Who Cares?

Care coordination and cooperation to enhance quality in elderly care in the European Union

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Introduction

There is arguably no major area of social policy in the European Union (EU) in which Member States differ more than in the way long-term care for people who depend on ongoing social and medical help is organised and funded. Very large differences exist between and within countries in the division of labour: between informal care (provided by family members, friends and volunteers) versus professional services funded from public and private sources; or in the mix between home care and residential care provision. Also, public and private funding for long-term care varies across Europe to a degree that is not seen for any other social programme, including health care.

Long-term care as a set of separate social programmes and systematic social policy concern is still a relatively young subject, often reflecting the fragmentation of services and funding that still exists in many countries. Overall, differentiation as a policy field in its own right is only emerging in some countries, for example in several of the new EU Member States.

There is, however, increasing recognition that EU Member States face many common challenges and the interest to learn from the experience of other countries has gained momentum in recent years, for example as part of the Open Method of Coordination of the European Union. 1 A substantial number of countries have undertaken major reforms of long-term care financing and provision over the past ten years, but the future sustainability of public funding for social and health services remains a major policy concern as it is clear to many that the need for publicly provided services will increase with the ageing of the populations and the shrinking of the EU work force.

Results from recent Eurobarometer surveys illustrate the continuing high commitment of families to caring for older people who are in need for ongoing social support due to declining health and functional capacity (some 80% of care hours are provided by informal care even in high-spending countries). But many citizens are concerned that this reliance on family care is too high and may not be sustainable, while many give the quality of publicly provided services significantly lower rating compared with health care.

Though it is quite clear that a complete professionalisation of long-term care will not be feasible, - neither does it seem to be desirable -, policy-makers, researchers and other stakeholders have repeatedly identified the following issues as key for the development of long-term care systems in Europe:

1. The need for a more efficient co-ordination, perhaps even integration of health and social care systems with respect to financing, improved needs-assessment, organisation, professional responsibilities, and shared visions of all stakeholders involved.

2. The need for more user-oriented services and a care approach that facilitates dignity and respect for older users of long-term care services in relation to equal access, choice, and quality of life.

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Politicians, other stakeholders and the public are therefore eager to know what lessons can be drawn from the experience with long-term care policies in other countries, information that often is difficult to access, due to data limitations and the local governance of long-term care.

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Moreover, this paper builds on work that the *European Centre for Social Welfare Policy and Research* has undertaken in the areas of long-term care policy as part of broader EU social policy, such as on the challenges of better integrating health and social care, on the quality of social services and on care indicators. The authors gratefully acknowledge the sponsors of this other research, namely the European Commission (DG Research and DG Employment, Social Affairs and Equal Opportunity), the United Nations Economic Commission for Europe (UN-ECE) and Member Countries of the European Centre for Social Welfare Policy and Research.²

The paper is in three sections. The first provides a backdrop through a summary of key trends and stylised facts on long-term care. The second section reviews a number of common policy challenges and section three presents examples of good practice on how to address these. The paper starts with an executive summary.

The authors are grateful for comments on this paper from Niclas Jacobson. We also thank Katrin Gasior who prepared graphs and tables. Any remaining errors are those of the authors.

² The views expressed in this discussion paper are those of the authors and do not necessarily represent those of the Swedish government, the European Commission, or the UN-ECE, or any of its Member Countries, such as the Member Countries of the European Centre.
Executive Summary

Introduction

This discussion paper for the Conference on Healthy and Dignified Ageing under the Swedish Presidency of the European Union summarises key trends and stylised facts on long-term care. It reviews common policy challenges and good practice examples with a focus on more efficient co-ordination between health and social care to improve quality and efficiency, user-orientation and dignity of care.

Long-term Care in the European Union: Diversity and Common Trends

Information on other countries’ organisation, financing and provision of long-term care, including comparable indicators is a key prerequisite to foster the policy exchange and mutual learning in the European Union. A set of care indicators from national and European sources has been brought together and crosschecked by the European Centre for Social Welfare Policy and Research.

How do countries differ in the division of labour between formal and informal care, home care and institutional or residential care?

- As the bulk of around 80% of care hours in all countries is still provided by informal carers in families, who are typically women and/or older workers, informal carers and public policies have experienced difficulties in reconciling care and labour market participation.

- Formal long-term care services are still extremely limited in some EU-countries (e.g. 0.7% LTC beneficiaries of population 60+ in a NMS) and it is doubtful that this is a sustainable policy in the future when the number of very old people increases sharply and the labour force continuous to shrink.

- One noticeable common characteristic of long-term care services in the EU is the much larger share of 65+ that receive care in their own home (on average 7.6%) in comparison with those receiving care in institutions (on average 3.3%). This is in contrast to the situation in the United States of America, where only 2.7% of the 65+ population receives home care as against 4.3% in institutional care on average.

- In 30 UN-European countries reviewed, an average (and median) of 3.5% of people aged 65+ receive care in an institutional setting (EU: 3.3%, max. 6.5%) and it is care services provided at home, ranging from zero to 25.1%, that make a difference in terms of how many people can access to care.

What are overall spending levels and how will they develop?

- Public spending varies between 0.3 and almost 4% of GDP, the bulk of which (unweighted average of 17 EU countries reviewed: 51.2%) is on care in institutions, in spite of stated policy preferences to support home care in EU countries and the fact that only 3.3% of people receive residential care; whereas the 96.7% of the elderly population who live in their own homes...
(either independently or with some assistance for independent living) receive less than half of all publicly funded support.

- Ageing of the population is only one of the factors to drive spending growth in the future. The availability of family care, the trend towards better quality of services and workforce issues are also important.

Who is funding the current mix of services?

- Despite the fact that care in institutions takes 51.2% of public resources for 3.3% of persons in need only, it still demands high private contributions from users (mostly above 60% of up to much more than an average worker’s income), resulting in social assistance being necessary as “funding source of last resort” for (too) many people.

What are policies to make long-term care financing sustainable and how might the economic crisis impact on long-term care?

- Policies of freezing benefit levels and contribution rates have not been socially sustainable and will need to be replaced by more sophisticated strategies, in particular the constant strife for improving the mix of supportive service for care provided at home.

- The current crisis puts any plans to expand public services under special scrutiny. This may slow down progress to make the needed public investments to upgrade long-term care to provide more and better services and increase dignity and quality of living in old age. This applies in particular to those countries starting from still very modest levels.

How do countries respond to key policy challenges?

Better integration between health and long-term care has many facets, including:

- Better discharge management can improve care and avoid expensive re-admissions to or bed-blocking in acute hospitals;

- Extending home care provision is key to making long-term care sustainable for the future;

- Successful coordination of care raises the crucial question of who will provide the needed stewardship within the current public-private mix of service provision and funding among health and social services, in particular given the trend towards more market orientation;

- There remains much scope for mutual learning and further developing of long-term care policies at the interface between health and social services.

Strategies to protect dignity and to have a stronger focus on the individual

- Dignity of care and a stronger focus on the individual are now protected in more and more countries by charters of rights for people in need of care. This
has also been driven by European and international imitative of human rights and of the rights of older people in particular.

- Privacy in nursing homes, an important aspect of dignity of care and quality of living for people with care needs, differs widely between countries, and improving the situation will need important investments in infrastructure in some countries.

- In addition to binding new normative frameworks, quality assurance and user protection, - the weak point in residential and even more so in home care -, must be continuously monitored and the results of quality assessments made publicly available.

*How can access to mainstream health care for dependent older people be improved?*

- Fighting discrimination of older people in their access to quality health care needs more attention.

- Major improvements should be possible in rehabilitation, mental health and in more rational use of pharmaceuticals but investment in specialised research in health care for older people is also key.

*The role of choice in publicly provided long-term care*

- Demands for greater empowerment of users and market driven reforms have pushed for increasing the role of choice programmes in care across Europe, of which the growth of cash benefits, particularly attendance and care allowances, are just two types of examples.

- EU countries have always been characterised by different types of welfare mixes. Strategies to increase choice by means of a purchaser-provider split and competitive tendering have further differentiated the structure of provision, in particular in countries that relied hitherto mainly on public providers.

- However, it has been shown that neither ‘care-markets’ with a higher share of private for-profit and non-profit providers nor an increasing purchasing power of users do automatically guarantee more choice for users. Additional mechanisms like case and care management, information and counselling as well as more differentiated services are necessary to support and secure choice for users and their families.

*Alzheimer diseases and other dementias*

- Care assessment and recognition of care needs for people with dementia have improved in some countries as part of recent reforms but more needs to be done to improve care for dementia patients, including better early detection, better tailored training and education of health and social service professionals, including of general practitioners.
Long-term care workforce policies

- Health and long-term care are important “job machines” in EU countries, creating between 1995 and 2006 around 4.5 million jobs in the EU15, - a substantially higher rate of job growth than the economy at large, with social services jobs again growing faster on average than health care. The majority of social service jobs is now in elderly care in many countries: e.g. they account for two-third of social services in England. But the looming workforce crisis in health and social services and the ageing of this workforce needs to be addressed now in order to be prepared for the growing number of people with care needs.

- This may call again, though for decades now without much success, for better working conditions in long-term care, better-qualified jobs and pay schemes that are competitive with related sectors, like health care. But could, as an alternative to this largely failed traditional approach, something like a “pink card” regime of officially recruiting qualified staff at large scale from non-EU-Member States inside and outside of Europe temporarily into the EU in order to compensate for domestic staff shortages be a viable strategy – and an alternative to irregular migration of informal care workers, making up to more than 90% of all around-the-clock home care work in some EU Member States today?

What efficiency gains could help to cope with future challenges?

- There is a clear case for stepping up the search for efficiency gains in care provision by improving co-operation with health care, applying modern technology more broadly and supporting family care to help people stay in their own homes for longer.

Drawing lessons from good practice

There are a number of good practice examples – especially on local and regional level – that illustrate how some of the common challenges of elderly care can be tackled. Interesting innovations include, among other, the following elements:

- The role of new assessment tools and joint, co-operative assessment practices to classify and estimate individual care needs, above all by carefully listening to the persons in need and their families, training the carers, and by making tool testing an integral part of a good practice. This may be rewarding for all parties involved, the assessment teams, the claimants and their families, family carers, and also intrinsically rewarding for the formal care providers.

- Involving family members and all stakeholders in a continuum and continuous quality assessment and quality improvement process.

- Developing new job profiles such as the case and care manager, the life assistant, the personal assistant and other multi-purpose professionals that are able to combine health and social care approaches.

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1 See European Commission, 2008b.
− Innovative examples of 24-hour integrated health and social care on a local level, with simultaneous improvements for clients (immediate access and service, no waiting time) and much less public expenditures by intelligent use of inevitable surplus capacities for prevention efforts (resulting e.g. in 30-40% reduction in hospitalization).

− Measures to protect the dignity of individuals from neglect and abuse and focus on personal needs.

How can these good practice examples be “scaled-up”, adapted to the situation of other countries, and diffused? What are the obstacles for implementation on a broader scale?
Long-term Care in the European Union: Diversity and Common Trends

This section provides an overview of key trends in long-term care:

− How do countries differ in the division of labour between formal and informal care?
− What is the mix of services provided and who is funding them?
− What are overall spending levels and how will they develop?
− What are policies to make financing sustainable and how might the economic crisis impact on long-term care?

Box 1: Defining long-term care and the role of indicators

“Long-term care” brings together a range of health and social services, that are tailored to the needs of people who rely for an extend period of time on the help of others for basic activities of daily living due to chronic disease of other causes of disability (including dementia and other mental health reasons). This includes assistance from both informal and formal carers.4

For the indicators on publicly provided long-term care that are analysed in the charts and tables of this paper, the expenditure and recipient numbers do not include mainstream health care services, such as specialised care in acute hospitals and the like. For some national data, certain low-level services may also have been excluded, following current practice of Eurostat and OECD data sets.

Work of the European Centre on these European and international data sources and on data from national sources has shown that there is still much uncertainty about care indicators for international comparisons and cross-border policy exchange. This has been systematically addressed as part of the project “Mainstreaming Ageing: Indicators to Monitor Implementation” (MA:IMI)5, which has been jointly funded by European Centre Member Countries, the European Commission and the UN-ECE.

Glaring knowledge gaps in this respect that still exist obviously makes it more difficult to perform a comparative analysis and can hamper informed decision-making. These gaps are in striking contrast to the common concerns of European Union Member States over the impact of ageing on the sustainability of public policies on long-term care. It will be vital for the further policy exchange in this field that information on public expenditure and benefit recipients, informal care provided in families and a basic disaggregation of these indicators by age-groups and sex becomes available in Member States on a routine basis.

What is the scope of care needs and of long-term care provision?

The ageing process of the European population has been characterized by the “ageing of the aged” as the number of those aged 80 years and older increases in a

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4 There is now an emerging European consensus on the definition of “long-term care”, although national reporting practices and compliance with international definition still varies a great deal (see European Commission, 2008a and Huber/Rodrigues, 2008).

5 For more detail on this project, see http://www.euro.centre.org/detail.php?xml_id=1415
disproportionate way (Marin and Zaidi, 2008). Another characteristic of this ageing process is that gains in life expectancy are increasingly concentrated in the older age groups and as data for 2006 shows, those reaching that age may expect to live between 6 to 10 years more on average (Figure 1). In the future, the 80+ population will account for an increasingly higher share of both the overall and old-age population (Figure 2). Thus, within the EU, the 80+ account for between 17.4% (Romania) and 31.4% (Sweden) of the total old-age population in 2006, but their share is projected to rise substantially to between 29.5% (Slovak Republic) and 44.1 (Germany) by 2050.

Data present in Alzheimer Europe (2006) on prevalence rates of dementia (Figure 3), as well as EU-SILC data on severe activity restriction, show the age groups of 80+ to be particularly at risk of facing dependency. As a result, even under the assumption of otherwise improved health conditions, EU Member countries will be faced with an increased number of people at risk of needing care, as the share of 80+ increases sharply, as depicted in Figure 2.

The share of those aged 65+ receiving publicly funded support to secure care has for the most part remained stable in the past decade in the EU (Table 1). While for the countries on the top echelon of provision of long-term care services (Denmark, Netherlands, Finland, Austria, UK (England)) this means that they have at least kept pace with demographic ageing, for some Member States this means that they have yet to address the issue of provision of long-term care services (most notably the Baltic States and Hungary). Marked differences in the share of 65+ accessing formal care across the EU still persist (Figure 4 and Figure 5), reflecting the diversity of policies and outcomes in EU countries.

Available data show that there is more than one path to ensure access to formal services to a wider share of the 65+ population. For example, countries like Finland, Austria and UK (England) differ in the underlying way in which provision of long-term care services is organised and yet ensure that a similar share of their 65+ population receives support from the State in securing care.

- One noticeable common characteristic of long-term care services in the EU is the much larger share of 65+ that receive care in their own home (on average 7.6%) in comparison with those receiving care in institutions (on average 3.3%). This is in contrast to the situation in the United States of America, where only 2.7% of the 65+ population receives home care as against 4.3% in institutional care on average.

Nowhere in the EU do 65+ who are cared for in institutions represent more than 6.5%. This fits not only with the stated preferences of people (Eurobarometer, 2007), but it seems to be the key in providing care to more people as countries that rely heavily on home care services are also those that have a higher share of their 65+ with access to formal care services (Figure 6). It is reliance on home-care services rather institutional care that makes a difference in terms of allowing for older people to access care,

Care provided by family members, friends or other informal carers still represents the bulk of care provision to the elderly in Europe, even if the profile of supplied informal care differs according to cultural preferences, living arrangements of older people and
availability of formal care services and design of benefits (these last two acting more as supplement rather than as substitution to informal care). Thus, reduced availability of care services and/or long-term care schemes that advocate more family participation may translate into a higher share of co-resident relatives having to provide care (Figure 7).

Although informal care can be expected to make-up for gaps between care needs and available long-term care services and this is also the preferred option of care by most EU citizens (Eurobarometer, 2007), policy-makers may feel tempted to see informal care as a free resource that will ultimately make-up for deficiencies in provision of publicly provided care. However, this grossly underestimates the costs of informal care - namely in terms of foregone employment - and may lead to an undervaluation of the needs of caregivers, thus placing too much of a burden on carers (Figure 8) and jeopardizing the availability of care.

Care allowances provided directly to carers and attendance allowances provided to those in need of care, but that may function as “routed wages” to carers (Ungerson and Yeandle, 2007), have arisen partially as a means to support informal caregivers. Care giving responsibilities are shouldered mostly by middle-aged women across the EU Member States (Figure 9), which are one of the target groups of EU and national employment policies that aim to increase labour market participation.

As reconciling employment and care duties remains difficult (Figure 10), policymakers may find themselves managing a fine balance between supporting informal care as a mean to reduce the care bill supported by the public purse and enhancing female employment as foreseen by the Lisbon Strategy. Some of these more unregulated cash benefits have also given rise to “informal markets of care”, where illegal migrant workers supplement or replace care provided by families (in some countries up to an estimated more than 90% of all around-the-clock home care services), raising issues of its own (see Long-term care workforce policies below).

What is then the correct balance between supporting informal care and meeting the goals of enhanced labour market participation of women and older workers (both prime deliverers of care to older people)?

**How much does long-term care cost?**

The size of public resources devoted to long-term care within the EU reflects the provision of long-term care services in the different Member States as well as their policy options (Table 2). Thus, relative low availability of long-term care services in Lithuania and Poland translate into low public expenditure (0.3% of GDP), whereas Sweden devotes the highest share of GDP to long-term care among Member States (3.9% of GDP), also concentrating more care on those individuals most in need.

The overall scope of long-term care is still relatively modest in most countries compared to other social programmes (typically in the range of 1.0% to 1.5% of GDP, compared to less than 7.5% percent of GDP that is spent on health care overall for the average of EU15 countries). To some extent, this reflects the rather strong cost-containment measures long-term care has often been subject to, compared with other social programmes (including health).
For example, in many cases, benefits are means or income tested, requiring substantial private cost sharing (as a minimum, those living in long-term care institutions are usually required to contribute with the bulk of their retirement income). In addition, some of the new long-term care insurance programmes that have been introduced in the last 10 to 15 years, had caps on benefits as cost-containment measure, which led to a contested, controversial erosion of benefit levels in real terms (Germany and Austria) which has been addressed in recent reforms (e.g. Germany).

As seen above, most beneficiaries of long-term care services are cared for in their own homes but the share of people aged 65+ receiving care in institutions is low in any given EU Member State. Yet the majority of countries for which information is available devote between 54.8% (Poland) to 72% (Belgium) of their public resources to institutional care (Figure 11).

The importance of institutional care in overall public expenditure in long-term care merits a closer look at differences among countries (Figure 12). While the share of 65+ being cared for in institutions is correlated with total (private + public) expenditure, other factors come into play. One of the variables most likely to influence expenditure is quality, as higher staff ratios, more privacy and other amenities can translate into higher unit costs (Huber et al., 2009). Differences in cost-sharing by users and their families, i.e., different public-private mixes in financing institutional care, are another factor impacting differences in public expenditure among Member States.

Cost-sharing mechanisms of institutional care are now a staple across the EU and the cost of institutional care borne by the user or the family can be very high (Figure 13). However, variation across and within countries is also very high, reflecting differences in location of nursing homes and/or differences in quality and amenities (single room vs. shared room), but monthly costs superior to 60% of an average workers’ wage are well within the expectable range in most countries. Even if social assistance can provide support for poorer individuals in need of care, affordability can be an issue facing most beneficiaries of institutional care.

These figures are in contrast to average payments required for acute health care for which both public social protection schemes and private health insurance have managed to contain costs faced by private households. For publicly provided health care, for example, older people with functional limitations are usually exempt from co-payments, or public health care systems have other income protection built in their co-payment regulations. For long-term care, however, public benefits for nursing home care are in many cases means-tested, meaning that assets have to be spent down. For other countries, the public coverage is strictly limited to certain levels of reimbursements, or reimburses only care services, but not board and lodging. In both cases, the cost that private households have to shoulder is on average large (see Figure 13).

Despite the potential catastrophic financial consequences that individuals requiring long-term care are likely to face, the insurance market has so far not been able to provide protection against this risk, possible for both supply and demand side limitations. In Europe, only France has a sizeable market of voluntary private long-term care insurance (around 3 million insurance-policy holders, Le Corre, 2008), but in the UK and United States this market has remained small (Brown and Finkelstein,
Thus, users’ fees for institutional care continue to account for most of the private expenditure on long-term care (Huber et al., 2009).

The crucial question however, is who is getting better value for its money and the answer has remained open for debate. Taking the example of neighbouring countries like Austria and Germany, with similar health conditions and age structures, the share of old age receiving attendance allowance is almost twice as high as in Austria, 17.8% in comparison to Germany with 10.5%. Is Austria wasting resources by supporting too many people with low-level needs of care, or is this a sound strategy of spending small amounts of money in preventing further deterioration of health that could otherwise require higher and more expensive levels of care later on?

Care allowances provided directly to carers and attendance allowances provided to those in need of care show some of the difficult decisions that EU Member States have made in balancing the generosity of their public schemes of long-term care (Figure 14 and Figure 15). In both cases, Member States seem to have opted to chose between two types of generosity: “coverage” generosity, by providing benefits to a higher share of their populations albeit of low amount; or “benefit” generosity, by providing more generous benefit levels but restricting them to a smaller number of beneficiaries.

What will drive public expenditure in the future?

Unlike pensions, the link between demographic ageing and observed public expenditure on long-term care is weak in a cross-country comparison (Figure 16). It is rather the share of 65+ receiving public support that is correlated with public expenditure, but as stated above, other factors such as quality and reliance on private expenditure also play a role.

Nonetheless, expected future increases in long-term care spending are a major policy concern that has influenced the design of long-term care programmes and their timing, often resulting in delayed introduction of new schemes or in the postponements of reform or the upgrading of existing ones, for example by easing cost-containment or abolishing means-testing.

There has been considerable progress with moving away from simple projection models that are mainly based on demographic projects to more sophisticated models that include a number of other determinants of spending. The sensitivity analysis of alternative scenarios can provide important hint for the design of long-term care policy.

ECFIN has recently released a new report (ECFIN, 2009; updating and expanding earlier work in 2006) that looks at the impact on public expenditure on long-term care of alternative assumptions concerning demography, health condition, informal care, care mix (home versus institutional care) and unit costs of providing professional services, with the following findings (summary of results presented in Table 3):

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6 In the case of projecting long-term care needs the uncertainty and complexity is compounded as assumptions have to be made not only on demographics, but also on more tentative issues like evolution of health condition of the elderly population.
Demography has a strong impact, but it is far from being the most important driving force behind possible cost increases (for example, it could partially be offset by improvements in the health condition of elderly people);

- The “hidden” importance of informal care provision is brought forward, as even a small decrease in informal care can have the greatest of impacts on demand for long-term care services and consequently on public expenditure;

- Given its higher unit costs, increased reliance on institutional care may according to this modelling exercise lead to a huge increase of costs, especially when compared with home care.

From these findings; a number of policy implications emerge. Namely, improvements in disability prevalence in old age can have a great impact, which highlights the importance and potential cost-effective nature of improved prevention and rehabilitation. Because of lower unit costs, home care services can result in a lower bill for the State budget and institutional care should be targeted only to those not able to be cared for in their homes. Provision of informal care may come under pressure, but its continuing availability in the future is crucial to keep public expenses under check.

The impact of the economic crisis

With the current economic crisis, there is the real risk that the existing cost-containment pressure on long-term care services may increase. Because publicly financing of long-term care services in all countries provides only part of overall care provided, and in all countries heavily relies on the contribution of both formal care provided in families and additional private financing, public policy may be tempted to shift at least some of the responsibility of long-term care back on private households.

The recent Ageing Report by ECFIN makes the point that public expenditure in health care “might be (nearly) inelastic to GDP changes” (ECFIN (2009): 185) and if the current financial crisis takes the form of a permanent downward shock to potential growth then there is a risk that age-related expenditure (in which long-term care is included) may rise in the future at a higher pace than GDP.

There is consequently the risk that investment in long-term care may suffer, even if it is urgently needed to upgrade quality of care, such as for improving care in institutions, but also to put a proper scope and mix of home care services into place. This could hit countries in particular that are still in the early stages of setting up and of upgrading their long-term care services: as the 2008 Joint Report on Social Protection and Social Inclusion put it “Postponements of plans to modernise and develop long-term care infrastructure can be expected”.

Because equities and real estate have been the assets that have suffered the greatest depreciation of value in the current financial crisis, there could be an increase in the number of old-age people in need of social assistance to be able to afford care, as they

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7 Improvement in health condition of the elderly can have a twofold impact on long-term care: on the demand side by reducing the need for long-term care (both in number of people and severity of needs); and on the supply side by allowing more elderly people to act as informal carers themselves.
are faced with reduced savings for retirement (private savings, defined-contribution private pensions and home ownership).

What strategies can policy makers and stakeholder groups pursue to keep improved elderly care - and the corresponding investment needed - on the policy agenda?
Key Policy Challenges

This section reviews a number of key policy challenges in long-term care and what strategies and policy responses have been put in place in response. Examples are:

- How can fragmentation of services be overcome and health and social services be better integrated?
- What measures have been taken to protect dignity and have a stronger focus on the individual
- How has consumer choice been used as policy instrument?
- Does Alzheimer diseases and other dementias receive adequate attention?
- How can a sufficient and well-trained long-term care workforce be maintained?
- What does it take to improve and secure quality of services?
- Are there experiences with efficiency gains that will help to cope with future challenges?

Better integration between health and long-term care

Though issues concerning coordination and integration of services are high on the agenda in most Member States, national health and social care systems remain, at best, loosely coupled systems facing a number of important challenges when it comes to coordinating services for older people with long-term care needs. Increasingly market-led mechanisms of provision, combined with a lack of managerial knowledge in bringing about co-operation and co-ordination between different agencies and professionals continue to hamper the first tentative steps towards integrated care systems (Billings and Leichsenring, 2005).

Older persons with complex needs for services, e.g. combining acute health care (in particular for chronic conditions), rehabilitation, nursing care and other social services typically remain confronted with fragmented provision structures. For instance, if an older person is discharged from hospital with long-term care needs, in many countries costs for community care services will not be covered by health insurance. In some countries, there might be a hospital discharge manager in place who can inform home care services and/or the family of the person in need of care.

As community care services are financed and organised by local authorities, the communication-flow between the hospital staff and local social workers will most probably be lacking. Access to rehabilitation services might become difficult as these services are organised by yet another agency. Family members are confronted from one day to the other with what one could call a “care responsibility shock”, i.e. the need to re-organise the housing situation of the older relative, to gather information on home care services, to choose between different providers, and to pay for these services. Still, in order to keep their relative at home, they will most probably have to take over parts of the personal care, often without any information or counselling.

Other “synchronisation failure scenarios” that might occur in this context include:

- The hospital discharges an older person in need of long-term care on Friday afternoon without any earlier notice to family members or community care services.
The community care service is taking an older person in charge without a multidimensional needs assessment.

- The home help provider is rendering services without any individual care plan.
- The home nurse recognizes problems of hygiene at the home of one of her patients but does not inform the home help service, neither does she call the family members living in another town.
- The GP does not inform community care services about a problematic situation and/or prescribes an X-ray to an older patient living alone without informing him/her about transportation services.

Due to these difficulties already at the offset of long-term care many older people end up being readmitted to (another) hospital or staying longer in the hospital as necessary. This inadequate use of acute (hospital) care for patients who would more adequately and more efficiently be cared for in specialised facilities or in a community setting, is only the most visible evidence of the need for reforms. Such perceptions concerning ‘bed-blockers’ gave rise to a number of initiatives and projects which, however, only in exceptional cases became a mainstream service.

How can discharge management be improved?

In many Member States, coordination mechanisms were developed in the context of hospital discharge management – training for ‘discharge managers’ has been introduced and improved, for instance, in Austria, Germany, and the UK. Discharge management has also become an important part of disease management programmes, including primary care and rehabilitation. However, these programmes of ‘managed care’ or ‘integrated provision’ often remain restricted to the health care system. Discharge managers as a part of this system experience difficulties when it comes to shared decision-making and care planning with patients, their families and the local system of long-term care providers.

Improvements would include the extension of “Rapid Response Teams” and “intermediate care facilities” (UK) that focus particularly on rehabilitation and/or the development of user-friendly arrangements after discharge. as well as counselling and adaptation of housing to increase the opportunities for improvements or at least a smooth attendance during the period between hospital discharge and moving back home. Inter-agency working and networking between health care, social and housing departments seem to be the most difficult features to be achieved in this respect.

Will governments be ready to develop new job profiles and training as well as pooled budgets for long-term care, rather than thematic and budgetary silos with the incentive for stakeholders to shift burdens to other sectors, rather than financial means?

Extending home care provision

Home care provision has been extended by organisations gathering nursing care, social work, home help and other expertise under one organisational roof, thus promoting inter-professional work and mutual understanding. The co-ordination of home nursing and social care professionals is an important first step towards more
person-centred care. However, as patients are discharged from hospitals increasingly at earlier stages, these services are progressively more confronted with clients needing heavier and more intense care. In addition, as these services are often subject to quite important out-of-pocket payments of users and complicated, means-tested tariffs, access remains unequal and restricted. An important aspect in this context is that needs assessment is largely reduced to physical handicaps leaving people suffering from dementia or other cognitive diseases with inadequate support.

In many Member States, long-term care services are, as a part of social assistance schemes, only slowly moving out of ‘poor law’-regulations, with respective consequences for take-up rates and users being treated by charity. Extending the purchasing-power of users by means of long-term care benefits (e.g. in Austria, Germany and France) is certainly one way to improve the situation of people in need of long-term care but experiences have shown that it is indispensable to complement such schemes with information and counselling services to support beneficiaries and their families in their choices.

Will governments agree to create additional demand for services by means of information and counselling?

“Gerontological coordination” and “care trusts”: Acknowledging the characteristics of long-term care

To improve local access, assessment and information, in France such centres (so-called CLIC) were founded all over the country. The French experience with ‘gerontological coordination’ highlights an interesting aspect of the debates on integrated care. The term ‘gerontological coordination’ has been introduced to underline the specificity of long-term care in terms of health and social aspects. It is thus intended not to integrate long-term care under the roof of the health care system as further ‘medicalisation’ of long-term care should be avoided.

One of the most important experiences of CLICs is the improvement of mutual understanding and the development of a common language between health and social care staff – an issue that takes time and sometimes needs support from third parties, both aspects that remain scarce in the realm of long-term care.

Will governments provide framework conditions to develop mutual understanding between stakeholders involved, and create ‘care trusts’ with constraints to provide mutually agreed care and developmental plans by all stakeholders?

Restructuring housing and residential care

New kinds of housing structures have been designed, for instance in the Netherlands and in the Nordic countries (service-housing) to make use of community care structures and local resources. Residential care homes, however, are still one of the main pillars of long-term care in many countries – often built during the 1960s as large-scale institutions to satisfy mainly housing needs of older people, they have gradually been transformed into nursing homes. As home care is expanding, people remain at home as long as possible and thus consider care homes only as the last alternative. The ever higher average age of residents in institutional care (around 85 years) and the ever more fragile health conditions and correspondingly shorter
duration of stay in residential care are empirical evidence of this overall trend of transforming pensioner collective housing into nursing homes and pre-hospice type of institutions in many places.

As one consequence, care homes often fill the headlines of media due to scandals and quality problems. As an important part of the ‘chain of care’ the ongoing restructuring of these facilities towards small-scale units that are open to the neighbourhood and to exchange with other services needs further support, in particular in those countries, where they had been expanded since the 1960s. In this context, Member States with still a low level of care homes (Mediterrenean, Eastern Europe) have a good chance to not repeat the errors that had been made in many Western European countries. Will governments be able to learn from experiences and focus on tailor-made smaller units for people with individual needs, rather than on large medicalised institutions with a taylorised division of labour?

There remains much scope for mutual learning and further developing of long-term care policies as an emerging subsystem of its own

The individual initiatives to improve shortcomings at the interface between health and long-term care are still far from having become mainstream services. In reality, LTC as a system with its own vision and policies, structural preconditions (financing, professional standards, instruments and methods) and its own qualities yet remains to be developed – and learning will be a crucial factor for such a development. Different national frameworks, in particular with respect to financing and organisation, systemic development, professionalisation and professional cultures, basic societal values (family ethics), and political approaches are still prevailing. And in many cases these structural framework conditions hamper further spreading of innovative initiatives, even if positive evaluations prove the evident advantages of individual coordination and integration projects.

One of the most outstanding projects in terms of a ‘consolidated direct service model’ has evolved in Denmark over the past 25 years. The small municipality of Skævinge has founded its ‘Health Centre Bauneparken’ in 1984 and has shown that positive framework conditions supporting investment in innovative approaches, guaranteeing long-term funding and organisational development are able to achieve a sustainable impact (for more details see under the section Drawing Lessons from Good Practices).

Governance and financing

Coordinating or even integrating the various services and stakeholders involved in long-term care delivery seems to be the most logical idea if one considers the complex individual needs of many older people in need of long-term care. Of course, a wealth of medical knowledge is now influencing the sector, but more and more specific knowledge in social gerontology, social work, psychology and a whole range of various therapeutic approaches are gaining ground. Apart from this important professional differentiation, we are also witnessing a steady institutional change in long-term care with respect to the various forms in which help is provided.

This includes organisational settings such as the increasing development of private commercial and non-profit providers that are complementing general public services.
In this situation, it seems to be difficult to decide who should coordinate whom, with what means and based on whose rules. To put it more bluntly, if we agree that integrating different services towards a ‘consolidated’ long-term care provision a number of crucial questions occur:

Who should lead this integrated service? Who should develop a shared vision of such a service? Would such a service be public or private – or even mixed? How would users and carers be represented in such a service?

As a first step to answer these questions we could learn from successful coordination based on the following indicators:

- A common understanding of what integrated care provision is there to achieve: It seems useful to involve different stakeholders from the very beginning in the definition of objectives, procedures, target groups and rules of working.
- The definition of ‘client-orientation’ and its meanings for daily work, e.g. seamless functioning of service provision, considering the client and his/her family as a resource, should be part of a constant exchange and adaptation.
- Access procedures should be comprehensive to cover the user’s needs in various life domains, understandable and negotiable for the users and manageable for the professionals.
- Allowing enough time for the ‘integration process’ to be managed is the key investment to the process of mutual understanding: shared meetings, travel, team development, contacts and jointly agreed protocols and strategies are only some examples that, initially, take a lot of time but eventually will turn out as major asset in terms of job satisfaction and performance.
- Developing new job profiles such as the case and care manager, the life assistant, the personal assistant and other multi-purpose professionals that are able to combine health and social care approaches.
- Involving family members and other stakeholders in the assessment of needs and the individual care planning is vital: All too often however there is a continued mismatch between the responsibilities and expectations of the family and state intervention at all levels and within a variety of contexts.
- Sustaining autonomy and functionality of older people, maintaining or regaining their self respect, providing sufficient and accessible information and economical options to regulate the service use: Service providers thus have to improve their communication skills and the ways in which they assess, monitor and evaluate their performance.
- On a systems level, these approaches have to be underpinned by integrated planning processes to overcome budgetary and policy silos. Synergies and gains – also in terms of financial returns – can only be achieved, if health care reforms focus explicitly on the interfaces between health and LTC provision. Considering the prevailing decision-making and political power structures, relevant stakeholders under the leadership of public authorities are invited to develop a dialogue between equals, rather than just shifting the burden from health to LTC facilities,
How can access to mainstream health care for dependent older people be improved?

There is also a raising awareness that services of prevention and rehabilitation that could contribute to preventing or postponing dependency and functional limitations are still underdeveloped in many countries, resulting in reduced quality of life and lost opportunities to limit the need for long-term care services. There is now growing evidence that some of these measures are cost effective (Age Europe, 2005/HealthQUEST study). However, the issue of ‘cost-effectiveness’ in long-term care gets rather complicated as different budget-lines and financing agencies at different administrative levels have to be taken into account. For instance, if hospitals are able to reduce patients’ length-of-stay, this will reduce the costs for the health system but might as well increase the financial burden on local social care budgets.

More generally, older people with functional limitations can face multiple and intertwined barriers of access to adequate and high-quality mainstream health care services. This is for different reasons, including problems with mobility, gaps in training of geriatricians, age discrimination, but also health beliefs (low expectations) of some older people.

In response, many countries have started to address remaining gaps in geriatric services and in the knowledge of general practitioners in particular, for example to adequately address mental health issues of older people, such as depression and sleeping disorders. For example, some Member States have increased gerontology training for medical students.

There is also growing recognition that more need to be done to improve the often limited access to health care services of people living in institutions that can put older dependent people at health and safety risks. But countries differ in the degree of necessary investments and appropriate changes in service arrangements may have not yet been implemented, for example, when nursing homes are not a legally “recognised workplace” for physicians.

Most countries now have exemption rules that limit the cost-sharing requirements for health care services for older people. But in some countries, older dependent people are faced with financial barriers of access because of high cost sharing for health care, including prescription drugs and hospital care (especially in some of the new Member States). Poverty, deprivation and dependency are then often compounding risks, in particular for those countries where older people are at a higher risk of poverty.

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9 See also the section below on dementia.
The role of choice in publicly provided long-term care

Pushed by an active disability movement in the UK and the Netherlands (Ungerson and Yeandle, 2007), as well as by the increased market orientation in public long-term care for the elderly across Europe, care recipients’ freedom of choice is now a frequent presence in official documents referring to provision of long-term care services for the elderly. Consumer choice has also been one of the underlying rationales behind the introduction of attendance allowances benefitting those in need of care (Ungerson and Yeandle, 2007).

The drive for increased possibilities of choice by beneficiaries has indeed empowered beneficiaries in some Member States with an increased say over the care they receive. In several EU countries, those in need of care are given the choice of at least to some extend relying on relatives to receive care, to whom they may transfer part of their benefits. In some cases, a personal budget is even allocated to the beneficiaries who can then “shop around” for care that best suits their preferences. The rhetoric of consumerism has also lead to the opening of the market of care to other players besides the public providers, be it non-profit organisations or private commercial companies.

However, there still remain significant limitations to real opportunities of choice by beneficiaries. To begin with, most of these schemes come with strings attached that may act to limit choice. For example, the possibility to use attendance allowances to pay for relatives providing care is limited in many countries, as care within the family is still viewed as a “positive externality” that shouldn’t be paid for, or as a private sphere from which the State should steer clear.

Given the option to choose from enough different providers, people may opt for those offering better quality standards or immediate access to services. However, the possibility to choose requires the existence of enough affordable possibilities to choose from, e.g. there must be enough different and heterogeneous providers. Given existent constraints in the provision of long-term care services, the possibility to opt for the preferred alternative of care may be severely conditioned or even non-existent. Affordability of care, particularly in the case of institutions or more complex care needs, are still a concern and may limit beneficiaries’ choices as well. But a multiplicity of providers may still maintain an option to choose the one with shorter or no waiting list, better quality record, etc., always provided there is some market transparency and sufficient user information.

The characteristics of the care market may also lead to diminished possibilities of choice. The need to keep costs low may result in a limited and standardized supply of care options that allow for more economies of scale. The same drive towards cost containment may also lead to a concentration of private suppliers, a trend that seems to be already evident in such diverse countries as UK (England) and in Sweden (Trydegård, 2004), which would also conduce to limit the possibilities of choice by those needing care. Although the rhetoric of choice and market orientation may have contribute to reinforce one-another in the past, if the latter conduces to monopolies pushed by ever increasing emphasis on cost-containment that could put it at odds with the aim of increasing choice by beneficiaries.
From all these experiments “what have we learned from market design”\(^{(10)}\), when it comes to care for the elderly?

**Alzheimer diseases and other dementias**

With the trend to target care in nursing homes to the more fragile older people in care need, the nursing home population has become older on average and the share of people in nursing homes who are affected by dementia has increased, being now more than 50% in many cases, with dementia either their main or at least a contributing factor to their care needs. It has been estimated that a large part of all spending on long-term care is due to dementia, which is already today 1% of GDP or more in a number of EU countries (Brodaty, 2008).

Dementia in old age comes in many forms. Alzheimer’s disease is the most common type but other types of dementia are also common, such as vascular dementia, Parkinson’s disease-associated dementia and alcohol-associated dementia. The prevalence of dementia increases steeply in higher age groups (Figure 3), doubling approximately every five years, from around 1.5% of those aged 65-69 to almost one in four for those aged 85 and older.

Taking into account the projected “ageing of the aged” (see section above on demographic trends) it has been estimated that the numbers of people with dementia will double every 20 years, if today’s age-specific prevalence rates will persist (Brodaty, 2008). A large part of the spending increases projected for the future would consequently be due to increasing prevalence of dementia in the European population.

Because dementia lasts for about 10 years for the majority of people affected, and in many cases only needs intensive care in later stages, the informal care provided by families and other informal care givers is also very much concentrated on people with dementia. However, for those dementia patients with intensive care needs who do not have (co-resident) family carers to look after them, moving to a nursing home or a specially designed assisted living arrangements for dementia patients is the likely outcome at some stage of their disease.

It is increasingly recognised that the high concentration of long-term care resources and the great personal suffering involved call for strong efforts to invest in medical and pharmaceutical research in Dementia as well as for experimentation with alternative approaches of long-term care, but it is also recognised that more must be done to address the specific needs of dementia patients in the design of the provision and in the assessment procedures of long-term care programmes.\(^{(11)}\)

It is currently not possible to predict the speed and direction of medical progress in the field of dementia, such as with further rapid progress in the drug treatment of Alzheimer’s disease or even the development of a vaccine. But progress made in the last ten years suggests that policy makers and planners of long-term care should keep in mind that a number of different scenarios for the future are possible.

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\(^{(11)}\) See for example. H.Brodaty, “Why is research in dementia crucial for Europe?”, Presentation at the French Presidency Meeting “The fight against Alzheimer’s disease and related disorders.”
Current drugs treat symptoms but cannot stop Alzheimer’s disease.

Spending on such drugs increases fast (with a market share of 3 US billion for the leading drug world wide).

If Alzheimer’s disease can be delayed for 2 years (5 years), prevalence would decrease by 20% (50%) and consequently demand for nursing homes would be less.

If drugs do not delay the onset but only slow the rate of progress, there might be even many more people with dementia in the future. If treatment prolongs the late stages, demand for long-term care can be expected to increase. (This ambivalence and paradoxical consequences of medical progress were already seen with HIV/AIDS treatment).

Prolonged disease will likely increase the demand for informal care, making more and better support to informal carers key.

If drugs become available that can halt the disease, the demand for early diagnosis, including with (currently very costly) high tech diagnostic imaging may grow very fast, as will the spending on these drugs themselves.

Finally, in the most optimistic scenario, the availability of a vaccine may substantially reduce cost of long-term care, as long as the prevalence of other chronic diseases does not increase substantially.

Based on current standards of treatment and diagnostic possibilities, there is an emerging consensus that a number of strategies will most likely remain valid, irrespective of how medical progress will evolve over the near future:

Low-tech early detection will remain important and more needs to be done to train general practitioners to diagnose and manage early stage of dementia (which currently is in 50% of cases not picked up by GPs (Brodaty, 2008).

Increasing public awareness and perception will remain an important concern; this includes with the help of NGOs (such as Alzheimer associations) that need to receive sufficient funding.

Countries have made progress with better information for patients and relatives, including by phone (help) lines and over the Internet (good practice examples).

Support for (informal) carers can be effective and needs to be at the core of strategies to make care for an increasing number of patients with dementia sustainable for the future. A number of countries have reformed the assessment criteria for home care and for direct support programmes (including benefits of cash) for family carers in ways that better take the care-needs of dementia patients into account.

Training and education of professional care givers has also shown positive results.

**Long-term care workforce policies**

The increasing public and private spending on long-term care has resulted in a dynamic growth of the number of care workers as a majority employment in social
services is in the field of elderly care in a number of countries (e.g. it accounts for two-thirds in England). Of the 4.5 million jobs that have been added to employment in health and social services together in the EU15 from 1995 to 2006, social services were growing faster than the health sector\textsuperscript{12}.

But EU Member States share the concern that more needs to be done to overcome shortage of care workers that are either already manifest or expected for the near future. There is a growing shortage of the nursing work force in both health and long-term care, with both sectors increasingly in competition for human resources.

Care workers are increasingly in a much more complex care situation. Frail older people are of much higher age and show a higher degree of complex physical and mental illnesses. At the same time there are growing demands for more dignity as well as for improvements in quality and efficiency. This situation calls for a better skilled workforce at all levels.

In order to stay competitive, there is a continuous need to improve the attractiveness of long-term care as a workplace. This could go hand-in-hand with better quality of services, if training of staff is improved. In this context adequate salaries will certainly play an important role. Therefore, increasing salaries can be expected a major source of cost increases in the near future (OECD, 2005). However, the evidence on good practice to secure adequate staffing is currently limited, but a few examples are listed in a recent OECD report (Fujisawa and Colombo, 2009).

In some EU countries, the introduction of cash benefits had the explicit goal to foster family carers’ employment. As an example, France has apparently succeeded in bringing into the labour market female care-givers and unemployed people with the help of its allowance for care (\textit{Allocation personnalisée d’autonomie}, APA), such as groups that were in a disadvantaged situation in the labour market. In other countries, such as Hungary (Szombathely), job-rotation schemes that were introduced at provider level, in order to allow staff to participate in different projects and acquire management skills. There is some evidence that this helped reduce staff turnover (EUROFOUND, 2006).

Reorganisation of tasks and skills, namely by allowing less skilled workers to handle home-help and domestic tasks while nursing staff focus on specialized tasks and, could also allow for a more effective use of available workers (Fujisawa and Colombo, 2009).

The dynamic growth of the workforce of formal care workers in a number of countries was complemented by the hiring of undocumented care workers, mostly by private households, often of care workers from neighbouring or countries inside or outside the EU, where great differences in income and living standards currently persist.

The scope of informal care by undocumented migrants from poorer countries can be substantial and currently is crucial to the sustainability of long-term care in a number of countries (Austria and Italy are examples). It plays an important role in providing care for those who need assistance around the clock, while still living in their own

\textsuperscript{12} See European Commission, 2008b.
home. Unregulated attendance allowances as mode of financing long-term care and that households can use as they wish, have contributed to this trend.

While the availability of these undocumented care workers strongly increase the purchasing power of people in need of care in receiving countries, what are the effects on employment and income in the sending countries? And how can a basic social protection and protection at the workplace be guaranteed under these – often informal – arrangements?.

**Assuring and improving quality of services**

Not only the resources devoted to long-term care differ largely in Europe. There is also evidence that the quality of services is variable (OECD, 2005). According to the 2007 Eurobarometer Survey [no.283] on health and long-term care, European citizens are concerned about shortcoming of quality in long-term care services, which they rank significantly lower compared with health care.

Interestingly, people rank the quality of long-term care higher when asked for their own experience (within their family), and lower when asked for their opinion in general. Among the many aspects behind this “problem of reputation” one of the most important reasons seems to be the lack of information and knowledge. Long-term care is still often perceived as a segregated, dull and unpleasant part of personal services provided chiefly in closed institutions which, at best, cater for feeding, physical support and a clean environment – and unfortunately this is still true for many settings in a number of Member States.

However, the differentiation of services, the development of intermediary and home care, improved education and training have certainly contributed to more choice and more dignified supply structures. As a consequence of such modernisation processes, often based on market-led mechanisms to increase choice and user-centred care both in the community and in residential care facilities, quality has become a buzzword in long-term care services over the past decade. Also the European Commission has started to develop a strategy for supporting the quality of social services across the EU in order to “support the development, within the Social Protection Committee, of a voluntary EU quality framework providing guidelines on the methodology to set, monitor and evaluate quality standards” [COM(2007) 725 final].

This initiative addressed once again that concrete models to describe and improve the quality of long-term care for older persons – and of other social services – are scarce. The debate about quality in this sector is still very much based on beliefs and ideologies concerning, for instance, the legal basis of organisations, their size or their ownership, rather than transparent criteria that shed light on the type and quality of service delivered and ways for improving these.

Difficulties to define, assess and control quality of long-term care are encountered by all stakeholders involved, at any stage of planning, implementing and controlling respective services. For example, if policy-makers and public authorities decide upon the introduction of a new service or to open new care homes, they should be able to describe the expected quality of the service in tender documents. The same holds true if, for instance, a regional government responsible for long-term care services
introduces authorisation or accreditation mechanisms for service providers – be they public, private for-profit or non-profit.

In most cases, tender documents and accreditation rules will focus on structural quality requirements, perhaps even on some aspects concerning process quality – but as a matter of fact, tenders will be won by providers offering the lowest price, as public purchasers usually find it very difficult to define and measure outcome quality – if these features are considered at all. Problems of quality standard setting and quality control, therefore, make for a continued prevalence of price over quality competition.

The same applies for providers, and as they are not forced to show in a transparent way which quality they are producing they will rather invest in structural prerequisites to comply with general legal requirements. Residents and their families are only rarely asked for their views, their satisfaction or their proposals for improvement – with the excuse that they are ‘to a large degree’ unable or unwilling to express their preferences. Finally, public authorities in their role as control agency reduce their efforts to inspect and check the legally requested features – but even with this rather limited focus they are often confronted with severe shortcomings.

Wouldn’t it be an interesting exercise to set-up international, all-European quality assurance inspection teams (labelled “EUROCARE monitoring & inspection teams”, or so), in order to ensure a continuous quality assessment, improvement, feedback, transparency, learning, and upgrading process in the provision of long-term care services, both in care homes and in home care?

While most Member States are thus still struggling with ensuring structural quality requisites, over the past few years activities initiated both by providers and by public purchasers have started to focus on process and outcome quality. It now becomes increasingly obvious that all stakeholders have to be involved to further develop what quality in long-term care means from different perspectives. Quality cannot be assessed at one point in time but needs a continuous improvement approach by all stakeholders involved. However, such an approach to quality management in long-term care calls for awareness and knowledge building as well as for self-assessment, i.e. for investment in training and time for reflection:

− What do we – as policy makers, as management and staff, as users – understand by user-centred and dignified care?
− What support do we need to improve our performance?
− What mutually agreed indicators could tell us more about our performance?
− How can providers, purchasers and users enter into a dialogue on quality in long-term care?

If there is a tendency to move away from mere inspection of quality towards the implementation of a continuous improvement process, taking into account the specificities of social services of general interest, it is therefore important to provide an institutional framework to support this process. The Swedish initiative coordinated by Socialstyrelsen (The National Board of Health Welfare) to develop performance
indicators together with various stakeholders and the English Social Care Institute for Excellence (SCIE) are examples for this kind of institution-building. At the same time, many providers have started to apply quality management systems and to adapt existing frameworks to the specific needs of long-term care services. An example for such an adapted model is given in the following section.

Will governments be ready to dedicate just 1% of, for instance, construction costs of a care home, to this kind of support structures?
Drawing Lessons from Good Practices

This section illustrates policy challenges and responses with four examples of good practices.

These are focusing on the following key concepts:

- Communication and participation
- Coordination and integration
- Choice and empowerment
- Measures to protect dignity and to have a stronger focus on the individual

Valutazione Integrata dei Tempi Assistenziali – VITA (Integrated Assessment of Attendance and Care Time): An assessment tool to classify and estimate individual care needs

Dignity in old age, in particular in the case of complex long-term care needs, also means to be able to initiate a dialogue between the formal and the informal, between health, social and other supportive professionals, in order to avoid social exclusion of persons in need of care and their carers, the latter often being themselves in need of support (e.g. spouses). The assessment process is a crucial moment to get in contact with households at risk, in particular in countries where the use of social services has not yet become normality.

Individual needs for care are dependent on a broad range of contextual aspects that call for an extensive assessment from different professional perspectives and, of course, for an involvement of people in need of care. Traditional assessment tools often focus mainly on physical limitations, though mental health problems (dementia) are increasingly being taken into account. However, in most cases the assessment is carried out by a health or social care expert with the aim to regulate the access to long-term care benefits or services, rather than a dialogue about needs and potential choices to be arranged in the framework of formal and informal care provision.

When the Autonomous Region Bolzano-Alto Adige (Italy) with hardly 500,000 inhabitants started to prepare for the introduction of a long-term care scheme, the development of an adequate assessment tool to classify individual care needs and respective entitlements was identified as a key challenge.

This reform was undertaken to complement the existing universal health system and thus qualified all citizens in need of long-term care as eligible for non means-tested provisions. As such benefits can certainly never cover the entire costs of care, it was necessary also in this case to standardise the amounts to a degree that they only contribute to the global costs of care with the expectation that users and their families would also in the future have to contribute their resources. Nevertheless, it was seen as most important that the assessment procedure should be used to assess all individual care needs that encompass activities of daily living but also additional aspects such as social relations, the family and the housing situation. Rather than just
defining the statutory contribution, the assessment should be carried out with the aim
to inform and counsel persons in need of care and their family about potential
alternative care arrangements, including social and health services, to satisfy
individual care needs. Thus, an important aim of the reform was also to provide an
opportunity to choose between cash benefits (different levels according to needs) and
services (including funding of residential care).

During a process of several years, the respective tools and procedures were developed
and evaluated by a working group with representatives of all relevant stakeholders
and based on intensive research in relation to existing methods in Austria, Germany
and Luxembourg. Four different versions of the tool were tested, a final evaluation
with pilot assessment teams was carried out in 2005 covering about 1,000 persons
receiving disability pensions. The tool was called “Valutazione Integrata dei Tempi
Assistenziali” (VITA) which means “integrated assessment of attendance and care
time”.

The assessment scheme consists of about 40 items to assess the individual care needs
in all activities of daily living in terms of “time needed to satisfy the individual care
needs”: nutrition, personal hygiene, excretion, household and organisational matters,
mental health and social care needs (these latter items help increase the eligibility of
persons suffering from dementia and other mental health problems or learning
disabilities), and nursing care.

Items concerning nursing care are not included in the calculation of the result as these
activities (and services) are covered by the National Health Service. It is important to
note that all care needs are assessed in minutes and hours. These data are inserted into
the supporting software tool which automatically calculates the final result in four
levels of care, using “time-corridors” that were defined for each individual item in
order to guarantee standardisation and comparability.13

The more important and innovative feature of this assessment scheme is the joint
training of both health and social care staff who form so-called “assessment teams” to
visit claimants at home and who carry out the assessment procedure together with
their families or main carer. During a ten-day course, assessment teams consisting of
one health and one social care worker, are not only trained in the practical application
of the assessment instrument but also in communication, conflict management, and
the legal and structural framework (local and regional supply).

The aim of this training is to enable participants to establish a trustworthy relationship
between the assessment teams and services, and between them, the beneficiaries and
their families. This training-module will become part of mainstream education for all
health and social care professions to ensure the availability of trained personnel for
this assessment procedure. Furthermore, the approach should then also be applied in
care planning, case management and the general integration of social and health care
professions.

“For the first time somebody was listening to me and my real needs”, said one
claimant during the trial phase. And a family carer added: “During previous

13 For more detailed information see Leichsenring (2008): www.euro.centre.org
assessment procedures I was not even allowed to talk. Now there is someone listening to my view of [the claimant’s] needs and providing me with additional information”.

During the extensive testing of the various versions of the assessment tool, which in itself is an important aspect of ‘good practice’ in designing innovative policies, the following key features were underlined by the different stakeholders:

- By members of the assessment teams this new task was experienced as most positive, as a new challenge, in particular as family members expressed huge demand for information
- Families and claimants provided positive feedback due to fact that somebody asked questions about how they got along with care needs, rather than just looking at the medical diagnosis
- Family carers seemed surprised that their efforts were acknowledged and not just being taken for granted
- Members of the assessment teams saw that, once the initial scepticism had been overcome, claimants and their carers were eager to describe all details of their care needs and also respective overstrain
- In spite of, or better: due to this emerging trustworthy relationship, assessment teams developed new competences in identifying single cases in which claimants tried to act strategically – in particular, as the team members were able to exchange their impressions in a debriefing meeting.

**E-Qalin® - Involving all stakeholders in a continuous improvement process**

Quality management in steering and organising social services requires a broad movement towards new methods of shared learning which involve all stakeholders. The question is whether providers and/or public institutions will be ready and able to promote such approaches. Respective answers are likely to be influenced by national traditions, understandings of (care) work and, perhaps most importantly, by the resources available. Legal regulations towards a training boom are unlikely to happen – we have seen that governments have become reluctant to increase the educational levels of staff as this would have an immediate impact on the costs of services. Lack of personnel resources, however, may contribute to a more enlightened form of governance and the provision of more rewarding working conditions.

This context has given rise to the development of a model for quality management in residential care for older persons called E-Qalin®. In the context of an EU Leonardo da Vinci Project, several training and consultancy agencies, national and European umbrella organizations and almost 50 pilot homes in Austria, Germany, Italy, Luxembourg and Slovenia were involved in designing the model, and training modules to facilitate the application of the model in the daily work of care homes.

E-Qalin® seeks to map the reality of institutional care by inviting representatives of all stakeholders to assess and improve 66 ‘enabling’ criteria (structures & processes) and 25 key-indicators (results) from five different perspectives (residents, staff, management, social context, and ‘learning organization’). Following this self-
assessment process, in small ‘professional groups’ and in the steering group, a list of mutually agreed improvement projects guarantees enhanced services and the further involvement of stakeholders. A key-word and key-value within the model is thus ‘involvement’ as the participation of relevant actors in planning, implementing, monitoring and improving – the classical PDCA cycle (plan-do-check-act) of quality management – is considered an explicit asset and reflected in the results of the assessment. Apart from applying and adapting classical quality management mechanisms to the needs and expectations of the social and health care sector, E-Qalin® is genuinely based on training and the involvement of stakeholders to underpin a process of self-assessment and continuous improvement. It enables stakeholders by means of training, a manual, a case study and supportive software to assess, manage and improve their performance.14

To date, more than 200 care homes in Austria, Germany, Italy, Luxembourg and Slovenia have successfully applied E-Qalin®. The accompanying evaluation gave evidence of most satisfied users who were involved in the self-assessment process and the ensuing implementation of improvement projects. Furthermore, a procedure for external audits has been developed and gave rise to a “National Quality Certificate” piloted by the Austrian Ministry of Social Affairs and Consumer Protection.

In order to provide better links between the behaviour and orientation of individuals and public values such as social inclusion and solidarity further training and education is a central feature of E-Qalin®. Relevant stakeholders are enabled by means of specific training modules to enhance communication, social skills and systems-thinking within the organization. These skills are particularly important in this sector because staff are working in surroundings which, more than any other personal service, deal with the confrontation between lifeworld and political/economic subsystems, and thus between the public and private spheres.

24-hours integrated health and social care in the municipality of Skævinge

Back in 1984, the Danish municipality of Skævinge had started to reorganise its care services for older persons towards one of the first integrated care initiatives in Europe. During a 3-year process, hitherto fragmented services were brought together under one roof, the “Health Centre Bauneparken” by means of an organisational development process including joint training of health and social care professionals, the creation of autonomous groups and 24-hours care within the Health Centre and in the community, based on a rehabilitative and activating care approach – self-care.

This initiative was facilitated by the relatively extensive autonomy that was given at that time to all municipalities in Denmark concerning the organisation of health and social care, even to such small municipalities as Skævinge with its about 5,600 inhabitants, of which in 2003 about only 10 per cent were above the age of 67. Also the needs of about 200 persons below the age of 67 with needs of long-term care are covered by the Health Centre.

From this group of potential users, about 60 people may make use of the apartments in the Health Centre, about 200 receive domestic care, about 100 make use of

14 For more information, see the website www.e-qalin.net.
rehabilitation services and about 150 persons make use of the day care facility at the Health Centre (roughly 90 external citizens and the residents at the Health Centre). In addition, a group of 10 people use the ‘Garden room’, which is the day-care facility for persons with dementia, and 4-5 people with severe dementia are users of the ‘Small Garden Room’. Finally, more than 500 citizens have received support in getting material support or adaptations to housing.

The Health Centre ‘Bauneparket’ has an annual budget of about 5.5 million Euros and income of around 1.3 million Euros. The remainder of the budget is covered through general taxation. In 2003, a total of 136 professionals (full-time equivalents) from 13 different professional groups were employed by the Health Centre.

An evaluation of the project after 10 years highlighted the following key findings (Wagner, 2001; Colmört et al, 2004):

- Even though the number of older people had increased significantly, the operational expenditures had decreased over the period due to the preventative focus of the integrated care scheme.
- There was no waiting time for apartments in the Health Centre or for domestic health and social care services.
- The preventative efforts had resulted in a surplus of capacity that were used mainly to establish an intermediate care facility at the Health Centre in order to prevent unnecessary hospital admissions. Consequently, the number of days in hospitals was reduced by 30-40 per cent for all citizens in the municipality.
- No citizen from the municipality staying in a hospital had to wait for discharge after having finished treatment, as those citizens are cared for either in the intermediate care facility at the Health Centre or in the citizens’ own home.
- The municipality’s use of and expenditure to national health insurance was below the average of all other municipalities in its county.

Measures to protect dignity and to have a stronger focus on the individual

Against the backdrop of recurrent news about examples of severe shortcomings of quality of care, including substantial violations of patients’ rights and integrity, up to outright neglect, and in a context of increasing empowerment and self-organisation of family members and informal carers, there is now an increasing recognition that existing quality standards and quality regulation often have addressed fundamental issues of dignity of care and individual protection only in a piecemeal fashion.

Privacy: an essential element of quality of live in nursing homes

Privacy is an important aspect of dignity for those living in nursing homes and an essential element of their quality of life. As part of privacy, single room beds (or the choice of double-rooms for couples), has become the norm for residents in some countries, but has not yet been achieved in others (Table 4). For most nursing home residents, this is the preferred situation, according to user surveys (OECD, 2005). There are, however, cost-implications for this option, as older houses can often not be converted accordingly. Moreover, the building stock often is at the same time
amended with other amenities, such as with bathrooms attached, making living in nursing homes more “home-like” in general, but also to accommodate for the fact that it is increasingly more severely disabled or chronically ill people on which nursing home care is targeted.

The need to improve privacy and dignity (that are related concepts), is now also driven by recent policy developments to enshrine these values in charters of rights for people with long-term care needs, and also reflected in human rights declarations.

Examples are:

- England, Department of Health: “The essence of care”; and the Human Rights Act
- Germany: Charter of Rights for People in Need of Long-term Care and Assistance
- There is already a tradition in Nordic Countries to consider dignity of care and privacy of living in nursing homes as social rights, - and this is reflected by the relatively high resources made available for long-term care and privacy granted (see Table 4) -, but efforts continue to further develop ethical approaches and criteria for value-based care. An example is the “Chair of inquiry” appointed in Sweden, and its recommendations to that a national set of values for long-term care should be introduced into the Social Services Act.

This movement of enshrining basic rights of people in need of long-term care in the form of “charters” aims at a number of goals:

- They strengthen the role of legal position of people in need of care, as well as of their families and informal care givers;
- They foster a broad dialogue about the directions to further develop long-term care with a broad range of stakeholders, - that usually have already been involved in the drafting and negotiations that led to the Charta;
- Through these consultation processes, they help bridge the worlds of research, practice, policy processes and patient movements;15
- By providing a broader vision, they provide direction to implementation strategies of long-term care reform beyond the often day-to-day political struggle, including for funding long-term care.

This movement is mutually reinforced by developments at European level, where a number of core documents now explicitly refer to the rights of people with disabilities, of people in need of long-term care and assistants and the protection of rights and integrity of families in their role as care givers.

Among these are:

- The UN Convention on the Rights of Persons with Disabilities:

15 An example is the “Round Table for Long-term Care” in Germany.
− The Charter of Fundamental Rights of the European Union:

− The European Social Charter (Revised)

Besides, a new research area in the field of quality of long-term care has been the measurement and the construction of indicators to quantify and monitor progress with dignity of care.\textsuperscript{16} This is currently also discussed and tested in the framework of several projects under the EU PROGRESS programme of DG Employment, Social Affairs and Equal Opportunity, such as the project “\textit{Quality management by result-oriented indicators: Towards benchmarking in residential care for older people}”.\textsuperscript{17}

\textsuperscript{16} See for example Picker Institute Europe, 2008.
\textsuperscript{17} See http://www.euro.centre.org/detail.php?xml_id=1396
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Annex: Figures and Tables

Figure 1: Gains in life expectancy continue past the age of 80
Evolution of life expectancy at age 80 and its distribution among countries, 1990 and 2006

Notes: Data on Canada and the United States refer to 2005.

Figure 2: The future importance of the oldest-old
Current and projected share of the population aged 80+, 2006 and 2050

Source: Huber et al. (2009) based on Eurostat EUROPOP2008, and UNPP.
**Figure 3: Prevalence of dementia in Europe**

Prevalence of dementia in Europe by age groups (2005)


**Figure 4: Ensuring access to home-care**

Percentage of those aged 65+ receiving long-term care services at home (most recent date)

Sources: Huber et al. (2009) based on national sources, OECD *Health Data 2008*, EUROFAMCARE national reports and Eurostat demographic data.

Notes: See table 1.

EU average refers to the unweighted average of available observations of EU countries from different years.
Figure 5: A small percentage of old-age people receive care in institutions in most countries

Percentage of those aged 65+ receiving institutional care (2007*)

Sources: Huber et al. (2009) based on national sources, OECD Health Data 2008, Eurofamcare national reports and Eurostat, demographic data.

Notes: Data for Armenia, Hungary, Latvia, Russian Federation, Portugal, Slovak Republic, Slovenia, Spain and Ukraine may include non-dependent beneficiaries and those younger than the age threshold. For Armenia, Austria, France, Hungary, Poland and Slovak Republic the age threshold used was 60+. For the Russian Federation and Ukraine the age threshold used was 55+. Data for Austria institutional care is an estimation based on those receiving social assistance at state level. Data for France includes only beneficiaries of Allocation Personnalisée d'Autonomie (APA). EU average refers to the unweighted average of available observations of EU countries from different years. (*) Or most recent date.
Figure 6: The majority of beneficiaries are cared for at home in most countries

Share of those aged 65+ who receive long-term care services at home and in institutional settings (most recent date)

Sources and notes: See table 1.
**Figure 7: A large diversity of care giving in EU15 countries**

Percentage of the population aged 15+ providing informal care to a co-resident relative aged 60+, 1999

![Graph showing care giving diversity across EU15 countries.](source)


**Figure 8: Family burden? Over-reliance of dependent older people on their relatives in some parts of Europe**

Question 29.1: In your opinion, do dependent older people rely too much on their relatives?

![Bar chart showing reliance by EU countries.](source)

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Figure 9: Mid-life challenges
Providing care for older family members by country and age group

Source: Huber et al. (2009) based on EUROFAMCARE national reports; OECD (2005); National sources for Israel.

Figure 10: The challenge of balancing work and family duties
Employment Status of main carers by country and domain

Source: Huber et al. (2009) based on EUROFAMCARE national reports; Lamura G. et al. (2006); National sources for Germany and the Netherlands.

Note: For Germany and Ireland, figures are for carers aged 16-64; for the Netherlands the employment rate does not distinguish between part-time and full time work, only that the family carer must work at least one hour a week.
Figure 11: There are large differences in public expenditure on long-term care, both in scope and in structure of spending

Public expenditure on percentage of GDP and its distribution between care provided at home and in institutions, 2007

Source and notes: See table 2.

Figure 12: Explaining differences in expenditure on institutional care

Relation between expenditure on institutional care for old-age and share of old-age people benefiting from it, 2007*

Source: Huber et al. (2009).
Notes: See notes of table 2.
Trend line refers to the correlation between beneficiaries and total expenditure (when available) or public expenditure on institutional care for older people.

(*) Or most recent date.

Figure 13: Paying for institutional care
User’s fee for institutional care, in percentage of the APW net wage (2007*)

Source: Huber et al. (2009).
Notes: User fee refers to amount paid by user’s of institutional care, deducted from specific subvention, cash for care allowances or pension supplements conditional on dependency needs. Pensions were not deducted from the user’s fees.
For Spain and England, figures refer to private institutions only.
(*) Or most recent date.
Figure 14: Trade-offs in generosity in attendance allowances

Attendance allowances’ amounts in percentage of net wage of the APW and its beneficiaries (2007*)

Source: Huber et al. (2009).
Notes: Beneficiaries refer to those receiving cash only, or combination of cash and in-kind benefits at home. For Austria and Germany (all) beneficiaries also include those receiving institutional care. For Spain, Norway, Slovenia and Sweden, beneficiaries may be younger than 65. For France, Luxembourg and Austria (estimation), beneficiaries are 60+ in percentage of the 60+ population. Average values refer to average values received as cash or combination of cash and in-kind benefit at home, for those aged 65+. Exceptions are Austria (also in institutional care), Italy, Germany, Spain, Sweden and Belgium for which values are for all beneficiaries. Amounts for Norway refer to the maximum value and for Italy and Poland to the statutory amount (flat rate benefits). Average amount for France refers only to the average amount of support paid by the conseils généraux for those cared for at home. APW refers to the Average Production Worker as defined by the OECD (for more details see OECD, 2007). (*) Or most recent date.
**Figure 15: Trade-offs in generosity in care allowances**

Care allowances' amounts in percentage of net wage of the APW and its beneficiaries (2007*)

Source: Huber et al. (2009).

Notes: APW refers to the Average Production Worker as defined by the OECD (for more details see OECD, 2007).

(*) Or most recent date.

**Figure 16: Differences in age structure per se do not explain differences in public expenditure levels on long-term care**

Ageing and public expenditure on long-term care, 2007

Source and notes: See table 1 and 2.
### Table 1: The evolution of beneficiaries of long-term care services

Beneficiaries aged 65+ who receive formal long-term care services, in percentage of the population aged 65+

<table>
<thead>
<tr>
<th>Source</th>
<th>Total</th>
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<th>Institutional care</th>
<th>Year</th>
<th>Total</th>
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Notes: Beneficiaries of day-care centres and meals on-wheels only were excluded to diminish possibility of double-counting. Whenever cash benefits and in-kind benefits overlap for home-care, the broader (more beneficiaries) benefit was used. Data for Austria on institutional care (home-care) is under-estimated (over-estimated), as it’s based only on those receiving social assistance at state level. Data for France includes only beneficiaries of Allocation Personnalisée d’Autonomie (APA). Data for Israel includes beneficiaries of long-term care benefit only. Data for home-care in Italy refer to in-kind benefit (Assistenza Domiciliare Integrata, ADI). Data for home-care in the Netherlands refers to those receiving AWBZ financed home-care during the year. Data for home-care in Slovenia refers to beneficiaries of cash allowance (Allowance for Care and Help). Data for Spain includes only old-age users of public home-care (SAD), including non-dependent beneficiaries. Data for home-care in England refers to beneficiaries of community based services with possible double-counting, although Carers Allowance and Attendance Allowance were not included.
(a) May include non-dependent beneficiaries and younger than the age threshold (Hungary only for institutional care).
(b) The age threshold used was 60+.
Who cares? Care coordination and cooperation to enhance quality in elderly care in the European Union

(c) Unweighted average of available observations of EU countries from different years.
(d) The age threshold used was 55+.

Table 2: A diverse picture of public expenditure

<table>
<thead>
<tr>
<th>Country</th>
<th>Sources</th>
<th>Total expenditure (in % of GDP)</th>
<th>Institutions (% of total expenditure)</th>
<th>In-kind home care (% of total expenditure)</th>
<th>Cash allowances (% of total expenditure)</th>
<th>Old-age expenditure (in % of GDP)</th>
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<tr>
<td>Belgium</td>
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<td>1.5%</td>
<td>72%</td>
<td>27.9%</td>
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<td>Czech Republic</td>
<td>National sources</td>
<td>0.3%</td>
<td>67.7%</td>
<td>32.3%</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Denmark</td>
<td>Eurostat, NOSOSCO</td>
<td>2.7%</td>
<td>27%</td>
<td>73.3%</td>
<td>0.0%</td>
<td>1.7%</td>
</tr>
<tr>
<td>Germany</td>
<td>OECD, Eurostat</td>
<td>0.9%</td>
<td>57.7%</td>
<td>17.8%</td>
<td>24.4%</td>
<td>-</td>
</tr>
<tr>
<td>Estonia</td>
<td>OECD</td>
<td>0.5%</td>
<td>35.8%</td>
<td>4.5%</td>
<td>59.7%</td>
<td>0.1%</td>
</tr>
<tr>
<td>Ireland</td>
<td>National</td>
<td>0.6%</td>
<td>60%</td>
<td>40.4%</td>
<td>19.6%</td>
<td>-</td>
</tr>
<tr>
<td>Spain</td>
<td>National</td>
<td>0.3%</td>
<td>59.0%</td>
<td>27.0%</td>
<td>13.9%</td>
<td>0.2%</td>
</tr>
<tr>
<td>France</td>
<td>National</td>
<td>0.9%</td>
<td>57.4%</td>
<td>42.6%</td>
<td>20.7%</td>
<td>-</td>
</tr>
<tr>
<td>Italy</td>
<td>National</td>
<td>1.7%</td>
<td>26.2%</td>
<td>31.7%</td>
<td>42.1%</td>
<td>1.1%</td>
</tr>
<tr>
<td>Latvia</td>
<td>National</td>
<td>0.3%</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>0.1%</td>
</tr>
<tr>
<td>Lithuania</td>
<td>Eurostat</td>
<td>0.3%</td>
<td>64%</td>
<td>5.3%</td>
<td>32.3%</td>
<td>0.1%</td>
</tr>
<tr>
<td>Luxembourg</td>
<td>OECD, national</td>
<td>1.3%</td>
<td>67.2%</td>
<td>32.8%</td>
<td>2.1%</td>
<td>-</td>
</tr>
<tr>
<td>Netherlands</td>
<td>National</td>
<td>3.6%</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>2.5%</td>
</tr>
<tr>
<td>Austria</td>
<td>National</td>
<td>1.3%</td>
<td>43%</td>
<td>57.3%</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Poland</td>
<td>National, OECD</td>
<td>0.3%</td>
<td>53.8%</td>
<td>34.6%</td>
<td>4.4%</td>
<td>-</td>
</tr>
<tr>
<td>Slovenia</td>
<td>National</td>
<td>0.8%</td>
<td>25.7%</td>
<td>74.3%</td>
<td>27.5%</td>
<td>-</td>
</tr>
<tr>
<td>Finland</td>
<td>Eurostat, NOSOSCO</td>
<td>1.0%</td>
<td>48.3%</td>
<td>45.0%</td>
<td>6.7%</td>
<td>0.7%</td>
</tr>
<tr>
<td>Sweden</td>
<td>Eurostat</td>
<td>3.9%</td>
<td>58.7%</td>
<td>38.1%</td>
<td>3.3%</td>
<td>2.4%</td>
</tr>
<tr>
<td>England</td>
<td>National</td>
<td>1.2%</td>
<td>47.4%</td>
<td>24.2%</td>
<td>28.5%</td>
<td>1.2%</td>
</tr>
<tr>
<td>EU average</td>
<td>(k)</td>
<td>1.3%</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>1.0%</td>
</tr>
<tr>
<td>Iceland</td>
<td>Eurostat, NOSOSCO</td>
<td>2.2%</td>
<td>95.2%</td>
<td>4.8%</td>
<td>0.0%</td>
<td>1.8%</td>
</tr>
<tr>
<td>Norway</td>
<td>OECD, Eurostat</td>
<td>2.3%</td>
<td>50.2%</td>
<td>41.9%</td>
<td>7.9%</td>
<td>1.6%</td>
</tr>
<tr>
<td>Switzerland</td>
<td>OECD, Eurostat</td>
<td>0.9%</td>
<td>80.4%</td>
<td>19.6%</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Canada</td>
<td>OECD</td>
<td>1.3%</td>
<td>82.8%</td>
<td>17.2%</td>
<td>0.0%</td>
<td>-</td>
</tr>
<tr>
<td>United States</td>
<td>National</td>
<td>0.9%</td>
<td>66.3%</td>
<td>33.7%</td>
<td>0.0%</td>
<td>0.9%</td>
</tr>
</tbody>
</table>


Notes: (a) Although no age breakdown is available, figures refer mostly to “old-age”.
(b) “Home-care (in-kind)” may include expenditure on cash benefits taken together with in-kind benefits.
(c) Due to differences in sources, only “home-care (in-kind)” and “institutional care (in-kind)” add up to 100%.
(d) Sum doesn’t add up to 100%, due to expenditure that could not be attributed to either of the categories.
(e) Figures refer to “old-age” only.
(f) “Old-age” includes both private and public expenditure.
(g) Expenditure on institutions for mentally ill and for the treatment of addiction was not included.
(h) Data refers to 2003.
(i) Although data refers to 2008, it doesn’t include the new attendance allowance.
(j) Data refers to expenditure prior (2004) to the Dependency Law.
(k) Unweighted average of available observations of EU countries from different years.

**Table 3: Summary of results from the ECFIN projections on long-term care (2060)**

<table>
<thead>
<tr>
<th>Scenario</th>
<th>Average increase by 2060 (EU27 level [a])</th>
<th>Highest increases (Member States)</th>
<th>Lower increases (Member States)</th>
<th>Some other results and assumptions</th>
</tr>
</thead>
<tbody>
<tr>
<td>AWG reference scenario</td>
<td>105%</td>
<td>Czech Republic, Spain, Malta, Polan, Romania and Slovakia</td>
<td>France, UK and Sweden</td>
<td>Based on prudent assumptions on both disability among the elderly and growth of unit costs (in line with GDP per worker).</td>
</tr>
<tr>
<td>Pure demographic scenario</td>
<td>115%</td>
<td>Czech Republic, Spain, Malta, Polan, Romania and Slovakia</td>
<td>France and UK</td>
<td>Laissez-faire would put strain on informal care, doubling the number of people relying on informal care only on EU average; Assumption of no improvement of the dependency status of elderly as life-expectancy rises.</td>
</tr>
<tr>
<td>Constant disability scenario</td>
<td>95%</td>
<td>Czech Republic, Spain, Malta, Polan, Romania and Slovakia</td>
<td>France, UK and Sweden</td>
<td>Relatively optimistic scenario regarding evolution of dependency among the elderly (less 11.6% of dependent elderly in 2060 in comparison with “pure demographic scenario”).</td>
</tr>
<tr>
<td>Shift from informal to formal care (b)</td>
<td>128% (home care); 174% (institutional care)</td>
<td>Spain, Estonia, Hungary, Latvia and Romania</td>
<td>Denmark, France, UK and Sweden</td>
<td>Yearly shift into the formal sector (to either home care, institutional care or a combination of both) of 1% of disabled elderly who so far received only informal care. If shift occurs to institutional care, budgetary impact is higher due to higher unit costs.</td>
</tr>
<tr>
<td>Demand-driven expenditure</td>
<td>95%</td>
<td>Czech Republic, Spain, Luxembourg, Malta, Romania and Slovakia</td>
<td>France, UK and Sweden</td>
<td>Assumption that changes in long-term care provision are mainly demand-driven, and follow the general increase in national income rather than growth in unit labour costs.</td>
</tr>
<tr>
<td>Fast/slow growth scenario (of unit costs) (c)</td>
<td>95% (slow growth) 137% (fast growth)</td>
<td>Czech Republic, Spain, Greece, Polan, Romania and Slovakia</td>
<td>France, UK and Sweden</td>
<td>Impact of increasing or reducing by 1% per year the underlying rate of growth in unit costs (in the other scenarios it evolves in line with GDP per worker).</td>
</tr>
</tbody>
</table>

Source: ECFIN (2009)

Notes: (a) Including Norway.
(b) Highest increases in Member States refer to the shift to institutional care.
(c) Highest increases in Member States refer to the fast growth hypothesis.
### Table 4: Percentage of people living in rooms by number of beds per room

Percentage of residents living in a room with:

<table>
<thead>
<tr>
<th>Countries</th>
<th>Year</th>
<th>1 bed</th>
<th>2 beds</th>
<th>3 beds</th>
<th>4 beds or more</th>
</tr>
</thead>
<tbody>
<tr>
<td>Austria</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Styria</td>
<td>1997</td>
<td>33</td>
<td>44</td>
<td></td>
<td>23</td>
</tr>
<tr>
<td>Belgium</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Brussels</td>
<td>2003</td>
<td>a) 55.4</td>
<td>27.4</td>
<td>17.2</td>
<td></td>
</tr>
<tr>
<td>Brussels</td>
<td>2006</td>
<td>a) 59</td>
<td>24.8</td>
<td>16.2</td>
<td></td>
</tr>
<tr>
<td>Wallonia</td>
<td>2003</td>
<td>a) 65.7</td>
<td>22.2</td>
<td>12.1</td>
<td></td>
</tr>
<tr>
<td>Wallonia</td>
<td>2006</td>
<td>a) 65.3</td>
<td>21.6</td>
<td>13.1</td>
<td></td>
</tr>
<tr>
<td>France</td>
<td>2003</td>
<td>b) 82</td>
<td>17</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>Germany</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>1999</td>
<td>45</td>
<td>49</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>2007</td>
<td>55.0</td>
<td>21.8</td>
<td>1.3</td>
<td>0.1</td>
</tr>
<tr>
<td>Netherlands</td>
<td>2000</td>
<td>22</td>
<td>35</td>
<td>4</td>
<td>39</td>
</tr>
<tr>
<td></td>
<td>2005</td>
<td>c) 69.3</td>
<td>2.6</td>
<td>28.0</td>
<td></td>
</tr>
<tr>
<td>Norway</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>1991</td>
<td>d) 79.0</td>
<td>20.0</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2000</td>
<td>d) 86</td>
<td>14</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>2005</td>
<td>d) 95</td>
<td>5</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Poland</td>
<td>2006</td>
<td>e) 27.0</td>
<td>40.9</td>
<td>20.3</td>
<td>11.8</td>
</tr>
<tr>
<td>Sweden</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>2003</td>
<td>97.0</td>
<td>3.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>2005</td>
<td>98.2</td>
<td>1.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>UK</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>1996</td>
<td>46</td>
<td>44</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>2003</td>
<td>f) 84</td>
<td>16</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>


Notes: 
(a) Number of rooms in public maison de repos and public maisons de repos et de soins.
(b) Number of rooms.
(c) Number of rooms in nursing homes only.
(d) Number of rooms in institutions for old-age and disabled.
(e) Number of rooms. Small sample survey of 44 social welfare homes and 25 long-term care units and nursing homes.
(f) Private for profit institutions only.