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### **COMMISSION STAFF WORKING DOCUMENT**

#### **Long-term care in ageing societies - Challenges and policy options**

##### *Accompanying the document*

#### **COMMUNICATION FROM THE COMMISSION TO THE EUROPEAN PARLIAMENT, THE COUNCIL, THE EUROPEAN ECONOMIC AND SOCIAL COMMITTEE AND THE COMMITTEE OF THE REGIONS**

#### **Towards Social Investment for Growth and Cohesion – including implementing the European Social Fund 2014-2020**

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## Long-term care in ageing societies - Challenges and policy options

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#### Towards Social Investment for Growth and Cohesion – including implementing the European Social Fund 2014-2020

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## 1. INTRODUCTION

This Commission Staff Working Document, which is part of the Social Investment Package, deals with social protection against the long-term care (LTC) risks that affect women and men if they develop frailties or contract multi-morbidities as they age<sup>1</sup>.

As one of the annexes addressing how social investment at different stages of life can ensure better outcomes at lower or similar levels of cost and staffing, this document also links to the annexes on Investing in Health and on Social Services of General Interest.

It demonstrates that even late in life there are strong arguments for a social investment approach to social protection. If Member States where the number of very old people will triple in the coming decades are to be able to offer sufficient social protection against LTC risks they will need to find ways to contain the growth in the demand for LTC provision while also raising the efficiency of care provision. Thus, arguments focus on the economic and social returns that a determined strategy of social investment can achieve through a combination of reduced disability in old age, improved capacity of older people to manage functional limitations and higher productivity in care delivery.

In line with the Guiding Principles on Active Ageing adopted by the Council<sup>2</sup>, this document follows up the focus on independent living in the EY2012 on Active Ageing<sup>3</sup>. Moreover, in support of the objectives of Europe2020<sup>4</sup>, it suggests how one of the key challenges of population ageing may be addressed.

Across the European Union, long-term care for older people refers to a range of services and assistance for persons who over an extended period of time are dependent on help with basic activities of daily living (ADLs)<sup>5</sup> and/or instrumental activities of daily living (IADLs)<sup>6</sup>. In Member States with extensive provision, social protection against LTC risks also increasingly includes measures that help prevent, postpone or mitigate the onset of LTC needs.

It is estimated that one in two women and one in three men will come to need *intensive* long-term care as they age. The need for long-term care arises as a result of disability, which is usually due to health problems. But long-term care is organised and financed differently from acute health care in all Member States. Whereas health care is almost exclusively dispensed by health care professionals, a substantial part of LTC services is provided by untrained informal family carers. Therefore, it makes sense to view LTC provision as a combination of informal and formal care. Moreover, since social services such as home help are an integral part of formal LTC services and benefits, they also involve a skill-mix in staffing which differs from health care.

Long-term care is a highly gendered issue. Older women have a higher life expectancy and a different pattern of morbidity in old age, so most care recipients are women (both in home and

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<sup>1</sup> LTC provision for children and working-age adults with physical and mental disabilities falls outside the scope of this analysis. The focus is on the probability that older people will need LTC and on population ageing, which is likely to lead to a strong increase in the size of those older age-groups at particular risk.

<sup>2</sup> See: <http://ec.europa.eu/social/main.jsp?langId=en&catId=89&newsId=1743&furtherNews=yes>.

<sup>3</sup> See: <http://europa.eu/ey2012/>.

<sup>4</sup> See: [http://ec.europa.eu/europe2020/index\\_en.htm](http://ec.europa.eu/europe2020/index_en.htm).

<sup>5</sup> **ADLs:** Activities of Daily Living are self-care activities that a person must perform every day such as bathing, dressing, eating, getting in and out of bed or a chair, moving around, using the toilet, and controlling bladder and bowel functions.

<sup>6</sup> **IADLs:** Instrumental activities of daily living are activities related to independent living and include preparing meals, managing money, shopping for groceries or personal items, performing light or heavy housework, and using a telephone.

institutional care services)<sup>7</sup>. Moreover, the vast majority of both informal and formal carers are women<sup>8</sup>.

As a strand of social protection, long-term care provision is a Member State responsibility. While EU countries set their own level of ambition in LTC provision, they have also agreed a set of common objectives centred on access for all to financially sustainable, high-quality long-term care. These guide collaboration on LTC issues in the Social Protection Committee.

Differences between Member States in providing long-term care are more pronounced than in any other field of social protection. While this can make EU policy coordination more complicated, it also increases the potential benefits of EU-level collaboration. Given that Member States are at very different stages in their efforts to address the need for long-term care services, Europe could potentially add significant value by pooling the cost of research and development and by facilitating knowledge transfer and mutual learning on better ways of mitigating dependency and delivering LTC services.

Population ageing is the key common challenge in this field for Member States in the medium- to longer-term perspective. Over the next five decades, the number of Europeans aged 80+, and at particular risk of developing a need for LTC, is set to triple. In the same period the reservoir of potential formal and informal carers will reduce significantly as the working-age population will shrink, the number of women employed grow, retirement ages rise and family and living arrangements change. Given that formal LTC provision tends to be underdeveloped in several Member States at present and that Member States with extensive long-term care services already find it difficult to meet the demand, these prospects are daunting. Unless new, more effective ways of addressing the care needs of older persons are developed, long-term care services will be overwhelmed, and a huge gap will open between LTC needs and the ability of social protection systems to meet them.

This paper examines how long-term care needs may develop given the trends in demography and health. It describes the diversity of LTC provision across the EU and discusses the strengths and limits of present LTC approaches from a social protection perspective and in view of future challenges. It then analyses policies and gives examples of good practices that could help Member States meet the challenges and provide better protection against LTC risks.

It finds that there is a need for a longer-term strategy of social investment combining policies of

- (1) prevention, health promotion and rehabilitation with
- (2) systematic productivity drives in care delivery and
- (3) measures that raise the capacity of frail older people to manage self-care and independent living.

It examines the extent to which such practices are already successfully emerging and whether Europe can help Member States with the further development and dissemination of policies of this sort.

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<sup>7</sup> Hubert M. et al. (2009) Facts and Figures on Long-term Care: Europe and North America, European Centre for Social Welfare Policy and Research.

<sup>8</sup> Ibid.

## 2. EXPECTED GROWTH IN LONG-TERM CARE NEEDS

The scale of future needs for long-term care services among older women and men will depend on three factors:

- the *number of people in the age group 80+*, those most likely to need LTC;
- long-term care needs as a function of *average health status*, i.e. the extent to which older people, as they age, are likely to grow frail and develop multi-morbidities;
- the degree to which older people can *manage independent lives* in spite of functional limitations.

The number of people aged 80+ can be forecast with considerable certainty and is a given. Policy makers may influence the two other determinants, particularly in the medium to longer term.

The average health status in old age will result from health determinants in individuals' prior lives, including their health behaviours and living conditions as they age, as well as from effective medical treatments that preserve or restore physical and mental functions.

Their ability to live independently will depend on the age-friendliness of environments and living arrangements and on access to assistive technologies. Thus public policies need to focus not only on how to meet long-term care needs, as seemingly dictated by demography, but should adopt a more preventive stance, seeking to minimise the need for LTC services.

### 2.1. Demography

People tend to live longer, and the baby-boom cohorts are joining the ranks of the elderly. As a result the number of Europeans aged 80+ is set to rise particularly fast. This so-called 'ageing of the old' will be especially pronounced from 2030 to 2040. Between now and 2060, the number of people over 80 is expected to almost triple.

#### Development in number of people 65+ and 80 + in EU27, 2008-2060, millions

EU27	2008	2010	2020	2030	2040	2050	2060	% change 2008-2060
65+	84,6	87	103,7	123,5	143,1	149,9	152,7	80,50%
<i>Of which: 80+</i>	21,8	23,3	29,7	36,6	48,8	57,5	62,2	185,40%

Source: 2010 EUROPOP

Meanwhile, according to the 2012 Ageing Report<sup>9</sup>, the EU27's population of working age is expected to decline by 14.2 % (2010-2060). Thus, EU Member States cannot rely on a general increase in labour supply to meet the growth in long-term care needs that could result from a tripling of the number of people aged 80+. Even if more people are recruited into the workforce, there will be such competition for manpower that it will be very difficult to attract enough extra staff to formal long-term care to match growing needs. Moreover, the potential reservoir of informal carers, mainly spouses and daughters or daughters-in-law<sup>10</sup>, will also be affected by strong structural trends. With the changes in the structure of families and growth in female employment rates as well as higher pensionable ages and later retirement for women, the availability of informal carers will be limited.

<sup>9</sup> European Commission (DG ECFIN) — Economic Policy Committee (AWG), 2012, 'The 2012 Ageing Report — Economic and budgetary projections for the 27 EU Member States (2010-2060)', European Economy No 2/2012.

<sup>10</sup> Hubert M. et al. (2009) Facts and Figures on Long-term Care: Europe and North America, European Centre for Social Welfare Policy and Research.

## 2.2. Dependency levels — developments in health status

The increase in life expectancy has been accompanied by an increase in the occurrence of chronic diseases that can limit the ability to handle some daily activities. Thus, the need for long-term care does not arise from ageing itself, but is rather the consequence of the prevalence of frailty and multi-morbidity and the degree to which this causes individuals to be dependent on others for assistance with basic and/or instrumental activities in daily living (ADLs, IADLs).

There is an on-going debate on whether higher life expectancy increases the likelihood of functional impairments. Looking at recent trends in *severe* disability, the evidence is inconclusive: while data for a number of EU countries showed clear reductions from the early 1990s to the early 2000s<sup>11</sup>, for other countries, severe disability among older people seemed to have increased<sup>12</sup>. Moreover, different data sets found opposite trends (decline in Denmark, Finland, Italy and the Netherlands; an increase in Belgium and Sweden; and mixed evidence in France and the UK)<sup>13</sup>.

Indicators of healthy life years measure the number of remaining years that a person of a specific age can expect to live without any severe or moderate health problems or acquired disabilities (Eurostat, 2010). In 2009, men and women in the EU27 at age 65 could expect to live more than half of their remaining years with a frailty or disability that could affect their ability to manage instrumental and/or self-care activities of daily living.

	Healthy life expectancy at 65 Men	Life expectancy at 65 Men	Percentage of life expectancy at 65 without disability Men	Healthy life expectancy at 65 Women	Life expectancy at 65 Women	Percentage of life expectancy at 65 without disability Women
EU27	8,4	16,5	51,0%	8,6	20,1	42,7%

Source: Eurostat Statistics Database; Joint Action European Health and Life Expectancy Information System (JA EHLEIS). <http://dx.doi.org/10.1787/888932702936>

The key question is whether, as life expectancy increases, dependency levels in old age will increase, remain constant or decrease. We do not yet know the extent to which the prevalence of disability will be affected over the next decades, as possible changes in health behaviours and new treatments take effect.

For instance, Carol Jagger<sup>14</sup> found that with increasing life expectancy in the UK, there will be an increase in disability prevalence by 2030. Other international evidence suggests however that the health of older people in the EU will continue to improve.

<sup>11</sup> Lipszyc, B. et al. (2012), 'Long-term care: need, use and expenditure in the EU-27', Economic Papers 469, November 2012, available at: [http://ec.europa.eu/economy\\_finance/publications/economic\\_paper/2012/ecp469\\_en.htm](http://ec.europa.eu/economy_finance/publications/economic_paper/2012/ecp469_en.htm).

<sup>12</sup> Triantafillou J. et al, 2010, Informal care in LTC — European Overview Paper, INTERLINKS report.

<sup>13</sup> EU-SILC data quoted in *ECFIN (2012) Long-term care: need, use and expenditure in the EU-27, European Economy. Economic Papers. 469* also show a mixed picture for developments from 2006-2009.

<sup>14</sup> MAP 2030 / Carol Jagger — University of Newcastle.

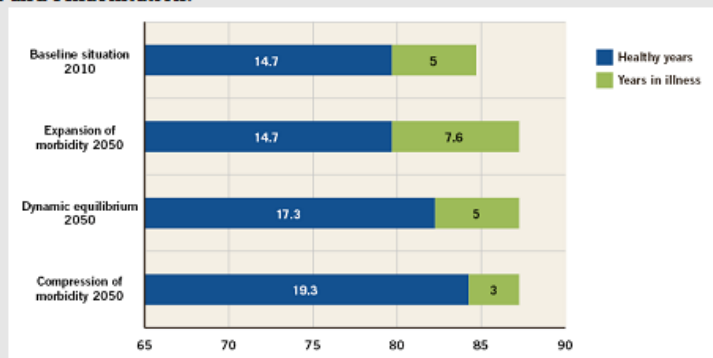
### Future LTC challenge illustrated by results of micro-simulation of trends in old age morbidity for Sweden

Micro-simulation using a 300.000 big representative segment of the present Swedish population (*LEV Project - Swedish Min. of Health & Social Affairs 2010*) has shown how policies leading to a compression of morbidity and a rise in the productivity of social and health care (including through greater deployment of assistive aids and use of home environment adaptation which enable people with ADLs to manage their handicaps and live independent lives) can help to meet future care needs - even at the height of population ageing.

In the illustrative figure for Sweden below, remaining life expectancy at the age of 65 in 2010 and 2050 is divided into healthy and unhealthy years. For 2050, where elderly Swedes can be expected to live about 2.5 years longer, three scenarios for this division are sketched: Expansion of morbidity, dynamic equilibrium and compression of morbidity.

If longer lives only lead to a growth in unhealthy years, the challenge in LTC provision will be very big. If morbidity can be contained to the same amount of years as in 2010 its relative weight in remaining life after 65 will drop. But the challenge will still increase with the growth in the number of very old people.

However, if a compression of the morbidity and of the extent to which it leads to LTC needs can be brought about (including through a growth in the ability to tackle part of the ADLs resulting from morbidity through deployment of new assistive technologies), the impact of the growth in the number of older people will be mitigated. Such a compression could result from a combination of healthy ageing life-styles and better prevention and rehabilitation.



Source: Statistics Sweden 2010

Lafortune and Balestat<sup>15</sup> have convincingly argued that, although different trends in severe disability have been observed among countries, the scale of the increase in the number of people over 65 is bound to lead to a rise in the number of severely disabled older people. A decline in the prevalence of severe disability could mitigate this growth, but it will not compensate for the large increase in the number of people in the age groups at risk.

At this stage, it seems safe to assume that the ageing of the population will lead to a significant *increase in the number* of frail older people with functional limitations and disabilities. Still, as highlighted above, the need and demand for long-term care is not just a function of the prevalence of disability.

### 2.3. Conditions influencing the capacity for independent living

The extent to which physical and mental impairment means people becoming dependent is influenced by a person's *perception* of their ability to manage despite functional limitations. It matters a lot whether people are encouraged and enabled to cope.

The ability to 'age-in-place' and avoid institutional care is usually beneficial for the mental and physical health of older persons. This is also clearly reflected in people's preferences. If they develop a need for long-term care in some form, the overwhelming majority of older

<sup>15</sup> Lafortune and Balestat (OECD 2007).



people would prefer to have home help and home care, enabling them to remain in their homes<sup>16</sup>. Four key factors influence the likelihood of this happening:

- People's capacity for independent living is influenced by *whether they live alone*. The availability of mutual support when living with other household members greatly enhances the coping ability of frail people. If they live on their own, their need for outside support is more likely to become an issue. Still, much can be done to improve their ability to continue to handle most essential aspects of everyday living.
- *Improving the age-friendliness* of the homes of older persons can play a great part in their ability to continue living independently when they become frail and develop multi-morbidities. The ability to remain in one's home depends to a great extent on whether risks are addressed, by removing obstacles and hazards in the home and installing facilitating devices. Raising older people's awareness of what they themselves can do to take simple measures to avoid accidents and facilitate access can greatly improve their ability to cope.
- *Assistive aids* and *modern ICT* offer promising opportunities to enable older people to go on living independently and help informal carers in providing care while preserving their private and professional lives<sup>17</sup>. Automated toilets, walking and lifting aids, power utensils, monitoring and communication tools are among the aids available, and there are rapid advances in this field. Developments in standard *Home appliances* can be of immense importance: for instance the widespread use of micro-wave ovens has been a great help to frail older people, enabling them to prepare their own hot meals. Monitoring and reminding devices can provide support. Care can be managed remotely, helping people to maintain independence safely. Technological devices for older or disabled people are becoming available at affordable prices. They can help improve cognitive health, reducing isolation and facilitating a wide range of activities around the house. Public procurement policies can support such developments.
- *Access to informal or formal home help and home care* services if older people cannot quite manage on their own. Tailoring such support so that it underpins a person's capacity for independent living is one of the key challenges for care providers, whether formal or informal. Carers can also use many new technology solutions to improve work coordination and to reduce workload and stress, so that they can plan and use their working time more efficiently.

### 3. PRESENT SUPPLY OF LTC IN THE EU UNDER DIFFERENT FINANCING AND DELIVERY MODELS

#### 3.1. Considerable differences in LTC provision

The way in which long-term care is treated in the social protection systems of EU Member States varies greatly, notably in the *relative weight* assigned to formal and informal care. There is also marked diversity in the way formal care is *organised* (e.g. by public, for-profit or NGO providers), *financed* (e.g. via general taxation, obligatory social security, voluntary

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<sup>16</sup> 'Health and long-term care in the European Union', Special Eurobarometer 283/wave 67.3, Dec. 2007.

<sup>17</sup> JRC (2013) *Can technology -based services support long-term care challenges in home care? Analysis of Evidence from Social Innovation Good Practices across the EU: CARICT Project Summary Report*. Authors: Carretero, S.; Stewart, J.; Centeno, C.; Barbabella, F.; Schmidt, A.; Lamontagne-Godwin, F. and Lamura, G. JRC Scientific and Technical Reports Series, EUR 25 695 EN, at: <http://ipts.jrc.ec.europa.eu/publications/pub.cfm?id=5899>.

private insurance or out-of-pocket payments) and *delivered* (e.g. as home care or institutional care).

In all Member States, informal care provided by relatives plays a significant role in the overall volume of long-term care provided. But there is enormous variation in the degree to which affordable formal services have been developed and are made available.

Formal LTC services may be provided in a variety of settings, including institutions, from traditional old people's homes to modern nursing homes, in supported living arrangements (e.g. residential care) or people's own homes (e.g. home help or home care). Long-term care may cover different mixes of health care and social services.

Several countries offer cash benefits or vouchers that can be used to pay for LTC services delivered by professional care providers and, in some cases, by informal carers. In countries where untrained family members can be contracted as informal carers and receive an allowance for the care they provide, the distinction between informal and formal care is blurred.

There is no consistency in the legal framework for providing long-term care across the EU. In many Member States, extended families are obliged to provide and/or finance care for their elderly relatives. But countries differ in the extent to which they enforce this legal responsibility and monitor whether care needs are actually met<sup>18</sup>. Where formal provisions are well-developed, the rules about when people in need of long-term care have an enforceable right to certain types and amounts of care are rather dissimilar.

At one end of a wide spectrum, some Member States basically or primarily still rely on families to tend to all of their elderly relatives' needs for long-term care. Families cope either by acting as informal carers themselves, or by arranging external help and financing it out-of-pocket. There is no or little pooling of risks across families through formal social protection.

A large number of Member States have developed some formal long-term care services and secured at least partial collective financing, either through social insurance schemes or through revenues from general taxation. Yet, the accessibility, affordability and quality of these formal LTC services differ considerably.

At the other end of the spectrum, a handful of countries with four decades of experience in providing extensive care seek to take comprehensive and integrated approaches to social protection against LTC risks in old age. Such approaches include aspects of other public health policies, such as preventive measures, active and healthy ageing, promoting autonomy and the capacity to live independently through e.g. assistive aids for self-care, provision of health and social LTC services, and end-of-life or palliative care.

### **3.2. Data on current LTC provision**

Comparable data at EU27 level on the current provision of formal and informal long-term care for elderly people are rather sparse.

For the purpose of the projections in the 2012 Ageing Report<sup>19</sup>, the picture of present public expenditure for long-term care has been assembled from data agreed by Member States (see Figure 1)<sup>20</sup>. In this scenario-building exercise, informal care is generally viewed as being of no direct cost to the public budget, whereas formal provision is understood to involve public

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<sup>18</sup> MISSOC: <http://ec.europa.eu/social/main.jsp?langId=en&catId=815>.

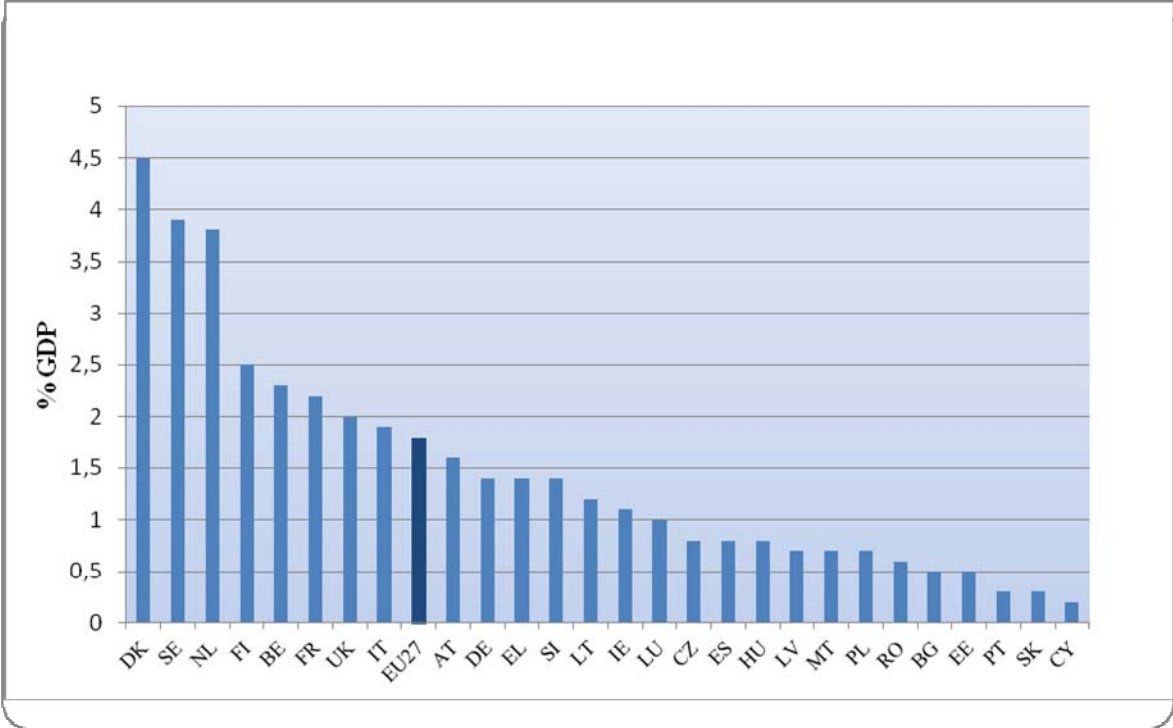
<sup>19</sup> European Commission (DG ECFIN) — Economic Policy Committee (AWG), 2012, 'The 2012 Ageing Report — Economic and budgetary projections for the 27 EU Member States (2010-2060).

<sup>20</sup> Data are from the SHA and/or ESSPROS databases and/or from Member States, and are agreed by Member States.

expenditure, calculated as the sum of publicly financed benefits in kind and in cash for long-term care purposes.

Public spending ranges from 4.5 % of GDP in DK to 0.2 % in CY or by more than a factor 20. The average for the EU27 is 1.8 % of GDP. SE, NL and DK are high-spending countries, with more than twice the EU average of their GDP devoted to long-term care. Five Member States spend between 2 % and 2.5 %, seven countries are in the 1-1.5 % range, nine in the 0.5-0.8 % span, and the remaining three spend 0.3 % or less.

**Fig. 1 Public expenditure on long-term care as percentage of GDP in 2010, all ages**



Source: based on data from the 2012 Ageing Report.

These variations in public expenditure on long-term care mainly reflect differences in the ‘coverage’<sup>21</sup> of formal systems of home care and institutional care. The estimates of coverage illustrate both the varying extent to which people with care needs receive formal LTC services and differences in the use of home care and institutional care. Some countries report little home care and also seem to have relatively limited ability to respond to demand for institutional care. Some countries like DK, LT, NL and SE show relatively impressive coverage rates in both types of provision, while a few rely predominantly on one or the other. In 2010, the UK, EL, IE, LU, AT, DE, FR and IT seemed to rely relatively more on home care, while institutional coverage rates, though moderate overall, were relatively higher in countries like CZ, BG, SI and HU.

<sup>21</sup> In the Ageing Report 2012 a proxy for ‘coverage’ is constructed by calculating the number of recipients of formal LTC benefits in cash and in kind reported by Member States as a percentage of people with dependency needs as measured by EU-SILC. As people may receive both kinds of benefit, the number of recipients may involve some double counting.

### 3.3. Composition of LTC provision

#### 3.3.1. Mix and cost of formal and informal care

Public long-term care expenditure largely depends on how much a country relies on formal care. Formal and informal care can be substitutes or complements, depending on the type of care and needs. While formal care is recognised as costly, both for the economy and the exchequer, informal family care also entails both opportunity costs and regular costs for families. Family care involves costs for the economy and the public budgets, as informal carers may not be able to find or stay in formal work, and may thus pay little or nothing in taxes and social contributions. Cost differences may also relate to differences in the quality and productivity of informal and formal care delivery.

Some countries combine a *de facto* emphasis on informal care with a legacy of traditional institutional care, in the form of old people's nursing homes. Still, most of these countries are transforming their nursing care models from institutional to community-based care and home care as part of a movement to de-institutionalise long-term care.

#### 3.3.2. Informal care

In most European countries, a large part of LTC for older people is provided by informal care-givers<sup>22</sup>. Even in countries with a well-developed supply of formal LTC, using narrow definitions of informal carers, the number of informal care-givers is estimated to be at least twice as big as the formal care workforce.

Over 90% of people providing informal care on a regular basis have a family relationship to the people they care for. Informal carers are typically spouses, middle-aged daughters or daughters-in-law<sup>23</sup>. The share of people providing some care is higher in northern Member States than in most southern ones. But in the south, informal care involves a larger share of heavy care with ADL, whereas help with IADL dominates informal care-giving in the north. When family carers only provide additional care, pressures may be lighter<sup>24</sup>. Estimates suggest that the economic value of unpaid family care as a percentage of the overall cost of long-term care in EU Member States ranges from 50% to 90%<sup>25</sup>.

Informal carers can be under considerable stress as they try to balance work and family duties, and most have received no training in caring for the elderly. Family care can entail substantial economic sacrifice, as informal carers may be forced to cut down their working time or leave paid employment altogether. Obligations to look after elderly relatives can cause poverty, not just while care is being provided, but also later, if care-givers are unable to build up sufficient pension rights.

In northern Europe, being an informal carer is not associated with a significant reduction in employment. This is because of good access to formal care support and policies enabling people to combine work and family responsibilities. In southern Europe, informal caring duties often mean cutting down on paid work, taking only part-time work, or early retirement. A similar pattern, though somewhat less pronounced, is found in some Member States in central Europe.

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<sup>22</sup> Triantafyllou J. et al, 2010, Informal care in LTC — European Overview Paper, INTERLINKS report.

<sup>23</sup> Hubert M. et al. (2009) Facts and Figures on Long-term Care: Europe and North America, European Centre for Social Welfare Policy and Research.

<sup>24</sup> Hubert M. et al., (2010) Informal carers: the backbone of long-term care, European Centre for Social Welfare Policy and Research.

<sup>25</sup> Triantafyllou et al., 2010.

### 3.3.3. *The public-private mix in the delivery and financing of formal care*

Member States use different combinations of financing and care providers. Long-term care can be organised as part of public health and social services financed by general taxation and provided by public sector workers, as in Denmark and Sweden, for instance. It may also be organised primarily via compulsory social insurance, as in Germany or Austria. Here, care services are provided mainly by non-profit organisations and financed by direct payments from the insurance authority or through cash allowances and vouchers for care recipients. Out-of-pocket private payments are more common for institutional care than for home care. For-profit providers have a minor role, though they exist in all Member States, and may play a significant role in the UK. About half of Member States regulate long-term care provision mainly at national level, and the rest share responsibility among central and lower-level authorities.

### 3.3.4. *In-kind services versus vouchers or cash benefits*

Cash-for-care benefits support individual choice regarding care received, while in-kind services may facilitate public authority control over the price/quality ratio. Cash-for-care benefits are particularly prevalent in a number of Member States. Some countries provide both in-kind services and cash-for-care benefits.

### 3.3.5. *Use of undeclared care and immigrant carers*

The underdevelopment of formal long-term care services in southern Member States has given rise to the practice of families employing immigrants — including some without legal status — as undeclared live-in carers for their ageing relatives. In Italy, migrant live-in carers are estimated to account for about three-quarters of all home-carers<sup>26</sup>. Such practices are also increasingly common in some central European countries (e.g. AT and DE<sup>27</sup>), though on a smaller scale.

Migrants also make up an increasing proportion of formal-care workers in Member States with extensive services, especially where staff shortages have encouraged them to develop policies to attract migrants in a controlled way. Big differences in pay and working conditions among Member States influence the inflow of mainly female migrant workers.

## **4. RELATIVE STRENGTHS AND LIMITATIONS OF DIFFERENT DELIVERY MODELS**

In a stylised appraisal of the relative strengths and limitations of present approaches to social protection<sup>28</sup> against the risks of developing a need for long-term care in old age, a number of points stand out. The following review of the range of current policy mixes focuses on the ways in which informal and formal care are financed, organised and combined<sup>29</sup>.

### **4.1. Leaving it to families to provide informal care for their ageing kin**

Traditionally, societies have relied on the moral commitment and willingness of families to provide support for their older relatives, if they develop functional and mental limitations.

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<sup>26</sup> Lamura, G. et al., (2008), 'Les travailleurs immigrés dans le secteur de l'aide aux personnes âgées: l'exemple de l'Italie'.

<sup>27</sup> Jandl, M., Hollomey, C. and Stepien, A. (2007), Migration and Irregular Work in Austria — Results of a Delphi-Study, International Migration Papers 90, International Centre for Migration Policy Development, Geneva: ILO.

<sup>28</sup> The stylised approach simplifies actual policy mixes to bring out essential differences. For an overview of country-linked policy-mix typologies see Kraus M. et al (2010), ANCIEN, A Typology of Long-Term Care Systems in Europe and Colombo et al.: Help Wanted, OECD 2011.

<sup>29</sup> Outcomes of different policy mixes are also affected by cultural (societal and individual) differences.

This is the main approach only in a minority of Member States. But in all Member States, informal care plays a substantial role in care provision for older people.

*Key advantages* of this approach include the seemingly low costs to public budgets; and care is likely to be provided by closely related and (generally) trustworthy carers, so is likely to be well-intended. Moreover, the public sector does not have to organise the financing, monitoring or delivery of such care.

*Drawbacks:* the near absence of direct public expenditure does not mean that family care is free. It comes at significant cost to families (i.e. primarily women as spouses, daughters or daughters-in-law) in terms of the working time of the carer, alternative employment income foregone and reduced accrual of social protection entitlements. There may also be out-of-pocket payments for care tools and assistive devices.

The principle that every family is expected to care for its own family members also implies that there is no sharing of the burden/cost of care across families. In this approach, there is no pooling of the long-term care risk. Those with relatives in need of care do not receive any public support. Those with ageing relatives that can manage without LTC do not share in the societal LTC burden.

The rights of older people in need of LTC will therefore depend on the ability and willingness of their families to provide them with care. There are few, if any, means to influence the quality and appropriateness of care that untrained informal carers provide. Neither the quality nor the sufficiency of informal care can be guaranteed. Neglect and even abuse may occur for lack of family resources to provide care, or as an unintended consequence when family carers are exposed to the physical and mental stress of being alone with care duties and to the social hardship this may involve.

For society, family care involves opportunity costs as carers reduce their labour force participation and contribute less to GDP. In addition, the physical and mental stress and social hardship that informal care-giving can induce may hamper the future health status and material well-being of the care-givers themselves. The rather limited possibilities for improving productivity means that informal care delivery remains highly labour-intensive.

In short, when fully analysed, this approach has serious deficiencies in terms of equity, opportunity costs and efficiency.

#### **4.2. Getting families and households to pay out of pocket for their informal care needs**

A variation on this model involves the family hiring someone from outside the family to provide informal care, possibly even taking on the role of live-in carer.

*Key advantages:* There is no public involvement in financing and organising long-term care. This can be seen as a solution to care needs if families are unable to provide care themselves, or if formal services are unavailable or unaffordable. Family members need not miss out on employment opportunities. On the contrary, they are likely to have paid employment to pay for the live-in carers.

However, as this approach tends to involve undeclared work — and by illegal immigrants — there are indirect costs in taxes foregone. While the hired carers may prefer this work to the alternatives open to them, their services are affordable because they are clearly underpaid and do not earn entitlements to social protection. In some Member States where live-in migrant carers deliver a substantial part of LTC provision policy makers have sought to mitigate these problems by legalising and formalising such arrangements. As above, the downsides are that

the quality of care cannot be guaranteed, and prospects of better productivity and quality are very limited.

### **4.3. Providing support to family carers**

Another option is for the authorities to organise support for informal care. This may entail economic support, through a contract involving a cash allowance for care performed, or crediting of social protection entitlement, as well as training and care leave. It can also involve offering protection in legislation or collective agreements to help reconcile informal care duties with formal employment for family carers<sup>30</sup>.

*Key advantages* are that the willingness and ability of family members to provide informal care is harnessed at relatively limited costs to public budgets, while some social protection pooling of the LTC risk is secured. There is some quality assurance and some monitoring that needs are in fact met. Training and care leave takes significant pressure off carers, which may have positive effects on the quality of care provided by the family. The likelihood of the primary carer leaving her employment may be reduced, especially if some formal respite care is available when necessary<sup>31</sup>.

The *drawbacks* are less of a concern than in the other variants relying on informal care. But the cost to families can still be considerable and there is only limited risk pooling for LTC needs. Unless support covers home adaptations and support for assistive devices, productivity improvements are still likely to be limited.

### **4.4. Replacing informal with formal care in various models of LTC financing & delivery**

#### *4.4.1. Publicly financed public provision*

The greatest involvement of the public sector is found in those Member States where LTC is financed from general tax revenue, organised as a public service and delivered by trained public sector workers to those who need care. This is then an individual right (e.g. DK and SE). In those countries, most LTC services take the form of home help and home care, while nursing care is reserved for people suffering from severe mental and physical limitations.

*Key advantages* include: a solid financing base with full pooling of LTC risks across the population; maintenance of a larger formal workforce contributing to GDP; jobs with upgrading opportunities for lower-skilled workers; well-trained professional carers; and alleviation of the burden on families, so that people with dependent elderly relatives can continue full-time employment. The rights of those needing care are far better protected. Quality can be fully monitored and there are opportunities for growth in productivity, including through re-engineering and capital substitution<sup>32</sup>. Taking care into the formal sector unlocks it from the constraints of families and makes the cost of delivering long-term care far more visible and amenable to public policies.

*Drawbacks* are that it tends to involve far higher public spending on long-term care (though not necessarily much higher societal cost) and that public authorities assume the bulk of the responsibility of social protection against long-term care risks in old age. Confronted with constrained choices between various spending items addressing the different needs of

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<sup>30</sup> Dublin Foundation study.

<sup>31</sup> Family carers may acquire knowledge, skills and competences through their caring activities, which employers and unemployment services could take into account if they are recognised, even though they have been acquired in an informal way.

<sup>32</sup> Re-engineering involves changing the way social protection against the LTC risk is organised, e.g. through a greater emphasis on prevention and empowering for self-sufficiency. Capital substitution entails replacing and amplifying human labour by productivity-enhancing technology.

different categories of citizens, policy makers face the difficult task of securing affordable quality care while offering decent pay and working conditions to publicly employed professional carers. Obviously, the supply and quality of care (and protection against the risks of becoming dependent) may fall short of needs and expectations. Public budget constraints can have an immediate negative impact on the amount and quality of care provided. Moreover, the lack of a direct link between the financing of care and entitlements can weaken the sustainability of systems and the ability of older people who need long-term care to enforce their rights to definite amounts of care of appropriate quality.

#### 4.4.2. *Social-insurance funded care, delivered by private non-profit or for-profit providers*

In this variant, non-profit NGOs such as welfare associations and faith-affiliated social service organisations deliver the bulk of formal care. For-profit providers may also have a role, but in most Member States, this is rather limited and primarily concerns residential or nursing home care. Services may be paid directly by a social insurance body or may be payable with vouchers or care allowances provided to care recipients.

*Advantages:* Generally, this approach can lessen the burden on families, as is the case in countries with public provision, though in some Member States, it coexists with an emphasis on informal care, for which it may also provide some financing. Where social insurance is mandatory, it provides broad risk-pooling and a rather solid financing base. Expenditure is covered by earmarked social security taxes and is therefore less open-ended than in systems with financing from general revenue. Entitlements tend to be easier to enforce as they are backed by contributions and may entail clear definitions of the amount and type of care to be provided to people with certain diagnoses of dependency. An environment with more types of care providers can allow more consumer choice and may result in competition, with a positive impact on quality and cost. It may also make long-term care a more attractive field of employment, as professional carers can build careers with various types of employers.

*Drawbacks:* Contributions are levied on a somewhat narrower tax base than general revenue and will have to be raised as needs increase. Reimbursements, care allowances and vouchers may not cover the total price of care, thus requiring some out-of-pocket payments by recipients or their families. The separation between financing and care-providing bodies makes quality control more complicated, but may generate incentives to productivity drives. Preventive measures, such as home adaptations and access to day-care facilities may not be (fully) covered. Access to rehabilitation may not be covered or fully reimbursed.

#### 4.5. **In sum**

Current approaches to social protection against long-term care risks differ widely in terms of *risk pooling* and *equity in access*. Policies also differ markedly in their capacity to optimise the *quality and efficiency* of care delivery. Approaches with a heavy emphasis on family care are at a particular disadvantage in relation to these key dimensions of care provision. Given future challenges these disadvantages are set to become major deficiencies.

In many Member States, public expenditure is at present only the tip of the iceberg when it comes to calculating the societal cost of caring for frail older people in Europe. Expanding formal services, leading to higher public expenditure, will result in hitherto hidden costs becoming visible, with social protection to cover long-term care being developed to share the risks of disability in old age more equitably. Importantly, it will not be possible to ensure equality of access to long-term care, guarantee its quality or develop productivity unless most of the current informal care is lifted into the formal sector.



## 5. POLICY OPTIONS FOR ADDRESSING FUTURE LTC CHALLENGES

### 5.1. The overall challenge in LTC

Over the next five decades, the shrinking of the population of working age will tend to limit economic growth and make it more difficult to recruit formal carers. Changes in living and family arrangements, a rise in female labour force participation rates and higher retirement ages will reduce the reservoir of informal carers. At the same time, the threefold increase in the number of those in the age groups most likely to need long-term care is likely to lead to very substantial growth in demand for such care. In short, the challenge is to find ways to contain the growth in demand for long-term care while improving the capacity to provide more, better care with fewer human resources and less funding.

### 5.2. The challenge for public budgets

The Ageing Report 2012, which examines the challenge in terms of its impact on public spending, expects that the steep rise in the number of people aged 80+ will generate a substantial increase in needs for long-term care, raising pressure to expand care provision. The effect of ageing itself is expected to result in at least a doubling of public spending on LTC for the EU27, i.e. from 1.8% to 3.6% of GDP in the period 2010-2060 (as shown by the so-called ‘base case scenario’).

It is therefore important to find ways to limit the growth in public spending, while avoiding a rapidly widening gap between the need for care and the supply available.

### 5.3. Policy responses needed to tackle the challenges

National policy makers are seeing the future challenge for long-term care as that of ‘closing the gap’ between growing care needs and stagnant to shrinking resources. The key questions are finding policy mixes that can enable Member States to close that gap. Important contributions towards doing so could conceivably come from:

- raising the *productivity* of care delivery
- reducing the *incidence and overall prevalence* of frailty and disability
- reducing *dependency*, i.e. enabling older people to continue to manage *independent living with functional limitations*

The first element in a coherent strategy concentrates on possibilities for delivering more, better care with fewer resources in terms of manpower and money. The others focus on containing the growth in needs for long-term care, through measures to prevent morbidities or to slow their disabling course, while enabling elderly people to manage without care, or with far less care than today, despite functional limitations.

The *productivity* of care provision can be raised through better organisation, financial incentives, quality control and re-engineering including through capital substitution. Current change and innovations suggest that productivity growth will be far greater than assumed in standard labour economics. Systematic productivity drives will be limited to formal long-term care and it will therefore be important to replace informal by formal care. But support for family carers, through ICT and assistive devices, for instance, can also help raise both the productivity and quality of informal care.

Active and healthy ageing and a determined emphasis on *prevention and rehabilitation* can reduce the incidence of frailty, postpone its onset and reverse or mitigate the course of frailty, functional limitations and disability. People who are fit when they become old and seek to remain physically and mentally active not only have a better chance of avoiding or postponing frailties, they are often also better at managing functional decline when it occurs.

General prevention and health promotion schemes for all ages, with special awareness programmes for people in their 50s to very old people hampered by functional limitations, can be built into social protection. Avoiding premature erosion of physical and mental fitness and damage inflicted through mal-medication and accidents such as falls would bring large benefits, both in cost savings and quality of life. It will be important for prevention policies to target some of the main diseases/physical conditions that cause dependency. Another priority would be to promote early detection of emerging limitations and frailties, and to offer mitigating measures, including assistive aids. A wide range of preventive measures and policies have been demonstrated to be clinically effective. Encouraging senior citizens to participate in physically and mentally stimulating activities in various settings, such as universities, language schools, sport centres, volunteering organisations and day care centres, can halt the course of decline and help maintain and sharpen faculties<sup>33</sup>.

A fall leading to a broken hip or a spell of serious illness can send an otherwise fit older person into rapid decline, requiring extensive care. But *cost-effective rehabilitation* has proved to be possible even in late stages of life. Obviously, rehabilitation is most effective if provided immediately after an incident, before serious frailties set in. Several Member States have included rehabilitation in their long-term care approaches as a cost-effective tool, although this is not yet standard practice.

Physical and mental restrictions in older people need not be perceived as ill health and a threat to their *ability to lead independent lives* as long as sufficient resources are available to compensate for the deficits. It will be crucial to make the necessary social investments in age-friendly adaptations of older people's private homes and in new assistive devices, including those that allow for self-monitoring, self-care and self-management. This is about empowering and enabling older people with functional limitations to manage a higher degree of self-sufficiency. ICT can facilitate social interaction with family and friends and allow for emotional support, even when people are largely bound to their homes and relatives do not live nearby. Public procurement can be used to secure assistive devices at affordable prices. Public policies can also encourage older people and their relatives to pay out-of-pocket for assistive devices to help older people look after themselves day-to-day. The aim would be to enable and empower older people with functional limitations to get by with much less long-term care than today, so that they can retain autonomy with choice and dignity despite the physical and mental effects of ageing.

Well-known concepts such as 'ageing in place', 'continuity in care', 'care integration' 'self-care' and 'smart homes' would be part of strategies that can successfully begin to tackle future challenges in long-term care. Social experimentation followed by dissemination and scaling up of successful approaches have for some time formed part of long-term care strategy development in Member States such as DK, NL, SE and the UK. Ageing in place, independent living and rehabilitation can be achieved through age-friendly environments, assistive technology and appropriate provision of home help and home care.

For some countries with well-developed formal provision, focusing on prevention, productivity and independent living will seem a logical extension of present efforts. Others will have to make substantial changes. If risks are to be effectively shared and individual needs guaranteed, genuine social protection programmes covering long-term care will have to be developed. This will involve shifting care from the informal to the formal sector to develop the productivity and quality of care delivery systematically. It will entail making visible the hitherto hidden privatised cost of long-term care. But it will also offer the prospect of

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<sup>33</sup> Susann Rohwedder and Robert J. Willis, Mental Retirement, Journal of Economic Perspectives—Volume 24, Number 1—Winter 2010, pp. 119–138.

substantial GDP growth and higher employment rates. This way, Member States can benefit in major ways from formalising and modernising their LTC provision.

Key questions for further investigation would be:

- To what extent can prevention and rehabilitation affect the incidence and course of frailty and disability in old age?
- To what extent can systematic productivity drives in care delivery, including thorough capital substitution and service innovation, bring possibilities for delivering more and better care with less manpower?
- How much potential is there for raising the capacity of frail older people to manage independent living through age-friendly adaptations, smart technologies and assistive devices?
- Would a combination of these complementary approaches, which require determined social investments over a long period, be sufficient to bridge the gap between the need for long-term care and the supply?

Obviously, these questions cannot be fully answered in this paper. But a review of some good practices in Member States can give an insight into the potential of a social investment approach to the long-term care challenge.

## 6. GOOD PRACTICES IN MEMBER STATES APPLYING SOCIAL INVESTMENT APPROACHES TO LTC

Key elements of the necessary strategy are already emerging in several Member States. This chapter summarises some good practices<sup>34</sup> in *preventive* approaches to healthy and active ageing, successful *rehabilitation*, efforts to improve the *capacity for independent living*, *support for informal carers* and the *use of ICT* in drives for *higher productivity*. Practices reviewed also include measures to create more *age-friendly environments*, including support for *home adaptations*, and efforts to *raise quality* in both formal and informal care provision.

### 6.1. Comprehensive national approaches

In **Sweden**, policies have begun to combine the complementary strategies of (1) productivity drives, (2) health-promoting and preventive measures and (3) investments in home adaptations, ICT and assistive devices to enable older people to continue living independently even after developing functional limitations. National policies are increasingly oriented towards using combinations of efforts in these three areas to bridge the gap between care needs and provision, which would otherwise grow larger over the next 30 years. It is estimated that systematic efforts of this sort over a long period can enable Swedish municipalities to continue to meet demand for long-term care.

In **Denmark**, where long-term care is provided by local government, the municipality of Fredericia<sup>35</sup> realised that the age profile of its population in 15 years' time would make it very difficult to meet long-term care needs through existing approaches. It decided to embark on a new strategy to encourage and enable elderly people to live independently for as long as possible. Experiences with a so-called 'rehabilitation for everyday life' approach demonstrate that with teams of physiotherapists and ergonomists, it is possible to bring many older people from needing care on a regular basis to basic self-sufficiency and autonomy. Through combining preventive measures of active and healthy ageing, greater productivity in care

<sup>34</sup> Please consult the Annex for further details.

<sup>35</sup> See: <http://www.fredericia.dk/Borger/Sider/default.aspx>.

delivery can be achieved. While raising the ability of frail elderly to manage independently, Fredericia has documented the possibility of raising the overall quality of protection against LTC risks. In addition, job satisfaction for formal care staff can be improved at lower costs, with fewer staff. Some of these innovative approaches are becoming part of overall policy approaches in areas of the UK and Germany.

## **6.2. Prevention**

A preventive approach is preferable to acute and reactive care, not only in financial terms but also regarding the individual's health status. Encouraging older people to remain independent in their home and community, while staying socially active, can bring significant savings in the short, medium and longer term. Prevention should be regarded as an investment, as also exemplified by the 'Re-ablement' approach discussed in the Annex. Integrated care based on collaboration within health care services and among social, health and community care providers results in better outcomes for older people, while addressing resource efficiency and sustainability. This is illustrated by the LinkAge Plus programme cited in the Annex.

*Health promotion* and prevention also involve quality assurance in different aspects of care. Studies have shown that 17% of older people use at least one inappropriate medication and that almost 60% of older out-patients take medications that are suboptimal or lacking an indication<sup>36</sup>. Adverse drug reactions or events (ADRs or ADEs) include falls with or without fractures and more general geriatric syndromes (e.g. cognitive impairment, urinary incontinence, etc.).

## **6.3. Rehabilitation**

Although not yet common practice, rehabilitation at an early stage, properly used, has proved to be cost-effective in long-term care and highly beneficial for patients. Research<sup>37</sup> has identified general success factors for rehabilitation programmes. In-patient geriatric care should be combined with out-patient geriatric follow-up, based on early recognition of patient needs. Frailer participants generally benefit from individualised interventions, while group interventions are successful for the less severely disabled<sup>38</sup>. An effective rehabilitation programme must start with a multidimensional geriatric assessment in which problems are identified and recommendations are drawn up. Monitoring should ensure that recommendations are properly implemented.

Successful innovative practices have been developed for strokes, traumatic brain injury and hip fractures. In most cases, respiratory rehabilitation and cognitive rehabilitation can now be implemented. In some Member States, rehabilitation is clearly identified as a specific service (e.g. Germany, see the Annex), whereas in others (e.g. England, Denmark, Sweden and the Netherlands) it is an integrated part of comprehensive programmes of health care and health promotion.

## **6.4. Productivity and capacity gains from innovation, including through use of ICT**

The use of ICT (information and communication technologies) to support carers and increase the productivity of care delivery is spreading in Member States and gradually moving from the experimental stage to being scaled-up, thus innovating and improving the way care is organised and delivered and the way home environments are adapted<sup>39,40</sup>.

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<sup>36</sup> <http://www.dh.gov.uk/health/2012/03/new-medicines-service/>.

<sup>37</sup> Stuck AE, Siu AL, Wieland GD, Adams J, Rubenstein LZ (1993) Comprehensive geriatric assessment: a meta-analysis of controlled trials. *Lancet* 342, 1032-1036.

<sup>38</sup> Cohen HJ, et al (2002) A controlled trial of inpatient and outpatient geriatric evaluation and management. *N Engl J Med* 346, 905-912.

<sup>39</sup> See: <http://is.jrc.ec.europa.eu/pages/EAP/eInclusion/carers.html>.

Social and ICT innovations enable new ways of organising society around active ageing and independent living for older people, as shown by the CARICT project for all of Europe (see Annex) and by examples from Scotland, England and Italy. These new approaches have all brought higher productivity and substantial savings while raising the quality of services as well as the quality of life of older people with LTC needs and their carers.

## **6.5. Quality assurance**

Quality assurance in LTC remains a major challenge in a context of workforce shortages, the complexity of delivery and the difficulty of monitoring. However, some Member States have already made major efforts to improve quality, combating elder abuse and promoting the professionalisation of long-term care delivery. In the field of prevention of elderly abuse, the Dutch policy (see Annex) stands out as particularly innovative and thorough. The implementation of the recent Borloo Plan in France, which covers various aspects of the organisation and delivery of LTC, stands out as a key initiative to tackle a multitude of weaknesses in provision by launching a comprehensive national approach.

This brief review of innovative approaches to providing long-term care emerging in Member States illustrates the potential returns from pursuing innovation-driven social investment strategies and their potential in efforts to avert a crisis in unmet needs as the number of old people grows.

## **7. CONTRIBUTIONS FROM EUROPE<sup>41</sup>**

The EU can offer Member States significant support in their efforts to tackle present and future challenges in LTC. The diversity of systems is a major opportunity for mutual learning, for which the EU can act as a facilitator. A number of policy departments are already involved in these matters and involved in facilitating the exchange of experience among Member States and stakeholders.

### **7.1. Prevention**

Healthy ageing and independent living have been promoted in Member States as part of the European Year 2012 for Active Ageing and Solidarity between Generations. Upon joint suggestion from the Social Protection Committee (SPC) and the Employment Committee (EMCO) the Council on 6 December 2012 adopted Guiding Principles for Active Ageing, which highlight the following policies as key routes to autonomy and independent living in old age: Health promotion and disease prevention; Adapted housing and services; Accessible and affordable transport; Age-friendly environments and goods and services; Maximising autonomy in long-term care.

The Active Ageing Index (AAI)<sup>42</sup> is a new monitoring tool developed by the European Centre Vienna in collaboration with the United Nations Economic Committee for Europe (UNECE)

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<sup>40</sup> JRC (2013) *Can technology -based services support long-term care challenges in home care? Analysis of Evidence from Social Innovation Good Practices across the EU: CARICT Project Summary Report*. Authors: Carretero, S.; Stewart, J.; Centeno, C.; Barbabella, F.; Schmidt, A.; Lamontagne-Godwin, F. and Lamura, G. JRC Scientific and Technical Reports Series, EUR 25 695 EN, at: <http://ipts.jrc.ec.europa.eu/publications/pub.cfm?id=5899>.

<sup>41</sup> This is only a brief summary. A fuller inventory of European initiatives of relevance is given in here: [www.ec.europa.eu/social/BlobServlet?docId=8710&langId=en](http://www.ec.europa.eu/social/BlobServlet?docId=8710&langId=en).

<sup>42</sup> See: [http://europa.eu/ey2012/ey2012\\_main.jsp?catId=975&langId=en&mode=initDetail&initiativeId=186&initLangId=en](http://europa.eu/ey2012/ey2012_main.jsp?catId=975&langId=en&mode=initDetail&initiativeId=186&initLangId=en).

and the European Commission's DG Employment, Social Affairs and Inclusion. The index measures the performance of countries in four domains that together determine active ageing potential: (1) employment of older workers; (2) social activity and participation of older people; (3) independent and autonomous living of older persons; and (4) an environment that enables active ageing. The index aims to help shape future research and policy agendas and influence how existing large-scale data-sets are developed to address the impact of population ageing by following the policy discourse on active ageing and solidarity between generations.

Taken together, these policies, already developing in Member States, to some extent with comprehensive commitments to social protection against LTC risks in old age, are a promising social investment approach to containing the growth in LTC needs while raising the ability of older people to live independently. Importantly, EU policies can underpin the further roll-out of such policy efforts at national level. There has been collaboration on LTC issues at EU level over the last decade, notably in the Economic Policy Committee (EPC) and the Social Protection Committee (SPC).

## 7.2. Productivity and capacity gains from innovation including through use of ICT

ALIAS (AAL Joint Programme<sup>43</sup>) has developed a mobile robot system that interacts with elderly users and provides assistance in daily life, promoting healthy ageing and independent living.

*Public procurement* policies and new European instruments for *long-term investment* can help establish the environment for large-scale European production of innovative assistive devices at affordable prices.

*DG CNECT* has for decades followed technology developments that can help tackle LTC challenges and promote independent living. DG CNECT is involved in work on moving from innovation to production and marketing, and scaling up and implementation in public policy. Together with DG SANCO, it leads the EIP pilot on healthy and active ageing. DG CNECT also co-funds projects such as the CARICT Project<sup>44</sup> at the EC JRC<sup>45</sup>. This project documents the role played by ICTs in supporting informal carers. InCasa (ICT-PSP) has developed an ICT-based system to protect frail elderly persons and prolong the time they can live well in their own homes.

## 7.3. The European Innovation Partnership Pilot on Active and Healthy Ageing (EIP AHA)

This initiative aims to identify and remove barriers to innovation in health and long-term care delivery. By intensifying work between all stakeholders on innovative solutions, it seeks to increase our ability to scale up good practices and secure faster, large-scale deployment of new knowledge and technology. The overarching objective is to extend average healthy life years in the EU by 2 years by 2020. The partnership brings together various stakeholders from the demand and supply side and promotes the development of innovative products that

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<sup>43</sup> The Ambient Assisted Living Joint Programme is a joint research and development funding programme. Its main objectives are to improve the living conditions of older people through the use and development of AAL solutions based on ICT technologies, and to strengthen the competitiveness of European industry in the AAL domain. For further information see: <http://www.aalforum.eu/page/aal-joint-programme>.

<sup>44</sup> See: <http://is.jrc.ec.europa.eu/pages/EAP/eInclusion/carers.html>.

<sup>45</sup> See: <http://is.jrc.ec.europa.eu/pages/EAP/eInclusion/carers.html>.

contribute to healthy ageing and facilitate the independent living of frail older people. The focus is on three areas: (1) prevention and health promotion, (2) health and social care for older people and (3) active ageing and independent living of older people supported by innovative products.

The ICT research programme has for decades supported technology developments to help tackle LTC challenges and promote independent living. The Competitiveness and Innovation Programme supports moving from innovation to production and marketing, and scaling up and implementation in public policy.

The Lifelong Learning Programme and its successor will help facilitate independent living by providing funding for the acquisition of ICT skills by seniors.

#### 7.4. Quality assurance

In the **SPC**, Member States have compared approaches and exchanged experiences in relation to common objectives of guaranteeing access for all to adequate long-term care, while promoting quality and ensuring that adequate, high-quality long-term care remains affordable and sustainable. In the Joint Reports on Social Protection and Social Inclusion, Member States have reported on their approaches and recent progress towards the common objectives. Various peer-reviews on LTC in the Member States have provided opportunities for mutual learning. Member States have also sought to agree a set of common indicators for measuring advances towards the common objectives, and in 2008, the SPC adopted a special report on LTC. The SPC has also agreed a European Quality Framework for social services of general interest, including LTC services. Still, LTC has remained the least-developed of the social protection strands for which Member States have agreed common objectives. Recognising this, the SPC has recently stepped up its work on LTC issues in its subgroup on ageing issues in social protection SPC-WG-AGE. This group is currently considering a proposal for a major work programme on Innovative Approaches to LTC, which may run till the end of 2013.

Beyond the work of these committees, LTC issues have been covered in the **Research Programmes** of the EU and in work on the potential of ICT developments to care for older people and ensure independent living. The Ambient Assisted Living Joint Programme (AAL) aims to enhance the quality of life for older people. It funds projects using intelligent products and the provision of remote services, including care services, to improve the lives of older people at home, in the workplace and in society in general. It has a total budget of around EUR 700 million for the period 2008–13, sourced approximately 50–50 from public (national and EU) and private bodies.

As part of its servicing of the SPC and the Social OMC, **DG EMPL** has accumulated extensive experience on LTC. The unequal distribution of LTC needs has been connected to health inequalities and arduous working conditions. Long-term care has been considered in opportunities for job growth and the future supply of jobs for the low-skilled (see the April 2012 Employment Package<sup>46</sup>). In future, the structural funds, including the ESF, are expected to give more attention to health and social inclusion issues, entailing wider possibilities to use the funds. New orientations in social policy towards social experimentation also offer prospects for innovation and improvement in long-term care provision.

**DG JUST's** Daphne programme deals with elder abuse. An act on accessibility is planned. The gender equality roadmap includes a proposal to develop a directive on leave for carers.

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<sup>46</sup> "Towards a job rich recovery", COM(2012) 173 final, "Exploiting the employment potential of the personal and household services, SWD(2012) 95 final and "Action Plan for the EU Health Workforce", SWD(2012) 93 final.

*The European Parliament* has given particular attention to the LTC-related issue of Neglect and Abuse of Older People and allocated money to research and NGO projects on policies to prevent and tackle the danger of such violations of the basic rights of frail older people. The AGE Platform is one of the organisations that have examined the issues and come up with proposals for a preventive approach in the WeDO project.

The Lifelong Learning Programme and its successor will continue to provide funding for the acquisition of skills and competences by carers, whether formal or informal, as well as funding and tools for the recognition and validation of the skills acquired.

Important *OECD* work on financing and staffing issues in LTC and on quality assurance has been co-funded by the European Commission<sup>47</sup>.

## 7.5. Public finances and research

DG ECFIN, cooperating with Member States in the *Ageing Working Group* of the EPC, has focused on how age-related increases in public expenditure for long-term care may affect the stability of public finances. A methodology has been developed for collecting a set of data and carrying out public expenditure projections for long-term care over several decades. Results have been reported every third year since 2006 in the Ageing Report. Furthermore, a working paper elaborating on the Ageing Report<sup>48</sup>, focusing specifically on LTC, has just been published in the Economic Papers series<sup>49</sup>.

The EU and Member States have also launched two specific Joint Programming Initiatives (JPIs) aimed at facilitating active and healthy ageing.

The More Years, Better Lives JPI addresses the challenges and opportunities of demographic change by developing multi-disciplinary knowledge as the basis for future research, innovation and policy making.

The Joint Programming on Neurodegenerative Disease Research (JPND) aims to increase coordinated investment among 13 participating countries in research aimed at finding causes, developing cures, and identifying appropriate ways to care for those with neurodegenerative diseases, in particular Alzheimer's. As such, it will improve understanding of these diseases and contribute to ensuring early identification and treatment thus reducing the social and economic impact for patients, families and health care systems.

Five thematic priorities for future research include: the origins of neurodegenerative disease; disease mechanisms and models; disease definitions and diagnosis; developing therapies, preventive strategies and interventions; and healthcare and social care. A joint transnational call was launched in December 2012 to address the evaluation of current health care policies, strategies and interventions for neurodegenerative diseases.

Additional funding for research on Alzheimer's is provided through the Innovative Medicines Initiative (IMI), a EUR 2 billion public-private partnership between the European Commission (FP7) and the European Federation of Pharmaceutical Industries and

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<sup>47</sup> Colombo et. Al: Help Wanted, OECD 2011 and Colombo et al.: MONITORING AND IMPROVING QUALITY IN LONG-TERM CARE IN OECD COUNTRIES, forthcoming OECD 2013.

<sup>48</sup> See for instance: European Commission (DG ECFIN) — Economic Policy Committee (AWG), 2009, 'The 2009 Ageing Report: Economic and budgetary projections for the EU-27 Member States (2008-2060)', European Economy No 2/2009; European Commission (DG ECFIN) — Economic Policy Committee (AWG), 2012, 'The 2012 Ageing Report — Economic and budgetary projections for the 27 EU Member States (2010-2060)', European Economy No 2/2012.

<sup>49</sup> Lipszyc, B. et al. (2012), 'Long-term care: need, use and expenditure in the EU-27', Economic Papers 469, November 2012.



Associations (EFPIA). PharmaCog is a pan-European partnership of experts working on delivering high-quality Alzheimer's medication. The EMIF (European Medical Information Network) project has the goal of creating a common information framework of patient-level data that will link up and facilitate access to diverse medical and research data sources. One of the two areas addressed will be Alzheimer's, with a view to identifying the mechanisms that make some people more susceptible to the disease than others.

In the 6<sup>th</sup> and 7<sup>th</sup> Framework Programmes for Research **DG Research** has furthermore financed projects on health systems and LTC issues (e.g. ANCIEN, INTERLINKS, SHELTER, COURAGE, RightTime PlaceCare, REFINEMENT, MentDis\_ICF65, etc.)<sup>50</sup>. Projects centre on needs mapping, quality measurement, LTC delivery, role of financing systems in quality of care, development of best practices in long-term care organisation, and specific mental health issues in old age.

With the *Administrative Committee*, the European Commission is currently examining how Regulation 883<sup>51</sup> on the coordination of social security systems can be revised to ensure better long-term care coverage for mobile persons. As social protection for long-term care needs is increasing in importance, the EU social security coordination rules have to take these developments into account. In 2012, the Commission launched an Impact Assessment to analyse the different options for revised rules on the coordination of long-term care benefits. The aim is to enhance the effectiveness of the coordination regime, improve the social security protection of vulnerable citizens wishing to live in another Member State and improve legal certainty for all stakeholders. The Commission plans to finalise the Impact Assessment at the end of 2013 and to launch the revision in 2014.

## **7.6. Possible follow-up actions**

Together, these initiatives and activities by the European Commission and other EU institutions form a framework of potential support for developing social protection against LTC risks. There are thus substantial possibilities at European level to offer help to Member States in introducing innovative social investment-oriented approaches to providing long-term care.

### *Steering role of the SPC WG-AGE*

The immediate task at EU level should be to make more connections between these initiatives and activity areas and raise synergies between them. Developing the SPC-WG-AGE into a focal point for LTC-related activities across Commission services could be a first step. With regular reporting to Member State delegates in the SPC-WG-AGE from initiatives run by different services, a functional inventory of LTC activities could emerge and the interaction between these improved.

A programme of work has been proposed with contributions from experts, Member States and Commission services leading to an SPC report on *Innovative approaches to social protection against LTC risks*. This would entail involvement of or contact with external partners whenever required.

The intention is to organise knowledge generation and best practices exchange to explore avenues to innovative, better social protection against LTC risks in view of the shared OMC goals. Ideally, such social protection would consist in a continuum of policies from early

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<sup>50</sup> <http://www.ancien-longtermcare.eu/>; <http://interlinks.euro.centre.org/>; <http://lnx.starcomitaliaweb.eu/>; <http://www.healthcompetence.eu/converis/publicweb/project/3075;jsessionid=5360e5766198167404d643735d2b?show=Person>; <http://www.mentdiselderly.eu/>; <http://www.righttimeplacecare.eu/>.

<sup>51</sup> Regulation (EC) No 883/2004 of the European Parliament and of the Council of 29 April 2004 on the coordination of social security systems

prevention to practical delivery of LTC, including the role of informal care. Thematic meetings would include a keynote address from an expert followed by presentations from one or two Member States with particular experience in the topic under investigation. Each of these would be used to introduce discussions and exchanges of expertise between delegates.

Among the key challenges for policy makers and stakeholders, this proposal for a work programme focuses on the following:

- *limiting the growth of LTC needs through prevention, rehabilitation, and increased capacity for independent living*
- *ensuring access to LTC services for those in need*
- *securing the quality of care*
- *maintaining the financial sustainability of LTC delivery*

In order to address these issues, a sequence of thematic working meetings is set out. For each topic covered the **gender dimension** should be clearly addressed.

### **Expected contribution from JRC-IPTS**

A new JRC-IPTS project for 2013-14 aims to support DG EMPL in helping Member States to develop long-term care strategies promoting independent living of older adults — especially frail adults — through technology-based solutions. These solutions cover any kind of technology, including ICT, that empowers clients to manage despite frailties (self-sufficiency), better organises the provision of care or increases the productivity and quality of long-term care delivery (capital substitution for care manpower).

The **main objective** is to produce **guidelines** for the Member States to design long-term care strategies that can increase the capacity of older adults for independent living even when they become frail or contract multi-morbidities, with the use of technology and based on the case studies of good practices. This project will have the following specific objectives:

- To identify good practices in technology-based services and solutions for independent living at home for different needs of older adults, which have been successfully implemented.
- To analyse the good practices case by case in terms of **business case, business model, technology and organisational change, technical standards**, quality, scale and scale-up, and national and EU role for leadership and transfer.
- To produce a manual for policy makers on long-term care strategies for policies to increase the capacity of older adults for independent living with the use of technology.
- To identify the **role of the EU** in supporting Member States in implementing these technological services.

The specific added value of this project is helping decision-makers make an informed choice on this important topic, also from an economic and technical point of view and with regard to their own LTC delivery situation. The approach is definitely pragmatic and policy-oriented.

## **8. CONCLUSION**

Europe needs to prepare for a tripling of the number of people in the age group where people are most likely to need long-term care. The current modes of responding to older people's long-term care needs are not sustainable in view of this major demographic shift. This paper has tried to highlight ways of responding to this challenge by reducing the need for long-term

care through prevention, rehabilitation and the creation of more age-friendly environments, and by developing more efficient ways of delivering care.

Social innovation and social investment are called for to develop new ways of closing the gap between long-term care needs and provision. This paper presents some promising examples of good practice from a range of Member States. The EU can play a major role in promoting innovation and social investment in this area, e.g. through the European Innovation Partnership on Active and Healthy Ageing and the Ambient Assisted Living Programme. It can mobilise the structural funds for boosting investment in age-friendly environments and more qualified professional carers.

Progress towards financially sustainable and socially adequate social protection against long-term care risks should continue to be monitored by the EU's Economic Policy and Social Protection Committees. A successful response to the challenges of rapid growth in the number of people aged 80 or over will be crucial for the dignity and quality of life of older people and their relatives. It will also be decisive for achieving a number of goals set in the context of the Europe 2020 Strategy — sound public finances in ageing societies, a high level of employment and the reduction of poverty.

It is therefore suggested that future work with Member States on LTC gives particular attention to *a social investment-oriented strategy*, which combines preventive measures of healthy and active ageing with productivity drives in care delivery and measures to increase the ability of older men and women to continue independent living even as they become frail or develop disabilities. Moreover, as increasing priority is given to the quality of public expenditure in EU policy guidance through Country-Specific Recommendations, these should also focus on improving the effectiveness of spending in this area, so adequate social protection against long-term care risks can be ensured even at the height of population ageing.

## 9. ANNEX

### **ACTION programme, Sweden**

The ACTION programme (Assisting Carers using Telematics Interventions to meet Older people's Needs) is directed towards frail elderly persons who prefer to stay in their own homes, but are in need of support.

The ACTION service aims to strengthen the self-management capabilities of older people and their families. By means of ICT, family carers can get on-demand support from local service centres staffed with qualified professionals. The service primarily helps informal family carers. Also, networking and mutual exchange between service users is facilitated.

The service offers information, education and support to older people and their family carers via the following channels: access to an extensive information database about caring in daily life, services available and coping strategies; physical and cognitive training programmes and relaxation programmes; support and social company from other users via the integrated videophone system; support and advice from skilled care practitioners working in the call centre via the videophone system; individual and group computer education about how to use the ICT-based service; and comprehensive education, ongoing supervision and a certification programme for care practitioners working in an ACTION call centre. The main outcome of this service is a strong improvement in quality of life, reduction of isolation of the patient and the carers, the improvement of carers' preparedness, and therefore reduction in the need for home help services and delayed entry to nursing homes. The service is available to carers in several municipalities at a low price<sup>52</sup>.

### **Examples of prevention**

Prevention through the '**Re-ablement**' approach in the UK<sup>53</sup> aims to maximise independence and quality of life in older age, while reducing costs, by aiming for the lowest appropriate level of care for individuals. Key principles are: encouraging individuals to do things for themselves, focusing on real practical outcomes within a specified timeframe, and continuous rather than one-off assessment to decide on individual care needs (Allen and Glasby, 2009). One retrospective longitudinal study demonstrated that an average of 60 per cent of people leaving homecare re-ablement no longer required a homecare package and, 24 months later, had still not required a homecare package.

Recently, the UK Department for Work and Pensions (DWP) put in place the **LinkAge Plus** programme, a scheme worth £10 million to improve the wellbeing of older people through promoting stronger partnership, better information and access to services, and putting older people at the forefront of service design and delivery. The LinkAge Plus principles can be replicated in a variety of contexts. Case studies demonstrate the potential of the approach and a business case has been developed<sup>54</sup>, Taking falls as an example, on average, a fall resulting in a hip fracture costs around £20000 to the taxpayer. Evidence suggests that 15 weeks of balance classes reduces the likelihood of a participant falling by around 50 per cent. This illustrative example suggests that each £1 spent on balance classes by the taxpayer in

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<sup>52</sup> The Telecare Development Programme in Scotland 2006-2011, (2011) New Heaven Research.

<sup>53</sup> CSED Homecare Re-ablement Retrospective Longitudinal Study, Social Policy Research Unit (SPRU), University of York, Acton Shapiro research organisation.

<sup>54</sup> Watt P. and Blair I. (2009).

LinkAge Plus areas could yield health and social care savings of £1.35 plus benefits to the individual of around £0.90, from improved longevity and quality of life. Combining the costs and benefits of these services with a holistic approach to service delivery increases the net present value in the example to £2.65 per £1 invested.

### Examples of health promotion

Based on existing successful experiences over the last decade, the **UK NHS** created in 2011 the **New Medicine Services**<sup>55</sup> (NMS, October 2011 until March 2013) to provide early support to long-term care patients, to avoid inappropriate medication and to maximise positive benefits to clients. At this stage, the evidence suggests that the NMS will deliver net benefits of at least £210 million (discounted) in the worst-case scenario (i.e. highest cost and lowest benefit) over a 10-year period. This is purely in cash terms, and does not consider the potential wider health and economic benefits of the NMS, or the notion that £1 saved from a health intervention is worth £2.40. In the central scenario, net benefits are estimated at £1.5 billion (discounted) over a 10-year period.

### Examples of rehabilitation

**Germany:** CARITAS Bremen<sup>56</sup> has developed a rehabilitative approach as part of a programme that aims to support people moving back home, with the help of a ‘bridging person’ (‘Pflegeüberleitungsperson’). An innovative integrated care contract provides extended rehabilitative training, e.g. after acute hospital admission, to restore the mobility of older people and help them regain their autonomy and better cope with disabilities. The care unit is located in a care home, close to the department of physiotherapy, logo-therapy and occupational therapy. Following the programme, home care is available for up to seven days after discharge.

#### 9.1. Productivity and capacity gains from innovation including through use of ICT

The **CARICT** project<sup>57</sup> has investigated the potential impact of information and communication technologies (ICTs) on formal and informal carers by looking at experiences from a number of Member States. It documents that ICTs can offer a cost-effective way to improve the quality of care provided to dependent older people. ICT installations providing monitoring and assistive aids may allow people in need of care to carry on with daily life activities without recourse to continued formal or informal care. Key factors for success are care coordination, personal support and social integration. The project also documents that the burden on care-givers can be substantially eased by offering access to training about health and care issues and care-giving to frail people.

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<sup>55</sup> Introduction of the New Medicine Service (2011), Department of Health, Impact Assessment 5101, from <http://www.legislation.gov.uk>.

<sup>56</sup> Kümpers S, et al., (2010) Prevention and rehabilitation within long-term care across Europe, European Overview Paper.

<sup>57</sup> JRC (2013) *Can technology-based services support long-term care challenges in home care? Analysis of Evidence from Social Innovation Good Practices across the EU: CARICT Project Summary Report*. Authors: Carretero, S.; Stewart, J.; Centeno, C.; Barbabella, F.; Schmidt, A., Lamontagne- Godwin, F. and Lamura, G. JRC Scientific and Technical Reports Series, EUR 25 695 EN, at: <http://ipts.jrc.ec.europa.eu/publications/pub.cfm?id=5899>.

Telecare<sup>58</sup> in *Scotland* covers a range of devices and services that use technology to enable people to live with greater independence and safety in their own homes.

Examples include devices that trigger a response from a call centre, such as falls monitors and motion sensors. The responses may range from a phone call to the person, to alerting a local carer, neighbour or social service or alerting emergency services if appropriate. Other examples include devices that directly alert the person in the home to a particular hazard, such as a water-level monitor in a bath. IT developments are continually extending the range of devices and services available and, as a result, there is much scope for telecare to help older people with particular health and social care needs to remain in their own homes and optimise their independence and quality of life. Telecare (2006-2011) involved investments of £20 million, and is estimated to have saved approximately £80 million. Nearly half of these savings arose from avoiding care home admissions, while a similar figure arose from avoiding hospital in-patient stays. Clients and carers are referred to telecare by social services and/or by social workers or health professionals. The trial period achieved its aims to increase the use of telecare in mainstream service provision, improve assessment procedures for service users, train service providers' staff to incorporate telecare within care packages, ensure telecare services are delivered to recognised standards, and enhance innovation in telecare services. The Scottish government is now implementing a new telecare/telehealth initiative running from 2012-2015, called Delivering Assistive Living Lifestyles at Scale. This is intended as phase one of the wider Scottish Assisted Living Programme, which will utilise new technologies to support people with health and social care needs in their own homes.

*E-Care*<sup>59</sup> is as a pro-active case management service in operation since 2005 in *Italy*. The main objective of the E-Care project is to maintain independent living for the elderly in their own homes through customised care plans designed according to individual needs. E-care is a service organised as a 24-hour/7-days-a-week call centre that offers a wide range of services targeting physically frail or socially isolated elderly people aged 75+ living at home. The service provides older people with information on health, social care and social alarm services. A call centre functions as an intermediary between the frail elderly and social and health care providers. On a regular basis, an operator contacts the elderly to check their well-being, health conditions and needs. In the case of a problem, the operator and the patient decide together upon the action to take: intervention of a doctor or a volunteer organisation for social support. A unique electronic file records the basic individual history and a software platform allows for information-sharing and data transfer between care services. The E-Care platform has also been used to integrate services such as:

- Uffa che Afa' — an initiative set up to support vulnerable people during severe heat waves
- a tele-geriatrics service to support people who need care after hospital discharge
- a dementia-specific telecare service
- the 'Giuseppina' service, which provides free home delivery of food and medication as well as transport services to hospitals or social events

E-care has reduced the number of hospital admissions and led to a decrease of 50% in users accessing hospital services.

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<sup>58</sup> See: <http://www.scotland.gov.uk/Publications/2010/10/27154413/6>.

<sup>59</sup> See: <http://www.ict-ageing.eu/index.php?s=E-care+Project>.

## Quality assurance in LTC

**Framework for the Prevention of Elder Abuse and Neglect<sup>60</sup>: The Netherlands** has implemented an ambitious and very comprehensive legal and institutional framework to fight elder abuse. The framework covers all stakeholders and most dimensions of the phenomenon through initiatives in 10 areas:

- 1: Prevention (guide for municipalities on preventing elder abuse, including a special initiative on financial exploitation)
- 2: Targeted information and awareness-raising for *older people* on elder abuse
- 3: Screening of *paid care staff*, including via mandatory certificates of conduct (VOG)
- 4: Toolkit on *volunteers* and elder abuse (awareness raising and guidelines for conduct)
- 5: *Reporting* elder abuse to authorities (mandatory for abuse by professionals, mandatory protocolling of abuse in home environments, specific guidelines)
- 6: E-learning, *training* and education of care staff (in collaboration with trade unions etc.)
- 7: Elder-abuse *hotlines* (established in centres for reporting of domestic violence etc.)
- 8: Aid and *support for victims* following a report of neglect or abuse
- 9: Support for victims of disruptions in informal care
- 10: Approach to perpetrators (principles for handling abuse cases: a serious offence requiring a legal approach entailing intensified monitoring of reported elder abusers; moreover, if professional care staff commit elder abuse, the IGZ Assessment Framework stipulates that the care institution must suspend the offender and that a report of criminal activities should be filed with the public prosecution service, where appropriate.

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<sup>60</sup> See: <http://www.preventelderabuse.eu/european/Multimedia/Get/186>.