Long-term Care
in the European Union
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Foreword —
Long-term care in the European Union

Providing citizens with a high level of protection from the risk of illness and dependence is a crucial objective of the Member States and the European Union. Our societies’ ability to deliver long-term care services of good quality for all those that need them must be secured and preserved.

A wide variety of approaches to the delivery of long-term care has been developed across Europe. As a result there is a wealth of experience and ideas to refer to as the Member States seek to modernise, expand and improve services in response to demographic ageing and other challenges.

The fact that Member States have agreed common objectives at European level in the framework of the open method of coordination in the field of social inclusion and social protection is very encouraging. They have made the provision of universal access to high quality affordable long-term care a key goal and the European Commission is working with the Member States to help them deliver on that commitment.

The European Union also offers support for mutual learning among Member States facing similar challenges. This enables national authorities to learn from each other, drawing the best from experience gained and crystallising out good practice.

The added value in this approach is amply illustrated in this booklet, which is drafted with a wide range of concerned citizens and stakeholders in mind. It summarises the findings of a report on the multiple challenges in the provision of long-term care across the Union and emphasises some important policy lessons that the Member States have drawn from their experience.

Obviously, access to care should not become increasingly dependent on the individual’s ability to pay. To avoid such a scenario, a sustainable mix of public and private financing may need to be found. Meanwhile, better value for money and continuity in care can be achieved through careful coordination of social and medical services. Significantly, greater affordability and higher capacity can be obtained without sacrificing citizens’ autonomy or dignity by giving priority to the development of home and community-based care over provision in residential institutions. Obtaining the high-quality care which the EU is striving for may require increased support for informal carers and improvements in the recruitment and working conditions of care staff.

I am confident that this publication will give readers the chance to learn much about recent developments in long-term care systems across Europe and I commend it to them.

Vladimír Špidla
European Commissioner for Employment, Social Affairs and Equal Opportunities
Introduction

All European Union Member States are committed to ensuring universal access to high quality and affordable long-term care for their citizens. As populations grow older, the financial and logistical challenges of meeting this pledge to the elderly become harder to overcome. This is true now and will become even more evident in the future as governments have to operate against a background of increasing and competing demands with limited resources.

This publication draws on the experience national authorities communicated in the reports they submitted to the European Commission in September 2006 setting out their policies towards social inclusion, pensions, health care and long-term care (LTC). We focus on the last of those four areas.

The following pages analyse the main challenges national authorities face when providing long-term care and the strategies they are devising to ensure their overall political commitment is put into practice to meet individual needs.

National definitions on long-term care vary within the European Union. These reflect differences over the length of stay, range of beneficiaries and the often blurred dividing line between the available medical (health care) and non-medical (social) services. Some countries, for instance, prefer to concentrate on out-patient rehabilitation treatment earlier than others which focus more on providing care in hospitals or similar establishments.

For the OECD, LTC represents ‘a cross-cutting policy issue that brings together a range of services for persons who are dependent on help with basic activities of daily living (ADLs) over an extended period of time.’ Long-term care can include rehabilitation, basic medical treatment, home nursing, social care, housing and services such as transport, meals, occupational assistance and help with managing one’s daily life.

The care is usually provided to individuals with physical or mental handicaps, the frail, elderly and people who need special help in managing their daily lives. As the OECD notes: ‘Long-term care needs are most prevalent in the oldest age groups... who are most at risk of long-standing chronic conditions causing physical or mental disability’.

As Europeans live longer, the public resources devoted to health and long-term care are the second largest component of overall social protection expenditure, coming behind retirement and survivors’ pension expenditure. With citizens living longer, there will be an even greater demand to provide LTC services, either in a domiciliary or institutional setting.

It is estimated that the total number of people over 65 will increase by 77% by 2050 compared to 2004. The rise in the over 80s will be even greater: 174%. According to a 2007 Eurobarometer survey, a majority of Europeans think that it is likely, or unlikely but possible, that they will be dependent on long-term care at some point in their lives.

Against that background, projections prepared by the Economic Policy Committee and the European Commission in 2006, indicate that in 2050 public long-term care expenditure will increase by 0.7 percentage points of GDP compared to 2004 due to population ageing.
National policy developments

Long-term care is addressed through three mutually agreed and interconnected objectives for the services provided: universal access, high quality and long-term sustainability.

1. Access to adequate long-term care

There is general agreement that access to health care should not be restricted by one’s ability to pay or depend on an individual’s income/wealth. The need for care, should not lead to poverty or financial dependency.

However, universal rights do not always ensure universal access and inequalities and obstacles continue to exist. Hurdles range from lack of insurance coverage and certain types of care to lengthy waiting times, insufficient information and complex administrative procedures. These can vary from region to region within the same country, not just between Member States.

It can prove difficult to provide the continuum of care some people need. Efforts in some countries to help patients recover maximum self-sufficiency through rehabilitative care, for instance, can be thwarted when elements of long-term care are not considered eligible for reimbursement in certain social health insurance based systems.

Costs are also a barrier, especially for low-income groups who may have to meet some of the expenditure themselves. Many countries, such as Cyprus, Estonia and Ireland, have introduced co-payments for long-term care. In Germany, a small, but growing percentage of the population (currently 1%), has taken out voluntary private complementary insurance to cover costs such as accommodation fees in nursing homes. This is in addition to specific long-term care insurance and social assistance mechanisms.

Various schemes exist to reduce the direct costs to individuals of care. These include:

- co-payment exemptions and co-payments based on income;
- extra financial aid and welfare benefits to the elderly, dependents, disabled and chronically ill;
- state coverage of long-term care for low income households;
- nationwide uniformity of co-payments; and
- state subsidies for the use of private services.

There is a general trend away from institutional care – except for those with severe disabilities – towards developing tailor-made home and community care services. Modern technology, in the shape of ehealth, tele-monitoring, telemedicine and independent living systems, facilitates care at home or in the community. The shift in emphasis allows individuals to have a greater freedom of choice over the care they require. The result is that people can live in a familiar environment in their own homes, close to family and friends, for as long as possible, while having the back-up of institutional care if necessary.
To achieve this, careful cooperation between national, regional and local authorities and constructive partnerships with the private and voluntary sectors are required. Failure to develop this integrated approach can lead to fragmentation between services and administrative hurdles that make it harder for people to receive the care they need.

As an example: people discharged from hospital should be able to access tailored home care provision or receive these services within a community setting. When such follow-up provision does not exist, accessibility to tailored long-term care is limited. Germany is tackling this by assigning case managers to patients needing transfer care when moving from a hospital to their home or another institution. From 2009, this will cover all aspects of LTC organisation for individual support, and care counsellors will call on patients wherever they are being looked after.

2. High level quality in LTC services

The quality of LTC services people receive varies enormously. So, it is not surprising that surveys and reports have revealed levels of dissatisfaction and drawn attention to deficiencies. The issues raised range from inadequate accommodation and lack of privacy in nursing homes to excessive use of restraint and force. These complaints are among the reasons Member States are developing or changing regulations and legislation to ensure sufficiently high standards are put in place and respected.

It is not easy to assess the quality of the different long-term care services provided. This is already difficult enough for formal settings like nursing homes or hospitals, but is even more complicated for informal environments ranging from one’s own to friends/relatives’ homes. The OECD classifies the different indicators used according to structure (size of rooms and staff ratios), process (the mechanisms and assessments in place) and outcome (prevalence of certain medical conditions). These reveal that in general the trend is towards an improvement in quality.

Increasingly, the emphasis in long-term care is moving away from compliance with certain minimum requirements towards a focus on more comprehensive quality assurance involving issues such as patients’ rights and continuous staff training. At the same time, to ensure quality care is provided, standard indicators, such as staff ratios and adequate training may not be suitable for assessing care provided at home by informal carers.

National authorities are addressing the need for quality improvement measures in different ways. Some (Netherlands, Slovakia) are using quality accreditation measures, coupled with monitoring systems (Cyprus, Germany, Greece, France, the Netherlands). Others (Germany, Luxembourg) employ clinical guidelines based on evidence-based medicine. To prevent regional inequalities in the provision of LTC and arbitrary assessments of patient needs by regional and local authorities, many countries (Czech Republic, Germany, Estonia, Spain, Sweden, Latvia, Lithuania, Slovenia, United Kingdom) apply uniform quality assurance mechanisms.
Yardsticks to assess the quality of care being given are becoming more sophisticated and reliable. But they are still in the early stages in many Member States. They involve such factors as the support provided to informal caregivers, increasing patient choice, ensuring the capacity of the long-term care workforce and the technologies which can help them in their tasks. Evaluating the standard of care people receive is complex. This is particularly true when it is provided in an informal, rather than institutional setting, and is often based on measurements of satisfaction levels and unmet needs.

Germany: Quality assurance in LTC

When people receive long-term care at home, family members providing the care are entitled to various support schemes. These include Nursing Care Allowance, in-kind benefits, and other entitlements such as pension contributions, accident insurance protection and training courses. Outpatient care is also available to take some of the strain off family members. To ensure the quality of the home care, Health Insurers’ Medical Services make statutory visits, trained carers provide compulsory care consultancy, and long-term care insurers are required to hold free care courses for family members and volunteers. Additional services (outpatient facilities such as residential facilities, technical aids etc) also aim to relieve family carers.

The Long-Term Care Insurance Act encourages the development of internal quality management in care institutions combined with external controls according to nation-wide uniform quality inspection guidelines. LTC assurance is guaranteed through contracts between the long-term care insurers and long-term care providers. The latter are responsible for quality assurance (internal quality management/structure and process). The former oversee the quality of care provided in care institutions and have sanction powers. Under these contractual arrangements, purchasers have the right to inspect establishments and impose penalties if they are not satisfied with the conditions.

In Europe there is general agreement on the need to avoid ill-treatment or abuse of patients. This was repeatedly stressed during a conference on ‘Protecting the dignity of older persons – the prevention of elder abuse’ held in Brussels in March 2008. All participants emphasised that respecting the dignity and fundamental rights of the frail and elderly is a major challenge facing European society. The conference focused on good practices, awareness raising campaigns, support hot lines, quality standards in long-term care homes, training of professionals and support for informal carers.

Sweden: Freedom of choice and dignity for the elderly

Sweden has recently introduced a system enabling people to choose where they would like to receive their long-term health care. They can select between private providers of home care services and care in institutions. To ensure patients have real choice, it is generally agreed they must have access to sufficient information on the alternative providers and services available, possibly through a one-stop shop.

One suggestion raised in a recent peer group review was the potential use of personal budgets to enable individuals to select between formal and informal care. They could use a virtual account to buy care, employ assistants or pay for personal services suited to their particular needs.
3. Long-term sustainability

The long-term sustainability of public expenditure on health care, and on LTC in particular, will come under heavy strain as societies have to cope with ageing populations. However, these pressures could be mitigated if citizens remain in good health as they grow older. A preventive approach, the integration of health and long-term care services and use of new technologies and ICT can also help to keep costs under control.

LTC funding varies across the EU, reflecting different traditions and priorities. But four factors are at play:

- The schemes and population covered by LTC;
- A country’s welfare funding arrangements;
- The degree of private financial involvement; and
- The demarcation between public and private sector responsibility for LTC.

Comprehensive public programmes can be financed in the following ways:

- Social insurance (Germany, Luxembourg, Spain);
- Taxes (Nordic countries, Latvia);
- Means-tested schemes (United Kingdom, Cyprus); and
- Mixed financing systems combining resources from insurance schemes and taxes with different budgets and institutions responsible for provision and purchase of LTC (Belgium, France, Greece).

As recognition of the need to ensure a solid long-term financing base for LTC grows, several Member States (Germany, Luxembourg, Netherlands, Sweden) are looking to achieve this either by establishing dedicated universal social insurance schemes and contributions or through taxation (Austria, Sweden).

While recognising the need to find an adequate mix between public and private sources of finance, there is general agreement that a social insurance or tax-based system is more efficient than one left entirely to private initiatives. At the same time, Member States are considering a potential mix of public and private provision, notably in the social sector. The latter sources of finance tend to contain two separate elements. The first consists of private health insurance for LTC. The second involves individuals making co-payments to publicly provided care for which very little or no reimbursement is provided.

Prevention and rehabilitation policies

Encouraging an active and healthy lifestyle has obvious significant benefits for individuals. It also has the potential to foster wider advantages for society at large by reducing public health costs, allowing people to remain active for longer and preventing productivity rates being damaged by absenteeism through illness. Vaccination and screening programmes, and campaigns to promote healthy ageing are in place in most EU countries. While such programmes are an important step forward, it is too early to assess their impact and good coordination between different providers in promoting preventive care policies is important.

Rehabilitative care is essential to enable a patient to regain maximum self-sufficiency, to function as normally as possible and to return to a satisfying working environment. Effective promotion of such care, as Member States have recognised, requires the existence of well trained and qualified staff and efficient use of information and communication technology (ICT).

Slovakia: Prevention and rehabilitation

Municipal authorities in Zavar and Bansk Bystrica City have introduced projects involving local stakeholders, residents and partners to help the mentally ill and severely disabled receiving institutional care to live in as dignified and inclusive a fashion as possible. In Zavar, social workers propose treatment and care plans, involving ergo therapy, psycho-pharmaceutical treatment and rehabilitation. These are centred on individual needs and enable patients to participate actively in local activities.
Care coordination

Care coordination is crucial to ensure a high level of quality in the care provided, an efficient use of resources and the tailored and seamless treatment care some patients may require. It involves coordination between national, regional and local authorities and services to anticipate and overcome obstacles that may arise. Problems can stem from the separate budgets used to finance different services, the organisation of service delivery and the many bodies involved in the health and social sectors.

Portugal: Integration of health and social care

Under a far reaching reform of the LTC system, care will be provided through a wide range of multidisciplinary services: convalescence units, medium-term rehabilitation units, long-term and maintenance units, palliative care units, day centres and units for promoting functional independence, discharge management teams, hospital teams for support to palliative care, integrated continuous care teams and community teams for support to palliative care. In particular, the network created will encourage continuity between community-based care, hospital care for acute patients and social support, complementing primary care and specialised hospital care. Flexibility enables the system to be adapted to different needs around the country.

Belgium: Improved coordination between different levels of government

Three social protocols have been signed between the Federal Government and the regional and community authorities that are responsible for long-term care and social services. Two of these, agreed in 2005, aim to improve working conditions and staff levels in the community, residential and home care sectors. They include the conversion of purely bed facilities into those with the possibility of medical care for patients and the introduction of specific employment contracts for LTC staff. The third protocol sets out budgetary and organisational arrangements over six years. Collective employment agreements are needed to put elements of the package into practice. The fact that these are slow in coming has meant that only a small number of residential homes have been converted into facilities with more developed medical care.

In some countries, national strategies and priorities have been established to ensure the uniform provision of services. This is especially important given that LTC is usually devolved and handled by sub-national levels of government (Spain, Sweden, United Kingdom). Similar objectives can be achieved through framework contracts, as in Germany, between LTC insurers and providers.

Integration of LTC delivery can be achieved through single entry points or local assessment teams on the one hand (Netherlands, United Kingdom) or through the decentralisation and integration of services at regional and local levels (Spain, Sweden, United Kingdom). Several countries (Belgium, Germany, Spain, Finland) have made or are in the process (Hungary, Latvia, Malta, Poland) of making arrangements to integrate LTC provision and to ensure uninterrupted care.

The test of success in providing a continuum of care can be measured by the extent to which the medical, nursing and social services provided fit together for the specific needs of individual patients. To achieve this, two elements are important: the coordinated provision of services and better management of transfers between care settings (the home, hospital and nursing home). National authorities are now devoting more attention to introducing measures that will make different services work more effectively together.
Many examples exist of countries aligning the financing of LTC with health and social care components:

- **Germany**: introduced comprehensive LTC insurance to provide support for formal and informal carers;
- **Austria**: integrated LTC allowances for formal and informal care;
- **Spain**: coordinated regional health and social services financing;
- **Sweden**: integrated municipal acute health care and LTC funding; and
- **UK**: most social services funding devolved locally with the possibility for hospitals to charge local authorities if they cannot discharge patients due to the lack of LTC services.

Other initiatives include policies to improve care coordination, especially between health and social budgets (Spain, France, Ireland, Luxembourg, Latvia, Poland, Portugal) and plans for common assessment schemes and evaluation by multidisciplinary teams to define the care plans to be used (United Kingdom, Ireland, Belgium, Denmark, Germany, Estonia, Spain, Sweden, Slovakia, Finland, Latvia, Portugal, Italy).

Appropriate support for informal carers is necessary. This can include information, training, counselling, respite care, social security formalisation and financial support. Other forms of assistance are also available:

- **Financial aid** (Austria, Czech Republic, Germany, Estonia, Denmark, Hungary, France, Spain, Slovakia, Finland, Italy, Ireland, Sweden);
- **Tax credits and exemptions** (Spain, Germany, Greece, France, Luxembourg);
- **Work leave to care for relatives** (Austria, Spain, Finland, Germany, Netherlands);
- **Treatment of care periods as part of carers’ contributions towards pensions**; and
- **Formalising carers’ status and including them in social security schemes**.

Czech Republic: Improved coordination between health and social care

Measures have been introduced to ensure that the financing of health and social care in institutions where they are provided together is as efficient as possible. The guidelines are set centrally, but the degree of coordination and cooperation is decided on by local authorities and individual facilities. The geriatric and after-care ward in Liberec hospital which focuses on psycho-social stimulation and therapy, as well as traditional treatment and rehabilitation, is a good example of the system in practice.

Special attention is given to social work to ease the patients’ transition back to their homes or into the social service system. Where home care is not an option, social workers help place patients in either a medical establishment (hospice or rehabilitation centre) or a social facility, such as a nursing home or sheltered housing, according to their needs. Their discharge is timed to ensure continuity in their health and social care.

Faced with shortages, many Member States (Spain, France, Lithuania, Sweden, Czech Republic) have introduced policies to increase nursing staff, improve training and offer education policies for health and social care professionals to respond to the increase in demand. Some (Poland, Latvia Estonia) are improving working conditions and pay to discourage specialised staff from seeking work abroad.

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- **Treatment of care periods as part of carers’ contributions towards pensions**; and
- **Formalising carers’ status and including them in social security schemes**.

- **Financial aid** (Austria, Czech Republic, Germany, Estonia, Denmark, Hungary, France, Spain, Slovakia, Finland, Italy, Ireland, Sweden);
France: Solidarity for Old Age

This government plan aims to increase the number of care professionals for the elderly by offering more places in training centres leading to professional nursing diplomas and to make it easier for people already working in the sector to acquire these professional qualifications.

Austria: Support to informal carers

A pilot project involving ‘Counselling Cheques’ enables people requiring round the clock care and their family members who provide it to access qualified counselling on a range of issues. Another scheme in Vienna, Lower Austria and Burgenland offers a fortnight’s holiday, and a social programme involving exchange of experiences through a qualified moderator, for care-giving family members. Meanwhile, any care the patient may require is ensured by paid professional providers. An amendment in 2007 to social security legislation has improved the pension situation of carers looking after a relative.

Conclusion

National authorities are examining different ways of addressing the expected growth in demand for long-term care services. This will come at a time when the number of working age women and men, able to provide informal care will decrease just as the number of dependent elderly persons increases. In addition, the trend towards smaller families and rise in incidences of single parent families reduce the pool of people able to provide informal care.

There is general agreement that providing LTC in a home or residential setting rather than institutional care is the preferred option of LTC recipients. In order to meet the increased demand, Member States will need to:

• Tackle the expected shortfall in qualified LTC staff;
• Develop a sustainable mix of public and private sources of finance;
• Ensure effective coordination within various long-term care systems; and
• Implement in practice the principle of universal access to long-term care.

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