LONG-TERM CARE IN THE EUROPEAN UNION

1. INTRODUCTION .................................................................................................................. 2

2. BACKGROUND AND STYLISED FACTS .................................................................................. 3
   2.1. Definition of Long-term Care and current developments .................................................. 3
   2.2. Demographic ageing and incidence of dependency ........................................................ 4
   2.3. Projected expenditure on Long-term Care ....................................................................... 8
   2.4. Responsibility for provision and trends ........................................................................... 13

3. NATIONAL POLICY DEVELOPMENTS ............................................................................... 16
   3.1. Access to adequate long-term care ............................................................................... 16
   3.2. High level quality in LTC services ............................................................................... 20
   3.3. Long-term sustainability .............................................................................................. 24

4. CONCLUSIONS .................................................................................................................... 35
LONG-TERM CARE IN THE EUROPEAN UNION

1. INTRODUCTION

The social protection systems established in the Member States have the aim, amongst others, of ensuring access for all, to high quality care. The widespread extension of coverage against sickness and invalidity, along with other factors such as the rise in the per capita standard of living, improved living conditions and enhanced health education, are the main reasons for the improvement of the overall health status of the European population. The development of social protection systems has considerably reduced the risk of poverty, which in the past was often linked to ill health, old age or accident, and has made a significant contribution to improving the state of health of the people of Europe over recent decades. The development of social protection systems has made it possible to shield people from the financial consequences of ill-health and, at the same time, sustain the rapid, ongoing advancement in medicine and treatment.

The improvement of the health status of the European population is exemplified by the increases in life and healthy life expectancies. For Europeans, a high level of protection against the risk of illness and dependence is a vital asset that must be preserved and adapted to the concerns of the modern world, particularly demographic ageing. It is in light of these developments and the concerns over expanding expenditure that Member States committed to the modernisation of their social protection systems. Social protection is a way of covering, at the level of an entire society, costs which often exceed the means of an individual or his/her family, ensuring that paying for healthcare does not lead to impoverishment and that even those on a low income have reasonable access to care. These results have been achieved using a wide range of systems – based on insurance or the direct provision of services – the prime responsibility for which, under the Treaty, falls to the Member States.

In light of these national sustainability concerns and the EU Member States' commitment in meeting the increasing long-term care needs of the population, the Luxembourg Presidency Conference "Long-term care for older persons", held on 12 and 13 May 2005, emphasised that, despite the multiple means of addressing this social risk, it is inherently a public responsibility and therefore the competence of the Member States: "In some countries the responsibility is shared between the health and social welfare administrations, in others it is treated as a separate social risk." The joint EU Commission and AARP Conference "The Cross Atlantic Exchange to Advance Long-Term Care" held in Brussels on 13 September 2006, emphasised that, given the extended longevity in the EU and the United States, an increasing demand for long-term care can be expected.

The increased demand for long-term care services represents a policy challenge for many countries as current supply is considered to be insufficient and inadequate in terms of meeting current and especially future needs and thus ensuring adequate living conditions for long-term care recipients. Recognition that there is no comprehensive system for the provision of long-term services in the US and in large parts of the EU was,

however, coupled with a firm commitment, on the part of EU countries, to ensure universal access to high quality and affordable long-term care.

Member States submitted national reports on social inclusion, pensions and, for the first time, health care and long-term care in September 2006. This paper reviews the 2006 national reports in relation to long-term care. It analyses the main challenges Member States face and their strategies to tackle these challenges in the fields of long-term care in the light of the agreed common objectives. With regard to the data used in this paper, the Indicators Sub-Group of the Social Protection Committee is currently working towards the development of common indicators for the Healthcare and Long-term Care strand of the OMC\(^2\) and thus the tables and graphs presented in this paper are for illustrative purposes only.

### Common objectives for health care and long-term care

Member States are committed to **accessible, high-quality and sustainable health care and long-term care by ensuring:** (j) access for all to adequate health and long-term care and that the need for care does not lead to poverty and financial dependency; and that inequities in access to care and in health outcomes are addressed; (k) quality in health and long-term care and by adapting care, including developing preventive care, to the changing needs and preferences of society and individuals, notably by developing quality standards reflecting best international practice and by strengthening the responsibility of health professionals and of patients and care recipients; (l) that adequate and high quality health and long-term care remains affordable and financially sustainable by promoting a rational use of resources, notably through appropriate incentives for users and providers, good governance and coordination between care systems and public and private institutions. Long-term sustainability and quality require the promotion of healthy and active lifestyles and good human resources for the care sector.

### 2. BACKGROUND AND STYLISED FACTS

#### 2.1. Definition of Long-term Care and current developments

It is important to note that, within the European Union, different definitions of long-term care coexist. The OECD has defined long-term care as "a cross-cutting policy issue that brings together a range of services for persons who are dependent on help with basic activities of daily living\(^3\) (ADLs) over an extended period of time."\(^4\) Elements of long-term care include rehabilitation, basic medical services, home nursing, social care, housing and services such as transport, meals, occupational and empowerment activities, thus also including help with Instrumental activities of daily living (IADLs).\(^5\)

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\(^2\) [http://ec.europa.eu/employment_social/spsi/common_indicators_en.htm](http://ec.europa.eu/employment_social/spsi/common_indicators_en.htm)

\(^3\) 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.

\(^4\) OECD 2005 Long-Term Care for Older People

\(^5\) 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.
care is usually provided to persons with physical or mental handicaps, the frail elderly and particular groups that need support in conducting their daily life activities. "Long-term care needs are most prevalent in the oldest age groups [...] who are most at risk of long-standing chronic conditions causing physical or mental disability."6

Member States use a variety of definitions that do not always concur. The variations occur in the determination of the length of stay, the identification of the care recipient and the available taxonomies defining the long-term care services provided. Additionally, the demarcation between healthcare (medical component) and social care (non-medical component) is often blurred. The same can be said with regard to rehabilitative services and the length of time spent in hospital (acute care) or in an institution before discharge with some countries clearly favouring lengthier rehabilitation rather than hospital or institutional stays. Additionally, differences in the evaluation of 'dependency' and its coverage, whether support should be provided in kind or in the form of financial benefits, the recipient of that support and the general demarcation between the role of the public sector the private sector or the family are prevalent. Long-term care is often defined as a variety of health and social services provided on an ongoing or extended period of time basis, for individuals who need assistance on a continuing basis due to physical or mental disability7.

Different levels of organisation and different divisions of responsibility (public-private), as well as differences in demarcating the boundary between the medical component and the social care component, result in a great variation of long-term care services, their organisation and their role within the social protection systems of the EU Member States. Additionally, in certain countries, LTC is often associated with the notion of a 'care continuum' or an integrated approach, including elements of other public health policies such as preventive measures, active ageing, autonomy promotion and empowerment, social assistance, healthcare and end-of-life or palliative care. LTC is often intertwined with and cuts across other public policy fields such as the combating of social exclusion and provision of social security for formal and informal carers. The definition of LTC, the services and benefits provided as well as the population coverage, vary between Member States.

2.2. Demographic ageing and incidence of dependency

The demographic developments in Europe are well documented. As stated in the Commission's 2006 Demographic Report, "Demographic ageing, i.e. the increase in the proportion of older people, is above all the result of significant economic, social and medical progress giving Europeans the opportunity to live a long life in comfort and security that is without precedent in our history."8 Expenditure dedicated to Health and Long-term care, being the largest behind retirement and survivors' pensions, represents a substantial share in overall social protection expenditure. Demographic ageing and societal changes do not necessarily translate into an increased demand for Long-term care services. It is the increases in life expectancy and the incidence of disability and

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6 OECD 2005 Long-Term Care for Older People
7 OECD Observer 2007, Long-term care: a complex challenge
8 The demographic future of Europe – from challenge to opportunity, European Commission, October 2006
dependency that drive increases in demand for Long-term care. The increases in life expectancy at birth for both males and females (Figure 2) have clear implications for current and future needs in terms of LTC. Indeed, increased longevity will spur future demand for LTC services in both the formal and informal setting. Setting the medical element of LTC aside, increased longevity has and will bring about additional demands in terms of rehabilitation, prevention of ill health in old-age, adequate living conditions for the elderly population (social assistance and pensions) and various policies aimed at enhancing participation in societal activities and empowerment schemes. Life expectancy at birth, having risen by some 8 years since 1960, is projected to rise by a further 6 years by 2050.

Fertility rates below the replacement level and demographic ageing translate in a greater share of old and very old people in the future. It is expected that the number of people aged 65 and over will increase by 77% by 2050, whereas the working age population (15 to 64) is expected to decline by 16% by 2050 due to fertility rates below the replacement level. The old-age dependency ratio, referring to the number of people aged 65 years and above relative to those between 15 and 64, is projected to double, reaching 51% in 2050. Europe is expected to halve its old-age dependency ratio, from four people of working age for every elderly citizen currently to a ratio of two to one by 2050.

**Figure 1: Age pyramids for the EU25 population in 2004 and 2050**

Source: EPC and European Commission (2005a)

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11 Ibid
Population ageing results in an increasing share of old and very old people in the population, leading to new patterns of morbidity and mortality, such as an increase in (often multiple and reinforcing) degenerative and chronic diseases. Figure 3 identifies the self-reported need for LTC according to age groups, showing a greater prevalence of dependency and disability for older age-groups. Demographic ageing, coupled with fertility rates below replacement level and a prevalence of chronic disease in the older age groups (Figure 3), can serve as a proxy of the future demand for LTC. A higher prevalence of chronic diseases and dependency patterns in old age does not mean that LTC is a sole concern for the elderly population despite their predominance as LTC recipients.
**Figure 2:** Source: Eurostat 2004 Demographic Projections (Baseline scenario)\(^{12}\)

**Figure 3:** Self reported chronic disease prevalence by age group EU25\(^{13}\)

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\(^{12}\) The demographic future of Europe – from challenge to opportunity, European Commission, 2006

\(^{13}\) Source: ESTAT, EU-SILC 2005
Data-gathering on the incidence of dependency or disability is difficult. Countries use varying definitions regarding the degrees of intensity of dependency (moderate to severe) as well as heterogeneous concepts when measuring the incidence of chronic conditions. The intensity of dependency will inevitably affect the type of follow-up care to be provided. Despite the importance of data collection on chronic disease incidence, few countries collect such data. "Chronic disease represents one of the most relevant problems for health-related quality of life, especially for the elderly, and is one of the main causes of utilisation of health services. Chronic disease often affects the psychological or physical abilities of people for a long time or even indefinitely. […] Several of these chronic conditions are significant because they are major causes of death, disability or hospitalisation (hypertension, diabetes, chronic heart disease or stroke)." 14

The most important element in addressing the future needs for LTC services (both formal and informal) is the degree of additional life-years spent in good health or the health status of the elderly population. Indeed, since demographic developments point out to the increased longevity of the population, a serious challenge or opportunity in terms of public health is the prevention of ill-health in old age, i.e. delaying the onset of disability or dependence. Demographic developments increase the pressure on long-term care systems to provide more and better curative medical care but also more rehabilitative, nursing and social care.

2.3. Projected expenditure on Long-term Care

A shared perception that came to light in the national reports and the Joint AARP conference is that long-term care expenditure will increase in the near and distant future in order to meet growing demand. The Council requested that the EPC provide projections for public spending on long-term care. The 2006 EPC/EC projections predict an increase in public long-term care expenditure of 0.7 percentage points of GDP (with FI, SE and SI showing a 1.8, 1.7 and 1.2 increase) due to population ageing (Table 1). It must be noted, however, that this increase may be higher as the projections are based on current institutional and policy settings, whilst many Member States are only starting to develop a comprehensive framework for long-term care provision.

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Table 1: Estimated expenditure on long-term care and projections until 2050\textsuperscript{15}

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\textsuperscript{15} In the case of Austria, the public long-term care expenditure of 0.6% of GDP in 2004 includes federal long-term care expenditure only.
The methodology applied in the EPC projections allows for the inclusion of a wide range of variables affecting future long-term care expenditure and for the inclusion of a maximum number of Member States in the projections through the use of macro-level data. Specifically, the methodology allows for changes in several variables in order to model different assumptions underlying the projection calculations. The variables in which changes can be computed include: the future numbers of elderly persons (population projections); the future numbers of dependent elderly persons (prevalence rates and projections of dependency); the balance between formal and informal care; the balance between home and institutional care within formal care provision; and the costs of care units. The inclusion of these variables has substantially enhanced the projections, compared to the 2001 exercise. Despite this improvement, one needs to remain cautious in the interpretation of these projections as gathering data in order to set baseline expenditure levels proved very difficult.

Table 2:\ Changes in the older populations of the EU and the US, 2004-50

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Table 2 shows that the total number of elderly persons (65+) is projected to increase by 77% by 2050 with 2004 as the base year. The growth of the oldest old population (80+) is projected to be even more significant amounting to 174% between 2004 and 2050. This higher overall growth in the oldest old population is important when one considers the higher prevalence of disability or dependency in the oldest old age group and their need for long-term care provision. The key variable is the evolution and incidence of dependency rates in the future. The projections assume an important

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16 According to the 2006 EPC projections public long-term care expenditure in Germany is projected to increase from 1.0 % of GDP in 2004 to 2 % of GDP by 2050 due to population ageing, if benefits rise in line with GDP per worker. In an alternative scenario, assuming that benefits rise in line with the general inflation rate, expenditure would stay constant at 1.0 % of GDP. This scenario has been developed by the EPC to better reflect the German system of long term care with nominally fixed benefits, which have not been amended since the introduction of long term care insurance in 1995. A future dynamic sampling of the benefits in line with the general inflation rate is discussed as an element of the forthcoming reform.

17 The Cross-Atlantic Exchange to Advance Long-term Care, Special CEPS Report, S. Tsolova, J. Mortensen, 2006, p.16
increase in life expectancy. It is fair to assume that the increase in overall life expectancy will be coupled by an increase in disability-free life expectancy or the years spent without any need for assistance with DLA. It is argued that disability rates in the older age groups are declining. There are two possible scenarios, one pessimistic and one optimistic. The pessimistic scenario (pure ageing scenario) assumes that the increase in life expectancy is not followed by a decline of dependency or disability rates, hence the additional life years are spent in ill health or in need of assistance. The optimistic scenario (constant disability scenario) on the contrary, assumes that the increase of disability-free life expectancy is in line with the gains in life expectancy, hence translating into a contraction of demand for long-term care services.

Table 3: Projection of dependent population, in millions – pure ageing and constant disability scenarios

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<td>Constant disability scenario</td>
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Note: Excluding Greece, France, Portugal, Cyprus, Estonia and Hungary for which no data were available

Source: DG ECFIN calculations

Table 3 shows that a pure ageing scenario would result in more than a doubling of the number of dependent persons by 2050, whereas the constant disability scenario, assuming that disability-free life expectancy increases in line with the gains in life expectancy, would only result in a 31% increase in the number of dependent persons for the EU25.

In addition to the incidence of dependency and its prevalence among older old age groups, other variables possibly influencing the future demand of long-term care services are the foreseen changes in the organisation and provision of long-term care services: unit costs, the balance between formal and informal care and within formal provision and the balance between home and institutional care.
In some Member States, the projected increase in demand for long-term care, coupled with the increased labour participation of women involves an increase in the demand for formal long-term care services, since women will be less available for informal care provision. Additionally, the trend towards providing formal long-term care in the home rather than in an institutional setting may lead, in some countries, to an increased demand for formal home care. Such a change would necessitate clear national action in the promotion of at home rather than institutional formal care and a complementary use of assistive and preventive technologies supporting the autonomy of older persons. Figure 4 sets out two scenarios projected by the AWG for public spending on LTC in 2050: i) pure ageing (no change in age-specific disability/dependency rates which, given expected increase in life expectancy, illustrates relative increase in the share of lifespan spent with disability/dependency); ii) constant disability (contraction of age-specific disability/dependency incidence such that the share of lifespan spent with disability/dependency remains constant). Moreover, a sensitivity test which has been applied to the two scenarios shows that a 1% yearly shift of informal care recipients to the formal sector may result in an additional expenditure of 0.6% of GDP at the end of the projection period. It can thus be assumed that even in the case of a contraction of the age-specific disability/dependence incidence, the trend would be towards an increase in public spending on long-term care.

The optimistic scenario of an increase in disability-free life expectancy projects a low public expenditure on formal LTC of 1.3% in 2050. A high public LTC expenditure of 2.3% of GDP is projected for the EU25 in 2050, allowing for the sensitivity test. The latter projection combines the (pessimistic) pure ageing scenario with a projected increase in formal LTC provision (resulting from a shift from informal or no care to formal institutional and home care). Although these projections foresee an increase in public spending for formal LTC provision in 2050, it must be stressed that these appear to be conservative. Indeed, the calculation mechanisms are based on a no-policy-change assumption. Firstly, data was not made available for all countries. Secondly, formal LTC expenditure includes expenditure spent on institutional and home care, combined with cash benefits dedicated to LTC. Countries with a currently low public expenditure dedicated to formal LTC provision, are projected to have a minimal increase in public spending for formal long-term care. Similarly, the increase in formal care sensitivity test

Source: Directorate General for Economic and Financial Affairs, European Commission
assumes that "until 2020, the number of persons receiving informal (or no) care falls by
1% per annum: half of these persons are assumed to receive formal care in institutions
and the other half would receive formal care at home."18

2.4. Responsibility for provision and trends

In 2007, a Eurobarometer surveyed Europeans' attitudes about the quality, availability, accessibility, and affordability of long-term care for dependent people in need of help19. The results of the survey show that the majority of the Europeans think that they will become dependant for a prolonged period of time at some stage during their life (Figure 5). The likelihood of becoming dependant is positively correlated with the age of the respondent.

**Figure 5: Do you expect that at some stage during your life, you will, for a prolonged period of time, become dependent upon the help of others because of your physical or mental health condition?**

![Figure 5: Do you expect that at some stage during your life, you will, for a prolonged period of time, become dependent upon the help of others because of your physical or mental health condition?](image)

**Note:** *DK is “don’t know”*

Long-term care provision varies across Member States in terms of population coverage, the extent of provision and also in terms of the schemes used. Countries are firmly focused on enhancing tailor-made home and community care services and moving away from institutional care. This does not mean that institutional care provision is to be dismantled. Rather, institutional care must be maintained for those with severe disabilities/conditions, for whom home care is not the most appropriate alternative. According to the OECD, a majority of countries are primarily concerned by the need to develop and expand home or community care, with the development of an appropriate quality level of LTC receiving the same degree of attention throughout the studied countries20. Where available, home or community care is preferred to institutional care.

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Moreover, even where provided, care in institutions should be provided within a community setting ensuring the social inclusion and participation of their residents in accordance with the prevailing societal values and norms. The goal is to help individuals remain at home for as long as possible, while providing institutional care when needed. This also supports individual choice and preferences: in general people want to live for as long as possible in their own homes, close to their family and friends. The Eurobarometer survey shows how European expectations of how they will receive long-term care are largely consistent with their preferred ways of receiving help in the event of dependency. It is interesting to note that their expectations and preferences favour home-based care over institutional care. Respondents both expect and prefer to receive long-term care in their homes—whether by family (most preferred and expected by 45%), a professional care service, or a paid carer.

**Figure 6: Preferred versus expected ways of being looked after in case of dependency**

![Bar chart showing preferred versus expected ways of being looked after in case of dependency](image)

Although national customs influence differences in these views among countries, it is clear from these results that nursing home care is a much less preferred option across most of Europe. Moreover, wide consensus exists among respondents that public authorities should provide appropriate long-term care for the elderly (93%), that the state should pay professional carers to take over from family carers to give them breaks (91%), and that the state should provide an income to individuals who have had to leave the work force or reduce their role in order to provide care (89%). Additionally, a sizable majority of respondents (70%) believe that individuals should be obliged to contribute to an insurance scheme that funds long-term care and that the house of a person unable to afford long-term care should not be sold to pay for needed services. Significant variations occur among countries also on these two issues. Finally, over 70% of Europeans feel that the dependent person in need of care is forced to rely too heavily on their children. While this perspective does not seem to vary greatly at the socio-demographic level, significant country variation occurs.

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22 The OECD Health Project, Long-term Care for Older People, OECD 2005
Despite the above described trend of moving away from institutional care towards home or community care, LTC services are still necessarily provided in hospitals in an acute or non-acute setting (nursing homes). The length of stay and the services provided depend on the medical, financial and family conditions of the LTC recipients. Home and community services typically include: a) home medical visits, home nursing, home assistance (e.g. cleaning, shopping, meals-on-wheels) and home adjustment (e.g. rails, walk-in baths), b) day or short-stay hospitals, day care and transport, night care centres, service housing (typically rented individual apartments with associated medical and social services) and c) tele-assistance. Geriatric, transition and rehabilitation wards are means of ensuring the transition from acute to home settings.

Similarly to the difficulties encountered when assessing the expenditure (private and public) dedicated to long-term care, it is difficult to measure the exact degree and coverage of LTC provision. Difficulties in measurement stem from varying definitions of what constitutes long-term care, what schemes are included under the LTC concept and the length of stay. Some countries are favouring longer lengths of stay in institutions than others. Some countries focus on the provision of a medical care continuum whereas others discharge patients from institutional care faster, whilst emphasising rehabilitative or preventive follow-up of care. The structure and organisation of the different LTC schemes vary between European countries, reflecting more the organisational features of each system rather than population structure and demographic developments. The variations reflect the differing national approaches to familial solidarity (occurrence of informal care and support towards carers) as well as identifiable disparities between the demand for and the provision of publicly funded LTC services.

Although home care or community services are less expensive than acute care in an institutional setting, the resources allocated to the home care sector vary between countries. In the majority of countries, publicly funded institutional care still accounts for more than half of the long-term care expenditure. Despite the fact that most countries wish to expand community and home care, either for financial reasons or in order to provide patient-centred services, the share of home care as a component of public spending on LTC varies. In the countries with the least developed LTC systems, the share of public spending on home care as a proportion of total LTC expenditure is minimal. Other countries have made significant steps in the direction of increasing the public spending dedicated to home and/or community care. The schemes included in the LTC definition and the legal status of the LTC providers will affect the degree of comparability between the various schemes and their levels of expenditure. Figure 7 shows the degree of variation in overall (institutional and home care) long-term care expenditure.
3. NATIONAL POLICY DEVELOPMENTS

3.1. Access to adequate long-term care

The national reports show how strongly interlinked the three commonly identified objectives are. They emphasise the strong synergies between improving access, enhancing quality and ensuring sustainability in a number of policies. Thus, the reader will find the same issues addressed in more than one section, albeit from a different perspective reflecting these synergies. This section will address the common objective of accessibility.

Member States are committed to **accessible, high-quality and sustainable health care and long-term care by ensuring**: access for all, to adequate health and long-term care and that the need for care does not lead to poverty and financial dependency; and that inequities in access to care and in health outcomes are addressed.

EU Member States are strongly committed to ensuring access for all, to adequate health care and long-term care. Solidarity and equitable financing (progressive financing through income-related taxation and contributions, risk pooling, risk selection prohibition and risk adjustment mechanisms) are principles inherent in health care systems. Moreover Member States aim to ensure that access does not depend on ability to pay, income or wealth and that the need for care does not lead to poverty and financial dependency. Universal or near universal rights giving access to care can be found in all Member States, either through National Health Systems (NHS), providing access rights to all residents in a country, or through Social Health Insurance Systems, where access

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23 For Germany, expenditure on vocational integration is not included.
rights are typically granted to those making contributions (and their families) with the State (through taxation) ensuring access for non-contributing individuals.

However, universal rights do not necessarily translate into universal access and there remain significant sources of inequalities in access that demand further attention. Member States investigated how social protection systems – including access to care – contribute to reducing health inequalities by means of a peer review in January 2007.24 The supply of LTC is considered to be inadequate to meet current and especially future needs given demographic developments. EU countries have expressed their intention to ensure universal access to quality care. Despite the formal provision of universal access, barriers to access still persist, unevenly distributed across the population. These include lack of insurance coverage, lack of coverage/provision of certain types of care, high individual financial costs of care and geographical disparities of supply. They also include lengthy waiting times for certain treatments, lack of knowledge or information and complex administrative procedures.

Increase in population coverage

Many Member States recognise the inadequacy of their long-term care systems in the light of population ageing, socio-demographic developments and changing needs (BE,EE,EL,ES,LT). Whilst committed to ensuring access, Member States acknowledged that comprehensive and universal access to long-term care is effectively hindered through various obstacles that need to be addressed. Differences in access to a range of long-term care services can be observed for various population groups, some of which are not yet fully covered by social insurance schemes. Indeed, long-term care offers especially limited coverage. In this context, Member States want to expand long-term care services. This includes increasing population and care coverage under health insurance schemes and enhancing the availability of specialised services, home or community (close to home) care (medical, nursing and social care) and residential care when the alternative is no longer medically appropriate/adequate (e.g. BE, CZ, EL, HU, ES, LT).

Content of the health benefit package

Long-term care does not refer to the same range of services in all countries. Some countries focus on the medical component, separating medical from social care. The provision of integrated services for dependent and elderly persons, albeit accepted as an overall goal to be pursued by the various responsible authorities for long-term care, is not available everywhere. This, in turn, limits and undermines the provision of a continuum of care with adequate follow-up of the care given to dependent and elderly persons. Many Member States wish to promote rehabilitative care (PT,CZ,EL,FI,FR) with a view to restoring patients' skills so as to regain maximum self-sufficiency in order to function in a normal or as near a normal manner as possible. Rehabilitative care can be provided in an institutional and a community setting. More importantly, rehabilitative services should be provided in order to allow, where possible, the patient's reintegration within the labour market. In social health insurance based systems, however, some components of long-term care can be excluded from the positive reimbursement list or may not be included as part of the long-term care benefits available. This often has implications

either for cost-sharing (not reimbursable services) or for direct payments (out-of-pocket payments). Indeed, cost-sharing, direct payments and informal payments are the main administrative and organisational hurdles faced by vulnerable groups when seeking access to long-term care services.

**Ability to pay and cost sharing for Long-term care**

High private costs, which are seemingly higher than in health care (out-of-pocket payments and voluntary private insurance), impose a major financial burden on users and their relatives and act as a barrier to access, particularly for low-income groups. Indeed, it is often the case that elements of medical and social care provided to dependent or elderly persons are not covered by the basic insurance packages, leading to a high occurrence of co-payments and out-of-pocket payments. This is associated with the recourse to private provision resulting from either the inadequacy of public provision/insurance and/or the country's organisational structure and financing. Several countries have introduced co-payments, insurance premiums or means-tested systems for long-term care provision (e.g. CY, EE, IE). Policies to reduce the individual direct costs of care include: co-payment exemptions and co-payments based on income; extra financial aid/welfare benefits granted to the elderly dependent, disabled and chronically ill; state coverage of social long-term care for low-income households in a Social Assistance framework (e.g. FR, NL, BE, HU, DE); nationwide standardisation of co-payments; and state subsidies to use private services.

Out-of-pocket payments are, to varying degrees, borne by the majority of people both in health and long-term care services, with varying consequences in terms of accessibility of the services and equity issues. Out-of-pocket payments, and the degree to which they are regressive, depends in turn on the organisational features of each long-term care system and the availability of supplementary insurance coverage. In Germany for example, despite the existence of specific long-term care insurance and social assistance mechanisms, there is currently a small (1% of the population) but growing market of voluntary private complementary insurance to cover costs that are borne by individuals (e.g. accommodation fees in nursing homes)\(^25\).

**Waiting times and regional diversity**

The shortage of publicly funded long-term care services has resulted in substantial waiting times for existing care, particularly residential care. Uneven geographical provision (across regions, urban versus rural, within cities) can also be observed as social services are typically the responsibility of local authorities or regions. To tackle this, Spain, for example, is planning the implementation of a uniform basket of long-term care services across the autonomous regions making long-term care accessibility a priority for social inclusion policy. The newly launched “Autonomy and Dependency Care System” was designed to guarantee care for dependents and promote their autonomy. It provides for a wide range of care services both at home and in care centres, and for financial and every day support to their families. 100% coverage by 2015 is the target. Additional factors influencing the prevalence of waiting times and lists include the availability of medical and nursing staff as well as their level of pay and working conditions and the infrastructure capacity of the country.

\(^{25}\) The OECD Health Project, Long-term Care for Older People, OECD 2005, p.118
Tailored community and home care services and integrated LTC provision

Countries are firmly focused on enhancing tailor-made home and community care services and moving away from institutional care (which has to be maintained for those with severe disabilities/conditions, for whom home care is no longer the most appropriate alternative). Information and communication technology (ICT) (e-health solutions such as tele-monitoring, tele-medicine and independent living systems) can help to ensure independent living and more user-oriented services. For example, such technology can enable better self-management of chronic conditions and can support informal carers in their role. The goal is to help individuals to remain at home for as long as possible, while providing institutional care when needed. This also supports individuals' choice and preferences: in general people want to live for as long as possible in their own homes, close to their family and friends. The provision of home care services in conjunction with enhanced information and communication technology depends on resource availability and the degree to which long-term care is provided in an integrated framework.

As highlighted in the National Reports, provision is to be expanded through coordination between the national, regional and local levels of government and in partnership with the private and notably the voluntary sector. In Finland, the authorities are also planning joint municipal-level provision. The fragmented provision of long-term care services (between different levels of care and between different administrative levels) can reduce the accessibility of long-term care services. For example, hospital discharge ought to be followed by tailored home care provision or care within a community setting. In Germany, patients are entitled to "transfer care" from hospital to the subsequent care setting (at home or institutional) which is organised by case managers. From 2009 this entitlement will be extended to a comprehensive case management in order to establish individual support in all questions of LTC organisation and provision by "care counsellors" that call on the patient wherever necessary: at home, in the hospital or in an institution. When such follow-up provision is neither available nor planned, the accessibility of long-term care services is threatened. Indeed different patients have disparate and often multiple needs for long-term care services. The assessment of those needs and the provision of the various services must be carried out in a way that respects the choice and dignity of the person in need of care. The uniform and tailored provision of long-term care services depends in turn on the organisational features of each system and the degree of coordination between the different services operating within these systems.

Increased provision of tailor-made services - Czech Republic

Social care for disabled persons and older persons was mainly provided in institutions or via nursing care in the home or in nursing homes. The authorities are enhancing the provision of services increasingly focused on the needs of individuals. Emphasis is placed on respecting and protecting the individual’s rights and on creating an environment where their rights are implemented. Several examples have been highlighted to exemplify the increased provision of individualised or tailor-made services: Contact Centre of the Czech Alzheimer's Society; Charity Ostrava Hospice Care initiative for the provision of palliative and integrated specialised services (mobile hospice unit); initiatives at the local level in Ceska Lípa where daily short-term hospital services for persons with Dementia have been developed as an outcome of Community Planning. Local funds have been earmarked and served for the opening up a day centre for the elderly and for the support of family carers in their caring roles. Equally, several community-oriented services have been developed in Ostrava. In addition to the
reconstruction and modernisation of existing residential facilities, it has increasingly been putting emphasis on extending in-field, out-patient and community-orientated services in recent years, with the objective of supporting clients' independence in their own social surroundings.

3.2. High level quality in LTC services

Member States are committed to accessible, high-quality and sustainable health care and long-term care by ensuring: quality in health and long-term care and by adapting care, including developing preventive care, to the changing needs and preferences of society and individuals, notably by developing quality standards reflecting best international practice and by strengthening the responsibility of health professionals and of patients and care recipients.

The quality of long-term care services for dependent persons varies widely both between and within countries. Patient satisfaction surveys and reports of poor quality have raised concerns and prompted public, private and national initiatives to improve the quality of care services and enhance quality reporting and assessment mechanisms. Evidence regarding quality deficits in long-term care has emerged from a multitude of sources such as the media, advocacy groups, public reviews, long-term care providers and quality accreditation and monitoring associations. Examples of poor or inadequate care quality in both institutional and community settings include: inadequate housing (nursing homes), lack of privacy, poor social relationships and use of restraints, amongst others.

Concerns over poor quality of long-term care services have played an important role in the lead up to reforms aimed at enhancing access to long-term care services and increasing funding for this area. Many Member States have introduced or improved regulations and legislation for assessing and enhancing the quality long-term care services. Improving quality standards plays a major role in ensuring adequate care quality for dependent persons, whether for informal (family) care, formal home care services or in institutions. Efforts must be made to improve quality of care in this field, which is often considered low and which tends to vary greatly within countries (e.g. HU, MT, PL, PT, EE, EL).

26 The study "Deinstitutionalisation and community living – outcomes and costs: report of a European Study. Volume 2: Main Report", prepared by Mansell J, Knapp M, Beadle-Brown J and Beecham, J (2007) Canterbury: Tizard Centre, University of Kent, for the European Commission can be found at the following link: http://ec.europa.eu/employment_social/index/vol2_web_report_en.pdf. The Study confirms that institutional care often exhibits poor quality levels. Community-based services, when adequately established and managed, can deliver better outcomes in terms of quality of life and ensure that disabled people can live as full citizens. The Report makes the case that community-based services are often not more expensive than institutional care once the needs of residents and quality of care have been taken into account when calculating the costs.
Residential Groups for people with long-term mental disorders – Slovenia

The authorities have promoted the establishment of Residential Groups for those with long-term mental disorders that were admitted several times to psychiatric hospitals. The aim is to avoid repeated hospitalizations, institutional care or inadequate care at home with the development of small care units accommodating up to 14 users in a community setting, a context which exhibits higher privacy than in institutions.

Care Offered to Persons with Dementia – Austria

The project has been running from November 2006 and resulted in the compilation of a Handbook on Dementia, which lists and describes the services and institutions available to persons with dementia in qualitative terms and which was published in spring 2008.

The increasingly pervasive and all-encompassing nature of long-term care services renders quality definition and measurement a difficult and complex task. Indicators of the quality of care are used to assess and evaluate the quality of the services provided in both the institutional and community settings. Such indicators have been developed over time and used extensively for nursing homes and home care settings. Inevitably they refer to formal long-term care services rather than informal provision, which is much more difficult to measure and evaluate. The OECD classifies the indicators along the dimensions of structure, process and outcome. The classification is used to encompass the wide range of possible quality indicators and to identify trends over time in quality assessment and control procedures. An upward trend in quality indicator development has been observed\(^\text{27}\). In addition, outcome related measures are being developed to provide a more comprehensive assessment of the level of quality of long-term care services. This does not mean that structure and process quality indicators are unimportant, but rather that some assessment of the actual health impact on the dependent population is also necessary and complementary.

\(^{27}\) The OECD Health Project, Long-term Care for Older People, OECD 2005, p.67
Increasingly, quality regulations for long-term care are evolving from basic or minimal requirements for the structure and process of care into more comprehensive and complex quality assurance mechanisms combining procedural, structural and outcome oriented indicators such as continuous staff training and education obligations coupled with patient's rights protection mechanisms allowing greater patient participation and consultation. Quality in long-term care services can be addressed through formal regulatory and licensing mechanisms. The increased emphasis in the promotion of the provision of long-term care services in a community or home setting has brought about the challenge of assuring quality in a different framework for which the structural and process indicators are often inadequate. Considering that the bulk of care in a home setting is provided by informal carers, structural indicators of staff ratios and adequate training do not reflect this situation.

The national reports describe various quality improvement measures. Quality standards for structures, procedures and outcomes as well as quality accreditation measures (NL,SK) coupled with quality monitoring systems (CY,DE,EL,FR,NL) are a few of the tools available to Member States for ensuring high quality long-term care. Clinical guidelines based on evidence-based medicine (DE,LU) are yet another quality-enhancing tool. In the case of long-term care, more patient-centred patterns of care including more tailor-made services with greater patient involvement in decision-making also enhance quality. Uniform quality assurance mechanisms (CZ,DE,EE,ES,SE,LT,LV,SE,SI,UK) can address regional inequalities in provision and deter arbitrary discretionary assessment of patients' needs at local or regional level.
Freedom of choice and dignity for the elderly - Peer Review – Sweden

Member States examined the national efforts to provide high quality LTC services for the elderly by means of a peer review in September 200728. The peer reviewers from other EU countries visited Sweden and examined its recent introduction of client choice models at municipal level. The increased use of direct customer choice between private providers for home care services as well as for care in institutions in the Swedish municipality Nacka was of great interest to many of the participants, as was the effects on keeping a higher number of smaller private care companies interested in providing home care services in Nacka. An important precondition for real choice by consumers of care is sufficient information about the available providers and services. "One-stop shops" could draw the information together to help users and their families to arrive at an informed choice.

Based on the experiences of peer review participants from other countries it was discussed if personal budgets could be an interesting complementary instrument between informal and formal care. Personal budgets can allow individuals to use a virtual account to buy care, employ care assistants or pay for personal services suited to the person's needs. The importance of linking the provision of health services and social services more closely with each other was also highlighted. During the peer-review, participants also engaged in discussions regarding the measurement of quality and the need to develop indicators for quality measurement.

Quality Assurance in Long-term Care - Germany

A series of measures have been enacted in order to further develop the quality of long-term care and quality assurance mechanisms in both the institutional and home setting.

In the homecare setting, people in need of LTC and respectively the family members providing care are entitled to a variety of support schemes ranging from Nursing Care Allowance, in-kind benefits and other entitlements such as pension contributions, accident insurance protection and training courses. Additionally, Outpatient care services are available in order to relieve the family member providing care. A number of measures exist in order to ensure that the care provided within a home setting is of high quality. These include statutory visits in the home environment by the Health Insurer's Medical Services, obligatory care consultancy by trained carers (allowing the identification of deficits in care and leading to a possible combination of long-term care benefits in order to meet the needs of the care recipient and relieve the carer), the requirement for the long-term care insurers to hold free care courses for family members and volunteers, and the possibility to combine the above-mentioned measures with additional services aimed at the relief of family carers (outpatient services such as residential facilities, additional aids such as home alteration and technical aids) following the assessment by the long-term care insurers.

In the institutional setting, the Long-Term Care Insurance Act (Social Code Book XI) pursues the goal of encouraging the development of internal quality management within care institutions, but at the same time also sets out essential external control according to nationally uniform quality inspection guidelines. Long-term care quality

assurance is ensured through the use of contracts between the long-term care insurers and the long-term care providers. The providers are primarily responsible for quality assurance (internal quality management/structure and process), whereas the long-term care insurers oversee the quality of the care provided in care institutions (deliverables/output) and hold sanction powers. Under these contractual arrangements, the purchasers have inspection powers and can impose sanctions. New legislation further strengthens the quality approach within the LTC system by giving consumer-friendly transparency for the quality performance of care institutions and by introducing the development of LTC standards within the LTC insurance system.

Despite the upward trend in quality of care indicator development, the use of outcome indicators for quality monitoring still remains in its infancy in the majority of Member States. Moreover, quality and its evaluation, is increasingly viewed as a subject that encompasses several important factors such as the support given to family caregivers, increasing consumer choice through the promotion of consumer-directed care, ensuring the capacity of the long-term care workforce and assistive technologies. Measuring quality of long-term care services along the various dimensions is a complex task. Whereas there are accreditation and evaluation mechanisms for formal institutional and community-provided care, the monitoring of the quality in an informal setting is much more difficult and is often based on measures of satisfaction and unmet needs rather than quality measures stricto sensu.

One basic requirement for quality assurance, of particular relevance to long-term care, is the active deterrence of patient maltreatment or abuse. This was highlighted during the Conference on "Protecting the dignity of older persons – the prevention of elder abuse", which was held in Brussels on 17 of March 2008. The Conference allowed the opening up a European debate on the protection of dignity and the prevention of elder abuse. It was acknowledged that protecting the dignity and fundamental rights of the frail elderly is becoming a major challenge for societies across Europe. A number of examples of good practice were examined (awareness raising campaign, support hot line, quality standards in long-term care/home care services, and training of professional carers and support for informal carers) and several countries presented their national strategies for tackling and preventing elder abuse. Different proposals for future policy action were listed in the discussion paper highlighting the role the OMC can play in the promotion of further activities on how to protect dignity in old age and on how to prevent elder abuse.

### 3.3. Long-term sustainability

#### 3.3.1. Financial sustainability

The majority of European countries are concerned with the future financial sustainability of their LTC systems and their ability to cope with the demographic developments exposed above. Ageing is expected to bring about increases in public spending on healthcare and LTC in particular. However, considerable budgetary savings on health-care expenditure may be realised if the projected increase in life expectancy over the long-term is accompanied by an increase in healthy life years and an

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29 The Cross-Atlantic Exchange to Advance Long-term Care, Special CEPS Report, S. Tsolova, J. Mortensen, 2006
improvement in the health status.\textsuperscript{30} A preventive approach and an integrated provision of health and long-term care services, which may be enhanced by the use of ICT and new technologies, could bring about savings in terms of the ageing-related costs and an improvement in the health status of the elderly population.

Long-term care funding or expenditure varies across the EU. Differing funding arrangements have developed over time reflecting, in most cases, the various social philosophies implemented in order to cover the risk of dependency (risk pooling). Four elements are important when analysing how long-term care expenditure is organised in the different member states: the schemes and population coverage of the provision of long-term care, the welfare funding arrangements of a given country, the degree of incidence or involvement of private sources of finance and the prevalent demarcation of responsibility between the public and private spheres.

In the EU, countries use benefits-in-kind, cash allowances and earmarked budgets, or a mix of the two in the provision of long-term care services. Some countries provide comprehensive public programmes financed through social insurance (e.g. DE, LU, ES), whereas others fund their programmes through taxation (Nordic countries, LT) or means-tested schemes (e.g. UK, CY). Others have a mixed financing system (e.g. BE, FR, EL), combining resources from insurance schemes and taxes, with different budgets and institutions responsible for the provision and purchasing of long-term care. There is increasing recognition of the need to create a solid financing basis for long-term care and ensure the availability of much needed resources. Several Member States are moving in this direction, either through the establishment of dedicated universal social insurance schemes and contributions (e.g. DE, LU, NL, SI) or through taxation (AT, SE) in order to put long-term care on a sound financial footing.

Both the EU and, for that matter, the U.S.A. recognise that it is necessary to find an adequate mix between public and private sources of finance. Independently of the country’s public financial arrangement, private direct payments will also play a role, although EU Member States are committed to designing funding schemes that do not hinder universal and comprehensive access to quality long-term care. The 2005 Luxembourg Presidency Conference had already concluded that a social insurance or tax-based system appeared to be more efficient than left entirely to the private initiative\textsuperscript{31}. In terms of provision, the national reports and both conferences point to a potential mix of public and private (notably social sector) provision. Private sources of finance refer to two separate elements. Firstly, private health insurance covering long-term care needs can be made available but it is often offered on a supplementary/complementary basis or for high income groups. Secondly, and most importantly, private household payments are often requested either in the form of co-payments to publicly provided care, and/or out-of-pocket payments for which very little or no reimbursement is offered.

\begin{itemize}
  \item "A market system may not in practice provide enough long-term care services which are available in a timely way and of adequate quality." Long-term Care for Older People – Conference organised by the Luxembourg Presidency with the Social Protection Committee of the European Union – Luxembourg, 12 and 13 May 2005, PP.92
\end{itemize}
A multitude of driving factors can explain the variation in the level of expenditure on long-term care. Some countries have more comprehensive and developed long-term care systems than others. Some countries provide the bulk of long-term care in a residential or home setting, which is often cheaper than the acute care setting. Additionally, some countries rely more or less on informal care provision with varying levels of subsidies for informal carers. Information and data gathering on private expenditure for long-term care is lacking for a number of countries.

3.3.2. Systemic sustainability

Care coordination

Care coordination is seen as crucial in enabling a high level of quality and an efficient use of resources in the provision of long-term care services in an institutional or community setting, thus permitting an adequate continuum of care irrespectively of the different levels of long-term care provision (local, regional, national) and organisation. Coordination problems at the interface between medical, social services and informal care can result in negative outcomes for users and in an inefficient use of resources. Coordination problems impinge on the financing of the system on the one hand (coordination, or lack of, between the different budgets involved), and the organisation of service delivery, and coordination, or lack of, between the different levels of organisation and between the various bodies involved (health versus social services) on the other.

Integration of health and social care - Portugal

The authorities have recently enacted a far-fetching reform of the Long-term Care system. It is the Government's strategic intention to develop a new integrated model between the health and social sectors, which should be sustainable and implemented as a network, and in which the various types of services will be articulated amongst them and with the different levels of the health and social welfare systems. The care will be provided through Convalescence units, Medium-term and rehabilitation units, Long-term and maintenance units, Palliative care units, Day centres and units for promotion of functional independence, Discharge Management Teams, Hospital teams for support to palliative care, Integrated continuous care teams and Community teams for support to palliative care. The new model allows for the development of new services, or care lines, aimed at offering responses adjusted to the needs of various elderly groups with dependency problems at different moments in the evolution of illness and the possible social risks that might occur. More importantly, the Network will therefore favour continuity between community-based care, hospital care for acute patients and social support, complementing primary care and specialized hospital care levels. Persons in a situation of dependency are approached from a global, integral, multidisciplinary, equitable, harmonious and community-based perspective. The network is based on a flexible model that enables adapting it to different territorial needs, gradual development of different types of services, more efficiency in the use of resources and a better control and systematization of new kinds of interventions, as well as a higher involvement of professionals through the creation of expert groups and specialized professionals who encourage and spread professional practice aimed at the overall recovery of the elderly person in a situation of dependency.
Multiple and often mutually reinforcing chronic ailments need some degree of care integration, as they require the provision of different types of care and access to specialised treatments. Care professionals must ensure that patients follow a coherent path of care with the appropriate treatment provided in the appropriate setting irrespectively of the organisational features of the long-term care systems. Better coordination between health and social services can also avoid duplication of action and service provision. Transferring long-term care patients from acute care settings and ensuring that such care is provided in more appropriate settings can reduce the financial burden associated with expensive acute care while enhancing the quality of the care provided.

The concept of a continuum of care must be assessed by how well the medical and social services provided, fit together at the individual patient level\(^\text{32}\). Each patient has specific needs that require a combination of medical, nursing and social services. It is often the role of the service providers to assess the individual needs and provide holistic services based on each individual needs assessment and offer coordinated, tailored and a patient specific continuum of care. It is reasonable to argue that there is no model for the provision of a continuum of care since each patient will require an individualised provision that should be tailored according to his needs. Care coordination is crucial in the provision of a care continuum for individual patients. The care continuum approach aims at promoting a uniform and coordinated provision of services. Two elements are important, one is the coordinated provision of a range of services (particularly for the home care setting where patients may require different services to be provided at the same time in one place) and the other is a better management of the transitions/transfers between services and settings (the patient's home, the acute hospital and the nursing home). Member States have or are introducing "measures designed to make services work together more effectively and to manage transitions between services more efficiently, both for benefit of the user and for a better use of resources.\(^\text{33}\)"

### Improved coordination between different levels of government – Belgium

Three Social Protocols were agreed between the Federal Government and the authorities responsible for long-term care and social services (Regional and Communities' authorities). With regard to the care provided to elderly persons, the two Protocols that were agreed in 2005 aimed at enhancing the working conditions and staff levels in the community, residential and home care sectors. A conversion of beds into facilities with added medical services provision and the creation of specific employment contracts for LTC personnel aimed towards the promotion of integrated care provision in an innovative collaborative framework between primary healthcare facilities and institutions in order to prevent or postpone the institutionalisation of elderly persons have been agreed. The third Protocol, agreed between the Federal authorities, the Regions and the Communities, fixes the budgetary and organisational framework for long term care for 6 years. The Protocols aim towards the integrated provision of LTC, with some coordination between PHC, institutional and community care facilities, whilst ensuring the adequate level and qualification of the staff employed in the sector. An eventual legal and budgetary coordination between the different settings is foreseen. The main problems experienced so far is the limited signature of collective employment

\(^{32}\)The OECD Health Project, Long-term Care for Older People, OECD 2005, p.34

\(^{33}\)Ibid, p.35
agreements and the consequent lack of implementation of conversion of residential homes into more medical community care facilities and the lack of follow-up from one setting to the other.

Some Member States have sought to encourage coordination and an integrated long-term care provision by setting up national strategies and priorities. National guidelines and targets can ensure uniform provision across the wide spectrum of service providers and the different levels of government involved in the management and financing of long-term care services. Since long-term care is usually provided in a devolved context and run by sub-national levels of government, national standards can ensure uniform provision and financing for all the regions of the country (ES, SE, UK). Such an approach allows greater involvement of all these stakeholders so that different services are well informed about each other and can provide similar information to patients. Another mechanism relies on framework contracts between long-term care insurers and providers (DE). In addition to national strategies, an integration of long-term care delivery and an alignment of long-term care finance are also aimed at improving the continuum of care.

The integration of long-term care delivery involves creating single entry points or local assessment teams (NL, UK) on one hand and the devolution and integration of long-term care services at the regional or local level (ES, SE, UK) on the other. Several countries made (BE, DE, ES, FI) or are in the process of making efforts (HU, LV, MT, PL) to enhance and promote integrated long-term care provision, allowing uninterrupted care continuums for patients and evaluation and monitoring mechanisms by multidisciplinary teams (UK). Spain, for example, applies common standards throughout its territory. Additionally, many countries have sought to align the financing of long-term care referring to its health and social care components: Germany introduced comprehensive long-term care insurance providing support for informal and formal carers; Austria integrated the long-term care allowances provided for informal and formal care; Spain coordinated health and social services financing at the regional level whereas Sweden integrated acute health care and long-term care funding at the municipal level; the UK has devolved most of its funding for social services at the local level with the possibility for hospitals to charge local authorities if they are unable to discharge patients due to the lack of long-term care services.

Policies to improve care coordination, particularly between health and social budgets, have been promoted (e.g. ES, FR, IE, LU, LV, PL, PT, ES). To improve the quality of long-term care in several countries (UK, IE, BE, DK, DE, EE, ES, SE, SK, FI, LV, PT, IT) there are plans to develop common assessment schemes and evaluation by multidisciplinary teams that would define the care plans to be followed by the care user. Similarly, the care coordinating role envisaged in the UK for community matrons is planned in the Italian context through the establishment of District Managers. Additionally, in addressing the trend towards deinstitutionalisation, many Member States have attempted to coordinate the provision of long-term care at local or regional level, with mixed outcomes (e.g. FI, ES, HU, LT, LV, SE) and consequences in terms of access to, and the quality of, long-term care. Addressing access and coverage of the population has important implications for the financing of the system and vice versa. For example, the decentralisation of long-term care service provision (e.g. BE, ES, DE, CZ, FI, SE, LT, LV, PT) and the promotion of care in a community setting (Most Member States) must be sustainable, thereby ensuring coordination of the system's financing between different budgets and different organisational levels (e.g. BE, CZ, DE, ES, FR, IE, LU, LV, PL).
Improved coordination between health and social care - Czech Republic

The authorities recognise the need to promote some degree of financial integration between health and social services, which are clearly demarcated. Measures have been introduced at a central level to ensure alignment and effectiveness in exploiting means of financing for healthcare and social services in residential facilities, where healthcare and social care are provided together. The Health Ministry promotes a link between primary healthcare and social services. The Social Services Quality Standards guidelines from the Czech MoLSA also put emphasis on the use of existing community resources and on the integration of services. The degree of co-ordination and co-operation is left to the local authorities and the individual facilities. The Geriatric and After-Care Ward in Liberec Hospital is an example of an after-care health facility that focuses on psychosocial stimulation and therapy as well as on traditional treatment and rehabilitation. Great care is given to social work to ease the patient’s transition back home or into the social service system. This after-care requires the effective use of funding from many sources. Where home-care is not an option, the social worker helps place the patient in another healthcare facility (hospice, rehabilitation centres) or social facility (hospices, nursing homes, short-term hospitals, and sheltered homes) according to their needs and physical condition. Timing of patient discharge is planned to ensure continuity in their healthcare and social care. Other examples include: AREÍON Emergency Care by the Life 90 Civic Association is aimed at providing support for persons remaining in their home environment; The Deaconate of the Evangelical Church of the Czech Brethren (hereafter DECCB) is an independent Christian NGO that provides a wide spectrum of social and community health services and the Prague 8 Community Centre for Senior Citizens are examples where multidisciplinary social and health workers' teams are providing support to people in need in a coordinated framework (of funding and managerial ownership).

Care coordination efforts are aimed at the provision of an integrated set of services (medical and social), that would allow on the one hand, a consumer-tailored care continuum accounting for individual needs, and, on the other, a more efficient use of resources (through the coordination of different budgets and earmarked funding) targeted on individual needs. Such efforts aim at limiting the inefficient use of and duplication of resources, whilst at the same time allowing for an enhanced consumer-tailored long-term care provision. Mindful of the demographic ageing of the population and changing family structures, it is expected that there will be an increase in demand for formal long-term care services (medical, nursing and social care) in both institutional and home settings.

3.3.3. c) Prevention and rehabilitation policies

Given the constraints on public finances allocated to long-term care and the difficulties experienced in raising additional resources through increased contributions and taxes, promoting healthy and active lifestyles (through healthy ageing, preventing obesity, smoking, alcohol and drug abuse throughout the lifecycle), health and safety at work and preventive care (screening, vaccination and immunisation) can make a positive contribution to improving the overall health status of the population, a point which was highlighted at the 2005 Luxembourg Presidency Conference. Aside from the positive health outcomes (life and healthy life expectancy, mortality rates), promoting healthy ageing and preventive care policies also helps to increase labour market participation and productivity rates. Most Member States have generalised vaccination and screening programmes and campaigns to promote healthy ageing which are either being promoted
or in place. One issue that often remained unaddressed in the national reports is the
degree of efficacy of these campaigns and the degree of care coordination that exists
amongst the different providers and levels of provision in promoting preventive care
policies.

Similarly, rehabilitative care is to be promoted (e.g. PT, CZ, EL, FI, FR, LV) with
a view to restoring patients' skills and thus helping them to regain maximum self-
sufficiency and to function in a normal or as near normal a manner as possible.
Rehabilitative care can be provided in an institutional or a community setting. More
importantly, rehabilitative services should be provided in order to help, where possible,
the patient reintegrate in the labour market. The promotion of rehabilitative care depends
to a large extent on the efficient use and promotion of ICT products and services for
independent living. The national reports and the EU/AARP conference highlighted the
importance of active ageing, healthier ageing and adapting the environments where
people live. Additionally, the national reports identified the need to train and provide
adequately qualified staff in the areas of rehabilitation and geriatrics as a pressing
concern. Such an evolution would enhance needs-tailored accessibility in an integrated
framework and ameliorate the quality of the services provided. Related to the above
identified concerns with care coordination, the provision of a care continuum (especially
the transitions from the acute health sector towards community-based services) may be
facilitated with the development of overall national health strategies accounting and
instigating age-friendly policies at various levels involving geriatric specialists (primary
care and acute hospital care for example). These are presented as necessary
complements to long-term care provision from a service-user point of view.

Prevention and rehabilitation – Slovakia

Municipal authorities in Zavar and Banská Bystrica City, have implemented local
projects aimed at the promotion of a dignified and inclusive life for the residents in
institutional care facilities (mentally ill and severely disabled persons). The successful,
thus far, projects engage in preventive and rehabilitative activities for social services' residents in an integrated framework involving the participation of local stakeholders, residents and partners. Social workers in Zavar, propose treatment/care plans (ergo therapy, psycho-pharmaceutical treatment, rehabilitation) centred on individual patient needs aimed at the promotion of their active participation in societal activities. These pilot projects can serve as examples for local concerted action with the involvement of all concerned social services providers and users.

Improved services for clients of long-term social care institutions – Latvia

National Programme co-financed from the European Regional Development Fund “Improvement of infrastructure and equipment of social care and social rehabilitation institutions” - The programme contains one joint cooperation project between local government and state social care and social rehabilitation institutions from each of the regions (5 projects in total). Each of the projects envisages provision for the clients of long-term social care institutions of additional services, such as halfway homes, day-care centres, social rehabilitation, skill (including vocational skills) development, specialized workshops, short-term care, group apartments, etc…, in order to provide the clients staying in these institutions a possibility to return to their residences in their local government and to join the labour market if possible. This project stems from the need to upgrade long-term care institutions and ameliorate the services/care provided.
3.3.4. Workforce shortages and training

Community care, home care, residential care and day care are labour-intensive sectors with staff costs accounting for the majority of the overall costs in these settings. Labour supply in these settings is a major preoccupation for Member States, particularly when considering medical, nursing and social care labour shortages. In the home or community care setting, the problem of insufficient and inadequately trained staff is exacerbated by the fact that the bulk of the care provided in that setting tends to be carried out by family or informal caregivers. Supply shortages of this kind cannot be viewed in isolation, but are related to the labour situation in other care settings. Indeed, it is often the case that staff employed in nursing homes will also be employed in the home care sector. In view of the looming shortages in the trained medical (particularly nurses and geriatric doctors) and social workforce in the US and the EU, many Member States have introduced policies to increase nursing staff, ameliorate training and education policies for healthcare and social care professionals, in order to deal with the increased demand for services in this field (e.g. ES, FR, LT, SE, CZ) including discouraging emigration due to better working conditions and better pay (e.g. PL, LV, EE). Continuous training and evaluation can be significant in maintaining quality of staff. Most Member states have introduced or are introducing training and lifelong learning schemes in order to maintain the staff's expertise and enhance their capacity in dealing with specific long-term care specialties such as geriatrics.

Validation of the Acquired Skills and Experience scheme: A bridge between the acquisition of professional certification in medico-social nursing care and the possibility to develop new specific skills for professionals dealing with the elderly - France

Within the implementation of the government plan "Solidarity for Old Age", aimed at increasing the recruitment of care professionals for elderly people, at home and/or in institutional settings, two measures were taken: the increase in the number of positions offered within the training centers leading to the acquisition of nursing professional diplomas and, more importantly, the facilitation of the possibilities to acquire that extensive professional certification for already employed personnel. The "validation of the acquired skills and experience" thus enables the candidates to the training schemes and already employed staff within the sector to validate and formalize their experience gained thus far through its recognition and inclusion within the training curriculum. The validation of the acquired experience scheme has been open since 2007, to the medico-psychological aid diploma and is currently extended and applied within the national "Plan to combat Alzheimer and similar illnesses", with the introduction of, a compulsory, gerontology training for all formal socio-medical professions.

Both in the US and in the EU, care provided by family relatives and friends is a substantial part of the long-term care provision to those in need (even in countries where formal home and institutional care systems are available, such as Sweden). As informal care will continue to play an important role and given the strong focus on home provision, the national reports stress the need to develop structures that support informal caregivers. This was reiterated by the 2005 Luxembourg Presidency Conference and the 2006 EU/AARP conference, which both stressed the importance of ensuring smooth coordination between formal and informal care and of informal carers receiving appropriate support when pursuing their care activities. Policy proposals related to informal care include: information, training, counselling, respite care (allow caregivers time off), financial aid to informal carers (e.g. AT, CZ, DE, EE, DK, HU, FR, ES, SK,
FI, IT, IE, SE), tax credits and exemptions (e.g. ES, DE, EL, FR, LU), allowing informal caregivers to reconcile care provision and paid employment, notably through work leave to care for relatives (e.g. AT, ES, FI, DE, NL) and considering care periods as part of the contribution period for pension purposes, formalising their status and including them in social insurance schemes.

As noted previously, staff shortages in the long-term care sector in both the institutional and home settings, coupled with demographic developments and changing family structures, will most likely result in an increased demand for formal care-giving in both settings. The quality of the workforce inevitably influences the quality of the long-term care services provided. In addition to adequate qualifications and constant training, Member States have had to devise ways to support and sometimes formalise the working conditions of informal caregivers. The distinction between the formal and informal caregivers is an exemplification of the fragmentation of the provision of services in this sector.

**Formal and Informal care provision**

Traditionally, Long-term care needs have been met within the private sphere or the extended network of families: "maintenance obligations have traditionally been met in kind by women within the family."\(^{34}\) Considering that women are increasingly participating in the formal labour market, the identification of an informal accounting of LTC needs, met by the family members and friends, poses a serious challenge of reconciliation between caring and employment participation. Recognising that the bulk of LTC provision is carried out within an informal setting has brought to the fore national concerns regarding the availability and role of informal carers. Formal home or community care tends to be cheaper in relation to acute institutional care. Additionally, many systems rely heavily on informal carers or family members for the provision of home care. This however is not included in cost calculations and the lack of support towards informal carers does not mean that it is a budget neutral option. Informal carers are in some countries heavily relied upon without necessarily receiving compensation for their caring activities. In response to the European Commission's consultation process of European NGOs on the reconciliation of work and family life, AGE called for the establishment of a new type of leave that would allow workers time off to care for dependent family members. This type of leave would hold a particular resonance for women in late middle age - the so-called sandwich generation - who, while participating in paid employment often take responsibility for the care of their dependent ageing parents as well as their grandchildren\(^{35}\).

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**Home Care provision and support to informal carers**

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\(^{34}\) Luxembourg proceedings, p.62

Austria - A funding model to recipients of the long-term care allowance of at least category 3, who require care around the clock (24-hour home-care) was adopted. Currently, a pilot project "Counselling Cheque" is being carried out. The counselling cheque is meant to enable persons in need of care and their care-giving family members to avail themselves of qualified on-site counselling on a broad range of issues of nursing and care. BPGG created the legal basis for benefits to care-giving family members: a close relative of a person in need of care entitled to at least category 4 of the long-term care allowance, is in principle entitled to a financial grant if he/she has been the primary carer of the person in need of care for at least one year and is unavailable due to illness or other important reasons. The grant is to contribute towards the costs of professional or private substitute care. A pilot project in Vienna, Lower Austria and Burgenland has offered 14 days of holidays and recreation for care-giving family members. In addition to recreation, the holiday stay also includes a social programme (e.g. exchange of experiences through a moderator...). Any care services as may be required during the stay may be rendered by professional providers against payment. According to the results of scientific studies, care provided by relatives is one of the most important pillars of the system which must in any event be given continued support. The 2007 Act to Amend Social Security Legislation has improved the situation of care-giving family members in the context of preferential continued insurance or self-insurance in the pension insurance system during periods in which care is provided to a close relative. The Agreement on the Social Care Professions aims at upgrading of professions in the area of care for the elderly and the disabled and creating an incentive for regular employment in this field. In implementing the agreement, the job profile “home helper” is to be introduced nationwide. In the past few years numerous options were created for family members providing care: counselling and discussions for care-givers, temporary accommodation in a nursing home if care-givers go on holiday or fall ill, financial support for substitute care for persons with dementia, advice on medication and aids, as well as various ombudsperson offices and information platforms.

Germany - It is especially important to improve the security in old age of carers who, on a non-professional basis, look after someone in need of care for at least 14 hours per week in the person’s own home and do not work, or at least do not work more than 30 hours per week, because of the care. The long-term care insurance providers make contributions to the statutory pension insurance for these carers, depending on the level of care and the scope of the caring work. This is designed to recognise the high commitment of carers who often fully or partially give up their own job to provide care. Since over 90% of the carers subject to pension insurance are women, the long-term care insurance companies are thus making an important contribution to the independent social security of women in old age. Thanks to pension insurance and statutory accident insurance, caring is largely made equal to employment subject to social insurance. The family carer and other voluntary carers usually do not have a contractual relationship with the person in need of care. For home care, it is possible to combine Care benefit (monetary) and care benefits in kind. Other services to support care at home include: If the informal carer cannot provide care, the long-term care insurance provider will pay the costs of an alternative carer. If the alternative care is provided by a close family member, only the care benefit o the care level identified is paid and in addition, if necessary, reimbursement for proven necessary expenditure incurred by the carer in association with providing the alternative care; Entitlements to care in a fully in-patient facility for a transitional period after in-patient treatment or in other crisis situations where care at home or short-stay care is not possible or is inadequate for the time being; Entitlement to
short-stay care in a day care or night care facility including necessary transport from home to the facility and back again if adequate care at home cannot be ensured or if it is necessary to supplement or strengthen care at home; Benefits for the social security of non-professional carers (old age pension, accident protection); Care aids and technical aids for conversion of the home due to the need for care; Free training courses in care for family members and volunteer carers and since 2002 there has been an entitlement to an additional care sum for people in need of care with a considerable need for general supervision and care. With the LTC reform that will step into force on July 1st 2008, home care provision will be further strengthened: Employees that want to provide care for family members will be entitled to "care leave" of up to 6 months with guaranteed return to the previous job. During care leave, LTC insurance (of the patient) pays contributions for health, LTC and unemployment insurance (of the person providing care during care leave).

The expected increase in the demand for formal long-term care services can be explained by the following interdependent factors: firstly the number of working age women able to provide family or informal care will decrease at a time when the number of elderly dependent persons is increasing; secondly the increased labour market participation of women means less time at their disposal to dedicate to providing care as well as a change in their social care role; thirdly the changing family structures such as smaller families and the increase in the prevalence of single-parent families means that family members are further apart and with a lesser potential to care for the dependent family members in an informal, unsupported setting. Demographic developments (ageing) and the changing family structures (family breakdowns, etc), pose serious challenges for the future financial and systemic sustainability of the LTC sector.

In both the institutional and home care settings the main concern for policymakers is recruiting and retaining an adequately qualified and skilled workforce. The qualifications, the availability and the working conditions of the workforce are crucial in the provision of long-term care and its quality. In the institutional setting (nursing homes and institutions), the developments in medical and assistive technologies require an almost constant upgrading of the workforce skills and qualifications as well as measures to ensure their retention in the long-term care sector. In addition to the structural and process quality deficits in institutional long-term care services, the earmarking of specific funds allowing the upgrading of the working conditions of the workforce and its training is all the more difficult in light of existing budgetary constraints. The increased incidence of cost sharing mechanisms and co-payments coupled by the limited financial resources dedicated to long-term care inevitably limit the possibilities for the upgrading of the working conditions and pay rises for the staff formally employed in the sector.

36 The OECD Health Project, Long-term Care for Older People, OECD 2005, p.69-70
4. CONCLUSIONS

Member States are concerned and are looking at various mechanisms to address the expected increase in demand for Long-term care services in light of the demographic ageing of the population and the prevalence of disability and dependency, particularly among the elderly. Despite the recognised need and desire to provide accessible, high quality LTC services, current supply does not necessarily translate into a comprehensive and universal framework for LTC provision. What is evident throughout the national reports is that the promotion of LTC provision catering for consumers/patients/dependents in a home or residential setting is the preferred alternative to institutional care. Additionally, there is a widespread consensus on the need to address the expected workforce shortages in the LTC sector (formal care) as well as devising new ways of support towards family or informal carers.

In order to meet the foreseen increase in demand for an accessible, resource-efficient and high quality long-term care provision, Member States are striving to ensure a sustainable mix of public and private sources of finance. Measures include changes in financing mechanisms. Secure long-term care financing is still to be achieved in many countries however. Another issue of concern is the degree of care coordination existing within the various long-term care systems. Care coordination encompasses the search for financial and systemic sustainability of long-term care systems whilst affecting the degree of accessibility and the quality of the care provided within each national setting. Care coordination is seen as crucial in enabling a high level of quality and an efficient use of resources in the provision of long-term care services in an institutional or community setting and thus ensuring an adequate continuum of care.

In addition to the sustainability of the financing mix which is determined by the organisational features of long-term care systems, Member States are committed to ensuring near universal access to long-term care. One important element is that, the individual ability to pay or the share of private sources of financing should not hinder that accessibility. It remains to be seen how this principle can be implemented in practice. In terms of quality, the trend highlighted in the report is that where available, care in a community or residential setting is preferred to the care provided in an institutional setting. Member States are committed to a high level of quality in the care provided in a residential or community setting and are striving to ensure such a level. Measures include uniform standards and quality accreditation mechanisms coupled with legally enforced evaluation methods. Where they do not currently exist, efforts are being made to implement equivalent quality assurance and accreditation mechanisms.

Equally important is the issue of the long-term care workforce. Particularly in the countries which are facing long-term care worker and nursing staff shortages, adequately recruiting, training, and retraining long-term care workers remains a challenge. Several measures are being implemented including higher wages, the improvement of training and working conditions and the formalisation, where possible, of informal carers into the social security schemes. Informal care is an issue of concern for many countries. The amelioration of working conditions and social security formalisation schemes (for informal carers), which pose problems for quality assurance in long-term care provision, remain a challenge.