interlinks

Health systems and long-term care for older people in Europe
Modelling the interfaces and links between
prevention, rehabilitation, quality of services and informal care

Work Package 6

Governance and finance of long-term care across Europe

Overview report (DRAFT)

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1 Background

Faced with a series of demographic, social and technological changes, countries across Europe have found themselves trying to respond to a series of long-term care (LTC) challenges, including:

- Responding to increased numbers of frail older people and older people with dementia, while maintaining the quality of services
- Ensuring equal access to appropriate services
- Changes in social/family structures (often reducing the availability of informal care)
- Co-ordination of the different policy areas, governance levels, agencies and professionals that are involved in the delivery of LTC services
- Rising public expectations and the need to improve and assure quality
- Financial sustainability (in a difficult economic context but also long-term)
- Staff recruitment and retention
- The need to develop more preventative and rehabilitative approaches

Against this background, this report focuses on the governance and financial responses to such issues, seeking to identify key themes across different European countries and to draw out the key lessons learned.

Although different countries have responded in different ways, there have been a number of broad trends explored in more detail in the main body of this report:

- Growing recognition of the importance of LTC and of rising needs and costs
- Increased use of market mechanisms to try to contain costs, improve access, quality, effectiveness and value for money
- Increased decentralisation to move services (and decision-making processes) closer to the people using them (and perhaps to pass funding responsibilities from national to regional or local levels)
- Growing recognition of the support provided by informal carers and the need to do more to support carers in this role
- Empowering service users and their relatives (informal carers), increasing their purchasing power and choice options, and involving them in governance
- Institution-building in the sense of establishing organisations/agencies with explicit tasks in LTC regulation, planning, monitoring and/or delivering.

Key definitions

In exploring the governance and financing of LTC, this report adopts a basic working definition provided by Hodges et al. (1996: 7), who see the term 'governance' as relating to:

> *The procedures associated with the decision-making, performance and control of organisations, with providing structures to give overall direction to the organisation and to satisfy reasonable expectations of accountability to those outside it.*

This seems particularly useful given the emphasis on accountability to those 'outside' the individual organisation – which might be a helpful starting point given the whole systems focus of INTERLINKS (see also Section 2 of this report for further discussion of key concepts).

In line with all INTERLINKS outputs, this report defines and conceptualises LTC as a range of services for people who have ongoing care needs related to the activities of daily living, due to chronic conditions of physical or mental disability. Such services include assistance with everyday activities of household management, self-management, transport and social activities, as well as more intensive personal care such as bathing, dressing and mobility. LTC is seen as encompassing both informal and formal support systems, with informal care accounting for the majority of LTC activity. Formal services include a range of community-based provision, such as public health, primary health care, home care, rehabilitation services and palliative care, as well as residential care, nursing homes and hospices. It also refers to treatments that halt or reverse the course of disease, disability and long-term conditions. Throughout the focus is on older people aged 65 or over and their families/informal carers – although we recognise that there are inevitable overlaps in some countries with the issues facing services for adults of working age.

When seeking to examine the interaction of different health and social care services, Hudson et al. (1997) have identified a series of barriers and success factors for whole systems governance approaches relevant to LTC (see Figure 1).

Figure 1 Summary of key barriers/success factors (Hudson et al., 1997)

Barriers to inter-agency collaboration include:

- **Structural barriers** (fragmentation of responsibilities across agency boundaries, within/between sectors).
- **Procedural barriers** (differences in planning horizons and cycles; differences in budgetary cycles and procedures; differences in information systems and protocols regarding confidentiality and access).
- **Financial barriers** (differences in funding mechanisms/bases; differences in the stocks/flows of resources).
- **Professional barriers** (professional self-interest and autonomy and inter-professional competition for domains; competitive ideologies and values; threats to job security; conflicting views about clients/consumers' interests and roles).
- **Status and legitimacy barriers** (organisational self-interest and autonomy and inter-organisational competition for domains; differences in legitimacy between elected and appointed agencies).

Principles for strengthening strategic approaches to collaboration include:

- **Shared vision** (specifying what is to be achieved in terms of user-centred goals; clarifying the purpose of collaboration as a mechanism for achieving such goals; and mobilising commitment around goals, outcomes and mechanisms).

- **Clarity of roles and responsibilities** (specifying and agreeing 'who does what', and designing organisational arrangements by which roles and responsibilities are to be fulfilled).
- **Appropriate incentives and rewards** (promoting organisational behaviour consistent with agreed goals/responsibilities, harnessing organisational self-interest to collective goals).
- **Accountability for joint working** (monitoring achievements in relation to the stated vision; holding individuals and agencies to account for the fulfilment of pre-determined roles and responsibilities; and providing feedback and review of vision, responsibilities, incentives and their inter-relationship).

1.1 Methods

This overview report is based on data from three main sources:

- Inclusion of several *key questions* relating to contextual, governance and financial issues into the work undertaken in previous INTERLINKS reports on prevention and rehabilitation, quality and informal care (Kümpers et al. 2010, Nies et al. 2010, Triantafillou et al. 2010). These focused on mechanisms used to embed good practice in everyday practice.
- A brie*f review of existing European overviews* and projects to ensure wherever possible that we build on existing data and frameworks (see Appendix 1).
- Production of *short national reports* exploring key issues of context, governance and finance in Austria (AT), Denmark (DK), England (EN), Finland (FI), France (FR), Germany (DE), Greece (EL), the Netherlands (NL), Slovakia (SK), Sweden (SE) and Switzerland (CH) (building on the Hudson et al. framework set out in Figure 1).

1.2 Structure

After this brief introduction, Section 2 explores key concepts in more detail, while Section 3 examines the key issues, contextual factors and key stakeholders influencing the delivery of LTC in different countries. After this, Section 4 investigates three key governance mechanisms identified by analysis of the national reports:

- Using market mechanisms to stimulate greater choice and competition while at the same time ensuring sufficient collaboration and an ability to take a whole system approach.
- The different tasks and functions that need to be performed at different national, regional and local levels.
- The contributions made by both formal and informal spheres of care (including how best to support family carers, to develop an approach based on partnership or co-provision and to recognise the contribution made by migrant workers).

Section 5 explores issues of funding and financial sustainability, addressing the different financial mechanisms being used to steer and develop LTC. Section 6 then draws together key conclusions and lessons learned, with more detailed national examples provided in Appendix 3.

2 Key concepts for the governance and finance of LTC

2.1 Key definitions and frameworks

The primary working definition of LTC used in this report, in line with Hodges et al. (1996: 7), is outlined in Section 1. Stemming from the economic sector, governance as a term was adopted by social and political sciences in the 1970s and has since undergone a marked rise in usage: 'Good governance' was determined in 1992 by the World Bank as a criterion for the granting of loans to developing countries. In 2001, the European Commission defined in its 'White Paper on European Governance' that this refers to the rules, processes and behaviour affecting the way in which powers are exercised at European level, particularly as regards openness, participation, accountability, effectiveness and coherence.

Generally speaking, governance comprises the processes and systems by which an organisation or a society operates, but the concept is not set univocally. Governance can rely on different tools: central planning for how to supply specific demand is based on hierarchy and is accomplished by the state or non-profit agencies and market competition is based on decentralized action and involves for-profit companies. In practice, in particular with respect to health and welfare systems, mixed approaches have entered the scene as governance in these sectors and imply "that private actors are involved in decision-making in order to provide common goods and that non-hierarchical means of guidance are employed" (Héritier, 2002).

Over the past decade the term governance has thus been used mainly to characterise non-hierarchical, non-centralised forms of coordination, which involve public and private, governmental and non-governmental organisations in the production of publically provided goods. Some authors have coined the functioning of networks involving public-private partnerships and civil society as 'co-governance', while others have proposed to reserve the term 'governance' for horizontal forms of coordination in which the state is not involved at all (Schuppert, 2008: 19).

In this report on governance in the realm of LTC for older people we assume a conception of governance in which the public, private and third sectors, as well as households have shaped specific 'welfare mixes' according to national, political and cultural characteristics or 'pathways' (Esping-Andersen, 1990; Evers, 2005). However, as we shall see, governance of LTC has only partly been influenced by traditional welfare regime types, in particular when it comes to characterise the 'familistic welfare systems' of the Mediterranean countries (Strohmeier Navarro Smith, 2010: 279) or Central and Eastern European transition economies.

Governance theory assumes that the state, market-oriented actors and civil society are working together in order to solve collective problems. It thus also assumes implicitly that the collaboration between the stakeholders serves the common interest (Mayntz, 2008: 54) to plan, provide and control public services. As a meta-actor, however, it is the state that provides the rules which determine the modes of collaboration between the various agents involved – with the ideal-type result that the traditional intervention state is being replace by an 'enabling' state (Dingeldey, 2008: 318ff.).

2.2 Governance in emerging long-term care systems

In public welfare policies and in the context of 'new public management' approaches we have seen a general trend towards increasingly market-oriented governance mechanisms accompanied by decentralisation and the multiplication of actors (Nies et al., 2010; Kazepov, 2010). In most countries this has involved the substitution of public providers by private service provision or at least a stricter purchaser-provider split within public authorities and the emergence of new types of providers (for-profit or non-profit) to complement public provision. In theory, the enhanced division of roles between public and private actors should enhance the problem solving capacity of the supply system and improve quality by means of competition between providers. However, this expectation has only shown scarce evidence over the past 20 years (Börzel, 2010: 10; Leichsenring et al., 2011).

With a view to the governance of emerging LTC systems and their link to health systems it has been argued that market-mechanisms might exacerbate or even endanger networking, coordination or integration of service provision as an integral characteristic of LTC quality (Nies et al., 2010; Billings and Leichsenring, 2005; Leutz, 1999; Kodner, 2002). Models to improve the provision of LTC according to the principle of integration are still being developed and cover a broad range of integration aspects, such as shared information among professionals from different sectors, standardised communication formats, single access points or defined multi-disciplinary pathways of care. Similar aims have been defined within health care systems, where so-called 'managed care models' are addressing existing gaps between financial aspects and inefficient delivery of services. Being derived from a management approach, they aim for the application of principles and techniques including risk sharing between the providers and financers of primary and secondary care, selective contracting with service providers and increased beneficiary cost sharing. Their overall aim is to efficiently steer the costs of providing health benefits and improve the quality of health care (Amelung et al., 2009: 5). However, while Health Maintenance Organisations (HMO) in the US or similar approaches in Canada (Fleury, 2002, Tourigny et al., 2002) are offering a complete continuum of services with a health maintenance approach, in Europe the impact of managed care on LTC has hitherto been restricted.

Models of integrated LTC thus seek to close the traditional division between health and social care and focus on stated goals of public policy, i.e. by aiming at sustaining and promoting the autonomy of the older persons in order to delay, or avoid nursing home placement (Egger, 2007: 10). Different forms of integration are often described as steps on a continuum going through linkage, coordination, networking and cooperation from a full segregation to a full integration (Leutz, 1999; Nies, 2004).

Such pathways towards complex, dynamic integrated models are demanding solutions by and involvement of all actors involved, be it from the public or private sphere. Therefore different models of steering supply and demand can also be found side by side in LTC provision; depending on the circumstances, one party may take the lead in a specific case and leave it to another under different conditions (Kooiman, 2005: 162), thus creating different 'governance mixes' (Schuppert, 2008) when it comes to the coordination of health and social care services.

The empirical findings from differences in country-specific governance models, actors and mechanisms will be illustrated in detail in the following chapters, with a specific focus on the governance of networking, coordination and integration between loosely coupled LTC and health systems.

3 Key issues, contextual factors and the role of stakeholders

It is not the task of this report to repeat demographic developments and the common process of population ageing in Europe.[1] While all countries participating in INTERLINKS are reporting that the share of the population aged 80+ is the fastest growing segment in their population (Huber et al., 2009: 27), we may take for granted that LTC needs are growing everywhere. However, the extent of growth and the way in which societies are dealing with related challenges are not an automatic process. The different approaches that will be discussed in this report, how governments deal (or do not deal) with the challenges linked to increasing care-needs, should be interpreted on the basis of key issues that are both the result of (past) governance approaches and the levers that future approaches may use to further develop LTC systems. At the same time, these approaches are influenced by contextual variables showing national characteristics, path-dependencies and legacies in health and welfare politics. Such information is provided in this Section by means of comparative tables focusing on selected indicators, in particular:

- Assessment and access to LTC benefits and services
- National expenditures on LTC
- Coverage and availability of services (service mix)
- General political structures and welfare regimes
- Selected indicators on values, user expectations and family ethics

3.1 Different definitions of LTC

The broad range of LTC needs implies significant discretion for assessment and the definition of eligibility criteria. These definitions thus become an important lever for including or excluding entire groups of people with care needs from access to benefits and services. For instance, it is well known that many assessment tools have focused mainly on physical disabilities. However, with a growing share of older people with cognitive impairments, eligibility criteria have been amended accordingly in many countries. Still, many national schemes contain clearly defined exclusion criteria, for instance:

- In Germany, where specialised medical doctors or nurses are carrying out the assessment, people with care needs of less than 50 hours per month are not eligible for benefits from the LTC Insurance.
- In Austria, the threshold for receiving the LTC allowance has recently been increased to 60 hours of care needs per month. Also in Austria specialised medical doctors and nurses undertake the assessment. This approach has also been adopted in Slovakia, thus showing that defining LTC needs always includes a political or governance aspect, rather than purely objective facts.
- Although scientific studies and pilot projects had originally been carried out to define LTC needs, for instance in France, ample discretion remains when it comes to individual needs assessment.

As a result of these differences, the share of older people with potential LTC needs (either assessed and approved according to the national definitions or estimated according to SHARE and EU-SILC)[2] in the

[1] See http://epp.eurostat.ec.europa.eu/statistics_explained/index.php/Population_projections.
[2] See European Commission/DG ECFIN, 2009: 133-138.

population varies significantly between Member States, ranging from 2.4% in the Netherlands to 5.2% in Finland (Table 3.1). These differences can only partly be explained by higher proportions of older people in the population, for the share of people with potential LTC needs also varies greatly, from 16.2% in Greece and the Netherlands to around a third of the old-age population in the Slovak Republic, Finland and the UK. Differences in disability rates among European countries may reflect national variations in reporting, response rates, variations in lifestyles and socio-economic standards among countries, or differences in health behaviour risk factors. These differences are widely recognised and literature recommends caution in the cross-country analysis of these varying disability rates (see Avendano & Mackenbach, 2008; Hairi et al., 2008).

Table 3.1 Share of older people with potential LTC needs in total population (around 2008)

Country	Population 65+ with potential LTC needs based on disability rates or according to national eligibility criteria		
	n.	% of total population	% of 65+ population
CH	n/a	n/a	n/a
DK	164,000	3.0%	19.4%
DE	3,201,000	3.9%	19.5%
EL	338,000	3.0%	16.2%
ES	1.728,000	3.9%	23.1%
FR	2,263,000	3.6%	22.3%
IT	2,515,000	4.3%	21.2%
NL	387,000	2.4%	16.2%
AT (1)	360,000	4.4%	25.4%
SI	76,000	3.8%	23.8%
SK (1) (2)	87,000	1.6%	13.1%
FI	274,000	5.2%	31.4%
SE (1)	497,000	3.4%	19.6%
UK	3,094,000	5.0%	33.1%

Source: European Commission/DG ECFIN, 2009: 138; Eurostat; Confédération Suisse, 2011.– Notes: (1) own calculations based on national data; (2) people 60+, cared for more than 8 hours per day.

3.2 Different levels of resources spent

The huge differences between Member States in total spending on LTC that are exhibited in Table 3.2 can be explained by various aspects:

- First and foremost, LTC expenditures are not an individual budget line in any country; national, regional and local budgets are often involved.

- Secondly, at all levels there are various health and social care related expenditures to be considered. These are often overlapping and paid by different levels and agencies. In many cases these expenditures are reported as part of the national health accounting (OECD), but they are not always integrated with social care expenditures. In addition, it is not always clearly stated, whether social care expenditure includes services and benefits for people with disabilities at working age, as well as older people.
- Thirdly, the difficulties in data collection lead to delays, so that data are often out-dated. The following data are thus to be taken as indicative rather than absolute, and comparative interpretations should be understood with caution.

In spite of these general difficulties with data to exactly delineate expenditures for LTC, Table 3.2 shows some general trends and clusters of countries with an already elevated share of LTC expenditures in the GDP (NL, SE, DK), countries with an average expenditure around 1 to 1.3% (AT, DE, FR, UK, FI, CH) and countries with a share of less than 0.5% (ES before the introduction of the LTC legislation, SK as an example for most Eastern European Countries).[3]

Table 3.2 also shows how governments have implemented the various options for public spending on LTC. The global policy objective to support "care at home, rather than institutional care" is hardly reflected by these data – with the exception of Denmark all countries spend the larger part of budgets on residential care.

[3] For further details on data limitations and general trends in expenditure see Section 5.

Table 3.2 Total public expenditure on LTC and its distribution between home care and residential care (around 2008)

Country	Total expenditure as a percentage of GDP	Residential care (in % of total expenditure)	Home care (in % of total expenditure)	Cash benefits (in % of total expenditure)
CH (5)	1.0%	73.9%	26.1%	(0.7%)
DK	2.7%	26.7%	73.3%	-
DE	0.9%	57.7%	17.8%	24.4%
EL	-	-	-	-
ES	0.3%	59.0%	27.0%	13.9%
FR (4)	1.2%	57.4%	42.6%	
IT	1.7%	26.2%	31.7%	42.1%
NL	3.6%	-	-	-
AT (1)	1.3%	42.7%	57.3%	
SI (5)	0.8%	25.7%	74.3%	(27.5%)
SK (2)	0.5%	69.0%	4.9%	26.1%
FI (3)	1.8%	69.0%	31.0%	-
SE	3.9%	58.7%	38.1%	3.3%
UK	1.2%	47.4%	24.2%	28.5%

Source: Huber et al., 2009: 99; Office Fédéral des Assurances Sociales (OFAS), 2006; WP6 National Reports; own calculations. Notes: (1) The Austrian LTC allowance is used by beneficiaries to also pay for residential care (about 20% of recipients) or home care services (about 25%) – or for informal care arrangements with migrant carers (about 10%) it is thus difficult to distinguish exact shares of expenditures. (2) 60+ population; (3) National Report Finland; (4) Without specific surveys it is currently not possible to delineate the share of beneficiaries who choose services in-kind and those who choose purely cash benefits; (5) Due to differences in sources only residential care and home care add up to 100%.

3.3 Different levels of service provision

Expenditure alone does not provide the full picture of provision within LTC services. However, data on the number of users of individual services and/or residential care are even more difficult to obtain, particularly for home care services. It is almost impossible to establish the number of beneficiaries/users who will receive one or more services. This is in part due to the services often being distributed from a number of different providers. Furthermore, data do not reflect the amount of service hours received by individual users, though it must be assumed that, in most cases, formal home care has to be backed up

by informal or family carers. Table 3.3 shows some estimates that provide an impression of the proportion of older people in need of LTC with support by formal services in residential or home care.

For the purpose of comparative policy analysis and to inform decision-making it would be helpful to contrast the above figures on the beneficiaries of formal care with sound estimates of older people in need of care, so as to gauge of the relative importance of informal care. For example, taking the figures of the European Commission/DG ECFIN (2009) for Germany, there would be approximately 3.2 million dependent older people, of which only half receive some kind of formal care. As shown by Table 3.4 however, different sources often provide quite dissimilar portraits of LTC in Europe, which means that the number of those benefiting from formal care may surpass the estimated number of people in need of care. This is the case for Denmark, Malta, the Netherlands, Sweden and Norway for European Commission's own estimates (see European Commission/DG ECFIN, 2009: Table 33). More precise data on the beneficiaries of LTC, together with data on public expenditure, is therefore needed for most European countries.

Table 3.3 Share and ratio of older people (65+) in residential and home care

	Formal care		
Country	In residential care (a)	Supported by care services at home (b) (1)	Ratio of residential and home care (a)/(a+b)
CH	6.6%	11.5%	36.4%
DK	4.6%	17.0%	21.3%
DE	3.4%	6.3%	35.3%
EL	3.7%	7.9%	31.8%
ES (5)	4.1%	4.2%	49.4%
FR (3)	5.3%	9.2%	36.7%
IT	1.4%	3.0%	31.5%
NL	5.2%	21.1%	19.8%
AT (2) (3)	3.3%	14.4%	18.7%
SI (5)	4.0%	9.0%	30.9%
SK (3) (5)	1.7%	2.3%	42.9%
FI	5.7%	16.5%	25.5%
SE (2)	6.0%	9.7%	38.3%
UK (4)	3.3%	12.7%	20.6%

Source: based on Huber et al., 2009: Table 5.1; European Commission/DG ECFIN, 2009: 138; Eurostat; own calculations. - Notes: (1) data are partly influenced by the fact that people using two or more services may have been counted several times; (2) own calculations based on national sources (AT, SE) and estimates; (3) population 60+; (4) data refers to England only; (5) data may include 0-64 users.

The levers to regulate the availability and the utilization of services consist of legal regulation and economic (dis)incentives. For instance, in Denmark the construction of new institutions was legally banned during the 1990s so that residential care in this country mainly means 'service housing'. Public

administration may also decide on purely public provision or on promoting the market-entry of new providers. The latter has been experienced in particular in countries such as England, Sweden and Germany, but also partly in Finland, the Netherlands or Italy, mainly by means of competitive tendering and/or the creation of quasi-markets. Other steering mechanisms concerning the market-entry of new providers include authorisation or accreditation rules and other quality thresholds, but also inspection and enforcement procedures (see Nies et al., 2010).

Furthermore, public administration may use prices (free market vs. fixed prices) and costing (out-of-pocket contributions of users) to steer the 'long-term care market'. For instance, user contributions in residential care (see Huber et al., 2009: 121) can range from less than 20% of an average wage (FI) to 80% (NL) or even more in countries where no maximum amount has been set (AT). For home care even more diverse regulations can be observed. These characteristics are in stark contrast to regulations in health care where user contributions are still an exception (in particular in primary health care) or much more restricted.

Table 3.4 Comparison of the absolute numbers of beneficiaries of LTC according to different sources

	European Commission, 2009	*Huber et al., 2009*	
	n. (2007)	*n.*	*Year*
CH	n/a	222,366	2005
DK	171,000	248,887	2007
DE	1,589,000	1,667,988	2006
EL	239,000	n/a	n/a
ES	362,000	604,671	2006 (1)
FR	1,505,000	1,078,000	2007 (2)
IT	524,000	537,550	2005
NL	622,000	644,580	2006
AT	185,000	321,231	2006 (2)
SI	24,000	42,655	2007 (1)
SK	31,000	34,808	2005 (1) (2)
FI	107,000	186,647	2006
SE	318,000	248,955	2007
UK	1,352,000	1,291,000	2008 (3)

Source: based on Huber et al. 2009: table 5.1; European Commission/DG ECFIN, 2009: 138; Eurostat; own calculations. - Notes: (1) data may include 0-64 users; (2) population 60+; (3) data refers to England only.

The number of people employed in the formal sector of LTC also provides important contextual information about the nature of LTC systems, as well as their potential for the creation of jobs. Despite some comparability issues (see notes on Table 3.5), data presented in Table 3.5 depicts the contrasting strategies followed by countries in the provision of LTC. Thus, countries with a higher level of provision of formal LTC services have a higher share of their 15-64 population employed in the formal care sector, e.g. Sweden and Denmark. Countries that rely more heavily on informal care or that provide public

support to older people mainly through cash benefits have created much less jobs in the formal care sector, e.g. Slovak Republic or Austria.

Table 3.5 Number of people employed in the formal LTC sector as a share of the labour force (population aged 15-64)

	n.	*Year*	*Share of the 15-64 population*
CH	95,368	2008	1.81%
DK	79,961	2007	2.22%
DE	594,616	2007	1.09%
EL	n/a	n/a	n/a
ES (1)	10,856	2006	0.04%
FR (2)	863,000	2003/2008	2.12%
IT (3)	125,717	2003	0.33%
NL (4)	100,000	2005	0.91%
AT (5)	55,000	2006	0.98%
SI	n/a	n/a	n/a
SK	10,573	2008	0.27%
FI	n/a	n/a	n/a
SE (6)	254,800	2005	4.32%
UK (7)	92,133	2001	0.28%

Source: based on Fujisawa & Colombo, 2008: Table 1; Marquier, 2010; Tugores, 2005; SALAR, 2007; BMASK, 2008; Eurostat and OECD Health Data 2010.- Notes: (1) data refer to nurses in institutions; (2) data refer to workers employed in Établissements d'Hébergement pour Personnes Âgées (care homes) in 2003 and formal LTC workers providing care at home in 2008; (3) data refer to nurses and other care staff in residential care; (4) data refer to refer to nurses and other care staff providing home care; (5) estimation based on national sources; (6) data refer to workers employed in health and social services in the local authorities; (7) data refer to England and Northern Ireland.

3.4 Political structures and welfare regimes

Although the classification of welfare regimes (Esping-Andersen, 1990) has been criticised in particular from a perspective that focuses on LTC, the legacies connected to the development of health and social care services should not be underestimated. For instance, it is not surprising that, in the Nordic 'social-democratic' welfare states, services in kind are considered to be the most important support mechanism for people in need of care, compared to conservative/corporatist welfare states where cash benefits have been introduced as a key instrument to satisfy needs. While some convergence can be observed with respect to both these devices, and due to the fact that general policies strive towards keeping older people in need of care at home as long as possible, particular features such as the role of families and informal carers show distinct differences (Bettio & Platenga, 2004). For instance, adult children in the Nordic countries have no legal obligation to provide care or financial support for their

parents, which is in stark contrast to most other countries, especially the Mediterranean family-based welfare states. Issues of political regimes are discussed more fully with regards to centralization and de-centralisation in Section 4.2.

Table 3.6 provides an overview of the main characteristics of selected countries with regard to their political systems, welfare regimes and level of administrative responsibility. It shows in particular the fragmented administrative responsibilities in most countries. With the exception of the Nordic countries, Ministries of Health and those responsible for social affairs are split; in England the Department of Health is also responsible for social care. Furthermore, in most countries decentralized decision-making can be observed – with respective differences in supply and access regulations.

Table 3.6 Political structures and welfare regimes

Country	*Characteristics of political system*	*Type of welfare regime*	*Administrative responsibilities*
CH	Federal Republic	Liberal	Cantons
DK	Constitutional Monarchy, decentralised	Northern social-democratic	State, municipalities
DE	Federal Republic	Conservative/corporatist	Federal State (Ministry of Health), LTC insurance fund (assessment, authorisation, contracting, quality control), Regional governments (quality control)
EL	Presidential parliamentary republic, centralised	Mediterranean	
ES	Federal State with Autonomous Communities	Mediterranean	Federal State (framework legislation), Autonomous Communities (impementation, co-financing)
FR	Presidential Republic, centralised	Conservative/corporatist	Central State (Ministry of Health, framework legislation, Ministry of Work and Social Affairs), quality assurance Départements (Conseils généraux), care attendance regulation
IT	Parliamentary Republic	Conservative/corporatist, mediterranean	Regional governments, NHS
NL	Constitutional Monarchy, centralised	Mixed	Central state (Ministry of Health, Welfare and Sports), AWBZ (LTC Insurance), delegated agencies, municipalities
AT	Federal Republic, decentralised	Conservative/corporatist	Regional governments, Federal government (LTC allowance),
SI	Parliamentary Republic	Emerging Central and Eastern European welfare state	Central government
SK	Parliamentary Republic	Emerging Central and Eastern European welfare state	Central government (Ministry of Social Affairs), municipalities

FI	Semi-presidential parliamentary republic, decentralised	Northern social-democratic	Central government (Ministry of Social Affairs and Health), municipalities
SE	Constitutional monarchy, decentralised	Northern social-democratic	Central government (Ministry of Social Affairs and Health), municipalities
UK	Constitutional monarchy, parliamentary republic, decentralised	Liberal	Central government (Department of Health), NHS, Local authorities

3.5 The role of different stakeholders and welfare regimes

An additional factor that contributes to the fragmentation of LTC systems is the increasing number of stakeholders involved in service delivery. While in central European countries the role of private non-profit organisations as providers of care has a long tradition, private for-profit organisations are on the rise everywhere. This development includes the Nordic countries where, however, a majority of services are still publicly provided. Table 3.7 shows an overview of the specific 'welfare mixes' in the provision of services in terms of market-shares of public, private non-profit and private for-profit providers. It should be underlined that the emergence of private for-profit providers has been a phenomenon of the past 20 years only. However, the type of privatization depends a lot on the regulatory framework. While, for instance, the care home sector in the UK has become an 'LTC industry' with the usual market-mechanisms of mergers and acquisitions of large investment firms, the German for-profit home care agencies are to a large extent small enterprises with 5 to 10 employees.

Table 3.7 Different welfare mixes in the provision of LTC services (estimated market shares of different providers by type of service in percent, around 2010)

Country	*Public providers*		Private non-profit providers		Private for-profit providers	
	Residential	Home care	Residential	Home care	Residential	Home care
CH (1)	30%		30%		40%	
DK						
DE	5%	2%	55%	37%	40%	62%
EL						
ES (1) (2)	23%		24%		53%	
FR	23%	15%	55%	65%	22%	20%
IT (1)	30%		50%		20%	
NL (1)	0%		80%		20%	
AT	55%	8%	24%	91%	21%	1%
SK	29%	46%	14%	9%	-	2%
FI	56%	93%	-	-	44%	7%
SE	75%	-	10%	-	15%	16%
UK	8%	16%	12%	20%	80%	74%

Sources: Huber et al. 2008; Leichsenring et al. 2011; IMSERSO (ES); Statistisches Bundesamt (DE); Office fédéral de la statistique (CH); National reports. Notes: (1) only aggregate data for residential and home care available; (2) No clear distinction can be made between private providers in Spain – in this table non-profit providers thus include all those with a formal contract with the Autonomous Communities; private for-profit providers include those with an authorization only, i.e. all costs have to be covered by the individual resident.

Table 3.8 synthesizes the above data in relation to the provider mix in the selected countries by outlining the ratio of services provided by the public, third and private sectors, as well as the informal care contribution to LTC. The information given does not reflect the level of provision in each country i.e. whether services meet LTC needs/demand, rather it aims to demonstrate who is providing LTC in each country.

Table 3.8 LTC provider mix and level of provision, by country

Country	*Public*	*Third sector*	*Private*	*Expectations of Informal carers to provide care*
Slovakia	High	Medium (Church)	Medium	High
Finland	High	Medium (NGOs)	Medium	Medium
Switzerland	High	Medium	High	Medium
Austria	Medium	High (charities and other non-profit organizations – traditionally affiliated to churches and political parties)	Medium	Medium
Netherlands	Low	High (non-profit organizations, mutuals)	Low	Medium
France	Low	High/medium (non-profit organizations)	Medium	High
Sweden	High	Medium (trusts, co-operatives)	Medium	Low
Greece	Medium	Medium (NGOs, church)	High	High
England	Low	Medium (social enterprise, voluntary, non-profit organizations)	Medium High (residential care and nursing homes)	Medium
Denmark	High	Low	Medium	Low
Germany	Low (in-patient and out-patient services)	High (in-patient and out-patient services)	Medium (in-patient services) High (out-patient services)	Medium

Some additional features provided by national reports may help to get further insight into specific characteristics of regional backgrounds:

- In Slovakia LTC is provided to a large degree informally within the home or through public services. There are 443 public social service care facilities (governed by municipalities and regions) compared to 67 church facilities and 168 private facilities (SOSR, 2008 in: Bednárik et al., 2010). LTC is funded by taxes (relating to social care) and public insurance (relating to health care), with user's out-of-pocket payments contributing considerably to funding.
- In Finland the majority of residential homes and around half of sheltered accommodation are provided through public social services. In addition a number of services are run by NGOs and private companies. In 2006 12% of residential home services and 57% of sheltered housing services were privately provided (Klavus & Meriläinen, 2010).
- In Switzerland governance and provider trends vary between regions and for French and German speaking areas. However, there is strong private sector growth in the field of LTC (Repetti et al., 2010).
- Austrian care services provided at home are almost entirely managed by third sector organizations. Around 55% of residential services in LTC are publically provided with the remaining facilities split between private and non-profit organizations (Leichsenring et al., 2009, in Rodrigues, 2010).
- In the Netherlands the vast majority of LTC services are provided by private not-for-profit organizations. Organisations operating within the mainstream service framework (AWBZ) require a permit from the Ministry of Health, Welfare and Sports. Private for profit organizations contribute to a minor, but increasing part of the provider market of home care services (van der Veen et al., 2010).
- Provision of LTC in France is extremely mixed. The long standing public and still dominant third sector provision has been complemented by private provision over the last 15 years, using financial incentives given to for profit nursing homes and home care agencies to enter the LTC market but also by favouring direct hiring of personal assistants either directly or through providing agencies. This was part of a planned policy approach with stated objectives was more focused on job creation and "cleaning the grey market" than really increasing patient choice (Naiditch, 2010).
- The Swedish system supports the notion of a welfare mix of service providers under the overall responsibility of a decentralized state governance system. Providers of LTC services are varied, however public provision still dominates (Ljunggren & Emilsson, 2010).
- LTC in Greece is based on a mixed provider system under the governance paradigm of managed competition, however there is a lower level of service provision compared to many other European countries. Informal, domestic care forms a large part of LTC provision. Public services are provided via social services to those in greatest need. The private sector is dominant in the provision of LTC services. However the state also provides institutional care, clinics for chronic disease, psychiatric hospitals and KAPI preventative centres for the elderly. Although it is worth noting that some KAPI centres are under financed and not appropriately staffed, demonstrating gaps in capacity to run public services in Greece. The third sector and private companies are also providers of residential homes and home care services (Kagialaris et al., 2010).
- English health and social care have experienced a growing emphasis on choice and completion. There is a strong commitment to publically funded and accessible services which are provided by a mixture of public, third sector and private providers (Allen & Glasby, 2010).
- Similarly, in Denmark there is a strong commitment to public funding and universality in LTC and wider services. A public/private provider mix is becoming more prevalent and is supported at a governance level. However, the third sector is not a developed provider of LTC services (Campbell & Wagner, 2010).

- In Germany delivery of nursing and social care services is provided by a mixture of private and non-profit providers. It has been commented that this competition has not always lead to greater patient choice due to lack of sufficient co-ordination of the patient pathway (Dieterich et al., 2010). The German care system is based on a limited insurance entitlement that does not cover all care demands of insured persons.
- In Spain, the social services and health systems in LTC operate in parallel and in an uncoordinated manner, with distinct assessment systems, distinct training and distinct professional cultures. Spain has a decentralised health and social system where Regional Ministries of Health and Welfare are fully responsible for providing health and social care to the population. This LTC model, with separate health care and social services and their interventions, has changed under the new national legislation which came into force in 2007 and established for the first time specific rights of people with care needs and their caregivers. The challenges facing the new LTC system include the coordination of a much decentralised system of autonomous regions and the central government to ensure financial benefits, services and programmes, or to steer regional agencies and assessment bodies in applying national criteria.

To sum up, it has become evident that each country is characterized by its own unique 'welfare mix' within LTC provision due to historic legacies and interrelations with wider finance and governance structures. For this reason any analytic clustering of countries must be undertaken with caution. However, the following comparative features are worth noting:

- There is an evident association between social insurance funding models and a high level of involvement from the third sector having developed from political parties and religious provision (Evers & Laville, 2004). As public provision of LTC services has for a long time not been part of the social insurance system in these countries (DE, AT, FR, NL), large third sector associations have pioneered in the organisation of services, closely engaged with government through subsidies and regulation. Interestingly, only the Netherlands (AWBZ) and Germany (LTC Insurance) have integrated LTC as an explicit 'fifth pillar' into their social insurance system, while Austria (tax-funded LTC allowance) and France (tax-funded APA) have tax funded systems for LTC.
- The Mediterranean family-based model also shows signs of convergence, for instance with the planned introduction of a tax-funded LTC Allowance in Spain or with the dissemination of KAPI centres to promote prevention and local service provision. Furthermore, LTC in these countries (EL, ES, IT), but partly also in Austria and Germany, has become an area of 'globalised outsourcing' of tasks hitherto provided by women in the family. The phenomenon of informal 'migrant carers' (EL, ES, IT) or 24-hours care by women from neighbouring low-wage countries (AT, DE) is adding a new facet to existing welfare mixes.
- The emergence of new private actors, in particular in the Nordic countries and the UK, but also in Continental Europe, has contributed additional complexity to the mixed economy of LTC provision. New accreditation and control mechanisms based on legal regulation have almost completely substituted traditional relations between private (non-profit) providers and statutory authorities that were based, apart from basic legal dispositions, on subsidies and trust. Furthermore, market-mechanisms to regulate these new relationships (see Section 4.1.1) have altered the role of different stakeholders to a large degree, e.g. German local authorities have almost completely lost their capacities of social planning to regulate the development of services.

3.6 Selected indicators on values, user expectations and family ethics

LTC involves intimate personal relationships and impacts on privacy and ultimately the entire life world of people in need of care. The values and expectations of individual users are an important factor for policy-making and governance. For instance, it makes a difference to propose major investments in social services or care homes in societies that have different expectations for the level and importance of provision for these services. Findings from a Eurobarometer survey carried out in 2007 suggest that about two thirds of Greek and Slovak citizens expect (and prefer) to be cared for by a relative in their own home, while less than 30% of Danish, Dutch or French would expect such care (Table 3.9).

The same survey revealed that 98% of Slovak citizens and 81% of Spaniards think that people with LTC needs have to rely "too much on relatives", suggesting that expectations seem to adapt to what is on offer – only about 42% of Danes (NL: 58%; DE: 66%; UK: 67%) agree with this statement (European Commission, 2007: 73).

Table 3.9 Expectations of European citizens: "If you needed regular help and long-term care, in which of the following ways you would be most likely to be looked after?"

Country	*Total*	*In your own home …*			*In the home of one of your close family members*	*In a long-term care institution (nursing home)*	*Don't know*
		… by a relative	*… by a professional care service*	*… by a personal carer hired by yourself or by your relatives*			
AT	1009	36%	28%	11%	6%	11%	8%
DK	1007	22%	51%	18%	2%	6%	1%
DE	1510	45%	26%	9%	4%	8%	8%
EL	1000	66%	15%	12%	3%	3%	1%
ES	1007	49%	17%	7%	5%	10%	12%
FI	1026	41%	33%	8%	2%	14%	2%
FR	1039	24%	45%	13%	2%	12%	4%
IT	1017	38%	15%	16%	5%	9%	17%
NL	1001	29%	37%	9%	1%	16%	8%
SE	1001	31%	31%	12%	1%	21%	4%
SI	1037	44%	12%	9%	5%	25%	5%
SK	1075	68%	10%	7%	4%	7%	4%
UK	1313	42%	26%	10%	5%	8%	9%

Source: European Commission (2007) *Health and long-term care in the European Union.* Brussels: European Commission (Special Eurobarometer 283).

4 Key governance mechanisms

Various governance mechanisms can be identified within emerging LTC systems. Again, based on national legacies and idiosyncratic policy styles, a mix of the following approaches has developed:

- *Public/Social programming* that used to be the most prominent in the 1970s and 1980s, is the public regulation of supply by planning services and personnel, based on population size and estimated need. Although public and social planning as a whole approach tends to have been replaced by market mechanisms, aspects of this approach remain in some countries (see table 4.1). For example, in Denmark public authorities have retained a general approach of social planning with state-led provision, block grants, activity-related subsidy, a local basic contribution and a local activity-related contribution. User-orientated mechanisms such as service vouchers and cash payments have been incorporated into the approach in many countries. In Greece, where private and informal care dominate LTC, public and social programming is used only to provide care to the poorest people with LTC needs, through subsidies, partial coverage of costs and direct provision.
- *Market mechanisms and New Public Management (NPM)* include tools such as competitive tendering, contracting and competition within quasi-markets of LTC provision. These mechanisms are evident in the majority of countries in relation to LTC. Section 4.1 explores national experiences of market-mechanisms and their driving rationales.
- *Consumerism* as a subset of market-mechanisms focuses on maximising user (and carer) choice, giving them a greater role in decision-making about their care. Within LTC consumerism can be seen in greater use of cash and direct payments, often used to support home care and personal assistants. It can also be seen in increased use of personal budgets, designed to encourage users to choose their own care from various services and benefits on offer. Consumerism as a governance mechanism appears against a backdrop of increased user involvement. This trend incorporates quality management (Nies et al., 2010: 20) and greater involvement of users and carers in designing and evaluating services.
- *De- or Recentralisation (Rescaling)* of responsibilities has a strong impact on LTC provision as it involves both de- and re-centralisation of administrative, financial and regulatory mechanisms (Vabo, 2010: 313). Section 4.2 explores national experiences of the organisation of LTC governance within multi-level governance structures.
- *Pro-active government initiatives to promote coordination/integration* can be identified many countries where government initiatives focused on gaps and interfaces in LTC, for instance pilot projects focusing on multidisciplinary approaches in prevention and rehabilitation (Kümpers et al. 2010). Government initiatives for joint working also focus on funding and financial flexibility between health and social care organizations.
- *'Muddling-through' and incorporating informal care* is a type of governance that relies on informal care, with consequences such as 'illegal' migrant care. The extent to which countries 'muddle through' or are developing governance approaches which acknowledge and support the input of informal carers is discussed in section 4.3, also drawing on key findings from the INTERLINKS work group on informal care (Triantafillou et al., 2010).

Table 4.1 displays the extent and use of specific mechanisms, guided by the following typology:

- User-oriented- vouchers and cash benefit

- Commissioning-type of service decided ex-ante and competition takes place in the tendering process
- Non-market-based social planning mechanisms i.e. public/social programming

Table 4.1 Governance mechanisms used in LTC

Country	*Main governance mechanism used*
Austria	User-oriented through the LTC cash benefits, combined with subsidies to providers (fixed prices). Limited social-programming (e.g. building quasi-public care homes).
Denmark	Social programming with direct provision, block grants, activity-related subsidy, a local basic contribution and a local activity-related contribution. Minimal user-oriented (cash/voucher).
Finland	
France	Previously more social programming orientation (in kind services) with recent strong trend for a consumer orientation (through vouchers and fiscal incentives and for provider competition).
Germany	User-oriented through the LTCI cash benefits for service users and informal carers (Care Attendance Allowance and Care Allowance). Little user-orientation in formal care. It is distributed as limited in kind services. Limited social-planning of LTC services. Municipalities have almost no impact on LTC steering. Regional LTCI Boards supervise the care delivery with little ambitions on a comprehensive planning of nursing and social care.
Greece	Informal care in LTC is the rule and the private sector predominates in both home and residential carer provision. For those without family support traditional social planning through subsidies, partial coverage of costs, direct provision in financially weak groups.
Netherlands	User-oriented through mechanisms of cash benefits and care in kind; Acceptance of service providers to operate on the market; tendering of domestic care services; steering capacity and regional budgets by care offices.
Slovakia	User-oriented mechanism, with cash benefits, ex-ante needs assessment and subsidies for informal carers.
Switzerland	Between a commissioning and a programming approach, depending on the canton. In the French speaking cantons, social planning is prominent. In German speaking cantons, there is more commissioning approach involving managed competition between service providers.
Sweden	With the growth in outsourcing by means of public tendering by municipalities, the longstanding monopoly of public provision has been eroded as new private for-profit providers have succeeded in winning tenders against provider agencies within municipalities. Public procurement had until recently been based on a rationale that guaranteed a local monopoly (replacing the public monopoly) to providers who won the tender, denying users any choice among providers. Nowadays, municipalities may choose to introduce the 'user choice' model by giving vouchers to users who may then choose between different accredited providers.
United Kingdom (England)	Older people's services are commissioned by local authority adult social services (social) and Primary Care Trusts and GPs (health). LTC services are commissioned from a mixed economy of acute hospital trusts/social enterprises, mental health trusts, GPs and various community care providers (private, public and third sector). Within this commissioning approach there is a strong commitment to user-orientated mechanisms of personal budgets throughout adult social care and personal health budgets.

The table strongly displays the importance of market-mechanisms in the governance of LTC. Even in countries such as Denmark, which retain social programming approaches, consumerism is introduced through use of cash and vouchers. In several countries market-mechanisms are clearly visible in the form of competitive tendering and in others consumerism is widespread because of the administration of cash benefits or private sector dominance for LTC.

4.1 Market mechanisms in LTC

Various market mechanisms have been adopted into governance frameworks within health and social care for LTC in Europe. There has been a widely observed trend in Western democracies towards the inclusion of markets, quasi-markets,[4] de-centralised bureaucracy, greater contracting and increasing consumer choice. This marketisation did not start in health and social care or the public sector, rather management techniques were imported from the private sector and adopted into the governance of public services. Adoption of private sector and business approaches within public services are acknowledged as a major feature of 'New Public Management' (Hood, 1991, Stewart & Walsh, 1992, Denhardt & Denhardt, 2000).

What has been the rationale or perceived benefits of implementing market-mechanisms? Governance strategies of market competition are based on the assumption that these conditions give providers incentive for greater quality and cost-efficiency by targeting and responding directly to demand. In relation to health and social services, use of market mechanisms has also been driven by a quest to achieve greater user-orientation and choice (Huber et al., 2008, Glendinning, 2009). The benefits of market-based approaches to governance are seen to be maximised when competition is used in conjunction with consumer choice (Le Grand, 2007: 41). The theoretical benefits of using market-mechanisms to govern service provision have been argued as follows:

- User autonomy: allowing users to make their own choices from a range of services. Choices in LTC services can relate broadly to location/setting, type of provider/professional or type of treatment.
- Responsiveness: competition incentivises providers to tailor services to users' preferences and incorporate user feedback.
- Efficiency and value for money: a competitive environment can foster a more cost-conscious approach within provider organisations, increasing efficiency and helping to manage and contain costs where required. There is also an incentive to price services 'competitively'. Coupled with increased user responsiveness and market knowledge this can provide a high level of service value for users.
- Cost containment – an increased capacity to control and work within a set budget, as service provision can be outsourced and competition acts to drive down prices.
- Equity: where there is no choice between providers, service improvement relies on feedback to a single service provider or higher authorities. This process can favour the voices of more confident and articulate service users. In theory, within a market-oriented governance system each service user has the ability to exercise choice between providers. This can ensure greater equity of power between service users regardless of social status issues.

[4] A market where providers compete for custom and individual users choose between services. However, payment for services is made by a statutory authority or third party rather than the individual in the form of a voucher, earmarked budget or funding formula

- Access: market competition can give providers added incentive to seek out gaps (e.g. under-serviced or disadvantaged groups), and develop new ways to meet their needs.

In reality, there is rising doubt about whether market-orientation has contributed to achieving these theoretical aims with respect to LTC provision. For instance, users of LTC services are not always capable of choosing between services they do not know – while information and counseling centres are still scarce, it is necessary to promote mechanisms for enabling user choice, in particular for hard-to-reach groups. As already mentioned it is also doubtful, whether competition may facilitate coordination and cooperation between agencies.

Another problematic issue concerns the extension of (new) providers. On the one hand, it is most desirable, in emerging LTC systems, to increase service offers. On the other hand, market mechanisms tend to advantage large providers looking for further growth in particular in advantaged districts, rather than ensuring service provision in remote areas. These drawbacks have been experienced in particular in Germany, where local authorities have widely lost their abilities to steer social service infrastructures, e.g. with respect to care homes (Leichsenring et al, 2011) and in England, where large investment firms are shaping the 'long-term care industry' with an increasing concentration of large providers and related problems of accountability and choice (Scourfield, 2007). Most of the larger care home groups in England are owned by venture capital groups bringing new capital into the care sector, "but they may also change the fundamental structure of the market in ways as yet poorly understood" (Banks, 2007: 4).

The INTERLINKS work group on quality in LTC highlighted different ways in which quality could be ensured within such market mechanisms and which additional measures are needed to correct risks of 'market-failure'. Nies et al. (2010: 7) describe how contracting and purchaser/provider split approaches may have an inherent quality assurance function. For instance, access for providers may be steered by means of minimum standards or specific quality requirements defined during the contracting process. It is also commonplace for contractors to drive up quality by organising quality management systems with providers and reviewing outcome data.

Although market-based governance strategies – and respective measures to regulate the market – promise desirable outcomes, they have often failed to reach such results in practice, in particular when it comes to address gaps between health and social care, to promote coordination and inter-agency working, and in terms of continuity of service. National experiences show some of the problems faced and conditions which can impede the realisation of desired results, as highlighted in the following.

An issue faced by policy-makers and service planners is *how to best steer competition and choice approaches:* To what extent and how should government intervene in LTC provision to ensure that the real needs of older people and their informal carers are being met? In all national approaches there is some level of state regulation, financing or planning, thus a quasi-market, rather than pure market approach is used to govern LTC or wider national health systems. However, there are differences in the extent to which governments take on a command and control approach. For example, Sweden, France and England demonstrate a high level of government intervention in terms of service planning and contracting (long-term collaboration), whereas Germany and the Netherlands take a more pro-competitive approach but still aim to provide some balance between stakeholders and ensure universal coverage (Blank & Burau, 2004).

The introduction of market-mechanisms has led to the *involvement of new actors*. Private and third sector providers are increasingly contracted to deliver public services, replacing a more trust-based system. Balancing responsibility and activity between government and non-government sectors is viewed as central to the successful governance of LTC in Europe (Mossialos et al., 2002: 227). The provider mix evident in European countries has evolved in light of several factors, most notably the historical context of care provision, funding structures and the policy frameworks and financial incentives for different sectors. Working within these varied contexts, policy-makers are tasked with creating the right conditions and incentives to get the best service outcomes from new actors. In doing this they face key governance issues including:

- How to avoid fragmentation within the LTC system?
- How to encourage collaboration amongst varied and often essentially competing actors?
- How to ensure equity among LTC service users?
- How to achieve value for money?

4.1.1 Using competition in LTC

In introducing competition at the provider level there are two different approaches to consider:

- The purchaser is the public authority (acting as a monopsony[5]), buying and selecting services from different providers.
- The purchaser is the user/person in need of care: choosing (e.g. using cash benefits or vouchers) from different providers that have previously been accredited or authorised to act as care providers.

These two approaches raise different questions, both in terms of the market mechanisms used and the influence of user choice. Although the monopsony model can allow for economies of scale (contracting to a single provider) and may help to balance the power of existing monopolies or strong trade unions, it appears compromised by the legacy of public provision, especially in Scandinavian countries. For instance, in Sweden although many private sector and some third sector services are contracted, public provision of health centres for LTC, residential and sheltered accommodation remains the norm. In Denmark and Finland the benefit of market stimulus through the local contracting of private sector providers is acknowledged, however there is no stated objective to reduce the public role to be solely the purchaser and remove the provider function. In France, local authorities which are responsible for regulating LTC show a great diversity regarding how competition, between non-profit and for-profit providers, is embedded into local policies.

In other countries, competition between providers has been encouraged by granting those in need of care with cash benefits or individual budgets (AT, UK, FR, IT, SI, NL) whereby users themselves become the purchasers of care. This type of funding bestows purchasing power on service users (Nies et al., 2010: 49) and it is meant to enhance user choice and responsiveness of providers to their needs. With regards to questions of equity this type of competitive mechanism has been seen to overcome social class inequalities, compared to interventions involving service users' 'voices', which tend to favour the articulate middle class (Le Grand, 2007). However, in practice, in numerous countries this approach is

[5] A market where a single purchaser chooses from multiple providers.

seen to lead to the emergence of a 'grey' market of care delivered by migrant carers (Di Santo & Ceruzzi, 2010).

Several factors can impede the success of managed competition within LTC. In Greece there has been an ongoing power struggle between the state and private sector, most prominently characterized by the creation of the National Health System (ESY) in the 1980s to arrest the growth of the private sector in health. Although reforms of 2001 introduced a new paradigm of mixed market managed competition, this conflict of status (due to public underfunding) between public and private sectors continues to undermine the potential for longstanding collaborative relations – a necessary condition for this governance model – and equal access. To illustrate this latter point it has been seen that public LTC services are disproportionately used by those with low incomes (older people, migrants and the unemployed), whilst those who can afford to pay or have private insurance tend to use the private sector (working age population). It may also explain how the number of nursing homes in the Netherlands could so rapidly expand after the Exceptional Medical Expenses Act was introduced. This Act was incorporated in a health care context and provided a mandatory insurance for expenses that could not be covered by a regular insurance system.

The cultural dominance of medical services forms another barrier to developing a managed market for LTC. This is especially relevant where there is also underfunding of public services. Priority-setting for public expenditure, as well as the incentives for developing services in the private sector, are strongly focused on acute and medical services. Where there is little knowledge of the role or services involved within LTC for older people, demand is less visible, hindering the development of such services in all sectors. INTERLINKS data suggests that this lack of awareness of the social care-based aspects of LTC for older people is a fundamental barrier to service development (SK, EL).

Further disincentives come in the form of unequal legal status for public and private providers of LTC. In Slovakia private providers find it very hard to compete with the publically provided services which were, until March 2011, subsidised by the local and regional governments (Example 1, appendix 3). It is noted that even though these private services are often more flexibly designed to meet client needs they remain priced out of the market (Bednárik et al., 2010). On the contrary in France, despite the opening of care provision to private organisations, authorisation procedures for home care agencies still differ according to the nature (for-profit, non-profit or public) of those agencies which overall tend to gives a 'market advantage' to for-profit agencies (Naiditch & Com-Ruelle, 2009).

The German experience of market-mechanisms in LTC (Example 2, appendix 3) demonstrates a lack of local steering capacity, thus increasing fragmentation in LTC delivery, rather than contributing to a coordinated system and improvements in LTC provision as expected, when the LTC insurance had been introduced. Competition between providers created barriers to coordination as, for instance, regional and local government lost control over service provision due to the leading role of LTC insurance funds. Although a leading role for insurance funds is not necessarily a problem in itself, in Germany these funds have not yet developed sufficient steering capacity themselves, nor assumed the level of public responsibility required. Kümpers et al. (2010) highlight the significance of supporting local collaboration in relation to developing preventive and rehabilitative services. As market mechanisms have been seen to undermine local integration between health and social care providers, this can threaten the consolidated approach needed as the basis of prevention and rehabilitation processes.

There are also issues of investment linked to the relatively poor status of social and welfare services. National reports highlighted additional disincentives for providers to develop integrated services in LTC including:

- a cultural divide between health and social services and organisations,
- relatively poor working conditions in social and welfare services,
- lack of professional associations for social and welfare services employees,
- complex financing, i.e. the often absent or partial coverage from state insurance or tax funds complicates the financial aspects of running LTC services for providers.

Issues around informal care and women's workforce position are additional factors reported to impede the governance model of managed competition. Demand for and thus development of services is clearly lower where the lack of jobs means that women still have no realistic choices and continue to provide care at home. Issues of informal care are further explored in section 4.3 and are interlinked with the underdevelopment of the concept of LTC in many countries. This phenomenon is particularly visible in policies concerning informal care (Triantafillou et al. 2010) and in countries where unemployment rates exceed the European Area average (ES, SK, EL).

The introduction of market-based mechanisms in the delivery of care has also brought about a significant change in the regulatory framework regarding quality. Contracting of care services supposedly based on price/quality led to the need to define quality ex-ante and to replace relations based on trust and professional ethics with legal contracts. As quality proved difficult to gauge, quality tends to have been defined in terms of inputs/outputs rather than outcomes/processes and emphasis was put on cost-containment, competition for the provision of care services has often been based on price rather than quality (Nies et al., 2010).

4.2 Decentralisation and recentralisation in LTC

Centralisation and decentralization are highly relevant for LTC governance in terms of the varied organisations which have responsibilities for co-ordination and service delivery. Some countries have a longstanding history of decentralised governance of public services and LTC. However, in all countries there has been a growing trend from the 1970s to bring services closer to users by transferring responsibility towards a local level. In some instances recognition of the risks around providing LTC has led to a centralised/high level discussion and reform measures. This section will examine national experiences of practical approaches to such de and re-centralisation.

Within governance literature decentralisation has been used to describe various structures and processes with respect to the vertical distribution of responsibilities, but also in relation to the horizontal division of tasks (Kazepov, 2010). Within this report it is used broadly, encompassing all transfer of authority, power and funding responsibility for LTC from a national to a sub-national level. Initially this will focus on tiers of national, regional and local government. However, the discussion of decentralisation also incorporates devolution of power to allied government agencies as well as privatisation of services. In health and social care 'decentralisation' has also been used to describe the

shift from acute services to care at home (Wasem, 1997). For the purposes of this report this sector-specific definition will not be used, as decentralisation is conceptualised at a broader governance level.

4.2.1 Risks and benefits of decentralisation

National rationales and objectives for decentralisation of responsibility and function in LTC of older people include the following expectations:

- Greater health and social care integration
- Encouraging innovation
- Increased accountability for joint working (specific targets, policy drivers and legislation to incentivise joint working at a local level is in place in e.g. UK, FI, SE, although its success remains unproven)
- Enabling a more user-orientated LTC system
- Greater efficiency of cost

Within strategic policy all countries take a tiered approach to the governance of LTC. Typically acute health services are directed at a regional level whilst the responsibility for planning and delivering home care services is overseen at a local authority or municipal level. In many countries (AT, DE, FR, NL) there is less emphasis on the local level of governance. In practice, governance of de-centralisation contends with issues such as:

- How to tackle differentiated provision and inequality of opportunity due to regional difference;
- Barriers between medical, nursing and social care, e.g. in terms of evident differences in organisational or working cultures, as well as financial processes, levels of professionalisation and legal status; also, a bias towards concentration on health services within formal services, with social care tending to be incorporated into informal provision has been observed;
- Local responsibility for services, but without the necessary flexibility or resources to steer service and provide outcomes in LTC;
- Cost-shunting between different levels of government.

In the example of Germany (Example 2, Appendix 3) the steering and governance instruments have little alignment to local municipalities. The unequal budget responsibilities of higher and local bodies are observed in many European countries to different extents. Often local actors are given responsibility for services but without the corresponding means and resources to implement new practices or change outcomes (FR). Countries (SE, UK, AT) have developed strategies with shared responsibilities for LTC (across levels of government and other organisations), in an attempt to overcome this fundamental problem.

A step towards the development of a shared vision of LTC at the local level in Germany is the implementation of local community-oriented support centres, based on the LTC Further Development Act (2008). They offer advice for people with care needs and case management for older people with complex LTC needs. Furthermore, they also fulfil some coordination tasks of LTC services – however so far they are without significant resources or independent power. These innovative networks mostly represent new cooperation forms between nursing and social work. However, it is thought that with the lack of local co-ordination and steering capacity inherent in the German LTC governance structure these centres are unlikely to be mainstreamed in comprehensive advisory services.

In principle financial barriers between the health and the care sector could be solved locally by direct agreement between a local authority or groups of local authorities and a region (DK). Another strategy could be to empower local health and social care communities to pool aspects of their budgets, to delegate commissioning responsibilities for a particular client group to a lead partner and to create integrated service providers (CH, UK, FR). The transfer of responsibilities from a central to a local administration can lead to privatisation if the local power does not get enough funds. This is the case in Switzerland where the transfers of responsibility to local authorities are not sufficiently accompanied by financial empowerment, leading to an implicit privatisation of care services.

A main target to overcome horizontal and vertical gaps in LTC governance should be to create an integrated comprehensive health and social care strategy on different levels with shared responsibilities and joint actions. Towards these objectives the UK implemented a new duty for local partners to carry out an annual 'Joint Strategic Needs Assessment' (JSNA) of the local area. From 2008 local authorities and health trusts have undertaken mandatory JSNAs. These needs assessments are focused on identifying health issues and inequalities within local communities and form a basis for service planning. There is a specific focus on older people and commissioners have access to nationally created tools for projection of older populations and their service needs. In France, the new health and social agencies put in place in April 2010 could be an institutional tool for a joint approach, at a regional rather than local level.

In the Netherlands the necessity to achieve true integrated dementia care exists in a lot of the regions that participated in the National Dementia Program. On instigation of the Dutch Ministry of Health, the Alzheimer Association with the national branch-organisation of care insurers has begun with a new Program for Integrated Dementia care. 16 regions thus started making progress in developing integrated care. The first results were available in 2009 and fully fledged integrated dementia care is expected to be implemented throughout the country in 2011. Now that care and welfare organisations are trying to collaborate more intensely so that integrated care can get a definitive shape in the region in due time, finding funds for case management is one of their priorities. In 2009 several care institutions and long term insurance agencies in the Netherlands started a joint venture commissioning integrated dementia care (see example 3, appendix 3).

Despite undergoing a legislative shift of responsibility to regional and local self-governing municipalities, Slovakia reports a history of poor planning and co-ordination activities. Their experience is of a fragmented LTC system for older people and their carers, with a variety of legal and institutional systems of assessing needs and entitlement. This demonstrates the importance of a co-ordinated approach to the devolution of responsibility. Creation of a coordinated and continual approach to addressing LTC need is complicated by the fact that the share of tax to satisfy social needs of older people is not earmarked for LTC. This increases risks that finance may disappear into the general budgets of self-governing regions (Bednárik et al., 2010).

4.2.2 De-centralising LTC systems

The different structures which underpin the governance of LTC in terms of funding, organisation of institutions of government and the role of different sectors in assessment and provision, also complicate the measurement and comparison of decentralisation in LTC systems. Two different levels of

decentralised structures are apparent within the selection of European countries, with some of them incorporating aspects of both.

- *Decentralisation of LTC to municipal/local council level* (SE, DK, UK, FI, CH, FR, SK): Within these predominantly tax-funded systems, responsibility for planning, co-ordinating, financing and delivering LTC services belongs to the lowest level of government.
- *Regional government/government agency responsibility* (AT, EL, FR) or *regional LTC bodies* (NL, DE), consolidation of LTC administrative function and one-stop-shops (CH, FR) for LTC users and professionals: In many cases these approaches demonstrate attempts to re-centralise or consolidate local actors in order to strategically address LTC need.

The development of de-centralisation of LTC policies on a vertical line shows tiered responsibilities across national, regional and local levels with insurance companies playing varying roles in some countries. Only in selected cases (e.g. UK, FI, SE) the legal framework for LTC policies is at the state level, while health care is in most cases regulated at the central level. The state retains responsibility for monitoring and analysing health and medical care (although in some cases this is also the remit of localised trusts, e.g. UK), produce legislation and other guidelines. The practical tasks of service delivery are managed by municipal bodies or insurance companies (e.g. DE, FR, NL). In several countries (e.g. SE, CH, AT, SK) different competences at regional and municipal levels are established. Crucial for strong local care authorities are a mandatory legal framework and an adequate level of freedom in financial decisions. In Bismarckian countries with powerful health care insurers, local or regional authorities should have enough countervailing power to be a valuable partner in designing a well functioning LTC system.

Decentralisation of LTC functions and responsibilities to a local level can be exemplified in the Finnish, Swedish and Danish systems:

- Finnish municipalities are legally obliged to organize health and social services for their residents. There are currently 342 municipalities with a median size of less than 6,000 inhabitants. Municipal services for older people comprise of home care, support for informal care, service housing, institutional care, preventive care services and rehabilitation. A municipality can provide the services independently, together with other municipalities or purchase services from private sector providers. The municipality can also admit the client a service voucher for purchasing services from predetermined private providers. In addition, private companies offer elderly care services ranging from various types of support services to all inclusive service housing. The municipality (or several municipalities jointly) is obliged to draw up a policy strategy that has been approved by the local council. The drafting of the strategy should be carried out collectively by representatives of the administration, residents, clients and family members, and central interest groups. The strategy must take into account the elderly population in all aspects of municipal decision-making and activities, such as community planning, housing and traffic policies, cultural and recreational activities, and educational facilities. The execution of the strategy is integrated into the municipal budget and financial plan and monitored on a regular basis for continuous development of elderly care services and related activities (Klavus & Meriläinen, 2010).
- The Swedish Health and Medical Services Act (HMSA) and Social Services Act (SSA) responsibilities across LTC provision are placed at either county council or municipality level, with collaboration between councils within regions. The HSMA sets out the respective responsibilities of county councils

of acute care, GPs and rehabilitation. The SSA sets out the responsibilities of municipalities i.e. social care home help in regular housing, home care, special housing nursing homes and day activities. Companies, trusts and cooperatives often provide services, but the local authorities retain the ultimate responsibility for supply and maintenance of the level of care. Councils and municipalities have the right to finance the activities by levying taxes and fees within the limits set by the legal framework (Ministry of Health and Social Affairs, 2007; Ljunggren & Emilsson, 2010).

- In Denmark the local authorities have autonomy and responsibility for providing LTC services within the primary sector, including prevention, rehabilitation and LTC social and home care. Acute and specialised care are regional responsibilities and the five health regions play an explicit role as a platform for planning and enhancing quality (Campbell & Wagner, 2010).

Denmark's local government reform of 2007 (Example 4, appendix 3) provides a clear example of the rationale behind devolved responsibility for service planning. Local authorities became the gateway to the public sector and thereby took on a frontline role in both health and social care, with regions taking explicit responsibility for quality. One of the overt reasons for assigning sole responsibility to local authorities for, for example, all prevention and rehabilitation services, was to reduce the occurrence of 'grey zones' where patients move from the secondary to the primary sector (Christensen & Hansen, 2006: 43). Proximity to citizens gives local authorities opportunities to follow and affect citizens' health. Furthermore, local authorities were enabled to establish a holistic, cross-sector and coherent prevention and rehabilitation system, involving a broad range of health concepts in an integrated and localised range of services (Campbell & Wagner, 2010). Within local health budgets preventive services are incentivised and rewarded through activity-based local authority contributions.

In Denmark, localised capacity in LTC has enabled successful multi-disciplinary centres for LTC. Set up by local authorities, the concept is an organisational unit, usually led by senior nurses or physiotherapists, that offers patients who have been referred by their GPs targeted health promotional, preventative and rehabilitative support, training, guidance and/or treatment, co-ordinated and delivered by a multi-disciplinary team. LTC centre teams include all or some of the following: nurses, physiotherapists, occupational therapists, psychologists, doctors, social workers, dieticians. All health centres have in common the need for strong partnership and joint working between GPs, hospitals, patient associations and training and exercise providers. The stated aims are to increase cross-sectoral working, improve quality, increase recruitment and improve continuity for patients (Campbell & Wagner, 2010).

The second approach of *regional LTC responsibility* can be observed in Austria, the Netherlands, France and Switzerland:

- According to the *Austrian* Constitution, LTC is a responsibility of the existing nine regional governments (*Länder*), unless competencies are covered by the social insurance system. Since no federal framework law on social assistance exists, there are nine Social Welfare Acts regulating LTC services. This meant that each regional government has set its own regulations concerning benefits, means-testing and eligibility. However, in practice it is Federal government that manages and distributes the Austrian LTC allowance, while the regions took on, among other, the tasks to develop and implement plans for LTC services and residential facilities, and to set minimum quality standards for social care services (Grilz-Wolf et al., 2004; Österle/Hammer, 2007, Rodrigues, 2010).
- Regional Care Offices in the *Netherlands* are another example assigning responsibility and function to a regional level. On the basis of individual assessments of people with LTC needs, under the

responsibility of the national centre for LTC assessment (CIZ) and a national health insurance board (CVZ), regional Care Offices ensure payments and service provision of the main part of LTC to citizens of that region. They perform their task of allocating care to patients by purchasing care from suppliers in the region. The offices have a number of functions such as commissioning services by annual contracts and promoting quality assessment of care providers. The means of care offices to ensure quality of care are mainly financial incentives, and regularly consulting with local care providers, patients' organisations and local authorities about developments in demand and supply of care. The operating of the office in a region is usually commissioned by the Ministry of Health Welfare and Sports to the largest health care insurer in the region: in 2009 the 32 Care Offices were operated by 12 health care insurers (van der Veen et al., 2010).

- In *Switzerland* further attempts to create a strategic overview of health priorities can be seen through the Regional Conferences of the Health Departments Directors (CDS) (Example 5, appendix 3). However, as cantons have independent sovereign powers to apply federal law as they choose, the conferences can only produce recommendations rather than actionable policy. The intercantonal strategies displays a strategic step towards re-centralisation, but one where there are still some barriers to overcome due to wider governance structures in Switzerland.
- In *France* since the 2002 Law, the responsibility for regulating and implementing LTC has been partially devolved to the general council (executive body of the local political sub regional level). But this responsibility lies mainly in the provision of home and residential care as primary care rehabilitation, with acute hospitals regulation and funding under the responsibility of the regional hospital agencies. The new regional Health Agency (ARS) installed (April 2010) according to the HPST law, has been given responsibility for planning and regulating all the previously fragmented sectors and may thus exert some steering capacity in co-ordinating LTC. In theory, the reform provides these regional bodies with legal means to pool funding in order to better integrate health and social care. For example, funding has been earmarked to support projects which have sought to compensate shifts in provision between health care settings (e.g. from hospitals to primary or rehabilitation care) and improve coordination and management regarding chronic diseases or improved discharge from hospitals. Also the agency steering committee is entrusted with designing, tendering and selecting projects aiming at improving the quality of services (Naiditch, 2010).

4.2.3 Centralising LTC issues and systems

In recent years many countries have responded to growing pressures around the delivery of LTC services by reviewing LTC at a national level.

- In *England* this took the form of an open public consultation targeting all key stakeholders, called the 'Big Care Debate'. When starting to consult around future options for funding LTC for older people (and people of working age), the government quickly realised that very few people understood the current system and so could not meaningfully comment on future options. The 'Big Care Debate' was therefore a national initiative to raise awareness of the current LTC system, seek views on current provision and involve current service users and carers, key stakeholder organisations and the wider public in debates about future funding options. The new Coalition government have set up a LTC Commission to explore future funding options, and policy commentators expect the key themes from the Big Care Debate to be influential to the Commission's work.
- The *German* experience offers two clear examples of centralised attempts to improve the LTC system. The first is the introduction of LTC insurance (LTCI) which has significantly extended coverage

of LTC for older people in Germany, although there is consensus that further adjustment is needed to counter financial pressures based on a growing number of benefit recipients (Example 2, appendix 3; see also Arntz et al*.,* 2007).

- The *Netherlands* are experiencing similar financial pressure and reform debates in relation to their longstanding national mandatory insurance for LTC (AWBZ), which also has a connected national organisation dedicated to LTC needs assessment (CIZ). The second example is the German Charter of Rights for people with LTC needs. The charter forms an overview of existing books of law focused specifically on LTC and sets benchmarks for health and social care in this area. The creation of the charter in 2005 brought together federal Ministries, service user representatives, consumer groups and insurance providers. The charter has been successfully applied in several LTC settings and increasingly appears in national and regional legal frameworks (Sulmann, 2010).

4.2.4 Centralising and de-centralising quality management

Nies et al. (2010) illustrate some key issues around centralised and decentralised approaches for quality aspects of LTC in European countries. Many of the advantages and limitations highlighted are relevant to LTC governance more generally. For instance, national level quality frameworks give opportunities to standardise practice and collect comparable data across regions. The Austrian development of national professional qualification and educational standards is an example of successful centralisation for LTC. These are regarded as important improvements that have acted to standardise previous regional variations in professional education. Another key benefit of having a national overview is the increased opportunity to transfer innovation and good practice between regions. However, in order to foster innovative practice in the first place some flexibility is needed at a local level. So an overall message is that LTC governance should not take an either/or approach to central or de-centralised structures, rather it should allow appropriate flexibility and regulation within all tiers, whilst aiming to avoid duplication and conflict between them.

The quality systems for LTC are seen to be influenced by national modes of governance (Nies et al., 2010). Where public funding and state regulation are dominant, inspection tends to be the main quality assurance mechanism. However, in countries that have incorporated competition between mixed providers, self-directed accreditation and certification are becoming more commonplace. Although these changes to quality management are adapted to the complexities of multiple organizations involved, they do not ensure quality at the interfaces of health and social care or between provider organizations. For LTC, integration and interfaces between organisations are essential to the quality of patient pathways and experience. Examples such as the Dutch Healthcare Inspectorate's (IGZ) disease specific indicators for integrated care lead the way in creating an integrated quality management system (Nies et al., 2010: 33).

4.3 The governance of informal care

In Europe, informal carers provide the majority of LTC for older people (Marin et al., 2009). Changing demographic and social factors result in greater LTC need and add to pressures on families to provide informal care. National governments face a series of related challenges, including:

- How to balance national reliance on informal care with progressive employment policy
- How to recognise informal carers as 'partners' or 'co-providers' of care, improve the status of this role and give them a voice in relevant decision-making processes
- How to best support carers in their everyday work, in particular older carers and those that have significant care needs themselves
- How to safeguard the quality of informal care
- How to approach regulations for migrant workers within informal care

Informal care takes the form of predominantly female work within families and of neighbours, but it also concerns a wide informal market of migrant workers. In previous work on informal care (Triantafillou et al., 2010), it was suggested that the definition of informal as opposed to formal care corresponds to a set of common characteristics:

- Care is mainly provided by family, close relatives, friends or neighbours
- Carers are non-professionals and not trained to provide care; but in some cases they may benefit from special training
- Carers have no contracts regarding care responsibilities
- Carers are not paid although they more and more commonly obtain financial contributions
- Carers perform a wide range of tasks (also performed by formal carers) including emotional support and assistance
- No limits to time spent on care – never/rarely officially 'off duty'
- No general entitlement to social rights

Triantafillou et al. (2010) also describe the developmental state of policies targeting informal carers and the extent of their implementation through various supporting measures and some good practice examples, based on three major findings.

- Firstly, before 2000, recognition of the important role of families and informal care networks was not a key issue in most European countries. Over the past decade, changing perceptions of care and how informal care could best fit into the delivery of services by professional organizations, led to corresponding efforts to encourage the legally recognized status of informal carers. Determinants for this changing perception include a mixture of demographic and epidemiological factors coupled with economic, social and cultural changes (such as women seeking increasing access to the labour market). These gave rise to higher levels of need for LTC services, while at the same time questioning the sustainability of informal care networks, especially in countries where professional services were lacking and in which informal carers (predominantly women) were still providing the majority of LTC for older people (Marin et al., 2009).
- Secondly, the Lisbon employment target of enhancing employment rates, especially for women and senior workers (55-64 years), was another strong incentive for recognition of informal care. It called for measures to allow female carers to gain access to the labour market, as well as for senior workers to remain able to work and to provide care.
- Thirdly, policies to ensure the continued and optimal contribution of informal carers, alongside professional services, depend strongly on the degree of accessibility of older people with LTC needs to professional services. Access to services is directly linked to the level of development of LTC policies in each country, which depends on the time period when each one acknowledged the strong impact of ageing on LTC provision and thus the fact that LTC services ought to be considered as an

essential component of their respective welfare states. While this recognition took place in the decade of the 1970s for the Scandinavian countries and the Netherlands, it came twenty or more years later for most of the other EU15 countries.

4.3.1 Main issues and gaps in governance of informal carer support policies

Triantafillou et al. (2010) identified three significant issues leading to the numerous gaps in governance principles of policies for informal carers, relating to their optimal connection with overall LTC policies addressing older people's needs.

The first issue is that informal carers are often both care-providers and as well as people in need of care and should be supported in both regards. Amongst the European countries examined, the contribution and role of informal carers ranges between two extreme models and is directly related to the degree of access to professional services. In the first model (Mediterranean welfare regime), the informal carers' contribution is assumed as they take on almost the entire service provision due to lack of pubic professional services. At the opposite end of the scale, in the superseded carer model (Twigg & Atkin, 1994) represented by Sweden and the Netherlands, carers have the choice not to provide hands-on care due to the provision of adequate and easily accessible formal services for older people. In this case, a specific informal carer policy seems to be less pressing, as long as the professional services remain available and accessible, while being responsive and of satisfactory quality for both stakeholders; but of course this comes at the price of higher LTC funding. In between these two extremes, in countries where formal services are accessible to some extent, informal carers continue to play two entangled roles: as co-providers of services with the professionals; and/or as co-clients together with the older person, with needs for support from formal services (Carretero et al., 2009). Both roles call for measures responding to their specific needs, including those addressing the issue of how to support the oldest informal carers in the long term to avoid all types of care burden, as well as those allowing an optimal balance between work and care.

The second issue relates to achieving a balance for informal carers between working and caring; in order to reach the Lisbon target regarding levels of women's and seniors' employment, how can this choice be made possible without compromising the care they provide?

The development of cash benefits was foreseen as a potential tool to solve this dilemma. Their introduction in the area of LTC gained momentum during the early 1990s in almost all European countries but with very different dynamics. In countries with limited access to professional services, cash benefits came as a new tool for refunding the LTC system, relying more on a market approach while not endangering LTC financial sustainability. In Sweden and the Netherlands, with relative ease of access to formal services, cash benefits appeared linked to a political climate favouring more market-driven mechanisms. In the Nordic countries, aligned with the New Public Management ideas, cash benefits were considered as a means to fight against the 'paternalistic and inefficient way' of planning and delivering public services, as they would enable the opening of the market to non-public providers and boost more responsiveness and quality through competition (Da Roit & Le Bihan, 2010). In the Netherlands, cash benefits were also perceived as a tool to fight against the dominance of professionals in shaping older people's choices, by giving them direct purchasing power in seeking care arrangements that would best fit their needs and expectations (Evers et al., 1994).

In this regard, cash transfers were designed for people with LTC needs (attendance allowance, direct payments) to financially compensate the (informal) carer they had chosen; some countries also developed care allowances as direct cash payments to the carers. Both benefits were aimed at helping informal carers solve the dilemma between working and caring, by giving them (indirectly or directly) some financial compensation for their provision of care, particularly if they had to stop work or reduce working hours. One effect of this 'commodification of care' (Ungerson 2003) was to blur the border between formal and informal carers and bring into question informal carers' previous status i.e. as people providing care with an engagement based on gift and reciprocity; as being non-professionals and not trained to provide care; as performing a wide range of tasks including emotional support and assistance; and with no limits to time spent on care. In a growing number of countries, as a result of these cash benefits, it now appears that a proportion of informal carers benefit from special training and obtain financial contributions based on some form of contracting linked to social rights (OECD).

What are the major impacts of these changes? Data and research are beginning to show that, as cash benefits were also conceived as cost-cutting devices for formal services, in most countries they were set at a level which usually did not allow beneficiaries to care and work under good conditions; also, as they came with a lower level of social rights' coverage than that of a worker in the labour market, they increased their risk of social isolation and poverty (Fontaine et al., 2009). So it appears that funding LTC through cash mechanisms to informal carers may contradict the goal of a high level of employment for women and older people, as it more frequently acts as a 'care-trap' mechanism. Only in the northern countries where cash benefits spread to a more variable, but rather limited extent (slightly more in NL and FI), were the levels of high-dependency care benefits set to be comparable with professionals' salaries and with similar social rights.

It has also been suggested that the introduction of cash benefits as a driver for optimizing the balance between informal and formal care in the provision of care delivery in different countries, was strongly influenced by the historical and legal balance in the sharing of responsibilities for people with LTC needs between families, state and the market (Triantafillou et al., 2010).

- In countries where families have primary financial responsibility for dependants (EL, ES, FR, IT, SK), there is also a corresponding assumption of their responsibilities for providing practical care, thus allowing the state to continue to limit its financial intervention in formal service provision. Furthermore, in some of these countries (IT, EL), the lack of formal support services for older people has led to a high reliance on privately paid migrant care workers. This may also endanger future access to professional resources by reinforcing the trend to set formal care providers' wages at the lowest level, thus giving them the lowest status in the professional hierarchy in the labour market.
- In countries where the state has primary financial responsibility for dependants (SE, NL), this 'formalisation of informal care' contributed to a various extent to a refocusing on families' responsibilities (Da Roit & Le Bihan 2010), giving them a more important role in the care process (FI), while relieving the financial contribution of the state.

The third and major issue lies in the difficulty of isolating sub-policies specifically designed for informal carers from overall LTC policies designed for older people. The 'invisibility' of informal carers' support policies stems from the fact that at all levels, whether political, organisational or delivery, the needs and wishes of informal carers tend to be conflated with those of the person they are supporting (Arksey & Glendinning, 2007). Decision makers appear to take for granted the existence of a natural harmony

between these two actors, neglecting the complex and frequently conflicting dynamics of care-giving relationships. So when assessing the effectiveness of measures regarding informal carers, it is important to disentangle the carer's opinion from that of the older person, acknowledging that they may not coincide.

At delivery level, the provision of cash benefit is an ambivalent mechanism: empowering and giving more choice to the older person through a cash benefit may not necessarily positively impact on the caregiver's situation, as older people's choices may not be in line with the carer's e.g. the choice to work instead of caring may not be accepted by the older person. If attendance allowances are used to pay informal carers, she/he can be placed in a situation of subordination with respect to the recipient, especially in cases of economic weakness. On the other hand, depending on the health status of the person in need, it could be the carers who take complete control of the benefit and the care arrangement, without respecting the older person's wishes and needs. In short, external guidance, support and monitoring are essential to cash-centered personalized service provision.

This is equally the case regarding services in kind**:** though providing services to older people may, at first sight, seem to be in the best interests of informal carers, as these services take over 'hands-on' care, conflict of interest may nevertheless arise as the cared for older person may not agree to the substitution of the family carer by a professional worker. Similarly, respite care will bring the expected relief to informal carers only if they feel that the proposed setting guarantees a good quality service and is appropriate to the older person's care needs, while being acceptable to the older person. On the other hand, it may be that accommodation is planned according to the user's needs while not responding to the informal carer's situation or expectations. This is also true for measures at an organisational and policy level, such as flexible working arrangements to allow informal carers to care and to work: when not based on specific or general labour regulations, but only on colleagues' good will, their level of take up and thus impact are rather limited. This latter point calls for a broader approach to the formation of support policies for informal carers, extending their scope into labour and work policies (as for child care), which implies a different governance approach.

So the issue of whose needs are or should be targeted in LTC policies has to be clearly addressed: building a sound policy for older people does not automatically imply an appropriate policy for informal carers. Bur reciprocally, putting too much reliance on informal carers by strongly supporting them may endanger LTC policies at large by lowering the real level of formal services needs.

4.3.2 Approaches to informal care

Responses to these issues have included the mainstreaming of carer issues into national policies, service developments, support from voluntary and campaigning organisations, development of individualised funding and acknowledgement of the role of migrant workers.

At a formal policy and legislation level the visibility of carer issues in government legislation and guidance are variable across Europe. In the UK strong NGO support for carer issues has led to wide coverage in government literature including a long-standing national strategy for carers (Department of Health, 1999), while in Greece there is no clearly formulated LTC policy and no policies for the support of informal carers. Triantafillou et al. (2010) highlight the importance of care issues being incorporated into wider employment and equalities papers and Acts, rather than becoming disconnected aspects

within health and social care policy. For example, in the UK the Equalities Act (October 2010) includes carers as a group for the first time, protecting them from discrimination from employers or providers of goods and services.

But even when issues of informal care have been incorporated into national policies these often do not address the complexity of informal care work such as caring for specific conditions, carers with their own significant care needs or incorporation of migrant workforce.

- In *Sweden* the National dementia guidelines as of 2010 (Example 6, appendix 3) present evidence around a range of different support measures for informal carers and stress the importance of supporting carers from the outset. The English dementia strategy shares this carer focus and acknowledges the complexities of supporting carers, as it states, 'Family carers of people with dementia are often old and frail themselves, with high levels of depression and physical illness, and a diminished quality of life' (Department of Health, 2009).
- In *Austria* flexible use of informal care is achieved by reliance on a relatively large and well established informal care market, based on migrant caregivers from neighbouring countries. The 'in-cash' tradition of benefit means that these workers can easily be accommodated into the system and are paid by amounts received by care recipients through LTC attendance allowance.
- The *English* system also utilises individualized funding for care recipients to provide flexible care options. People who provide over 35 hours of care per week have a legal right to financial support, as long as the person being cared for has been assessed as in need of care and is receiving an allowance to cover this care.
- In *France*, informal caregivers for Alzheimer patients can also receive financial support. However, only 9% of French families get paid for their help. The vast majority still offer care on a non-paid basis. In many countries the financial support offered to informal carers is seen as a token or symbolic sum rather than a practical support tool, for instance in the Netherlands informal care support is around only €250 per annum.
- The German LTCI has created a long-term assistance allowance for informal carers and an allowance for professional nursing care on different compensatory levels. Both can be combined to release family carers and ensure that the poorest older people receive the care they need. The idea is to avoid an overuse of families in low-income contexts and to allow formal services to pick up some of the informal care work for low-income families. In other countries the intended relationship between formal and informal care services is often unclear. How should these care services work together?
- In Slovakia, the relationship between both formal and informal care are mainly substitutive rather than complementary. Older people receive care either at home or in residential facilities, but intermediary structures or combined approaches in the community are rare. However, a government evaluation of procedures to improve LTC has helped to clarify the use of formal services and informal caregivers.
- In *Germany*, the lack of coordination between formal and informal care sectors has recently (2008) been subject to a LTC reform by further developing the LTCI Act. However, it is doubtful that these current changes will lead to a substantial and comprehensive system change towards integrated care. A clear limitation of health care reforms is their focus on medical care and on medical professionals. This tends to create a barrier towards the possibilities of integrating formal and informal care fields.

- Policies in the Netherlands stipulate that, during the individual assessment it is also considered what the social network is expected to contribute to care delivery on an informal basis. Moreover, the Netherlands has a quite well developed network of day care and respite services for frail older people and meeting centres for people with dementia. Further, there is a network of local support centres for informal carers.
- In France, while information and counselling are becoming more widespread, and despite small-scale interventions, training, education and psychosocial support remain neither legally defined, nor fully reimbursed. Temporary stay and day care, while being promoted types of support, are still insufficient and underused (with less than 1% of places compared to classical settings). This is thought to be the result of a lack of knowledge or fears of users and informal carers regarding the quality of such services.

Part of the integrated care approach involves cooperation and coordination between professionals, volunteers, and informal carers, considered as both co-providers of care as well as clients themselves, with their own needs and support requirements. The potential role of NGOs for addressing interfaces between sectors and driving carer issues forward, as well as for service design and delivery needs to be acknowledged and integrated into LTC systems (Example 7, appendix 3).

4.3.3 A classification of measures to analyse informal carer governance policies

When examining the way the respective needs and choices of both the informal carers and the older people they care for are addressed in LTC policies, the three following dimensions have been evidenced as having a major impact:

- The respective degree of access to and availability of services in-kind and in-cash;
- The balance set between the purchasing power of benefits in-cash with respect to benefits in-kind;
- The difference in the way each type of benefit is regulated with respect to their use and quality.

Triantafillou et al. (2010) used a bottom-up and analytical approach as a first step towards clarifying the underpinning goals of policies directed toward supporting informal carers and their optimal connection with general LTC policies. Drawing upon previous work by Glendinning et al. (2009), a framework was developed that allowed a classification of the wide diversity of possible measures resulting from both informal care and LTC policies. This classification is based on a division of support measures (whether in-kind or in cash) into two broad categories:

- those that intend to respond to informal carers' specific needs, and
- those addressing both their needs and the needs of older people they care for (unspecific).

In each case these support measures are then sub-categorized as either direct or indirect as follows:

- *Specific direct measures* supporting informal carers are those that *help them perform* their caring tasks, for instance measures such as training of informal carers. These may not require any direct input of formal carers or may include them in a 'hand-in-hand' approach, e.g. training formal carers in how to include and support informal carers in a shared provision of care.

- *Specific indirect measures* are those that *enhance the opportunity for informal carers to care in appropriate conditions,* e.g. legal care leave; flexible employment arrangements for working carers, entitlements to pension rights and accident insurance.

Table 4.1 Specific measures for the support of informal carers

Specific measures	*Examples*
Direct Supporting and Improving performance of care	In-kind • Information, training, education • Opportunities for the exchange of experiences • Training of formal carers in how to include and support informal carers in a shared provision of care In cash • Care allowance
Indirect Facilitating informal care	Legal rights • Flexible working arrangements • Care leave • Pension and accidence insurance • Advocacy group. legislative recognition

Non-specific measures (targeting both the older person and the informal carer) are called direct when they *primarily target the informal carer* (e.g. respite care) and indirect when they *primarily target the older person* (e.g. housing adaptation, attendance allowance). In particular any in-kind service for older people in need of care is to be classified as such.

Table 4.2 Non-specific measures for the support of informal carers and older people

Non-specific measures	Examples
Direct (primarily targeting informal carers)	• Respite care • Support groups • Stress relief by voluntary work initiatives
Indirect (primarily targeting older people)	In-kind • All home and residential care services for older people • Housing adaptation, technical supplies. etc. • Meals on wheels In-cash: • Attendance allowance

This framework allows a relative comparison between countries, of approaches in support policies for informal carers, within LCT policies for older people. It can be used to compare the comprehensiveness, the level of availability (do they exist or not), and accessibility with judgments for each measure based on their financial accessibility (level of private payment) and (if known) level of take up. This framework also shows how sectors such as labour, employment, environment and immigration contribute to these policies. Finally, it can help in shedding some light on issues such as how participative democracy,

gender equality or inter- and intra-generational equity underpin the governance of informal care policies within systems of LTC.

5 Finance and Sustainability

This section examines some of the mechanisms which have been used to steer finance in LTC and aims to explore some of the key challenges in financing LTC, including:

- Monitoring financial information where distinct LTC systems are only just emerging and where budget for LTC is often fragmented: between health and social care; between central, regional and local levels; and between people classified as having disabilities and older people with more generalised care needs.
- Creating equality across services rather than the source of funding or entry point influencing the nature and ethos of services provided.
- Ensuring effectiveness where many solutions have been 'quick fixes' and 'bolt ons' rather than comprehensive reform projects.
- Overcoming culturally specific understandings and strong public opinion about the nature of the relationship between state, family, employer and individual and the popularity of different funding systems (e.g. taxation, Insurance, means-testing).

5.1 Public expenditure and resources

Within governance in Europe there are few separate national systems or budgets for LTC. This creates a problem for those monitoring and planning finance, whereby information can slip into the silos of health and social care sectors and the real financial activity and outcomes for LTC remain hidden. As public resources are gathered from different budgets, no countries have implemented a completely separate LTC budget and in fact, for most it is difficult to have a clear idea of how much is spent on LTC for older people. Of the countries surveyed Denmark comes closest to having an integrated budget at the local level for LTC. The Netherlands and Germany are an exception to this rule with distinct LTC insurance systems and budget stemming from the Exceptional medical expenses Act (NL) and LTC Insurance (DE), respectively.

Situated at the boundaries between health and social care, LTC services draw resources from both health and social care systems. This means that different funding sources, financing and access principles (see "Access and Equity" below) and budgets usually apply to LTC within each country, depending on the nature of services involved. Health care is usually provided in the framework of 'mandatory' universal health insurance (financed generally by obligatory tax or social insurance contributions), which aims at being comprehensive in the coverage of the population and therefore tends to be free at the point of delivery. Social care services, on the other hand, have often evolved from social assistance laws. As such their financing relies heavily on tax revenues and user' fees and tend to be means tested based on the user and their family's assets.

The divide between health and social care is acknowledged as key barrier to joint working in almost all countries surveyed. It is mentioned as one of the motivations behind practices of 'cost-shifting' between

health and social care services. An example of this is the early discharge of patients from hospitals (UK), for example following the introduction of hospital funding based on Diagnosis Related Groups (DRG) (DE, FR, AT). In Finland, many residential homes have been renamed as sheltered homes so that municipalities may shift some of the health costs to the National Health Insurance. As the insurance covers medication in sheltered homes, while in residential care homes these costs have to be covered by municipalities.

Difficulties in accounting for LTC expenditure also arise from the fact that different stakeholders (e.g. municipalities or regional states) may be responsible for the governance and financing of different components of LTC (FR, AT, UK, SE, DK, SK). Nevertheless, Table 5.1 provides an overview of the estimates of public expenditure on LTC and the diversity of spending levels is evident. Countries such as Denmark, Sweden, Finland and the Netherlands have much higher expenditure levels (as a percentage of GDP) than the rest, with France, Austria and England as an intermediate group and the Slovak Republic with the lowest share of its GDP devoted to LTC.

Table 5.1 Expenditure on Health and LTC as a percentage of GDP in selected countries, around 2008

	OECD			*DG ECFIN*			*INTERLINKS*
	Total expenditures on LTC, 2008	*Total health expenditures, 2008*	*Total LTC + Health care*	*Public expenditure LTC, 2007*	*Public health care expenditure, 2007*	*Total Public LTC + Health care*	*LTC expenditures (1)*
AT	1.3	10.2	**11.5**	1.3	6.5	**7.8**	1.3
CH	2.1	10.8	**12.9**	0.9	7.4	**8.3**	0.9
DE	1.3	10.4	**11.7**	0.9	7.4	**8.3**	0.9
DK	2.0	9.8	**11.8**	1.7	5.9	**7.6**	2.0
EL	n/a	n/a	-	1.4	5.0	**6.4**	n/a
ES	0.8	8.5	**9.3**	0.5	5.5	**6.0**	0.5
FI	2.2	8.2	**10.4**	1.8	5.5	**7.3**	1.0
FR	1.7	11.0	**12.7**	1.4	8.1	**9.5**	1.4
IT	n/a	n/a	-	1.7	5.9	**7.6**	1.7
NL	3.5	9.7	**13.2**	3.4	4.8	**8.2**	3.6
SK	0.2	4.6	**4.8**	0.2	5.0	**5.2**	0.5
SE	3.6	9.1	**12.7**	3.5	7.2	**10.7**	3.5
SI	1.1	8.3	**9.4**	1.1	6.6	**7.7**	0.8
UK	n/a	n/a	-	0.8	7.5	**8.3**	1.2 (2)

Sources: OECD (http://www.oecd.org/health/sha); Huber et al., 2009; European Commission/ECFIN, 2009; INTERLINKS National Reports.- (1) Public expenditures for LTC, around 2009; (2) England only.

There is a weak link between public expenditure on LTC and demographic ageing, as measured by the share of those aged 80+ in the total population. Observing any consistent relationship between these

measures is further confused by the existence of large differences in public LTC expenditure figures provided by various statistical sources. As seen in other studies (OECD, 2005 and Huber et al., 2009), most public resources are devoted to institutional care, despite the fact that only a minority of those over 65 are cared for in institutions (the un-weighted average for the 65+ population for the EU countries for which there is information is 3.3% only – Huber et al., 2009: 72). In fact, financing institutional care has been a central issue in the debate on reforming LTC systems in many countries (see "Sustainability and Reform" below), as well as on the sustainability of LTC systems (European Commission/ECFIN, 2009).

Getting a realistic picture of LTC expenditure and rank order by country is further complicated by the possibility for some level of substitution between acute care and LTC. In some countries there may be a tendency towards providing LTC in acute settings (classified as health) and in others towards residential care (classified as social or LTC), countries which spend more on LTC might correspondingly spend less on health care and vice versa.

Care services tend to require a fee (co-payment) to be paid by the users[6], with social assistance taking responsibility for paying if users' income is insufficient. Still, estimates for private expenditure (either users' fees or private insurance premiums) in LTC remain scarce and marred with concerns over reliability. For example, depending on how benefits are designed and on data constraints, it may prove difficult to disentangle the part of the cash benefit that is used to pay for services from additional out-of-pocket expenditure, or payments to undocumented carers (AT). Nonetheless, available figures show that user' fees for institutional care can be quite high in many countries (see Huber et al., 2009).

5.2 Access and equity

A number of problems are associated with different funding sources and varying eligibility tests, as these have been seen to form the basis of inequality in the provision of services for citizens in Europe. Access to LTC is made conditional on assessed care needs only, and/or on means-tests. Examples of the first are Sweden, the Netherlands and Denmark, both supporting dependent older people mainly through care services in kind. Austria and Germany also provide benefits based on assessed needs only, but in this case benefits are provided in cash or as a combination of cash and services in kind. Access to LTC in England, Slovak Republic, Greece (by way of targeting health services to low-income or isolated persons) and France (through means-tested co-payments) is subject to various forms of means-testing. Privately funded services run alongside these options providing alternatives with varied take-up across Europe.

In the Slovak Republic cash benefits for compensation for the needs of older dependent people are means-tested, so that only those in the lower income groups are eligible. Eligibility for the full rated personal assistance benefit (attendance allowance) is limited to those with an income equivalent to 75% of the average wage. Those with a higher wage have a decreased benefit rate. The Care Allowance is also subject to a means-test taking into account the people in need of care income. For pensioners the Care Allowance is provided as a lump sum.

[6] Even if care services in a strict sense do not have to be paid for (for example when provided in care facilities in DK), fees are demanded for other components such as accommodation, food or other necessities.

In most countries access and equity are assured by public funding of service delivery, while some other countries assume that people will self-fund, but public support prevents the poorest from impoverishment. Although LTC systems can be broadly characterised as providing benefits on the basis of needs assessment only or means-test, most LTC systems actually combine both elements. Thus, health care provided through the National Health Service (UK) and health related services provided by nurses (FR) are both delivered on the basis of need, with only limited financial barriers to users being reported. Benefits provided to those assessed as in need of care in Austria and Germany fall short of actual care needs. For example, in the region of Lower Austria a person assessed as needing 120 hours of care per month is only eligible for a maximum of 60 hours of subsidised care, leaving the users or their family to cover this gap. The German LTC insurance benefit only covers the service part of institutional care, leaving accommodation costs to be paid by the user. In both cases, the state may provide additional support to pay for services, but this is usually means- or even asset-tested (AT). Also in France, where needs assessment is an acknowledged universal right, the attendance allowance associated with it comes with means-tested co-payments that vary from 10% to 90%.

While for health care 'social protection systems and private health insurance have managed to contain costs faced by private households' (Marin et al., 2009: 15), the level of cost-sharing in LTC is substantially higher. For example, in Finland users paid 22.5% of total LTC costs, while in municipal health services that share was only 4.2% (Klavus & Meriläinen, 2010). What users must pay for institutional care can amount to a high percentage of their income – up to 80% of their pension, plus the attendance allowance and convertible assets in the case of Austria (Rodrigues, 2010) – and assets must usually be spent down before accessing means-tested social assistance. As a means of protection against high fees, many countries have set ceilings on the amounts that users may be required to pay (DK, SE, FI, CH, NL), or established minimum amounts that users can keep as personal expenses when entering a nursing home (AT, SK, FR, NL). Still, even if co-payments are set as a fixed share of income (FI, CH), the skewed pattern of LTC use towards lower income groups may translate into highly regressive payment structures (Klavus & Meriläinen, 2010), with payments made by the user being proportionally higher in the poorer income groups.

The example of the distribution of income-based payments in institutional care (FI) indicates that the interpretation of equity in the context of financing of LTC can be ambiguous (Example 8, appendix 3). In Finland as the payment is set at a fixed rate of income, the users of care at all income levels contribute an equal share of their disposable income in exchange for receiving a more or less equal selection of institutional care services. Aside from the value-based question of whether payments for health and social care services should make up a higher proportion of higher capacity to pay, the payment structure for institutional care is by definition proportional to income at the level of the individual. However, as the payment is only levied on those individuals receiving institutional care, its incidence across the entire distribution of income is determined by the frequency of institutional care use at various parts of the distribution.

In Finland, public institutional care services are used mostly by low-income older people and consequently a major portion of the total financing liability accumulates in the lower end of the income distribution, making the payment structure highly regressive. Whether or not this represents a true equity gap is not straightforward to conclude and depends on the view taken towards relative verses absolute inequality, or system level verses individual level inequality. It could be argued that despite the

regressive nature of the entire distribution, the fixed percentage payment scheme is unfair for older people with very high incomes. In the present example a service user in the highest income decile pays over three times as much for the same institutional care services as a service user in the lowest income decile. In France there is also evidence of a strong anti-redistributive effect, due to the skewed financial incentives given to users to hire a personal assistant, either directly or indirectly through an agency (Naiditch, 2010).

5.3 Steering mechanisms

So far we have seen mechanisms used to steer the financing of LTC in European countries, for instance:

- Definition of eligibility/targeting
- Co-payment/user charges

Other significant mechanisms used to steer finance for the best outcomes include:

- Pooled funding (Example 9, appendix 3)
- Price setting (use of caps and fixed prices)
- Prevention agenda (e.g. investing in community-based prevention and rehabilitation in order to reduce demand for expensive acute and residential care services - see Kümpers et al., 2010)

5.4 Sustainability and policy reforms

In the European context of tightening budgetary conditions, population ageing may lead to increased care needs in the future that could put added pressure on public spending. Fiscal sustainability of LTC systems have thus been the focus of several projection exercises (see European Commission/ECFIN, 2009; Oliveira Martins & de la Maisonneuve, 2006; Comas-Herrera & Wittenberg, 2003).

At a national level concerns over the sustainability of LTC relate not only to its fiscal sustainability (i.e. to what extent public expenditure will remain contained), but also on assuring that dependent older people will be able to access adequate care. Key issues in national LTC debates include:

- How an ageing population and uncertainty around their future mortality/morbidity will impact on public expenditure, particularly the effect of a growing absolute number of people entering the last years of their life-course (what is referred to as the "red-herring hypothesis" in health economics[7] – see Felder et al. 2010) – this is present in all countries, with some going as far as considering their current systems as financially unsustainable (UK, FI, SE). The critical issue is determining whether healthy or unhealthy life years are added.

[7] The hypothesis is that health expenditure is not linked to age per se, but rather to the time of death, so that an ageing population does not necessarily translates into mounting health costs as "individuals will simply enter the costly final phase of their lives at a higher age" (Felder et al., 2010: 205).

- How to fund the care for older people – either institutional care (UK, DE), or more generally how to publicly support those in need of LTC, as is the case of Slovak Republic (see below).

- How to prevent care gaps from occurring as informal care may reduce in the future (DE, AT) and hiring qualified staff for the care sector may become increasingly difficult (DK, FR, NL; see also Fujisawa and Colombo, 2009).

In the face of these challenges several reform options are being considered. Some of these rely on a piecemeal approach, tweaking some aspects of the current systems or enhancing some of the reforms already implemented. Thus, Denmark hopes to improve efficiency of services through user choice and market-mechanisms, or through the use of better screening tools for needs assessment. Unpaid volunteer work has attracted considerable attention in Sweden, as volunteers are asked to take on increasing responsibilities, which has raised concerns over the possible substitution of underfunded public care by volunteers. Some piecemeal measures implemented in the past have proven to be unsustainable in the long run and have since been corrected. For example, freezing benefit amounts (AT, DE) had led to the erosion of the real value of benefits and incentivised users to seek solutions in the informal market of care.

In some of the countries surveyed more profound reforms are being debated, as additional funding sources are considered. The Slovak Republic is giving serious consideration to introducing a compulsory LTC insurance system, in either health or social care. In England the debate is ongoing on a complete overhaul of the present LTC system, involving a greater partnership between the state and the individual (HM Government, 2009). Similarly, some of the reform options being considered for the Dutch Exceptional Medical Expenses Act (AWBZ) involve a greater reliance on individuals (i.e. on private payments). In 2007, funding for domestic help moved from the LTC insurance to Dutch local authorities, with services such as home cleaning no longer being covered (Glendinning and Moran, 2009). In France, the expected law for financing LTC is intended to rely strongly on an individual mandatory type of LTC insurance which would be mutual and thus secured through a fund.

Underlying the sustainability debate in many countries is the role played by informal care, care which in most European countries continues to provide the bulk of LTC at least when provided at home (see Triantafillou et al., 2010). In Austria, Germany and France, LTC systems were set up as a supplement to care provided by the family, with cost-containing motivations in mind (even if not explicitly stated). There are however, growing concerns over how much care families will be able to supply and for how long, as carers themselves will be ageing and more isolated. This in turn may pose added pressure on public social protection systems or give rise to gaps in care provision which already exist in many countries.

The financial sustainability of LTC depends also on the degree to which health care and other components of social LTC services will be integrated in comprehensive reform steps. The country examples point towards a variety of possibilities to pool various funding sources:

- The Greek national report highlights the importance of integrating health and social care at a local level.

- Switzerland reports that the federal government refers to case management as a means to improve cooperation between ambulatory and residential care, as well as between medical and social services.
- The Swedish company 'Tio Hundra' has contracts with both the county councils (responsible for nursing and hospital care) and the municipality (responsible for social care).
- In England, use of 'total place' welfare budgets seek to move decisions over benefit payments to a local level, with welfare spending incorporated into pooled area-based budgets.

National governments have also started to foster various support mechanisms for local cooperation for integrated LTC:

- The Netherlands report a central state cooperation with municipalities, welfare organisations and housing corporations.
- The Finnish response has been to improve clients' active participation in the planning of appropriate care.
- In the UK special attention has been given to joint commissioning, creating integrated service providers for LTC services.
- Slovakia has taken a step toward the governance of integration by highlighting elements of an integrated LTC system under new legislation.

There is an important link between investment in prevention and rehabilitation services for older people and the future sustainability of LTC is increasingly acknowledged in EU countries (Kümpers et al*.,* 2010). Embedding prevention and rehabilitation into national systems has the potential to reduce demand for more expensive acute and residential care. Steps towards achieving more prevention-based approaches can be seen in many EU countries where preventive measures are becoming mainstreamed into policy and legislation e.g. in Denmark preventative home visits for people 75 and over are legally enforced and in England national guidelines on the development of older people's preventative interventions have been published by the Department of Health.

However, the vast majority of initiatives in prevention and rehabilitation, but also in integrated care delivery in general, tend to be small-scale, time-limited pilot projects. Lacking long-term financial commitment from governments the development of such initiatives for older people remains vulnerable to tightening national budgets and 'cuts'. Further evidence around, often hard to prove, impacts of preventive and integrative approaches are needed to gain state confidence in such measures, spread more preventive approaches across whole systems and achieve the resulting cost-benefits.

6 Conclusions

The initial hypothesis of the INTERLINKS consortium consisted in the assumption that LTC systems are just emerging in Europe, with some countries having approached the challenges at a faster pace than others. Related assumptions had been underlined with respect to prevention and rehabilitation in LTC (Kümpers et al., 2010), informal care (Triantafillou et al., 2010) and quality assurance (Nies et al., 2010). Looking at related issues in the area of governance and financing of LTC at the interfaces between health and social care, the impression of a partly neglected construction site of public social policies is even further supported.

The complex and fragmented mix of political responsibilities, funding mechanisms, service providers and purchasers cuts across a range of areas and administrative levels:

- Across national, regional and local level,
- Across the hospital and community care divide,
- Across the health and social care divide,
- Across public, private and third sectors, and
- Across the formal and informal sectors, including idiosyncratic phenomena such as the growing role for migrant care workers in some countries and individuals purchasing and designing their own support arrangements.

In a comparative perspective, it is particularly striking that basic data about the number of (potential) beneficiaries, comprehensive data on expenditures or the number of providers and professionals involved are still at a level of an 'educated guess'. This is partly due to difficulties and differences in definitions, but shows once more the challenges 'at the interfaces' between health and social care as well as the characteristic importance of informal care.

However, despite this complexity and despite long-standing problems around service fragmentation, low status and (not even documented) underfunding, there are a number of positive developments that have been identified, including:

- A much greater policy emphasis on developing more joined-up approaches to the provision of LTC.
- Growing awareness of the need to address historic funding shortfalls and reform the system in order to make it financially sustainable, including new principles of funding.
- Growing emphasis on trying to find the best mix of public and private provision in order to contain costs and improve quality.
- Greater awareness of the need to support family carers.
- Greater emphasis on choice and control for individuals and families.

Depending on the history and culture of different national systems, however, there remain a series of tensions to be resolved and balances to be struck between:

- Using market mechanisms to stimulate greater choice and competition while at the same time ensuring sufficient collaboration and an ability to take a whole system approach.
- The different tasks and functions that need to be performed at different national, regional and local levels.
- The contributions made by both formal and informal spheres of care (including how best to support family carers, to develop an approach based on partnership or co-provision and to recognise the contribution made by migrant workers).
- The different roles and responsibilities (including funding) of the state, the family and the individual in an ageing society.
- Governing to ensure quality in all aspects of LTC provision while containing costs to meet tightening national budgets.
- Governing to embed prevention and rehabilitation into LTC provision in countries that traditionally tend to focus funding on acute and residential care.

In response, participating countries have developed a number of responses summarised in the main body of this report, including the following issues that could be recognized in a positive stance:

- Greater visibility of LTC issues. Acknowledging the need for reform and reconceptualising LTC at a national level, including public consultations around what LTC means in national contexts, what stakeholders are involved and review of funding options for the future (NL, DE, FI).
- Establishing distinct finance and governance administration systems for LTC, for instance separate tax or social-insurance and assessment processes (DE, ES, FR, AT).
- Developing more strategic overviews for LTC and platforms to share local good practice at a regional level (DE, DK, NL).
- Increased marketisation of LTC, with a growing mix of providers competing for both public and private funds has shown ambivalent results. However, drawbacks have been identified that led to complementary measures and (often local) steering mechanisms to ensure quality and guide appropriate service to those with greatest needs, e.g. competitive tendering or cash benefits combined with a higher level of advice and/or case management (all countries in various ways).
- Wider incorporation of carer issues into policy and legislation across government, including national carer strategies, employment and equalities Acts. Carers have been included in national legislation of most countries covered by this study (DE, UK, AT, SE, FI).
- Direct payments and other benefits in cash, designed to allow for greater choice and flexibility around individual care support services. Also in this case, drawbacks and evidently negative outcomes have been addressed by additional measures to amend, for instance, legal shortfalls concerning existing informal care arrangements with migrant carers, to facilitate better information and promote less bureaucratic practices (AT, IT, DE).
- Providing incentives for health and social care partnership working at a local level, essential for ensuring development of high quality prevention and rehabilitation services, has been addressed by funding for integrated pilot initiatives or opportunities to pool health and social care budgets. A problem of such initiatives is often their short-term character or the fact that regulations are changing too quickly to allow for cultural change.
- Greater investment in short-term and transitory rehabilitation services, aiming to improve patient pathways, reduce demand on acute beds and improve cost efficiency of the system, e.g. comprehensive geriatric assessment and rehabilitation units (AT), short-term enabling rehabilitation programmes (DE, UK, NL).

- Greater governance roles for service users and carers to allow care providers to respond to the real needs of older people. Greater user and carer involvement are becoming embedded within quality systems, service design and evaluation.
- The creation of disease specific, pathway-focused quality indicators (for diabetes, stroke, COPD, heart failure etc.) or national strategies for specific conditions (dementia). These visions, guidelines and indicators have the potential to address the links and interfaces between health and social care and the various types of organisations and stakeholders involved in LTC.

Despite significant national and cultural differences, similar issues are being faced and the solutions explored among participating counties – making the sharing of good practice, lessons learned and potential unintended consequences at EU level more important than ever before.

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Appendix 1: EU literature quick scan

Search criteria and scope

This document provides the results of a quick literature scan on the issues of governance and finance on a European Union (EU) level carried out in parallel to the national reports. The searches comprised the WHO and OECD library databases (WHOLIS and SourceOECD and OECDiLibrary respectively), as well as the Research Papers in Economics (RePEc) and Social Science Research Network (SSRN) databases. These searches were carried out during February 2010, using the following keywords (or a combination of them): LTC, social care, elderly care, governance, finance, expenditure, funding, and reform. This quick scan covered EU-wide papers, articles and reports that addressed the issues of governance and finance in LTC for dependent older people. Within each of these broader areas, the searches focused particularly on:

- Forms of regulation and governance (e.g., rescaling structures of governance);
- Modernisation in LTC organisation and management;
- Funding systems in LTC;
- Public/private mix in governance and finance;
- Estimations and projections of public expenditure on LTC and its drivers.

The inclusion criteria for the quick literature scan were the following:

- Should have a comparative scope (literature based solely or mostly on national cases was not considered) or a EU-wide approach to the subjects within the area of LTC;
- Systematic reviews were desirable;
- Preference for literature with impact on policy, or addressing overall trends or analysis, over more academic literature on clustering of countries around *models* of LTC provision or organisation;
- Published after 2000, with preference for more recent papers (e.g., only the most recent of the Ageing Reports from the European Commission was included);
- Available abstract and full text in English.

The references retrieved from the quick literature scan are presented in the reference list. Concise summaries for of these references – main findings, scope and keywords – are presented in the next section.

Finally, appendix 1 provides an overview of current and project public expenditure on LTC in European countries according to some of the sources surveyed here.

Findings from selected publications

From the publications surveyed (see References) those considered most relevant for the issues of governance and finance were selected and a much concise analysis of its findings is presented below, as well as some keywords.

Reference:

Lundsgaard, J. (2005) "Consumer Direction and Choice in Long-term Care for Older Persons". OECD Health Working Papers No. 20, OECD, Paris.

Keywords: Cash benefits, user choice, informal care.

Scope: Overview of cash benefits for care in OECD countries, distinguishing between care allowances and attendance allowances and analysing its consequences for user choice in LTC.

Findings: The author identifies enhancing user choice as a way to address quality aspects of care, particularly those that are experienced by users but hard to model or quantify. Mechanisms to increase user choice through cash benefits may also be linked with support to informal care: not only beneficiaries of cash benefits are sometimes allowed to compensate informal carers, but cash benefits may be provided directly to carers – care allowances. Cash is the preferred option of state support over in-kind benefits for dependent people in many countries (e.g., Germany) and although concerns over quality of care and elder abuse are present, actual deficits of quality are few and the biggest issue may well be over-burdened carers.

There is also a focus on the fiscal and labour market implications of these cash benefits and although paying informal carers may allow access to a larger pool of resources (informal carers) increasing value for money, this may have potential side-effects. Cash benefits for carers may work as a disincentive to take-up paid work, or lead to the creation of informal care markets.

Reference:

OECD (2005) *Long-term care for older people*. Paris: OECD.

Keywords: Governance, financing, reform, expenditure, public/private mix, user choice.

Scope: Comparative analysis of LTC policies in OECD countries, looking at the main policy issues, as well as recent reforms, policy trends and data (e.g. beneficiaries and expenditure).

Findings: On the expenditure issues, the book points out some factors that might explain differences in expenditure levels among countries, namely, different public/private mixes and "amenities" that are included in institutional care. Institutional care places the heaviest financial burden on both families and public resources.

The book also analyses the current arrangements for increased consumer-direction and choice in LTC, particularly in home care: personal budgets and employment of care assistants, payments to those in need of care and payments to informal care givers as a form of income support. These arrangements are linked with the development of a more diversified LTC sector (as cash benefits and personal budgets are usually demand-side arrangements) and informal care support.

Reforms made in funding of LTC systems are also presented, from the introduction of "universal" public schemes (social insurance-based schemes in Germany and Luxembourg to a tax-funded system of allowances in Austria) to reforms performed in existing systems (e.g. increased targeting in Sweden).

Reference: Oliveira Martins, M. J. and C. de la Maisonneuve (2006) *The Drivers of Public Expenditure on Health and Long-Term Care: An Integrated Approach.* Paris: OECD (OECD Economic Studies, No. 42).

Keywords: Expenditure, projecting expenditure, econometric models.

Scope: A simulation exercise on future health and LTC expenditures in OECD countries (until 2050), involving a series of scenarios related to future demography, dependency in old-age, unit costs and availability of informal care.

Findings: The paper indentifies some of the main drivers of expenditure regarding LTC: demographic drivers (including health status of older people) and non-demographic drivers, e.g., reliance on informal care and unit costs (in the context of this paper associated mainly with wages and productivity in the care sector). Demographic effects could almost double expenditure (see table A1 in the appendix 1), but the impact on expenditure would be greater in the scenario that assumes higher unit costs (which the authors assume as a very likely scenario given the labour intensive nature of the care sector and the reduced scope for productivity gains) or reduced availability of informal care.

As for the calculated age-expenditure profiles, these remain relatively flat until the 65-69 age group and rise exponentially for the older age groups. The share of dependent people though seems to be fairly uniform across countries.

Econometric modelling of expenditure seems to confirm the participation ratio of the 50-64 age group as a good proxy for availability of informal care and suggests that income-elasticity could be small (i.e., that higher income would not influence greatly demand for care or better care).

Reference:

Burau, V., Theobald, H. and Blank, R. (2007) *Governing Home Care: A Cross-National Comparison*. Cheltenham: Edgar Elgar.

Keywords: Governance, informal care, home care, public/private mix, gender.

Scope: Comparative analysis of the governance of home care (including informal care) in Estonia, Italy, Japan, Germany, New Zealand, UK, Sweden, the Netherlands and the US.

Findings: Some of the tensions between the state, market and the family in the governance of home care are analysed, mapping both the ideas and institutions that frame governance of home care. The authors point to the fragmentation of governance (between different areas – health and social care –

and levels of governance – national and local level – and providers – public and private providers) as one of the underlying impediments to better performance of home care. This fragmentation is observed on the delivery level, but also in budgets and regulations.

User choice is one of the issues addressed in this book and while some countries seem to allow choice within care services (i.e., between different providers), others extend this choice to informal care as well (e.g. Germany and Italy). Dissimilarities between countries reflect differences in care regimes (cultural settings), social institutions and in the interplay between different levels of governance. Fragmentation can limit the scope of governing arrangements (e.g., the autonomy of Swedish municipalities translates into local variations as to the possibility to choose between providers – thus limiting the national-level guideline or policy goal), while cohesion can act as a lever for governance. Overall, the authors identify a trend of divergence between countries in governance of home care.

Home care is a highly gendered area of governance and while sustainability of women as informal carers is key in the agenda of many policy-makers, the Lisbon Agenda may impose further challenges and increase the need for formal care services.

Reference:

Pavolini, E. and Ranci, R. (2008) 'Restructuring the welfare state: reforms in long-term care in Western European countries' in: *Journal of European Social Policy*, Vol 18(3): 246-259.

Keywords: public/private mix, governance, finance, modernisation.

Scope: Analysis of reforms in LTC systems of six European countries (Germany, Sweden, France, Italy, Netherlands, UK) from the viewpoint of the changing public/private mix and governance.

Findings: The authors argue that many European countries have sought to balance the need to expand social care with budgetary constraints and that reforms introduced have shared some characteristics: combination of cash and in-kind benefits; establishment of social care markets based on competition; empowerment of users; introduction of funding measures that aim to foster family care giving. Among the identified "paths of innovation" are: a) ageing in place, i.e., enhancing the possibility to be cared at home (including informal care in the care continuum as it is increasingly recognised as complementary to professional home services); b) targeting of care resources on North European countries (UK and Sweden – namely by concentration on provision or support of core care services), while countries in Continental Europe increased financial resources allocated to care (France and Germany); c) introduction of a clear split between the functions of financing and provision; d) user empowerment (e.g. through cash benefits) as part of the market mechanisms introduced in care provision. As a result, the state has changed its role from direct provider to enabler/regulator of the self-determination of users.

Reference:

Huber, M., Maucher, M. and Sak, B. (2008) *Study on social and health services of general interest in the European Union: final synthesis report*. Brussels: DG Employment, Social Affairs and Equal Opportunities.

Keywords: Governance, financing, modernisation of LTC, regulation.

Scope: Overview of social services in the EU, including LTC with a focus on the issues of modernisation and governance of social services and key policy trends, although financing and expenditure are also included. Countries covered are: Czech Republic, Germany, France, Italy, the Netherlands and Poland.

Findings: The issues of governance and finance of LTC services are addressed particularly in chapters 9 through 12 of this report. The report identifies key drivers of structural modernisation (although not all confined to LTC): adaptation to changing needs; search for improved efficient and effective provision in a context of cost containment; promotion of access to social rights; search for quality improvement; stronger user orientation, empowerment of users and more user choice; quest for improving social/societal outcomes.

While previously LTC services acted on insufficiency of resources or lack of home-environment, they are now expected to provide better (more medicalised) care to a larger and more differentiated share of the population and to protect against catastrophic financial losses associated with LTC needs (particularly in institutions).

The quest for improved efficiency and effectiveness has also been gaining ground in LTC, influenced by concepts of New Public Management. This has led to an increased effort to improve measurement of performance, namely through performance indicators, benchmarking and outcome assessment.

The strengthening of user orientation has been seen as a strategy not only to enhance quality and efficiency of services, but also user satisfaction. It has been developed under various "strands of thinking": welfarism, participationism and consumerism – with a greater emphasis on the latter. Personal budgets, or similar benefits, as a way of empowering users are on the rise, and user empowerment seems to go hand-in-hand with marked-based regulations that entail a move from public to private (commercial or non-profit) provision of services.

Rescaling, i.e. the process of changing division of power between administrative levels, has been considered a central tool to enhance quality and efficiency. In the field of LTC the report identifies a trend towards decentralisation of governance in LTC, from national to local organisation of services.

Among the methods used to ensure service provision, there has been a trend towards reducing public-programming regulation in favour of market-based or quasi-market regulation. Possible caveats are that continuity is an important issue in LTC services and successful commissioning depends on mature relationships between providers and commissioners, which may limit the effects of competitive tendering and contracting.

Regarding the integration of health and social services, this has been recognised as a cause of difficulties in the coordination of care packages for dependent people and some measures that favour integration are listed. Still, the issue seems to be yet unresolved in most countries.

Reference:

Rothgang, H. and Engelke, K. (2008) *Long-term care: How to organise affordable, sustainable long-term care given the constraints of collective versus individual arrangements and responsibilities,* Discussion paper for the Peer Review on Social Protection and Social Inclusion.

Keywords: Financing, expenditure, public/private mix, care workers.

Scope: Overview of the reforms introduced in funding of LTC systems and their social and financial implications.

Findings: In order to limit public spending, many countries have reformed the financing arrangements of their LTC systems. The starting point – how much is spent already today – is hampered by data limitations as different sources present different results in terms of public expenditure, not least of all due to the difficulties in framing or setting the boundaries of LTC. While setting the boundaries of LTC care may be a tool to control costs, it may also obstruct the provision of integrated care.

There is a strong case to be made in favour of universal (based on needs) coverage of LTC services, not least of all given the issues associated with private insurance for LTC (e.g., limited coverage, need to be compulsory and then becoming very much a form of social insurance). Given the risks posed by demography on the fiscal sustainability of public systems, some kind of buffer fund may be worth considering.

Labour shortages on the care sector are also likely to pose further challenges to the fiscal sustainability of LTC. Measures from both the demand and supply side are recommended: support for family care-giving (demand-side approach to limit demand of formal services) and stratification of tasks and roles (higher paid workers should organise and manage, while the “hands on” tasks could be performed by workers that don’t require highly-qualified training) and use of voluntary care workers.

Reference:

Glendinning, C. (2009) *Combining choice, quality and equity in social services provision*, Synthesis report for the Peer Review on Social Protection and Social Inclusion.

Keywords: User choice, public/private mix, governance, care markets.

Scope: Overview of the national policies and EU-wide discussion and policy recommendations on user choice in social services for the elderly. It covers Estonia, Hungary, Italy, Lithuania, the Netherlands, Portugal, Romania, Spain UK and Denmark.

Findings: Some countries in the EU still face major inequalities in access to good quality social services, not least of all because of the unequal service provision within countries. Universal access (according to need) to basic services of good quality could reduce the risks that access to quality care remains confined to a minority of individuals.

While several countries have introduced market-arrangements for the provision of care services, it has not been easy to attract new market entrants, particularly to some more sparsely populated areas – existence of barriers to entry. No evidence exists that increased competition will result in lower costs, quite on the contrary.

Quality assurance is fundamental, but countries vary greatly in levels of service quality. In countries now starting to extend care services, too high quality requirements may prove counterproductive and lead to providers exiting the market. When in place, quality assurance is still very much based on service inputs rather than user experiences and outcomes.

Reference:

Fernandez, J. L., Forder, J., Trukeschitz, B., Rokosova, M., McDaid, D. (2009) *How can European states design efficient, equitable and sustainable funding systems for long-term care projects for older people?* Copenhagen: World Health Organisation.

Keywords: Financing, public/private mix, equity.

Scope: Policy-oriented paper on the funding options available to policy-makers regarding LTC for older people. It provides general guidelines to ensure socially and financially sustainable funding systems.

Findings: Given the potentially huge costs associated with LTC needs, both in terms of income and assets there is a strong case towards some collective funding solution. Thus far, private insurance for LTC has not proven to be an adequate solution as its importance remains marginal, or limited to a supplementary role in most EU countries. Similarly, reliance on informal care is not likely to be possible forever. This further strengthens the case for state intervention in funding LTC.

Although funding options and expenditure level ultimately depend on what societies find acceptable, some broad policy options are presented. These options involve either a universal-based system that covers the population in need of care (financed by tax revenues or through insurance-based systems), or a safety net system, targeting resources to the poorer among those in need of care (means-tested), or a combination of the two (dubbed “progressive universalist funding systems” by the authors).

In devising and setting-up funding systems for LTC, some steps should be taken. The chosen system should be built on a consensual basis and should be transparent and comprehensive in terms of its funding sources. It should strike a balance between flexibility (e.g., management and assessment by front-line managers) and transparency (e.g., clear set rules as is usually the case with insurance-based systems) in the assessment of needs and provision of support and attention should be paid to the coordination with other systems and stakeholders (including informal carers).

Reference:

Huber, M., Rodrigues, R., Hoffmann, F., Gasior, K. and Marin, B. (2009) *Facts and Figures on Long-term Care – Europe and North America*. European Centre for Social Welfare Policy and Research, Vienna.

Keywords: Expenditure, public/private mix, user choice, cash benefits.

Scope: The book includes indicators on expenditure, beneficiaries, informal care and other topics related to LTC, providing a comparative overview of figures and policies on LTC in Europe (including CIS countries), Canada, USA and Israel.

Findings: The book points towards some policy trends in the field of LTC for older people. Chiefly among these are the growing importance of cash benefits, home care (at least in the policy discourse), the tendency towards a decentralisation of governance or service delivery and somehow conflicting trends towards universalism (e.g. the social insurance-based funding systems in Germany and Luxembourg) and greater targeting (e.g. in Sweden).

Cash benefits have gained importance over the last years as a form of public support to those in need of care or to carers themselves. The book highlights some of the possible consequences that the design of cash benefits may have over labour supply of carers (and thus a series of constraints that are imposed on the beneficiaries of care allowances) or public expenditure (which is why some of these cash benefits have embedded cost-containing measures).

Public expenditure is being mostly allocated to institutional care and despite this users are still required to pay substantial amounts if required to take-up institutional care, which helps to explain why this is also where most private resources are spent on LTC.

Reference: European Commission, ECFIN, (2009) The 2009 Ageing Report: Economic and budgetary projections for the EU-27 Member States (2008-2060). European Economy 2/2009, Brussels.

Keywords: Expenditure, projecting expenditure.

Scope: The paper provides estimates on actual and projected public expenditure on LTC (until 2060) for EU countries (plus Norway), according to several scenarios.

Findings: The paper projects the future needs of LTC according to shifts in the dependency rates (i.e., the share of older population that is disabled and requiring the provision of a care service), demography and policy settings. The paper contains only projections on public expenditure and not explicit policy recommendations for reforming long-term care.

The scenarios used in the projection exercises include: the AWG reference scenario (based on a "prudent" set of assumptions); a "pure" demographic scenario (population with disability grows in line

with population ageing only); a constant disability scenario (where disability rates decline); shifts in informal care (from informal care to formal care, with further scenarios disaggregating this shift to home care, institutional care or a mix of both); a demand-driven expenditure scenario (implying that costs with LTC grow in line with GDP per capita growth); and a fast/slow growth in unit costs.

On an average level, the highest budgetary impact would come from shifts from informal care to formal institutional or mixed care (home and institutional care), while even the more benign scenario of a shift to home care only would more than double current public expenditure. Other high impact scenarios are those associated with a fast growth in unit costs and with pure demographic ageing (i.e., unfavourable dependency rates in the future). Even the most favourable scenarios would imply a close to 100% increase in public expenditure for the EU average by 2060 (see table A1 in the appendix 1).

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Appendix 2: National reports

Building on the Hudson et al. (1997) framework outlined in Figure 2 in the main body of the report, each participating country produced a national report covering the following key themes/questions. To aid consistency and facilitate cross-national analysis, a sample report from the work package leaders was circulated, and each participant was asked to follow the same overarching structure:

1) If you were explaining your LTC system to someone with no knowledge of your country, what three main contextual factors would they need to know? (This might include issues such as the history of services, particular professional cultures, attitudes to state services, the role of families and of women, the ethnic make-up of the community, the role of service user organizations etc) – max 1 page A4

2) How are LTC services governed and financed (max 1 page A4)? For example, descriptions might include:

   - Which agencies are involved and how are they organised?
   - Who (if anyone) co-ordinates care and how?
   - Who decides on issues of eligibility?
   - How are services funded and by whom?
   - What mechanisms are in place to promote inter-agency collaboration?
   - What are the respective roles of the public, private and voluntary sectors?
   - What role is played by patient groups and/or by individual patients?
   - What role is played by families?

   NB In particular, please comment on ways in which services seek to promote:
   - Equity of access
   - Effectiveness

3) To what extent is your system fragmented by the following barriers:

   - Structural?
   - Procedural?
   - Financial?
   - Professional?
   - Issues of status and legitimacy? (max 0.5 pages of A4 per barrier)

4) To what extent and how does your system try to promote:

   - Shared vision?
   - Clarity of roles and responsibilities?
   - Appropriate incentives and rewards?
   - Accountability for joint working? (max 0.5 pages A4 per success factor)

5) What do your LTC services cost (please include a basic overview/simple national estimates)? (max 0.5 pages A4)

6) How financially sustainable is the system and what work has been done to explore this in future given current demographic changes? (max 0.5 pages A4)

7) What are the key factors influencing debates about the sustainability of LTC in your country (for example, demography, social changes, changes in technology etc)? (max 0.5 pages A4)

8) What examples of good practice would you like to share with other countries (up to 3)? Please provide a brief overview/explanation (0.5 pages A4)

9) What tensions or difficulties would you like to highlight (up to 3)? Please provide a brief overview/explanation (0.5 pages A4 max)

10) How does your system try to embed good practice in everyday practice (e.g. in terms of incentives/disincentives, sanctions, legal framework etc)? (1 page A4 max)

Initially national reports were based on the expert knowledge of each INTERLINKS partner, supplemented where appropriate by additional national literature searches and/or informal interviews with key national stakeholders. However, as with other INTERLINKS reports and work packages, a key feature of the project was the use of *National Expert Panels* (NEPs) to review, critically analyse and validate initial draft reports. After this, representatives from each participating country met to conduct a thematic analysis of this material, including:

- Identifying initial similarities and differences in national reports
- Exploring cross-cutting themes emerging from this initial overview
- Constantly checking back to make sure that the emerging themes continued to provide a helpful explanation of the data
- Pairing participants from different countries to work together on each emerging theme
- Agreeing the key policy and practice issues (including national case studies) within each theme
- Drafting an initial overview report
- Meeting again to complete the analysis, confirm key themes and agree a final report

Appendix 3: National practice examples

Example 1 – Slovakia: Unequal legal position of public and non-public providers

Background

In Slovakia, social services are provided by *registered providers*. The registration is administered by regional self-government (Upper regional units – URUs). Each provider has the duty to give proof about their specialized skills and about fulfilling requirements concerning personnel, material, financial, spatial and hygiene conditions.

Description

The Act No. 448/2008 Coll. on social services distinguishes two types of social service providers: *public provider* (municipality, legal person established by municipality, URU and legal person established by URU) or *non-public provider* (e.g. legal Church person, civil association, foundation, non-profit organization, entrepreneur or self-employed person).

At present, the majority of social services are provided by public providers of local or regional nature, but participation of non-public providers is also needed. Non-public providers run ca 35 per cent of social service facilities, mainly operating for seniors and disabled persons (Source: Statistical Office of SR: Social service facilities in Slovak republic in 2009).

Financing of public providers is guaranteed mainly by budgets of municipalities and URUs and by fees of clients. Non-public providers are financed mainly by private sources (clients´ s out-of pocket payments), but – under the legal conditions – also by grants from public resources (from budgets of self-government). According to the Act the non-public provider can receive financial grant from public resources only in the case when the municipality or URU is not able to cover ADL client´s needs under its own responsibility and therefore commissions social service by non-public provider. Non-public providers were disadvantaged by this rule because without public grants undertaking their tasks was difficult. The mentioned rules negatively impacted clients: they could not exercise the right on provider choice and, when they chose a non-public provider, who was not provided with a public grant, the client had to pay the market price.

Those regulations "against" non-public providers were marked by *Constitutional Court´s judgment* as infringing the right to freedom of trade and in conflict with the Slovak Constitution. Based on the judgement, those regulations lost their force from August 2010. So, in law and in application praxis, equal position of both the public and non-public providers will be guaranteed as well as the right of client to choose the provider of social service according his/her own preferences. It can be expected that the new legal situation will lead to improvement of competition in the social services market and will support quality improvement within social services.

Outcomes

Despite the new legislative development the current situation has a negative impact on the public financial resources for social services (the productivity of national economy became lower), that also impacts clients and providers – both public as well as non-public. Therefore, the Government considers in a near future the implementation of the *multi-sourced approach* to finance system of social services. At present, government attempts to provide temporary solutions through ad hoc measures, e.g. by grants from state budget for both public and non-public providers, or by reimbursement expenses of self-governments arising by performing of the new tasks resulting from the Act on social services.

Example 2 – Germany: Market Mechanisms in the LTC System

Background

In Germany the statutory Long-Term Care Insurance (LTCI) has been introduced incrementally since 1995. While statutory health insurance is a fully comprehensive system, LTC Insurance is based on a limited insurance entitlement that does not cover all care demands of insured persons. The LTCI licenses care providers in agreements known as 'care contracts'. They regulate the legal benefits in-kind benefits for home and residential care that insures persons can claim. Paragraph 72, Social Code Book XI (LTCI Act) has established the option for all registered care providers to enter the care market and bill with the LTCI. This intended open competition brought an increasing amount of private and third sector out-patient care services. From 1999 to 2007 the number of outpatient nursing care services increased by about 11%. In this period the companies supported 17% more persons in need of care with 18% more employees.

Description

Nevertheless, there is no free competition on the long-term care market because care services including the in-kind transfers are negotiated (with respect to a fixed range of services) between insurance funds and professional care providers. The individual cash benefit has been limited to a fixed level depending on the degree of care needs, even if the demand of the users increases. In accordance with the last Care Reform in 2008, the benefits for care service has been advanced after 13 years. Prospectively, the financial situation of the German statutory LTC Insurance remains tight. While in the first years after introduction the net results of revenues and expenditures were positive, they have turned negative to the first time in 1999 and in some following years. Due to an increasing number of benefit recipients and less contributors caused by unemployment, the expenditures will rise in the future. Related to national economy, the expenditures of LTC Insurances have been legally fixed at the level of monthly revenues. In case of high up and downturns there is no official control mechanism of expenditures. Increasing costs for LTC demands have to be balanced by higher contributions to the LTC Insurance or subventions by the national budget. Until now a limited private care market besides the care services financed by LTCI could be established. Avoiding the high costs of legal care services persons in need of care more and more choose illegal care helpers and give way to establish a "grey care market". In order to contain this development the German Government has started an initiative to legalise illegal care workers from abroad.

Outcome

In Germany provision of nursing care and some domains of social care services are regulated by the National Government and financed as well as controlled by the legal and private LTC Insurances. For governments and regional and local municipalities, the only way to influence market mechanisms is to negotiate rates for nursing care and home care services. These governments are also responsible for social care and local services structures for LTC. In fact there is no shared accountability for a comprehensive care provision including social care. This gap in direction and steering cannot be resolved by market mechanisms that are in permanent tension between free-market competition and statutory control.

Example 3 – Netherlands: Commissioning of Integrated Dementia Care in the Netherlands

Background

In the Netherlands, people who (by the national needs assessment organisation CIZ) have been declared eligible for LTC, have a statutory right to care and services in the framework of the LTC Act called AWBZ. The regional AWBZ 'care offices' (CO) are responsible for ensuring that claimants get proper care. With this aim in mind, the CO purchases care from all providers in its working area, in a process of negotiation and commissioning. The CO is the only purchaser of LTC. With each provider, a contract is agreed for capacity, price and quality of the purchased care. The provider will supply care and services to individual patients within the framework of the contract, matching the provided care with the patient's CIZ assessment.

This procedure is not considered appropriate for integrated dementia care (IDC). Regular purchasing of care 'products' neglects the aspects of community dementia care that are highly desired by patients and informal carers. Such aspects are coherence between LTC services, a link with non-LTC care and services, support to informal carers of the dementia patient, and tools for bringing about continuity and coherence, such as case management.

To improve the situation, a first requirement is a definition of dementia care. A broad working group presided by the Ministry of Health Welfare and Sport on the introduction of Integrated Dementia Care states that IDC consists of a combination of cure, care, social support and living facilities that may change in the course of the disease. Furthermore, a distinction is made in three stages: before diagnosis, diagnosis and allocation of care, delivery of care and services. For each stage a number of activities are mentioned, with a total of 17 examples including: information; referral; co-ordination and case management; treatment; ADL support; transportation; respite care; crisis intervention; and transfer to residential care. The elements of good IDC have been laid down in a guideline (Ministry of Health, Welfare and Sport, 2009).

For each activity one or more designated participant in the integrated care system is responsible. The participants are the same organisations that used to be involved in dementia care on an unintegrated basis, for example residential care, community mental health care, GPs, the LTC insurance office, local authorities, home care organisations. Together, the participants of IDC accept responsibility for its features of integration.

Now, how can this variety of care and services be purchased in an integrated way, leaving intact the existing (statutory) mode of purchasing?

Description

The guidelines issued by the working group not only specify good IDC, but also directions on how care providers in a region can build IDC, and directions to COs on how to deal with such IDC when purchasing dementia care. IDC is regionally based; regions are loosely defined adherence areas, together covering almost all of the country. The typical size of a region is half a million inhabitants (including 7,000 dementia patients).

IDC does not include entirely new LTC services, rather the package complies with set of quality features for dementia care, so the purchasing procedure need not be much different from the usual one. The CO prepares a general purchasing plan of LTC care in open consultation with all providers. The total demand of care and the variety and capacity of providers is considered. In this purchasing plan the number, intensity and quality of residential days are also included. The CO issue a tender and providers offer their bids, but care and services that belong to dementia care are only be commissioned if it is part and parcel of a bid of an IDC network. The providers in the IDC network jointly draft an IDC plan that specifies the dementia care and services offered and by which organisation. It also specifies organisational features, the planned effort of case management and the way referrals are undertaken.

This will allow the care office to contract care providers in the usual way, on a cash for service basis, except that the presence of IDC will be considered, as well as its organisational quality and the presence of case management in the package. However, a CO might as well decide to fund the complete IDC (i.e. the main contractor) with a calculated lump sum; the main contractor will then be responsible for the care delivered by the IDC network and for distributing the money.

Similar to IDC, case management is not a new care product. If it were, it would require special assessment and specific statutory rights for patients and every provider would be allowed to offer this new type of care. Instead, the care office considers case management as an essential part of IDC. The IDC itself may define the operational properties of its case management. Its funding may come from additional sources, like the province, or a one-time project subsidy from a charity fund. There is a general wish to have case management funded in a more structural way.

For IDC, no extra money is available from the CO. What then are the incentives for care providers to be in an IDC network? Generally, being part of an IDC network may increase the likelihood of being awarded a (larger) contract with the CO. Also, it may bring some financial advantage by funding from additional sources.

Even though an IDC plan must be present, the criteria that the CO will use to check it may vary. The national guidelines include a check of the appropriateness of an IDC plan, but a CO has autonomy to decide on this. In some regions it is even possible that dementia care is provided without an IDC network being present; also, in some regions the way the CO maintains a criteria of an IDC network is rather weak. Partially, this is by necessity, as in one out of every four regions IDC is still absent or just in a state of primary development (by 2009). A new care standard for IDC is being developed for the end of 2011, which will specify in a mandatory way what care has to be included in IDC for being funded.

Outcomes

In 2010, care offices have purchased IDC in almost all (59 of 65) regions. Agreements have been made about responsibility for care delivery including: financial responsibility; number of hours of case management; case load of case managers; and overhead costs.

Co-operation within IDC seems to lead to better care for the patient. Case management is now regarded a prime intervention in almost all regions; availability of and access to case managers has improved, but funding varies and is still a concern. Fixed procedures and multidisciplinary co-operation lead to earlier

and better diagnosis. From the successful initiatives it can be concluded that it is possible to build an IDC network within a couple of years.

Some factors for successful purchasing practice can be identified: involvement of CEOs of care providers (rather than operational managers); clear agreements between IDC participants; an active role of representatives of the national Alzheimer association ('Alzheimer Nederland'); commitment of all participants and willingness to make an investment of time and resources.

The IDC guidelines of the departmental working group mention a list of indicators of the development of IDC networks, and a monitor of patients' experiences. First results (in 19 IDC networks) are that patients and informal carers experience a case manager[8] as very important for continuity and integration of care. Meeting centers (Alzheimer café's) for people with dementia and their carers are very much appreciated. Early recognition and respite care are relatively unknown services. Domestic help is not found sufficiently responsive to dementia patients' needs. In spite of the presence of IDC networks almost everywhere in 2010, the degree of involvement of desired partners, like local authorities (absent in 40%) and GPs (absent in 45%), was not satisfactory in 2010. The situation is currently being re-assessed (spring 2011).

[8] The case manager in Dutch dementia care is described in more detail in INTERLINKS Practice Example 'Case managers for people with dementia and their informal caregivers' (http://interlinks.euro.centre.org/node/59)

Example 4 – Denmark: Local government reforms, 2007

Background

In Denmark, strong public services already have a long tradition within the care system. A nationwide local government reform came into force in 2007.

Description

The objectives of the reform 2007 were to encourage collaboration and multidisciplinary working between different stakeholders, thereby ensuring more efficient use of resources, and greater focus on population needs, including LTC, at the local level. It was also intended to contribute to greater coherence between the administrative levels. The stated aims are to increase cross-sectoral working, improve quality, increase recruitment and improve continuity for patients (Campbell and Wagner 2010).

The reforms meant that regional and local authorities gained overall responsibility for providing and commissioning comprehensive care services and can exert strong local/regional steering capacity. This change intended to provide a better basis for ensuring cohesive patient treatment and care, and simplified access to examination, treatment and care. Under the new structure set out in the reforms local authorities are the gatekeepers for public LTC services and adopt a significantly stronger role in health and social care.

Five new regions became responsible for the health sector, i.e. hospitals, psychiatric treatment and the Danish Health Security. The regions are responsible for coordinating strategic planning and enhancing quality. Within the reformed system, services remain predominantly delivered by public providers. However, competitive instruments are also used to enhance efficiency and quality of care provision. A growing emphasis on choice has led to transparency in the use of resources. Local LTC is exposed to competition from private providers, with the intention of contributing to more efficient task solving. Thirdly, specific incentives were set to stimulate the development of innovative care concepts.

Outcomes

Local authorities are still transforming and there is a general consensus that the full impact cannot yet be ascertained. However, local service developments show very promising signs, particularly in regard to bringing together health and social care services. In Denmark LTC services, such as community-based prevention and rehabilitation, have gone through a major change process in terms of organisation, management and delivery.

In Denmark, localised capacity in LTC has enabled successful multi-disciplinary centres for LTC. Set up by local authorities, the concept is an organisational unit, usually led by senior nurses or physiotherapists, that offers patients who have been referred by their GPs targeted health promotional, preventative and rehabilitative support, training, guidance and/or treatment, coordinated and delivered by a multi-disciplinary team, that may include all or some of the following: nurses, physiotherapists, occupational therapists, psychologists, doctors, social workers, dieticians. All health centres have in common the need for strong partnership and joint working between GPs, hospitals, patient associations and training and exercise providers.

Example 5 – Switzerland: Intercantonal cooperation for health policy

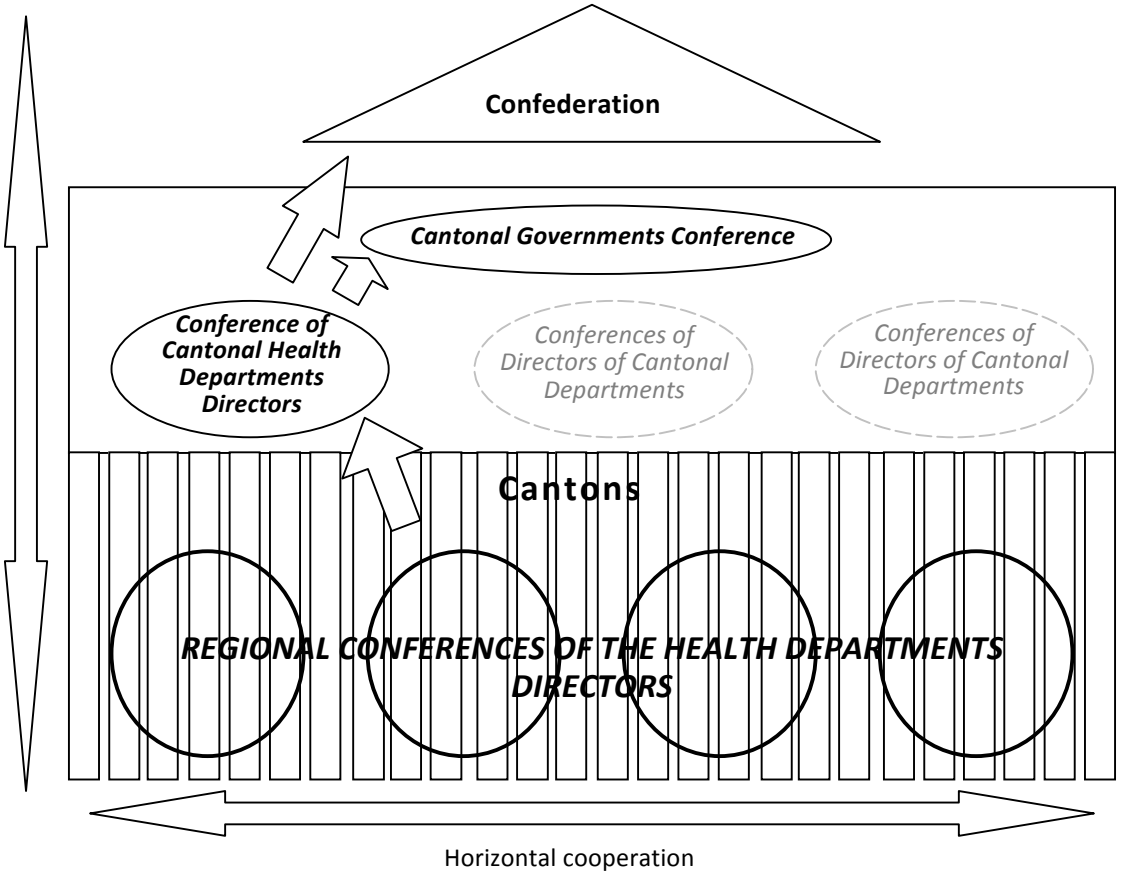
Background

Since 1919, Swiss cantonal governments meet in a political coordination body, called *Conference of Cantonal Health Departments Directors*[9] since 2004. Its aim is to promote collaboration between the 26 Swiss cantons, the Confederation and leading health organizations.

Description

The intercantonal cooperation for health policy is based on four different levels: the Cantonal Governments Conference; Conferences of Directors of Cantonal Departments (like economy or education, etc.) including health departments; finally, Regional Conferences of the Health Departments Directors (CDS). The roles of the Conferences of Cantonal Departments Directors are to coordinate their own field of intervention and to develop common positions and responses to Federal government initiatives. The Cantonal Governments Conference considers intercantonal "horizontal cooperation" as basic and essential for a vertical cooperation between cantons and confederation.

Structure of vertical and horizontal cooperation in the field of politics of health



[9] Conférence suisse des directrices et directeurs cantonaux de la santé (CDS)

The CDS is financed by the cantons, it has a steering committee including regional conference participants that meet eight times a year to prepare themes for a plenary assembly. Several permanent commissions work on specific themes and delegate collaborators to many federal working committees. The plenary assembly is comprised of all cantonal health directors (all taking part in at least one regional conference) and meets twice a year.

The objectives of CDS are to improve cooperation and to work towards a better intercantonal coordination in order to develop national strategies concerning health policy.[10] If cantons act alone, as separate and independent sovereign states, their influence towards the Federal State is limited. That is why to be able to take a common stand *vis-à-vis* the central power is also an important aim. Each Regional Conference as well as the Conference of Cantonal Health Departments Directors plays the role of a discussion forum for the Cantonal Health Directors as well as of partners for the federal authorities. They are however more involved in the implementation of federal political decisions.[11]

Cantons are distributed into four Regional CDSs: The Latin Conference of the Sanitary and Social Affairs;[12] The Conference of the Health and Social Department Directors of Central Switzerland[13]; The Conference of the Health Directors of Eastern Switzerland;[14] and The Conference of Health Directors of Northern Switzerland [15].

Currently, there is no specific collaboration to achieve a strategic view for long-term care on a national or on a regional level. Initiatives remain specific to some cantons. However, Health Insurance Law Reform[16] will soon be implemented, about which the Conference of Cantonal Health Departments Directors has taken a specific position and demanded a delay of its entry into force initially planned for 2009.[17]

Outcomes

Decisions taken within the conferences are non-binding for cantons, the latter remaining sovereign. They are limited to "recommendations". Therefore, this policy of regionalization can primarily be viewed as an answer to difficulties stemming from the very small size of some cantons. However, the sovereignty of the cantons limits the possibility of a real coordination in the field. The cantons continue to implement federal law according their own specific approaches. This diversity persists to this day and prevents the country from having, for example, common definitions and truly global policy developments in the long-term care field. Regional conferences may however be seen as the possible basis for future regional policies in health and social services, stemming from the need for supracantonal planning and coordinated approaches in the long-term care field.

[10] Information obtained by e-mail from the CDS (1st November 2010)
[11] Information obtained by e-mail from the CDS (1st November 2010)
[12] Conférence latine des affaires sanitaires et sociales (CLASS)
[13] Zentralschweizer Gesundheits- und Sozialdirektorenkonferenz (ZGSDK)
[14] Gesundheitsdirektorenkonferenz der Ostschweizer Kantone (GDKOS)
[15] Nordwestschweizer Gesundheitsdirektorenkonferenz (NWGDK)
[16] Nouveau régime de financement des soins
[17] According to the Conference, the important modifications for cantonal politics of long-term care needed more time to be adapted by each canton to the new configuration.

Example 6 – Sweden: Informal care support in the Swedish National Dementia guidelines

Background

In May 2010 the first Swedish Guidelines regarding dementia care was published. The development of guidelines goes hand in hand with the considerable increased focus on dementia care in Sweden during the last decades. Public attention and general awareness has increased, diagnostic and care procedures have been developed, supported living for dementia patients has been improved and allocation of resources to dementia care has increased.

Description

In Sweden the responsibility for formal care with regard to social services is divided between three levels: the national, the regional/county, and the local level. The main focus of the guidelines is on the municipality and primary care, managed by the county councils, other guidelines address doctors, nurses and other health and social care professionals. The main focus is on specific matters regarding the patients but some parts are guidelines that are of importance for informal carers.

The guidelines state that informal carers should be offered support as early as possible to maximize the positive effects.[18] The national guidelines present the following evidence around different interventions:

Circumstance/ type of intervention	*Difficulties within the circumstance*	*Effect by type of intervention*	*Evidence of effect*
Informal carers to patients with dementia *Educational programs*	Increased risk of psychological and physical problems and decreased QoL	Can decrease depression and stress among informal carers. Can increase informal cares way of coping with patients' behavioural problems. Decreases the burden of caring and prolongs stay at home	Strength of evidence 3 Some scientific base.
Informal carers to patients with dementia *psychosocial support programs*	Increased risk of psychological and physical problems and decreased QoL	Decreases worries and depression	Strength of evidence 2
Informal carers to patients with dementia Combination programs	Increased risk of psychological and physical problems and decreased QoL	Can prevent illness and increase QoL	Strength of evidence 4
Informal carers to patients with dementia *Relief care*	Increased risk of psychological and physical problems and decreased QoL.	NA	Strength of evidence 4

[18] http://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/18012/2010-5-1.pdf: 10.

Informal carers to patients with dementia *Specific and adopted support*	Increased risk of psychological and physical problems and decreased QoL	Can be positive	Empirical
Informal carers to patients with dementia *Specific and adopted relief care*	Increased risk of psychological and physical problems and decreased QoL	Can be of value to the patient and the informal carer.	Empirical
Informal carers to patients with dementia *psychosocial support programs on distance/remote*	Increased risk of psychological and physical problems and decreased QoL	Reduces isolation and increases control, reduces visits to GP of informal carers.	A good scientific base

The guidelines are recommendations and the parliaments have decided to set aside funds, among others to support the implementation. The implementation is carried out in different ways within the country. A common way of implementation is in the form of projects. Municipalities can apply for extra money to start these projects and there are criteria's for getting the project accepted, one criteria is that the project should be coherent with the guidelines, another is that municipalities and county councils cooperate within the project. The amount of money set aside for the projects (not only for dementia) was 300 million SEK in 2010.

Outcomes

This increased focus on dementia care has been expressed in relation to supporting informal carers. Several programs to improve the conditions for those who deliver informal care have been initiated by the government over the last decade and managed by the National Board of Health and Welfare. The work within these programs has most likely contributed to further awareness of on the exposed situation that informal cares can be subject to. The explicit inclusion of evidence around informal care support measures in the guidelines has helped to focus local service development.

Example 7 – Germany: Development of the volunteering sector within LTC

Background

In Germany mainly welfare organisations and local parishes are responsible for volunteer work in residential and nursing homes, while in home care services, up to now, volunteers have not made a significant contribution. The Complementary Nursing Act of LTC Insurance of 2002 (§ 45a-c Social Code Book XI) gave informal carers and for the first time volunteers more space to create new care arrangements in the care infrastructure of LTC. According to the new law, patients with dementia or psychiatric disorders receive up to €460 towards support per annum. Within this budget, persons with "higher needs of assistance" or their family carers are enabled to use care services such as day-care or short-term care services, as well as specific care services on a home-based and payable low-threshold offers. Low-threshold services are characterised by co-operation between professionals and volunteers with specific training opportunities and supervision to meet the criteria defined by law.

Description

A further development of this informal infrastructure appeared in 2008 within the latest Care Reform Act (§ 45d Social Code Book XI), which expanded the target group of entitled persons in need of care and their carers and increased the benefit to €1,200-2,400 per annum, depending on the degree of support. To obtain access to this support the applicant has to have at least a care level "0". Another guideline based on § 82b Social Code Book XI has given residential homes the option to charge costs for management, trainings and expenses of engaged volunteers within the fee agreements with the LTC Insurance.

The dissemination of low-threshold services is proceeding within welfare organisations or home care agencies on a local level. The newly created volunteer projects often are organised by not-for profit care providers or self-help groups. The main challenge is to establish a new support structure attracting volunteers by increasing access and fostering acceptance of voluntary work. In that purpose public relations and networking with similar services as well as offering a comprehensive training and guidance for volunteers should be offered.

Outcome

The role of voluntary work and the situation of volunteers in the care sector are unclear. Volunteering is appreciated as complementary to professional service offers and informal care within the family and not as a substitute for regular nursing or caring activities. However, the increasing shortage of professional carers and a shrinking amount of family carers will strengthen the call of embedding more volunteers in the care sector. However, increasing volunteer work alone cannot solve the deficit of carers in the future. Research results in the field of voluntary work display a great potential of volunteers that could be attracted to the social area. The growing group of active elderly people has become a key target group within the marketing of volunteering opportunities. In practice, experiences in nursing homes and LTC since 2003 have shown that voluntary work with care-dependent older people or people with

dementia presupposes a specific interest in this area. Cooperation between professionals and volunteers is still described as difficult and requires a clear distribution of work tasks, supervision and counselling of volunteers and acknowledgement of their engagement. In addition, to increase the attraction of voluntary work to potential actors depends on specific living-conditions of the volunteers themselves. Without careful design and planning of volunteer training and work programmes, the availability of volunteers could decrease in the future, therefore potential volunteers will be a highly demanded group in the welfare sector.

Example 8 – Finland: Income-based LTC payment system

Background

In Finland user charges for LTC in institutions are set as a fixed rate of net income. Currently the rate is 85% of the patient's disposable income, excluding a monthly minimum amount of € 97 that must remain for the patient's own use.

Description

The use of public institutionalized care is highly concentrated among elderly in the lower income groups. In 2006 over half of the patients in public residential homes or inpatient wards of hospitals belonged to the three lowest income deciles. The skewed pattern of institutional care use reflects the distribution of payments across income groups. The average payment in the two lowest deciles amounted to € 150 compared to € 65 in the two highest deciles. While the frequency of institutional care use was lowest in the richest decile, the average annual payment among users of care was clearly highest. This was due to the fact that high-income patients contributed in absolute terms substantially more for the care provided in elderly care institutions. On average a patient in the poorest income decile paid € 4,600 per year for the same services that cost about € 14,000 for a patient in the richest decile.

The distribution of payments relative to income can be measured by a summary index of progressivity. When the average payment share of high-income individuals is higher (lower) than that of low-income individuals, payments are distributed progressively (regressively), and the index obtains a positive (negative) value.

Outcomes

The Finnish income-based payment scheme constitutes a fixed share of income at all income levels and is in this sense proportional. However, as the use/need of institutional LTC was higher among elderly in the lower income groups, the distribution of payments turned out highly regressive (progressivity index = -0.392).

Example 9 – UK (England): Pooled budgets

Background

Section 75 partnership agreements, legally provided by the National Health Service Act 2006, allow budgets to be pooled between health bodies and health-related local authority (social care) services, functions can be delegated and resources and management structures can be integrated. Legal mechanisms allowing budgets to be pooled are thought to enable greater integration between health and social care and more locally tailored services. The arrangements allow commissioning for existing or new services, as well as the development of provider arrangements, to be joined-up. They were previously referred to as Section 31 (1999) Health Act flexibilities.

Description

The Section 75 is simply the legal opportunity to build a new organisation or 'trust' combining the resources of existing organisations which have similar objectives and visions in health and social care. By increasing the budget greater scope is given to the possibilities of the services provided. There isn't a single course of action which follows on from implementing a Section 75. Different localities have used them in different ways, typically creating joint care Trusts, integrated commissioning organisations or integrated provider organisations.

Mental health services are the type of provision most commonly grounded through use of Section 75 agreements. However there are several examples of integrated provision locally tailored towards older people, this often takes the form of a multi-disciplinary nursing teams at practice level supported by a pooled budget and a joint management structure.

In practice the new structures were designed with specific aims of:

- facilitating a co-ordinated network of health and social care services, allowing flexibility to fill any gaps in provision
- ensuring best use of resources by reducing duplication and achieving greater economies of scale
- to enable service providers to be more responsive to the needs and views of users, without distortion by separate funding streams for different service inputs

Outcomes

There are some promising indications from individual projects that joint working from pooled budgets leads to positive outcomes for service users. The impacts of integration have been highly commended in localities and include: improved accessibility to intermediate care, occupational therapy, physiotherapy and district nurses; faster rates of assessment, provision of care and installation of home equipment; and reduced use of acute hospital services.

There is much consensus that setting up a Section 75 and implementing organisational change is a complex, labour intensive task, often involving initial tensions of organisational cultures whilst roles and responsibilities are redefined. However, evidence of efficiencies gained by forming single structures gives incentives to embark upon the route of pooling budgets and forming joint structures. For instance, in one northern city a single commissioning unit was created using a Section 75 partnership agreement.

Back office savings are estimated to be around €1.5 million per annum. These savings result from shared systems and overheads used by the integrated unit team. The location of the team in shared premises, single health intelligence system, single performance management system and aligned indicators and shared outcome goals contribute to more efficient and focused working practice.