

MISSOC SECRETARIAT

MISSOC ANALYSIS 2009

LONG-TERM CARE



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TABLE OF CONTENTS

I. Introduction	3
I.A. Demarcating the subject.....	3
I.B. Organisation and matters of policy	4
I.C. Specifying modalities of a LTC-system.....	5
I.D. Interim conclusions.....	6
II. Accessibility	7
II.A. Categorical classification. Social insurance vs. social assistance.....	7
II.B. Conditions for receipt of benefit.....	11
II.C. Modalities	11
III. Quality	13
III.A. Elements of choice	13
III.B. Quality assurance	15
IV. Care Coordination	23
IV.A. Evaluation of dependency	23
IV.B. Benefits package	24
IV.C. Benefits provision	26
IV.D. Case or care management	27

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I. Introduction

The European Commission and the MISSOC-Secretariat agreed that an analytical report on long-term care should be written in 2009 focusing on three elements: choice; quality; and integrated care/coordination of care. This report aims to place in context both present and future policy debate about long-term care at the Community level, with particular emphasis on ensuring accessibility, quality and the sustainability of national long-term care schemes.

The MISSOC Analysis is based on information found in the MISSOC tables, and demonstrates how these regular updates of social security legislation can be used in a more policy-oriented way. The Analysis is based on the concept of long-term care as described in these tables, and as such does not take into account the European legal qualification of this benefit, as interpreted by the European Court of Justice. For this analytical report it must also be noted, however, that for the topics of Quality and Care Management the tables do not contain any information and that use was therefore made of the national Strategic Reports on social protection and social inclusion. Experts from the MISSOC Secretariat [currently contracted to Bernard Brunhes International (BBI)] have drafted this paper in consultation with the European Commission and the National Correspondents from those countries participating in the MISSOC. This document is however the sole responsibility of the Secretariat. Prof. Yves Jorens (Scientific mentor in the MISSOC secretariat) took lead responsibility for developing this document, in collaboration with Prof. J. Hajdu.

I.A. Demarcating the subject

The ILO Convention nr. 102¹ - the basic text when it comes to defining and enumerating social security benefits - presents a “*classic*” typology of social risks (medical care, sickness, unemployment, old-age, employment injuries, maintenance of children, maternity, invalidity, loss of support suffered by the widow or child as the result of the death of the breadwinner). However, a changing society and demographic trends have led to the emergence of new social risks, such as “*dependency*” and the need for “*long-term care*” (hereafter: “*LTC*”). The improvement in the health status of the European population is exemplified by an increase in life and healthy life expectancies². According to the European Commission, high levels of protection against the risk of illness and dependency are vital assets that must be preserved and adapted to the concerns of the modern world, particularly demographic ageing³.

¹ ILO Convention C102 concerning Minimum Standards of Social Security.

² EUROPEAN COMMISSION, *Joint report on social protection and social inclusion 2008*, Brussels, European Commission, 2008, ec.europa.eu/employment_social/spsi/joint_reports_en.htm, 80 (hereafter: EUROPEAN COMMISSION, *Joint report 2008*).

³ *Ibid.*

An academic literature provides a description and analysis of these emerging phenomena.⁴ The OECD has defined long-term care as "...a cross-cutting policy issue that brings together a range of services for persons who are dependent on help with basic activities of daily living over an extended period of time"⁵. The notion "basic activities of daily living" covers self-care activities that a person must perform every day such as bathing, dressing, eating, getting in and out of bed or a chair, moving around, using the toilet, and controlling bladder and bowel functions. Generally, three categories of person are specified: (1) persons with physical or mental disabilities, (2) the frail elderly and (3) particular groups that need support in conducting their daily life activities. These particular risks can be seen as being the unavoidable side effects from other (more stereotypical) social risks, such as old-age, sickness and invalidity.

I.B. Organisation and matters of policy

The principles that inform the development, organisation and institutional framework for LTC require the elaboration of new policy initiatives. Although not common within the classic branches of social security law, an LTC-system necessitates careful consideration of financial requirements and administrative structures.

In general, it is not expected that the system itself should have universal coverage. The principle of solidarity/equitable financing of the system would, in that case, reflect the ability of citizens to pay. It is based on progressive financing through taxation or income-related social contributions and/or, in the context of insurance, after-premium financial compensation, risk pooling and risk selection prohibition, and adequate risk adjustment across insurers and regions.⁶

In essence, the first question would be whether the LTC-system could be implemented within either a Bismarck-oriented model (which is social-insurance-funded and controlled by legal private organisations) and/or the Beveridge system (which is tax-funded with a wider infrastructure of public ownership and control of authorities)⁷. This would be a question about accountability and the regulation of public funding.

⁴ N. KERSCHEN, J. HAJDU, G. IGL, M. JOËL, K. KNIPSCHER and I. TOMES, "Long-term care for older persons", *Bulletin luxembourgeois des questions sociales* 2005, 25 and further, ec.europa.eu/employment_social/spsi/studies_on_health_care_en.htm (hereafter: N. KERSCHEN a.o., *Long-term care for older persons*)

⁵ As cited by EUROPEAN COMMISSION, *Joint report 2008*, 81.

⁶ EUROPEAN COMMISSION, *Review on preliminary national policy statements on health care and long-term care. Memorandum of the Social Protection Committee*, Brussels, European Commission, 2005, 7, ec.europa.eu/employment_social/spsi/docs/social_protection/spc_ltc_2005_en.pdf

⁷ DRIEST, "Long-term care in Europe. An introduction", in J. HASSINK en M. VAN DIJK (eds.), *Farming for health*, Utrecht, Netherlands Institute of Care and Welfare, 2006, (101) 102, library.wur.nl/frontis/farming_for_health/08_driest.pdf.

I.C. Specifying modalities of a LTC-system

Various legal and political questions arise concerning the scope, range, prospects for and further organisation of an LTC-system. The formulation of these issues can be drawn up in different ways.

I.C.1 A question of choice? User status of people needing LTC. Variety of benefits

An elementary question is whether a person would have a free choice, or the right to have a say and to have a choice, about the way LTC is accessed and/or received. It must be stressed that the particular social risks covered by LTC do allow for a certain amount of choice. It is believed that having more flexibility in terms of how to receive care can increase the patients' autonomy or self-determination as well as that of their informal care givers. Allowing more choice in the system, does not only enhance the role of the patient/consumer but also implies that the providers of services should take more account of the individual wishes of the persons concerned, rather than take as starting point the services they could offer.

I.C.2. Institutional care versus tailored home/community care

Another policy issue refers to the location and nature of the services provided. Institutional care embraces care provided in hospitals in either an acute or non-acute setting (nursing homes), whereas home/community care focuses on the provision of services within the domestic surroundings of the user/patient⁸. In general, countries are firmly focused on enhancing tailor-made home and community care services and moving away from institutional care. However, this does not mean that institutional care provision is to be dismantled⁹.

According to the European Commission, home or community care is preferred to institutional care. The goal is to help individuals remain at home for as long as possible, while providing institutional care when needed. This also supports individual choice and preferences: in general people want to live for as long as possible in their own homes, close to their family and friends. This is also considered to be a cheaper or budget-neutral alternative to institutional care¹⁰.

⁸ In the MISSOC tables, informal care is described as care provided by spouses/partners, other members of the household and other relatives, friends, neighbours and other persons, who typically but not necessarily already have a social relationship with the person to whom they provide care. Long-term care services can however also be supplied by professional providers, employees of any organisation, in the public or private sector, including care provided in institutions, as well as care provided to persons living at home by professionally trained or untrained care assistants, belonging to particular organisations or institutions. Home care corresponds to long-term care provided to patients at home while residential care relates to long-term care provided in an institution, which at the same time serves as residence to the care recipient.

⁹ EUROPEAN COMMISSION, *Long-term care in the European Union*, Brussels, European Commission, 2008, 13, ec.europa.eu/employment_social/news/2008/apr/long_term_care_en.pdf (hereafter: EUROPEAN COMMISSION, *Long-term care in the European Union*).

¹⁰ EUROPEAN COMMISSION, *Joint report 2008*, *supra* footnote 3, 84.

I.C.3. Private and/or public organisation of LTC

The oldest form of social security goes back to family-related structures. From the 16th century onwards and especially during the 19th and 20th centuries public authorities gradually started to play a more significant role. Since the Second World War many Welfare States have taken the lead in the care of dependent people, and dependent older people in particular¹¹.

This conclusion draws attention to the importance of informal care and of care provided by private institutions within an LTC-system and the complementary role of public intervention.

I.C.4. The quality issue

The quality of long-term care services for dependent persons varies widely both between and within countries. There is a considerable concern that there is a quality deficit. For that reason, and in recent years, several initiatives have been taken that should improve the quality and provide for the effective enhancement and monitoring of the quality of long-term care services.

I.C.5. Funding - financial sustainability

Depending on the legal and social principles underpinning provision, the funding and financing of a Member State's LTC-system will vary.

Some countries provide comprehensive public programmes financed through social insurance, whereas others fund their programmes through taxation or means-tested schemes. Others have mixed financing, combining resources from insurance schemes and taxes, with different budgets and institutions responsible for the provision and purchasing of long-term care. There is increasing recognition of the need to create a solid financing basis for long-term care and to thereby ensure the availability of much needed resources¹².

I.D. Interim conclusions

Taking into account the questions and issues mentioned above, the description and analysis of LTC schemes throughout the EU may be presented as follows:

(1) Accessibility: In which branch (healthcare, sickness, invalidity, long-term care) is the risk of dependency covered? Is it covered by social insurance or social assistance? What are the conditions for which benefits are granted? Qualifying period; means test; age; minimum level of dependency; duration of benefits? Are there user charges for benefits in kind? What is the level of benefits in cash? Do benefits vary according to the level of dependency?

¹¹ N. KERSCHEN a.o., *Long-term care for older persons*, supra footnote nr. 2, 41.

¹² EUROPEAN COMMISSION, *Long-term care in the European Union*, supra footnote nr. 6, 24.

(2) Quality: are there elements of choice in the national schemes? This would include choice of providers, choice of type of provider (formal-informal); choice between benefits in kind and cash benefits; personalised budgets; measures and benefits for the carer. Is there a quality assurance scheme?

(3) Care co-ordination: evaluation of dependency (evaluators, indicators, categories, interaction between health and social services); benefits package (which types of benefit are provided?); benefits provision (who are the providers of benefits?)

II. Accessibility

II.A. *Categorical classification. Social insurance vs. social assistance*

II.A.1. *Demarcating and defining the social risk and coverage provided by the member states*

Table 1: definition of LTC

DEFINITION OF SOCIAL RISK(S) / LTC BENEFITS	RANGE OF DEFINITION(S)	COMPARISON WITH THE OECD DEFINITION	MEMBER STATES
Yes	General definition	Member state's definition is equal or broader (more sophisticated and detailed) than the OECD definition	BE, CZ, LV, LU, PT, ES, DE
		Member state's definition is more restricted (less sophisticated and detailed) than the OECD definition	CY, DK, EE, FI, IS, LT, NL, SI, SE, AT
	Various descriptions, depending on the particular scheme / benefit		FR, IE, IT, PL, CH, LI
No			BG, GR, HU, MT, NO, RO, SK, UK

The OECD has defined long-term care as "*a cross-cutting policy issue that brings together a range of services for persons who are dependent on help with basic activities of daily living over an extended period of time*"¹³. Elements of long-term care include rehabilitation, basic medical services, home nursing, social care, housing and services such as transport, meals, occupational and empowerment activities, thus also including help with instrumental activities of daily living. Generally, three categories of persons are in scope: (1) persons with physical or mental disabilities, (2) the frail elderly and (3) particular groups that need support in conducting their daily life activities.

This description is - among others - often used as a benchmark in order to define the *social risk* behind LTC. The definition seems to be based on the (dis)ability to conduct basic instrumental activities of daily living (IADL).

The table (Table 1, above) evidences diversity in both scope and characteristics of LTC. For example:

- Some Member States do not have a legal (universal) definition of the social risk(s) covered by their LTC system. This does not mean that there is no focus at all: the social risk might be implicitly defined by other subjects. Bulgaria (BG), for instance, is not common with a particular description of the social risk; it is however indirectly defined by the categories of disability, reduced work capacity, etc.
- A few Member States redirect to related definitions within the different branches of the national social security and/or public assistance schemes.
- Most Member States apply a specific definition in order to mark out the social risk. Some of these Member States have a definition which coincides with the OECD description, and therefore is based on the notion of IADL. Spain (ES), for example, defines the risk as "*...the situation of a person who, on account of age, disease or incapacity, and linked to lack or loss of physical, mental, intellectual or sensorial autonomy, requires assistance from (an)other person(s) or considerable help to carry out essential daily activities or, in the case of persons with a mental disability or illness, other forms of support for their personal autonomy*". On the other hand, some member states are familiar with a rather abstract and/or minimal definition. A good example is Cyprus (CY): "*...need of care due to mental or physical incapacity or social distress*".

¹³ As cited by EUROPEAN COMMISSION, *Joint report 2008*, *supra* footnote 3, 81.

II.A.2. Statutory organisation. Social security (insurance) and/or public assistance?

Table 2: statutory organisation

STATUTORY ORGANISATION	CLASSIFICATION	MEMBER STATES
Global care system and/or unifying legislation	Social security	BE (Flemish region), LU, NL, SE
	Public assistance	CY, DK, EE, ES, UK
	Combination of both social security and public assistance	/
Differentiated approach (disintegrated care system)	Social security	CZ, CH, AT, LI
	Public assistance	HU, LV, MT, RO
	Combination of both social security and public assistance	BG, FI, FR, GR, IS, IE, IT, LT, NO, PL, PT, SK, SI, DE

In order to understand a Member State's view of and policy towards LTC, the statutory organisation (public law) and legislative technique must be charted. The legal framework often indicates whether or not a Member State deploys an integrated and deductive approach towards the particular social risk. On the other hand, the existence of several piece-meal arrangements could be a result of historical factors.

It should be borne in mind that the present analysis aspires towards a global (integrated) approach in classifying the Member States' LTC systems. This means that both social security (insurance) and social assistance schemes are taken into account in order to compare the key elements (accessibility, quality and care coordination) of each national system. The provision of benefits should indeed be assessed on the question whether residents have a subjective right on LTC or not. Therefore, it is necessary to view LTC as a whole, and include every possible scheme and benefit that meets the risk of dependency and help with daily living activities - irrespective whether or not the beneficiary has to fulfil certain (means- or contribution-related or other) conditions.

Irrespective of the organisation through either an integrated or distributed care system, LTC may be part of a social security (insurance) branch, and/or a public assistance scheme. Both concepts are rather theoretical and based on legal doctrine, and are therefore not always clean-cut and do sometimes even conflict. Nevertheless, the distinction between social security and social assistance is useful in drawing up a typology of LTC.

On the one hand, social insurance schemes can be defined as schemes in which social contributions are paid by employees or others, or by employers on behalf of their employees, in order to secure entitlement to social insurance benefits, in the current or subsequent periods, for the employees or other contributors, their dependants or survivors.

On the other hand, social assistance schemes can be defined as schemes covering the entire community, or large sections of the community, that are imposed, controlled and tax-funded by the government.

Most of the Member States are acquainted with a differentiated approach, and spread their benefits related to LTC over several branches of their existing social security and/or public assistance system. Within this line of thought, it is most likely to approach LTC via both social security and assistance schemes.

Only a few Member States have a 'pure' globally oriented system, being either social security related or within the public assistance scheme.

Some Member States' schemes could be types as 'characteristic', and are therefore well-placed within the above mentioned typology:

- Cyprus (CY) has a centrally organised global care system, based on the idea of public assistance. The scheme is financed by the state budget. Benefits are means tested, which means that the scheme bears the costs for those whose resources¹⁴ are not sufficient to meet special needs for care. This implies, for instance, that the beneficiary has to contribute a certain amount of his/her social insurance pension towards the fees for residential care. Furthermore, a welfare officer (official) supervises the management and spending of the personal budget (allowance).
- The same goes more or less for Latvia (LV), although this member state does not have unified legislation: the legal provisions consist of the co-ordination of various schemes related to social services for the elderly, disabled and children.
- Belgium (BE) shows a rather complex system, of which only the Flemish region is familiar with a global (one particular legislation) care system. The scheme is more social security oriented, since the beneficiary has to pay a contribution to a 'zorgkas', and therefore does not include a means test.
- A striking example of the co-ordinated approach throughout both social security and assistance schemes is that in Lithuania (LT): there is no special legislation; LTC is granted through several branches: social services on the one hand, invalidity and sickness (healthcare; social security) on the other hand. The schemes are financed by both social security contributions, as well as the general state budget. Benefits in cash do not require a means test, in contrast to allowances for institutional care (which do require a means test).

¹⁴ Within the context of the present analysis, the notion 'means test' is defined broadly and is deemed to include earnings, assets, property (real estate), as well as all other types of income. Nevertheless, most of the Member States' respondents only seem to have taken into account earnings, benefits, allowances and pensions.

II.B. Conditions for receipt of benefit

Long-term care raises several issues. Should it be services to be provided as in patient or outpatient care and ambulatory care? Should it be collective or individualised? Should it be targeted to the actual needs of the beneficiary? Should it be a service or rather cash to finance the service the beneficiary chooses? A lot of debate also takes place on the nature of care for patients and the best ways to organise it. Should it be social or health care? Should it be provided in kind or in cash? The debate is difficult and whether there is a tendency towards more integration and how they relate to each other, is not always very clear.

All the European countries have different conditions on which benefits in kinds and/or cash are granted. These conditions can be the qualifying period, the existence of a means test, age limits, minimum level of dependency or duration of benefits (limited or unlimited). In many countries, there is no condition of qualifying period required, except for Austria, Belgium, Germany, Iceland, United Kingdom, Italy, Ireland and Greece.

Means testing schemes are an important element for countries such as Austria, Belgium, United Kingdom, Cyprus, Hungary, Lithuania, Slovakia and Poland provide social assistance instead of social insurance. These countries rely primarily on means-tested schemes, which cover only persons with income and assets below a certain level. These means-tested schemes are funded by tax revenues. Bulgaria, Greece, Iceland, Latvia, Lithuania, the Netherlands, Norway, Sweden, Switzerland and Germany do not apply the means testing scheme in favour of social insurance financed provision.

Furthermore, in most of the countries age conditions are applicable, except for Cyprus, Czech Republic, Denmark, Finland, Germany, Iceland, Italy, Latvia, Lithuania, the Netherlands, Sweden, Spain and Norway.

Additionally, in most of the countries a minimum level of dependency is required in order to receive benefits except for Estonia, Greece, the Netherlands, Norway and Portugal.

Moreover, the duration of benefits is unlimited in most of the countries such as Portugal, Norway, the Netherlands, Poland, Greece, Germany, Estonia, Denmark, Bulgaria, Cyprus, Italy, Czech Republic and Spain.

II.C. Modalities

User charges for benefits in kind, levels of benefits in cash as well as variation in benefits in cash according to the level of dependency can create a barrier to accessing long-term care. User charges in particular can cause problems for low-income groups, who may have to meet some of the expenditure themselves. It is often the case that elements of medical and social care provided to users/patients are not covered by the basic insurance packages, and this in turn can lead to a high occurrence of additional out-of-pocket payments like e.g. co-

payments¹⁵ (used in Cyprus, Estonia and Ireland). Measures to reduce the individual direct costs of care include: co-payment exemptions and co-payments based on income, extra financial help granted to the dependant, disabled and chronically ill patients, state coverage of social long-term care for low-income households in a social assistance scheme (e.g. France, Netherlands, Belgium, Hungary and Germany), nationwide standardisation of co-payments and state subsidies to use private services.

Almost all Member States have a system that provides benefits in cash (except for Latvia). The value of these benefits is determined by various kinds of indicators or formulas. Most common are fixed amounts, as stated expressly in the applicable statutes and Acts (e.g. France, Germany, Greece, Ireland, Lithuania, Portugal, Romania, Spain, Slovenia, Switzerland and the United Kingdom). Other Member States provide benefits (sums), calculated as a certain percentage (%) of - for example - the beneficiary's retirement pay (Bulgaria and Greece). Another method consists of adjusting the benefit to the applicable degree of needs and/or the type of services to be provided (Cyprus, Italy, Luxembourg, Netherlands, Norway, Poland and Slovakia).

A substantial majority of the Member States demand a contribution from the beneficiary (except for Greece). This is either incorporated within the national social security system or conceived as a separate contribution. In this last case, most of the Member States do somehow limit the individual contribution to a certain percentage of income (Latvia), or at least bear in mind the financial resources and capacity of individual beneficiaries (e.g. Slovenia, Spain, United Kingdom).

Only a minority of the Member states impose taxes upon the benefits (except for, in some cases, Malta, Slovenia, Spain and United Kingdom).

Almost all Member States relate the value of benefits to the level of dependency.

¹⁵ The user pays part of the cost (certain percentage) per item or service; see www.euro.who.int/HEN/Syntheses/hcfunding/20040704_4 (consultation 22 June 2009).

III. Quality

III.A. Elements of choice

III.A.1. Adapting to evolving needs and increasing patients' choice and involvement

Today, in long-term care, the role of the user/patient is often very limited. Therefore, it is very important not only to take into account the patients' needs but also their expectations including the desire for choice. Consequently, several countries want to ensure greater system responsiveness to more autonomous clients. This can be attained by increasing patients' choice concerning care providers and/or insurers, by greater patients' involvement in the organisation of care and decision making (e.g. ensuring patient representation in committees/agencies), and by giving the patient control over income e.g. use of allowances to patients or personal budgets. This in turn requires improving transparency and making better information available to users so that choices can be made based on knowledge and advice as well as the strengthening of patient rights.¹⁶

For many years there has been a growing acceptance of the important role of informal care givers and recognition of the need to support their role as long-term care providers. This is to a certain extent linked to the growing interest and debate on arrangements to increase choice and flexibility in long-term care.

The reasons for this change are many-fold: in general, it is believed that having more flexibility in terms of how to receive care can increase the users' personal autonomy and that of their informal care givers. It fits into general measures introduced to reconcile work and family life; it should empower dependent people by giving them the choice of buying care that better suits their needs; it sustains independent living of dependent people, avoiding costly institutionalisation; and it should help to develop a more diversified sector of formal care providers in creating new and better quality jobs in the sector.

Although in general, unpaid and unrecognised family work at home would remain the most important support, several incentives have been developed that should support the informal caregivers to stay at home and to take care of their dependants. Linked to this is the situation where the dependant persons needing care from their families act as employers of care assistants and are therefore able to hire and fire, schedule and supervise directly the provision of care by the consumer or client employed care assistant.

The measures taken however vary considerably. Some countries provide no special protection (Hungary, Italy, Netherlands, Lithuania, Portugal, Belgium). This does not immediately imply that these persons are completely unprotected as measures were taken in the framework of labour law that allow people to reconcile work and family life and in particular to take leave to stay at home in order to take care of their sick dependent family

¹⁶ EUROPEAN COMMISSION, *Review on preliminary national policy statements on health care and long-term care. Memorandum of the Social Protection Committee*, Brussels, European Commission, 2005, http://ec.europa.eu/employment_social/spsi/docs/social_protection/spc_ltc_2005_en.pdf

members. In some countries, this will be unpaid leave, while in others a certain income support may be provided.

Other countries provide a separate benefit, an amount of money as compensation for a loss of income of the care provider (UK, EE [benefit however paid to the person in need and not to the caregiver], MT, PL, CH, BG, FI, SK, NO (discretionary amount)), while others consider periods of care as periods of contribution for the pension system (Germany, Spain, CZ); take account of these periods in the calculation of the benefit (CH) or foresee a more attractive pension (GR) or grant a supplement to the pension (IS).

In other countries, by the fact that these persons are employed and receive a contract, they are covered by the social security system (FR, BG, SI).

Home care is delivered through different mechanisms. Some use an agency-based formal home care service, as in the Netherlands, Norway and Sweden, while other countries like Austria and Germany deliver indirectly support to informal care via payments to the person needing care that may then be channelled to informal care givers.

A diversity of cash benefit programmes has been created for patients, who are nursed at home, in order to allow them and their families more individual choice among care options. These cash benefit programmes include personalised budgets and consumer-directed employment of care assistants, direct payments to the patient but with a choice about how to spend it in support of care, or direct payments to informal care givers in the form of income support. The purpose to which the money is put is therefore of no relevance. Allowing people free choice, should also help in allowing the persons needing care to substitute between the different care services.

Users can employ a personal care assistant with personal budgets and consumer-directed employment of care assistants. They can choose to employ a formal or an informal care giver (for example a friend or a relative). Sweden has recently introduced a system of free choice between private providers of home care services and care in institutions. In order to guarantee this free choice, the patients must have access to sufficient information about the alternative providers and services available. The patients are able to use a virtual account to buy with their personalised budget care, employ assistants or pay for personal services suited to their particular needs.¹⁷ Also in Germany reforms have led to a system that is better adapted to the individual needs (including a comparable list of all services and benefits available) and an integrated network of the services available in the direct neighbourhood of the person concerned. For that reason so-called “points of care support” were set up, that work with care managers.

However, the fact that free choice is possible in some countries, does not imply that no restrictions exist. In some countries, this ‘free choice’ does indeed have limits and can vary between systems where only services can be bought within a certain range or from a limited number of providers, whereas in other systems some accounting is required, i.e. the services

¹⁷ EUROPEAN COMMISSION, *Long-term care in the European Union*, 22,
[http://ec.europa.eu/employment_social/news/2008/apr/long term care en.pdf](http://ec.europa.eu/employment_social/news/2008/apr/long_term_care_en.pdf)

bought have to be approved, be it afterwards or just in other systems, no accounting is required for a certain amount of the budget. In the Netherlands, for example, the personal budget is only available for certain functional forms of care, such as nursing, general care and guidance; the budget is not available for treatment or institutional accommodation. In Cyprus the claimant cooperates with a welfare officer for developing his/her personal care plan (e.g. type of care, frequency) based on individual needs for care services in-kind and/or cash benefits.

Table 3 provides an overview of coverage and choices (see. IV.B. Benefits package: which are the (types of) benefits provided?)

III. B. Quality assurance

An issue that today plays an important role in long-term care and that will become one of the most important topics is the question on the quality of LTC-services. It cannot be ignored that the quality of long-term care services differs enormously within countries varying from inadequate housing, poor social relationships and lack of privacy in nursing homes up to shortcomings in services such as inadequate treatment of chronic pain, depression, bedsores or inappropriate use of chemical or physical restraints. An additional element is that contrary to for example health care, people without specific qualification may work in long-term care, as well as involvement by lay persons with no specific qualifications and very little training.

The assessment of the quality of long-term care services is however a complex phenomenon especially when it is provided in an informal, rather than institutional environment.

These complaints and challenges are among the reasons that several countries are developing or changing regulations and legislation to bring quality in long-term care up to expectations including increasing public spending and initiatives for better regulation of long-term care services, such as by establishing quality assessment and monitoring of outcomes.¹⁸ It is hoped that providers will be motivated to invest in activities to improve quality of care, provided that consumers and decision-makers use public information on performance and quality to select providers.

Quality regulations for long-term care have indeed developed. Whereas in the beginning, they were more related to minimum requirements for structures and processes of care, covering ratios of staffing and the safety of buildings, now instruments are developed for outcome measurement, strategies for continuous quality improvement, implying also requirements for protecting patient's rights, privacy and participation. The need for the introduction of controls by supervisory bodies, which are independent from both agents of supply as well as demand, is in this respect important.

¹⁸ OECD, *Long Term Care for Older People*, Paris, OECD, 2005, 12-13, www.euro.centre.org/data/1216815268_61772.pdf

It is clear that in the future, the lack of staff could reduce the quality of long-term care enormously. Political systems may therefore be obliged to pay attention to the improvement of pay and working conditions, as well as the infrastructure, to attract more qualified staff.¹⁹

The methods and instruments used today to install quality improvement measures are many-fold but can be divided around three axes: (a) mechanisms of assessment; (b) authorisation and accreditation systems and (c) quality control and quality management processes.

Quality standards for structures, procedures and outcomes as well as quality monitoring systems coupled with quality accreditation measures are a few of the tools available to European countries to guarantee high quality long-term care. Another quality enhancement tool are the clinical guidelines derived from evidence-based medicine. More patient-centred patterns of care including tailor-made services with greater patient involvement in decision-making also enhance quality. In order to prevent regional inequalities in the provision of long-term care and arbitrary assessments of patient needs by regional and local authorities, uniform quality assurance mechanisms are used by many countries.²⁰

Although there is an understanding that quality is an important element, the way quality issues are integrated fully depends on the initiative of the Member State as there is no European Framework for Quality.

III.B.1. Assessment and evaluation

The assessment and evaluation of health interventions (services and medicines) are critical to determining if such interventions are medically justifiable, safe and effective and whether there are cheaper alternatives; as such they help to improve the quality but also to support financial sustainability.

Several countries (e.g. Belgium, France, Hungary, Germany, Luxemburg, Malta) have in this respect set up independent authorities responsible for the evaluation (or the gathering of information necessary for evaluation) of medicines and technical interventions in terms of safety, cost-effectiveness and evidence-based care. Some (Germany, Sweden) are collaborating with the European Health Assessment Network. Moreover, guidelines and recommendations will be created by means of the results of the evaluation and assessment. The valuable information gained by an improved monitoring system will lead to better evidence-based policies.²¹ In 1999, a reform of tariffs of old age and nursing homes in France introduced a systematic self-assessment process that has to be carried out by the provider organisation with the objective to install a participative process of continuous improvement. The resulting self-assessment instrument (ANGELIQUE) contains more than 100 items and

¹⁹ OECD, *Long Term Care for Older People*, Paris, OECD, 2005, 13, www.euro.centre.org/data/1216815268_61772.pdf

²⁰ EUROPEAN COMMISSION, *Long-term care in the European Union*, 7, http://ec.europa.eu/employment_social/spsi/docs/social_protection/brochure_ltc_080924_en.pdf

²¹ EUROPEAN COMMISSION, *Review on preliminary national policy statements on health care and long-term care. Memorandum of the Social Protection Committee*, Brussels, European Commission, 2005, 16-18, http://ec.europa.eu/employment_social/spsi/docs/social_protection/spc_ltc_2005_en.pdf

may be complemented by an external evaluation which, however, does not replace the usual inspection procedures that are mainly focusing on residents' rights. The instrument assesses the strengths and weaknesses of six key areas of concern (ethical rules, in particular with respect to the rights and liberties of the residents; the satisfaction of implicit or explicit needs of residents, in particular of persons in need of care and their families; a better management of the organisation, in particular to guarantee sustainability ; the improvement of human resource management; the improvement of the image of residential care, based on an improved quality and a better management of financial costs that are linked to malfunctioning)²². In the Czech Republic for example the independent accreditation agency "United Accreditation Commission of the Czech Republic" (SAK CR) has evaluated the quality of the healthcare administered in hospitals²³. In Cyprus, a new legal framework has been developed in order to regulate home-care by voluntary organisations and private bodies, and to define models and standards, suggest quality improvements of long-term care services, and is based on national studies.²⁴

III.B.2. Authorisation and accreditation

As new private providers and/or new kinds of services have gained ground through privatisation, specific authorisation and accreditation mechanisms have developed in several countries (Czech Republic, France, Germany, Italy and the United Kingdom). A distinction can be made here between the accreditation of education and training institutions, professionals and service providers and the types of services that can be provided. Quality assurance is more systematically organised by targeting funding and making principles of organisation and reporting mandatory. Specific authorisation and accreditation is applicable in for example the United Kingdom, where all care services have to register, which involves inspection and some degree of checking if certain standards are met. However, there is no formal accreditation by a third party. Because of privatisation, new kinds of quality standards such as Key Lines of Regulatory Assessment (KLORA) were introduced in the United Kingdom because the existing registration and inspection arrangements were believed to be insufficient for residential and nursing homes.

In France, Italy, and the Czech Republic, only public subsidies or reimbursements are allocated to authorised and publicly controlled individual or collective providers when certain quality criteria are met.

In Italy the law from 2002 has developed standards for authorisation and accreditation in order to promote processes of continuous improvement in the areas of health and social services to ensure equal access and appropriate services. While authorised service providers

²² M. HUBER, M. MAUCHER and B. SAK, *Study on Social and Health Services of General Interest in the European Union*, Vienna/Brussels, European Centre for Social Welfare Policy and Research, ISS, CIRIEC, 2008, 301-305, www.euro.centre.org/data/1216816977_32580.pdf

²³ Strategic report on social protection and social inclusion, 2008-2010, Czech Republic, 53-55, 59-60, http://ec.europa.eu/employment_social/spsi/docs/social_inclusion/2008/nap/czech_en.pdf

²⁴ Strategic report on social protection and social inclusion, 2008-2010, Cyprus, 93-94, http://ec.europa.eu/employment_social/spsi/docs/social_inclusion/2008/nap/cyprus_en.pdf

may provide services to the public, accredited service providers are entitled to be contracted by public authorities namely the National Health Service and to receive reimbursements.²⁵

In the Czech Republic the standards of SAK CR (United Accreditation Commission) were accredited by the “International Society for Quality in Healthcare” (ISQua). However, no national accreditation system for the quality and safety of healthcare exists in the Czech Republic, the development of which is considered to be the number one concern in order to guarantee evaluation of healthcare quality outcomes and the smooth operation of European healthcare coordination.²⁶ In Spain the Law 39/2006 introduced the accreditation of centres, services and entities working in the field of personal autonomy and care for dependency to guarantee the right of people in a situation of dependency to receive quality services. Accreditation of the centres, services and non-chartered private entities providing services to people in a situation of dependency is obligatory under the Law if these people are to receive the financial benefit paid for receiving a service.²⁷

In the framework of national and EU competition regulations, each country will have to treat all providers (public, private, non-profit, commercial, international, national or local) equally by means of at least regionally or nationally identical authorisation and accreditation mechanisms. Generally, accreditation processes are based on a quality management approach. Consequently, accreditation requires structural quality criteria, mission statements, procedural specifications and expected output criteria from the organisation. As a result, special skills and knowledge of managerial staff (such as quality managers and accreditation officers) are needed for the involvement of both staff and other stakeholders. This implies that provider organisations have to invest in specialised training and guidance as for example in the Czech Republic or in Germany.

III.B.3. Mode of quality assessment and development

A. Quality control

Quality control is used to guarantee that all the activities necessary to design, develop and implement a product or service are effective and efficient with respect to the system and its performance. The quality of products and services can be controlled by means of inspection, quality assurance and the specification of minimum standards. The most common assessment tools of quality control used are internal and external control, self-regulation and check-lists.

In Belgium for example, the quality of the institution is controlled by approval standards and care providers/care persons are trained. Presently, the Walloon Region is creating a quality reference guide specifically for daytime facilities, day care centres, rest and care homes.

²⁵ M. HUBER, M. MAUCHER and B. SAK, *Study on Social and Health Services of General Interest in the European Union*, Vienna/Brussels, European Centre for Social Welfare Policy and Research, ISS, CIRIEC, 2008, 301-305, www.euro.centre.org/data/1216816977_32580.pdf

²⁶ Strategic report on social protection and social inclusion, 2008-2010, Czech Republic, 53-55, 59-60, http://ec.europa.eu/employment_social/spsi/docs/social_inclusion/2008/nap/czech_en.pdf

²⁷ Strategic report on social protection and social inclusion, 2008-2010, Spain, 83-85, http://ec.europa.eu/employment_social/spsi/docs/social_inclusion/2008/nap/spain_en.pdf

Furthermore, health and welfare institutions are directed by Flemish Government guidance to develop an internal policy on the basis of a quality manual for responsible assistance and consumer-centred services.²⁸

In Bulgaria, enhancement of the quality of long-term care is attained by reconstruction and improvement of the existing services, investment in new services, optimisation of the structure and capacity of the professional staff, and by being more effective in control and observation of the criteria and standards for provision of social services.²⁹

a) Monitoring systems

Monitoring systems of staff and hospital activity have to guarantee quality levels, promote informed policy in relation to the services or provide feedback to the various actors in the field of long-term care. Therefore, the development of better monitoring systems is vital to the improvement of quality measurement and control.

b) Inspection

The inspection of structural quality features by public authorities is the traditional and still most frequently found way of controlling social services. This includes criteria such as, for instance, square metres per child; quality of spaces to sleep, to eat, to play, hygiene measures in kitchen and bathrooms or criteria for quality of meals. In Cyprus for example the “Homes for the Elderly and Disabled Law” provides for compulsory registration and inspection in order to comply with the prescribed standards concerning hygiene and safety of premises, sanitation and buildings, staff qualifications. On the other hand, the “Centres for Adults Law” provides for the mandatory registration and inspection of the Centres responsible for day-care and home-care services to ensure that the Standards for Centres for Adults are met³⁰. In Malta, Government homes and long-term care facilities are subject to inspections comparable with those carried out in the private sector, coordinated by the Department of Health Care Services Standards. The aim of this quality improvement is the conversion of these government residential homes into nursing homes.³¹

In the United Kingdom specialised agencies were launched: - an independent “Commission for Social Care Inspection” (CSCI), which is responsible for the regulation of all care homes, private and voluntary health care, and a range of social care services in accordance with National Minimum Standards; A “General Social Care Council” (GSCC), which is responsible for raising professional and training standards for the social care workforce; -The “Social Care Institute for Excellence” (SCIE), which functions as a knowledge base and which promotes best practice in social care services and the “Training Organisation for Personal

²⁸ Strategic report on social protection and social inclusion, 2008-2010, Belgium, 67, http://ec.europa.eu/employment_social/spsi/docs/social_inclusion/2008/nap/belgium_en.pdf

²⁹ Strategic report on social protection and social inclusion, 2008-2010, Bulgaria, 73-75, http://ec.europa.eu/employment_social/spsi/docs/social_inclusion/2008/nap/bulgaria_en.pdf

³⁰ Strategic report on social protection and social inclusion, 2008-2010, Cyprus, 93-94, http://ec.europa.eu/employment_social/spsi/docs/social_inclusion/2008/nap/cyprus_en.pdf

³¹ Strategic report on social protection and social inclusion, 2008-2010, Malta, 66-67, http://ec.europa.eu/employment_social/spsi/docs/social_inclusion/2008/nap/malta_en.pdf

Social Services" (TOPSS, now "Skills for Care"), which is responsible for the improvement of both the quality and quantity of practice learning opportunities for social work students.³²

Through the reform in 2008 of the long-term care system in Germany, the number of quality controls has been increased so that from 2011 onwards, all long-term care institutions will be checked, in principle without prior notice, once a year. In particular, the long-term care situation of the patients and the effectiveness of the care measures will be monitored. As a result of this reform more transparency is achieved, so that good care can be more easily recognised. The results are made public (through internet etc., but summary results of the controls with quotes as 'very good' or 'problematic' also have to be published in the care institutions) so that people in need of long-term care can compare the quality of the services delivered.

c) Quality standards

It is important for long-term care services that quality standards are defined and improved in relation to infrastructure, staff and the way the services must be carried out. Consequently, variation in services across institutions or geographical areas can be reduced. As a result, appropriate long-term care can be guaranteed. In the Czech Republic National Quality Standards are defined in the Czech "Social Services Act 2006" and monitored by a social services inspection³³. In Latvia, quality standards are set and the responsibility of health professionals and of patients and care recipients is strengthened in order to guarantee quality in long-term care and to adapt care, including preventive care, to the changing needs of society and patients.³⁴ In Germany it has been agreed very recently that standards for experts based on the current medical scientific knowledge will be adopted, which will offer guidelines to the professional caregivers. Already in 2005, a Charter of rights of people in need of long-term care was accepted, which describes the rights of these people and contains internal quality principles.

d) Quality assurance

Quality assurance, however, is only of limited relevance in social services as it focuses on revealing errors and the enforcement of requirements, while more active quality management would try to plan, steer and monitor the quality of service to prevent errors and unintended effects of activities. In many Member States even this instrument of quality assurance has not yet been put into practice nation-wide.

³² M. HUBER, M. MAUCHER and B. SAK, *Study on Social and Health Services of General Interest in the European Union*, Vienna/Brussels, European Centre for Social Welfare Policy and Research, ISS, CIRIEC, 2008, 301-305, www.euro.centre.org/data/1216816977_32580.pdf; J. MALLEY, "Improving the quality of long-term care services in England", *Euro Observer* 2007, 7-8. Strategic report on social protection and social inclusion, 2008-2010, United Kingdom, 83-85, http://ec.europa.eu/employment_social/spsi/docs/social_inclusion/2008/nap/uk_en.pdf

³³ M. HUBER, M. MAUCHER and B. SAK, *Study on Social and Health Services of General Interest in the European Union*, Vienna/Brussels, European Centre for Social Welfare Policy and Research, ISS, CIRIEC, 2008, 301-305, www.euro.centre.org/data/1216816977_32580.pdf

³⁴ Strategic report on social protection and social inclusion, 2008-2010, Latvia, 74-75, http://ec.europa.eu/employment_social/spsi/docs/social_inclusion/2008/nap/latvia_en.pdf

In Germany, acceptance by the care institutions of internal quality measures is compulsory for concluding a contract with the Care Funds. In Austria, the pilot project “Quality assurance in the long-term care sector” and a follow-up project “Quality assurance in homecare” was launched. In the framework of these projects, certified staff with the specific expertise in home care and great competence in counselling visited people in their homes in order to collect data on concrete care situations by means of a standardised questionnaire and to support care-giving family members. This quality assurance approach became a standard service of the Federal Republic offered in an institutionalised framework and on a considerably larger scale.³⁵ In Poland, the most important instrument for quality assurance is mainly the structural national quality standards (for example fire-alarm system, escalators, trained staff). The Residential care institutions that do not meet these quality standards must work out an upgrading plan.³⁶ In Lithuania the Minister of Health approved the “Healthcare Quality Assurance Programme for 2005-2010” in order to ensure good quality of health and life of the country’s population, to shape a systemic approach towards the quality of healthcare, assurance and continuous improvement thereof and to coordinate activities in this area.³⁷

e) Self-regulation

Self-regulation of professionals is a regulatory model which enables the government to have some control over the practice of their profession and services. Other mechanisms of quality assurance can be added to this basic principle in the development of social services. Furthermore, “evidence-based” professional approaches are developed in order to improve general quality frameworks.

B. Quality management and models of excellence

Quality management is focused on the developing process to achieve quality of products and services, while models of excellence have the aim of continuous quality improvement. Quality management as well as models of excellence use internal quality management and third party certification as assessment tools. However, models of excellence also utilise other assessment tools such as social auditing and benchmarking. Examples of quality management are International Standards Organisation (EN ISO 9000ff.), Practical Quality Assurance System for Small Organisations (PQASSO) (United Kingdom) and sector specific HKZ (Netherlands), KTQ, MuQ, QUOFHI (Germany). In the Netherlands national legislation has recently defined standards and procedures on the quality of care institutions, which are based on quality management approaches and put special emphasis on the client perspective. Furthermore, policies to improve quality in long-term care strategically focus on supporting and training professionals working in this sector (“*Zorg voor beter*”) to integrate

³⁵ Strategic report on social protection and social inclusion, 2008-2010, Austria, 63-64, http://ec.europa.eu/employment_social/spsi/docs/social_inclusion/2008/nap/austria_en.pdf

³⁶ M. HUBER, M. MAUCHER and B. SAK, *Study on Social and Health Services of General Interest in the European Union*, Vienna/Brussels, European Centre for Social Welfare Policy and Research, ISS, CIRIEC, 2008, 301-305, www.euro.centre.org/data/1216816977_32580.pdf

³⁷ Strategic report on social protection and social inclusion, 2008-2010, Lithuania, 77-78, http://ec.europa.eu/employment_social/spsi/docs/social_inclusion/2008/nap/lithuania_en.pdf

care and housing in specific neighbourhoods, and to use technology to improve the efficacy of care interventions.³⁸

Furthermore, Total Quality Management (TQM), European Foundation for Quality Management (EFQM) and the sector specific E-Qalin (Austria, Germany, Italy, Luxembourg, Netherlands, Slovenia and the Czech Republic) are examples of models of excellence.

a) Certification by third parties

Certification by a third party is an assessment tool which can be used to increase competitive advantages in quasi-markets. This assessment tool is voluntary, presently not wide spread and mainly based on “classical” quality management systems such as the model of the European Foundation for Quality Management (EFQM) or the norms of the International Standards Organisation (ISO 9000 series). Moreover, because the third party certification was initially created for manufacturing and commerce, it needed to be adjusted to be applicable in the framework of social services.

b) Other sector-specific instruments

Service providers themselves are developing quality criteria, indicators or even standards between themselves on a European level or initiatives of specific sectors in order to introduce benchmarking on local, national and European levels. However, approaches based on quality management, models of excellence and benchmarking are slowly gaining ground in Europe. Nevertheless, in some countries (e.g. in the Netherlands and Germany) the ideas of quality management, an outcomes focus and stakeholder transparency have spread across government departments, the voluntary sector, and the funding and regulatory bodies. Still, in these countries, both public authorities and providers are in a pioneering phase in defining and analysing quality criteria regarding social services.

In Germany in order to ensure quality in the institutional environment, internal quality management is developed within care institutions, but at the same time essential external controls are created according to nationally uniform quality inspection guidelines. Furthermore, through the use of contracts between the long-term care insurers and the long-term care providers, the providers are primarily responsible for quality assurance (internal quality management/structure and process), whereas the long-term care insurers oversee the quality of the care provided in care institutions (deliverables/output) and hold sanction powers.³⁹

³⁸ M. HUBER, M. MAUCHER and B. SAK, *Study on Social and Health Services of General Interest in the European Union*, Vienna/Brussels, European Centre for Social Welfare Policy and Research, ISS, CIRIEC, 2008, 301-305, www.euro.centre.org/data/1216816977_32580.pdf

³⁹ EUROPEAN COMMISSION, Long-term care in the European Union, 22-23, http://ec.europa.eu/employment_social/news/2008/apr/long_term_care_en.pdf; Strategic report on social protection and social inclusion, 2008-2010, Germany, 105, http://ec.europa.eu/employment_social/spsi/docs/social_inclusion/2008/nap/germany_en.pdf

IV. Care Coordination

Care coordination is essential to guarantee a high level of quality in the care provided, an efficient use of resources and the tailored treatment care some users/patients might require. People needing long-term care indeed require a lot of services, which may be decided individually. Contrary to practice in the medical field, where needs are defined by diagnoses and medical practice rules determine how needs are to be met, the service needs of people needing care do not depend solely on diagnoses of the reason for their care need, i.e. the degree of care they need, but also on other factors, such as equipment and location of their home, the willingness to family members to help and their financial situation. Care provided to these persons should be multidimensional as a wide variety of professional categories are to be involved in the various services needed. As a result, coordination of care requires policies that help create patient-centred care that are more coherent both within and across care settings and over time. The services should be better adapted to the needs of individual patients and ensure they get suitable care for acute episodes as well as care focussed on stabilising their health over long periods in less costly environments (such as home).

In order to foresee and overcome obstacles, care coordination involves coordination between national, regional and local authorities and services. However, problems can arise due to the separate budgets used to finance diverse services, the organisation of service delivery and the many agencies involved in the health and social sectors. Care coordination is successful when the medical, nursing and social services fit together for the specific needs of individual users/patients. In order to achieve this, two elements are important namely the coordinated provision of services and better management of transfers between care settings (the home, hospital and nursing home). In different countries, national authorities are now introducing different kind of measures to make health and social services interact together more effectively.

IV.A. Evaluation of dependency

In a number of countries, health and social services are treated as a joint responsibility between health and social services. However, historically, health and social services have always been organised by different institutional actors, provided by different professionals, and even fragmented into specialised services. In most of the European countries the separation between health and social services causes problems in coordination of care packages for dependent people. From the perspective of long-term care at the European level, there is the need to provide legal or regulatory clarification and to establish rules that transcend these health versus social care boundaries. Recently, in some countries measures have been introduced in order to integrate health and social care services.

Almost all Member States apply a system in order to verify and evaluate the needs of a person making an appeal to long-term care. The only exception seems to be Norway, where there is no regular form of control and evaluation. Of course, this evaluation is carried out by

medical/professional experts, such as doctors, nurses and social workers. Some of the Member States have somehow institutionalised these tasks, by creating an official state-related body (e.g. the Netherlands, Bulgaria). On the other hand, some Member States have implemented a system of authorisation (Czech Republic, Poland, Spain).

Mostly, the indicators to be fulfilled, in order to obtain long-term care, are marked (in the abstract) as “...the person’s ability to carry out the activities of daily living”. Many of the Member States (e.g. France, Germany, Poland, Portugal, Romania, Slovakia, Spain, Switzerland) apply a (sometimes sophisticated) range of indicators and categories/classifications.

IV.B. Benefits package

MULTIDISCIPLINARY APPROACH (benefits in kind and/or in cash?)	ORGANISATION (choice of provider / spending / benefit)	MEMBER STATES
Only benefits in kind	Only state-run	/
	Only private institutions and/or informal caregivers	/
	Combination of both public and private institutions and caregivers	DK, EE, FR, IS, LV
Only benefits in cash	Freedom of choice regarding the spending of the allowances	BE
	No freedom of choice regarding the spending of the allowances	/
Combination of both benefits in cash and in kind	Possibility to choose and/or combine and/or substitute both types of benefits	CY, IE, LU, MT, NL, PL, RO, SK, SI, SE, CH, DE
	No possibility to choose and/or combine and/or substitute both types of benefits	BG, CZ, FI, GR, HU, IT, LT, NO, PT, ES, UK, AT, LI

Table 3: coverage and choices (benefits)

In order to meet the physical and financial difficulties related to the social risk of LTC, a Member State must develop a specified approach towards the providence of benefits. In the first place, this necessarily implies that the Member State has to opt for a certain type (nature) of benefit(s) (benefits in kind and/or in cash?).

Secondly, the question remains how the Member States will present the benefit to the persons entitled to LTC. If the Member State opts for the provision of benefits in kind, it

should either organise its own services (home care, [semi-] residential care, other services), or delegate the realisation of this legal duty to private and/or informal institutions, financed by the Member State's budget. Essential within this line of thinking is that beneficiaries have a claim to help in kind (material services), provided by the state or co-operative institutions. It is remarkable that none of the Member States only allow for allocation of benefits in kind, provided by only state-run or private institutions. The four Member States that only provide benefits in kind (namely Denmark, Estonia, Iceland and Latvia) do offer services through the combination of both public and private institutions.

- A good example is Estonia (EE): the global care system provides (only) for benefits in kind. Within the social assistance scheme, beneficiaries are entitled to (1) home care (e.g. cleaning and care of the housing, procurement of food, pharmaceuticals, other necessities and firewood or other fuel, information and assistance in administrative matters), (2) semi-residential care (e.g. day care centres), (3) residential care (e.g. nursing homes, old-age homes, housing for disabled and old-age) and/or (4) other benefits (e.g. technical appliances [incl. prosthesis] financed by the State and community based mental health services).

On the other side of the spectrum, there are the schemes that rely wholly on the provision of benefits in cash.

- There is only one example of this technique, namely the Belgian system (BE; Flemish region). The scheme (*zorgverzekering*) provides a fixed allowance, to spend freely by the beneficiary. Of course, the material care is provided by private service providers, or persons close to the recipient (informal caregiver).

Most Member States have implemented a combination of both benefits in cash and in kind, in most of the cases due to a differentiated approach within the statutory organisation (see table 1 p.7 - there is a perceptible correlation (86,67 %) between the disintegrated statutory organisation⁴⁰, and the provision of both benefits in kind and in cash). The existence of both types of benefits is mostly the result of a disintegrated system and spreading over several branches of social security (insurance) and/or public assistance. This may even lead to the impossibility of to choosing or substituting between benefits in cash or in kind.

- This may be explained by reference to the Norwegian (NO) LTC-approach. The system (provided piece-meal, mainly through health care legislation) focuses on benefits in kind, provided by formal caregivers (public and private sector), as well as informal caregivers (spouses, partners, parents). Besides the help in kind, there are (minimal) benefits in cash, such as the basic benefit and attendance benefit for disabled persons. Persons entitled to LTC have no option to chose and/or combine both types of benefits. The system also provides a cash benefit for the informal carer, paid by the municipality.

⁴⁰ Meaning that a Member State's system lacks a unified/central legislation exclusively related to the risk of LTC, and only provides for piece-meal arrangements through different branches (social insurance and/or social assistance).

Not all Member States prevent the freedom of choice to combine, mix and/or substitute multiple kinds of benefits.

- The Netherlands (NL) is familiar with a global care system (social security and health care), which provides both benefits in kind and in cash. Although the legislation basically provides for benefits in kind, the insured person can opt not to obtain care provision in kind, but to receive a personal care budget to enable him/her to purchase care independently.
- In Germany (DE), people can freely choose between benefits in kind and cash benefits. Benefits in kind can be obtained from ambulatory or institutional care institutions or care providers that have concluded a contract with the Care Funds. In case the person in need decides to look for the necessary care him- or herself, s/he can receive cash benefits that s/he can freely spend in the way which is most appropriate. A combination of benefits in kind and cash benefits is also possible.

IV.C. Benefits provision

In all countries, patients receive help with activities of daily living (together with lower-level care) from formal providers or informal providers. All the Member States - except for Hungary - seem to be familiar with both informal and formal care. In Switzerland and in Germany, informal care is not allowed when it comes to medical treatment.

Regarding professional providers, most of the Member States acknowledge the provision of services by (1) state institutions, (2) private sector (sometimes contracting with municipalities), and/or (3) non-governmental organisations. A combination of these three kinds of service providers is widespread. Some individual Member States limit the possibilities within this field to only one type (e.g. Italy where only the state provides services, next to informal caregivers).

In certain countries, long-term care is increasingly considered as one aspect of a broader 'integrated' approach, including preventive measures, active ageing, social assistance, promotion of autonomy, health care and end-of-life care. In order to ensure this integrated care provision of services, in some countries, national strategies and priorities have been launched. Normally, long-term care is delegated and handled by sub-national levels of government (Germany, Spain, Sweden, United Kingdom). By means of framework contracts, as in Germany, similar objectives can be achieved between long-term care insurers and providers. Integration of long-term care provision can be attained through single entry points or local assessment teams on the one hand (Germany, Netherlands, United Kingdom) or through the decentralisation and integration of services at regional and local levels (Spain, Sweden, United Kingdom), on the other hand. Several countries are in the process of arranging (Hungary, Latvia, Malta, Poland) or have arranged (Belgium, Germany, Spain, Finland) integrated long-term care provisions.

In the Netherlands, for example, within the field of long-term care, the need for integration of services and the necessities to cope with increasingly complex clients with multiple care

needs has been discussed. One of the means to provide integrated care is to share services, or even for organisations to merge. The integration of services has resulted in a wave of mergers between home-care providers, between home-care providers and institutional care (patients homes, nursing homes) providers, as well as between institutional providers themselves.

Also in Portugal, there has been a far reaching reform of the long-term care system. Through a wide range of multidisciplinary services, integrated care is provided: 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. The created network will encourage continuity between community-based care, hospital care for acute patients and social support, complementing primary care and specialised hospital care. Flexibility allows the system to be adapted to different needs around the country.⁴¹ A similar system of integrated care also exists in Germany.

IV.D. Case or care management

Case or care management is a comprehensive and systematic process of assessing, planning, arranging, coordinating and monitoring multiple long-term care services for the individual client across time, setting and discipline. The methods used are focussed on the needs and demands of the patient. In some European countries the phenomenon of case or care management is well-known as for instance in the Netherlands, the United Kingdom, Germany, Austria, Italy, France and the Nordic countries.⁴² It is seen as a mechanism for linking and coordinating segments of a service delivery system to ensure the most comprehensive programme for meeting an individual's needs for care.

Case or care management activities are performed by an individual case or care manager, or by a team of health and social service professionals. It is also undertaken in a variety of organisational environments (e.g. in a freestanding local or regional entity with formal or informal responsibilities for 'brokering' long-term care services; an insurer or other funding agency; a provider institution like a home care organisation, medical clinic or hospital; or supportive housing).

The case or care management function can stand alone, or can be bundled with other administrative and client management activities as, for example, when it is part of a "chain of care".⁴³ Care coordination is seen as crucial in enabling a high level of quality and an efficient use of resources in the provision of long-term care services in an institutional or community setting, thus permitting an adequate continuum of care irrespectively of the different levels of long-term care provision (local, regional, national) and organisation. It is

⁴¹ EUROPEAN COMMISSION, *Long-term care in the European Union*, http://ec.europa.eu/employment_social/news/2008/apr/long_term_care_en.pdf

⁴² K. LEICHSENTRING, "Developing integrated health and social care services for older persons in Europe", *International Journal of Integrated Care* 2004, 6-7.

⁴³ The role of informal support in long-term care, *Joshua Wiener*

often the role of the service providers to assess the individual needs and provide holistic services based on each individual needs assessment and offer coordinated, tailored and a patient specific continuum of care. It is reasonable to argue that there is no model for the provision of a continuum of care since each patient will require an individualised provision that should be tailored according to his/her needs. Care coordination is crucial in the provision of a care continuum for individual patients and aims to promote a uniform and coordinated provision of services.⁴⁴

Case or care management has three main aims namely improving client utilisation of support and services, developing the capacity of social networks and services to promote client well-being; and promoting service effectiveness and efficiency.⁴⁵ It is concerned with providing services to a specific target group and need not be seen as the mechanism for providing all forms of care for those who need assistance in coping with everyday living.⁴⁶ It is designed not just to influence care at the individual client level, but also at the system level through the aggregate of a myriad of care decisions at the individual client level which exert pressure for change upon patterns of provision themselves. An underlying objective is to render those patterns of services more relevant to individual needs.

Case or care management has been located in a variety of different settings. These settings include social service departments/units, hospitals, geriatric and psychiatric multidisciplinary teams, primary care, independent agencies, and even independent actors. It differs country by country. Effective implementation of case or care management will need to identify appropriate settings to provide case or care management for individuals with different kinds of needs.

Furthermore, some implementations of care or case management sometimes appear to consider the core tasks more as administrative activities (involving mainly brokerage and service allocation) rather than integrating these with tasks such as support and counselling (requiring staff with human relations skills). Another approach has involved some staff defined as having different jobs for different clients, for example as social worker for some and care manager for others.

In order to maintain continuity of responsibility throughout all the phases of a client's "career" with the service, case or care managers could be made responsible for continued monitoring and review after entry to institutional care.

In various countries health and social welfare systems are separate institutional entities making it more difficult to move people between systems and to ensure a continuous and integral patient follow-up. This has negative implications for access as well as quality. Better care coordination in general is expected to have positive effects on care quality and financial

⁴⁴ The OECD Health Project, Long-term Care for Older People, OECD 2005

⁴⁵ *David Challis Preface: Achieving coordinated and integrated care among LTC services: the role of care management* 145

⁴⁶ *David Challis Preface: Achieving coordinated and integrated care among LTC services: the role of care management* 147

sustainability, as it avoids overuse / unnecessary care, in particular the doubling of procedures.⁴⁷

A wide variety of initiatives have been undertaken in the Member States to promote care coordination. A large number of Member States draw attention to the importance of patients registering with a GP / family doctor who functions as their first point of access to the services. The family doctor can provide patients with preventive and curative care and serves as a professional guide to the patient referring him/her to other (correct) types of care, determining the number of places the patient has to appear and the order of appearance. This ensures the use of a coherent path of care via a GP referral system.

In Belgium the personalised patient-centred care has been established. Many alternatives are available for long-term patients, but for lack of information or coordination, they do not always benefit from the most appropriate supply of care and services. In this sense, approved institutions referred to as "Integrated Service for Care at Home" (*Service Intégré de Soins à Domicile* - (ISD)), organise multidisciplinary concertation in a care zone around a person who needs complex care. This multidisciplinary concertation gives a concrete assessment of the patient's autonomy in the context of care at home, develops and monitors a care plan and breaks down the various tasks between professional care providers in different disciplines and those providing aid. In addition, in the Walloon Region, home care and service coordination centres have the job of ensuring the best combination of healthcare in the narrow sense of the word, and services needed to keep dependent persons at home (housekeeping, family, social services etc.).

With the introduction of so-called "points of care support" in Germany, people in need are entitled to individual comprehensive advice, based on care management. These points of care support guide the persons concerned through all available services.

In model regions in Austria the recipients of long-term care benefits granted under the Federal Act are sent a voucher for free qualified counselling by certified nursing professionals together with the administrative decision regarding their entitlement to long-term care benefit or the application receipt. In the Länder registered inhabitants are informed about the range of social services as well as long-term care benefits in the framework of a home visiting service. Furthermore, upon applying for care services (home help, meals on wheels, etc.) those in need of care and their relatives are provided comprehensive counselling in a case-management framework in counselling centres for care and support at home. An internet platform for care-giving family members was set up in August 2006 to meet the requirement of providing comprehensive information to help carers in their every-day lives. Careproviding relatives are informed about long-term care benefits, social and labour law provisions concerning carers, mobile social services, technical aids for care, therapies at home, courses and self-help groups, financial benefits as well as institutional further care. They are also kept up-to-date on offers to ease the strain on carers, e.g. holidays for caregiving family members, temporary care and financial aid to support care-giving relatives⁴⁸.

⁴⁷ SPC Health care & LTC review, final, 30 Nov. 2005 15

⁴⁸ http://ec.europa.eu/employment_social/spsi/docs/social_inclusion/2008/nap/austria_en.pdf

In Latvia the social service workers of the local governments receive information from family doctors and assess the case in correlation with other documents testifying to the necessity of the social service. In case of necessity team meetings are held between various specialists to decide jointly with health care specialists on a service provision as well as in which sequence the services should better be provided in order to achieve the best possible result.