Long-Term Care: Introduction

Since December 2001[1], long-term care has been one of the topics of the open method of coordination (OMC) developed by the European Council and the States of the European Union with the assistance of the Commission[2]. The national reports delivered by the States in that frame deal with policy analyses, strategies and future developments within a broader economic scope. They describe the challenges that confront their social protection systems at national level, ongoing reforms and policy directions in the medium term. The OMC reports also deal with health care in general and they were written within the framework of the guidelines developed by the European Council concerning namely universal access to care, a high quality of care and financial viability in care systems. An additional report has been prepared on request of the European Commission DG Employment and Social Affairs[3] and looks at how future spending on long-term care might be affected by different hypotheses in relation to demography, dependence and incapacity, formal and informal care and the cost of care. It covers Germany, Spain, Italy and the United Kingdom.

The goal of the material presented in the present publication is different. As in other MISSOC-Info[4], this issue contains reports provided by the MISSOC network member States to give a comprehensive and synthetic overview of legislation on long-term care in the respective 29 countries member of MISSOC network in March 2006. Even if the reports show that long-term care has been on the agenda in most of the countries, some of them show that a legislative intervention is not considered necessary.

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1 Publications at EU level: Jozef Pacolet et alii, "Social protection for dependence in old age in the 15 EU Member States and Norway, Summary report", European Commission, Employment and Social Affairs, Social Security and Social Integration series (1998) : report financed by the European Commission and the Belgian Ministry of Social Affairs, that examines whether the German solution of a social insurance system should be taken as an example and what effects this would have on the rest of the Union of 15 European Policy Committee, "Budgetary challenges posed by ageing populations: the impact on public spending, health and long-term care for the elderly and possible indicators of the long-term sustainability of public finances". Directorate General for Economic and Financial Affairs of the European Commission: Brussels 2001; Communication from the Commission to the Council, the European Parliament, the Economic and Social Committee and the Committee of the Regions, "The future of health care and care for the elderly: guaranteeing accessibility, quality and financial viability", COM (2001) 723 final.

2 Article 2 of the Treaty states that "The Community shall have as its task, by establishing a common market and an economic and monetary union and by implementing common policies … to promote throughout the Community …a high level of employment and of social protection …" In this regard, the Communication of the Commission "A concerted strategy for modernising social protection" (COM(99)347 final) guarantees a high and sustainable level of health protection one of the four priority objectives of European cooperation in the field of social protection. In its conclusions of 29 November 1999, the Council approved the objectives contained in the Communication and requested that European cooperation should be developed in this field, where health care systems and their methods of financing are a matter for national governments.

3 A. Comas-Herrera and R. Wittenberg, "European study of long-term care expenditure", Report to the European Commission, Employment and Social Affairs DG, Report nr VS/2001/0272, PSSRU Discussion Paper 1840, February 2003

4 MISSOC-Info are published on http:/ec.europa.eu/employment_social/social_protection/missoc.en.htm

In the following analysis we will briefly consider demographic development in relation to care requirements. Following this, the need for care will be discussed within the framework of the law, including the difficult task of finding a legal definition. And finally important aspects of the need for long-term care, such as organisation of the services, provision of services and quality assurance in the different countries will be described. An overview of the current status of the discussion will conclude this introduction.

Demographic change and Long-term Care

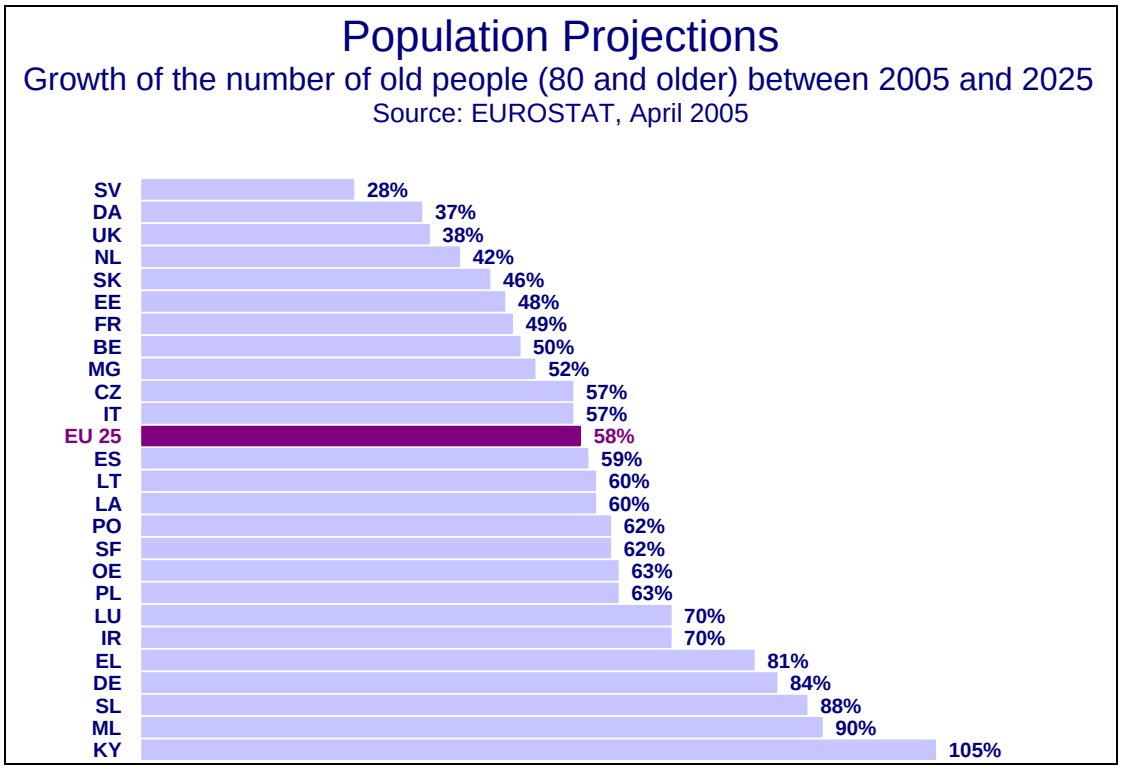
The probability of getting sick or being in need for long-term care increases with the age. Long-term care can mean many different things but can be schematically described as a chronic or disabling condition that requires care or constant supervision.

In the next 20 years the population aged 80 or more will increase enormously in some countries.[5] Graph 1 shows that at European level this population will increase by nearly 60%.

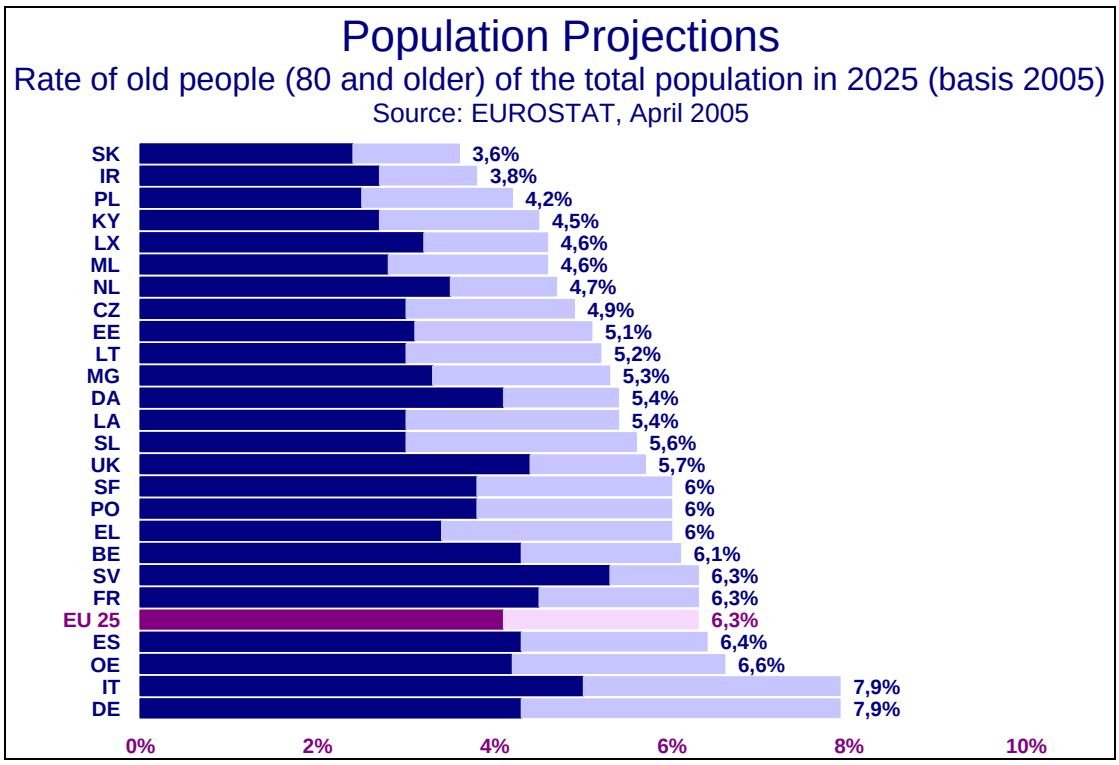
Even if this forecast for the next 20 years can only be very rough, it nevertheless shows a trend which will have serious effects on pensions, health provision and the care provided for those in need of it. On the one hand, care will be affected in the direct sense: to be specific, the need for qualified care workers and household helps will increase strongly, and in particular in countries with very high growth rates of the elderly (in Cyprus for example this age group will more than double), the question arises as to how it can be ensured that these care services can be provided.

5 EUROSTAT, April 2005.

Graph 1:



Graph 2:



Graph 2 shows the ratio of the older people (80 years and older) to the rest of the population in 2005 and in 2025. In the year 2005 the average share of old people of the total population of the European Union amounted around 4% and will increase in the next 20 years to around 6%. Some countries are less affected like Slovakia, Ireland or Poland with an figures around 4% in the year 2025; others are more affected like Italy and Germany with figures around 8%. These data raise the question of long-term securing of financing of social protection systems and therefore also financing of the care which is needed.

Taking long-term care as a specific legislative topic

Generally speaking, countries have chosen quite different approaches to tackle with the social problem of the need for long-term care.

Only a few States have chosen to install a specific legislation dealing with long-term care. Some of them use the social insurance involving the employers and the workers to cover it (e.g. Austria, Germany, Luxembourg, Spain).

Others (like France and Czech Republic) have chosen to integrate long-term care in a national social assistance programme. These programmes differ widely from the classical social assistance schemes. France turned to a cost-sharing mechanism based on the model of sickness insurance regulations and has organized a specific financial scheme[6]. This also seems to be the case in the Netherlands as some services will be transferred from the Exceptional Medical Expenses Act to the local social assistance authorities. In Belgium, the Flemish Community has introduced with reference to its competence in the field of social assistance a flat rate obligatory insurance largely funded by individual premiums.

Other countries have not taken a specific initiative for long-term care. In Hungary for example, the need is covered within the frame of the existing rules of health care and/or social assistance, and also in the countries with consistent decentralised health care responsibilities dedicated to the local authorities like in the Nordic countries. In other countries, the charge for long-term care has been and is considered to be primarily a matter for the family.

In the States where the mechanisms dedicated to disabled persons have been extended or applied to, there has been an adaptation of the goals of the measures. The objective for policies for people with disabilities is social integration through work or at least through some activity.

6 MISSOC-Info 02/2005 on User charges: see report from France.
http://europa.eu.int/comm/employment_social/social_protection/missoc_info_en.htm#02/2005

Defining long-term care: a difficult task

A common denominator is that "long-term care" means in almost all the countries examined the "need for assistance by a third person including both medical and non-medical assistance" or, in other words, long-term care refers to the presence of functional limitations, to a status of reduced individual autonomy or capacity for self-care due to certain conditions.

But a closer look at the terminology used to describe the phenomenon reveals that the wording in long-term care legislation, policy and statistics varies widely from one country to another. Concepts such as "chronic disease", "disability", "handicap" or "dependency" describe the situation to be tackled with. The beneficiaries are "old age disabled", "impotent persons", "persons in need of care", "persons with a daily living or a cognitive impairment" or "dependent persons". N. Kerschen[7] also mentions the term "in need of nursing care" in the English speaking area or the person who has "lost his independence".

When reference is made to old people, the age limits, if they exist, vary from 60 to 65 .

Some definitions refer to the elements of cause of the need for long-term care. This is particularly the case in countries where there is a close link to (local) health care services and to health prevention measures. All definitions include descriptions of the levels of need as well as the duration of the need.

In some legislations there is even no specific definition for the person who needs or benefits from long-term care. Long-term care might not be considered as a specific social risk in every examined country. This could mean that either the social problem of taking care of these persons is not perceived as such because the number of persons concerned is not significant, or because there are some other political priorities. It could also mean that the social problem arising is tackled by other already existing mechanisms and that there is no need for a specific legislative intervention. For example, it happens that no major distinction is made between the disabled persons and the elderly dependent persons.

The EU Institutions uses the word "dependence"[8] or the phrase "of health and care for the elderly"[9]. Following "old people's greater morbidity (often as a result of a combination of illnesses) and the seriousness and more chronic nature of age-related diseases, which can lead to dependence on others"[10] and "long-term care consists of assistance to persons who are unable to live autonomously and are therefore dependent on the help of others in their

7 N. Kerschen (coordinator), J. Hajdu, G. Igl, M.-E. Joel, K. Knipscheer, I. Tomes, Long-Term Care For Older People. Report for the European Conference on "Long-term Care for Older Persons" organised by the Luxembourg Presidency with the Social Protection Committee of the European Union Luxembourg, 12 and 13 May 2005.

8 COM (2001) 723 final op cit supra p. 1.

9 § 43 of the Göteborg European Council called on the European Council, June 2001.

10 Communication of the Commission on the future of health care and care for the elderly: guaranteeing accessibility, quality and financial viability, 5 December 2001 p. 4 and 5.

everyday lives"[11] or even "the term "long-term care" is used in a general sense including both health care related aspects and social non-health-related ones"[12]. In the joint report of the Commission and of the Council "supporting national strategies for the future of health care and care for the elderly"[13], of 10 March 2003 long-term care consists of assistance to persons who are unable to live autonomously and are therefore dependent on the help of others in their everyday lives.

The Court of Justice of the European Communities has also been confronted with national long-term care provisions, especially with difficulties to "export" acquired rights on long-term care benefits within the frame of regulation 1408/71 on coordination on basic social security systems. In the *Molenaar* judgement (C-160/96)[14] the CJEC classified one of the two benefits of the German care insurance (*Pflegeversicherung*) as a "sickness benefit" to which Regulation 1408/71 was applicable, because under the German law everybody insured against sickness has to contribute to the care insurance scheme. In the *Jauch* case (C-215/99)[15], the CJEC declared that the Austrian care allowance had to be considered as sickness benefit in cash (traditional benefit) which cannot be entered into Annex IIa and therefore had to be exported. The Austrian care allowance (*Bundespflegegeld*), a non-contributory benefit, had been listed in Annex IIa of the Regulation 1408/71 and granted to recipients of pensions who need care. The lack of definition could be explained by historical considerations – when the regulation was adopted long-term care was not a social risk as such - but it could also be that the court has difficulties to name this new benefit. Thus, it is interesting that the new regulation 883/2004 does not include the long-term care benefits in the list of matters covered by its article 3 but the concept of long-term care appears in the frame of sickness benefits; article 34 speaks about "long-term care benefits in cash" without giving a definition of long-term care. This "imperfect recognition" of long-term care shows at least that the question is very controversial at the European level, especially concerning the nature of these benefits and their status for the coordination of legislations (exportation, accumulation rules,...).

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11 Communication from the Commission to the Council, the European Parliament, the European Economic and Social Committee and the Committee of The Regions, "Proposal for a Joint Report Health care and care for the elderly: Supporting national strategies for ensuring a high level of social protection" COM(2002) 774 final, Brussels, January, 3 2003.

12 "Review of Preliminary National Policy Statements on Health Care and Long-term Care" Memorandum of the Social Protection Committee SPC Health care & LTC review, final, 30 Nov. 2005 p. 7 footnote 2.

13 No 7166/03, SOC 116, ECOFIN 77, SAN 41 p. 13

14 ECJ 5 March 1998 Case C-160/96 : Manfred Molenaar, Barbara Fath-Molenaar v. Allgemeine Ortskrankenkasse Baden-Württemberg. Point 19 refers to the German national legislation when stating "care insurance benefits are designed to develop the independence of persons reliant on care, in particular from the financial point of view. The system introduced is aimed at encouraging prevention and rehabilitation in preference to care and at promoting home care in preference to care provided in hospital".

15 ECJ 8 March 2001 Case C-215/99 : Friedrich Jauch v Pensionsversicherungsanstalt der Arbeiter

Questions arisen by long-term care

People who experience difficulties in performing daily activities will inevitably need to find a solution to their problem. Some will develop self-help strategies and make use of technical aids, while others will call on relatives or friends, and others yet will turn for help to professional services, at home or in institution (i.e. government/communal organised, charitable care or commercial care). People may also combine various forms of care. Thereby the organisation and financing of the systems are important as well as the benefits for the persons in need and their carers.

Organisation of long-term care

The field of Long-term Care belongs (most of the time) to the “conventional” health system, but also of the medical-social sector because long-term care help meets both health and personal needs. The range of services to be provided is broad. Medical services, which also support various definitions, have to be provided to these persons. Home health care consists of services received at the beneficiary’s home, and can include skilled nursing care, physical or occupational therapy or home health aid services. But health care can also be provided in institutions varying from dispensaries to hospitals.

Long-term care is primarily basic services designed to minimize, rehabilitate, or compensate for loss of independent physical or mental functioning, in other words to assist people with support services such as activities of daily living like dressing, bathing and using the bathroom. The services include hands-on and stand-by or supervisory human assistance. This care can be organized as a personal home care. Another service consists of adult day care for persons living at home: supervision for the elderly is provided during day-time when family members are not at home.

An alternate level of care in a hospital is care received as a hospital inpatient when there is no medical necessity for being in the hospital even for those persons waiting to be placed in a nursing home or while arrangements are being made for home care. Respite care includes services that can provide family members a rest or vacation from their care giving responsibilities.

Long-term care covers also a variety of services including social and recreational in a group setting.

Some of the services existed before the “long-term care” appearance, others not. The medical offer is on its way of being adapted to the change in needs for an elderly population in situation of long-term care. Other services had to be created specifically. Some of them appeared spontaneously as a result of the market; but most of them, especially for people who could not afford the market offer has to be created or installed by the legislator, sometimes in the form of reorganization of already existing institutions. A "tailored" - in part subsidized - service market with specific operators and specific forms of organization has been or is being built up gradually.

Depending on the form and focus of the system, care is organised on the national, regional, municipal or communal levels, or on several of these levels. In those countries with a strongly developed communal care system, such as the Nordic countries, the communes have chief responsibility for organisation over the entire range of care. Furthermore, Estonia, for example, described decentralisation as one of the main targets in reforming the welfare system. Care in the patient's own home in the form of non-cash services is also organised on the communal level in many countries, in particular in the Nordic ones. In countries with their own insurance structure to cover the need for care, organisation is, in contrast, on the regional level, depending on the regional responsibilities of the insurance institutions, as in Germany for example. And in other countries, like Malta, the system is mainly organised on the national level.

Care in the home can be provided by members of the family or other persons close to those needing care, by profit-based or non-profit organisations or by the commune itself, with different concepts being practised in different countries: for example, communes in Finland are free to select the respective form of organisation and in general, the communes provide care services themselves, as is also the case in Estonia and Norway. In most other countries, out-patient professional help is, in contrast, provided by private service providers, who are commissioned either by those in need of care themselves or by the relevant institutions.

The role played by the persons themselves and their families is not to be underestimated: a large proportion of long-term care is provided by families even in countries where long-term care is significantly subsidised or partly directly paid by Social Security provisions. In other words the State encourages the “informal care” with different measures: fiscal incentives (e.g. Belgium, Greece, Spain or Hungary), recognition of the informal activity in acquisition of pension rights (e.g. Estonia, Germany, Lithuania, Luxembourg, Hungary or Austria) or respite care (e.g. Finland, United Kingdom).

For example, the new Dutch Act on social support (*Wet Maatschappelijke Ondersteuning*) which will be carried out by the municipalities, is explicitly conceived on the principle that citizens have to attempt first to find help in their own social environment and only if this proves impossible the municipality will provide services.

In the same way, in Finland - according to the newly-passed Act on Support for Informal Care which entered into force at the beginning of 2006 - elderly people (persons aged 80 and more) have the right to have a joint assessment of the need for care with the community. According to this assessment, the community and the elderly make a plan of what services are needed and who is going to provide them.

Financing of the benefits

The question of financing has received attention from policymakers. Most of the States which have introduced a range of measures in the field of social protection have adopted complex adjustments to the existing legislation and financial principles. Although the solutions differ considerably from one State to another the potentially high costs have often troubled the debate about the “right” balance between the roles of the public and private sectors. As a

result most of the countries have decided providing protection up to a certain limit for people who require long-term care. Fragmented funding is the main common characteristic on the financial side.

Alternative funding formulas have been investigated. A savings or investment plan may help pay for long-term care services as well as equity in housing - the profit from the sale of a home can fund long-term care costs with a move to cheaper accommodations. As an example some countries have introduced the possibility of a “reverse mortgage”, which is a loan based on the amount of equity built up in a home. A life insurance policy may also offer the opportunity for a loan or withdrawal of the cash value. Some people hire privately care services independently, some are cared by their spouse or children.

The present publication only deals marginally with this kind of individual solutions which could apply for every social risk and which are not specific to long-term care. Nevertheless these solutions are generally considered as very important. They are often encouraged by national legislation especially through generous tax or social contributions exemption or diminishing rules.

The dependency of the services on income correspondingly follows the rules of the respective systems which are in use: the insurance systems generally do not depend on the resources of the beneficiary, while services of the public welfare services depend on them. In general it can be stated that cash payments in most countries depend on income. Exceptions are here Germany and Austria, where cash payments are made in the form of fixed amounts (which vary with the level of care required) or Luxembourg, where payments are made according to the need for care (they are calculated in terms of number of hours of care needed).

In Denmark the services are provided independent of income if it is probable that the need for care will be long-term. In the case of temporary need for care, the services are provided dependent on income.

Diversity of benefits

A very large range of different services are described in the reports, which cannot be described fully in this summary. We will therefore restrict ourselves to some specific examples and noteworthy trends.

The offered benefits are, although generally defined, as much individualised as possible. Not only they are affected by the level of incapacity of the concerned person but also by the place, the personal living conditions, the environment and the available offer of services. These various long-term care services can be provided at home, in the community, in assisted living, in nursing homes. The services offer is provided by public, private or a mix of public and private institutions.

An important principle in this regard is the priority given to care in the home as opposed to in-patient care, which is emphasised in nearly all the national reports. In particular those countries which up to now have been characterised by clear institutionalisation in the area of care, are trying to strengthen services which are provided on an out-patient or home basis.

For example, Lithuania or the Czech Republic have either recently strengthened the home-based aspects of care services by law or are demonstrating a clear trend here. In order to achieve this goal, in Lithuania, responsibility for institutional care has been moved from the state to the local level, so that now both institutional and home care are organised on the same level. In the last five years, Greece has strengthened home care with the project "Assistance at home".

In order to strengthen the influence and independence of the persons affected, in the Netherlands, for example, a demand-orientated structure is implemented, so that now it is the requirement of the persons affected which is decisive for the care services which are received, rather than the services which are available on offer. The principle in Finland of allocating vouchers for services which are needed points in the same direction, with the persons requiring the care being able to select their service providers – in so far as they are recognised by the communal authorities.

Services at home can generally be claimed in the form of benefits in cash, whereby the cash benefits are either paid to the persons in need of care, like for example in the Czech Republic, in Estonia and Ireland, or those in need of care can decide in favour of cash benefits in order to pay the person providing the care (in some counties this only applies for non-professional carers) - e.g. Cyprus, Germany, Luxembourg, Slovakia. In Latvia and the United Kingdom both forms of payment are possible; the monetary payments can be made either to the carer or to the person requiring the care. In Austria the beneficiaries receive solely benefits in cash to organise and finance the care of their own choice and in Hungary the payment is made directly to the carer.

A large variety of care services are available in the countries; the care which is needed by the affected persons must be laid down in some form or other, with different procedures being described: for example in Norway, "Care Managers" are employees working within the municipal system of domiciliary care services and determine the degree of assistance required by the affected persons as a part of the municipal system. In the Netherlands an independent organisation (CIZ) determines whether a person has a claim to care services and, if appropriate, to what services; similarly, in Germany, the medical service of the health insurances (*Medizinischer Dienst der Krankenversicherungen, MDK*) assesses the need of long term care and gives a recommendation to the insurance. Finally, in Spain a system was presented on the national level on 21 April 2006 according to which the need for assistance is laid down according to a standard scale. If this procedure is laid down in law - as intended – the standard scale will apply for the whole country. The Autonomous Communities as well as the Municipalities will be involved in the development of the new system.

Care Quality control

In most countries, the quality of facilities and service providers is regulated either by law or by ordinance at the national level, or regulation by law is planned for the near future, such as in the Czech Republic or in Lithuania. Exceptions from this are Denmark and Finland, where, because of the responsibility on communal level, there are no legal arrangements at national level. However, Finland does issue recommendations at national level.

France does not place so much emphasis on structural characteristics in its quality standards, but is much more concerned with the process. Here there is the duty to evaluate the activities and the quality of the care services, and since 2005 the facilities have had to be evaluated externally every seven years. On the other hand, in Malta, a specific department for the control of the care standards has been implemented. Further development of quality standards is actively supported, for example, in Germany, in Liechtenstein or in Austria, by means of model and pilot projects on the national level. In Austria, measures of quality assurance, that were originally introduced as a pilot projects, have already been institutionalised.

The quality of facilities and services can be controlled either centrally by the relevant ministries or their specialist departments or on a decentralised basis on the regional or local level. The Netherlands have gone one step further and have founded institutions affiliated with health care insurance companies, which are responsible for controlling and supervision, and therefore have an overall perspective with regard to the progress and quality of each case.

Protection of the persons affected, both by law and also by establishment and involvement of corresponding organisations for older people, has been on the agenda in numerous countries in recent years.

Recent discussions

Some countries are increasingly looking to private insurance to provide alternative solutions but experience suggests that pricing long-term care insurance is fraught with difficulties and there is a strong need for a stringent underwriting process; two main reasons explain this situation: (i) the size of the market remains too small and the level of benefits far too weak to allow for a good coverage and (ii) the fixation of the price is very difficult since the future cost of long-term care is fundamentally unknown. Hence, the insurance companies solve the difficulties raised by the uncertainty on future costs by transferring a large part of the risk on policy holders, which limits their financial exposure. A first way consists in excluding high risk people, these exclusions being based on medical or age criteria. More specifically, they adopt very restrictive criteria to define the extent of the coverage – usually exclusively dedicated to high care levels – and impose waiting periods for pre-existing conditions. Moreover, given long-run uncertainties, most policies impose a cap on the total use of care, and benefits often consist of nominal annuities that are not indexed on the Consumer Price Index.

In addition to questions of long-term financing of social and care services, the systems for providing the services are themselves on the agenda, which include restructuring, rationalisation and quality improvements: Luxembourg for example has modified the existing insurance system by stressing a better rationalisation; in Latvia, Slovenia and Slovakia comprehensive restructuring measures are planned, which serve for easier access to services and rationalisation of the system. For example in Slovenia, it is planned to draw together the entire area of care into one law. Other countries, such as Portugal or France, describe programmes or measures for care improvement. Included in the planned quality

improvement measures are also shortening of waiting times and greater flexibility in the choice of the service provider (e.g. Denmark), diversification of the offering and more emphasis on out-patient care (e.g. Finland, United Kingdom) as well as strengthening of integration (e.g. Sweden, United Kingdom).

Finally, Liechtenstein and Cyprus report that they are planning holistic future concepts for policies regarding old people.

In summary it can be stated that the systems regarding the need for care, including their financing, are organised in various countries by different branches of the social security system on different political levels, and that there are considerable differences between the systems. Based on demographic development, an important theme is that the systems should also be financially sustainable, and this is also being approached in different ways.

Bibliography

A. Comas-Herrera and R. Wittenberg, "*European study of long-term care expenditure*", Report to the European Commission, Employment and Social Affairs DG, Grant number VS/2001/0272, PSSRU Discussion Paper 1840, February 2003.

Jacobzone S. *et al.* : "*The health of older persons in OECD countries: is it improving fast enough to compensate for population ageing*", Labour Market and Social Policy Occasional Paper No 37, OECD, Paris 1999.

A. Österle, *Equity choices and long-term care policies in Europe : allocating resources and burdens in Austria, Italy, the Netherlands, and the United Kingdom"*, Aldershot, Hampshire, England ; Burlington, Ashgate, 2001.

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