project coordinator at Finisterre. |

## XII. Home Care and Assistive Services for an Independent and Dignified Life—Bulgaria

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| 1. Abstract | The project (2012-2015) was implemented by the Bulgarian Red Cross (BRC) in its capacity as the Executing Agency (EA) in partnership with the Bulgarian Ministry of Health, Bulgarian Ministry of Labour and Social Policy and the Swiss Red Cross (SRC).<br><br>The goal of the project is to introduce a model for complex provision of health care and social services at home as a form of long-term care for older people with chronic diseases and permanent disabilities that draws on the Swiss experience.<br><br>The project is built on a partnership with relevant institutions, public authorities and stakeholders, among them the Bulgarian Doctors' Union, the Bulgarian Association of Professionals in Nursing, the National Health Insurance Fund, municipal authorities, and patient organization. |
| 2. Target group and number of population covered (region/s) | 350 older people (aged 65 years and over) with LTC needs (chronic diseases and permanent disabilities) in Vratza Region which includes the municipalities of Vratza, Byala Slatina, Oryahovo and Krivodol. |
| 3. Qualification as social innovation and/or social innovation potential (please highlight): | **a. <u>It is oriented towards exceptional societal challenges/social issues</u>**<br><br>**b. <u>It suggests new solutions in the respective societal, cultural and economic context</u>** |

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| | **c. It creates new patterns of social practices to overcome shortcomings of traditional arrangements**<br>d. It tends to overcome the traditional dichotomy between technological and social innovations<br>e. It promotes the integration and/or collaboration/partnership of heterogeneous stakeholders that have hitherto not co-operated<br>**f. It includes reflective and multidisciplinary approaches towards the key goal of societal usefulness**<br>**g. It creates structures and processes that are sustainable and realise new growth potentials in terms of regular employment**<br>h. It involves end-users as co-producers of services or products<br>**i. It creates new roles and partnerships** |
| 4. The initiative is clearly addressing LTC challenges as it is characterised by the following key-issues (please highlight): | **a. multidisciplinary work is a value and principle**<br>**b. clients' needs are at the centre of all interventions**<br>**c. continuity of care and mechanisms to overcome barriers at the interfaces between social and health care are addressed**<br>**d. continuity of care and mechanisms to overcome barriers at the interfaces between formal and informal care are addressed**<br>**e. it is supported by legislation which explicitly addresses the coordination/integration between health and social care**<br>f. incentives to improve cooperation between health and social care facilities or services (e.g. financial, contractual advantages) are in place<br>**g. relevant information is efficiently transferred between services or agencies, e.g. by means of a joint care plan based on a dialogue with users/patients and their informal network**<br>h. equal access (considering culture, gender and class) is guaranteed to all citizens<br>**i. individual care needs are assessed by a multidisciplinary team (with multidisciplinary methods)**<br>**j. individual capacities of users/patients are enabled and strengthened**<br>**k. leadership and management capacities are enhanced through appropriate training**<br>l. quality assurance is guaranteed across health and social care services and/or facilities<br>**m. agreements between services and/or organisations are based on contracts**<br>**n. IT and communication technology are used to make administration more efficient**<br>o. IT and communication technology are used to facilitate the service |

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| | (e-health, e-care, ambient assisted living)<br>p. conditions for the involvement and participation of users/patients and carers are ensured (e.g. shared decision-making)<br>**q. multi-disciplinary teams are established, supported and continuously trained**<br>r. an integrated access point (eg concerning referral, financial issues, payment regulation, one-stop-shops) is available<br>s. integrated discharge and follow-up planning is fostered (mainly for residential and/or hospital-based facilities)<br>**t. case management is carried out by trained and specialised staff with relevant job-profiles**<br>u. funding is ensured by defined budgets<br>v. involved staff is participating regularly in advanced and further training<br>**w. evaluation studies concerning structures, processes and outcomes are carried out and available**<br>x. outcome indicators are used to measure and further develop the initiative<br>y. quality management serves to implement continuous improvements<br>z. the initiative is controlled for costs and cost-advantages |
| 5. Status of the initiative | a. National or regional project (terminated)<br>b. European/international project (terminated)<br>c. **National or regional project (ongoing)**<br>d. **European/international project (ongoing)**<br>e. Implemented practice (at least in restricted areas)<br>f. Widely spread practice/rolled out |
| 6. Type of the initiative | a. New product<br>b. **New service**<br>c. **New platform (new legal framework and platform)**<br>d. New organisational form<br>e. **New process**<br>f. New market<br>g. New business model |
| 7. Rationale and objectives: *Why was the initiative implemented? What social needs does it satisfy? Which societal challenges were* | The integration of health and social care services faces difficulties within eastern European countries. Bulgaria is a new member state with the least developed infrastructure for long-term care. Insufficient development of regulations, division of governance regarding home care services between ministries, the lack of vision for the integration of the |

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| *addressed (context conditions)? For which target groups? With which objectives?* | health and social care part of LTC have negatively affected the provision of home care services. Social care services provided at home are available and funded by local municipalities or under national programs (Mincheva and Kanazireva, 2010).<br><br>These services cover only the support given to disabled and older persons in performing daily activities. Only poorly developed home nursing services are available due to limited public and private funds. (Genet et al., 2012). The provision of home care services is covered mainly through organisations with donor financing or private entities.<br><br>The main barrier in the development of such services is the legal regulations that prohibit nurses to practice their profession autonomously and provide medical care on their own, without the supervision of a doctor. The education and training levels for the practitioners in healthcare-related LTC services (physicians and nurses) are not in accordance with national standards and requirements (Neykov and Salchev, 2012). The low payment level and poor career prospects for social workers create difficulties in motivating and retaining employees in the sector (Beleva, 2010).<br><br>To cover the gaps in regulations and practice, the BRC has proposed the following objectives:<br><br>- to establish home care services to improve user quality of life in the target region;<br><br>- to establish an institutional framework for sustainable provision of home care services in Bulgaria, including proper legislative regulation, payment mechanisms, national quality standards and unified training programmes for the staff;<br><br>- to raise awareness about home care services at all levels of Bulgarian society and to validate the model proposed as a form of integrated provision of health and social services to older people with chronic diseases and disabilities. |
| 8. Description: *What? How was change made possible? Who is involved? How many users are served per year? What is the role of users?* | In 2003, the Bulgarian Red Cross was the first organization in Bulgaria to provide home care services. Based on the experience gathered and the context described above, in 2012 the BRC initiated a project called "Home Care and Assistance Services for an Independent and Dignified Life" (2012-2016).<br><br>In the context of the policy relevance of the established objectives, the project team ensured communication with policy makers as the project is implemented in partnership with the Ministry of Labour and Social Policy, the Ministry of Health and the Swiss Red Cross, and is funded by the Swiss Agency for Cooperation and Development. Other relevant stakeholders involved include: the Bulgarian Doctors' Union, Bulgarian Association of Professionals in Nursing, National Health-Insurance Fund, municipal authorities, and patient organisations.<br><br>The project aims to support the development of several policies for the sustainable provision of home care services (legal and financial provisions), including quality standards, payment mechanisms, |

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| | employment measures, and standardised training programs for staff. The BRC has been working in the area of Active Ageing for more than 10 years across many different programmes, including the 'Home Care and Assistance Services towards an Independent and Dignified Life' project, as the initiative enables ill or disabled older people to remain at home and to maintain a degree of independence.<br><br>Four Home Care Centres (HCC) were established in the region of Vratza in the municipalities of Vratza, ByalaSlatina, Oryahovo and Krivodolby in December 2012. The selection of municipalities was based on the following criteria: large numbers of older people, labour migration of working age residents, lack of sufficient health and social services for older people. Beneficiaries (older persons) are selected based on assessment of their individual needs and based on continual communication with their relatives, GP's and specialist doctors as well as with social assistance departments and other relevant stakeholders. The eligibility criteria for long-term care services are defined by the Ministry of Health and the Ministry of Labour and Social Policy. For most of the centres the financing was secured by donor programs and the BRC's contribution. Only in the case of one of the centres was the funding covered by the donor programs, BRC and the municipality. During the implementation of the project no beneficiary had to pay for the services. Each centre's team consists of nurses and home-helpers, and the medium number of staff per centre is 10-12 persons. The total number of users per centre is between 70-100 older people. 33 home-carers and 17 nurses were trained and then employed within the centres. They serve approximately 350 beneficiaries per year.<br><br>The BRC employs and provides training to staff involved in the project (nurses and home-carers) as the BRC is licensed by the National Association for Vocational Education and Training to provide such trainings.<br><br>A proposal for changes to the existing legislation governing health care services has been elaborated and was submitted to Parliament in June 2014. The design of the draft proposal came after analysis of existing legislation in Bulgaria as well as study of practices and regulations in other European countries. The draft law proposes changes regarding better integration of quality standards in health care and social services at home, standardised cost for these services, and adequate payment mechanisms for home-helpers. The legislative changes were elaborated by experts with solid backgrounds in health and social care working in groups facilitated by the BRC. Experts included representatives of the health and social ministries, the National Health Insurance Fund, the Bulgarian Doctors' Association, Bulgarian Association of Nurses, etc.<br><br>In 2012, the BRC and SRC elaborated a proposal for the introduction of a new profession that hitherto had not existed in Bulgaria - the "home-carer". The proposal was developed together with relevant policy makers from the Ministry of Labour and Social Policy and the Agency for Social Assistance and will be submitted for approval at the National Agency for Vocational Education and Training after further discussions with |

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| | government representatives. |
| 9. Impact: *Have objectives been realised? How was it measured, shown, evaluated? What are the demonstrated or potential impacts on users, informal carers, staff, inter-organisational collaboration, costs? What is the systemic impact (extent to which the initiative changes the way that LTC is provided across systems or services)? Has the example proven to be sustainable, or mainstreamed? Has the example been implemented elsewhere?* | The initiative is currently halfway completed and several of its basic objectives have been achieved to date:<br><br>- Elaboration of draft legislative changes<br>- Introduction of a new profession/specialty "home-helper"<br>- Approbation of the home care model in the region of Vratza<br>- Creation of workplaces: Professional teams of nurses and home-helpers have been created. 50 job positions were created in the region of Vratza – a total of 33 home-carers and 17 nurses have been trained in the project and employed to work at the centres.<br>- Provision of the services: Provision of regular care at home to 350 beneficiaries selected by a joint committee, composed of the manager of the respective HCC, a representative of the respective municipality, and a representative of the Regional Department for Social Assistance and the Regional Health Inspection.<br>- Continuous training of the staff: For home-carers, training consists of 120 classes including theory and practice, while training for nurses involves 160 classes. Training focuses on the specificities of providing health and social care to older people with various diseases in the home environment. Training for nurses includes additional modules on how to perform individual needs assessment, designing care plans, and monitoring the work of the home-carers. The nurses and home-carers employed at HCC receive regular support and practical training by experts from the Swiss Red Cross. The trainings include different topics, among them: care planning, care for patients with bedsores, hygiene in services provided at home, wound management, etc. These trainings raise the skill level of staff and improve the quality of care. As a consequence the needs of beneficiaries are more appropriately addressed.<br>- Inclusion of Roma in home care services provision: The specific needs of the Roma community in the context of provision of home care services were assessed by a feasibility study. The study was carried out in the region of Vratza between June and August 2013, and based on the results, eight additional job positions for Roma home-carers were created, two in each HCC. They were successfully trained in September 2013 and employed at the HCC. Currently, the proportion of Roma working at the HCC is 25% of the total number of job positions created by the project.<br>- Introduction of a data and cost-management software in the HCC: With the support of the Technical University in Sofia, a software programme was designed for data and cost-management of home care services. It was introduced to HCC staff in December 2013 and staff members were trained accordingly. The data gathered will serve as the basis for cost-pricing of services and a minimum standard for a service catalogue will be created.<br>- Awareness has been raised among community, health and social service providers through informational materials, national conferences, round tables at the regional level, and media coverage.<br>- Systemic impact and possibility of future services at the national level: |

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| | On the basis of the Home Care Project, the integrated provision of health care and social services to older people in their homes has been defined as one of the basic areas to be developed in the future in the National Strategy on Long-term Care 2014-2020 adopted in January 2014 and the Bulgarian Red Cross has taken active part in its design and implementation.<br>- The project will also develop national quality standards for home care. The question of whether the offer for the Roma population and other minority groups in Bulgaria needs to be adapted will also be clarified, to enable care methods for these groups to be implemented in a targeted and efficient way.<br>- Finally, on the basis of experience and results, proposals and recommendations for health care service provision at the national level will be made in order to drive forward health service reforms. It is expected that a home nursing system will be established at the national level, as a way of tackling demographic and socio-economic challenges in the health system in an effective and modern manner. |
| *10. SWOT Analysis* | *Strengths: What solutions were found to overcome key-challenges? What facilitated problem-solving?*<br>- The development of a health system that provides home care reduces the pressure on hospitals and on the target population: older people can continue to live independently at home in a familiar environment and health care-related costs are reduced as home nursing is cheaper than hospital care (many older people in Bulgaria are isolated, both in medical and social terms);<br>- The development of integrated national quality standards for home care, with clear definitions of who is responsible for which tasks;<br>- Proposal for the introduction of the new job profile 'home-helper', in order to guarantee the future provision of social services by qualified staff;<br>- Training courses for both nurses and home-carers before being employed by the HCC;<br>- Raise awareness about home care services at all levels of Bulgarian society in order to validate home care as a form of integrated provision of health and social services to older people with chronic diseases and disabilities;<br>- Wide partnership with other competent institutions and stakeholders;<br>- The establishment of an institutional framework for sustainable provision of this type of services in Bulgaria.<br>*Weaknesses: Which gaps/obstacles have been witnessed/experienced?*<br>- The project is still on-going (until 2015) and it is still possible that some of the objectives (e.g. the establishment of an institutional framework) may not be achieved.<br>*Opportunities: Which improvements could be implemented? What additional activities will be needed to deliver on targets? How could the initiative be scaled up or rolled out?* |

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| | - The project addresses the gaps in home care service provision in Bulgaria and the lack of integration of health and social care services, demonstrating that the exiting human resources could be better exploited by strengthening legislation on regulation contained within the Health Law and through the involvement of relevant policy makers in the field;<br>- A positive reception of the home care model by the Vratza region of Bulgaria has paved the way for a possible expansion of the initiative to other regions;<br>- The assessment of care needs carried out by a joint committee comprising the manager of the respective HCC, a representative of the respective municipality as well as of the Regional Department for Social Assistance and the Regional Health Inspection;<br>- Job creation: open positions for home-carers and nurses to serve the local population and serving as an incentive to work in more rural areas;<br>- Inclusion of Roma in home care service provision based on the specific needs of the Roma community;<br>- Use of IT and communication technologies: a special software program was designed and introduced into the work of the HC centres for data and cost-management of services.<br>*Threats: What pressures does the initiative currently experience that could threaten its existence?*<br>- Funding, unless the Ministry of Health, Ministry of Labour and Social Policy develops the project further within the National Strategy on Long-term Care 2014-2020 by establishing an institutional framework for sustainable provision of this type of services in Bulgaria;<br>- The possibilities for further expansion of the programme to other regions hinges on the adoption of the draft proposal containing changes to the Health Law. |
| Website | http://en.redcross.bg/projects/active_projects/home_care_project.html. |
| Sources | Beleva, I. (2010) *Thematic Report 2010: Care for dependent elderly and gender equality in the EU: Dependent Elderly and Gender Equality in Bulgaria.*<br><br>Genet, N., Boerma, W., Kroneman, M., Hutchinson, A., Saltman, R.B. (2012) *Home care across Europe. Current structure and future challenges*, [online]: http://www.euro.who.int/__data/assets/pdf_file/0008/181799/e96757.pdf<br><br>Mincheva, L, Kanazireva, G. (2010) *The Long term-care system for elderly in Bulgaria*. [online]: http://www.ancienlongtermcare.eu/sites/default/files/ENEPRI%20RR%20no%2071%20_Ancien_%20Bulgaria.pdf<br><br>Neykov, I., Salchev, P. (2012) *Annual National Report 2012 Pensions, Health Care and Long-term Care Bulgaria*. [online]: http://socialprotection.eu/files_db/1206/asisp_ANR12_BULGARIA.pdf |

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| | Phone interview and email consultation were conducted with Siana Metodieva of the Bulgarian Red Cross. |

## XIII. Integrated Help-at-Home Development Programme—Lithuania

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| 1. Abstract | Integrated Help at Home Development Program is aims to ensure better accessibility and larger variety of services of integrated help at home for older people, disabled adults and children and their family members. The programme envisages building and equipping mobile teams consisting of a social worker, an assistant social worker, a nurse, and if needed, a physiotherapist and a rehabilitation counsellor. These teams visit the care recipients at home and provide complex services, and also assist and counsel family members. The programme also seeks to facilitate cooperation of volunteers and community members in organizing and providing integrated help at home.<br><br>The programme was approved in 2012 for implementation between 2013-2015 with financing of 20,625 mln. Lt. from the European Social Fund. The initiative involves 21 local municipalities (out of a total of 60) in Lithuania and is anticipated to employ 299 nurses and their assistants and to establish 67 mobile teams. The Ministry of Social Security and Labour predicts that training will be provided to 614 members of mobile teams (incl. nurses, social workers, and assisting personnel).<br><br>The integrated help-at-home program is planned and organized by local municipalities which are responsible for assigning the responsible provider institution, which in most cases are local social services centres. The program offers care recipients both social and health care services as both social workers and nurses are on staff. |
| 2. Target group and number of population covered (region/s) | The program targets older people, disabled adults and children and their family members. It is being implemented in 21 municipalities out of 60 municipalities in Lithuania. The anticipated number of integrated help-at-home recipients is 760 older and disabled individuals and the number of family members that receive counselling is 810. |
| 3. Qualification as social innovation and/or social innovation potential (please highlight): | a. **It is oriented towards exceptional societal challenges/social issues**<br>b. **It suggests new solutions in the respective societal, cultural and economic context**<br>c. **It creates new patterns of social practices to overcome shortcomings of traditional arrangements**<br>d. It tends to overcome the traditional dichotomy between technological and social innovations<br>e. **It promotes the integration and/or collaboration/partnership of heterogeneous stakeholders that have hitherto not co-operated**<br>f. **It includes reflective and multidisciplinary approaches towards the** |

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| | **key goal of societal usefulness**<br>g. **It creates structures and processes that are sustainable and realise new growth potentials in terms of regular employment**<br>h. **It involves end-users as co-producers of services or products**<br>i. **It creates new roles and partnerships** |
| 4. The initiative is clearly addressing LTC challenges as it is characterised by the following key-issues (please highlight): | **a. multidisciplinary work is a value and principle**<br>**clients' needs are at the center of all interventions**<br>**c. continuity of care and mechanisms to overcome barriers at the interfaces between social and health care are addressed**<br>**d. continuity of care and mechanisms to overcome barriers at the interfaces between formal and informal care are addressed**<br>**e. it is supported by legislation which explicitly addresses the coordination/integration between health and social care**<br>**f. incentives to improve cooperation between health and social care facilities or services (e.g. financial, contractual advantages) are in place**<br>g. relevant information is efficiently transferred between services or agencies, e.g. by means of a joint care plan based on a dialogue with users/patients and their informal network<br>h. equal access (considering culture, gender and class) is guaranteed to all citizens<br>**i. individual care needs are assessed by a multidisciplinary team (with multidisciplinary methods)**<br>**j. individual capacities of users/patients are enabled and strengthened**<br>k. leadership and management capacities are enhanced through appropriate training<br>**l. quality assurance is guaranteed across health and social care services and/or facilities**<br>**m. agreements between services and/or organisations are based on contracts**<br>n. IT and communication technology are used to make administration more efficient<br>o. IT and communication technology are used to facilitate the service (e-health, e-care, ambient assisted living)<br>p. conditions for the involvement and participation of users/patients and carers are ensured (e.g. shared decision-making)<br>**q. multi-disciplinary teams are established, supported and continuously trained**<br>**r. an integrated access point (e.g. concerning referral, financial issues, payment regulation, one-stop-shops) is available** |

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| | s. integrated discharge and follow-up planning is fostered (mainly for residential and/or hospital-based facilities)<br>t. case management is carried out by trained and specialised staff with relevant job-profiles<br>**u. funding is ensured by defined budgets**<br>**v. involved staff is participating regularly in advanced and further training**<br>**w. evaluation studies concerning structures, processes and outcomes are carried out and available**<br>x. outcome indicators are used to measure and further develop the initiative<br>y. quality management serves to implement continuous improvements<br>**z. the initiative is controlled for costs and cost-advantages** |
| 5. Status of the initiative | a. National or regional project (terminated)<br>b. European/international project (terminated)<br>**c. National or regional project (ongoing) but funded from European social fund**<br>d. European/international project (ongoing)<br>e. Implemented practice (at least in restricted areas)<br>f. Widely spread practice/rolled out |
| 6. Type of the initiative | a. New product<br>b. **New service**<br>c. New platform (new legal framework and platform)<br>d. New organisational form<br>e. **New process**<br>f. New market<br>g. New business model |
| 7. Rationale and objectives: *Why was the initiative implemented? What social needs does it satisfy? Which societal challenges were addressed (context conditions)? For which target groups? With which objectives?* | Demographic change and rapid ageing generate a growing need for LTC and social services which are largely unfulfilled by the current institutional social care system in Lithuania. LTC has become an increasingly urgent social policy issue. The discussions involve three main issues: (i) who should pay for LTC; (ii) how services for older and disabled people should be designed; (iii) how can the LTC labour force be recruited, trained, and sustained.<br>Policy makers are trying to ensure that social integration of older and disabled people through reforms and implementation of social innovations programs are focused on more personalized social services provided at home that meet individual needs and ensure some level of independence.<br>Social care and health care systems in Lithuania are separate which |

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| | makes providing LTC that meets the needs of users difficult. The idea of the programme is to integrate both spheres in providing social and health care services involving not only professionals, but volunteers, community and family members as well.<br><br>The programme enhances access to social care and nursing for current and potential care recipients (older and disabled people). Accessibility to such services has previously been limited for various reasons (e.g. long distances between social service centres, limited mobility, lack of funds, etc.). Care recipients rely mostly on home caregivers who often lack elementary knowledge of care principles. One of the goals of the programme is to provide home care training to family members and volunteers and increase the quality of home care. Integrating the services of social workers and nurses from the healthcare sector into one team supports the establishment of a new LTC model which would also satisfy the needs of care recipients and their family members. The integrated services are expected to substitute existing home care provided by family members, allowing the latter to return to labour market where applicable.<br><br>The programme aims to ensure high quality integrated services (nursing and social care) at care recipients' homes and to provide home caregiving training to family members. One of the objectives is to encourage informal help attracting community members as volunteers to participate in the integrated caregiving process. In a broader sense the programme also aims to identify best practices that would ensure the development of a standard LTC model for all municipalities, thereby reducing inequalities in access to care between municipalities. |
| 8. Description: What? *How was change made possible? Who is involved? How many users are served per year? What is the role of users?* | Analysis of the current situation indicates that the existing institutional care-based system cannot meet the needs of LTC recipients. Policymakers have taken measures to deinstitutionalise social institutional care by inviting local municipalities to participate in social innovations projects that temporarily address issues related to three key dimensions of LTC policy – financing, delivery, and workforce.<br><br>The initiative offers a clear care model that integrates nursing and social care at recipients' homes. Furthermore, it provides high-quality training for both formal and informal carers supporting higher quality of home caregiving services. The programme offers a temporary solution for all three of the above-mentioned issues related to LTC.<br><br>The management of health care and social care is the responsibility of two different ministries in Lithuania. The Health Ministry is in charge of nursing and the Ministry of Social Security and Labour is in charge of social care. Local municipalities are responsible for planning nursing and social care services and social services and/or nursing centres are responsible for organization and delivery of caregiving in given municipalities.<br><br>The programme enables certain care recipients to get access to professional care that was not accessible for most of them before. These new users previously relied mainly on informal care given by family |

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| | members, relatives or neighbours who usually do not have the necessary caregiving skills. 760 individuals received care through the programme and 810 family members received training between 2013-2015.<br><br>The programme helps to alleviate the labour shortage in some municipalities. People involved in the project are trained and provided with the qualification which allows them to stay in the labour market in the future.<br><br>Integrated nursing and social care at recipients' homes provides family members with temporary respite from ongoing caring responsibilities. Family members receive counselling and training – this additional support may help them to reconcile work and caregiving activities. |
| 9. Impact: *Have objectives been realised? How was it measured, shown, evaluated? What are the demonstrated or potential impacts on users, informal carers, staff, inter-organisational collaboration, costs? What is the systemic impact (extent to which the initiative changes the way that LTC is provided across systems or services)? Has the example proven to be sustainable, or mainstreamed? Has the example been implemented elsewhere?* | The programme implementation period is 2013-2015. Consequently, the outcomes have not yet been evaluated. However, all local municipalities have implemented most of the commitments described in the project tender: they have established mobile teams, hired additional health care staff and social workers and organized their training. Some municipalities have additionally hired rehabilitation specialists, physiotherapists and/or masseurs to improve the health conditions of care recipients and have worked to facilitate family members' integration into a social environment and labour market.<br><br>It is anticipated that the programme has had significant positive results by helping to decrease stress and depression and improve quality of life of care recipients. The mobility of the teams has meant that professional services are available in peripheral and remote areas where access to professional care was minimal before.<br><br>The project foresees providing training and counselling for family members to increase family caregivers' knowledge of effective and safe caregiving strategies and to improve their emotional coping skills in order to reduce or prevent stress and enhance their quality of life.<br><br>The programme has strong implications for development of a systemic integrated LTC approach in Lithuania where integrated care has not yet been applied on a large scale. The programme has contributed to the improvement of the unemployment situation in local municipalities by creating jobs for nurses and assisting personnel. However, there is no evidence yet that the new service model will be sustainable or mainstreamed outside the current project.<br><br>Similar practices of health and social care integration have been implemented in Greece as described in Daniilidou et al. (2008), where LTC for older people is based on a mixed formal and informal care system. The other example of structural home care integration comes from Sweden, where care is provided without service gaps, fragmentation or lack of cooperation between Home Care Services (provision of medical support) and Home Help Services (provision of social services) as described in Hedman et al. (2007). |
| 10. SWOT Analysis | *Strengths: What solutions were found to overcome key-challenges? What facilitated problem-solving?* |

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| | - Guaranteed funding helps to overcome silo thinking and allows facilitators and carers to go the extra mile if the users' needs require it;<br>- Multifunctional teams provide different services to support the quality of life of older and disabled people; team nurses provide services that were previously available only in health care institutions;<br>- Creation of social values, new social ties and local relations based on solidarity.<br><br>*Weaknesses: Which gaps/obstacles have been witnessed/experienced?*<br><br>- Separate administration of health and social care systems is not a good precondition for expanding the model across Lithuania after the project has ended.<br><br>*Opportunities: Which improvements could be implemented? What additional activities will be needed to deliver on targets? How could the initiative be scaled up or rolled out?*<br><br>- Positive experience may lead to the design of an appropriate funding model that could be transferrable to other municipalities.<br><br>*Threats: What pressures does the initiative currently experience that could threaten its existence?*<br><br>- The initiative is funded by the European Social Fund for the period 2013-2015; funding prospects outside the state and municipality budget are vague. |
| Website | NA |
| Sources | Daniilidou, N., Economou, C., Zavras, D., Kyriopoulos, J., Georgossi, E. (2008) Health and social care in aging population: an integrated care institution for the elderly in Greece, *Int J Integr Care*, 3: 1-5.<br><br>Hedman, N., Johansson, R., Rosenqvist, U. (2007) Clustering and inertia: structural integration of home care in Swedish elderly care, *Intl J Integr Care*, 7: 1-4.<br><br>Ministry of Health and Social Security (2013) More care and home care services. Press release, 26.06.2013. http://www.ndt.lt/enews/id-ndt-news-daugiau_slaugos_ir_globos_paslaugu_namuose.html<br><br>Order on approval of the integrated help-at-home development program No. A1-353 issued in July 20, 2012 by Minister of Health and Social Security. http://www3.lrs.lt/pls/inter3/dokpaieska.showdoc_l?p_id=430819&p_query=&p_tr2=2<br><br>Order on approval of the state projects funded by the 2007-2013 Human Resource Development program Priority 1 'Quality Employment and Social Inclusion' No. A1-562 issued in December 10, 2012 by Minister of Health and Social Security. http://www.esparama.lt/es_parama_pletra/failai/sadm/teises_aktai/14_pr_integralios_p/SADM_A1-562_20121210.pdf<br><br>Expert consultation was conducted with Zana Grigaliuniene, lecturer in the social sciences department at Šiauliai University, Lithuania. |

## XIV. Recognition of informal skills, Piedmont region—Italy

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| 1. Abstract | Having worked for a long time in the care sector without any structured training, informal carers have often nevertheless accumulated important skills that are also required in professional care. The official recognition/certification of such skills, training programmes, and an increase in formal employment contracts are at the centre of an initiative that has been promoted by the regional administration of Piedmont in collaboration with provincial governments and other local stakeholders since 2008. The initiative has been created to enhance the effectiveness of home based care that is carried out by privately paid migrant care workers. The commitment of the Piedmont region sought to create tools to identify and assess (informally acquired) skills, and to establish services to support and organise this process through certification and mentoring. In 2010, the tool was tested by means of a survey in which carers' self-reported skills were assessed. Based on the survey results a special commission could decide on further tests, including simulation, to validate the capacities declared by the carers. The results also allowed allocating carers for additional training at a precise level or to orient them directly towards a final exam. Once having passed this exam, participants receive a certificate of attendance to officially certify the skills possessed by the carer.<br><br>In addition to the skills recognition component, the programme also supports local networks of services for people with home care needs. This includes information, reception and orientation training, matching demand for home care with skilled carers, and help with the administrative management of employment contracts. Lastly, the programme also includes subsidies to households for temporary replacements of carers in training. |
| 2. Target group and number of population covered (region/s) | The programme targets two groups of beneficiaries: older people with LTC needs (and their families) and privately paid home care workers (usually with a migrant background).<br><br>In 2013, 18,176 people (households + privately paid care workers) contacted the front office and received information about the programme and an initial consultation/orientation. On a voluntary basis, 8,851 of these people decided to become users of the programme. Users are either a) older people with care needs and their families, or b) privately employed care workers (personal assistants, often with a migrant background). 2,302 of these users consisted of households with individuals in need of care and their family members, and 6,549 were private care workers.<br><br>A total of 617 paid personal assistants decided to participate in and managed to complete the training courses offered by the programme, thus obtaining the certification formally recognising their acquired skills. While this service was available to all care workers participating in the wider programme, the majority did not complete training course because |

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| | either they were already certified, or they left the training programme after finding employment.<br><br>The programme has achieved a total of 1,008 formal employment contracts for home carers working in family settings (including 442 from non-EU countries).<br><br>In the regional territory, a total of 144 branches were opened, involving 219 local partners (public and private). |
| 3. Qualification as social innovation and/or social innovation potential (please highlight): | **a. <u>It is oriented towards exceptional societal challenges/social issues</u>**<br>**b. <u>It suggests new solutions in the respective societal, cultural and economic context</u>**<br>**c. <u>It creates new patterns of social practices to overcome shortcomings of traditional arrangements</u>**<br>d. It tends to overcome the traditional dichotomy between technological and social innovations<br>**e. <u>It promotes the integration and/or collaboration/partnership of heterogeneous stakeholders that have hitherto not co-operated</u>**<br>**f. <u>It includes reflective and multidisciplinary approaches towards the key goal of societal usefulness.</u>**<br>**g. <u>It creates structures and processes that are sustainable and realise new growth potentials in terms of regular employment</u>**<br>h. It involves end-users as co-producers of services or products<br>**i. <u>It creates new roles and partnerships</u>** |
| 4. The initiative is clearly addressing LTC challenges as it is characterised by the following key-issues (please highlight): | **a. <u>multidisciplinary work is a value and principle</u>**<br>**b. <u>clients' needs are at the centre of all interventions</u>**<br>c. continuity of care and mechanisms to overcome barriers at the interfaces between social and health care are addressed<br>**d. <u>continuity of care and mechanisms to overcome barriers at the interfaces between formal and informal care are addressed</u>**<br>e. it is supported by legislation which explicitly addresses the coordination/integration between health and social care<br>f. incentives to improve cooperation between health and social care facilities or services (e.g. financial, contractual advantages) are in place<br>**g. <u>relevant information is efficiently transferred between services or agencies, e.g. by means of a joint care plan based on a dialogue with users/patients and their informal network</u>**<br>**h. <u>equal access (considering culture, gender and class) is guaranteed to all citizens</u>**<br>i. individual care needs are assessed by a multidisciplinary team (with multidisciplinary methods) |

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| | **j. individual capacities of users/patients are enabled and strengthened**<br>k. leadership and management capacities are enhanced through appropriate training<br>l. quality assurance is guaranteed across health and social care services and/or facilities<br>m. agreements between services and/or organisations are based on contracts<br>**n. IT and communication technology are used to make administration more efficient**<br>o. IT and communication technology are used to facilitate the service (e-health, e-care, ambient assisted living)<br>**p. conditions for the involvement and participation of users/patients and carers are ensured (e.g. shared decision-making)**<br>q. multi-disciplinary teams are established, supported and continuously trained<br>**r. an integrated access point (eg concerning referral, financial issues, payment regulation, one-stop-shops) is available**<br>s. integrated discharge and follow-up planning is fostered (mainly for residential and/or hospital-based facilities)<br>t. case management is carried out by trained and specialised staff with relevant job-profiles<br>u. funding is ensured by defined budgets<br>**v. involved staff is participating regularly in advanced and further training**<br>**w. evaluation studies concerning structures, processes and outcomes are carried out and available**<br>**x. outcome indicators are used to measure and further develop the initiative**<br>**y. quality management serves to implement continuous improvements**<br>z. the initiative is controlled for costs and cost-advantages |
| 5. Status of the initiative | a. National or regional project (terminated)<br>b. European/international project (terminated)<br>c. National or regional project (ongoing)<br>d. European/international project (ongoing)<br>**e. Implemented practice (at least in restricted areas)**<br>f. Widely spread practice/rolled out |

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| 6. Type of the initiative | a. **New product**<br>b. **New service**<br>c. **New platform (new network)**<br>d. **New organisational form**<br>e. **New process**<br>f. **New (labour) market**<br>g. New business model |
| 7. Rationale and objectives: Why was the initiative implemented? What social needs does it satisfy? Which societal challenges were addressed (context conditions)? For which target groups? With which objectives? | In the Piedmont Region, 23.7% of the population are over 65 years of age, which is 2.5% above the national average (Demoistat, 2013). There is high need for care, in particular as 30% of older people in this region are living alone (Health for all, 2012). Family care is the most important source of care, but the traditional model of care by (female) family members is facing huge challenges. Whilst women's labour force participation and mobility of the labour force generally have increased, family carers have been gradually replaced or complemented by live-in migrant carers who are coming mainly from Romania, Ukraine and Belarus but also from Asia, Africa and Latin America. These care arrangements suffer from a number of caveats, in particular related to the lack of regulations in terms of labour and migration law, professional profiles, working conditions and social security, but also with respect to quality assurance and the relationships between migrant carers, families and the formal sector of home care. Furthermore, migrant carers are often still working in the context of an informal economy with related difficulties to match demand and supply.<br><br>The initiative taken in the Piedmont Region addresses these open questions in an integrated way by shaping a system of services to support quality care, focusing on the skills of live-in (migrant) carers by acknowledging those skills that have already been acquired and by improving those that are lacking, thus contributing to the professionalisation and regulation of privately employed personal assistants. By doing so the initiative also addresses the need for public support and supervision of care in the 'grey' area between informal (family) care and formal care services, also with a view to reduce illegal employment.<br><br>In the context of the Italian model of care provision, which basically conceives care at home as a family matter and the employment of personal carers by families as just another form of informal ('unprofessional') care, the irregular working conditions of mainly migrant personal carers need to be overcome. The initiative promotes solutions by developing a market for regular care and managing the mixed system of public and private services. This innovative approach leads to a cultural change, because it promotes a change in the relations between formal and informal care and their quality. The recognition of personal carers' skills and the clear definition of their role within in the care process thus have brought about both social and economic changes within a regular care market, as interviews with families and personal |

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| | carers, i.e. the main target groups of the initiatives, confirmed at the end of the experimental phase. |
| 8. Description: What? How was change made possible? Who is involved? How many users are served per year? What is the role of users? | The programme promotes the creation of a comprehensive service network to support care in the family by privately paid personal carers. This includes:<br>- Local kiosks provide information, training (inception and orientation), brokering (matching demand and supply) and administrative support (management of employment contracts);<br>- The assessment, recognition and certification of informal skills as well as related training activities by a designated 'Skills assessment team' consisting of care experts, trainers and representatives of the public employment agency. This includes an analysis of the individual's CV, an in-depth interview and a preliminary identification of skills as well as a practical assessment of skills through simulation methods;<br>- Incentives for employers (families) by means of subsidies to households who need a temporary replacement of personal carers who are participating in the programme (assessment and training).<br><br>Individual competencies are certified by the 'skills assessment team' and are combined to qualify to be a certified 'personal assistant', a certification which is (irregularly) recognised in the Piedmont Region and can thus facilitate the acquisition (through an ad hoc additional training) of the national professional title of a health and social care worker (operatore socio-sanitario). If the assessment of skills indicates that an individual is lacking specific competencies (especially in the field of health care), these may be acquired by completing specific training modules that are offered free of charge. The programme was made possible by the creation of regional networks involving public and private stakeholders, including informal stakeholders, who often identify families seeking care practitioners (e.g. parishes). Apart from the public administration of the Region Piedmont, local authorities, social enterprises, trade unions and voluntary associations participate in the initiative.<br><br>In total, 8 regional networks were created following a joint programme. Each network is managing the programme within its catchment area, thus adapting the implementation to the local needs to allow for a better match between the general aims and the specific local context. Still, there is a constant and systematic exchange between the networks to prepare for a sustainable future strategy. At the regional level, collaboration and co-design are fostered through the technical committee of the programme, consisting of representatives from training, employment and social policy agencies of each of the 8 regional networks in the Piedmont Region. Users (families as employers, private carers as employees) are not represented in the technical committee.<br><br>Each network chooses its own method of promotion. On the whole, pharmacies and supermarkets are proving to be an ideal location to recruit potential end users.<br><br>In 2013, 18,176 people received information and an initial |

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| | consultation/orientation from programme staff after contacting the front office. Of these initial beneficiaries, 8,851 volunteered to become users of the programme's services (2,302 people in need of care (and their families) and 6,549 privately employed care workers). |
| 9. Impact: Have objectives been realised? How was it measured, shown, evaluated? What are the demonstrated or potential impacts on users, informal carers, staff, inter-organisational collaboration, costs? What is the systemic impact (extent to which the initiative changes the way that LTC is provided across systems or services)? Has the example proven to be sustainable, or mainstreamed? Has the example been implemented elsewhere? | The objectives of the initiative have been widely achieved.<br>*How has this been measured, displayed, evaluated?*<br>Through the periodic monitoring of quantitative indicators of outcome. Data is collected on<br>- First time users (number of families and paid personal assistants): +246% more users than planned were reached<br>- Number of users joining the program (families and paid personal assistants (EU/non-EU): +69% were reached as against original planning<br>- Number of paid personal assistants: 22% less than expected could be recruited<br>- Number of paid personal assistants who have started/completed training: 4% more than expected could be recruited, and the targeted number to complete training could be achieved<br>- Grants for the provision of contracted care services: 12.6% more than planned were received.<br>- What is the demonstrated impact on potential users, informal carers, staff, inter-organizational collaboration, costs?<br>- The monitoring does not include impact indicators.<br>*What is the systemic impact (the extent to which the initiative will change the way in which LTC is provided for all systems or services)?*<br>The services created with this programme were incorporated into the labour services system and one of the results of the programme was the standardisation of services. This element was necessary to achieve an accreditation system for the job services, which began in the Piedmont Region in 2012. A video presentation available on the programme's website, created at the end of the experiment, suggests a high level of user satisfaction.<br>*This is an example proven to be sustainable, or integrated?*<br>The services activated by the programme (local kiosks, training and certification courses and financial incentives for contract regularization) remained active even after the pilot phase came to an end. Sustainability of the programme depends on the choices made by each of the 8 networks running joint programmes. At present, each network has continued service provision, even though in certain areas, services operate at a reduced level (e.g. reduced hours). |
| 10. SWOT Analysis | *Strengths: What solutions have been found to overcome the key challenges?*<br>- Activation of all relevant partners (both formal and informal) in the system |

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| | - Promotion of integrated public-private partnerships<br>- The level of service provision is determined according to the needs of the end users. For each beneficiary of the service (or home care worker), individual care plans are prepared, according to the services that the project delivers. The caregivers who choose to undertake the recognition of skills have a personal plan for the evaluation and integration of skills.<br>- Investment in the definition of the partnership<br>- Investment in training and in the recognition of informal skills of workers in long-term care (including the use of designated assessment tools and the design of modular training courses)<br>- Investment in training for paid personal assistants<br>- Use of innovative channels in the promotion of the initiative in order to reach out for potential users (supermarkets, drugstores)<br>- Problem-solving by the definition of networks, joint planning and programme management and an integrated approach among different sectors of the Region<br>*Weaknesses: What gaps/barriers have been witnessed/experienced?*<br>- The maintenance of regular contracts for personal care workers has proven to be difficult as families often experience difficulties in managing administrative procedures<br>- Funding to ensure temporary replacements of the personal carers who are attending training courses is not sufficient<br>- There is a lack of regular regional funding to ensure the maintenance of basic and equal services throughout the region<br>- There is a lack of involvement of formal home care providers, in particular as the health sector of the regional administration was not involved. This program provides an interface between labour, training and social policies, but there is still no integration between social and health care.<br>- At Regional level, there is a lack of a professional profile of caregivers. At present, although this program has increased the recognition of skills, official recognition of "paid personal assistants" is currently still under debate, and not yet legally acquired in the Piedmont region.<br>*Opportunities: improvements that could be implemented? What additional activities are needed to achieve the objectives? How could the initiative be scaled up or rolled out?*<br>- Improving the coverage of needs, dissemination of the initiative across the entire region (up-scaling to national level?)<br>- Involvement of hospitals and health care stakeholders in the networks<br>- Regional-level definition of a professional profile for the paid personal assistants.<br>*Threats: What pressures does the initiative currently experience that* |

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| | *could threaten its existence?*<br>- Lack of funds. The project started as an experiment and has created regional networks that currently maintain their activity beyond the pilot project's termination. Budgets are territorial. Currently at the regional level there is no other funding, but the Piedmont Region is searching for new sources of regional financing to increase the activities of such networks beyond current levels.<br>- Difficulties of households in maintaining regular contracts, because they are considered too expensive. |
| Website | http://www.regione.piemonte.it/pariopportunita/cms/index.php/lavoro/assistenti-familiari/411-convegno-piemonte-ass-fam-2013 |
| Sources | *Piedmont Region job market portal:*<br>http://extranet.regione.piemonte.it/fp-lavoro/centrorisorse/studi_statisti/monografie_studi/index.htm<br>http://daspiemonte.crisp.unimib.it/pentaho/PDFViewer?solution=dasPiemonte&path=documentazione&action=MdL_Piemonte2013.pdf<br>*Demographic data:*<br>http://demo.istat.it/<br>*Online publications:*<br>Qualificare info, April 2012: http://www.qualificare.info/home.php?id=600<br>Qualificare info, March 2010: http://www.qualificare.info/home.php?id=452 |

## XV. UP-TECH project, supporting caregivers of Alzheimer's disease patients—Italy

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| 1. Abstract | This randomized controlled clinical study aims to reduce the burden on family carers of older Alzheimer's Disease (AD) patients in order to allow the patients to live at home for as long as possible. It is currently being implemented in five health districts of the Marche Region in Italy (Pesaro, Ancona, Macerata, Fermo and San Benedetto del Tronto). The project will: a) provide sound evidence for the effectiveness and cost of different support programs for caregivers and AD patients living in the community; b) decrease caregiver and patient distress and avoidable use of care resources (hospital and residential care and prescription drugs).<br>It is the first project in Italy that targets both AD sufferers and their carers. This population is often neglected by the care system which tends to inappropriately use prescription drugs, hospitals and residential care. The clinical study's main components are: a) funding a case manager/social worker to provide counselling, follow-up telephone calls and information about services, aid and subsidies; b) the use of second generation telecare devices at home; c) the establishment of a collaborative working group (120 professionals) to restructure the whole process of dementia care at the regional level. This study is innovative because it combines scientific methodology with a regional home-based care intervention. |

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| 2. Target group and number of population covered (region/s) | The programme has two target populations: older AD patients and their family caregivers. The program reached 1,385 older people including patients suffering from AD (438) and their family caregivers (947). |
| 3. Qualification as social innovation and/or social innovation potential (please highlight): | a. It is oriented towards exceptional societal challenges/social issues<br>**b. <u>It suggests new solutions in the respective societal, cultural and economic context</u>**<br>c. It creates new patterns of social practices to overcome shortcomings of traditional arrangements<br>**d. <u>It tends to overcome the traditional dichotomy between technological and social innovations</u>**<br>**e. <u>It promotes the integration and/or collaboration/partnership of heterogeneous stakeholders that have hitherto not co-operated</u>**<br>**f. <u>It includes reflective and multidisciplinary approaches towards the key goal of societal usefulness.</u>**<br>g. It creates structures and processes that are sustainable and realise new growth potentials in terms of regular employment<br>h. It involves end-users as co-producers of services or products<br>**i. <u>It creates new roles and partnerships</u>** |
| 4. The initiative is clearly addressing LTC challenges as it is characterised by the following key-issues (please highlight): | **a. <u>multidisciplinary work is a value and principle</u>**<br>b. clients' needs are at the centre of all interventions<br>**c. <u>continuity of care and mechanisms to overcome barriers at the interfaces between social and health care are addressed</u>**<br>d. it is supported by legislation which explicitly addresses the coordination/integration between health and social care<br>e. incentives to improve cooperation between health and social care facilities or services (e.g. financial, contractual advantages) are in place<br>f. relevant information is efficiently transferred between services or agencies, e.g. by means of a joint care plan based on a dialogue with users/patients and their informal network<br>g. equal access (considering culture, gender and class) is guaranteed to all citizens<br>**h. <u>individual care needs are assessed by a multidisciplinary team (with multidisciplinary methods)</u>**<br>i. individual capacities of users/patients are enabled and strengthened<br>**j. <u>leadership and management capacities are enhanced through appropriate training</u>**<br>k. quality assurance is guaranteed across health and social care services and/or facilities |

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| | l. agreements between services and/or organisations are based on contracts<br>m. IT and communication technology are used to make administration more efficient<br>**n. <u>IT and communication technology are used to facilitate the service (e-health, e-care, ambient assisted living)</u>**<br>o. conditions for the involvement and participation of users/patients and carers are ensured (e.g. shared decision-making)<br>p. multi-disciplinary teams are established, supported and continuously trained<br>q. an integrated access point (e.g. concerning referral, financial issues, payment regulation, one-stop-shops) is available<br>r. integrated discharge and follow-up planning is fostered (mainly for residential and/or hospital-based facilities)<br>**s. <u>case management is carried out by trained and specialised staff with relevant job-profiles</u>**<br>t. funding is ensured by defined budgets<br>u. involved staff is participating regularly in advanced and further training<br>v. evaluation studies concerning structures, processes and outcomes are carried out and available<br>w. outcome indicators are used to measure and further develop the initiative.<br>**x. <u>quality management serves to implement continuous improvements</u>**<br>y. the initiative is controlled for costs and cost-advantages |
| 5. Status of the initiative | a. National or regional project (terminated)<br>b. European/international project (terminated)<br>c. **<u>National or regional project (ongoing)</u>**<br>d. European/international project (ongoing)<br>e. Implemented practice (at least in restricted areas)<br>f. Widely spread practice/rolled out |
| 6. Type of the initiative | a. New product<br>b. **<u>New service</u>**<br>c. New platform (new legal framework and platform)<br>d. **<u>New organisational form</u>**<br>e. **<u>New process</u>**<br>f. **<u>New market</u>**<br>g. **<u>New business model</u>** |

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| 7. Rationale and objectives: *Why was the initiative implemented? What social needs does it satisfy? Which societal challenges were addressed (context conditions)? For which target groups? With which objectives?* | *Why was the initiative implemented?*<br><br>The epidemic of Alzheimer's Disease represents a critical public health issue in many developed Countries. As AD causes concomitant and progressive cognitive and functional decline, it has a significant impact on care costs and is the major cause of nursing home admission. In 2010, there were 35.6 million people with dementia worldwide, a number which is estimated to increase to up to 65.7 million by 2030 and 115.4 million by 2050. In Italy alone, it was estimated that approximately 250,000 people were suffering from Alzheimer's Disease (AD) and similar forms of dementias in 2005, a number which is likely to be underestimated as AD and various forms of age-related cognitive deterioration are complex to detect and diagnose. Although family caregivers provide the bulk of informal care, thus relieving the formal care system of having to supply a large amount of assistance, informal caregivers are often referred to as the "hidden second patients." Indeed, AD severely affects patients' families, on whom the main burden of care falls, putting caregivers at high risk of stress, anxiety, mortality and lower quality of life. Consequently, patients living with distressed caregivers are at higher risk of behavioural disturbances, agitation, use of psychotic drugs and institutionalization.<br><br>*What social needs does it satisfy? What societal challenges have been addressed (context conditions)?*<br><br>The project addresses the social needs of family carers while they deliver assistance. Family carers are a fundamental aspect of the familistic Italian LTC system as public support for care for older persons has been marginal compared to other EU countries. In Italy, the majority of publicly supported services for Alzheimer's patients is provided by day care centres a few hours per day during weekdays and by Alzheimer Evaluation Units (AEUs), which periodically evaluate AD sufferers and only prescribe medication belonging to a few specialized categories. The majority of the caregiving is carried out by families, usually older wives and daughters, with the help of foreign female private care workers, if the family can afford to pay.<br><br>The intervention is expected to provide sound evidence for the effectiveness and cost of different programs to support AD patients and their caregivers living in the community. The intervention also aims at decreasing caregiver and patient distress and avoidable use of care resources (hospital and residential care and prescription drugs).<br><br>If the social and health-related interventions being carried out as part of the clinical study on patients with Alzheimer's disease and their families in five districts of the Marche Region are successful (the evaluation will use a rigorous scientific design), the intention is to extend these solutions to every family with an AD sufferer in the same region.<br><br>*For which target groups? With what objectives?*<br><br>Older people (mean age 81.7 years) with moderate stage Alzheimer's disease, living in the community and their family caregivers. The primary caregivers are usually spouses of the AD patients (30%) or their children |

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| | (55%), females (71.5%) with a low educational level (30.1%). Caregivers often suffer from other diseases themselves (1.1 diseases per caregiver, on average). This group represents a primary target for preventive measures, as the people in it are exposed to adverse events that often can be averted by helping them avoid social isolation and providing them with guidance and light support.<br><br>The project strives to decrease the stress and distress of family caregivers to allow older Alzheimer's sufferers to live at home for as long as possible. By supporting the caregivers, the goal is to ultimately improve quality of life and foster healthy and active ageing. |
| 8. Description: *What? How was change made possible? Who is involved? How many users are served per year? What is the role of users?* | This is the first study of its kind in Italy as it targets a population of users (patients with moderate Alzheimer's disease and their caregivers) that are often neglected by the health and social care systems. Lack of support usually leads to a deterioration of their conditions and inappropriate use of prescription drugs, hospitals and residential care. The main objectives of the UP-TECH project are thus: 1) to reduce the care burden on family caregivers of AD patients; and 2) to keep AD patients at home. This will be achieved with the use of case-management strategies, new technologies in the home of patients, preventive home visits by trained nurses and integration of existing services. The case-management intervention is provided by an ad-hoc trained (and hired) case manager/social worker, providing support consisting of at least 3 sessions of individual counselling; monthly follow-up phone calls; stress management training; and information about services and benefits offered by the Italian social welfare system and the local volunteer organizations. The technological device intervention involves the testing of a set of devices including luminous paths, home-leaving sensors, sensors to detect falls at night, gas and water leak sensors, and automatic lights. These devices are assembled by an external contractor and linked to a single-board microcontroller which transmits alarm signals to the caregivers when needed, thus functioning as a second generation telecare system. In addition, all participants receive three home visits by a specially trained nurse. Home visits take place at baseline and likewise occur at month-6 and -12. The visits are aimed at collecting exposure and outcome data, but also at providing a brief counselling/training of the caregiver regarding practical aspects of patient assistance, such as daily management of drug treatment, ergonomics of the home environment, stress management and care burden.<br><br>In addition, the plan is to restructure the whole process of dementia care at the regional level with the contribution of a collaborative working group composed of over 120 professionals, established by the project through the implementation of a web-based application. This ICT tool will support the overall governance of this sector and the evaluation of different pharmaceutical approaches to AD treatment.<br><br>*How was change made possible? Who is involved?*<br><br>A multi-component strategy has been implemented in order to increase the participation of stakeholders. The engagement of service staff |

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| | (neurologists, geriatricians, other physicians, nurses and social workers) was stimulated by raising the public visibility of the project through 1) the establishment of a Project Steering Committee, including members from all institutions involved; 2) a press conference, attended by local politicians and regional experts; 3) in loco meetings with professionals working in the five districts, including GPs and other Municipal staff; 4) the realization of advertising materials for mass distribution, such as a brochure explaining the project in plain terms. These strategies helped to build the consensus among service staff and other stakeholders and fostered their collaboration in the definition of problems and solutions. Local volunteering associations have been involved as well through ad-hoc calls for proposals, and the dissemination of information regarding the project in order to foster the participation of those patients receiving the service. The caregivers and the AD patient themselves have helped to define the primary challenge and the intervention strategies by consenting to participate in the study, thus providing data and helping to determine the efficacy of the solutions.<br><br>*How many people are served each year?*<br><br>Presently, 290 families per year.<br><br>*What is the role of the users?*<br><br>Patients and their families play a central role. Their involvement and collaboration with the project staff ensures the success of the interventions. |
| 9. Impact: *Have objectives been realised? How was it measured, shown, evaluated? What are the demonstrated or potential impacts on users, informal carers, staff, inter-organisational collaboration, costs? What is the systemic impact (extent to which the initiative changes the way that LTC is provided across systems or services)? Has the example proven to be sustainable, or mainstreamed? Has the example been implemented elsewhere?* | *Have objectives been realised? How has this been measured, displayed, evaluated?*<br><br>The objectives were achieved. The impact will be empirically evaluated by way of a third questionnaire administered at the end of August/beginning of September, 2014. In order to examine the effect of the case management on the caregiver-AD patient dyad, the caregiving burden, the anxiety and the depression and the quality of life of the caregiver will be measured using validated assessment instruments, as will the healthcare resource consumption of the dyads.<br><br>*What are the demonstrated or potential impacts on users, informal carers, staff, inter-organizational collaboration, costs?*<br><br>Since the beginning of the intervention, the 438 families have received regular visits and follow-ups by staff involved in the project (nurses, social workers, etc).<br><br>The project has also enabled the creation of a public partnership network that includes:<br><br>- The Government of the Marche Region supports the initiative financially and provides a strong endorsement of the project to restructure the provision of care services.<br><br>- The Health Authority of the Marche Region is the organization directly managing the health care services in the region. Its professionals are participating in the project by directly providing services to AD patients and their caregivers. |

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| | - The municipalities of Pesaro, Ancona, Macerata, Fermo and San Benedetto del Tronto are responsible for the provision of social services to Italian citizens.<br>- The Regional Centre of Volunteering (an NGO) is coordinating and providing technical support to the volunteer associations, which are directly engaged in the project and provide help to the families of patients with Alzheimer's disease.<br><br>For the implementation of the program €1,080,000 has been invested over four years (2011-2014).<br><br>*What is the systemic impact (the extent to which the initiative will change the way in which LTC is provided for all systems or services)?*<br><br>At a macro level, the project promotes the innovation of care services. For instance, the use of an ICT-based tool to record and store patient data is now allowing the creation of a regional register of AD patients. This register will have a strong impact on the health and social care systems, as it will be possible to: a) know how many patients are affected by this disease and to monitor their condition; b) monitor and evaluate the different therapeutic approaches in different regional areas and control the prescription drug expenditure; c) integrate the health and social care services.<br><br>At a micro level, the initiative implemented a preventive approach to the problem of AD and care burden, and through low cost social interventions, it prevented avoidable waste of health care resources. During the home visits for instance, case managers discovered that many caregivers did not even know about existing support services and procedures to apply for legal benefits. In addition, case managers and nurses trained the caregivers on how to manage the patient medications or to reschedule the daily routine (including simple home adaptations, diets, and other healthy behaviours), in order to improve the well-being of the patients and help prevent behavioural disturbances.<br><br>*Has the example proven to be sustainable, or mainstreamed?*<br><br>It is an example of integration of services and strategies.<br><br>Sustainability will depend on the choices made by the health and social service authorities of the Marche Region. |
| 10. SWOT Analysis | *Strengths: What solutions have been found to overcome the key challenges? What has facilitated problem-solving?*<br><br>- Promotion of integrated public partnerships and the new system of care.<br>- The active role of caregivers in the care system.<br>- Use of case manager and ITC instruments for case management.<br>- The evidence-based evaluation, monitoring, and training of health professionals involved in the project<br>- Use of a strategy of engagement of actors at multiple levels: at the macro level the network of stakeholders; at micro level the |

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| | construction of interdisciplinary teams and the involvement of users and their caregivers.<br><br>*Weaknesses:* What gaps/barriers have been witnessed/experienced?<br><br>- Internal cooperation among the interdisciplinary teams can be a challenge as it is difficult to work in an integrated way and to change the perspective by which each case is considered by the health professionals and carers.<br><br>- The low level of awareness of the available services in the area on the part of the health professionals involved.<br><br>*Opportunities: What are improvements that could be implemented? What additional activities are needed to achieve the objectives? How could the initiative be scaled up or rolled out?*<br><br>With an ambitious strategic perspective the activities of the intervention can be improved:<br><br>- Extending the solutions to all AD patients and their families in the Marche region (even after a possible end of the project, by using care services staff as case managers);<br><br>- Completing the case-management interventions, the nurse home visits, and the installation of new technologies and integrating UP-TECH activities with the volunteer associations through new calls for proposal targeting the voluntary sector;<br><br>- Mainstreaming the use of the web-based Alzheimer register;<br><br>- Evaluating effectiveness and cost-effectiveness of the interventions;<br><br>- Attract further investment in the area of Alzheimer's care, which is currently underfunded in Italy.<br><br>*Threats: What pressures does the initiative currently experience that could threaten its existence?*<br><br>- Lack of cooperation among the care staff requested to adapt their ways of working;<br><br>- Lack of cooperation between physicians from different specializations (GPs, neurologists, geriatricians, etc.) who would need to integrate their views in order to support coherently the patients and their families;<br><br>- Lack of coordination between voluntary sector and formal care sector;<br><br>- The Regional Government must continue to endorse the project, also by enacting regulations that recognize the new care pathways.<br><br>The main strategy planned to overcome these threats is to achieve the widest engagement of users and stakeholders by disseminating information on the successes of the initiative and the importance of investing in this area. |
| Website | http://up-tech.regione.marche.it/IlProgettoUpTech.aspx |

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| Sources | Chiatti, C., Masera, F., Rimland, J.M., Cherubini, A., Scarpino, O., Spazzafumo, L., Lattanzio, F. on behalf of the UP-TECH research group (2013) The UP-TECH project, an intervention to support caregivers of Alzheimer's disease patients in Italy: study protocol for a randomized controlled trial,*Trials*, 14:155. Doi:10.1186/1745-6215-14-155, http://www.trialsjournal.com/content/14/1/155 |

## XVI. Village Service—Austria

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| 1. Abstract | To facilitate voluntary work today, it is necessary to provide professional support and to set up transparent rules for gaps to be filled by volunteers. In Carinthia, the 'Association of Services for Households, Families and Companies' (Verein für Haushalts-, Familien- und Betriebsservice) has therefore established an initiative called 'Village Service' (Dorfservice) that serves as a regional development agency since 2007. As of 2014, the association has created support networks in13 Carinthian municipalities (District of Spittal) with 10 employees and more than 100 volunteers to strengthen social structures in the community. This entails the mobilisation of voluntary social work by installing a platform for social and health affairs in every single municipality. Apart from building new social networks in the district, the association also creates jobs for women returning from parental leave.<br><br>The professional support facilitates civil engagement by which gaps in social support can be closed, thus creating a lively process of social integration. The municipalities serve as important partners and as contact points for the users (www.dorfservice.at). In particular older people are making use of the services that consist in informal transport and visiting services, family help in case of emergencies, and information on health and social care services. Apart from organising services, the initiative's rationale consists primarily in regional development to promote solidarity in lively villages. 'Dorfservice' was one of the prize winners of the Austrian Award for Social Innovation 'SozialMarie' in 2012. |
| 2. Target group and number of population covered (region/s) | All citizens, in particular families with caring duties (children, frail older people) and older people in need of social care; volunteers.<br><br>By 2014, the service is active in 13 municipalities (covering a total of about 25,000 inhabitants) in the county of Spittal (Carinthia) with ten employees (women returning to work) who coordinate more than 100 volunteers who provide about 3,500 hours per year (e.g. about 50,000 km of transport services yearly; 250 interventions with simple maintenance tasks).<br><br>On average, 100-120 citizens per municipality are regular users of the service. |
| 3. Qualification as social innovation and/or social | **a. <u>It is oriented towards exceptional societal challenges/social issues</u>** |

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| innovation potential (please highlight): | **b. It suggests new solutions in the respective societal, cultural and economic context**<br>**c. It creates new patterns of social practices to overcome shortcomings of traditional arrangements**<br>d. It tends to overcome the traditional dichotomy between technological and social innovations<br>**e. It promotes the integration and/or collaboration/partnership of heterogeneous stakeholders that have hitherto not co-operated**<br>f. It includes reflective and multidisciplinary approaches towards the key goal of societal usefulness<br>**g. It creates structures and processes that are sustainable and realise new growth potentials in terms of regular employment**<br>h. It involves end-users as co-producers of services or products<br>i. It creates new roles and partnerships |
| 4. The initiative is clearly addressing LTC challenges as it is characterised by the following key-issues (please highlight): | a. multidisciplinary work is a value and principle<br>**b. clients' needs are at the centre of all interventions**<br>c. continuity of care and mechanisms to overcome barriers at the interfaces between social and health care are addressed<br>**d. continuity of care and mechanisms to overcome barriers at the interfaces between formal and informal care are addressed**<br>e. it is supported by legislation which explicitly addresses the coordination/integration between health and social care<br>f. incentives to improve cooperation between health and social care facilities or services (e.g. financial, contractual advantages) are in place<br>g. relevant information is efficiently transferred between services or agencies, e.g. by means of a joint care plan based on a dialogue with users/patients and their informal network<br>**h. equal access (considering culture, gender and class) is guaranteed to all citizens**<br>i. individual care needs are assessed by a multidisciplinary team (with multidisciplinary methods)<br>j. individual capacities of users/patients are enabled and strengthened<br>**k. leadership and management capacities are enhanced through appropriate training**<br>l. quality assurance is guaranteed across health and social care services and/or facilities<br>m. agreements between services and/or organisations are based on contracts<br>n. IT and communication technology are used to make administration |

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| | more efficient<br>o. IT and communication technology are used to facilitate the service (e-health, e-care, ambient assisted living)<br>**p. conditions for the involvement and participation of users/patients and carers are ensured (e.g. shared decision-making)**<br>q. multi-disciplinary teams are established, supported and continuously trained<br>**r. an integrated access point (e.g. concerning referral, financial issues, payment regulation, one-stop-shops) is available**<br>s. integrated discharge and follow-up planning is fostered (mainly for residential and/or hospital-based facilities)<br>t. case management is carried out by trained and specialised staff with relevant job-profiles<br>u. funding is ensured by defined budgets<br>**v. involved staff is participating regularly in advanced and further training**<br>w. evaluation studies concerning structures, processes and outcomes are carried out and available<br>x. outcome indicators are used to measure and further develop the initiative<br>y. quality management serves to implement continuous improvements<br>**z. the initiative is controlled for costs and cost-advantages** |
| 5. Status of the initiative | a. National or regional project (terminated)<br>b. European/international project (terminated)<br>c. National or regional project (ongoing)<br>d. European/international project (ongoing)<br>e. **Implemented practice (at least in restricted areas)**<br>f. Widely spread practice/rolled out |
| 6. Type of the initiative | a. New product<br>b. **New service**<br>c. New platform (new legal framework and platform)<br>d. New organisational form<br>e. New process<br>f. New market<br>g. New business model |
| 7. Rationale and objectives: *Why was the initiative implemented? What social needs does it satisfy? Which* | Modernisation processes and demographic developments have created particular challenges for rural areas, where traditional types of social support and family structures are much less available than traditional images of solidarity in rural environments would suggest. Traditional |

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| *societal challenges were addressed (context conditions)? For which target groups? With which objectives?* | economic activities in alpine valleys have disappeared, forcing workers to commute daily or even weekly to the larger cities. Furthermore, smaller families, increasing labour market participation of women and the lack of public transport make it difficult for the growing number of older people to organise their daily life in the community, in particular if they need care and assistance with activities of daily living. For instance, medical specialists may often be consulted only in towns at a distance of over hundred kilometres, but decent public transport is not always available.<br><br>On the backdrop of this situation a former teacher had the idea to bring together the mayors of four small municipalities and prepared an EU Leader project to establish the 'Village Service' that should serve as a platform to mitigate gaps in the regional support structures that had been identified during meetings with citizens and representatives of local associations and service providers. These events were organised in the participating and neighbouring municipalities asking citizens and representatives of existing organisations (churches, women's organisations etc.) for the needs of the village today. The key requests identified related to 'village development' in general, lack of infrastructure, access to health services, emergency situations in families, in particular as professional support that had been provided by so-called 'village helpers' during the 1960s and 70s. Furthermore, new types of voluntary work should be developed as a substitute to traditional forms of neighbourhood support that had withered away over the past decades. |
| 8. Description: *What? How was change made possible? Who is involved? How many users are served per year? What is the role of users?* | Based on a detailed analysis of existing gaps and citizens' proposals, an EU Leader project was established in four municipalities in 2007 with the following objectives:<br>- To install a platform for community development with professional guidance to provide information, to coordinate formal and informal resources in the community, and to facilitate voluntary work;<br>- To provide part-time employment for women returning from family leave or unemployment;<br>- To recruit and organise volunteers who provide support in daily living, e.g. gardening, shopping or transport of older people to reach the doctor, the pharmacy or the church, but also to support families in emergency situations;<br>- To provide training and counselling to volunteers to prepare them for visits and support of people with dementia, children and related challenges;<br>- To extend the service to surrounding municipalities within the district with adequate public relations and dissemination events.<br><br>With funding from several sources (municipalities, Employment Service, Federal Ministry for Social Affairs and Consumer Protection, EU Leader programme), the initiative started as a project in 2007 with a coordinator and six part-time employees who were trained to work in community development and networking as well as in recruitment, organisation and counselling of volunteers. All employees were women between 40 and 50 years of age, returning to the labour market, with different professional backgrounds. They were trained as 'Volunteer Tutors' in |

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| | courses with six modules each comprising one week of seminars. They are employed with a part-time contract (20 hours per week). Each employee covers two municipalities and thus dedicates about 10 hours per week to each municipality.<br><br>Initially the employed 'Volunteer Tutors' worked with about 40 volunteers that were organised to support users based on the following quality criteria:<br>- Volunteers dispose of a defined contact person;<br>- Their tasks and competences are explicitly described, on average, they should not offer more than 4 hours per week;<br>- They are offered opportunities to regularly exchange experiences and to receive training and counselling, if necessary (e.g. driving courses, but also how to deal with older people with dementia);<br>- They are paid general liability insurance and kilometre allowance for transport services.<br><br>Citizens are regularly informed and may contact 'Village Service' by phone or during regular consultation-hours in the individual municipal offices. All services are provided free of charge and consist in transport services (to visit for instance the GP or specialist doctors, pharmacy, public authorities), shopping, ordinary maintenance work, visiting etc., but also childcare and family help in emergency situations (this latter service is based on means-tested hourly charges between €9-€18). Furthermore, 'Village Service' also serves as a broker for formal home care services provided by various non-profit organisations, if necessary.<br><br>Starting with about 230 users during the first six months, the service continued to grow steadily as additional municipalities, employees and volunteers joined the initiative. By the end of the project phase (2009), the service covered eight municipalities. In spite of a lack of structural funding, 'Village Service' succeeded to continue its growth over the past few years. By 2014, the service is active in 13 municipalities (with a total of about 25,000 inhabitants), with ten employees who coordinate more than 100 volunteers. If a citizen calls a coordinator, local volunteers are contacted by phone or SMS and who confirms his/her availability first will be assigned the task.<br><br>The volunteers comprise all age groups (from 17 to 78), with the largest group representing 'young' pensioners, and 70% being female. Many of them are offering their skills as an opportunity to re-integrate into the community, as many of them returned to the villages after a working-life passed elsewhere. Continuous training is provided according to needs. Every six weeks there is a meeting to exchange experiences, and once per year a 'thanksgiving'-event is being organised.<br><br>A key-challenge in developing the initiative consisted in creating a regional network with formal care providers, to create an attitude of cooperation, rather than competition, and to facilitate mutual trust. Formal care providers initially feared to 'loose clients', so it was important to convince them that 'Village Service' provide residual social support only. Trust needed to be created also towards citizens and potential users as it is "not usual in our rural context to ask for help |

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| | without payment". Continual mediation, networking and information has therefore been necessary, but once the word of mouth had started to circulate, further expansion, including recruitment of new volunteers, could be achieved more easily. In fact, it is relatively straightforward to convince older people living on a minimum pension, who have to do an X-ray at the hospital, which is more than 100 km away, that it is more convenient to get a free ride with an accompanying volunteer, rather than paying 90 cents per kilometre, which would be charged if they use the ambulance for transport.<br><br>As of 2014, the 'Village Service' is funded by the regional government of Carinthia (about 50%), participating municipalities (about 25%) and sponsoring/donations (about 15%) as well as other sources (federal government, EU projects etc.), but funding is still dependent on yearly negotiations, in particular with the regional government. |
| 9. Impact: *Have objectives been realised? How was it measured, shown, evaluated?What are the demonstrated or potential impacts on users, informal carers, staff, inter-organisational collaboration, costs? What is the systemic impact (extent to which the initiative changes the way that LTC is provided across systems or services)? Has the example proven to be sustainable, or mainstreamed? Has the example been implemented elsewhere?* | The initiative has been evaluated in 2010/11 by an external researcher who became employed by the organisation after having finished the evaluation which, however, remained published. The study was based on document analysis, focus groups and individual interviews with promoters, employees, volunteers and users. The aim of the study was to investigate whether the original objectives had been reached, in particular with a view to the creation of 'social capital' in terms of value and resource orientation, participation and sustainability. It could be shown that most indicators had developed positively. Users experienced an apparent reduction of distress and retained that the service contributed significantly to help them stay put in the community. Also the volunteers experience a number of benefits through their activities, namely to 'give' time, but to get back many positive aspects: feedback, new types of experiences, a sense of belonging, integration into the community, cooperation across municipalities, new social relations, satisfaction with training and accomplishments, and professional supervision.<br><br>Also the mayors and municipal counsellors are ever more convinced of the initiative, in particular with respect to common developments and the cooperation across the boundaries of (small) municipalities so that further extension could be guaranteed. 'Village Service' is considered to be a social investment that indeed saves consistent social expenditures in other areas. For instance, municipalities save contributions for citizens who continue to live at home, rather than moving into residential care.<br><br>'Village Service' won several awards, e.g. an award as 'senior-friendly community' and for 'intergenerational living' as well as the 'Sozialmarie', the Austrian award for social innovation (http://sozialmarie.org/?language=en), in 2012.<br><br>The initiative has been contacted by a number of other Austrian municipalities and regions, in one region (Burgenland) a similar service has already been established. Further development aims at additional intergenerational activities in rural Carinthia, e.g. awareness-raising in kindergartens, schools and associations ('future-conferences') through a new EU LEADER project. |

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| | The key success-factors of the initiative are, according to the current Manager of the initiative, "participation, i.e. to provide, extend and support space and time for participation, and the creation of social values". |
| 10. SWOT Analysis | *Strengths: What solutions were found to overcome key-challenges? What facilitated problem-solving?*<br>- Bottom-up initiative coordinated with local and regional public authorities<br>- Professionally guided volunteering (yearly contracts, peer meetings, counselling, further training)<br>- Networking with existing resources (associations, social and health services, local businesses)<br>- High satisfaction of users (feedback) and volunteers (low volunteer turnover rate)<br>- Clear definition and delineation of volunteering (not more than 4 hours per week per volunteer, no 'professional care')<br>- Creation of social values, new social ties and local relations based on solidarity<br><br>*Weaknesses: Which gaps/obstacles have been witnessed/experienced?*<br>- No structural funding<br>- On-going debates about organisational structures, legal construction (association, cooperative or non-profit Ltd.?) and administration (centralized or decentralized?)<br><br>*Opportunities: Which improvements could be implemented? What additional activities will be needed to deliver on targets? How could the initiative be scaled up or rolled out?*<br>- The service is transferable to other rural areas (e.g. as already achieved in the region of Burgenland), but also in urban contexts it could be adopted, even if services might have to be adapted, e.g. concerning social isolation and poverty<br>- Structural funding for a period of five years is being envisaged and should be guaranteed for new start-ups<br><br>*Threats: What pressures does the initiative currently experience that could threaten its existence?*<br>- Funding |
| Website | http://www.dorfservice.at/<br><br>http://sozialmarie.org/?language=en |
| Sources | Ebenberger, A. (2012) *Dorfservice: a new structure of social services in the village*, Presentation at the workshop 'Innovative policies to support healthy, active and dignified aging', 5-7 November 2012, Feldkirchen an der Donau (Austria).<br>Expert interviews were conducted with Alice Ebenberger, CEO of 'Village Service,' and Lydia Engel who carried out the external evaluation study in 2010/11 and is now responsible for the EU LEADER project 'Intergenerational work in the Nockregion' on behalf of 'Village Service'. |

## XVII. VIRTU – Virtual Elderly Care Services on the Baltic Islands—Estonia and Finland

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| 1. Abstract | The archipelago areas of Finland, Åland and Estonia are facing many social, political and economic challenges. The social and health care sector is strongly influenced by demographic changes and is struggling with the challenge of ensuring equal services for rural and urban areas within a limited budget. The ageing population, long distances between urbanized areas and the insufficient number of qualified carers are common challenges in the area.<br><br>The VIRTU project sought to improve the standard of living of older people by supporting a healthy, safe and socially rich life at home instead of institutionalisation. Using virtual technology, VIRTU created a new service model which benefited senior citizens, their relatives, the municipalities and health and social care professionals in the archipelago.<br><br>The project provided virtual services to older people in close cooperation with the participating municipalities. By evaluating the content of the service model and the usability and adaptability of the virtual services as well as the experiences of seniors and employees, the project also aimed to determine the cost-effectiveness and productivity of the services.<br><br>The project was funded by the EU Central Baltic INTERREG IVA 2007-2013 programme. Beginning in May, 2010 and running through April, 2013 the total budget for the project was € 2,185,369, of which € 1,661,085 came from the EU's Central Baltic program. The main partners in the development work were the two Universities of Applied Sciences in Turku (TUAS and Novia), in Vantaa (Laurea) and in Åland. The Saaremaa Development Centre was the responsible partner in Estonia. |
| 2. Target group and number of population covered (region/s) | 98 older individuals from 16 municipalities participated in the VIRTU project (48 during the whole project period); the average age of the participants was 79. The population of these 16 municipalities varied from Eckerö's 926 residents to Naantali's 18,544. On average the share of population over the age of 65 is 17.5% in Finland and 17% in Estonia. |
| 3. Qualification as social innovation and/or social innovation potential (please highlight): | **a. It is oriented towards exceptional societal challenges/social issues**<br><br>**b. It suggests new solutions in the respective societal, cultural and economic context**<br><br>**c. It creates new patterns of social practices to overcome shortcomings of traditional arrangements**<br><br>**d. It tends to overcome the traditional dichotomy between technological and social innovations**<br><br>e. **It promotes the integration and/or collaboration/partnership of heterogeneous stakeholders that have hitherto not co-operated** [novel interactions between the public sector, third sector, social enterprises]<br><br>f. It includes reflective and multidisciplinary approaches towards the key goal of societal usefulness<br><br>g. It creates structures and processes that are sustainable and realise |

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| | new growth potentials in terms of regular employment<br>h. It involves end-users as co-producers of services or products<br>**i. <u>It creates new roles and partnerships</u>** |
| 4. The initiative is clearly addressing LTC challenges as it is characterised by the following key-issues (please highlight): | a. multidisciplinary work is a value and principle<br>**b. <u>clients' needs are at the centre of all interventions</u>**<br>c. continuity of care and mechanisms to overcome barriers at the interfaces between social and health care are addressed<br>d. continuity of care and mechanisms to overcome barriers at the interfaces between formal and informal care are addressed<br>e. it is supported by legislation which explicitly addresses the coordination/integration between health and social care<br>f. incentives to improve cooperation between health and social care facilities or services (e.g. financial, contractual advantages) are in place<br>**g. <u>relevant information is efficiently transferred between services or agencies, e.g. by means of a joint care plan based on a dialogue with users/patients and their informal network</u>**<br>h. equal access (considering culture, gender and class) is guaranteed to all citizens<br>i. individual care needs are assessed by a multidisciplinary team (with multidisciplinary methods)<br>j. individual capacities of users/patients are enabled and strengthened<br>k. leadership and management capacities are enhanced through appropriate training<br>l. quality assurance is guaranteed across health and social care services and/or facilities<br>m. agreements between services and/or organisations are based on contracts<br>n. IT and communication technology are used to make administration more efficient<br>**o. <u>IT and communication technology are used to facilitate the service (e-health, e-care, ambient assisted living)</u>**<br>p. conditions for the involvement and participation of users/patients and carers are ensured (e.g. shared decision-making)<br>q. multi-disciplinary teams are established, supported and continuously trained<br>r. an integrated access point (e.g. concerning referral, financial issues, payment regulation, one-stop-shops) is available<br>s. integrated discharge and follow-up planning is fostered (mainly for residential and/or hospital-based facilities) |

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| | **t. <u>case management is carried out by trained and specialised staff with relevant job-profiles</u>**<br>**u. <u>funding is ensured by defined budgets</u>**<br>v. involved staff is participating regularly in advanced and further training<br>w. evaluation studies concerning structures, processes and outcomes are carried out and available<br>x. outcome indicators are used to measure and further develop the initiative<br>y. quality management serves to implement continuous improvements<br>z. the initiative is controlled for costs and cost-advantages |
| 5. Status of the initiative | a. **<u>pilot project (terminated)</u>**<br>b. pilot project (ongoing)<br>c. project (terminated)<br>d. national/regional project (ongoing)<br>e. **<u>Implemented practice (currently in very limited scale in Estonia; however, restart of the service is currently planned in II half of 2014 in Estonia)</u>**<br>f. widely spread practice/rolled out |
| 6. Type of the initiative | a. New product<br>b. **<u>New service</u>**<br>c. New platform (new legal framework and platform)<br>d. New organisational form<br>e. New process<br>f. New market<br>g. **<u>New business model</u>** |
| 7. Rationale and objectives: *Why was the initiative implemented? What social needs does it satisfy? Which societal challenges were addressed (context conditions)? For which target groups? With which objectives?* | The aim at the individual level was to help older people in the archipelago area remain at home, to support their social interaction, improve their quality of life and increase their safety. The core purpose was to create and maintain social relations and to prevent loneliness. Loneliness is considered a great risk to an individual's ability to function and independence at home. The VIRTU project developed preventive working methods and practices.<br>The larger-scale aim was to create a functional social and health care service model for the region with the aid of virtual technology. The purpose of the service model was to support and complement existing services, not to replace them. In addition to older people, the service model also benefited municipalities and their social and health care professionals by utilising cross-sector collaboration. |

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| | Another key objective was to increase the service availability and safety of older people. Preventive services promote well-being and feelings of self-fulfilment as well as a desire to learn. The virtual connection to services can be considered a remote access service but it also allows many conventional services to be accessed.<br><br>The third key objective was the networking of different actors in a way that enables concrete benefits for the technology users. This required the collection of empirical data and a dialogue between various groups of professionals – including professionals from different fields. The use of technology required adequate employee orientation. Municipality employees participated in the project planning meeting and workshops. |
| 8. Description: *What? How? Who is involved? How many users are served per year? What is the role of users?* | An interactive VIRTU channel was developed together with the universities of applied sciences and the municipalities, and input from older people was also incorporated into the design of the model. The audio-video transmission service enabled users to interact via video and/or audio transmissions simultaneously with two or more people. Users could participate in discussions on various topics as well as participate in exercise and sing-along sessions. The partners in the VIRTU project produced various services and broadcasts for the users of the VIRTU channel based on participants' wishes (e.g. in Estonia consultations with a pastor and a representative of an electrical company were mediated). In collaboration with local businesses and organizations, concerts and other cultural events were broadcast on the VIRTU Channel. Again, these broadcasts were developed together with users based on their expressed interests. User participation was voluntary.<br><br>Aside from scheduled broadcasts, the VIRTU channel provided the opportunity to keep in touch with other users, including peers and care staff.<br><br>The VIRTU device is a touch-screen computer installed in the recipients' home. The software runs on the same principle as video conferencing systems used in the business world. This means that one can be in visual and audio contact with multiple persons at the same time. The image of the person speaking gains prominence on the screen while the other participants' images are smaller. Although more can communicate on the channel, the maximum number of video images shown on the screen simultaneously is 9.<br><br>The VIRTU device doesn't require anything from the client other than a data connection (internet; usually through a 3G internet stick) and an appropriate location for the device. The device is the size of a computer screen.<br><br>In Estonia, 40 people, 8 institutions such as day care centres and residential facilities, and 3 social workers had the device installed – altogether 51 devices were installed.<br><br>The purpose of the service was not to replace human contact with a virtual device, but rather to support and complement the existing services and to provide additional services to those who, for many different reasons, are unable to use the traditional services. The VIRTU |

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| | channel increases the opportunities for social interaction for elderly. In addition to the homes of older people, a VIRTU device was installed in the offices of the social care institution of the town of Kuressaare (*Kuressaare Hoolekanne)* which offers assisted living services for patients with mental illnesses.<br><br>The VIRTU channel was also used to support patient adherence to treatment plans. Treatment guidelines often require that medication is taken at fixed times yet many patients—particularly older patients—have difficulties remembering to do so with regularity. They not only need reminders, but also supervision after the medication has been taken. This was made possible remotely by the VIRTU channel. At the designated time, a social worker would call a patient via VIRTU to remind him/her to take their medication. The device is placed into patients' rooms so that the built-in camera captures the patient ingesting the medication. In addition, a patient's personal caregiver can be in contact with the patient in the evenings from his/her personal computer at home using VIRTU PC-client interface.<br><br>The VIRTU device relieves the burden on caregivers who take care of patients with mental illnesses. Depending on the case, care may be required several days a week or every day. Some of the visits may be done via the VIRTU device since visual contact gives more information than traditional phone call check-ups. |
| 9. Impact: *Have objectives been realised? How was it measured, shown, evaluated?What are the demonstrated or potential impacts on users, informal carers, staff, inter-organisational collaboration, costs? What is the systemic impact (extent to which the initiative changes the way that LTC is provided across systems or services)? Has the example proved to be sustainable, or mainstreamed? Has the example been implemented elsewhere?* | Due to the fact that there have not been many users of the VIRTU project, cost-effectiveness analysis is difficult to conduct. Replacing the traditional home visit with interactive distance visits could save on the travel costs and working hours of caretakers. The cost-effectiveness analysis is conducted using Naantali cases only. The benefit to older people was measured by assessing their quality of life, social contracts and the ability to live at home longer. The following quantitative variables were measured:<br>- service financial inputs compared to outputs,<br>- working hours saved,<br>- days saved in care,<br>- other economic gains due to technology.<br><br>The following qualitative variables were measured:<br>- quality of the internal process during the service implementation,<br>- service impact on employees' working conditions,<br>- service impact on clients' quality of life,<br>- social relations and perceptible quality of life,<br>- service impact on the clients' family.<br><br>It emerged from the analysis that when applied correctly and integrated with traditional services, using the interactive, virtual distance service in care for older people increases effectiveness on multiple levels. On the other hand, measuring cost-effectiveness is a very complex process and the appropriate variables have still not been found. The authors of the cost-effectiveness analysis state that VIRTU is a good preventive method in LTC. However, it is very important to determine the most important |

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| | cost-effectiveness factors in order to implement such a service on a larger scale in other local communities. The service has not yet been implemented elsewhere.<br><br>According to the project website several local municipalities in Saaremaa continued providing the service after the programme period ended, using the same devices but replacing the software (Helpponappi) (e.g. http://www.virtuproject.fi/?p=1972). However, only the video conferencing service has remained functional as live-broadcasting became unusable with the different software. In May 2014, a collaborative project by Saaremaa Arenduskeskus and telecom company Elion was in the process of reviving more complex service provision identical to the VIRTU project, allowing clients to use different hardware with greater flexibility (including touch screens, different operational systems of smart phones and tablets and also PC's). It is hoped that the new service will be piloted in the second half of 2014. |
| 10. SWOT Analysis | *Strengths: What solutions were found to overcome key-challenges?*<br><br>- Public-private partnership helped to overcome the restrictions caused by local government barriers.<br><br>- ICT was adjusted to meet the needs and skills (or lack of skills) of the target group.<br><br>*Weaknesses: Which gaps have been witnessed/experienced?*<br><br>- The continuity of the complex service was highly dependent on available financing – once discontinued, services gradually diminished.<br><br>- Legislation does not support a smooth transition from EU project to an unsupported public-private partnership initiative as the taking over of assets (e.g. software) by a private organisation may be considered to state aid.<br><br>*Opportunities: Which improvements could be implemented? What additional activities will be needed to deliver on targets? How could the initiative be scaled up or rolled out?*<br><br>- If successfully implemented, these services could easily be scaled up across municipality (or) county borders by way of private partnerships.<br><br>- Using ICT in providing services can serve to facilitate expansion of services and test new services on a small scale.<br><br>*Threats: What pressures does the initiative currently experience that could threaten its existence?*<br><br>- It is difficult to gather evidence (economic value) to present to those responsible for funding in order to support the extended provision of the service model. |
| Website | http://www.virtuproject.fi/ |
| Sources | Karppi, M., Tuominen, H., Eskelinen, A., Santamäki Fischer, R.&Rasu, A (eds.) (2013) Active Ageing Online: Interactive Distance Services for the Elderly on Baltic |

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| | Islands – VIRTU Project 2010–2013. Reports from Turku University of Applied Sciences 155. 316 p., 2013, ISBN: 9789522163578 http://julkaisut.turkuamk.fi/isbn9789522163578.pdf<br>A phone interview was conducted with Ms. Triin Arva, local government consultant at the Saaremaa Development Centre. |

## XVIII. WebNurse, online training for informal carers—Hungary

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| 1. Abstract | While the Social Welfare Act No. III of 1993 (and its amendments) focused on formal eldercare and made basic social meals, home help, home help with alarm bell system basic mandatory tasks of local governments, the New Constitution of 2012 shifted care responsibilities to families. Despite the increase in the proportions of older people in need of long-term care, financing of home help was cut by one third in 2013. 20-30% of the local governments have been for many years unable to provide the mandatory basic services. Short-term home nursing (14 days) is financed by the Health Insurance Fund but there is no long-term home nursing service. Families do not have the nursing/care skills and knowledge necessary to carry out care/nursing tasks. Responding to these challenges, the Hungarian Maltese Charity Service (MMSZ) created a web-based programme titled WebNurse (WebNővér) in the framework of the HELPS project of the Central European Research Programme of the European Union. WebNurse provides information and practical advice in six areas: nursing tasks, available services, mental support, nutrition advice, general care issues and legal advice. Access is free to ensure its rapid spread. WebNurse was launched officially at the beginning of 2014. The large numbers of daily visitors and returning visitors points to the success and importance of the initiative. |
| 2. Target group and number of population covered (region/s) | Family carers, informal carers as they generally do not have any care or nursing skills.<br><br>At the beginning of 2014, WebNurse was officially launched at a press conference. Hungarian-speakers everywhere can access and use the site over the internet (www.webnover.hu).<br><br>Monitoring of the site between 17th February and 23rd March, 2014 showed an average of 300 visitors per day, 15% of them returning visitors. Monitoring of site visits was not broken down by regions. |
| 3. Qualification as social innovation and/or social innovation potential (please highlight): | **a. <u>It is oriented towards exceptional societal challenges/social issues</u>**<br>**b. <u>It suggests new solutions in the respective societal, cultural and economic context</u>**<br>**c. <u>It creates new patterns of social practices to overcome shortcomings of traditional arrangements</u>**<br>**d. <u>It tends to overcome the traditional dichotomy between technological and social innovations</u>**<br>e. It promotes the integration and/or collaboration/partnership of |

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| | heterogeneous stakeholders that have hitherto not co-operated<br>f. It includes reflective and multidisciplinary approaches towards the key goal of societal usefulness<br>g. It creates structures and processes that are sustainable and realise new growth potentials in terms of regular employment<br>h. It involves end-users as co-producers of services or products<br>i. It creates new roles and partnerships |
| 4. The initiative is clearly addressing LTC challenges as it is characterised by the following key-issues (please highlight): | **a. multidisciplinary work is a value and principle**<br>**b. clients' needs are at the centre of all interventions**<br>**c. continuity of care and mechanisms to overcome barriers at the interfaces between social and health care are addressed**<br>**d. continuity of care and mechanisms to overcome barriers at the interfaces between formal and informal care are addressed**<br>e. it is supported by legislation which explicitly addresses the coordination/integration between health and social care<br>f. incentives to improve cooperation between health and social care facilities or services (e.g. financial, contractual advantages) are in place<br>**g. relevant information is efficiently transferred between services or agencies, e.g. by means of a joint care plan based on a dialogue with users/patients and their informal network**<br>h. equal access (considering culture, gender and class) is guaranteed to all citizens<br>i. individual care needs are assessed by a multidisciplinary team (with multidisciplinary methods)<br>**j. individual capacities of users/patients are enabled and strengthened**<br>k. leadership and management capacities are enhanced through appropriate training<br>l. quality assurance is guaranteed across health and social care services and/or facilities<br>m. agreements between services and/or organisations are based on contracts<br>n. IT and communication technology are used to make administration more efficient<br>**o. IT and communication technology are used to facilitate the service (e-health, e-care, ambient assisted living)**<br>**p. conditions for the involvement and participation of users/patients and carers are ensured (e.g. shared decision-making)**<br>q. multi-disciplinary teams are established, supported and continuously |

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| | trained<br>r. an integrated access point (eg concerning referral, financial issues, payment regulation, one-stop-shops) is available<br>s. integrated discharge and follow-up planning is fostered (mainly for residential and/or hospital-based facilities)<br>t. case management is carried out by trained and specialised staff with relevant job-profiles<br>u. funding is ensured by defined budgets<br>v. involved staff is participating regularly in advanced and further training<br>w. evaluation studies concerning structures, processes and outcomes are carried out and available<br>x. outcome indicators are used to measure and further develop the initiative<br>y. quality management serves to implement continuous improvements<br>z. the initiative is controlled for costs and cost-advantages |
| 5. Status of the initiative | a. National or regional project (terminated)<br>b. European/international project (terminated)<br>c. **National or regional project (ongoing)**<br>d. European/international project (ongoing)<br>e. **Implemented practice (at least in restricted areas)**<br>f. Widely spread practice/rolled out |
| 6. Type of the initiative | a. **New product**<br>b. New service<br>c. **New platform**<br>d. New organisational form<br>e. **New process**<br>f. New market<br>g. New business model |
| 7. Rationale and objectives: *Why was the initiative implemented? What social needs does it satisfy? Which societal challenges were addressed (context conditions)? For which target groups? With which objectives?* | The Social Welfare Act No. III of 1993 focused on formal eldercare and made basic social meals, home help and—since 2004—home help with an alarm system basic mandatory services of local governments. Despite this care policy, due to insufficient financing, 20-30% of local governments have been unable to provide the mandatory basic services for many years. Although the eldercare policy emphasised the provision of long-term care at home, and though the legislation governing eligibility for residential care changed in 2009 to include only those with more than 4 hours/day of nursing needs, development of the home help |

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| | service has stalled. The new constitution of 2012 clearly shifted care responsibilities to families, declaring that care for older persons is the responsibility of family members. Despite the increase in the proportions of older people in need of long-term care, financing of home help was cut by one third in 2013 while the number of recipients of care per carer rose from 4.3 in 2000 to 7.8 in 2012 and the formal system was incapable of handling the care tasks imposed on it.<br><br>Despite the responsibility laid at their door, family and informal carers generally do not have the knowledge and nursing skills needed to provide long-term care. Caring often results in mental, physical and financial problems for the carer. Their quality of life often deteriorates due to their lack of leisure time and shrinking social connections.<br><br>To answer these challenges a website with free access was developed by the Hungarian Maltese Charity Service (within the framework of the HELPS project of the Central European Research Programme of the European Union) to provide a complex solution for the acquisition of nursing skills.<br><br>The website is comprised of six areas: 1) Nursing (short explanatory videos, how to perform different nursing tasks), 2) map of social and health care services and service providers, their contact details and information on how to access the services, 3) mental support, 4) nutrition advice, 5) general care issues, legal advice. Advice is given through email communication with the option of allowing it to appear anonymously among the frequently-asked questions. It offers short explanatory videos on the various aspects of care (e.g. how to bathe a patient in bed, how to turn a patient, how to treat bedsores, etc.). It also gives information on how to obtain the various aids needed for the nursing task and on the services available at local level, legal advice and mental help, as well as nutrition advice from professionals. |
| 8. Description: *What? How was change made possible? Who is involved? How many users are served per year? What is the role of users?* | Within the framework of the HELPS (2011-2014) project, the website elaborated by the MMSZ has been continuously evaluated by experts from different fields as well as formal and informal carers. By the end of 2013 testing of the website was completed and it is currently being continually updated and upgraded. The problems, shortcomings and development opportunities were discussed in a series of workshops (e.g. new videos, correction of the contents).<br><br>In 2014, after WebNurse was launched, monitoring of the site between 17th February and 23rd March found an average of 300 visitors a day, 15% of them returning.<br><br>Breakdown of the popularity of the different areas visited (share of all visits): nursing instruction films 30%; map of services of social and health services 22%, mental support 16%; legal advice 12 %; general care advice 10%; nutrition advice 10%. The number of visitors viewing video clips has recently increased to 41%. |
| 9. Impact: *Have objectives been* | Several months were spent testing the page, mainly with the |

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| *realised? How was it measured, shown, evaluated? What are the demonstrated or potential impacts on users, informal carers, staff, inter-organisational collaboration, costs? What is the systemic impact (extent to which the initiative changes the way that LTC is provided across systems or services)? Has the example proven to be sustainable, or mainstreamed? Has the example been implemented elsewhere?* | participation of social institutions and experts working in the areas of social and health care. In the trial period between September 2013 and January 2014 the accessibility of the instruction films was tested: in light of the feedback, the resolution was changed to give optimal performance and more than 1,200 corrections, modifications and additions were made to the data of the services map.<br><br>The amount of direct feedback received in the short time since the WebNurse was made public is not sufficient to give a reliable assessment of its impact (25 positive feedbacks in the form of letters, a further 7 via the website). However, visitors during this time have not reported any problem with use of the site. They consider the video films and explanatory texts to be extremely helpful. There have been requests for help only in use of the service map and it is being continuously modified, updated and developed.<br><br>WebNurse is available to everyone with internet access. Sustainability requires continuous maintenance of the website (software development, payment of those involved) and professional staff (already involved) will be paid by the Hungarian Maltese Charity Service in the future. |
| 10. SWOT Analysis | *Strengths: What solutions were found to overcome key-challenges? What facilitated problem-solving?*<br><br>- The Hungarian Maltese Charity Service elaborated an easily transferable web-based programme with no regional limitation for informal carers to support them in carrying out LTC tasks.<br>- The website offers continuously tested, up-to-date knowledge.<br>- It ensures permanent involvement of experts from different fields.<br>- The website has a logical and well-elaborated structure making it easy to use.<br>- There is a possibility of interaction (feedback).<br>- The innovation ensures the acquisition of nursing skills.<br>- It has no regional limitation.<br>- It has free access and requires only basic internet skill on the part of the user.<br>- It covers the majority of important areas of long-term care.<br>- It is transferable.<br><br>*Weaknesses: Which gaps/obstacles have been witnessed/experienced?*<br><br>- So far, any problems with the website have successfully been solved. It is, however, a problem that carers with no computer skills have no access.<br>- A related problem arises if a carer does not have a computer, which may be the situation for low-income and/or older carers.<br>- Poor infrastructure in regions with no internet connection is a further problem.<br><br>*Opportunities: Which improvements could be implemented? What* |

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| | *additional activities will be needed to deliver on targets? How could the initiative be scaled up or rolled out?*<br>- There is ongoing testing and updating.<br>- There is a possibility to involve important stakeholders, state secretaries (Social Affairs, Health), other NGO's, market actors, professional staff.<br>- It would be important to teach internet skills to carers unfamiliar with computer use and the internet.<br>*Threats: What pressures does the initiative currently experience that could threaten its existence?*<br>- No threats so far. |
| Website | http://www.webnover.hu/<br>http://www.central2013.eu/nc/central-projects/approved-projects/funded-projects/?tx_fundedprojects_pi1[project]=113 |
| Sources | Tróbert, A.M. (2014) Az idős, krónikus beteget ápoló hozzátartozók kiégése (Burn-out of family carers caring for older people with long term care), poster, PhD conference, Semmelweis University, Budapest , 10-11 April, 2014.<br>Expert interview conducted with Anette Mária Tróbert, who is responsible for the mental advice area of the WebNurse website.<br>Information provided by Alpár Lázár, participant in the HELPS project.<br>Information provided by Eszter Mészáros, Hungarian project manager of the HELPS project. |