

# Home Care across Europe

## Case studies

Edited by

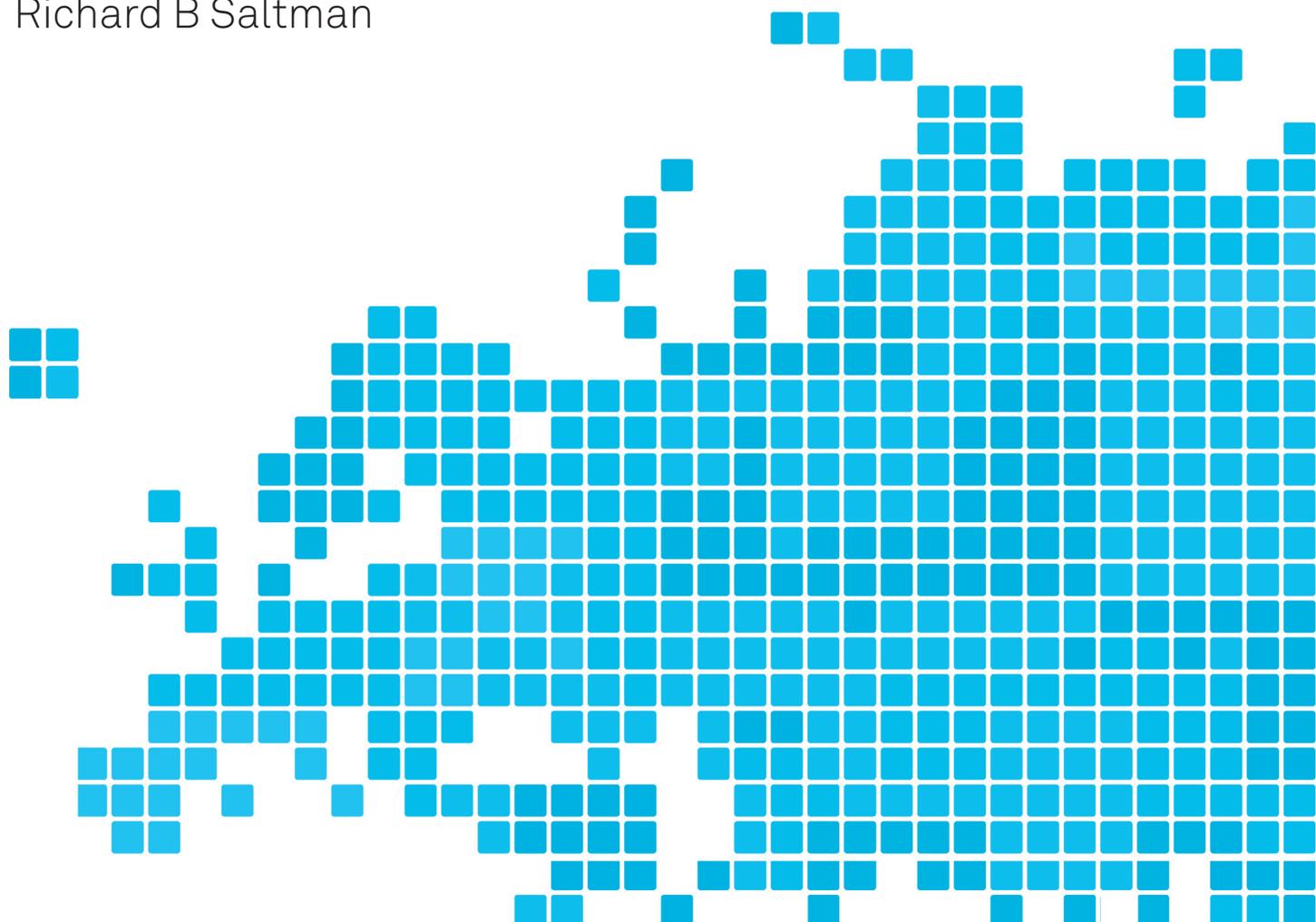
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The partnership is greatly indebted to the experts in each country who have contributed to the data and information on which this study is based. The names and affiliations of the country experts are listed with the country reports in this volume. Both the country reports and the full database of the EURHOMAP study are available at: <http://www.nivel.nl/en/home-care>.

The study has been funded by the European Commission (Directorate General SANCO).

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### **Note on the country reports**

For each country included in the EURHOMAP study a detailed report of the organization of home care and related issues is now provided in a structured way, based on the conceptual framework presented in Chapter 1 of the printed book.

In section 1 of each report the context of home care is described, including societal views towards caring for dependent people at home, geographical and demographical factors, features of related care sectors such as acute health care and long-term institutional health care.

Section 2 deals with the policy context in the country, including the governmental vision on home care and how access, quality and eligibility for services are regulated.

Section 3 describes the way home care is financed and the financial resources available for home care.

The focus of section 4 is on the actual organisation and provision of home care, including needs assessment, delivery of services, and human resources available for home care, as well as coordination within the sector and between home care and other types of (health) care.

Section 5 is dedicated to the clients of home care and their informal network that often plays an essential role besides the services provided by professionals. This section also addresses unmet needs for care and empowerment of clients.

Section 6 of each country report provides an overview of current problems in the home care sector in the countries.

Section 7 aims to sketch future developments and point to possible solutions in response to current challenges.

# Volume II – home care country-by-country

## **INTRODUCTION**

This book aims to fill an information gap on policies, organisation and provision of home care in Europe. The need for this information was amongst others identified in the 2006 Public Health Work Plan of the European Commission and the EURHOMAP project was granted to collect and disseminate the necessary information. In two volumes, this book describes both the formal home care systems and their reality in terms of system failures and unmet needs in 31 countries, including the 27 EU Member States, Croatia, Iceland, Norway and Switzerland. Country-by-country this Volume II presents detailed descriptions of the home care situation in Europe. The reports can also be found at: <http://www.nivel.nl/en/home-care>.

In order to provide the readers context to what they find in this volume, main points from Volume I as well as the methods of the study will be summarised.

## **CONCLUSIONS from Volume I**

### Backgrounds and challenges

Care provided at recipients' homes is not just legitimate because it is preferred by many people but also because it is typically more cost effective than care in institutions, particularly if available informal care is used effectively. Expectations about the possibilities for home care have grown as new technology facilitates care coordination and

enables distant monitoring and more complex treatments in the home situation (Tarricone & Tsouros, 2008). In many countries, the balance of long-term care tends to shift towards home-based care, as many governments pursue the concept of ‘ageing in place’ (OECD, 2005). Furthermore, general arguments applicable to long-term care, such as growing demand as a consequence of demographic and societal developments, are also valid for home care (OECD, 2011). If home care services would indeed prove more cost-effective than institutional care, demand for home care could grow even faster as a result of substitution policies.

At present, the role of governments in home care is not evident. On the one hand, they are under pressure to anticipate the future by developing at least a vision on home care and take appropriate steering measures. On the other hand, the health and social care sectors in some countries are showing a trend of retreating governments that are giving more space to private initiatives. In public opinion, however, the government has a clear role in the provision of care. In the light of continuing economic downturn, the question is to what extent the expectations of European citizens regarding publicly financed care can be sustained in the future and whether the relatively generous home-care schemes that exist in a number of countries will be sustainable.

In addition to the expected growing demand and financial constraints in the home care sector, the availability of home-care workers is another challenge. Home care is labour intensive and, as the ratio between the elderly population and the working age population is expected to rise in some countries extremely, the question is whether sufficient qualified staff will be available in the future. Scarcity also applies to informal carers, such as spouses, children, other relatives and volunteers. In many countries informal care is becoming scarcer as a result of growing mobility, urbanization and women’s increasing participation in the labour market, the latter traditionally providing the lion’s share of informal care (Mestheneos & Triantafillou, 2005; Gibson et al., 2003).

Decision-making for home care is extremely complex as the sector is so heterogeneous. It consists of a mix of social and health care services provided for the long-term, short-term recuperation after hospital discharge and palliative care (Genet et al., 2011). Social services, as compared to health care services, are generally more often organized at local level, have a lower level of professionalization and are less generously funded (Leichsenring et al., 2005).

Home care has a different meaning and purpose across countries, varying from a safety net function for those without relatives, on the one hand, to a right for all citizens, on the other hand. Consequently, countries currently show strong differences in features such as the role of professionals in home care; citizens’ eligibility for services; financial conditions; and regulatory mechanisms that steer the sector.

## Results and conclusions

European countries spent on average 0.6% of their health-care expenditures on curative home and rehabilitative home care and 3.5% on long-term nursing care at home (Eurostat, 08-12-2010). Figures on home care within the social care system (mostly domestic aid) are rarely available and statistics on private (out-of-pocket) home care expenditure are absent in many countries.

National governments in most countries have developed a vision on home care, however, these are neither detailed nor homogenous. Governance and decision-making on home care are typically strongly decentralized. Lack of homogeneity of policy visions relates to the different roots of home health care (nursing) and social home care (domestic aid). Visions developed at the national level mainly refer to principles, general entitlements and possible restrictions to the use of services. For instance, entitlements to home care for people with insufficient means and for other vulnerable groups are often set nationally. Restrictions may be concerned with price limits and defining the groups who are entitled to receive home care free of charge. Principles may state the

importance of quality and the need to assure the quality and responsiveness of services. Within these nationally set frameworks, local governments or private organizations are left to design and implement details, and therefore more detailed visions are commonly found at local government level.

There is a wide variation in financing of home care within countries. Different types of home care are financed differently and from various sources. Two main funding methods are: (i) a combination of taxation for home social care and health insurance for home nursing care; and (ii) a combination of taxation for home nursing care and social insurance for home social care. Specific long-term care insurance schemes are only found in two countries.

Means tested co-payments are usual and these can aim either to collect higher contributions from those with higher incomes or to provide (publicly funded) care free of charge to those with lower incomes. Those above a certain income ceiling may have to fully pay the services out-of-pocket.

Although all European countries have a home care infrastructure and provide publicly funded home care services to some extent, the study has identified unmet needs. Some types of services can be insufficiently available in countries or regions – for instance, psychological support and psychosocial care. Besides, certain population groups may be underserved due to financial restraint, prevailing eligibility criteria or differences in the availability of informal carers. Usually, deficits in formal care are inevitably compensated for by informal caregivers, but the division of tasks between formal and informal carers also depends on cultural values; the composition of families; and attitudes concerning ageing and the place of older people in society (e.g. the importance of staying independent). At present, especially in southern countries, people who consider themselves to be in need of care prefer informal care.

Even in countries where the preference is more towards professional care, informal carers are and will continue to be essential in home care. Safeguarding the potential of informal caregivers will thus become a major challenge for future governments. This will be a central issue – whether informal care is a voluntary choice or more or less imposed by lack of alternatives. It will be a challenge to find an optimal balance between informal and formal carers. Organized support and relief for informal caregivers was not available in most countries.

Generally, many *types* of home care services are available but often not very extensively. Clients had access to relatively extensive services in Austria, Belgium, Denmark, England, Ireland, Luxembourg, the Netherlands, Norway and Sweden. In the other countries considerable needs remained unaddressed by formally provided services.

Although public provision still is dominant in home care, private providers of home care are available in almost all countries and their involvement seems to be growing. A wide range of providers is working in the privately financed services. Two main groups are NGOs and similar organizations (relying on gifts or public funding) and completely privately financed services (through private insurance or out-of-pocket payments).

In most countries different types of agencies are involved in the provision of home care, each usually providing only part of the palette of services (e.g. only domestic aid or home nursing). Formal coordination among types of services is unusual and, if existing, voluntary and *incidental*. Coordination with home care is strongest for the transition from hospital care to home care and still rather weak at the interface with nursing homes. However, it is important to distinguish between home help and home nursing, as coordination between nursing care and other health-care providers is usually better than that between home help and other health-care providers. Integration of home care with other health-care services

is most developed in England, Italy, the Netherlands, Scandinavian countries and Slovakia; and least formally integrated in Bulgaria, France and Romania.

Quality assurance is generally not well developed in the home care sector. Measures to monitor and manage the quality of services are not routine in home care. This is especially true for services like domestic aid.

It may be concluded that home care is in demand, not just among citizens in Europe, but also among decision-makers. However, not all countries have an articulated policy on home care and in most countries, the available formal home care schemes fail to meet current demand for home care. Ambitions to develop and expand the home care sector in Europe will be restricted by prevailing financial constraints; unconventional solutions will need to be tried to bridge the gap between growing need and shrinking budgets. Retreating governments and the growing role of the private sector may be drivers towards a new balance between regulation, efficiency and flexibility of service delivery. Basic principles may be at stake, including the protection of frail dependent people against quality failures and unaffordable care. In general, client empowerment – *inter alia* by better information – will become more important. In their search for solutions in response to these challenges, policy-makers may need to look for other than the usual models and good practices to get inspired. The descriptions in this book provide possible entries.

## Methods

The EURHOMAP study has used the following two instruments.

- A *comprehensive set of indicators* which served as the structured framework for data collection in each country. These were developed on the basis of a systematic literature review (Genet et al., 2011) and the expertise of partners in the project.
- *Four case narratives (vignettes)* with related questionnaires, developed within the consortium, describing different situations of people living at home and in need of various sorts of care. Questions related to the vignettes asked about: the application procedure; eligibility for home care; the services available; financial implications; the role of informal caregivers and the alternatives if home care was not an option. In each country, experts from within home care in their country have answered these vignettes, providing a more integrated and ‘client-centred’ picture of home care (see Annex 2 of Volume I and Volume II).

The study used both desk research and interviews with country experts to gather the information needed. Experts were interviewed to complement or verify the information gained from desk research. Country experts have answered the questions related to the vignettes and provided information on the indicators. The experts were policy-makers, managers of home care agencies and coordinators in home care organizations. Most data have been collected until 2009 (otherwise it has been indicated in the country reports).

## Structure of the country reports

Each of the country reports in this volume consist of the following sections:

- Description of the context of home care, including societal views towards caring for dependent people at home; geography and demography; features of related care sectors, such as acute health care and long-term institutional health care. Also attention is paid to external influences.
- Overview of the policy context in the country, including the governmental vision on home care and how access, quality and eligibility for services are regulated.

- Description of financing and the financial resources available for home care. It includes the collection of funds (e.g. via insurance, taxation or private payment), the remuneration of providers (based on budgets or related to services allocated to clients), price setting and personal budgets or vouchers for clients. Like the policy context, financing is different for health care and social care services.
- Focusing on the actual organization and provision of home care, including needs assessment, delivery of services, and human resources available for home care, as well as coordination within the sector and between home care and other types of (health) care. It encompasses the activities organized within publicly and privately owned agencies and institutions which deliver social and health care services in the clients' homes. The availability of sufficient staff with adequate qualifications and skills to respond to the needs for home care in the population is particularly important. This includes professional development, training and continuing education. Special attention is paid to coordination, with seamless care as its intended result. Assessment and application for care are separately addressed.
- Dedicated to the clients of home care and their informal network. This section also addresses unmet needs for care and empowerment of clients.
- Providing an overview of current challenges and problems in the home care sector in each country.
- A sketch of expected future developments and possible solutions in response to current challenges.



# Austria

*Author: Vjenka Garms-Homolová*

## 1. The context of home care

### Country, population and health

One of the remarkable features of the small country of Austria is its heterogeneity. Not only the geography and the landscape differ between the east and the west and the north and south, but the demography and economy vary across the nine federal states as well. Policies, provision, and utilization in the home care sector also vary greatly and each expert interviewed in the preparation of this report emphasized that his/her statement only applies to a certain region, but may be not valid “next door.”

The territory of Austria stretches over 83,879 Kilometres. This is larger than the Czech Republic, but smaller than Hungary or Portugal. The population size is about the same as that of Sweden: 8.34 Million. The biggest federal states are Lower Austria and Styria, whereas Vorarlberg and the capital Vienna have the smallest areas, even though the largest proportion of Austrians lives there (almost 1.7 Million in Vienna only). Lower Austria follows with 1.6 Million inhabitants. The fewest people live in Burgenland, the south-east federal state. Not only the size of the population, also its density varies considerably. The mountain regions are less populated than other parts of Austria, with only 56 inhabitants per km<sup>2</sup> in Tyrol, and 59 in Carinthia, compared to 4,000 in Vienna (Statistik Austria, 2010a).

For decades, the population has been growing slightly, but steadily, and is projected to increase to 1.1 Million by 2050, almost all in Vienna, whereas the population in the remaining eight federal states will stagnate, or even decrease. The growth of the population is very small (only

36 thousand persons from 2004 to 2008), and therefore it must not be overestimated. In fact, the birth rate is low; the fertility rate amounted to 1.41, and in four federal states the birth balance is negative. This is one of the reasons for the progressive aging of the population. Until 2050, experts expect a stagnation of the group under 15 years of age; a reduction of those between 15 and 60 years of age (from 5,286,511 in 2008 to 4,962,088 in 2050); and a dramatic increase of those over 60 years of age (from 1,880,482 in 2008 to 3,236,548 in 2050).

Presently, the life expectancy at birth amounts to 77.62 years for men and 82.97 years for women; at the age of 60, life expectancy is 21.34 years for men and 25.13 years for women (Statistik Austria, 2009). The Austrian Health Survey carried out in 2006/2007 showed that 64.8% of all Austrians (60.4% of all men, and 69.0% of all women) suffered from at least one chronic disease. The prevalence increases with age: 84.3% in the group of 60 to 74 years old reported at least one chronic disease, but the same was reported by only 43% of those from 15 and 30 years of age. Still considerably higher was the prevalence in the population of those 75 years and older: 91.5%. The “healthy life expectancy” of 77.1 years was calculated for 80% of the males, and of 82.6 years for 76% of the females at birth. Compared to previous years, health has improved. (Statistik Austria, 2010b): – 37.5% of the entire population rated their own health status as very good, 38% as good, 18.5% as moderate, 5% as bad, and 1.0% as very bad.

#### Characteristics of health services and social services

There were 267 hospitals and 66,544 beds available in 2007. Less than half of the total (107 hospitals) belonged to the category “general hospital”, 53 to “hospitals for chronically ill patients” and 48 hospitals provided rehabilitation services, with 63,354 beds actually used. Accordingly, 765 beds for 100,000 inhabitants were available. The average length of stay amounted to 7.9 days. Generally, the number of beds is decreasing, and the hospitalization rates are increasing due to the shortage of the duration of hospital stays, with statistics showing a considerable increase in “revolving door patients”. According to the Austrian data, 81,161 health workers were active at the end of 2008; out of those 38.3 thousand were physicians, and out of them 12.7 thousand were general practitioners (Statistik Austria, 2010a and 2007).

The description of social services is complicated due to the federal system of Austria. Not only is the organization, infrastructure, and provision different but so do the philosophy of care and the definition of individual services differ from one state to another. This true for the institutional long-term facilities, but particularly for all other services including home care and home nursing, as we show in Section 4 of this report. According to a study ordered by the federal Ministry for Social Affairs and Consumer Protection, 779 long-term care facilities with about 54 thousand places existed in 2005 (Quantum, 2007). In most of the states, places for short-term care in institutions, assisted living, and other forms of “semi-institutional” care provision were available. However, the majority of older people who are ill or disabled or need support and help received so-called “mobile services” (for instance, home nursing, home care, home help and mobile meals) in their private homes. Additionally, counselling by a social worker or a nurse, support for the family caregivers, and other services are offered by the communities, states, or welfare.

#### Social indicators and conditions related to old age

In 2008, almost 4.3 million persons were in the work force. The average annual gross income of employees amounted to €28,262. Considerable differences could be observed between genders. The average annual gross income of men amounted to €34,787, but of women was only €20,864 (Statistik Austria, 2009). The annual gross income of the retirees was considerably lower than that of working people, amounting to €19,562. Again, huge gender specific differences were measured: While the average retirement income of men amounted to €24,302, the average income of women only was €15,726. Such differences are aggravated by regional disparities. The Austrian federal states are responsible for the social subsidy for persons that are economically weak and €328 million was spent for 152,479 Austrians in 2007 (<http://www.armutskonferenz.at>). This amount of money does not include the “subsidy for persons suffering from diseases”. The proportion of persons dependent on subsidy differed from one federal state to the other. The highest density of receivers of financial aid lived in Vienna, paradoxically few in Burgenland and in Carinthia. As far as the amount of money spent per capita (total population) is concerned, for this financial aid the differences are high, too (€117 in Vienna, €32 in Vorarlberg, but only €6 in Burgenland).

**Table 1:** Benefits for care in Austria: levels, criteria of eligibility, amount of benefits

Level of benefits/	Criteria of eligibility – hours of need for help/care per month	Amount of benefits per month (€)
Degree 1	50	154.20
Degree 2	75	284.30
Degree 3	120	442.90
Degree 4	160	664.30
Degree 5	180 plus extremely demanding care	1,242.00
Degree 6	180 plus a permanent presence of at least one person	1,655.00

### Attitudes related to old age

According to experts, attitudes to old age have changed. However, the perspective of policy makers and public media remains narrow. They tend to interpret the situation of the aged population from the point of view of its economy and (future) burdens of benefits that will be consumed by elderly people for their pensions, health care, and long-term care. The research on family matters has been focussing mainly on problems, for instance on care burdens. Very recently the “exchange of help” has gained attention. The “private attitudes” remain traditional, meaning that families are seen as responsible for the care of their older members, despite the fact that the task is often very difficult. Around 80% of all individuals get care and support by relatives at home and this arrangement is the most preferred type of care (Bundesministerium für Soziales und Konsumentenschutz, 2009). However, domestic violence against the elderly, especially against women, seems to thrive in this context (Kuss & Schopf, 2007) and this problem seems to be promoted by the fact that care benefits are paid regardless of the actual situation within the care setting.

## 2. Policy and regulation on home care

### 2.1 Governance on home care

More than 390,000 persons permanently need care in Austria. In 1993 the so-called *Bundespflegegesetz* (federal act on care benefits, also called “care money”) was enacted and the basic principle is valid now, stating: “Everybody who needs care shall have the opportunity to organize his/her care according to his/her own needs”. Care benefits are seen as the most important contribution to this aim. The money is “earmarked”, and has to cover the “additional” need that usually emerges when a

person loses his/her ability to manage his/her everyday life, together with new requirements connected with progression of the disease or disability. Correspondingly, care benefits are not intended to cover the full amount of needs and are not considered to be an additional income, but a contribution to an independent life in a community. Even if the regulation on care benefits is uniform for the entire federation, it is necessary to stress that its principles are interpreted differently in every single Austrian federal state.

### 2.2 Eligibility for home care services

#### *Home nursing & personal care*

As in many other countries, home nursing and personal care are different services. They are reimbursed by different budgets, and are subjected to different regulations. Since 1992 the health care insurance covers home nursing (which is a health service that provides injections, nutrition via tubes, decubitus ulcer care, etc.), if the need is verified by a physician. Eligibility is dependent on illness and the provision is limited to four weeks.

Personal care and domestic aid are seen as social services, and are not covered by the health care insurance but by care benefits according to the federal law (*Bundespflegegeldgesetz* – BPGG) or to one of the acts introduced by each of the federal states (*Landespflegegeldgesetze* – LPGG). Citizens who need such benefits (or their close relatives or legal guardians) have to apply. An informal application is sufficient. The addressee of the application is the institution responsible for the “prime basic income”. If a person receives a state pension, or the general old age retirement pension, the federal instances are responsible and the BPGG applies. People whose pension is provided (and regulated) by

one of the federal states have to send their application to their state government. However, the eligibility and the amount of benefits are equal in both cases, but the philosophy of the care provision may differ to a great degree.

Eligibility is dependent on a permanent need for care/help because of a physical, mental, psychological or sensory disability (see Table 1). Such a need has to prevail for at least last six months before the application. The eligibility is not dependent on the income, age, or cause. The situation is different with regards to benefits in kind. According to § 20, 1, BPGG, benefits in kind are possible, but the amount of service must not exceed the amount of benefits in money. In the case of service provision the income of the beneficiaries is taken into account (Bundesministerium für Soziales und Konsumentenschutz, 2009a). The use of the money and the quality of service is monitored for both care through care money and care in kind. Benefits in kind are limited in Austria. The normal way is the cash benefits, for which the eligible persons purchase services according to their needs.

Since 1995, people with dementia or other individuals suffering from severe mental or psychological impairments can get additional payment that enables them to buy an additional 25 hours of care monthly (Bundesministerium für Soziales und Konsumentenschutz, 2009b).

#### *Domestic aid and technical aids*

The coverage of domestic and technical aids necessary for home care does not depend on the degree of benefits for care. The insurance that is paying care benefits only has to pay when the expenditures for devices are not covered by the health care insurance. Clients co-payment is required for technical devices (e.g. a special bed). Consumables (pads, etc.) are only reimbursed to a very small extent. Financial aid is available for remodelling of the apartment: in such a case, client's income is decisive for the amount of the co-payment (Bundesministerium für Soziales und Konsumentenschutz, 2009a).

### 2.3 Quality of process and output

The Federal Association of Welfare has developed standards for the quality of the process of mobile services, especially for care provision, output as well as input (Bundesarbeitsgemeinschaft der Freien Wohlfahrtspflege,

o.J.A). The range of these standards and indicators extends from the management of human resources and external and internal communication, to development of teamwork and the quality of the service provision. The latter area includes the intake of clients, contracts between care providers and clients, care process (assessment, care planning, and evaluation), care visits, and management of complaints. As mentioned above, not only the use of the care money, but above all the quality of services is examined on a regular basis (§§ 33a, 33b, BPGG). Fully qualified visiting nurses are authorized to examine the domestic situation and the "suitable use" of the care money. This procedure takes place every year. Between 2001 and 2004, 20,146 home visits were undertaken. If quality problems occur the benefits in money can be replaced by benefits in kind (Bundesministerium für Soziales und Konsumentenschutz, 2009a).

### 2.4 Quality of input

- Various professions (nurses, nursing aids, social caregivers, home aids, social workers) are authorized to provide mobile services. The education of a nurse lasts three years (2000 hours of theory and 2480 of practical training), it ends with written and oral exams and a diploma as a nurse. Nurses are responsible for continuing education and training; they particularly have to account for any innovations and renew their knowledge. In the course five years the minimum is 40 hours of education, otherwise, they can lose their diploma as a nurse. Education of home helpers (providing domestic aid) is usually offered by organizations that provide home care services. Full-time education lasts four months (400 hours, both the theoretical education and practical training last 200 hours each); part-time education lasts seven months.

The required qualification for all professions in home care is regulated by the agreement on social professions established between the federal government and federal states (*Art. 15a B-VG zwischen dem Bund und den Ländern über Sozialbetreuungsberufe*, Wiener Landtag 2005). The same agreement regulates the job tasks of nurses, home care staff, and home aids. Additionally, quality standards developed by the Federal Association of Welfare for care providers require:

- Introduction of new staff in the organization;
- Guidelines for the communication with staff, promotion of professional competence;
- Guidelines for continuing education;
- Guidelines for the development of interdisciplinary teams (*Bundesarbeitsgemeinschaft der Freien Wohlfahrtspflege, o.J.A.*).

### 3. Financing

#### 3.1 General funding

About 99% of the Austrian population were insured by the statutory health care insurance. In 2008, the expenditure for health services amounted to €3 billion. The largest amount of money (28.8%) was spent on hospitals, only 4.5% for rehabilitation and 2.8% for prevention, early detection, and health promotion. Approximately €15 million was spent on the (medically oriented) home nursing sector, but the portion needed for the home nursing of the old population cannot be determined exactly. €250 million was spent on devices and aids, €350 million on rehabilitation, health maintenance and prevention, and €186 million on transportation (Statistik Austria, 2010b, 2009; 2008; 2007). For the funding of the “mobile services”, including home care, the federal law (*Bundespflegegeldgesetz – BPGG*) and the state law in each federal state (*Landespflegegeld-gesetze – LPGG*) are decisively important. However, the funding is complicated, and will be explained below.

#### 3.2 Financing of home care agencies

The sources of financing are federal care benefits, state benefits, and the communities (compare 2.2 and Quantum, 2007). As far as the federal benefits for care are concerned, €1,621 million was spent for those who needed care in 2006 (ibid). But even this money came from different sides, specifically, insurance institutions that were obliged to pay in the particular cases. The individual receivers of care benefits are obliged to pay for their care, so if a person receives services, the insurance responsible for his/her case pays directly to the care provider. As far as the care benefits from federal states are concerned it is very difficult to get accurate information (ibid; Schneider et al., 2006). Only few states are able to publish specific data on mobile services. A few states have

established institutions for the financial arrangements, for example the social funds that exist in some, but not in all, states. Quantum (2007) found out that out of the total state and community expenditures those for social services amounted to about €936.4 million in 2005, with 23% of this money (€215.1 million) being spent on mobile services, and €824.9 million invested in infrastructure. Communities contributed with 35%, federal states with the remaining 65%. However, the authors of the Quantum report (ibid) stressed repeatedly that the figures were not complete and that especially communities did not promote the transparency of expenditures on social services.

#### 3.3 Price setting of home care services

In every federal state, different price policies apply (Quantum, 2007). Some examples for 2005:

- In Burgenland, the fee for one hour of home nursing amounted to €24.80, of personal care to €19.90, and domestic aid to €14.90.
- In Lower Austria, the prices are based on the qualification of the staff. The fee for one hour of care provided by a nurse with diploma amounted to €27, by a nursing aid to €22, and by a home-helper to €19. Prices are dependent on the income of clients.
- In Upper Austria, single persons living alone had to pay between €0.75 and €18.84 per hour. If a family or a partner (including not married partners) is available, their income is taken into account.
- In Vorarlberg, the price for one hour of the home care was €8–9 per hour on working days and €12–13 per hour on weekends. The monthly rates for 24-hour-care provided by foreign care workers from Eastern Europe were between €1,500 and €2,100 (accommodation and board are not included).
- In Vienna, the price for one hour of home nursing was €22.13, that for domestic aid €16.86.

## 4. Organisation & delivery of home care

#### 4.1 Access and needs assessment

After an application for care benefits a physical examination and an assessment must follow. A physician assessment expert who is responsible for the

assessment will visit the applicant in his/**her** home and will recommend the degree of benefits that should be allocated. If the applicant already uses a home care agency, an opinion of its staff is required. The final decision-making must not exceed six months (Bundesministerium für Soziales und Konsumentenschutz, 2009a). Rarely, standardized assessment instruments are used. More often, the professional experience or intuition of the assessor play a decisive role. However, in some federal states (e.g. Styria) the assessment of needs is delegated to qualified nurses that use a comprehensive, fully standardized assessment (the interRAI home care).

#### 4.2 Delivery of services

The responsibility for social services and the provision of care differ from state to state (see Table 2). However, states are committed to provide sufficient infrastructure.

Since July 2007 it has been legal for 24-hour care to be provided in a private household by a single person who does not belong to an agency, if such a person is registered. This regulation also applies to caregivers of the EU member states, including those from Southeast Europe. Clients have to pay at least the statutory minimum wages. The caregivers must have a social security insurance in Austria or the country of their origin (regulated by: *Hausbetreuungsgesetz – HBeG; Standes- und Ausübungsregeln für Leistungen der Personenbetreuung*). Austria is traditionally absorbing foreign workers in the field of care and nursing (Lenhardt et al.2007; Lorenzo et al. 2007). Already in 2001, 6.7% of the nursing staff were foreign citizens, mostly from Southern or Eastern European countries, such as Bosnia-Herzegovina (28%), and Romania (13.4%). Recent and exact numbers are not available, but Schmid & Prochazková (2006) estimated that the number of staff from abroad amounted to 20–40,000 in 2006. The authors calculated that 10.5% of long-term care staff are from other countries.

#### 4.3 Coordination and integration of services

Collaboration is still not well developed but, according to public media, improvement is on the way, particularly as the integrated care for persons suffering from dementia will be intensified step by step. Communities of some federal states (e.g. Styria) have created “Integrated social and health services” (ISGS) that have been co-ordinating long-term care since 2004. In other parts of Austria, links have been developed since 2000 between the primary

care by physicians and the mobile services (home care) for the purpose of providing palliative care. In 2005, the federal government and governments of federal states have signed a contract that regulates the provision of social services by charity organizations, federal states, and municipalities. The aim is to improve the collaboration and reduce the competition (*Vereinbarung gemäß Artikel 15a B-VG zwischen dem Bund und den Ländern über gemeinsame Maßnahmen für pflegebedürftige Personen*, Wiener Landtag 2005).

#### 4.4 Actors and human resources in home care

Important actors are:

- Federal ministry of Social Affairs and Consumer protection (responsible for benefits for care and social services),
- Federal ministry of Health (responsible for the health sector),
- Governments of nine federal states (responsible for state benefits, and infrastructure),
- Communities (responsible for the infrastructure, and funding),
- Providers of mobile services and home care with different groups of their staff,
- District or community physicians (responsible for assessment and allocation),
- Physicians in hospitals and general practitioners responsible for prescription of home nursing and technical aids,
- Informal caregivers/family,
- Clients or patients,
- State, regional and local institutions (see Table 2).

#### 4.5 Use of tele-care

Emergency call for persons suffering from diseases is available in the entire country and can be covered by care money. In several field trials, more sophisticated tele-care, for instance video-communication, is being tested (Pfeller et al.2009).

**Table 2:** Delivery of home care in the nine Austrian federal states (main source: Quantum 2007)

State	Responsibility	Amount of hours in thousands in 2005	Explanation/Additional information
Burgenland	Social and health “parishes” ( <i>Sprengel</i> ) supervised by physicians	Personal care (called home care): 93.8. Domestic aid: 163.8	Some guidelines for home care and quality criteria are set down by the parishes
Carinthia	Eight associations for social help ( <i>Sozialhilfeverbände</i> )	Total: 723.6; home nursing approximately 145.7, personal care 350, domestic aid 300	Three home care providers worked in the whole country, 10 providers worked locally
Lower Austria	A centralized entry for persons discharged from hospitals or with handicaps; network of four (charity) organizations.	“units” (not hours) of home nursing: 1841.5. “units” (not hours) of domestic aid: 626.4	Four charity organizations provide the majority of care
Upper Austria	Parishes and 18 associations for social help	Home nursing: 238.8. Mobile care: 732.5. Long-term domestic aid: 134.7	–
Salzburg	The state with its districts and social offices	Information not available	16 providers (also commercial ones); not all of them offer the whole range of services
Styria	Integrated social and health services organized in parishes	Home nursing: 200; Personal care (called home care): 320; Domestic aid: 347	Five organizations provide home nursing (by a nurse with diploma), personal care (by nursing aids), domestic aid (by home helpers); number of clients: 5,500
Tyrol	63 parishes mostly organized by communities	Home nursing: 163.4. Home care: 164.4. Domestic aid: 205	7,577 persons received home care in 2005
Vorarlberg	67 associations for care ( <i>Krankenpflegeverbände</i> ) with 56,626 members	Total number of hours for home support, home nursing, personal care, and domestic aid in 2005: 376.7. In 2006: 386.6	Most of the associations were founded 100 years ago. Annual membership fee: from €22 to €33. Available: 52 mobile services with 2,841 clients, 31 services belong to the associations
Vienna	10 regional health and social centres	Home nursing: 748.4. Domestic aid: 3,652.7	–

#### 4.6 Monitoring the adequacy of care

If the status of the receiver of care benefits has changed, he/she is obliged to inform the insurance institution (§ 10 BPGG). In such a case, a new assessment is required.

### 5. Clients & informal carers

#### 5.1 Home care recipients

Exact and recent numbers are not available because the official Austrian statistics only report on the number of receivers of care benefits. Their number amounted to 341,978 in July 2008 (Bundesministerium für Soziales und Konsumentenschutz, 2009a).

#### 5.2 Empowerment of clients

Most federal states have signed a contract on patients' rights according to Art. 15a B-VG (Patientencharta), that offers a framework to protect clients' rights.

#### 5.3 Unmet needs for care

- Care benefits (*Pflegegeld*) are intended to cover the “additional” needs caused by loss of independence due to disability, disease, or frailty. Consequently, the money is not sufficient to cover the full amount of needs.
- Organisations of senior citizens call for a “care fund” that would be financed on tax basis. They ask for an annual adjustment of the benefits for care that are not connected to the testing of means and possessions.

- A system of care for persons suffering from dementia still has to be developed. Support for the family caregivers needs to be improved and intensified.

#### 5.4 Informal carers

Different forms of support are available to informal caregivers, in particular to caregiving families: training, counselling, respite person, subsidised holiday and contribution to the social insurance. The opportunities vary from one federal state to another. An important type of support is the leave for employees who are providing hospice care for a family member (<http://www.help.gv.at>). For this purpose €787,830 was spent in 2008. The average monthly contribution per case amounted to €680. The payment was dependent on the entire income of the household, but in 42% of the cases the total income was substituted.

- Children's formal liability to maintain both their parents and their grandparents exists in Austria (§ 143 ABGB). This legal obligation is dependent on a number of criteria, e.g.:
- Parents are not able to care for themselves
- If their ability is reduced partially only, children have to cover only a part of the obligation.
- The parent does not have any other relatives who are committed to care for her/his daily life.
- The child is able to cover his/her own basic expenses.

### 6. Disparities in the process of home care

Regional disparities are huge due to the fact that the philosophy, organization and care provision are different in each federal state. Experts believe that considerable injustice of the recognition of eligibility and allocation of care dominates the home care sector in many places. The greatest regional differences supposedly exist with regard to the quality of services. However, reliable information is not really available: "The large care providers in many states keep their cards close to their chests." Therefore, national standards for the assessment and care provision are necessary.

### 7. Concerns and new developments in home care

The shortage of staff (Krajic et al., 2005) and strains of working in the home care field (Hickel et al., 2003) are discussed increasingly: 20% of the health care staff complained that they have to work overtime, with working days up to 14 hours (reported by 27% of nurses interviewed), while 22% of nurses felt emotionally distressed and 20% physically overloaded. One of the most frequent causes of distress was communication with the relatives of clients. The absence rates of nursing staff and semi-professional caregivers were very high (Brunner et al., 2009; Palkovich et al., 2003).

Efforts to improve the quality of home care are on the way. Experts, pressure groups of customers, and the Federal Ministry for Social Affairs and Consumer Protection support the development of a quality certificate and are testing the procedure of quality audits.

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# Belgium

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## 1. The context of home care

### Country, population and health

Belgium is a federal state with a population of 10.7 million inhabitants (2009), spread over Flanders, Wallonia and Brussels Capital Region (BCR), and three official languages: Dutch, French and German. Although the GDP per capita for the country is above the average of the EU27 and EU15, considerable economic differences exist between the regions and communities. In the Flemish (Dutch speaking) region, for instance, the GDP is much higher than in the Walloon region (French and a minority German speaking).

The proportion of elderly people in the population is around the EU15 average; in 2008 17.1% of the population was over 65 and 4.7% over 80. Life expectancy at age 65 was 19.0 years and healthy life expectancy as a percentage of the total life expectancy at 65 was for women and men respectively 47% and 56% in 2006 (compared to 43% and 51% in 2006 in the EU25) (Eurostat, 2009).

### Characteristics of health services and social services

Ten percent of the GDP is spent on health, which is above the EU15 average (OECD 2009b). Health services are funded by national obligatory health insurance premiums and patient co-payments. In contrast to the French community, in the Flemish community social services are partly covered by the Care Insurance ('Zorgverzekering'; for home care as well as residential care). In the French

community social care financing, apart from private payments depends mainly on social welfare. This would partially cover for residential care. Possibilities for long-term care in Belgium other than home care are e.g. day care, and long-term institutional care such as nursing-home care and care provided at homes for the elderly. The Belgian social security system relies more on cash benefits than on in-kind benefits (which made up 7.6% of GDP compared to the 8.7% in the EU27 in 2007, Eurostat, 2009). For the EU15, the average length of stay in Belgian hospitals for acute care days in 2005 was high (OECD 2009c). Among 19 countries Belgium had the second most long-term care beds in nursing homes per 1000 population (OECD 2009a).

### Social indicators and conditions related to old age

As co-payments are in place for home care, the financial position of citizens is a relevant contextual factor. In Belgium, elderly persons are at higher risk of poverty than an average European elderly person (21% compared to 18% in the EU15) (Eurostat, 2010). Although formally children are not liable to pay for the care of their parents, in practice they may be required to financially contribute. *"If a parent or in some cases a grandparent needs residential care, the local Public Centre for Social Welfare can claim part of the costs back from the children and exceptionally the grandchildren provided that they have sufficient resources."* (Alzheimer Europe 2009).

### Attitudes related to old age

Care provided by relatives is considered "natural" and informal care largely exceeds care provided by professionals. However, the proportion of Belgians positively answering the question whether care is a responsibility for close relatives even if their career might be affected, is lower (28%) than the European average (34%) (TNS Opinion & Social 2007b).

## 2. Policy and regulation on home care

### 2.1 Governance on home care

Home care in Belgium consists of domestic aid, personal care and home nursing and can be preventative, curative and palliative. Home care came high on the political agenda 25 years ago resulting from the increase of chronic diseases and disabilities prevalence in an aging population and combined with the general preference of old persons to stay in their home as long as possible. The belief that home care would cost less than care in residential institutions and thus would slow down the growth rate of health and social expenses pushed also in this direction. In 'Protocol 3' in 2008, the federal government expressed their intention to stimulate home care and invest in affordable formal care and good coordination between care providers (Federale Overheidsdienst Volksgezondheid Veiligheid van de voedselketen en leefmilieu 2008). Also, as home care is conceived as inherently dependent on informal care, arrangements for the support of informal carers should be developed.

Home care responsibilities are shared between the federal government and the communities with the former setting the general frame and rules and the latter having to provide and regulate home care delivery: the *federal government* regulates home nursing financing and several health and paramedical professions and is responsible for the sickness and invalidity insurance. The *communities* (Flemish, French and German) and the Brussels GGC ('gemeenschappelijke gemeenschapscommissie', common community commission) are responsible for policy on e.g. preventive health care and home nursing (complementary to federal responsibilities in this area), domestic aid, personal care, elderly and disabled persons (excluding e.g. certain eligibility criteria and federal regulation on financial benefits). With regard to home care, communities finance and set agreement criteria of home care agencies.

It has remained unclear what exactly the division of responsibility between community and region is. The differences in governmental structure of the Walloon en Flemish regions are one of the difficulties. In the Walloon region there is a Walloon government, the French community government (including that in Brussels) and German community government. The Walloon government has to 'agree' on home care agencies. In the Flemish region and community there is just one

government. The Flemish government reigning area includes the Flemish speaking part of Brussels with regard to e.g. health care and public welfare policy. Finally, there is the government of Brussels Region.

In the Belgian context *home nursing* refers to personal care and technical nursing provided by qualified nurses and nursing assistants. This care is co-financed by the federal social insurance. *Family care* refers to personal care and domestic aid provided by non-nursing professionals (family carer and assistant for elderly). These are in contrast co-financed and organised by the communities and municipalities. Logistic home care services are a third type of care available. It consists of cleaning assistance, odd jobs (such as simple housing work such as small painting and sitting services and some general psychosocial and pedagogical support. In this report we will be looking at one part of this type of care, namely 'cleaning assistance'. These are also organised and co-financed by the communities and municipalities. Personal care and domestic aid can be provided by both Public Centres for Social Welfare and, mainly, by private providers. Next to these common home care services in kind, there are also separate services offered to persons with 'service vouchers' (meant for persons in relative good health) and Personal Assistance Budgets to handicapped adults. These services will be discussed later in this chapter.

Home care provided by nurses is mainly a federal affair while domestic aid and personal care are mainly affairs for communities. Despite inter-ministerial conferences (between the federal and regional level), the Flemish, the Walloon and of course also the BCR region continue to have divergent home care system and this is not going to change in the near future. In Belgium both the French and Flemish communities have their own policy. Three separate organisations are established in Belgium: the Flemish Community Commission, the French Community Commission (COCOF) and the Common Community Commission ('Gemeenschappelijke Gemeenschapscommissie'). Each commission has the authority to govern cultural, educational and personal activities. For example a long-term-care insurance is only available in Flanders and there exist important differences (in favour of Flanders) in professional resources and availability of health and social institutions. So convergence appears difficult to achieve due to strong political differences shaped by history leading to divergent economical development. In this regard the situation of the bilingual region of Brussels-capital

region is worth attention (De Lepeleire & et al. 2004). The communities finance personal care and domestic aid and are authorised for the Care Insurance and the local governments, next to organising care, may also finance some care themselves (Verhaever, 2005). The federal level is in charge of financing home nursing. In some domains, such as residential care for older persons, specific responsibilities are split up: financing is a federal responsibility and recognition of care institutions belongs to the responsibilities of the communities (Flemish, French and German).

The main policy document in Flanders is the *Home Care Decree* (Ministerie Vlaamse Gemeenschap 1998), in which home care (excluding services provided by nurses) is seen as a supportive instrument to enable clients to stay in their home environment. The later issued *Care & Living Decree* developed a more integrative vision on home care, i.e. coordinating home care (as defined in the Home Care Decree), with home nursing (not referring to independent nurses), and residential care. The latter decree aims to integrate care pathways and promote flexibility between self-care, informal care, home – and residential care, increase the quality of care, and to increase financial accessibility. A major priority of the Flemish government on personal care and domestic aid is to expand services, i.e. number of hours, geographical dispersion, number of service centres (providers), and availability of palliative care at home.

Regarding the French community, the community issued a first decree in 1984 on the recognition and subsidy of services for the elderly. Later, in order to better coordinate and manage care around the patient, a number of decisions were made (1989, 1999, 2004) to strengthen the primary care level with an enhanced role given to primary care physicians (2009) and to the 51 home care coordination centres (1999). The French Community Commission (Decree on the provision of ambulatory services in the area of social action, family and health, March 5 2009) and Common Community Commission (Ordinance on services and centres for aid to persons, November 7 2002) have their own regulation regarding ambulatory and home care and also residential care.

## 2.2 Eligibility for home care services

### *Home nursing & personal care*

Eligibility criteria for public funding of *home nursing* (as provided by certified nurses) are set by the National

Institute for Health and Disability Insurance (NIHDI). To receive home nursing a certain level of ADL dependency is required, measured by the 'Index of ADL' or a doctor's referral in case of specific technical nursing activities and a number of specific conditions. According to Flemish regulations, personal care should be delivered in those cases where the capacity of a person or his environment is insufficient due to mental or physical disabilities, or due to social circumstances (Ministerie Van De Vlaamse Gemeenschap 2009). A community level form is used to measure this. Priority *should* be based on the needs, the self-care ability and the availability of informal care (this last criteria does not apply in Wallonia). It is up to the providers to set the exact priority groups in accordance to the law (some eligibility criteria may not be used). *Co-payments* depend on e.g. income, age and disability level. That is, no client-copayments are needed in the costs for healthcare financed by NIHDI for widows, handicapped persons, orphans, and pensioners. Eligibility criteria for *reductions in co-payments and cash benefits* for personal care are set by the Flemish community and the municipalities. Pensioners in Wallonia may also receive reduction in co-payment.

*Cash benefits* for home care coming from the Flemish Care Insurance (FCI) require a need of long-term care and severe disabilities, depending on standardized scoring tests (i.e. BEL-score for home care and KATZ-score for home nursing). This is not the case in Wallonia where benefits in cash are less available (no personal budget or care allowance) as the private sector is less developed. Still, some competition does seem to exist in Wallonia as co-payments are not required for home nursing but are for family care. Family care will from now on be used interchangeably with 'domestic aid and personal care services not financed by NIHDI.

### *Domestic aid and technical aids*

Eligibility to domestic aid is similar to personal care in Flanders and in Wallonia: any disabled adult under the age of 60 or not considered as such but older than 60 is entitled to this care. Although in both communities, income is not an eligibility criterion, in practise, priority is often given to those increasingly dependent *and* with a low income. Domestic aid can also be purchased by means of service cheques, i.e. coupons for specific services such as cleaning assistance.

Technical appliances e.g. wheelchairs or special beds can be received through the Insurance Funds and the regional service centres; the NIHDI finances these appliances. The costs of renting and buying technical appliances can be financed through the Flemish Care Insurance benefits, under the same eligibility criteria as for cash benefits for personal care and domestic aid. Service vouchers are another possibility in Belgium. With these vouchers, bought by the users, able-bodied healthy people of 60 years and older can buy care (mainly domestic aid) from certified organisations (presentation Willockx). These coupons are meant for specified services such as for domestic aid and meals-on-wheels (see paragraph 5.3).

### 2.3 Quality of process and output

#### *Availability of quality criteria*

In Belgium, quality control on home nursing financed by NIHDI and provided by qualified nurses is practically absent. Nursing agencies (financed by NIHDI, with qualified nurses) have to be agreed by their respective umbrella organisation. However, to what extent and in what way quality is taken in to account in this agreement is unclear.

In Flanders, some regulation has been developed with regard to the quality of personal care and domestic aid (not financed by the NIHDI or provided by qualified nurses). Registration (required for public funding) implies that providers must adhere to norms on the process of care, for instance working client-centred and maintaining continuity of care (Vlaams Agentschap Zorg & Welzijn 2009). Norms on outcomes of care are not in place. Currently, there are no (not yet) regulations on the quality of home nursing. Quality within domestic aid and personal care consists of having a quality handbook, self-evaluation, a quality plan and writing an annual report.

Regarding Belgian nursing care and some personal care, financed by NIHDI, the only existing control applying to nurses is indirect as it is based on the existence of their professional registration number, which is checked in all payment transaction. Supervision only consists of checking if the declared services for payment purpose have really been performed. No data are available in term of service outcomes.

In Flanders, to be registered, providers of home nursing must have a sufficient qualification as a professional nurse. For services providing personal care and domestic

aid, not financed by NIHDI, there is external inspection by the Flemish Agency for Care and Health of the quality plans set up by the providers themselves and conformity to the quality criteria (Vlaams Agentschap Zorg en Gezondheidszorg 2010a).

In the French community, the external regulation of the quality of home delivered services is weaker. For French community family care (that is, domestic aid and personal care not financed by NIHDI) no external quality criteria apply at all. The organisations providing these services only have to comply to minimum number of personnel and whether professionals have the required educational level (Verhaever 2005). As no criteria of the quality of the services exist, no evaluation of the adequacy of the delivered services can be performed.

#### *Assessment of quality of services*

In Flanders, apart from norms for providers, there is also regulation on the assessment of quality of home care. Care providers are obliged to set up quality plans and evaluate their service quality, but are relatively free to choose the topics of evaluation. As stated in the Flemish Quality Decree, every two years providers must self-evaluate the process, structure and outcome of care, including an assessment of the client satisfaction. This also holds for nursing care providers, with the exception of independent nurses (which are estimated to provide half of home nursing). No such formal obligation exists in the French community.

In Belgium, organisations providing NIHDI-financed home nursing under an umbrella organisation exchange data on quality indexes within their umbrella organisation. Its content may differ according to agencies and their respective umbrella organisation. To what extent reports on quality are taken up in this is unclear. Self-employed/independent nurses and the associations they work in do not have such obligations.

#### *Accreditation and clients complaint procedures*

As previously mentioned, registration is required for care providers but accreditation does not exist in Flanders, neither in Wallonia. An important tool to safeguard care quality are procedures to deal with clients' complaints, which providers of personal care and domestic aid not financed by NIHDI) and local service centres in Flanders are obliged to maintain (Vlaams Agentschap Zorg en Gezondheidszorg 2009). Providers of home nursing services are not obliged to keep such procedures;

**Table 1:** Human resources in home care

Functions	Belgium (estimated number)
Domestic aids	n.a.
Carers at home	In Flanders (2003): > 20,000 In Wallonia (2008): 6,000 In 1998: In Flanders: 11,572 In Wallonia: 4,550
Nursing assistants (2003)	1,395
Nurses (2003)	16,839

Sources: Flanders: Nursing assistants and nurses: Estimation, based on (Verhaevert 2005).

Carers Flanders 2003: (Ver Heyen & Vandenbrande 2005).

Carers Wallonia 2008: Website Walloon government (14-04-2010),

<http://www.wallonie.be/fr/informations-generales/pratique/f-a-q/faq-pouvoirs-locaux-action-sociale-et-sante/services-a-domicile/index.html>

Carers Flanders & Wallonia 1998 (for seniors+family): Gazon & Ylief (2004).

complaints may be submitted to client federations (Kenniscentrum Mantelzorg vzw 2009). Regulation is not so stringent in the Walloon area.

## 2.4 Quality of input

### Education

The following professions (with their tasks and educational requirements) are involved in home care:

In Flanders but on the federal level:

- Care expert ('zorgkundige'): one additional year of secondary school for carers (Belgisch Staatsblad 2006), but most have followed training for polyvalent carer, and after completing a 120 hour course. Tasks: some nursing interventions delegated by and under the supervision of a nurse, they are allowed to perform 18 technical nursing tasks (Sermeus 2009);
- Qualified nurse (level A2): 3 year tertiary vocational training. Tasks: all nursing acts, such as wound care, injections, stoma care, catheterisation (Sermeus 2009);
- Certified nurse (level A1): 3 year BA-level education. Tasks: all type of entitled services and care coordination (Sermeus 2009);
- Nurse specialist: very rarely practicing in home care; level A1 or A2 plus one year university education. Tasks: all nursing acts and specific interventions such as diabetes education and wound care counselling (Sermeus 2009).

In the French community, but on the federal level:

- Nurse, in Wallonia, the "formal" split in nursing degrees (care expert-qualified nurse-certified nurse-nurse specialist) does not exist. However, some of them have on their own decision, gained an equivalent level of expertise, but they usually work only in hospitals.

Specifically, in Flanders:

- Cleaning assistant: no educational requirements and no certificate. Tasks: domestic aid, conversation with clients and observing problems (Sociaal Economische Raad van Vlaanderen 2005);
- Carer ('verzorgende'): secondary education in specified topics, or one-year training after secondary school. Certificate regular daytime classes or adult education. Tasks: ADL support, guidance, health education, supervising medicine intake, observing social and psychological well-being and supervising domestic aid (Sociaal Economische Raad van Vlaanderen 2003).

Specifically, in the French community:

- Family carer: (corresponding to Flemish carer) help with personal care (hygiene and medicine preparation), domestic aid, sitting services (keeping guard), psychological and physiological help and health education (Verhaevert 2005). They are not allowed to perform nursing care;
- Assistant for the elderly (corresponding to care expert); no formal control of the level of their training but usually one year of training (additionally

**Table 2:** Estimation of long term care (ltc) provided at home and in institutions 2006/2007

Recipient groups	Recipients of ltc at home in 2007	Recipients of ltc in institutions 2007	Families receiving family care in the Flemish community in 2006	Recipients of family and senior care in the French community in 2000
Total (% of pop)	152,318 (1.4%)	122,857 (1.2%)	74,406 (1.2%)	–
% 65+	89.8% (in 2004)	97.8% (60+)	73,8% (60+)	75%
% 80+	54.6%	75.3%	–	–

Source: Home health care and institutional care: OECD/HD, May 18, 2009.

Family care Flanders: (Hedeboom & Merckx 2007).

Family care Wallonia: Gazon & Ylief, 2004.

also continuous education in Home Agencies). Tasks: same as family carer but only to persons over 60 and disabled adults who are more than 66% disabled.

The nomenclature for nurses specifies the required education for each nursing activity (Belgian Royal Decree Nr. 78, Article 8, on the nursing profession). The general profile of nursing education is set by the Flemish government, including basic competences, key abilities and supportive training. The same process applies for the French community. For the education of care experts (in the Flemish community), guidelines have been developed.

#### Job description

Tasks of nurses have been laid down in the nomenclature: The NIHDI classification defines services that only nurses are authorised to perform on behalf of a medical prescription (technical nursing). Tasks of care experts have been specified in a federal decree (Federale Overheidsdienst Volksgezondheid Veiligheid van de voedselketen en leefmilieu 2006).

For cleaning women and carers 'professional profiles' have been developed by the sector to inform clients about the services they can expect. This information is not available in the French community.

#### Recertification

Recertification of nursing professionals does not exist. But there are some training requirements for the organisation nurses work for. Financing specific costs of the home nursing agencies (i.e. costs for organisation, coordination, programming, continuity, quality and evaluation – Royal Decree of 16 April 2002, modified by the Royal Decree of 7 June 2004) depends on meeting the following requirements:

- The organisation implements permanent education for at least 20 hours per year per full-time-equivalent nurse;
- The organisation guarantees consultation and peer review for at least 25 hours per year per full-time-equivalent nurse.

For nurses working independently, no such requirements exist.

#### 2.5 Incentives for providers

In both communities competition among agencies has been mild, as clients usually choose home care providers from an umbrella organisation linked to their Sickness Fund (for instance, Christian, Liberal, Socialist independent). However, in Belgium, a large number of self-employed nurses are more and more competing with the home nursing agencies. In 2002 the share of salaried home nurses of the total number of home nurses was estimated to be just 42% to 43%, and due to growing attractiveness of self-employment this percentage is expected not to have grown over the past years (Verhaevert, 2005). According to Walloon experts, independent nurses are less usual in the French community. Compensated by a fee for service system, self-employed nurses generally earn more than their salaried colleagues in agencies. When competition is present, it usually results in more services being provided than lower prices as NIHDI reimburses all services when performed by nurses with a weak control (experts).

Competition in domestic aid is rather high in Flanders as there are many providers (private as well as in agencies) with different payment systems. Another competition enhancing circumstance in the whole of Belgium is that many clients purchase domestic services using 'service cheques' (vouchers) which can be spent on

services provided by federally recognised ‘service cheque enterprises’. Finally, both family care providers and nursing care providers compete on ADL care, which they offer for different prices. Although this difference also exists in the French community, competition *between* organisations is said to be low in this regard as in Wallonia home care agencies integrate both types of carers. In the BRC, although competition is relatively high due to three different communities, competition is hampered by language barriers and lack of information among clients and referring agents about community care options.

### 3. Financing

#### 3.1 General funding

*Home nursing* care is financed alike in Flanders and Wallonia, namely through compulsory health insurance, membership fees, client co-payments and optional voluntary insurance. In 2007, federal expenditures on home nursing were around 857 million Euros (Paquay 2009). Co-payments generally are about 25% of the total costs, with maximum invoices set. In addition to home nursing, compulsory health insurance partly reimburses *technical aids* (but not *home adaptations*). *Domestic aid and personal care* (including *respite care*) are mainly financed through community taxation and client co-payments. In Flanders monthly cash benefits received from the Flemish Care Insurance (FCI) cover a large part of the client co-payments for family care (non-medical care). The FCI fixed premiums are obligatory in Flanders and voluntary in the Brussels region, but is non-existing in the French community. In 2008, the FCI Fund spent 148.5 million Euro on home care (Vander Auwera 2009). Co-payments can also be paid out of several special cash benefits for elderly or disabled persons, which stem from a mix of obligatory insurance premiums and taxation. In 2004, the Walloon government spent about 105 million Euros on family care incl. care for seniors (Detienne, 2004). Next to services in kind, also ‘service cheques’ are funded. These service vouchers are funded by the federal government.

#### 3.2 Financing of home care agencies

*Home nursing* (technical nursing as well as everyday personal hygiene) providers are paid by the Sickness Funds and recipients. For help with personal hygiene, low dependent persons (at most, total dependency for

washing and dressing) are reimbursed by NIHDI on a fee-for-service basis. For severely disabled clients, NIHDI directly pays providers a fixed sum per day for these services. In particular cases, such as palliative care or diabetic care, daily lumps sums are possible. Providers of technical nursing (e.g. intravenous or subcutaneous infusion and administration via epidural catheter) are reimbursed on a fee-for-service basis. NIHDI pays all technical nursing care based on declared services of the previous year. Services delivered by self employed nurses working alone are financed according to their activity through a fee for service payment scheme. In addition to payment for services, home nursing agencies receive a lump sum for overhead based on the number of FTE nurses (Sermeus 2009). Misuse of the fee for service system is prevented by limits on payments per day and, in case of lump sum, a minimum number of visits per day (Sermeus 2009).

For personal care and domestic aid providers not financed by NIHDI there are quota of subsidized hours in Flanders. In the French community there are subsidies per geographic zone and per service. The agencies receive a global budget for IADL services which usually does not cover the overall needs of their clients. The budget is based on the number of hours x costs of an hour of domestic aid and overhead costs. Also in the French community a yearly ceiling to the number of hours of ADL to be provided is laid down per geographical area (related to number and age of inhabitants) and per service (Verhaever 2005). In the French community clients can get up to 200 hours care per trimester, while such limitations do not exist in Flanders.

The Flemish Agency for Care and Health pays the (non-nursing) providers of *personal care* and *domestic aid* per hour and an additional fixed amount for specific types of overhead e.g. management and training of staff (Vlaams Agentschap Zorg en Gezondheidszorg 2010b). In case of help with cleaning, subsidies are also provided for a set number of FTE’s. In the French community there is no separate financing mode for these types of services. Each agency providing help with cleaning, domestic aid and personal care has got a ceiling in the number of hours to be provided. This ceiling is based on the total quota mentioned above. The calculation is based on the number of hours and type of services provided in the previous year and on the total number of hours allocated to that area (taking the population into account). Furthermore, the clients pay providers themselves either through a co-pay in cash per hour (for personal care and domestic aid) or

through service cheques. Domestic aid and personal care provided by a personal assistant can be paid from a client's personal assistance budget. This is an option specifically for those persons with a handicap. The budget for public personal care and domestic aid providers called Public Centers for Social Welfare are controlled by the town council (presentation Familiehulp).

There is no personal budget scheme available in the French community for any type of services, and in the Flemish community there are only some experiments with it (<http://www.VAPH.be>). Just like in the Flanders, a voucher is available in the French community in order to facilitate direct access to home help services. The average client's contribution amounts to 8 Euros while the government pays 20 Euros for them, but with voucher's use, this client's actual contribution can be reduced to less than 4, through different fiscal reductions and/or social charges exemptions (direct employ).

### 3.3 Price setting of home care services

Prices for home care are set on the federal or community level with the mechanism depending on the type of service:

- Nursing: prices are related to the level of ADL dependency, the type of care (activities performed in case of moderate disability; need for technical nursing), time of provision (daytime, weekend, etc.), the height of the nurse wages and costs of nursing materials. These are negotiated and fixed at national level through a complex mechanism. The bargaining process involves NIHDI, Sickness Funds, federal and regional political actors and professionals unions (physicians, nurses). The bargaining sometimes results in new services sometimes being overpriced relative to existing services;
- Personal care and domestic aid not financed by NIHDI in Flanders: prices are set per hour by the regional government (about 19 Euro in Flanders; in 2005). This is based on the salary of helpers and costs for staff training. In the French community, for an hour of work, costs vary according to worker status (directly employed, acknowledged or not) or salaried) from 10E to 30E. Also tariffs for home helps depend on revenue;
- Flemish separate service 'help with cleaning of the home' (by agencies called 'Poetsdienst'): a minimum average co-payment is set by the local government.

All governments try to keep down public expenditures on home care and, at the same time, try to offer affordable home care. The level of co-payments for clients is set as follows:

- For nursing: a national fixed share of the price with a ceiling amount per year. However, means-testing does take place. In Flanders, those (economically) vulnerable are eligible for reductions (Bond Moyson West-Vlaanderen 2009). In Wallonia, the co-payment mechanism (reduction) is based on income with an upper ceiling and with no contribution (exemption) below 600E/monthly income for a single client (minimum pension). Delivered services not included in the federal nomenclature for home nursing are to be pay out of pocket money (De Lepeleire & et al. 2004).
- Personal care and domestic aid (by family care agencies): fixed amounts set per community depending on income, household composition, and time of provision. Discounts exist also for severely disabled persons.
- Help with cleaning of the home (by agencies 'Poetsdienst'): the Flemish government sets a minimum average price. (If cleaning is provided by family care agencies calculation of the price is similar to personal care).

## 4. Organisation & delivery of home care

### 4.1 Access and needs assessment

To apply for care, the person in need, their family or a third person (e.g. hospital or GP) needs to contact a home care agency providing the care needed (who can also help with attaining cash benefits in Flanders). The clients and their families are the main applicants for personal care and domestic aid. Only a very small share of these recipients was recruited by nurses and GPs.

For general information on home care available Public Centres for Social Work (also providers of home care) can be approached, while for home nursing clients usually contact directly the organisation for home nursing or their sickness fund or GP. For technical nursing care (injections, wound treatment, gastro-intestinal care) a doctor's referral is required (Sermeus 2009).

Individual needs assessment for home care, except technical nursing, is performed by an officer of the agency (social worker) or by a nurse, depending of the kind of care needed. There are no rules in this regard for help with cleaning of the home. After assessment a care plan is made. The process may differ according to the setting: If performed in a geriatric service, it will be done by a multidisciplinary team. This team will organise discharge and forthcoming personal care plan with the ambulatory agencies. The needs-assessment for home nursing exists out of an evaluation/assessment of the ADL dependency (called the 'Index of ADL'). A similar instrument, but still different, is used for family care (personal care and domestic aid not financed by NIHDI) in Flanders ('Belschaal'). Although in theory the family care providers can use the results of the Index of ADL (the Katz scale), in practice it may happen that two assessments are taking place. Eligibility criteria for nursing are more formalised than for personal care and domestic aid. The index of ADL is always used in the French community but other additional assessment tools may be used and thus the resulting care plan may vary. Misuse of assessment power by agencies is counteracted by inspection on correct use of the index of ADL (Verhaever 2005). No such checks apply to the family care and help with cleaning of the home providers as they are contracted for a set number of hours.

#### 4.2 Delivery of services

*Nursing* care is delivered by non-profit home nursing agencies, which are more or less affiliated to Sickness Funds and by self-employed nurses. Many nurses are united in an association of private nurses. The latter group is the largest in Flanders, but not in Wallonia where the for profit sector is weaker. But in all regions its share is growing.

In 2003, there were about 250 family care agencies in Belgium. In Flanders, providers of *personal care and domestic aid* are a mix of public and mainly private agencies (Rekenhof 2007). Although in the French community there are more public than private agencies (Verhaever 2005), most hours were also provided by the private sector. In the French community, there are three main groups of providers which have integrated home nursing, family care and senior care, i.e. the ASD (Christian affiliation), CSD (socialist affiliation) and the ACCOORD (a multidisciplinary association) (De Lepeleire et al., 2004). In both the Flemish and French community there are usually several providers

in one area. In Flanders, most agencies providing *help with cleaning of the home* are public (municipalities and Public Centres for Social Work) (Hedebouw & Merckx 2007). However, the share and competition of private agencies is growing, especially in cities as there are said to be problems with the flexibility of Public Centres for Social Work.

#### 4.3 Coordination and integration of services

Several subsidised initiatives have been taken to integrate home care services. An example of such initiatives in the French community is the introduction of "Coordination Centres for Home Care and Services" (CSSDs) already in 1989 (the Picquet decree; BS/MB 4 8 1989). They were introduced to counter the fragmentation of home care organisation and the inefficient competition between nursing agencies and try to enhance instead cooperation inside agencies between physicians, nurses and social workers. To be acknowledged these organisation must include GPs, home nurses, family aid, home helpers and social workers and are supposed to deliver four disciplines and focus on people who are in serious need of care. Despite various subsidised initiatives for improving the coordination within home care and between home care and other service providers, coordination is seen as problematic.

As a federal initiative 'Integrated Services for Home Care' have been set up in some areas to organise multidisciplinary consultations within primary care and stimulate the development of multidisciplinary care plans (Sermeus, 2010). They are not available in all areas. They are mainly concerned with establishing the needs assessments, laying down care plans and assigning tasks to different providers and to organise multidisciplinary consultation (Gerken et al., 2010). They consist of a team of home nurses and at least one GP within a set area and are financed through the NIHDI. This was meant to ensure the quality of care and cooperation between home care professionals. Other formal structures of cooperation between home care agencies are scarce in Flanders. In the Walloon region, coordination exists in home agencies as many integrate domestic aid, personal care and home nursing. This is not the case for self employed nurses groups and of the Public Centres of Social Work who manage directly home care agencies.

GPs have an important role in home care, primarily because they make referrals for home care but also through home visits. In Flanders, although formal

cooperation with GPs is scarce, part of the independent home care nurses liaise with GPs because they work in GP practices on a part-time basis. Also, home nursing agencies usually have liaison nurses who regularly meet with GPs and hospitals' social services and organise the transfer of discharged patients to their home (De Vlieghe et al. 2005). In exceptional cases hospitals may provide specific services in a patient's home. In the Flemish community, institutional nursing home care and other home care are provided by different organisations. However nursing homes complement home care through providing day care. In Wallonia, all the previous arrangement may exist but on also a voluntary basis even if a more a team working approach is favoured by the new legislation and financial incentives.

#### 4.4 Actors and human resources in home care

##### *Actors in home care*

Although there are some differences between the French and Flemish community the main actors in home care can be summarised as:

- The Federal government (for regulation on home nursing only);
- National Institute for Health and Disability Insurance (NIHDI) (for funding of home nursing and registration of the agencies);
- Flemish and French government (regional governments) (regulation, mainly personal care and domestic aid; with the Care and Living Decree in Flanders; this has become increasingly important for home nursing too);
- Flemish Agency for Care and Health Care (management of the Flemish Care Insurance fund and funding of home care agencies for personal care and domestic aid);
- Flemish Agency for Disabled Persons (payment of cash benefits to disabled persons, e.g. for technical aids and home adjustments, wheelchairs, incontinence material but also the personal assistance budget);
- The six Sickness Funds (collecting premiums; registration of insured; checking and paying benefits);
- Home nursing agencies and self-employed nurses (provision of home nursing care);

- Private 'Family care' agencies (private providers of personal care and domestic services);
- Public Centres for Social Work (OCMW/CPAS) and their local service centres; these centres may set up domestic aid services, and they inform persons about available home care and other benefits and possibly offering technical aids, domestic aid, meals on wheels, and personal care; mainly, but not exclusively, to elderly people. In Flanders they are also the local office for the FCI.
- Agencies for help with cleaning in Flanders ('poetsdiensten', providing domestic aid).
- Municipalities (may provide additional cash benefits and/or deliver some services)

##### *Human resources in home care*

There is considerable overlap in services provided by different providers and agencies. For instance simple personal care (ADL) can be provided by nurses, nursing assistants, care assistants (called assistant for the elderly in Wallonia) and carers (though against different tariffs). Recent data on the number of home care workers are scarcely available. In 2003 there were around 20.000 health care professionals working in home care. Most workers providing personal care and domestic aid are employed, while a growing majority of nurses are self-employed (in 2002 it was 57%). Working conditions and salaries of employed nurses and other home care workers are set in a collective labour agreement. One of the aspects with which carers in Flanders were least satisfied was their wage (Ver Heyen & Vandenbrande 2005). In spite of this professionalization of domestic aid in the French community, the low income (around 1,200 Euro net for a full-time carer), unfavourable working conditions and a lack of supervision has induced a shortage of carers in certain Walloon areas. On average the gross annual income of registered nurses is between 22,798–37,596 Euro. Nursing assistants earn about 21,997–34,562 Euro per year (Colombo et al., 2011).

#### 4.5 Use of tele-care

Some insurers lend simple home alarm devices for a soft price. The use of more complex tele-care devices in the French community is unclear. In Flanders, tele-care is reported to be not widely used, even though it is available and partly financed by public subsidies. However, many

Flemish local and regional service centres offer alarm buttons and some offered signalling devices (e.g. fall and movement detectors) (Vanackere 2008a).

#### 4.6 Monitoring the adequacy of care

In the *Flemish community*, home care agencies must re-evaluate the clients' needs at least once a year (Vlaams Agentschap Zorg & Welzijn 2009). In complicated cases, monitoring is more frequent (through the Integrated Services for Home Care), i.e. every three months. Home nursing agencies are paid once a year for an evaluation of the client's needs (setting up a care plan). To what extent compliance to these requirements is evaluated is unclear. In the *French community*, monitoring of changing needs is rather weak because of poor control of home care agencies by their respective umbrella organisations. Occasionally, they finance social workers to oversee the assistant for the elderly's work.

## 5. Clients & informal carers

### 5.1 Home care recipients

Table 2 shows that recipients of long-term care at home outnumber institutionalised long-term care recipients. No data is available for recipients of home cleaning. The use of home nursing differs strongly between regions. In Flanders, over 70 Euros per insurant is spent on home nursing, while in Wallonia less than 60 Euros and about 25 Euros in Brussels (Verhaever 2005).

### 5.2 Coverage and unmet needs for care

In Flanders, there are concerns with the lack of hours being subsidised as several providers were unable to provide all care needed (Hedebouw & Merckx 2007). Hence, the government aims to better distribute subsidised hours home care. A survey among elderly people has shown that needs for personal care are more frequently unmet (unmet needs reported by 17%) than needs for domestic aid (by 7%) (Verhaever 2005). On the other hand there were signs of oversupply as many recipients were not in need of home care (Verhaever 2005). In Wallonia, legal and social subsidies are not sufficient for home domestic aid, especially for poor people. There is also a shortage in home helpers, providing domestic aid. All these reasons entail that gaps

between needs and delivered services exist (expressed by experts) but the real degree of discrepancy in volume and quality is not known.

### 5.3 Empowerment of clients

In both areas, empowerment of clients is rather weak. Theoretically, people are free to choose between residential and home care, but the costs of residential care are very high due to only 'care' costs being covered (Verhaever 2005). Care delivered in nursing homes is reimbursed at high rate only when services are based on health rather than on social needs and thus reimbursed by NHIDI.

Free choice of home care providers is hampered by lack of information among care seekers and referral agents (which results from affiliations of agencies to Sickness Funds). In Brussels the language is an additional barrier (Farfan-Portet et al. 2009).

Care seekers can obtain information on agencies, services and financial conditions with the Centre for General Social Work, the Public centres for Social Work, Local Service Centres and hospital social workers. However, comparative information on service quality among agencies is not available at all. There exists very few surveys of client satisfactions or experiences with services and they are voluntary. Even though media are beginning to pay attention to this issue, it is not high on their agenda.

There are several instruments with which those in need can choose their own provider. In Flanders, disabled adults and children are eligible for a personal assistance budget which can be used for a wide range of services, from guidance and accompanying services to IADL and ADL services. In both Wallonia and Flanders, service cheques (vouchers) are popular among any people to pay for small services, like cleaning the home, ironing, shopping and meals-on-wheels as it costs 7.50 Euros to an individual but is worth over 20 Euros (Rijksdienst voor Arbeidsvoorziening 2009).

### 5.4 Informal carers

According to the 2001 Belgium census 9.73% of the population aged 15 and over provided informal care mostly (88%) to a person belonging to their family (Belgian Census 2001). This percentage was significantly

different for males (7.9) and females (10.8) and significantly higher in Wallonia than in Flanders. In Flanders, formal support of informal carers is available, e.g. in 2003 122 nursing homes and rest homes provide respite care (Declercq 2004), courses on home care and dementia are organised and 'sitting services' provide company and support to the dependent when a caregiver is temporarily absent. These services are much less developed and thus less accessible in the Walloon area, even though it is shown that the Walloon population is more involved in informal care.

Belgian informal carers can in case of palliative care and care for a extremely sick family member take a career break while receiving monthly career brake compensation. The yet quoted census showed that the number of hours of care provided increases when informal carers are not employed or actively seeking a job, the opposite being true if he is active in the market. Hence, it seems that there is still a deficit of policies aiming at compensating for loss of revenue in case of job leave for care reasons (Belgian Census 2001).

## 6. Concerns and new developments in home care

The following problem areas have been reported on home care in the Belgium:

- A biased competition between independent providers and not for profit nursing agencies linked to different cost structures of self-employed nurses and nurses in organisation (Sermeus 2010);
- Some difficulty for persons in need to understand where to apply for home care and which services and benefits they are eligible to. This results from poor coordination between nursing care and help with ADL/IADL in Belgium;
- Rising health care costs due to biased financial incentives in the reimbursement system as nurses are able to provide help with ADL while paid differently than other home carers providing the same services. So Walloon home agencies, in order to safeguard their budget push nurses to provide this type of services which will then be reimbursed by the health insurance. In the French community, there are also biased incentives regarding the choice of care settings: in residential homes, the health insurance only pays nursing and medical care, not the stay (which is paid by the client). Patients can under

some circumstances be pushed to choose to move to a nursing home instead of receiving home care. Home care is in total less expensive but may be more expensive from a patient's perspective. This may be the case for patients which are totally disabled or chronically ill and in need of complex medical and nursing services and who are not entitled to social welfare;

- Shortage of home carers, (especially in Wallonia), linked to a deficit in funding and bad working conditions;
- Lack of care continuity in Belgium as a result of provider's fragmentation and non optimal agency's organisation: home helpers working in agencies are usually not available during the weekend and when directly employed too expensive.
- Unmet needs, due to problematic distribution of subsidised hours of home care (in some areas subsidised hours remain unused, in others there are too little hours available).
- A lack of quality control;
- Lack of transparency in the calculation of co-payments for family care;
- An additional problem in Brussels is a lack of coordination and communication between the communities. The complicated system with three sets of regulations, Brussels, Walloon and Flemish region, makes the available home care difficult to understand for those in needs.

It is unlikely that the Walloon region will adapt an insurance scheme for disability risk like the Flemish one. However some common trends in Belgian home care can be distinguished:

- Through the Federal Protocol 3, in which home care is a priority, it is expected that home care will develop;
- Strengthening of primary care is a strong trend. In Flanders, Cooperation Initiatives Primary Care (SEL) are recently being funded (e.g. through paying coordination time). These are meso level cooperations between at least GPs and Public Centres for Social Work (providing home care) trying to facilitate multidisciplinary cooperation and make agreements to coordinate service provision. In Wallonia the 2009 new regulation has set financial

incentives for GPs to work in group practice with other physicians (medical homes) and in teams (with nurses, social workers, physiotherapists, occupational therapist). But physician's unions are opposed to such arrangement as they are considered to be too much "collective", restraining their professional autonomy. So the future impact is yet unclear;

- Developing IT-infrastructure to facilitate the coordination of the care process by GPs (e.g. infrastructure for data exchange between various health care actors) (Demotte 2007). In this regard, the Global Medical File is almost generalised and its use, pushed by strong financial incentives, should facilitate the coordination by GPs of the care process;
- In Flanders, with the Quality Decree for all home care providers being effective per 01-01-2010 it is expected that quality of care will be further developed from now. Things are moving slower in Wallonia;
- Integrated service delivery is expected to develop as it is mentioned in Protocol 3 and pursued by the new Flemish 'Woonzorgdecreet' (home and care decree), which aims to streamline regulations on care, health and housing. Other forms of innovation to better integrate care at the patient level are disease and case management initiatives;
- The development of geriatric services in all general hospital to facilitate hospital discharge management and out reach assessment by geriatric teams is also on the agenda.

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# Bulgaria

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## 1. The context of home care

### Country, population and health

Despite a period of rapid economic growth after accession in 2007, Bulgaria is still the poorest country in the EU. The GDP per capita is about 40% of the EU average (2008; Eurostat, 24-02-2010). Long-term unemployment is high and the share of unemployed persons at risk of poverty was the highest in the EU in 2007 (over 60%; Eurostat, 17-02-2010). In the context of the SANE programme new jobs have been created in home care related services in Bulgaria.

The low population density and the negative population growth rate (-4.5% in 2008 compared to 4% in the EU27) are poor circumstances for service development and informal care. The share of the population over 80 years old is around the average for the EU (Eurostat, 24-02-2010). The life expectancy of those over 65 is 14.8 years, which is the lowest in the EU and the disability adjusted life years are comparatively low (WHO/HFA, 23-03-2010).

### Characteristics of health and social services

Compared to the EU average the proportion of the GDP spent on social protection benefits in kind is only half the proportion on average spent in the EU (Eurostat, 29-10-2009). Benefits offered by the National Health Insurance Fund need to be supplemented by co-payments (or covered by a possible voluntary insurance).

Home health care is not well developed in Bulgaria. Although visiting patients in their homes belongs to the

tasks of the independent GPs and their practice nurses, such home visits are sparsely made due to the lack of time. Furthermore, nurses exclusively working in organised home care services are very scarce. Hospital nurses are hired on a private basis by those who can afford. Anyhow, nursing is not well developed in Bulgaria, with only 4.1 nurses per 1000 inhabitants in 2006 (against 7.4 in the EU). The availability of nurses strongly differs between regions. As organised nursing services at home are rare in Bulgaria, home care is limited to social services. There are several types of social home care services. First, there are social care services at home, made up of meals-on-wheels, domestic aid and personal care etc. for people at least over the age of 60, in need of care and without family (but in practice often over 75 and income is taken into account). Then, the social assistance services. In total 2.9% of GDP was spent on Social Assistance in 2005 (The government of Bulgaria 2006), compared to 4.5% on health care (Eurostat, 24-02-2010). In contrast to the health care sector the social sector is mainly public. Social assistants, home helpers and personal assistants provide about the same services as does the social care at home service (i.e. personal care and domestic aid), but only to people with the highest degree of disability.

### Social indicators and conditions related to old age

Bulgarian elderly persons are the poorest in Europe. In 2008, over one third of the persons over 65 were at risk of poverty (Eurostat, 17-02-2010). The situation of care dependent elderly people furthermore suffers from the decreasing availability of informal care, which not just results from demographic developments but also from large scale emigration of younger people. By lack of public financial resources social and health care services often require private payments. For many older people this is an obstacle to access to services they need, in particular if support from the family is absent. Although the means of children are taken into account in the decision to grant social assistance, children are legally not obliged to pay for the care of their parents.

### Attitudes related to old age

Bulgarians, like the Polish, are most positive about informal care. A majority of 58% of Bulgarians think that care is a task for close relatives even if this would have career implications (TNS Opinion & Social 2007d). When it comes to formal care for an elderly dependent relative, home care is more than three times as popular than nursing home care (TNS Opinion & Social 2007c). Even though home care is rudimentary in Bulgaria its popularity is about the European average.

## 2. Policy and regulation on home care

### 2.1 Governance on home care

Social home services are a joint responsibility of the Ministry of Labour and Social Policy and the municipalities. The implementation of national social assistance policy is in the hands of the National Social Support Agency (with national, regional and municipal departments). The organisation and management of services at local level is a responsibility of the municipalities.

The governmental policy on home care is weak and mainly reactive. No policy paper has exclusively addressed home care. Existing policies have been developed after services were developed by NGOs. Both the Ministry of Labour and Social Policy and the Ministry of Health are aiming at de-institutionalisation in favour of ambulatory and community based arrangements. Medical and nursing services at home are under the Ministry of Health and provided by GPs and practice nurses. Although GPs formally should spend two hours per day on home care, prevention and health promotion, home visits by GPs (or their nurses) are sparsely made. Home nursing is unknown in most parts of the country as it is only developed on a very small scale by NGOs. Long term care only recently has got governmental attention after the adoption of the Health Strategy. For the future it is foreseen that community nursing will be provided by independently working home care nurses. Both Ministries aim to harmonise and coordinate isolated and fragmentary initiatives on home care.

The de-institutionalisation and decentralisation resulting from the 2003 change of the Social Assistance Act has profoundly changed the social services landscape in Bulgaria. From that time municipalities should develop

community based social services in their areas to substitute for the large state institutions where the quality of care much left to be desired.

The National program Personal assistant to persons with disabilities (providing personal care and domestic aid) is entangled with unemployment policies. It is in fact is a program for subsidised employment. A considerable proportion of community based social services is provided by unemployed people who have had little or no training for this job.

Most home social services arrangements in Bulgaria are part of the following three schemes: (1) *Home Social Patronage*; (2) *Social Assistance*; and the recently established national programme (3) *Social Services in the Home Environment*.

*Home Social Patronage* is a national scheme managed by municipalities aiming to provide basic care, including provision of food, some personal and domestic care and some cleaning services, to frail populations, like elderly, poor and disabled people. The social patronage is a type of community based social service financed from the municipal budget (with municipal financial means). It is possible for the municipality to directly provide this type of service by establishing a municipal organization for this purpose or to contract out the delivery of the service to a private provider.

The *Social Assistance* scheme enables the provision of personal care and support and domestic aid to people with disabilities by personal assistants. Personal assistants are informal carers receiving financial support from the Social Assistance scheme, run by municipalities.

Social services provided in the home environment are delivered under the Operational program "Human resources". The programme, which is locally managed by the municipalities, foresees in social activation and light household support (for instance, administration). One of the goals of the program is to ensure additional training and employment of persons who already have experience as social assistants or people helping in clients' household. Each social assistant serves several clients. The assistants spend equal time in each client's household, regardless the differences in clients' needs.

In addition to national schemes, municipalities may develop their own additional social assistance programmes. The municipality of Sofia, for instance,

developed its 'Assistance for Independent Living' programme, by which informal carers of disabled people can have some financial compensation.

## 2.2 Eligibility for home care services

### *Home nursing & personal care*

Making home visits is an official task of GPs which, however, is insufficient to meet all needs. GP home visits are covered by the basic health insurance package (Georgieva et al. 2007). It is up to the patients' GPs to decide whether nursing care will be provided in the home situation. Apart from the requirement that patients are bed ridden to be eligible for home nursing, no uniform national eligibility criteria do exist.

### *Domestic aid and technical aids*

Personal care, domestic aid and technical aid are only available for people with a disability holding a nationally regulated certificate of being disabled (meaning to have lost the ability to work for at least 50%) (Panayotova 2009). Apart from this, each scheme applies its own eligibility criteria. As financial resources are insufficient, those who are eligible for care not always receive the services. Municipal social assistance programmes may manage this by using the principle of 'who comes in first gets first'. Eligibility for National Social Assistance support payments is assessed by social workers in the local departments of Social assistance. Criteria are the applicant's and family members' financial means, living alone, disability level (90% or more unable to work) and home ownership.

For Home Social Patronage services one needs to be disabled, over the age of 65 (Centre for social support of children and families at risk 2010), unable to organize ones living needs, without close relatives taking care, and not own a home. The social patronage is a type of community based social service financed from the municipal budget. There is no subsidy from the state budget. It is possible for the municipality to directly provide this type of service by establishing a municipal organization for this purpose or to contract out the delivery of the service to a private provider.

In general, it is not possible to combine the use of services from different schemes; for instance, Social Assistance recipients cannot receive services from Social Patronage as

well. For services provided by NGOs (and not contracted by municipalities) these organisations define their own priority groups and set their own eligibility criteria.

Which technical aids are publicly financed and which criteria apply to be eligible for home adjustments (up to an amount of 300 Euro) are laid down in statutory regulations. Territorial (regional) Expert Medical Commissions use their own protocols for assigning technical aids. Consequently these may differ across areas.

## 2.3 Quality of process and output

### *Availability of quality criteria*

Improving the quality of social services has been a major aim of the new Social Assistance Act. The quality of national assistance programmes has been assessed with a method developed by the UNDP, focussing on facilities, staff qualification, health care, quality of nourishment and mechanisms to control the quality (Dimova 2004; Jeliaskova, Georgiev, & Abadjieva 2004). Also the feedback from clients is part of this method. Up to now the method has been applied on a limited scale, namely just for the assessment of social assistance agencies and their contracted private providers. The quality standards are set forth in the Regulation for application of the Social assistance Act. There are some general standards for food quality, medical care and requirements for the staff. The problem is that these standards are valid both for specialised institutions and community based services. It is an adequate approach, having in mind the difference between institutions and community based services.

As far as these exist at all, quality criteria are diverse and fragmented. Criteria developed and applied by municipalities for their own social services and for services delegated in the Social Patronage scheme are not harmonised and usually not made explicit in regulations. Private providers not contracted to one of the official schemes, have their own quality monitoring system. Their premises are subject to inspection on hygiene but the quality of their services is not monitored. For home care provided by GPs and their nurses the quality criteria used in primary health care apply, called the National Medical Standards. Rules for good medical practice have been developed by GP associations (Georgieva 2007). Other organisations such as NGOs are only subject to the same minimum requirements as for personal care and domestic aid.

### Assessment of quality of services

Providers of social services are not obliged to monitor their service quality. Instead, the compliance to the standards (set in the Regulation for application of the Social assistance Act about e.g. the building they are working in) is checked by the Inspectorate of the Social Assistance Agency and municipalities (Toptchiyska & Vasileva 2009). Not contracted social services providers are hardly subject to quality evaluations. The quality of health care provided by GPs and their nurses is monitored by the Regional Centres for Health (Georgieva 2007).

### Accreditation and clients complaint procedures

Municipalities assess the needs of applicants but may opt to 'contract out' the provision of services to NGOs. These NGOs need to be registered as a Social Assistance Agency with the Ministry of Labour and Social Policy. The registration is rather formal. The providers are submitting the papers related to their establishment, the building in which they are planning to develop the service. At the moment of registration, the issue whether the provider is able to guarantee the minimum quality standards, regulated in the legislation is not considered. Any sanctions for not meeting the quality standards are listed in a register. Medical institutions can be accredited with the Ministry of Health (Georgieva 2007). Registration based on some minimum requirements is necessary.

Clients who are dissatisfied with home health care services can file a complaint to the management of the providing agency or to a Regional Centre for Health (Georgieva 2007). In case of the latter, the exact complaint procedure has been legally established. Complaint procedures applicable to clients of social services are described in the contract between provider and the client.

## 2.4 Quality of input

### Education

Services in the National Programme "Personal Assistants to persons with disabilities" are provided by unemployed people who have been trained for only a couple of days for assistance work. In the other national programs the focus shifted more to the delivery of the service instead of tackling the unemployment. Social Patronage services are provided by professional workers, such as social workers, domestic aids and rehabilitators. The Bulgarian Red Cross is the only organisation whose as they call them 'home nurses' and 'home helps' (personal

care and domestic aid) have followed additional training specifically on home care (supported by the Swiss Red Cross).

The following positions can be identified in Bulgarian home care.

- *Social assistant*: mainly involved in social work, but also help with ADL; help with taking medicines; liaison with GPs; and guidance of clients (Toptchiyska & Vasileva 2009). Social assistants have followed a short training. The target competencies have been laid down in detail in the 'Handbook of Social Assistant' (Toptchiyska & Vasileva 2009) and will soon be incorporated in the Vocation Education and Training Law.
- *Home assistant*: involved in domestic aid, such as cleaning, cooking and shopping. In the Social Services in the Home Environment scheme, home assistants also provide personal care for disabled people needing help with ADL and IADL. There are no educational requirements to become a home assistant, but often they follow a short training course, and often they are unemployed and registered at the Employment Agency. Furthermore, their salary is at a minimum wage.
- *Personal assistant*: takes care of adults or children with a permanent disability by helping them with their daily needs; through personal care; domestic aid; help with eating and moving around; rehabilitation; administration etc. (Rules for the Implementation of the Social Assistance Act, par. 1). Personal assistants are usually persons of working age and co-habitant family member of recipient. No specific education or training is needed.
- *Sanitaries* of the Social Patronage provide domestic aid.
- *Home helpers* working for NGOs: these provide domestic aid and personal care. The Bulgarian Red Cross (BRC) has a National Training Center. It provides trainings for the home helpers, social assistants, nurses and volunteers. In 2008, licensed branches of training centres with trained trainers of home helpers and social assistants existed in nine towns in Bulgaria. BRC also organizes trainings for other organizations, which provide this type of service.

- *Nurse*: involved in health education and information; giving injections; wound treatment. If working with a GP, nurses mainly have administrative tasks. There is only one level of nursing; general education takes 4 years and is a bachelor university degree. Nursing education is offered by 14 medical institutions, for which training programmes and curricula have been developed nationally in the context of an EU-funded project. Adherence to the curricula is under the responsibility of the Educational Inspectorate.

#### *Job description*

Legal regulation on home care professionals is scarce. Those regulations that do exist, are not specific for home care. The absence of an official task description of home care nurses is one of the obstacles to allow nurses to work independently. With regard to personal care and domestic aid professionals, tasks are set either in national programmes (personal assistants, social assistants and home assistants) or by the providers (other positions, such as the Social Patronage or municipal social assistants). The National Classification of Occupations does not recognize 'home assistant' as a profession. The distinction between social, home and personal assistant has not been laid down (Toptchiyska & Vasileva 2009). All three professions are described as persons providing meals, domestic aid and monitoring of the health status in the home environment and providing information to the GP (Toptchiyska & Vasileva 2009).

#### *Recertification*

Obligatory recertification of nurses has not been introduced in Bulgaria. The National Nursing Association has developed a voluntary 5-year credential system, including the requirement to have followed a certain volume of continued education.

### 2.5 Incentives for providers

Competition among providers is absent in the Bulgarian home and community care. As the sector is not interesting for private providers, and in particular not for commercial providers, there is a considerable undersupply (Jeliaskova, Georgiev, & Abadjieva 2004). In a market in which the demand side is dominated by poor elderly people, offering services requiring out of pocket payments is not attractive. Another obstacle is that NGOs, according to the Health Insurance Act, are not allowed to provide health care services. For NGOs aiming to offer

comprehensive home care services, such as Caritas and Red Cross, this prohibition severely limits their possibility to offer complex services, including home nursing.

Theoretically, competition among private providers would be possible through the tender system which is in place for publicly financed domestic aid and personal care. However, as a result of lacking resources at the moment there are only few tenders.

## 3. Financing

### 3.1 General funding

In the light of existing needs in the population the funding of home care in Bulgaria is inadequate. Especially for home nursing resources are lacking. Available home care for a part also relies on foreign donor funds.

In 2006, only 0.23% of the total health care expenditures were spent on home nursing, compared to a European average of 3.6%. In 2005, 14 million Euro was spent on personal and social assistants, which is over three times as much as the amount for home nursing.

Due to its fragmented nature, home care is financed through a number of mechanisms. Basically health and social care are funded from the municipal budget or central budget. Through general revenue, the national government assigns budgets per municipality for social services. It is determined by the salary as well as support costs (Mincheva & Kanazireva, 2010). Additionally, for *social services* client-copayments are needed. Social assistants, home assistants and personal assistants working for a national programme are financed through national general taxation. Some municipals self-finance their own municipal home care programmes. When the social services are contracted out to private providers the budget funds are allocated to the private providers. Another important source of funding of NGOs are (foreign) donations. In the *medical care* financed by the National Health Insurance, even for private medical institutions who have contracts with the National Health Insurance Agency, the services can be provided without payment by the client, on the basis of a medical recommendation, done by the GP. Otherwise private nursing care provision is financed completely through out-of-pocket payments. The financial standards for the community-based services funded from the central budget are mainly per capita,

without taking consideration about the individual needs. There is no relation between the productivity of the services and the financial resources provided for.

### 3.2 Financing of home care agencies

In general, the volume of financing for home care depends on the yearly budget of the Ministry.

Home care providers can either be paid per capita or by a fixed budget based on the number of their employees. Which method is used differs between types of providers. For services in the national programmes municipalities are paid on the basis of the number of social assistants. The Ministry of Labour and Social Affairs, has set a maximum number of 'subsidised' recipients per municipality (25 or 65). Contracted private providers and Social Patronage providers are paid by municipality per capita and receive an additional lump sum for housing. The per capita amount differs for residential care and community care as well as the type of client (dementia, etc.) (Panayotova 2009).

Primary care (including home visits made by GPs) is paid on a weighted capita basis (depending on age). For GP home visits a small client-payment is needed of 2 Leva (1 Euro), the rest of the funding for the medical services of the GP is secured from the budget of the National Health Insurance Agency. For hospitals 'health care pathways' have been developed as a funding basis. However, up to now in none of these pathways home care has been included. For hospitals 'health care pathways' have been developed as a funding basis.

### 3.3 Price setting and co-payment

Tariffs of services in the Social Patronage scheme are set by the municipality. Clients' co-payments for these services are income dependent by national norms. The co-payment amounts about 5% of a state pension.

The level of co-payment for Home Social Patronage is set at local level by the municipality and is related to a fixed percentage of the recipients' income (around 60% of the pension) up to the costs of the service. The costs of the services are determined by the municipality.

For home visits by a GP a co-payment applies of 1% of the minimum income per visit. Informal payments continue to be made. Prices for medical care to be paid by

the insurance company are set in the National Framework Contract which is established every year. Technical aids are usually free of charge as long as they remain below the price limit.

Social assistance and home care services by NGOs are almost free of charge.

## 4. Organisation & delivery of home care

### 4.1 Access and needs assessment

If *home nursing* is needed a GP or medical institution will be involved, as home nursing requires a treatment plan from a doctor. GPs may choose to contact another home nursing provider (NGO or Home Social Patronage). Other nursing providers may perform an additional assessment (nurse or social worker), mostly using their own standard intake form. In case of Home Social Patronage a referral of the local Social Assistance Agency (SAA) is required.

To apply for *personal care* and *domestic aid* no doctors' referral is required. Delivery of a certificate of disability is based on document analyses and an interview with the client (Panayotova 2009). Applications for these services are usually submitted to the local Social Assistance Agency, performing the first assessment. Other options for application are the municipality and NGOs. Although organisations differ in the way they organise the assessment, a checklist is usually applied. The assessment procedures proceed as follows:

- Social Assistance on national level: clients apply to the local social support agency and then the care needs are assessed by a social worker or other professionals.
- Municipal Social Assistance programmes and Home Social Patronage: clients apply to the local Social Support Agency that selects those who are eligible for Home Social Patronage. Local checklists are used. Needs are assessed by Home Social Patronage professionals.
- NGOs: perform their own assessments. Their organisation differs, but usually the person in need is visited.

As Social Support Agencies, Social Patronage and NGOs work with priority groups and not for the general population, social workers have a considerable discretionary power in the needs assessment process.

#### 4.2 Delivery of services

Provision of personal care and domestic aid is mainly public or private not-for-profit. Very often, municipalities deliver directly home social patronage service and for the purpose they establish municipal entity or enterprise. Also there is a legal possibility this type of service to be contracted out /outsourced/ to private providers, mainly NGOs. Competition between home care providers is practically absent and there are little incentives for new private providers to enter the sector. As municipalities may have their own priorities and programmes and as NGOs are only active in selected areas of limited scope, the availability and the type of services delivered are geographically inequally distributed.

Formal home nursing services are delivered on a very limited scale by GP nurses, by nurses employed by NGOs and, in some municipalities, by the Home Social Patronage scheme. In addition, hospital nurses provide privately paid home nursing care as a sideline job to those who can afford.

#### 4.3 Coordination and integration of services

Usually, health care services and social services are separately provided. Health care is privately provided, while public providers and NGOs provide social services. Most of the health care services are provided by medical institutions, having contracts with the National Health Insurance Agency, so the presumption is that clients are not paying for these services. NGOs are not allowed to deliver health care services and this is a problem, because very often the clients need an integrated social-medical service. Even so, some NGOs and some Home Social Patronage providers offer home nursing, personal care as well as domestic aid. However, since home care generally is rudimentary, there is not much to coordinate and integrate.

GPs are expected both to make home visits and set up treatment plans for home nursing. Therefore, conditions for coordination of primary care and home nursing are usually positive. Contact between social home care providers and GPs is usually not formally established,

with the exception of formal obligation of social assistants to notify the doctor when the patient's health is deteriorating. Hospitals, homes for the elderly and hospices are not involved in home care. Nursing homes as such do not exist; part of the hospital capacity fulfils this function. Hospital long-term care units can be seen as substitutes for home nursing. In case coordination is needed, nurses providing home care can act as a liaison between the recipient and the hospitals (for instance in helping with medicine prescriptions; measuring blood pressure; and accompany the patient to during admission, treatments or discharge).

#### 4.4 Actors and human resources in home care

##### *Main actors*

The following main actors are involved in policymaking, financing and organisation of personal care and domestic aid:

- *Municipalities* (management of service delivery in Home Social Patronage and Social Assistance; maintaining and financing of municipal Social Assistance; identification of those in need of care);
- *Ministry of Labour and Social Policy* (maintaining and financing of national social assistance).
- *National, regional and local Social Assistance Agencies* (implementation of national social assistance policy: registration social service providers; checking service quality; performing needs assessments; intermediary between social/home assistants and clients);
- *Municipal-based Labour Offices* (intermediary social assistant (SAA); training of personal assistants);
- *Independent Home Social Patronage providers* (providing food; home nursing; personal care; domestic aid);
- *NGOs* (providing comprehensive home care services);
- *Individual home/social/personal assistants* (providing personal care, domestic aid, social activation, etc.).

The governmental involvement in *home nursing* has been limited until now. Main policy actors at present are: the Ministry of Health (regulation on conditions of provision nursing care), the Regional Centres for Health (quality control and registration), the NHIF (decides on basic health care package, e.g. home visits) and the Bulgarian

Association of Health Care Professionals (development of home nursing by accrediting home nursing courses provided by the NGOs).

NGOs providers and independent nurses are expected to become more important, in addition to the GPs and their nurses. NGOs have introduced home nursing. Some have set up 'home care centres' and provide training in home care to their personnel. A recent change in regulation has facilitated the possibility to practise as an independent nurse. The lack of integrated socio-medical services is problematic. NGOs are not allowed to deliver medical services, acting as medical institutions, which influences the quality of services. In domestic care it is difficult to put the boundary where the social services end and the medical ones start. In order to satisfy the needs of the clients, very often integrated social service is necessary, including elements of health care.

Home care professionals in Bulgaria are usually employed. Although possible now, independent practice is still not popular among nurses. The working conditions of home care professionals have favourable as well as unfavourable sides. The salaries of social home care providers are around the minimum wage. Their working conditions and salary have been laid down on national level. Community nurses earn about 250 Euro per month, which is much lower than what they can earn in hospitals. Working conditions and, to a certain extent, wages are laid down in the Labour Code and subsidiary regulation. Exact data on numbers of home care professionals is practically absent. Based on estimations, Table 1 shows that most home care providers in Bulgaria are personal assistants and it confirms that community nurses are practically absent.

#### 4.5 Use of tele-care

Despite attempts to introduce alarm buttons, at present tele-care applications are not available in the Bulgarian home care sector.

#### 4.6 Monitoring the adequacy of care

Formally, social assistants are obliged to report changes in health to the recipient's doctor. This is also seen as a task of the other assistants. The provider may monitor of the adequacy of home care services, but there is no regulation

on this. Only the national Social Assistance Scheme requires an assessment every six months. At that occasion a municipal social expert visits the client at home.

## 5. Clients & informal carers

### 5.1 Home care recipients

As shown in Table 2, numbers of recipients can only be estimated. It turns out that very little people receive home care. The table does not show the earlier mentioned large geographical variations. Variation in the characteristics of home care recipients strongly depend on the schemes that finance their services; e.g. the clientele of Home Social Patronage has relatively more complex needs than social assistance recipients, partly related to the age requirements.

### 5.2 Coverage and unmet needs for care

Shortage of formal home care supply forces providers to ration, for instance by the principle 'first come, first served'. Combined with a declining availability of informal care this may result in worrisome situations of unmet needs. For instance, a town of 90,000 inhabitants had 290 Home Social Patronage clients and 36 recipients of Social Assistance home care (expert opinion). A study by the Sofia municipality showed that there were about 19.000 potential clients for the Municipal Social Assistance programme, but only 725 of them could be served. Many people did not know how to get home care services and what their rights were. Normally, home care was only available during working hours and days.

### 5.3 Empowerment of clients

Although clients are in principle free to choose between providers, this is practically impossible due to a very low supply of providers. Social service providers are usually bound to a municipality and not all types of service providers are available in all municipalities. Even if all types of service providers are available, a lack of clients' knowledge about the available services may be an obstacle. Information on social services may be provided by the Social Assistance Agencies and social Assistance Directorate and in some areas the Community-based Bureaus for Social Services also offer information on the available services to elderly and disabled persons. For home nursing this information is provided by the

**Table 1:** *Human resources in home care*

Functions	Estimated total number
Social Services against New Employment Project (SANE) social Assistants in 2009.	1,700
Personal Assistants in 2006	+13,900
Home Assistants/Helps	n.a.
Social Patronage employees in 2005 (mostly kitchen staff)	4,772
NGO nurses (BRC and Caritas) in 2009	25–30

Sources:

Social assistants: (UNDP Bulgaria 2009); Personal assistants: (Toptchiyska & Vasileva 2009); Social patronage employees: (Dimova 2004).

NGO nurses: interviews with experts.

National Health Insurance Fund. Although the volume of publicly financed home care is limited, a personal budget is an option to disabled persons, giving them the possibility to purchase private home care. Under the Social Security Code disabled persons have the right to a monthly payment for disability and a cash supplement for external aid.

#### 5.4 Informal carers

Informal carers can be paid by the government as assistants in the Social Services in the Home Environment programme. However, there are strict criteria, e.g. being unemployed. These criteria have become less strict due to a growing need for human resources. Furthermore, relatives may be educated to perform some nursing tasks, e.g. injections. The extent to which this is provided is not clear.

### 6. Disparities in the process of home care in Bulgaria

There are little differences in where to apply, who assigns care and how and when home care is assigned and monitored based on differences in patient characteristics. Rather, these differences are based on the programme under which the service is funded. Finally, whether or not an applicant surpasses the assessment phase depends on the municipality one lives in. In towns with many persons in need the chance of receiving an assistant will be lower than elsewhere. Furthermore, some larger municipalities have their own additional social services.

### 7. Concerns and new developments in home care in the Bulgaria

The main home care related concerns in Bulgaria are:

- *Unmet needs regarding home care.* Although there is a well-developed legal framework for social services, a lack of financial resources and a small network of service providers lead to high unmet needs. The underfunding of social services has obstructed further development of these networks (Jeliazkova, Georgiev, & Abadjieva 2004). Hence, only the very poor are eligible to government funded home care;
- *Geographical inequality.* Services are not equally available in all municipalities and GPs may differ in visiting patients at home. Furthermore, a satisfactory needs assessment instrument for use in all municipalities is lacking (Jeliazkova, Georgiev, & Abadjieva 2004);
- *Sustainability* of the current system. Currently, social services largely dependent on foreign funds and are on a programme basis;
- *Quality of services.* A 2008 report on the quality of social services showed that needs assessments were inadequate and that clients were insufficiently involved in care plans (Panayotova 2009). Furthermore, the quality of human resources is problematic: non-professionals provide social home services; motivation is low due to low salaries and former unemployment and unavailability of an education for home care (Jeliazkova, Georgiev, & Abadjieva 2004);
- *Little information* among medical personnel in health care institutes about available home care services (Jeliazkova, Georgiev, & Abadjieva 2004).

**Table 2:** Estimation of long-term care provision at home and in institutions 2006/2007

Recipient groups	Personal assistant recipients in 2007	Personal and social assistant home care recipients through "Assistants of People with Disabilities" in 2007	Crude estimation home social patronage recipients (excl. places in canteens)	Institutional care adult recipients 31.12.2008
Total (% of pop)	31,093 (0.4%)	14,049 (0.2%)	+/- 4500 (0.06%)	12,040 (0.2%)
% female	n.a.	n.a.	n.a.	57.7
% 65+	n.a.	n.a.	n.a.	n.a.

Sources:

Home social patronage and institutional care: (National Statistical Institute of Bulgaria 2010) and interview Sofia Social Patronage.

"Assistants of People with Disabilities" recipients: (Beleva 2008) (under Assistants of People with Disabilities).

Personal assistant recipients in 2007: (Panayotova 2009).

Organisations involved in home care are just starting to evaluate how home care is developing in the country. The following trends with a relevance to home care can be identified:

- Continuation of de-institutionalisation of services for the most severe disabled;
- Governments' efforts to stimulate independent practice of nurses (and as there are hardly any organisations to provide home nursing);
- Professionalization of social assistances as a consequence of above mentioned concerns. Where it used to be a requirement to be unemployed for persons providing social assistance, the new programme is removing this requirement;
- New trends are set by NGOs, such as integrated home care services (home nursing and domestic aid) and the use of professional providers;
- An innovation is the Assistant for Independent Living of the Sofia municipality. This scheme aims to tackle the shortage of providers and the inflexible provision of the national programmes. Assistants no longer need to be unemployed and they are contracted for a flexible number of hours; several providers may serve one client; assistants may also be medical specialists. Sofia spent around 1,5 million Euro on Assistant for Independent Living in 2008, which is more than three times what it receives through one of the few national social assistance programme called 'the Operative program Human Resources Development'.

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# Croatia

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## 1. The context of home care

### Country, population and health

In 2003 Croatia applied for EU membership and was granted candidate country status in 2004. Croatia's demographic picture is changing due to negative population growth (despite a positive migration balance) due to the ageing of the population. The average life expectancy of Croatian people at age 65 is below the average in the EU (in 2006 14.25 for males compared to the European average of 16.8 and for females 17.78 compared to 20.54 – WHO/HFA, 27-05-2010). The same holds for the average disability adjusted life expectancy, which in 2002 was 63.8 for males and 69.3 for females (WHO/HFA, 27-05-2010). Croatia's economic situation in the period 2000–2005 was characterised by remarkable growth in economic activity. The average annual GDP growth was above 4% through the past decade, and in 2007 was 5.6%. According to Eurostat, in that year the GDP per capita in Croatia was 52% of the European average. Croatia is a country of noticeable differences among its regions partly due to decentralisation of many responsibilities. (Hrvatska Narodna Banka) The income per head in the richest region is 10 times higher than in the poorest region (Central Bureau of Statistics), – the poorest regions being the Central and East regions and the wealthiest being Zagreb and West region.

### Characteristics of health services and social services

Croatia spends 7.9% of GDP (2006) on health care (WHO/HFA, 10-12-2008). WHO estimations show

that private expenditures within total health care expenditure are around 17.5%. About 97% of Croatian citizens are covered by a public health system. Public funds for health care originate from two main sources: contributions for mandatory health insurance and funds collected by general taxation. The organisation of the health sector in Croatia shows some specific features. The primary healthcare system mainly comprises private GPs, gynaecologists and dentists contracted by the Croatian Insurance Health Institute (CIHI=HZZO), while secondary and tertiary care is largely performed by state-owned and state financed healthcare institutions. The hospital bed utilization was 85.6% and the average length of hospital stays is 9.35 days, with the number of hospital beds at 530 per 100,000 inhabitants in 2008. The number of medical doctors per 100,000 inhabitants was 250 in 2007 (WHO 2009). Large regional variations emerge in the country's healthcare capacities, with a concentration of medical institutions in the bigger cities, while some regions – particularly in the islands – show a poorer coverage of health services. Further problems in health care are the cost of seeing a doctor (co-payment at each primary care visit), long waiting times (due to a reduced role of primary care and overuse of hospitals) and delays in getting an appointment (Quality of life in Croatia 2007). In the UNDP survey (2006b), 21.8% of respondents complained of long waiting lists, while 17.2% cited the long time required to get an appointment, both of which constitute large barriers in preventing people from accessing medical services (Quality of life Croatia 2007). Older people live mostly in their homes and with their families and only 2% of the total population over 65 years lives in institutions. In addition to institutional care, homes for older and infirm people organize the provision of services and assistance within the local community. Centres for assistance and care are being established within the county offices for labour, health and social welfare.

### Social indicators and conditions related to old age)

In 2007, 30% of Croatians over the age of 65 were at-risk of poverty. This is relatively high compared to the EU countries, where on average 20% was at-risk of poverty. Even so, Croatia spent 12.2% of GDP on pensions in 2003, which is just below the EU15 average (Kašek et al., 2008).

### Attitudes related to old age

In Croatia there is no formal liability for children to take care of their dependent elderly parents. Furthermore, caring for dependent elderly parents is seen as a task for their children. The Eurobarometer-survey (TNS, 2007) showed that 50% of the Croatian respondents, compared to 37% of all European respondents, thought that care in this case should be provided by close relatives, even if this would affect their career. Also when asked who should care for an elderly dependent parent, most respondents said informal care was the most preferred option (48% said that they should live with their children and 18% said the children should regularly visit their parents to provide the necessary care). Moving to a nursing home was more popular in this case than professional home care being provided at home.

## 2. Policy and regulation on home care

### 2.1 Governance on home care

The Croatian government is increasingly focusing on non-institutional forms of care for elderly people as there is a shortage of places in institutions. Care for elderly citizens and for infirm people is provided mainly in their homes by Centres for Assistance and Care. These services are aimed at assisting elderly persons to stay in their own home cared by their own family members. In Croatia, home care, medical treatment at home, palliative care and protection of mental health are part of the primary care system. The main home care services are known as personal care (under the coverage of social care) and 'home nursing' is part of the health care sector. Home care is targeted at people who are not able to take care of themselves or, because of medical conditions, care is provided at home by nurses and GPs. The main aim is to keep the ill or elderly person in her/his own homes as long as possible, with the assistance carers and family members. The service comprises treatment, bathing, feeding and nursing at home, on recommendation by

a primary health care doctor. Apart from these services, which are covered by health insurance, other services are provided as well, these are covered by user fees paid by the patients or family members. (Voncina 2007).

The Ministry of Health and Social Welfare and the GP Association play the most important role in operating primary care, the system in which home care (personal care and home nursing) is embedded. Even so, as mentioned, there is a high level of decentralisation in terms of service provision. Decentralisation was implemented without having organised a local network of professionals that would work at a local level and would be able to manage local health needs and hence has created many problems (Mastilica 2005). As part of the general decentralization policy, a small but increasing share of public spending on health is being picked up by local governments (in 2002, county governments spent just 3% of their revenues on health care).

Another important actor in the field of home care is the Regional Hospice Centre in Zagreb which functions as an education and methodological centre for home care visits and consultations, courses, and volunteer meetings in Croatia. Furthermore, in elderly care, the nongovernmental sector's role is increasing (Merkur, Jemai, Mossialos 2006).

### 2.2 Eligibility for home care services

Eligibility criteria are used but are not uniform in the country. As mentioned, home care is targeted at people who are not able to take care of themselves. One eligibility criterion is the patient's health condition. The most important criterion is the functional ability of the elderly patient in relation to: the physical state (ranked into mobile, limited mobility, permanent use of wheelchair, permanently immobile) and psychological state (independent, limited independence, permanently dependent) as defined by the national standard in this field. The right to health care and assistance from private institutions for care and support financed by the CIHI requires a review of the relevant medical commission in charge at the CIHI with all supporting health documentation and medical records, and its approval. The frequency of nurse visits is also determined by the commission, with a range of 2, 3 or 5 times a week. Also physical therapy at home, proposed by specialist physiologists (determining the care to be provided), requires an approval from the medical commission of the CIHI. For meals on wheels also, the financial situation of

the families is taken into account by decision making of granted provisions. If a household has an income of about €4400–14,000 per person per year in the household the state covered assistance will not be provided. The patient and the family pay for everything. Households with an income of over €14,000 per person are not eligible for assistance provided by home care agencies – these high income families have to pay out-of-pocket if additional services are needed.

Whether the needs are met does not only depend on the eligibility criteria (and the information given by the old age insuree and their family members), but also largely on the education of the primary care team assessing the needs in geriatrics and gerontology.

Disabled people are entitled for wheelchair and transportation with special vehicles and health care at home – but personal care budgets still do not exist, nor do specialized institutions for disabled people.

### 2.3 Quality of process and output

#### *Availability of quality criteria and assessment of the quality of services*

CIHI monitors the needs of the patient and of the quality of care. The regulation of standards in health care institutions is the responsibility of the Ministry of Health and Social Welfare. Standards are set out in health care-related legislation. Recently, validated and accepted instruments have been established to manage, and monitor and guarantee appropriate quantity and quality in nursing care. Teams of health inspectors visit health institutions if there are organizational or professional failures. Licensing of professionals is the responsibility of the professional chambers. The Centre for Gerontology has started an initiative for clearly defined quality control procedures in the implementation of geriatric health care. In the social home care sector quality assessment and monitoring have not been established yet.

#### *Accreditation and clients complaint procedures*

No accreditation system has yet been established in Croatian hospitals. Patients are protected by the Law of Protecting Patients Rights (2004) and patients may file a complaint on county level at County Commission for Patients. There is no patient's complaint policy and procedure for home care providers.

### 2.4 Quality of input

#### *Education*

In Croatia, nursing education consists of secondary-level vocational education followed by BSc and MSc levels. Secondary-level vocational school qualifications are not recognized by the European Union educational system, requiring a necessary reform in that field. Licensing the registered nurses is another problem, because Croatian nurses with only secondary vocational qualifications do not meet the requirements for licensing in terms of the EU equivalence standards. Furthermore, matching the health and social home care demands on nurses with education should be an essential next step on the “to do” list. (Kalauz, 2008). All public sector nurses are registered. Croatia has a professional chamber of nursing, a nursing association and a system of registration for nurse certificates. There is also a Chief Nurse post in the Ministry of Health and Social Welfare.

#### *Job description*

Job descriptions of home care professionals have not been identified either in the social sector (personal assistant) or the health care sector (home nursing).

### 2.5 Incentives for providers

Providers contracted by the CIHI are competing with each other. In the private sector, price competition might exist, but there is no detailed information available.

## 3. Financing

### 3.1 General funding

Funds for social health insurance are collected mainly from payroll taxes paid by employees, and the self-employed and farmers' contributions. Social health insurance for certain vulnerable categories of the population is partly cross subsidized from payroll contributions and additionally funded by transfers from the central government budget and from county budgets, e.g. disabled and elderly persons. The compulsory health care insurance (by CIHI) covers acute home care visit, community care and home nursing completely, but covers only 85% of the costs of rehabilitation in the patients' homes (Merkur, Jemiai, Mossialos 2006). Funds allocated to health care are annually determined by the state budget and collected through the state

treasury. The Croatian Institute of Health Insurance – CIHI – receives compulsory insurance funds from the state budget. To summarize, the funds thus originate from three sources: contributions for compulsory health insurance, funds collected by general taxation and county funds collected from regional taxes. CIHI dispenses the majority of compulsory health insurance funds for provision of health services and a small proportion for infrastructure investments in publicly owned providers. Additionally, the central government and counties (from general taxation) fund investments into infrastructure and technical equipment and maintenance of publicly owned providers separately from CIHI. The state also separately funds care for elderly people and for health education (Voncina et al., 2006). Besides compulsory insurance and state and county funds, health care is also funded by voluntary complementary insurance and private supplementary insurance (covering co-payments for public provider services) health care. CIHI collects premiums for complementary health insurance on its own.

Patients are required to pay out of pocket to privately owned providers (not contracted by CIHI), and also (if they do not have complementary health insurance), co-payments to providers contracted by CIHI for services not fully covered or not covered (e.g. rehabilitation at home) by compulsory health insurance. Disabled persons are exempt from co-payments (Voncina et al., 2006; Merkur, Jemai, Mossialos 2006).

Social Welfare is financed through the state budget (European Committee of Social Rights, 2009). Domestic aid, part of social welfare, is provided to poor and elderly people through locally based Centres for Social Welfare and NGOs. Centres for Social Welfare services are provided free of charge (European Committee of Social Rights, 2009).

### 3.2 Financing of home care agencies

In order to receive public funds for providing health services, all providers regardless of ownership are required to enter into annual contracts with the Croatian Institute for Health Insurance that dictates prices for services and forms of payments (Voncina 2007). The providers are thus paid based on a fee for service payment model (Katic 2004). The national health care network of providers determines allocation of public financial resources between the 20 counties according to morbidity,

mortality, demographic characteristics, etc. NGOs are funded partially by the state, foreign donors and private companies (Voncina et al. 2006).

#### *Price setting of home care services*

Prices are determined with CIHI for each service, procedure and medical devices used in home care. There is no information available on how prices are determined, i.e. there is no explicit process. Each service has its number of points, which are multiplied with monetary unit.

## 4. Organisation & delivery of home care

### 4.1 Access and needs assessment

Assessment is through health services: the overseeing doctor and visiting nurses with the approval of the medical commission of the CIHI. In case of social home care for the elderly the first level of identifying the needs is performed by the primary care team, by the Centre for Social Welfare, and by the gerontological centre. The patients' condition, functional ability and psychological status are the three main domains of assessment. In case of need for home nursing the overseeing doctor and visiting nurses with the approval of the medical commission of the CIHI decide the eligibility. The right to physical therapy at home, proposed by specialist physiologists, is obtained by approval from medical commission of the CIHI, with all supporting health documentation and medical records. For privately provided CIHI contracted home care an approval is given by the CIHI for one month, while the frequency of nurse visits is determined by the commission, with a range of 2 or 3 or 5 times a week. The request is repeated every month for the duration of the need for assistance. Next to the medical commission of the CIHI also the centres for social welfare decide what kind of care to be provided.

### 4.2 Delivery of services

Health and social needs are met (medical care, maintaining personal hygiene, dressing if necessary, daily and weekly therapy (in the dosage machine)). Generally, needs have not been met for the evening, weekends and holidays nor housekeeping needs. Furthermore, services are only provided once a day.

There are a lot of different types of institutions providing home care (personal care and home nursing) and

physiotherapy care at the patient's home – on the basis of the family doctor's recommendation. Provision and funding of services are largely public, although private providers and insurers also operate in the market. The health care system is dominated by a single public health insurance fund: the Croatian Institute for Health Insurance (CIHI). To ensure equality of access to all citizens, the CIHI-contracted health care providers operate within the framework of the national health care network. Home care is organized by the health centres or by for-profit agencies in public or private ownership. Home nursing is mainly provided delivered by qualified nurses and GPs. There are also private home care services contracted by the CIHI providing home care (Katic 2004).

In 2001, 1,746,000 house calls were recorded in home care services and additionally 1,286,000 visits by the patronage service (health visitor's service) (Katic 2004). Most of these visits were performed by private home care services. Providers of primary care include:

- Teams of physicians of family medicine, a district nurse and geriatric care services from the Centre for Home Care and Rehabilitation (state or the private sector);
- Services of the local Centre for Social Welfare;
- Gerontology centre services (delivery of home meals once a day to health and socially vulnerable patients, lending service for orthopaedic aids, health care services and advice for the ill elderly person and members of their family, etc.).

For disabled people, help can be provided also by different specialist associations. Organised services for domestic help are only provided by voluntary organisations from different kinds of humanitarian associations. Social voluntary organizations play an important role in Croatia. However, in 2008 there were 23 centres providing in-home assistance and care (Croatian Bureau of Statistics, 2009).

There is an increasing number of NGOs that own a growing number of assets. They also mobilize large numbers of human resources, both salaried and volunteer workers. An increasing number of NGOs depend on a large extent on national funding (from the Ministry of Health and Social Welfare, the State Office for Civil Society) and foreign and private companies (Basic information about the non-profit (nongovernmental) sector in Croatia) (Ceraneo 1999).

#### 4.3 Coordination and integration of services

As the GP's recommendation and the provider's assessment group is the basis for using the home care services there is a structured link between primary care and home care.

#### 4.4 Actors and human resources in home care

The actors involved in home care in Croatia (personal care and home nursing) are:

- The Ministry of Health and Social Welfare: their role in home care is collecting compulsory insurance premiums, laying down quality requirements, etc.,
- The counties; their role in home care is partly funding compulsory insurance premiums for vulnerable people; funding health care infrastructure, etc.,
- The CIHI; their role in home care is paying contracted home care providers, laying down service prices in contracts with providers, assessing needs and approval of care funded by the compulsory insurance etc.,
- Centre for Social Welfare (local centres assessing the needs and monitoring the quality of services and changes in needs, etc.),
- Centre for Gerontology; actor active in setting up quality control procedures and a Referral Centre of the Ministry of Health and Social Welfare for the health of older persons,
- As personal care and home nursing providers: GPs, health centres, contracted private home care providers,
- Gerontology centre services; providing home meals once a day to health and socially vulnerable patients (lending service for orthopaedic aids, health care services and advice for the ill elderly person and members of their family, etc.).

#### *Human resources in home care*

The only qualified professionals working in home care are nurses. There are 30,000 nurses in Croatia. More than 7,000 of them have college or university professional qualifications. In 2004, home care services employed just 968 nurses, each performing on average 2,068 home visits per year (Health services yearbook 2004). Home nursing is provided by health centres that had in 2004 a

total of 870 nurses. The average number of insured per community nurse was 4,892 (Health services yearbook 2004). (Health centres provide other types of home care services as well.)

#### 4.5 Use of tele-care

There is the telephone-help system in the patients' home in use in Croatia, apart from patient organizations which for instance offer patient with Alzheimer disease a help phone.

#### 4.6 Monitoring the adequacy of care

CIHI only gives approvals of care provision for one month. Hence, the needs are usually re-assessed every month. There is a monitoring team from the CIHI, the relevant Centre for Social Welfare or others which monitor the needs of the patient, the quality of care and the need for the extension of additional assistance. Criteria are used, but there are some variations in practice.

## 5. Clients & informal carers

### 5.1 Home care recipients

Little data was available on the number of home nursing or social home care recipients. In 2004, home care services employed just 968 nurses, each performing on average 2,068 home visits (Health services yearbook 2004). Thus in total about two million home visits were made in 2004.

Data on personal care is inconclusive. In-home assistance and care was said to be provided to 1,525 persons in 2007 (Bagić et al. 2008). Furthermore, in 2007, two home care programmes, 'in-home assistance for the elderly' and 'day care and in-home assistance for the elderly' provided home and day care to 8,241 elderly persons (Ministry of Health and Social Welfare, 2008). The number of recipients increased up to 14,420 in 2009 (Ministry of Health and Social Welfare, 2010). These programs included home nursing, domestic aid and meals on wheels. About 338 severely physically disabled persons received personal assistant services (Human Rights Watch, 2010).

### 5.2 Coverage and unmet needs for care

There are greater opportunities to meet health and social needs of older persons in urban areas, while in rural areas there is less ability to provide services of mobile gerontological assistants and other services of social assistance as well as less inclusion of voluntary associations. There is also a difference in providing health care in the city and rural areas. In rural areas there is more expressed solidarity by the family (often in the community three generations live together), and by neighbours. In the cities there are insufficient numbers of homes for elderly and infirm people, so there is waiting for accommodation for a number of years. Furthermore, on the islands there are many areas where a high proportion of elderly people live, so there is a larger need for social home care.

Furthermore, there are said to be long waiting lists and high costs of home care provided by public providers. There are no exact numbers available on the number of people on the waiting list. Also, home nursing and personal care are only provided once a day and not in the evening, weekends and holidays. Hence, although no numbers are available on the number of persons receiving home care or on a waiting list to receive it, it can be assumed that there are large unmet needs. Finally, in practice, very often the number of approved services and their duration is less than demanded.

### 5.3 Empowerment of clients

The public providers are contracted by the CIHI and clients have free choice of provider. However, as mentioned, in practice there are long waiting lists and high costs. There are no personal budgets or cash-for-care arrangements. GPs are responsible for referral so they have to choose between institutional and home care and, in the case of home care, help clients to choose between providers.

### 5.4 Informal carers

The Centre for Gerontology provides cash benefit compensation to family members for sick leave due to care for a family member (mother, father, grandmother and grandfather). There is a special allowance for informal carers. Furthermore, carers are allowed to be employed over the retirement age. The mandatory retirement age for carers of family members are 67 years for women and 70 years for men.

## 6. Disparities in the process of home care

Frequently, smaller number of carer's contact hours are provided and financed than those for which the person is eligible (for example to provide help for bathing, housekeeping, bed sores prevention, care for persons with contraction of muscles and education and support to families). Health care and physical therapy approved by the CIHI Commission is free for the patient, but if the needs of the patient are higher, additional services are paid by the patient. For some services, eligibility depends on the amount and type of pension and/or paid supplementary health insurance.

As mentioned above, there is a difference between the city and rural areas: more informal care is provided in the rural areas – three-generation families are still living together. In cities there is a shortage of both formal and informal care.

## 7. Concerns and new developments in home care in Croatia

Current concerns in relation to Croatian home care are:

- Low effectiveness and efficiency of the services provided;
- Access is limited. As the health care budget has a deficit, a 20% co-payment for health care provisions (except for children, pregnant women, elderly people with low income level) is implemented – €2 per family doctor visit, €7 per outpatient specialist visit;
- The monopoly position of CIHI (BMI 2009);
- Old-age pensioners also have to pay health insurance, this is about 3% or 5% over €700 per monthly income.

A current development, laid down in the Development Strategy for Croatian Health Care (by Ministry of Health and Social Welfare), aims to increase transparency and cost-conscious management, introduce a progressive health care system, structure links between each provision level and introduce European standards. Furthermore, a voluntary additional health insurance was recently introduced. About 120,000 people had already registered for this system in the first two weeks of 2010. The monthly contribution depends on the income of the insured person, but is between €7 and €18. The voluntary

insurance leads to free of charge medical treatment (with the exception of medications). Unemployed persons pay half of the insurance contribution.

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# Republic of Cyprus

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## 1. The context of home care

### Country, population and health

Cyprus is a relatively small country that entered the European Union in 2004. The population was 800,000 in 2006 (83 per m<sup>2</sup>) (eurostat 2008). The Republic of Cyprus is *de facto* partitioned into two main parts, the area under the effective control of the Republic of Cyprus, comprising about 59% of the island's area and the Turkish-occupied area in the north since the military Turkish invasion in 1974 covering about 37% of the island's area. This report will solely focus on the area of Cyprus that is under the effective control of the Republic of Cyprus.

The proportion of the population over 80 was just 2.7% in 2005, but expectedly 4.7% in 2030. The life expectancy for 65+ females is comparable to the EU average (eurostat 2008) but healthy life expectancy is much lower. Males above the age of 65 live much longer than the EU average, but their healthy life expectancy is about average. These developments are likely to increase the need for elderly care in Cyprus.

### Characteristics of health services and social services

Health services are financed through compulsory health insurance premiums. No co-payments are required for low-income citizens. In 2006, Cyprus spent 6.4% of GDP on health, which is relatively low for a European country (eurostat 2008), 20-12-2008). Also the available human

resources are low. In 2006 there were 4.4 practising nurses per 1000 population compared to 7.4 in the EU (WHO/HFA 2008). The density of practicing physicians on the other hand is comparable to other EU countries. Private GPs perform home visits when paid privately. Hospital bed supply is relatively low, 3.7 hospital beds per 1000 population compared to 5.7 in the EU (eurostat 2008). Social home services are financed through national general taxation and require a client co-payment. Public social services are means-tested.

### Social indicators and conditions related to old age

Although in 2008 the GDP per capita was just below the EU average (eurostat 2008) the population over 65 at risk of poverty was the highest in Europe (51% in 2007) (eurostat 2008). The female labour market participation, as an indicator for the availability of informal care, is low in the EU context.

### Attitudes related to old age

There is no legal obligation for children to finance care for their parents. Relationships between children and their parents are generally close, like in most Southern European countries. According to the Eurobarometer, (TNS Opinion & Social 2007a) Cypriots' preferences regarding professional care for an elderly parent living alone and in need of a regular help are comparable to the average European's; i.e. home care is twice as popular as nursing home care. In recent years a privately paid domestic worker (most commonly foreign female worker), is preferred to care the elderly at home.

## 2. Policy and regulation on home care

### 2.1 Governance on home care

The main aim of the Cypriot services for elderly and disabled persons is to support these persons in such a

way that they can remain at home for as long as possible and to support their social integration within their social environment (website MLSI, 19-10-2009). Home care has gotten attention in Cyprus for a long time. However, the focus used to be mainly on social home services and assistance. The Strategic Plan 1999–2003 of the Ministry of Labour and Social Insurance (MWSI) aims to keep older people in the community for as long as possible. To that end the Plan aims to support families in the informal care of older family members and expand formal home care for older people (Golna *et al.* 2004). This has resulted in a support programme for informal caregivers and expansion of the programme for home caregivers. The 2006 National Report on Strategies for Social Protection and Social Inclusion, planned to introduce a bill on minimum standards in home care (provided by the non-governmental and private sector). Furthermore, an expansion of tele-care services for older and disabled people living alone was foreseen as well as the provision of information on suitable home carers to those not receiving public assistance yet. In the National Strategy Report on Social Protection & Social Inclusion 2008-2010 again it was stated that the government aims to expand medical care provided at home (MWSI, 2008). Furthermore, it accentuated the need to tackle human resource problems within home care and safeguarding quality of home care.

The government holds strict control over some parts of home care, mainly social home care. The MWSI is responsible for personal care and domestic aid services via its Department of Social Welfare Services.

The Social Welfare Services Department as part of the Ministry of Labour and Social Insurance aims to safeguard social cohesion and social solidarity; to provide social protection, achieve social inclusion and promote equal opportunities for all citizens in the Republic of Cyprus; to combat poverty and social exclusion and to promote the interests of individuals, families and communities. *The Law for Public Financial Aid* protects those eligible for financial aid with house adaptations (e.g. ramps, special equipment in bathroom, etc.) and domestic aid. Home nursing care is under the responsibility of the Ministry of Health (MoH). Its Nursing Service provides care to adults with health problems, particularly chronic diseases. As this service is still on a programme basis, community nursing is not available in all areas. In addition to these well controlled services there are many privately hired carers, often recruited from third-world

countries. The state has no control over home-based private care. There are two NGO's that offer home nursing care for adult cancer patients.

## 2.2 Eligibility for home care services

### *Home nursing*

For home nursing from the government nursing services a referral is required from a community nurse, doctor or hospital. For NGOs to visit cancer patients the referral can even be the patient him/herself or a relative or friend with patients consent. Eligibility to home nursing from the Nursing Services is based on uniform criteria set by the MoH (different for long and short-term home nursing). Eligibility to home nursing is means-tested but available informal care is not taken into account (although it may influence the visit frequency of the nurse). NGOs do not use the MoH eligibility criteria.

### *Domestic aid & personal care*

Personal care, domestic aid and subsidies for home adaptations and technical aids (with a special allowance for wheelchairs) are provided to those who receive public financial assistance (website MLSI, 19-10-2009) or those whose financial means are not enough to satisfy special needs (Golna *et al.* 2004). As more than 50% of the elderly are at risk of poverty, many of them receive these services. Those with an average monthly income or having savings over 3.417 Euro (or 5.117 for couples) are not eligible and should rely on the private sector. NGO's do not always use these requirements. NGOs providing cancer care lend aids without fee to patients. Furthermore, public financial aid for home adaptations is restricted to those with a very low income and there are many restrictions for those who are not home owners.

## 2.3 Quality of process and output

### *Availability of quality criteria*

No quality criteria exist for domestic aid and personal care. However, there are standards for Centres for Adults providing day-care and home-care services, as well as other services at home (MLSI, 2008). These standards are defined in the Centres for Adults Law (L.38(1)/1997) which provides for the compulsory registration and inspection of the Centres.

Nursing care provided by the state, however, is based on protocols and is guided, supported and supervised by

the governmental Nursing Services. Other organisations offering care in the community, including medical care providers, do not have to comply with any process or output standards. NGO's home nursing care also relies on protocols developed by their organization.

#### *Assessment of quality of services and complaint procedure*

Systematic evaluation of adherence to the quality protocols is not required by law. The Nursing Service closely supervises its employees. An evaluation and client satisfaction survey, carried out after the first pilot project of home nursing, led to adjustments and further introduction of the project. In September 2009 a satisfaction survey of social home care recipients has been undertaken. Currently, a legal framework is being developed on quality of home care provision by private organisations and NGOs (MLSI, 2008). This would include working standards.

#### *Accreditation and clients complaint procedures*

No accreditation or registration of home care providers exists. An instrument on quality control is a law on complaints for the public services. Clients' complaints about nursing are delivered to the Nursing Services, the MoH, the Ombudsman Office or the Officer of Patients' Rights. Complaints on personal care assistants or the related needs assessment can be submitted to the Social Welfare Department or the Ombudsman Office.

## 2.4 Quality of input

### *Education*

The following levels of education and tasks can be distinguished for home care providers:

- Community nurse for home nursing. Level 1 nurses: four years Bachelor degree (formerly: three-and-a-half years education with a diploma) with one year course in community nursing. Community nurses for home nursing perform clinical nursing care. Additional activities (e.g. IV-medication) can be performed if trained for. NGOs also employ nurses of level 2, with lower education;
- Community mental health nurse. Level 1 nurses: four years Bachelor degree (formerly: three-and-a-half years education with a diploma) with a post basic one year course in Mental Health Nursing. Community mental health nurses perform a wide-

spectrum of interventions in the Mental Health Sector, providing an appropriate community service for a range of individuals with mental health needs (home visits, counselling/psychological support for patients and their carers, crisis intervention, liaison services, cooperation with Local Authorities and other NGOs, etc.). Additional activities are specialized interventions to elderly individuals or their relatives (formal and informal carers), who may need psychological support for mental problems, depression, Alzheimer disease and other type of dementia;

- Health visitor. Education similar to community nurse. Health visitors perform preventive visits, mainly to mother and child;
- Social workers. Four year Bachelor degree. They supervise personal care assistants;
- Personal care assistants/personal carers/community carers. No specific education, but training on the job for those hired by the Social Welfare Services Department;
- Care assistants. Private individual providers without specific education. Many from 3rd world countries and unable to speak Greek.

Nursing education is legally supervised by the MoH inspectorate. Nursing education is provided by one of the State's Universities, the Cyprus University of Technology. However, there are also several private universities that provide nursing education.

### *Job description*

Nursing tasks are clearly described with a scientific framework specifically designed for it. Tasks of nurses have been legally set and delivery without nursing degree is prohibited. Nurse tasks are: health teaching, counselling, liaison work, assistance with prostheses, epithesis, orthosis, elastic stockings and other aids; assistance with movement and transfer from one place to another (incl. in/out of bed); assistance with eating, changing stomas and urinal bags; and help with catheters etc.; help with skin care, disinfecting, preventing bedsores; with taking medicine; occupational/physiotherapy and health education. A national job description has also been developed for trained personal care assistants, in line with regulations from the Social Welfare Department. Personal care assistants help with Instrumental Activities of Daily Living and Personal Activities of Daily Living. Full-time care assistants,

often from foreign countries, are working without any supervision in the private sector, but are sometimes paid from governmental resources. It seems they mainly help with housekeeping, shopping and personal hygiene.

#### *Recertification*

At present no recertification is required.

### 2.5 Incentives for providers

Home care for the poor is purely public and competition is practically absent for this segment. Although there is a shortage of providers, in the private sector competition does exist. As no standards, accreditation, regulation or price setting apply to the private sector, it is easy for new providers to enter the market.

## 3. Financing

### 3.1 General funding

Public sources of funding are mainly general taxation, and private donations. Both the MoH community nursing sector and personal care assistants are financed by the state, through general taxes. Personal care is funded through the Social Assistance Scheme. Not only public, but also private providers, family members and NGOs may be partially compensated through this scheme. Additionally, they may be subsidised through the Grants-in-Aid Scheme of the Social Welfare Services and through donations. The social insurance (premiums jointly paid by employees, employers and the state) funds free medical treatment for those on invalidity benefits (MWSI, 2007). In 2009, a health insurance scheme was being developed, but its design is still under development.

In 2006, 0.64% of health care expenditures (or 0.04% of GDP) was spent on home health care, which is comparable to what other new EU countries spend (eurostat 2008). Most of these expenditures on home care are private. These data only refer to GP home visits (practically absent) and care provided at the homes for the elderly, which both need to be fully paid out-of-pocket. The scale of provision of the Nursing Service is still low. Means-tested client co-payments are usually required for public home care services; and eligibility to personal care assistants is means-tested leaving private care assistants as the only option.

### 3.2 Financing of home care agencies

Public providers are mainly in salaried service of the government. The only publicly financed home care agencies are NGOs providing services through the entitlement under the Law for Public Financial Aid (PA). The NGO gets subsidised the salary of the home care professionals involved (or, for those not on social benefits, they pay 6 Euro per hour). Other sources of funding are donations. Cash domiciliary allowances granted to dependents may be used to pay family members (giving up work or with low income), friends and NGOs. These allowance are intended for paraplegics and quadriplegics who are in need of personal care due to wheelchair use and limited body functioning. In 2009, there were 613 persons receiving this allowance (Symeonidou 2009). These allowances depend on the needs and the type of care required with a set maximum. Private individual providers can also be fully funded (the full salary is paid) from public sources, if a client meets the criteria under the PA Law to obtain support for a 24-hour private carer. The Social Welfare Services, however, are not responsible to find an individual provider or to supervise the provision of care. In case of public provision professionals are paid a fixed salary. Professionals employed by community councils or self-employed are paid from the Public Assistance Fund (website MLSI: [http://www.mlsi.gov.cy/mlsi/mlsi.nsf/index\\_en/index\\_en?OpenDocument](http://www.mlsi.gov.cy/mlsi/mlsi.nsf/index_en/index_en?OpenDocument), 19-10-2009). The MWSI also receives client co-payments per hour of care provided.

### 3.3 Price setting of home care services

Prices of public services are fixed (irrespective of the type of care). For social services prices are set per municipality, based on the salary of the professionals. For personal and domestic care clients pay an income-related co-payment, set by NGO or government. Prices of private services are free. Home care for cancer patients offered by NGO's is a free service and not income based.

## 4. Organisation & delivery of home care

### 4.1 Access and needs assessment

Applications for a personal care assistant are submitted to the Social Welfare Service, which asks for a GP referral or sends a social worker for the required needs assessment. No national standard assessment form exists. The Department of Social Welfare Service decides on the

assignment of financial support (based on the assessed needs). Applications for public home nursing are sent to the Nursing Service. Usually, the nurse performs the needs assessment using a standard form. At NGOs the assessment is usually carried out by a multidisciplinary team consisting of a nurse, social worker, psychologist and physiotherapist.

#### 4.2 Delivery of services

Community home nursing is provided by the public sector in some urban and rural areas, – the Government's intention is the expansion of this service all over the country and it is provided by the private sector (particularly for cancer patients) by two private non-profit organisations island wide. Furthermore, an unknown number of hospital nurses are privately working in home care. The personal care providers are also of a mixed nature. Most of these providers are individually working and employed by families or the dependent person, paid by the government (75% of recipients are financed this way). Immigrant workers providing personal care are said to make up a large share of the personal care providers. A study by the MLSI showed that in 2005 the non-profit sector provided 8% of home care services and public personal carers (either employed by social welfare services or community councils) provided 17% of home care recipients with care (MLSI 2006). Some competition between private providers does exist.

#### 4.3 Coordination and integration of services

In contrast to public sector care, home care by NGOs has been organisationally integrated, i.e. they provide both nursing and help with activities of daily living (ADL) and also instrumental activities of daily living (IADL). In daily practice, workers from different agencies work together, but formal teamwork coordination does not exist in the primary care setting. Usually community nurses coordinate health services and social workers coordinate social home services.

Cooperation and coordination between home care and other types of care are poorly developed. Structured cooperation between home care, GPs and hospitals is usually absent (although one hospital employs liaison nurses). Much better is the collaboration between public nursing homes and public home care providers. The

Department for Social Welfare Services is responsible of social services in both contexts. Contacts between nursing homes and NGOs providing home care are rare.

#### 4.4 Actors and human resources in home care

##### *Organisations*

Organisations involved in the policy making, financing, organisation and provision of home care are:

- The Social Welfare Department: organising provision of domestic care services and setting and implementing legislation (MLSI 2000);
- Ministry of Health (MoH): regulating nursing services and health care services;
- The Nursing Services: The Nursing Services is the highest level of decision making policy for nursing personnel and nursing programmes;
- NGOs: providing home care;
- Social Welfare Services (governmental regional offices in 6 districts): providing personal care and domestic aid;
- Municipalities (sub-office of the welfare department) and community councils: providing home care assistants and employ social carers;
- Privately employed home care assistants: providing home care;
- Privately working hospital nurses: providing home nursing.

##### *Human resources in home care*

Table 2 shows that very few public nurses are exclusively involved in home care. In total there are about 130 public community nurses (against 2,144 nurses in the public sector). They are not all included in the home nursing programme, but may undertake home visits for their own programme. Nurses are mostly public servants. In addition, 814 general nurses are working in the private sector, part of which providing home nursing. Personal care assistants and social workers are employed by either the Department of Social Welfare Services, the Community Councils or the recipient. Finally, several social workers and assistants are employed by voluntary organisations. The number of personal care assistants has declined drastically over the past years. Between 2005 and 2007 the number declined from 3,461 down to 1,835.

**Table 2:** Human resources in home care

Functions	Estimation total number
Total number of personal care assistants (2005)	3,461
Total number of personal care assistants (2007)	1,835
Personal care assistants employed by the social welfare services (2005)	134
Personal care assistants employed by the voluntary sector financed by the government (2005)	191
Personal care assistants employed by families of persons needing care and cost covered by the state (2005)	3,136
Social workers	n.a.
Public home care nurses (2010)	20
Health visitors (preventive home visits) (2009)	96
Community mental health nurses (2010)	57

Source: home nurses and health visitors: experts.

Source: Personal care assistants: MLSI (MLSI 2006).

Working conditions and payment of public nurses, assistants and social workers (also working for NGOs but publicly paid) are set in the Civil Servants' Law and Regulations. The annual salary of a community nurse with five years experience is 16.300 euro per year. For non-public providers conditions and salaries are set by individual agreements.

#### 4.5 Monitoring of provided care

The monitoring of individual needs for care is not required but it happens, for instance by the Social Welfare Services and NGOs. Monitoring related to home nursing is part of the administrative process of the Nursing Services of the MoH. The same applies for the Social Welfare Department.

#### 4.6 Use of tele-care

There is a 'Tele-Care Scheme' (MLSI 2007) providing alarm buttons available for those entitled for Public Financial Aid. Otherwise client charges are in place. The use of tele-care services is still modest. Tele-care is also widely used by one of the NGO's providing home nursing care.

### 5. Clients & informal carers

#### 5.1 Home care recipients

In 2009 Community nurses provided services to 4,538 clients by 13,223 home visits and 1,105 counselling sessions in Primary Health Centres. Many home nursing

clients receive care from non-profit organizations. In 2004, for instance, one non-profit organization has provided home nursing to 660 clients (International Observatory on End of Life Care 2009).

In 2007, 3,596 (of which 659 state provided, 2,420 privately provided and 517 provided by local authority or NGO) clients received domestic aid and personal care (MLSI, 2008). This is a decline of about 18.5% from the number in 2005. This is said to be caused by a decline in carers and mainly lies in the decline of recipients in the state employed and private providers (MLSI, 2008). The number of personal carers (also called 'community carers') employed by local authorities and NGOs increased by 50%. In 2009, 396 persons received an allowance for Technical Equipment (Symeonidou 2009).

#### 5.2 Coverage and unmet needs for care

Among services not provided to the clients' home are 24-hour care, respite care, and in many geographical areas, home nursing and meals-on-wheels. Most available services often take a long period of time to be delivered. Many people entitled to personal care assistants are on waiting lists. Furthermore, due to lack of funding, usually fewer hours are received than a client is entitled to. Finally, people with average incomes may not be eligible and need to rely on (more expensive) private domestic aid and personal care services.

#### 5.3 Empowerment of clients

Obviously, clients can choose any provider if paid privately. In other cases, their choice is limited as

there are not enough providers of care (and non-profit providers usually focus on one type of client). The limited number of community nurses is an obstacle to free choice of home nursing providers. Although basically one is free to choose between institutional care and home care, the choice is limited by the financial resources of the client because institutional care is more expensive. Also, under specific criteria the Public Financial Aid can support someone to move to a nursing home (payment is a combination between the social insurance pension and public financial aid). A personal budget ('domiciliary allowances') is possible and can be paid to non-profit providers or family members. It is discretionary by law (depending on care needed) but means-tested (also family means). Intermediary organisations can help the client to choose private providers of domestic aid.

#### 5.4 Informal carers

The Public Assistance and Services Law of 1991 allows informal carers to receive (income dependent) monthly fees for their care services (Golna et al., 2004). However, this only applies to those who left their job to take care of a family member (MLSI 2006). Social workers check the correct spending of resources. Although informal carers are recognised to some extent, there is said to be a need among them for supportive counselling and education how to cope with the burden of care.

### 6. Disparities in home care

Pathways of those in need of home care depend on the financial position of the person. As professionals and programmes are not available throughout the country there are geographically determined inequalities in the access to services, like physiotherapy and home nursing. Home physiotherapy is available only from private sector.

### 7. Concerns and new developments in home care in Cyprus

Problems existing in the home care sector are:

- Geographical inequalities in availability of home nursing. This may change with the introduction of the new Health Care Scheme;
- Staff shortage. Lack of nurses obstructs an expansion of the home nursing programme and lack of personal care assistants leads poorly qualified assistants from abroad to immigrate to Cyprus. In Larnaca, a city of

75,000 inhabitants, 25 personal care assistants help about 200 patients. Many are on waiting lists (2009). No home nursing is available in Larnaca;

- Time consuming assessment procedures. Indications may take up to 3 months as a result of high workloads of social workers;
- Poor control of the private sector. No quality requirements or regulation on prices are applicable to the private sector. As public services are scarce and many providers are not properly qualified, this is a major problem;
- Public family doctors do not make home visits. Hence, the pressure on home nursing and hospital emergency care is higher;
- No formal discharge planning from hospitals, with few services in the community. This puts a huge burden on the family to make arrangements at the last minute to organise care in the home.

Much is changing in home care. Important developments regarding home care are:

- The introduction of a compulsory National Insurance Health Care Scheme will ensure better coverage of home care in Cyprus for the entire population as well as reorganizing the health care system to emphasize the community health nurse;
- Increasing numbers of hospital nurses privately provide home nursing as a sideline job;
- The increasing decentralisation of welfare services. The Social Welfare Services has created new local offices (MLSI 2007);
- Local voluntary organisations called Community Welfare Councils run by the community councils have developed rapidly over the past five years and provide a great amount of social services e.g day care centres and home care with care assistants;
- Higher proportion of nurses qualifying due to private institutions running Bsc nursing courses.

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# Czech Republic

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## 1. The context of home care

### Country, population and the aging process

Only 10.4 million inhabitants live in the Czech Republic in 4.08 million households with 2.51 members, on average, but households of retired persons have only 1.73 members. The population is ageing progressively. On the one hand, life expectancy is increasing. In 2001, Czech male newborns had a life expectancy of 72.1 years, and it was already 74 years in 2008. The newborn girls had a life expectancy of 78.4 years in 2001, and 80.1 years in 2008. A man, 65 years of age, still has 15.1 years to live, on average; a woman of the same age still has 18.4 years to live. On the other hand, the birth rate is low, despite the fact that the total fertility rate is continuously growing: The net reproduction rate was only 0.64 in 2006, and 0.73 in 2008. As a result, the ratio of the population of people 65 years and over that amounted to 14% in 2007 will increase. In ten years, more than 20% of Czechs will be 65 years or older (Ústav zdravotnických informací a statistiky České republiky 2009; Český statistický úřad 2009, 2008, 2007).

### Characteristics of health care and social services

Health services are funded by obligatory health care insurance. Health expenditures amounted to 6.6% of the entire GDP in 2007 (OECD 2009a). Services of curative or rehabilitative care caused expenditures of 3.8% of the GDP. At the same time, public spending per capita amounted to €735, out-of-pocket spending to €71.

According to the Ministry of Health of the Czech Republic, 5.2 general practitioners were available for 1,000 adult citizens (Ústav zdravotnických informací a statistiky České republiky 2008). According to OECD 3.6 physicians (0.7 GPs, and 2.9 specialists, or any other physicians) were available for 1,000 citizens of all ages in 2007 (OECD Health statistic 2009). The Czech statistics stated that 192 hospitals were available both in 2007 and 2008. There were 63,600 beds, of which 35% were in long-term care hospitals in 2007. The proportion slightly increased to 36.5% in 2008. The number of beds in these hospitals was 7,198 in 2008. Approximately 11% of all hospital physicians worked for long-term care patients (Ústav zdravotnických informací a statistiky České republiky 2008).

One of the purposes of health care is the provision of home nursing (including personal care) and rehabilitation at home (*osetrovatelská služba*) that is covered by the public health insurance. Nursing is intended to care for persons after a hospital stay or for chronically ill patients who do not need a hospitalization, but qualified care and treatment by a professional nurse.

A large part of long-term care in facilities and in private homes of the clients, including home care (*pecovatelská služba*) is part of the social services, and is subsidized on the basis of tax money. The 37,733 places in 452 facilities for senior citizens that were available at the end of 2008 belong to social services as well. Five different kinds of facilities in the institutional long-term sector are available (Ministerstvo práce a sociálních věcí České republiky 2009); the most important ones are:

- Homes for persons suffering from health problems (nursing homes). In 2008, 230 facilities with 8,100 staff members cared for 14,700 residents. The expenditures amounted to 153.5 Million €, the contribution by residents to 56.2 Million €.
- Homes for senior citizens (old age homes for residents who do not need permanent care). In 2008, the total number of facilities was 461, the total

number of staff 12,600, and the total number of residents 41,100. The total expenditures amounted to €299 Million, the contribution by residents to €133 Million.

- Special homes, mainly for long-term care psychiatric patients, persons addicted to substances, or severely demented and Alzheimer's patients. 148 facilities with 4,300 staff members and 8,200 residents existed in 2008. The total expenditures amounted to €68 Million, the contribution by residents to €26 Million.
- Post-acute care is provided after a discharge from a psychiatric clinic, or and after treatment for addiction.
- Therapeutic housing.

In the Czech republic, home care is called “social care” that includes basic care, personal assistance, care in difficult situations, some support for independent housing, respite care, day care, and many other routine daily tasks. The clients have to pay out of their own pocket. Social care is a relatively new service. However, the availability is improving. In 2007, home care was provided in 2,530 municipalities to 98,373 recipients. In 2008, the number of recipients increased to 128,250 persons; at the same time, the number of municipalities where home care is available also increased (2,696) (Ministerstvo práce a sociálních věcí České republiky 2007, 2009).

#### Social indicators and conditions related to old age

An average household member earned 6,096 Euros annually, but a person in a retired household 4,779 Euros only. In 2007, 2.71 Million persons belonged to the retired population; 2.02 million received their retirement income because of old age. In 2006, 2.6% lived below the subsistence minimum, a proportion that slightly decreased in 2008 (2.4%). But the risk of poverty increased from 5.8% in 2006 to 7.5% in 2008. It is particularly high among retired people. In 2006, 31.8% of them faced the risk of poverty, but this percentage has increased to 33% in 2008 (Český statistický úřad 2009, 2008).

#### Attitudes related to old age

Czech people view care for dependent persons as a commitment of the family. The majority of the experts interviewed regarded the family as the most important resource for persons in need of care.

Vidovicová-Ehrenbergerová (2003) and reports in public media have shown that ageism and age discrimination are common problems not only among the general public but, above all, among medical doctors and other health care workers, as well as among employees of social services and municipalities.

## 2. Policy and regulation on home care

### 2.1 Governance on home care

In the early 1990s, a scenario of social change was developed (Prusa 2008). One issue was the improvement of social security for old and impaired citizens who need support. Priority was given to creation of social services. New principles have been adopted by the policy makers: more democracy, less centralization, pluralism of financing and reimbursement, improvement of the status of the clients/beneficiaries, differentiation of services based on needs, increase of expertise and professionalism, change of communication with clients.

For home care, the following principles have been proclaimed:

- Respect for and dignity of the clients, support of their social participation and self-determination.
- Possibility to stay at home in the community and to continue the current lifestyle as long as possible.
- Protection for vulnerable groups in private homes and/or in facilities.
- Prevention of social disintegration (Prusa 2007).

The way to the realization has led to the development of the law on social services that went into effect in 2007 (Sbírka zákonů-zákon ze dne 14. března 2006). This law differentiates between three types of social services: social counselling, social care and social prevention.

**Table 1:** Benefits for care in the Czech Republic: Preconditions for eligibility and levels of payment

Degree of benefits	Degrees of dependency	Recipients 18 years of age or older. Minimum number of ADLs/IADLs required for care/supervision	Monthly benefits for Recipients 18 years of age or older	
			CZK	€
I	Low dependency	12	2,000	79
II	Medium dependency	18	4,000	159
III	Severe dependency	24	8,000	318
IV	Total dependency	30	11,000	437

Source: Ministerstvo práce a sociálních věcí České republiky (2009).

## 2.2 Eligibility for home care services

A sharp dividing line exists between home nursing and home care (a part of social services). Correspondingly, access to both services is different, and different criteria, assessments and allocation procedures are used. Home nursing is a medically oriented care out of hospitals, including, for instance, injections, care of persons with severe pressure ulcers or diabetes mellitus, or the post-acute care for individuals who do not need or do not want to be in hospitals. End-of-life-care belongs to this category also. Home nursing is understood as health care: It is covered by the health care insurance, if a general practitioner (GP) has confirmed the necessity. Home nursing is intended to care for persons after a hospital stay or for chronically ill patients who do not need a hospitalization, but qualified care and treatment by a professional nurse. Up to three hours a day are covered. A hospital physician is authorized to prescribe home nursing, too, but this prescription is only valid for 14 days after discharge from the hospital. If the patient's status requires the provision for a longer time, a new prescription – this time by the GP – is required (social act number 109/2009 and regulation 620/2006, January 2007).

“Home care” is a social service for individuals not needing medically-oriented home nursing, just basic personal care, support, and help in elementary or instrumental activities of daily living. Services that belong to social care have to be covered out of pocket of the client who can get a financial contribution from his/her municipality that is also responsible for the allocation of this financial contribution for care.

Medication, incontinence materials, and technical aids are covered by the public health insurance. A prescription by a physician is required. A co-payment is obligatory.

## 2.3 Quality of process and output

The law on social services number 108/2006 Sb. defines the term “quality of social services”, and determines the procedure of quality assurance. Fifteen “quality standards” have been introduced as criteria for staff, the organization, and the administration. Additionally, the relationship between providers and clients is regulated. Providers have to offer comprehensive information on the kind of services, aims, location, and their capabilities. Clients have the right to be informed about the mode of service provision, about the costs and prices. The regional office or the Ministry of Labour and Social Affairs can examine if the care agencies or their owners are legitimate and capable service providers. The quality of the services is checked frequently. Care providers are obliged to develop internal standards, for instance for the management of complaints (Standard no. 7).

## 2.4 Quality of input

All providers of social services, including those who provide home care, have to register (social act 108/2006 Sb). The purpose is to protect the clients. Home care can be provided by agencies, or single persons, if they are not closely related to the client. The law clearly describes which services can be considered as social services, and that a registration is mandatory according to social act 108/2006 Sb. (<http://itregister.mpsv.cz/socreg/>). Otherwise, the service cannot be recognized as social. For instance, a private cleaning company does not provide a social service.

The municipalities monitor the quality of the provision of social services and therefore also of home care. If major quality problems are identified, the municipalities have to inform the institution that was responsible for the registration of the agency. For the purpose of

quality control, the employees of the municipalities are authorized to enter the home of the clients in accordance with their agreement.

For home nursing, social act 109/2006 Sb. states that providing agencies must be contracted by the health care insurance institutions, and that they are responsible for qualified staff. The law on paramedic professionals differentiates the professions needing supervision from those who do not need supervision.

### 3. Financing

#### 3.1 General funding

The financing of home care is regulated by the law on social services (§ 101 and 102). Only registered services get a subsidy, one part of which is provided to the regions (*kraje*) that are obliged to finance services in their area of responsibility. The amount of the subsidy is dependent on the financial plan as well as on the plan of development of the service infrastructure in the region. As a consequence, different channels are used to distribute the subsidy: Firstly, the care providers are subsidized directly by the state, secondly by the region (*kraj*) that gets money from the state. Thirdly, they are subsidized by the municipality (*obec*) that gets money from the region. The clients pay for services that they get out of their pockets. However, they can apply for a contribution through which no co-payment may be necessary (see paragraph 2.2 and Table 1). The municipalities have to monitor whether the money was spent on social services. However, the client is relatively free in his/her decision how he/she will distribute the money and which of the social services he/she will use. It seems that control on the client level is not provided consequently. Home nursing (personal care and technical nursing) is financed by the health care insurance, if a general practitioner (GP) has confirmed the necessity.

#### 3.2 Financing of home care agencies

In 2007 the total expenditures on the core social service, the home care, was €70 Million, the contribution paid by clients amounted to €16 Million. Both payments increased in 2008. With regards to expenditures for the entire range of social services, the proportion of payment out of the clients' pocket increased, whereas the state payment decreased from 2008 to 2009 (Zarsky 2009). In 2006, the average per capita spending was €51.44,

while the average contribution by the clients was €7.13 (Ministerstvo práce a sociálních věcí České republiky 2007).

#### 3.3 Price setting of home care services

Home care is paid directly by the client, but the law sets down the maximum. In 2008, the fee for one hour of home care amounted to €3.96 (Prusa 2007). The prices have to be included in a contract between the home care agency and the client. The municipalities provide information on the prices as well as forms for the contracts.

Prices for home nursing are set by the health care insurance institutions (a list of VZP – *Všeobecná zdravotní pojišťovna* – the largest statutory fund in the Czech Republic with 6.2 Million members). The price list is oriented on the indication, qualification/specialization, and time required for the completion of the task (<http://www.vzp.cz>). A co-payment is required for care on weekends and between 10pm and 6am.

### 4. Organisation & delivery of home care

#### 4.1 Access and needs assessment

Because the care for persons at home is divided into two major areas (see paragraphs 1 and 2.2 above), two major routes lead to the services. The first is via a gatekeeper and leads to home nursing, rehabilitation, and a hospice programme. Gatekeepers are mainly general practitioners or (for hospitalized clients) hospital physicians. A home care worker then visits the client and performs an initial interview, examination and assessment of the client's social environment.

A different route leads to home care for persons who do not need medical nursing but primarily physical help and different forms of support. These persons can apply for a *contribution for social services* that enables them to maintain an independent life style. After applying, a social assessment (by a social worker) and a health assessment by a physician are required. A statement by the potential caregiver/caregiving agency has to be included in the application. Municipalities appoint the commission responsible for making decisions. Its members are: the assessment physician (*posudkový lékař*) who is a medical specialist employed by the Czech

Social Insurance Institution (*Ceská Správa Sociálního Pojištění*), and the representatives of the social services of that municipality.

The law on social services differentiates four degrees of dependency (see Table 1) in, for example, preparation/handling of meals, eating, personal hygiene, repositioning in bed, toilet use, walking, dressing/undressing, medication management, communication, participation in social activities and other easy instrumental activities of daily life.

#### 4.2 Delivery and use of services

Home care is provided by public administration, local governments or registered private home care agencies and single persons (Misconiová, 2006). Social services have to support persons in “unfavourable social situations” to maintain their human dignity, to recognize their individual needs, and to maintain social integration of any individual in his/her natural social environment (Social act number 108/2006 Sb., and the regulation of the Ministry of Labour and Social Affairs 505/2006 Sb.).

The basic service is social counselling for everyone and is free of charge. There are 654 institutions of this kind, with 1,700 staff members. Total expenditures in 2008 were € 20.5 Million.

The core of social services is home care provided by 594 contracted home care agencies with 5,500 staff members who served 115,000 clients in 2008.

Still less common is personal assistance for persons whose autonomy is limited because of old age, chronic diseases, or health problems: – 183 services of this kind existed in 2008, with 1,800 staff members working for 7,000 clients. The total expenditures amounted to € 15 Million and the contribution paid by clients amounted to € 3 Million.

An important service is *accompaniment and reading*. The aim is to improve communication and cognitive status. It also helps impaired persons to reach services, shops, doctors, and health facilities.

Still another service is *social activation* for senior citizens and persons with health problems. It is free of charge, and resulted in expenses of € 6 Million in 2008, when 223 services with a total of 660 staff members were active.

Respite care aims at relieving the burden of the informal caregivers and giving them the opportunity to take time off. (Availability in 2008: 161 services, 1,800 staff members; total expenditures: € 15 Million, contribution by a total of 11,000 clients: € 4 Million).

Not only domiciliary-oriented care but also semi-institutional services are available, for instance: day care/day centres, week centres/week care for persons with impaired autonomy, and assisted living.

#### 4.3 Coordination and integration of services

Compared to other EU member states, the degree of integration of services for the aged is low (Henrard et al., 2006). One reason is that health care and social care are sharply divided on any level (the level of the state government, of regions, and on the municipal level). The funding and operation of services is divided as well. The lack of integration and coordination has negative effects in everyday practice. The difficulty of the allocation and reimbursement of (medically-oriented) nursing and rehabilitation to clients of social services has been criticized. Clients of social services often do not get access to rehabilitation (Bruthansová et al. 2009). The authors mentioned that the health care insurances have neither prepared adequate assessment rules nor a standardized assessment that is necessary for a reliable identification of individual needs. This problem is aggravated by the different policies of the regions (*kraje*). Generally, physicians in charge, are not committed to recommending rehabilitation or treatment that would have preventative effects. As a consequence, many senior citizens who do not need hospital treatment are hospitalized.

#### 4.4 Actors and human resources in home care

Important actors are:

- Ministry of Labour and Social Affairs (responsible for social services);
- Ministry of Health (responsible for the health sector);
- Regions (*kraje*) (responsible for the planning, funding, and infrastructure);
- Municipalities (*obce*) (responsible for the actual supporting of clients, assessments, allocation and distribution of the *care money*);

- Home care providers (either single persons or home care agencies). A registration as a “social service” is important;
- Social workers in municipalities;
- Health Care Insurance Funds;
- General Practitioners;
- Hospital physicians;
- Informal caregivers/family;
- Clients or patients;
- Assessment commission;
- Inspection teams (for quality assessment and monitoring).

#### *Human resources in home care*

The overview of staff of different social services care has been provided in section 4.2 above. According to the European AD HOC study, the clients of home nursing received 30 minutes of home nursing weekly, 0.01 hours of home care, and 0.6 hours of home help, on average (Garms-Homolová, 2008).

The social act 108/2006 Sb. and the regulation 555/2006 Sb. have determined the qualification that is necessary for employment in social services. The commitment to continuing education is set by these acts. The registration of nurses is obligatory according to act no. 96/2004. The responsible institution is the Ministry of Health. Education to become a nurse is possible after secondary school. It takes 3.5 years. Recently, college and university education for nurses has been developed. However, such highly qualified nurses are not working in home care.

The very low wages of health workers lead to a permanent “brain drain.” Many nurses and nursing assistants prefer to work abroad (see section 7). The average annual salary of a nurse amounted to 910 € in 2007. The annual payment for work on Sundays amounted to 48 €, for the night shifts to 28 € (Ministerstvo zdravotnictví české republiky 2008).

#### 4.5 Use of tele-care

Only limited tele-care services are available at the moment. In all regions, emergency medical ambulances

exist that can be called in case of injuries or medical crises. Some help lines are available to persons endangered by a deterioration of their status.

Social services contain (Ministerstvo práce a sociálních věcí České republiky 2009):

- “Stress Care” or “Help for persons under pressure” (*tísňová pomoc*) dedicated to persons “at risk”, because of health status, capabilities, or endangered life. (Availability in 2008: 17 services, 120 staff members; Number of clients: 2,500; total expenditures: € 1.2 Million, contribution by clients: € 0.2 Million).
- Phone intervention in case of a crisis (free of charge, provision for a limited time span). Aim: frequent contact to a specialist for persons whose health or life is at risk, who are not able to control their own situation. (Availability in 2008: 42 services, 200 staff members; total expenditures: € 2.4 Million).
- In large cities, so-called help lines for persons with disabilities or need for care are available. Help lines for the prevention of falls exist in few communities.

#### 4.6 Monitoring the adequacy of care

The continuing need for care and for “care money” is monitored by the social office of the municipality. The procedure is similar to the decision making on eligibility (see section 4.1 above). The continuance of home nursing requires an opinion of a GP, and is regulated by the social acts 109/2009 and 620/2006 enforced January 1, 2007.

## 5. Clients & informal carers

### 5.1 Recipients of benefits for the home care

According to existing estimates, 80% to 90% of Czechs of 65 years of age or older are relatively independent. 13% need support in the area of house work, 7% continuous and intensive care and help, 2% long-term-care in facilities. Jerábek (2005) identified the need for daily care in 2% of the population of 65 years and older, but in 8% of the population of 80 years and older. In 2004, the proportion of people needing long-term care amounted to 0.76% of the entire population. This percentage will double until 2030 (ibid).

**Table 2:** Distribution of receivers of different degrees of benefits for care

Degree of benefits	Male recipients %	Female recipients %	No. of beneficiaries per 10,000 of the population in that age group	
			66 to 74 years	75+ years
I	35,3	43,4	165	842
II	33,8	31,0	119	589
III	19,2	15,1	51	267
IV	11,7	10,5	28	188
<b>Total</b>	<b>100</b>	<b>100</b>	<b>-</b>	<b>-</b>

Source: Zárský 2009, status: end of 2008.

Corresponding to the structure of the old population, the majority of receivers of benefits for care are women (total 65%). Female clients are frequently classified into categories of low benefits (see Table 2). For both genders, it is true that the lowest rate of beneficiaries lives in Prague, the highest in the North of the republic (Jerábek, 2005).

## 5.2 Empowerment of clients

The Government of the Czech Republic approved a programme in 2002 that includes principles of anti-discrimination and protection of human rights, employment of older workers, material welfare, pension reform and social security, health care and healthy lifestyle, social services and social inclusion, education and training, housing, transport, research, design, and other issues. A positive image of ageing, healthy ageing, and well-being in old age, are emphasized as well (Wija 2006). The aged citizens have to learn to use those societal opportunities that can improve their status and participation. Because research on the old population is underrepresented in the Czech Republic, the government stresses that research has to pay more attention to the subjects “ageing” and “situation of the old population and individual” (ibid.). Recently, the public administration started to become more sensitive to the situation of the aged citizens and of old clients of public services. Newly established councils of seniors are working as advisory bodies to regional authorities, and are increasingly involved in policy making. Regional administrations and local municipalities started to use the method of community planning, also for the development of social services.

## 5.3 Unmet needs

Experts interviewed for this project mentioned that:

- The following services cannot be covered easily: remodelling of apartments, rehabilitation programme at home, sometimes also medical care at home (experts mentioned the lack of incentives for GPs to visit people at home), around-the-clock presence of a person, 24-hour care, permanent monitoring, dementia care, extensive IADL care, tele-care, spiritual support, occupational therapy, training of walking abilities. Some experts stressed that the provision of services on weekends or holidays does not work properly;
- Clients are not informed satisfactorily. The consequences are: low utilization of services, low demand despite existing needs. Sometimes, the social office of the municipalities handles the applications for financial contributions for care restrictively. Lastly, the contribution might be lower than the actual need. Usually, only a small portion of needs can be covered.

## 5.4 Informal carers

The most important actors and care providers in home care are family members. The European Ad Hoc study has shown that persons who got home care by an agency received 20.84 hours weekly by relatives (Garms-Homolová, 2008). Much more care is provided to those persons who do not use an agency or another (professional) caregiver. Family members are officially not entitled to a reimbursement by the contribution for care (§ 59, 255/1946 Sb), but the everyday implementation is different. Additionally, informal care giving counts towards the retirement income. The payment for other informal caregivers is regulated by the regulation

182/1991 Sb., relevant also for the payment of the professional caregivers. In the Czech Republic, children are not liable for the care of their old parents.

Some experts interviewed in this project reported that families have positive and negative effects on the situation of potential home care clients: “The family helps to fight for more care, but the family also can refuse care or services that they do not want and provide care by themselves instead.” Often, families overestimate their capabilities. As a consequence individual needs of the dependent/ill family member are not covered properly. However, families are still the most important resources for the old and disabled. Commitments of employment are an obstacle with regards to informal caregiving. Some services are available only for persons living alone; clients living in a family do not have access to such services.

## 6. Disparities in the process of home care

Problems repeatedly mentioned by the experts interviewed were those of regional disparities. In some regions, the variety of services is limited.

- Limitations exist with regards to adequate housing and barrier-free apartments. Housing programs for very old and disabled mainly have progressed in Prague and in large cities, but even there, the number of adequate apartments remains limited;
- In rural regions, home health services, such as rehabilitation, specialised care, psychotherapy, and specialists for psychiatry or neurology are scarce. The same is true for personal assistance and volunteer organizations;
- Chiefly in rural areas, transportation to doctors and rehabilitation services is costly and not always possible. Home visits by doctors, nurses, social workers, physiotherapists, etc., are often not practicable. No mobile meals and few goods of daily life are usually delivered to a secluded village;
- The density of the networks of home care agencies is low in many rural areas and small communities because the potential market is so limited that services have difficulties to survive. The gaps in the labour market play an important role;
- From the point of view of the *care money*, the regional disparities appear in a slightly different light. Prusa (2008) studied the expenditures for home care/help. According to his results, the very low density of

services exists only in the mountain regions, whereas the rural flat lands have reached a very high density of home care services. The family structure has been considered as the main cause. Prusa (2008, p.17) stated that regions with a high level of health care (the capital Prague) offer particularly little home care, whereas gaps in the health facilities infrastructure are associated with a high density of home care/help. A significant, but negative correlation was identified between the number of spaces in long-term care facilities and home care agencies (Prusa 2008). However, in the whole republic, the need for institutional care is not covered satisfactorily.

## 7. Concerns and new developments in home care

- The wages in the health care sector are extremely low in the Czech Republic. For this reason, health workers, physicians, but also nurses and home helpers often decide to work abroad (Marecková 2004, Buchanan & Seecombe 2006). Even for qualified nursing staff, it is often more profitable to work as an illegal or legal home helper than to stay at home as an employee of a hospital, a long-term care facility, or a home care agency. Most frequent reasons for emigration are low salaries in the Czech Republic compared to the destination country, differences in salaries of doctors and other professions, expectations for a better life, better working conditions, and presence of family or friends abroad. The main barriers to emigration include separation from family and friends, expensive and lengthy formalities for working abroad, difficult living conditions, language barriers, and a guarantee that after returning home, health workers can find work (Wiskow 2006);
- Experts questioned in the EUHOMAP-Study have criticized that physicians are often reluctant to prescribe nursing or rehabilitation. Published experiences have shown that the health care insurance institutions are reluctant to reimburse the costs of health care for long-term care clients. However, such publications deal with the long-term care facilities (Bruthansová, et al. 2009);
- The progress in development of home care has stagnated (Prusa 2008), but other experts have emphasized that the existing agencies have increased their capacity (Zárský 2009): The numbers of staff working in home care and of clients have grown;

- Starting from 2010, the state will not subsidize the care providers. The subsidy will be provided to the regions (Kraje). The payment will cover the running expenditures related to social care provision/providers that are registered. The aims are: support of services that are operating in the whole republic or in more than one region; to develop infrastructures but above all to invest into education and training of staff; to develop regional plans; to develop quality etc.; to build reserves for the case of catastrophe or emergency.

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# Denmark

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## 1. The context of home care

### Country, population and health

Denmark is a small country with a population of 5,476,000 inhabitants and a population density of 128 inhabitants per km<sup>2</sup>. GDP per capita is €42,628 in 2008 (1), one of the highest in Europe. About 8% of the population has foreign roots.

The proportion of elderly people is growing. In 2008, 15.5% of the population were 65 years of age or above and 4.1% were 80 years or above. The estimates for 2030 are 23.3% and 7.8% respectively and for 2050, 24% and 10.3% respectively (1). So a relatively steep growth is forecast for 2050 with a growth of 261% in the group of 80+ years.

In 2006 the healthy life expectancy at age 65 was 12.6 years for males and 14.1 for females (2006). The prevalence of chronic disease was, regardless of age, 25.4 for males and 34.3 for females. For persons at the age of 65–74 year it was 36.3 for males and 42.7 for females. For persons above the age of 74 it was 44.7 for males and 52.4 for females (2).

### Characteristics of health services

Actors in the Danish health care services are at national, regional and local level. While law and regulations are at national level the performance is divided between what is perceived as two sectors. Regional authorities are responsible for acute and specialized care including hospitals and medical specialists (secondary sector). The municipalities are responsible for the primary sector

including prevention, rehabilitation and long term care e.g. home care and nursing homes. GP's are in-between; they are perceived as part of the primary sector while being regulated by the regions. Both acute and long term health services are funded by general taxation and with some additional co-payments for the patient e.g. for medication, dentistry and optician care. In 2008 about 9% of the GDP was spent on health care (including both sectors). The number of acute beds are 19,000 (including psychiatry) and mean length of stay in acute hospital is 4.5 days (3).

Denmark has progressed a long way with the deinstitutionalisation of older people. The aim is to provide assistance making it possible for most people to stay in their own home, or as long as possible. Following legislation, from 1987 conventional nursing homes have to a great extent been converted in favour of independent housing. These special living facilities for elders consist of 1–2 room flats with private bathroom and kitchen facilities. A number of flats are located in buildings with in-house health care services. The residents receive their pension and pay (a reduced) rent and they can subscribe to in-house facilities (meals, laundry, etc.). Nursing homes and special living facilities for elders are, with very few exceptions, publicly funded or subsidized, and an assessment by officers at the municipality is a prerequisite for moving in. A maximum of 2 month waiting time from assignment is being strived for. Nursing homes and special living facilities also provides day centres (activities) for the local elderly population and respite care. There are also other living facilities suitable for elderly or handicapped people but without in-house services.

### Social indicators and conditions related to old age

Children are not liable to support their parents. Citizens are entitled to a public funded basic age-related pension (OAP). The age for this OAP is gradually being raised from 65 to 67 years of age. Supplementing the basic

pension are income based and private individually funded pension schemes. 18% of the population above the age of 65 is considered at risk of poverty (2).

Citizens with reduced ability to work are granted a publicly funded social security pension, eventually supplemented by labour market or individually funded insurances. In 2008, 7.1% of the population between 18 and 64 years of age received social security pensions (1). Public expenses in relation to disability and rehabilitation benefits amounted in 2008 to around 4% of the GDP.

### Attitudes related to old age

In Denmark care for dependents is seen as primarily a public responsibility. According to the Eurobarometer, only 18% find this a task for close relatives if the respondents' career might be affected (4). Of the Danish Eurobarometer respondents, 58% said that care for a dependent elderly person should be provided by public or private providers at home, while 14% said that moving to a nursing home would be the best solution (4).

## 2. Policy and regulation on home care

### 2.1 Governance on home care

The Danish welfare system is characterized by universalism and primarily tax financed provision. National government develops the legislative framework for social and health policies and redistributes tax income to the public service (regional and local authorities) responsible for health and social provisions. While the prime responsibility for health care (e.g. hospitals, GP's, non-hospital based medical specialists) is with the 5 regions, the responsibility for social care and home care is with the 98 municipalities.

Home health care is regulated by national law and local standards. Citizens have a legal right to district or home nursing when referred by a GP. Access to rehabilitation, maintenance training and supportive/technical aids is described in national law (5) while personal and domestic care is implemented according to local standards within the realm of the law. The municipalities are cooperating with private and voluntary bodies to promote social welfare (6).

The aim of home care is to allow those with a temporary or chronic illness or who are close to death to remain in their homes. Home care also includes prevention and rehabilitation. Group based maintenance training and day-centres, as well as respite care, are usually placed in connection with the special living facilities but available regardless of type of dwelling.

### 2.2 Eligibility for home care services

#### *Home nursing and personal care*

In the event of social problems such as unemployment, illness or dependency, all citizens are entitled to social security benefits and social services including home health care, financed and provided by taxation and public service. Allocation is based on individual assessments by officers at the municipality. Possibilities within the household for providing 'usual care' are taken into consideration. Allocation of home health care including nursing, personal care, physiotherapy and occupational therapy is free of charge and independent of personal income or assets.

#### *Personal, domestic and technical aid*

Personal and domestic aid is provided by the municipality or private firms contracted by the municipality. Allocation of personal and domestic aid is based on legislation (5) and an individual assessment by an officer at the municipality. Any citizen regardless of age and income but with decreased physical or mental functionality or social problems hindering daily living can apply for aid. The aid is aimed at supporting self-sufficiency and quality of life and based on individual conditions and needs (5). While the legislation prescribes the kind of aid offered by the municipality, the amount of aid is based on local standards. An example is a person not being able to take care of own personal hygiene – e.g. in some municipalities the standard is a full shower once a week and in others every fortnight). After the assessment a document including a description of the decreased functionality, the possibility of aid from others in the household, and the type and amount of aid granted is sent to the person applying for aid and to the institution providing the aid. There is no co-payment. Technical aids are provided by the municipality (based on legislation) (5).

### 2.3 Quality of process and output

#### *Availability of quality criteria*

Quality criteria are being developed nationally and implemented locally. The local purchasing officers are to use quality standards in contracting care providers. It is the local authority's responsibility to fulfil the legislative standards and to ensure that private providers meet national and local service standards.

#### *Assessment of quality of service*

Quality of housing and care for residents and inhabitants of special living facilities are supervised and inspected by three bodies: i) democratically elected committees with the task of being a forum for dialogue between clients and local authorities, ii) the local authorities, which are obliged to inspect facilities twice a year, iii) health inspectors from the regional health authorities pay an unannounced visit once a year, inspecting local guidelines and other documents as well as interviewing residents and health personnel.

A Danish Health Care Quality Programme is being pilot tested. The aim is to generate continuous quality development across the entire healthcare sector, including municipalities, by providing standards of good quality and measures for, and control of, quality. Assessment of quality of home care services is being developed. In 2006 it was decided to establish national guidelines for a more coherent documentation of home care services (including personal care, domestic care, rehabilitation and prevention). There are 23 indicators that will provide the basis for measurements of results and effects nationally and across municipalities. The outcome indicators are partly based on yearly surveys among receivers of home care (e.g. perception on quality and continuity of care) while the process indicators are based on activities, content and expenses. In 2010 it will also be mandatory for personnel to report unforeseen events in all areas of home care.

#### *Accreditation and clients complaint procedures*

The accreditation standards must be approved by the International Society for Quality in Healthcare (ISQua) (7). Private providers of home care and domestic aid are accredited by local authorities. There are formal procedures for patient's complaints on services e.g. the Appeal Board on Health and the Appeal Board on Services Act.

### 2.4 Quality of input

#### *Education*

The following professionals with their educational backgrounds are involved in the provision of home care:

- Social and health helpers: 1 year vocational training finalized by a nationally recognized diploma. They take care of domestic aid and personal care;
- Social and health assistants: 2 years vocational training supplementary to the helpers training and finalized by a nationally recognized diploma. They take care of domestic aid and personal care for patients with severe conditions and basic nursing tasks for patients in stable conditions;
- Nurses: 3½ year education now at University level (bachelor degree). Nursing tasks include prevention, treatment, planning and assessments for all patients and partaking in personal care for terminally ill patients;
- Physiotherapists and occupational therapists training programmes are both 3½ year education at University level (bachelor degree). They are involved in rehabilitation and maintenance training as well as assessments in relation to supportive and technical aids and supervision of their use.

Different courses and further education, differing in extent and level, are available for the professionals, and some are funded by the municipalities according to local policies and perceived needs.

#### *Job description*

Required expertise and discretionary power of nurses and physiotherapists and occupational therapists has been legally defined and the individual professional is authorized by the health authorities. Descriptions of specific job profiles for the three professions are developed by the local authorities and include practical and technical care as well as leadership, assessment, supervision, development and education of patients and informal carers, together with formal education of students within the professions and vocational training. Descriptions of job profiles for social and health helpers and assistants are developed by the local authorities.

### Recertification

There is no demand for recertification. Withdrawal of authorization is possible in the case of violation of the requirements set by the health authorities (e.g. after a complaint and eventual court case).

### 2.5 Incentives for providers

The main provider is the municipality. In 2003 a free choice arrangement was introduced in an attempt to create competition in services between private and public providers. It became mandatory for the municipality to invite tenders for the provision of personal care and domestic aid. In 2008 there were two or less private providers (private 'for profit' firms) for domestic aid in one third of the municipalities, indicating that incentives are confined. A national committee handles claims of unfair competition (8, 9)

## 3. Financing

### 3.1 General funding

Home care is mainly financed by the municipalities. Finances for the municipalities are negotiated between the state on the one hand and a common organization for the 98 municipalities on the other hand. The municipalities differ to some degree in tax income due to differences in local income level although there are regulatory bodies established by the state. Levels of services are therefore influenced partly by law (5) and partly by finances available to the municipality. These factors result in some differences in home care services between municipalities.

In 2008 long-term care is calculated to account for approximately 20% of the total health care expenditures (1). Of this, 9% of the long term expenditures were used for home care and the additional 11% for care in nursing homes and special living facilities for elders.

### 3.2 Financing of home care agencies

A fixed budget is politically set for the specific municipality. Private firms authorized by the municipality are also publicly funded (by the municipality). In order to calculate prices in relation to the tender, personal care budgets and payment per type of service provided were introduced.

### 3.3. Price setting of home care services

Municipalities calculate prices for each type of aid in relation to their budget and tenders. According to the legislation minimum prices must be calculated for the following: personal care (within and outside normal working hours), meals-on wheels and domestic aid (including serving of meals, laundry and cleaning). The price setting only relates to direct care provision, i.e. excludes assessments and other services related to organizing home care services. Prices are calculated by including direct expenses, administration and overheads. Calculation is based on a very detailed description of each specific function but still results in prices which vary widely between municipalities (9,10), due to differences in service level set by each municipality.

## 4. Organisation and delivery of home care

### 4.1 Access and needs assessment

Anyone can apply for needs assessment. Pre-assessments for home care services are made in the home by assessment officers from the municipality with the exception of nursing, which is mandatory if required by the GP or hospital. Nursing and personal care is available 24 hours, every day. Training and domestic care is available at weekdays and within normal working hours. It is possible for the GP to pay home visits at all hours. An assessing officer from the municipality decides the amount of help provided for different tasks. Following the assessment a fixed form is filled in describing needs, tasks and time allocated. The client receives a written description of the assessment and allocated aid.

### 4.2 Delivery of services

Home care is mainly delivered by the municipalities. A few hospital departments do deliver some home care by specialist nurses or teams of specialists (nurses and medical doctors) e.g. in gerontology- psychiatry, problematic wounds and palliation.

### 4.3 Coordination and integration of services

There is variable coordination between differing parts of the municipalities (delivering different kinds of home care and other services). There is also coordination between home nurses/social and health assistants and GPs and there can be coordination between home nurses, GPs

and specialists from the hospital delivering home care. Who does the coordination and how it is done differs but for all it applies that when a person is discharged from hospital when the GP receives a short statement including treatment and follow-up. If home care is needed the hospital will apply for this by notifying the municipality ahead of the discharge. Furthermore some municipalities employ case managers taking care of transition between hospital and home, while in other municipalities the assessment officers does the coordination. The patient, and eventually the relatives, may be involved and the meeting can take place in the hospital, at the municipality or in the private home.

#### 4.4 Actors and human resources in home care

##### *Actors in home nursing and personal care*

- The Ministry of Interior and Health develops legislation and regulation and supervises access, quality and efficiency;
- The National Board of Health overviews and inspects quality of health and authorizes health professionals;
- The municipalities set standards of home care, assess needs and provide home care (or contracting private firms for delivering of personal care or domestic aid), also providing special living facilities and other living facilities for elders and handicapped people;
- Private firms delivering home/domestic care;
- Patients and their informal carers.

##### *Actors in domestic aid and supportive aids*

These are identical with the actors indicated for nursing and personal care.

##### *Human resources in home care*

In 2008, more than 100,000 persons were working in the home care services, about 88,300 in fulltime equivalents (see Table 1 below). Working conditions and payments are set at the national level in collective labour agreements. A 37 hour week and 6 weeks of leave per year plus public holidays are common for the entire workforce in Denmark. Working outside normal working hours gives extra pay or is converted to extra days off.

In 2007 there were 3,365 general practitioners (GPs), an average of 1,625 capita per GP, and 2/3 were in

partnerships with other GPs (11). Density varies considerably between regions. The level of income is very high compared to the average of Denmark.

#### 4.5 Use of tele-care

Alarm systems are frequently used and there is a growing interest for tele-care applications but no available documentation for types or their use. If a public organization delivers the application there is no co-payment by the client.

#### 4.6 Monitoring of adequacy of care

Both national and local authorities (municipality) are responsible for monitoring adequacy of care. Municipalities are responsible for setting standards of care, drawing up agreements and monitoring standards of care, regardless of provider. At the individual level it is the responsibility of the provider and the assessor to reach on changes in the needs of the recipient of aid.

## 5. Clients and informal carers

### 5.1 Home care recipients

In 2007 about 4% of the population above the age of 20 years and 19% above the age of 65 were receiving long term health care, for the main part (87%) domestic care, half of them receiving less than 4 hours a week. Of the total number of persons above the age of 65 receiving long term care, 85% were living in ordinary homes or living facilities for elders and disabled people while 15% were living in nursing homes or special living facilities. At the age of 80 or above a higher proportion of receivers of home care were living in nursing homes or special living facilities.

### 5.2 Coverage and unmet needs for care

A survey from 2008 showed an overall satisfaction with services in relation to personal care and domestic aid. In a representative random sample of receivers of homecare above the age of 67 years, 82% were satisfied/very satisfied with domestic aid and 95% were satisfied/very satisfied with personal care. Satisfaction differed marginally between home care and care in special living facilities, and there were no overall difference

**Table 1:**

Staff	Employed in 2008*
Nurses in leading positions	2,225
Nurses	5,965
Physic- and occupational therapists	3,455
Residential social worker	2,726
Social and health assistants	27,705
Social and health helpers	46,218
<b>In all</b>	<b>88,294</b>

Based on data from Statistikbanken (1). \*Calculated as full-time equivalents.

**Table 2:**

Recipient groups	All Recipients of home care	Proportion living in ordinary homes or living facilities for elder and disabled (2007)	Proportion living in nursing homes or special living facilities (2008)
18–64	26,730	24,124 (90.2%)	2,606 (9.8%)
65–79	63,950	54,152 (84.7%)	9,800 (15.3%)
80+	115,947	87,393 (75.4%)	28,554 (24.6%)
<b>Total</b>	<b>206,628</b>	<b>165,700 (80.2%)</b>	<b>40,960 (19.8%)</b>

Calculations based on data from Statistikbanken (1).

between suppliers (private firms vs. municipality). There were some differences, though, in satisfaction across municipalities (12).

### 5.3 Empowerment of clients

The client has a say in relation to how the allocated time for personal care and domestic aid is actually spent. Recipients are also allowed to choose between different providers. Persons below the age of retirement and with permanent and significantly reduced ability to function, and whose needs for assistance cannot be met by home care services, are entitled to hire private help funded by the municipality, provided that the help qualifies.

### 5.4 Informal carers

Availability for informal carers should be seen in the light of a labour market participation of 73% among women in the age group 15–64 (13). When informal carers are not able to provide usual care, respite care may be provided by the municipality. For example, when a wife is caring for her husband who has dementia, the husband may be offered day centre (e.g. once or twice a week) or a person (sitting) in the home for a few hours.

For persons receiving palliative care it is possible for a relative to be granted leave of absence and publicly funded substitution of loss of income (equivalent to unemployment benefit) for a limited period of time.

## 6. Current challenges and developments in home care

Current concerns in relation to Danish home care are:

- An increasing proportion of the population living with a chronic condition implies growth in health care services demand. A focus on cost-effectiveness highlights the need for developing shared care between the specialist and the general level (secondary vs. primary sector) and for most of the services to be placed in the primary sector.
- Long-term treatments and shared care arrangements imply a need for coordination with the aim of securing a coherent course of treatment and care for patients.
- The organisation of finance and services in different sectors does, to some extent, provide barriers for sharing of services across sectors. For instance, specialized treatments and rehabilitation are defined as the responsibility of the hospital. This results

in a financial barrier for specialists working in the secondary sector to provide services in the home of the patient (e.g. specialized home rehabilitation) or for the home care service to provide specialist care (e.g. peritoneal dialysis) in the home of the patient.

- The aim of managing most of chronic care in the primary sector also means a trend towards using the home of the patient as an arena for providing health care (prevention, treatment and follow-up) as well as a higher degree of self-care on the part of the patient and the family.
- Problems in recruitment of personnel in home care services results in the use of unskilled labour.
- A growing demand for regulation and documentation results in a greater proportion for staff time fulfilling these administrative tasks.
- International recession and a general demand for cuts in public finances are resulting in economic restraints on the municipalities and their level of services.

The following developments relevant to home care can be mentioned:

- There is a demand for both horizontal and vertical substitution, e.g. tasks being transferred from specialist (secondary sector) to generalists (primary sector), and from medical doctors to nurses and from nurses to assistants.
- Coordinated pathways between hospital services and primary care and social services are being developed e.g. out-reach hospital based team in relation to stroke, COPD and heart failure (14).
- In principle financial barriers between the health sectors should be solved locally by direct agreement between a municipality or groups of municipalities and a region. However, as the barrier is the same for all hospitals and municipalities a national solution would be better.

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# England

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## 1. The context of home care

### Country, population and health

The United Kingdom of Great Britain and Northern Ireland comprises four jurisdictions, of which England is by far the largest with a population of approximately 53 million people. The other countries (Scotland, 5.5 million people, Wales, 4 million and Northern Ireland, 1.5 million) have somewhat similar policies, structures and services on home care to those in England, though all also have some significant differences. This report will focus upon England. With its large population, England has one of the highest population densities in Europe and there is an increasingly large population of people aged over 65 (from 17% of the population in 2010 to 22% by 2030), partly as a result of significant changes in life expectancy over recent years (Office for National Statistics, 2010).

### Characteristics of health services and social services

Tax-based expenditure on health care services, which are free at the point of access, rose rapidly to £93 billion in 2007/8 and there were significant increases in services provided in both primary and secondary care, at a time when hospital length of stay and bed provision have both fallen. Conversely, nursing home beds and residential home places have risen – this sector is dominated by the for-profit independent sector, with attendant issues of competition, cost and value-for-money (Mickelborough, 2010). Social Services departments are the responsibility of Local Authorities (Councils) – there are about 150 in England. Local health services are commissioned by

Primary Care Trusts (PCTs), which are also responsible for managing General Practice services and Community Nursing services. Each Trust covers a population of around 500,000 people.

### Social indicators and conditions related to old age

As expenditures on care for older people rise and care for all ages of adults requiring home care improves (whatever their complex needs may be), it is becoming clear that state resources, benefits and pensions will come under pressure. The ability of recipients to pay the services themselves is relatively low. In 2008, 30% of Britons over the age of 65 were at risk of poverty compared to just 21% in the EU27 (Eurostat, 23-04-2010). These trends, with the attendant implications for informal and formal costs of care, are causing important policy questions to be raised about the nature of provision of the whole range of home care services (Shaping the Future of Care Together, 2009). In late 2010 a Government Commission on the Funding of Care and Support will examine a range of options for managing the growing financial burden of caring for older people in residential and home care, options which have already been explored in detail in a recent policy review (Featherstone 2010).

### Attitudes related to old age

There is no formal liability for children to maintain their parents, in any of the four UK legislations. Only 30% of the UK Eurobarometer respondents thought that care is a responsibility for close relatives, while this rate is 37% of all EU survey respondents. However, home care is a more popular option than a nursing home for an elderly parent who lives alone and can no longer manage to live without regular help (34% compared to 10%) (TNS Opinion & Social, 2007).

## 2. Policy and regulation on home care

### 2.1 Governance on home care

The Department of Health is responsible for regulation and implementation of policy on home care (Care Standards Act 2000), while the recently established Care Quality Commission is responsible for assessment of quality of services in both health and social care. Service provision and development is split between Local Authority Departments of Social Services with Adult Responsibility (CSSRs) and local health services commissioned, and sometimes provided by, PCTs. CSSRs have lead responsibility for initial assessment and commissioning of care packages, although this is increasingly being undertaken in partnership with NHS organisations. PCTs provide medical and nursing care, other clinical inputs and some technical aids.

There has been extensive policy discussion on, and regulation of, home care in England since the Care Standards Act in 2000 (HM Government, 2000). Since that time, increased recognition of the impact of an aging population, together with a diminishing social care workforce (Mickelborough, 2010), and rising costs of care, has led to home care becoming a priority. Recent Government policy documents have initiated a major discussion on the availability and cost of home and residential care for older people (Shaping the Future of Care Together, 2009). Developments include an increased rate of provision of new facilities for continued residence in the community (rather than residential care), particularly extra-care housing, and systems for re-enabling people who have acute events so that they can continue to live in the community. Still, maintenance standards of home care provision remain a concern (CSCI 2009) and for many clients much provision requires out-of-pocket or co-payments.

In the context of a general desire to be able to remain at home as long as possible (or at least out of residential home care) and for people to have an effective say in the function and form of home care, there are two policy thrusts – active involvement of the person who may require care in choosing options for care (also more broadly referred to as personalisation) (CSCI 2008) – and a move from outputs (or activity) based commissioning of care packages to outcomes based commissioning, where clear goals are set jointly by the client and professional staff, and measurable outcomes are then developed for each goal. In some areas these new ways

of commissioning and delivery are already in place, but many are still at early stages of development. There is already expansion in step-up home care provision in the shape of the above mentioned ‘extra-care’ housing which build on choice and outcomes based commissioning and which reduce the demand for full residential care.

In mid-July 2010 the UK Government announced major changes for the NHS in England which are predicted to take effect on or before April 2013. In essence, the stated purpose is to reduce bureaucracy by removing the management layers of Strategic Health Authorities and Primary Care Trusts. It is intended that future health care commissioning will primarily be in the hands of General Practice Commissioning Consortia, responsible for about 80% of the commissioning budget [about €88 billion per annum].

Because there is limited detail in the proposals, it is not clear what will happen to the current linkages between Primary Care Trusts [as part of the NHS] and social care functions, primarily the responsibility of Local Authorities: where these will be transferred to and what will happen to equality of access provision, within and between GP Commissioning Consortia areas. Nor is it clear how the statutory functions of PCTs will be changed, in relation to care of older people and the provision of continuing health care funding for people who are severely disabled. These functions are enshrined in regulation and Act of Parliament and the successors of the PCTs will not have the same status in law.

It is therefore not currently possible to predict what the final service configuration will be nor how the new interfaces will operate, other than to expect that the years 2010 to 2013 will see significant turmoil in the NHS which must affect the provision of home care services, perhaps particularly for those people most in need.

### 2.2 Eligibility

National minimum standard regulations govern eligibility for home care services in England (Department of Health 2003) and national assessment criteria have been in place since 2004 (Department of Health 2004). An example of such a standard is ‘A domiciliary care needs assessment regarding new service clients is undertaken, prior to the provision of a domiciliary care service (or within 2 working days in exceptional circumstances)’. Prospective service clients are assessed on a four point scale (low, medium, substantial or critical). Complex

cases are assessed on nine domains – client’s perspective, clinical background, disease prevention, personal and physical well-being, senses, mental health, relationships, safety, immediate environment and resources.

Data for the period 1993 to 2008 show a trend in which high intensity home care visits have increased while low intensity visits have decreased (The Health and Social Care Information Centre 2009a). Because of a lack of available resources, many Councils now only offer free home care services to people with substantial or critical needs, and, except for clinical services, publicly financed provision is means-tested against savings. But since there is no national standard formula for assessing costs of contributions towards home care there remains a variation between Councils on the interpretation of what constitutes moderate and substantial need and on whether the Council will pay for needs classed as less than substantial. In 2009 there were a small number of Councils who provided services free without means testing of the client’s assets. Furthermore, charges for all are capped and for those people with complex needs who use home care rather than residential care, the charges do not cover the full costs. Re-ablement services are an exception to client charges, for up to six weeks, as part of a drive to ensure that people are able to live in their own homes for as long as possible.

#### *Home nursing*

Services such as wound dressing and ulcer care are provided free at the point of care by the NHS, as are some physiotherapy and occupational therapy services. Some nursing services such as catheter care and long-term physiotherapy, which as part of a home care package might be provided by for-profit home nursing agencies, may attract a means-tested fee for service. Medical services are free and medications are free to all people who are not employed and to people who are aged 60 and over.

#### *Domestic help and technical aids*

Domestic help is provided as part of an assessed care package or to people who are in receipt of a short-term re-enablement package. Local Authorities no longer provide domestic help directly, but may provide grants to the voluntary sector, such as Age UK, to provide services to the client at below cost. The availability of some types of domestic help, such as the provision of meals, has receded significantly over the past decade (Mickelborough, 2010) as a result of the need to reduce

expenditure and a focus on more intensive interventions for people with greatest need. For example, on a census day in 2007, only 93,000 people aged 18+ in England were receiving a CSSR funded meal. Provider agencies are often from the charitable and volunteer sector (Mickelborough, 2010) and clients often fund, or part-fund, meals services themselves. Adaptations to homes to support home care are means-tested. Other aids are provided on long-term loan by the NHS and Social Services. Complex aids for living are provided free on long-term loan.

### 2.3 Quality of process and output

#### *Assessment of quality of services, accreditation and clients complaint procedures*

NHS provision of home nursing and personal social care is assessed and regulated by the Care Quality Commission (CQC), which took over the responsibilities of the Healthcare Commission and the Commission for Social Inspection (CQC 2-6-10)), through regular assessments of the commissioning of services by PCTs and Local Authorities and of the provider organisations of all health and social care. Agencies providing domestic aid and personal care and nursing care are required to register with the CQC and are assessed at least every 3 years, together with obligatory yearly self-assessment. This is performed using a standard format and recording system. Inspection is undertaken of those organisations reporting difficulties and a proportion of all others. The information is reported in the public domain through the registration information on the CQC website, from October 2010, when all providers that carry out regulated activities must be CQC registered.

There are currently around 750 agencies providing nursing services in England. In their report on the year 2007–08, the CSCI reported that social care for adults had seen a year-on-year improvement over the preceding six years (CSCI 2009).

The CQC now has extensive powers of sanction related to the provision of safe care (e.g. imposing requirements for improvement, financial penalties or, in the worst case, deregistration and effective closure). Serious clinical complaints are also investigated by the Commission.

During the period mid 2010 to mid 2011 the CQC is radically altering its quality assessment process. As a result of a change in (new) Government policy, the

CQC is no longer carrying out assessment visits, nor is it awarding quality ratings. It anticipates the design of a new information system which ‘will provide information about the quality of registered services for people who use and commission them, to help them make choices and decisions’, and expects that the system will be ready by May 2011.

#### *Availability of quality criteria*

Until October 2010 there were 18 national minimum standards relating to Nursing Agencies, established under the Care Standards Act 2000 and now regulated by the CQC. The standards were grouped under 5 headings – information, (fitness of) registered persons, recruitment and supply of nurses, complaints and protection, and management and administration. NHS hospitals, that may also supply nurses, were exempt from the legislation, although hospitals also come within the regulatory framework of the CQC.

The service quality of domestic help and personal care agencies is assessed using the national standards of care, produced by the Commission for Social Care Inspection (now part of the CQC) (CSCI, 2009). There are 27 standards in total, under the headings of client focussed standards, personal care, protection, managers and staff and organisation, and running of the business.

At the time of writing, in late 2010, there is no clarity on the approach or methods that the CQC will use to assure service clients and commissioners of the quality and effectiveness of care provided, other than it will have ‘essential standards’. Since it appears that there will be no site visits during this period of development, the chances of missing episodes of poor or dangerous care are heightened. For a recent update on (measuring) the quality of care, please see section 7.

## 2.4 Quality of input

### *Education*

There is a span of educational levels in the frontline personal care workforce, from no qualifications post-basic education, to Level 8 (Master level). Many professional staff, such as social workers, physiotherapists, occupational therapists, and some nurses, now hold graduate or Master-level degrees in their subject area. Professional staff providing home care may also hold awards that are registered with professional bodies and are a task requirement, but are not always formally

recognised as degree level, for example the Advanced Diploma in Nursing Studies, the most general nursing qualification in the UK.

Education of the home care workforce is guided by the Department of Health ‘Strategy for the Adult Social Care Workforce for England’ (2009), both in the state sector and the independent sector, although the educational requirements are not mandatory for some levels of staff.

Other levels of training held by home care professionals are:

- Domestic staff: level zero (no qualifications required); although a 12 week induction period which covers the basic principles of care (Common induction standards) is available and encouraged by the Skills for Care organisation (2008) which develops educational standards for home care in England. Help with hygiene.
- Day care workers, home care workers, personal assistants, other staff in caring roles, support workers and volunteers are encouraged to achieve National Vocational Qualification (NVQ) Health and Social Care level 2 & 3. However, in 2009 only about 30% of this workforce is estimated to have these qualifications (Skills for care, 2008). Employers are encouraged by the National Skills Council to support staff in obtaining these.
- NVQ Health and Social Care level 4 and Registered Managers Award level 4 is aimed at managers of care services. A range of academic awards and professional qualifications are accepted in lieu of some parts of the study programme.

Recertification periods and requirements vary across the professions: Nursing – three years, General Social Care Council – three years, Health Professions Council – two years.

### *Job descriptions*

Broad job descriptions, protection of title and registration requirements for the professions are provided by the regulatory bodies: General Social Care Council (social work and other social care workers from 2010), Nursing and Midwifery Council (community and home nursing) and the Health Professions Council.

Professional services provided by CSSRs are currently regulated by the General Social Care Council (GSCC 2-6-10). Social workers were the first to be regulated and the title refers only to those registered with the Council. During 2010, other groups of social care workers will be invited to register, commencing with all workers in domiciliary care agencies who provide care in people's homes.

All staff who work with vulnerable people in England, Wales and Northern Ireland must now be vetted by the Independent Safeguarding Agency (under the terms of the Safeguarding Vulnerable Groups Act 2006), which has the power to bar people who are deemed unsuitable from working in the care sector.

Individuals who provide social care on a personal basis and who are not employed by an agency or other body are not currently covered by regulations. This includes people who are employed through the use of personal budgets.

### 2.5 Incentives for providers

The primary incentive is the market place, since the majority of providers operate in the private sector, with Local Authority (Council) direct provision falling year on year and only a limited proportion of care being provided by the voluntary sector. Although the overall numbers of providers appears to be slowly falling over time, this may be because of mergers or acquisitions (Mickelborough, 2010).

Increasing regulatory demands related to quality and safety may provide additional incentives for larger providers over the smaller provider, who may struggle to meet required standards. However, the commissioning of specialist services or services for rural communities may also provide a form of incentive for the smaller provider.

Although the number of people receiving direct payments is still small in England, 73,000 in 2008–09, including carers (CSCI 2009), this number is increasing by 25% per annum, and there are currently pilot projects to evaluate the use of individual budgets (that is, where a person holds responsibility for the whole of their social care budget). While these new mechanisms may cause a loss to a current provider – particularly Councils' direct care teams – clients are able to choose new providers who may enter the market specifically to service people holding this type of budget.

## 3. Financing

### 3.1 General Funding

Gross annual public expenditure for home care services in England (provided through CSSRs) for 2007/08 was £2.7 billion (around €3.2 billion), reduced by client co-payments to about £2.3 billion. It is estimated that the minimum overall home care expenditure is £3.6 billion for 2008, including private payments (therefore about 4% of total health spending in England) (Mickelborough, 2009). Home care is funded principally through central general taxation which is distributed mainly through Local Authorities and the National Health Service, although Local Authorities also raise revenue through local taxation. A proportion of home care is privately funded by clients, either in the form of means tested co-payments to Social Services Departments who pay for care, or by private purchase. Local Authorities pay for the largest component of home care, including domestic help for those in greatest need, and some day and respite care. Aids are usually provided free or on loan, either by the NHS or the Local Authority. Some community nursing services and all General Practitioner services are paid for by the NHS. Personal care services, which might include a nursing element, are provided by Social Services and may be means tested. Some services, such as re-ablement after illness or accident, are paid for jointly by the NHS and Local Authority.

### 3.2 Financing of home care agencies

Home care agencies are either Local Authority in-house (about 17% of the total), NHS (about 2–3% of the total, through the PCT Community Nursing Services) or independent sector, which is mainly for-profit. Those in the private/independent sector are usually funded through Local Authorities (sometimes jointly with the NHS) through a commissioning process which is based on a care package developed through a client needs assessment. A care package might include personal care, provision of meals, rehabilitation and nursing care (for example, managing skin problems). Commissioning processes vary across Authorities. Clients with significant assets must usually co-pay for services from the agencies.

Direct payments are provided to individual clients and they hold the accounting responsibility. Reporting processes on the spending of these payments vary across Local Authorities.

### 3.3 Price setting of home care services

Different private providers may get different reimbursements for the same provision. Local Authorities and Health Services set prices through a commissioning process and prices are dependent on local circumstances and the type and extent of care provided. In practice these prices are similar across England, with the exception of London and the South-East of England (Mickelborough, 2010).

## 4. Organisation and delivery of home care

### 4.1 Access and needs assessment

No referrals are needed for assessment for state funded home care services in England. In 2007/8 over 2 million initial assessment contacts were made with Local Authorities, of which about 30% were made by potential clients or their relatives (The Health and Social Care Information Centre 2009b). Under statute (the Health Care Act 2000) it is Local Authorities who take the lead in assessment and who assess funding requirements using a Single Assessment Process. This is increasingly done in partnership with the National Health Services, especially for people who may have needs on discharge from hospital.

Assessment of personal and support needs is undertaken using a national framework that comprises nine components, each with a number of criteria. Clients are classified as having needs in one of four categories: low, moderate, substantial or critical. People with low or moderate needs are usually advised at an initial interview by Local Authority staff and in most areas of the country will not be eligible for state aid – though advice may be given on how self funded assistance may be accessed and, as indicated in 3.1, there may still be a contribution from the Local Authority. People with more complex needs may have a more detailed health and social care assessment, which would include an assessment of the need for different accommodation, including residential care. Funding is then available through an agreed ‘care package’.

### 4.2 Delivery of services

in 2008 home care services were provided by 4,780 domiciliary care agencies and 750 nursing agencies (some agencies provide both types of care). Domiciliary

care agencies are managed by Local Authorities (15%), the independent sector (74%) and the voluntary sector (8%). Of the nursing agencies, 96% are managed by the independent for-profit sector (Mickelborough, 2010). The home care agencies are local as well as national organisations, and may provide personal social care or nursing and professional care, or both. The NHS provides a limited number of specialist domiciliary services and provides community nursing and medical care, together with some short term intermediate care. Local Authority provider agencies are increasingly becoming specialist providers for complex cases.

### 4.3 Coordination and integration of services

Local Authorities in England (CSSRs) hold the responsibility of coordination and integration of services through the development of care packages. In 2006, about 1.5 million domiciliary care packages were provided (some of which were part paid for by clients). Such a large case load provides a significant coordination challenge to LA staff.

Care managers take the role of coordination at the client level while the commissioning process is used to achieve integration at the agency level. Because of the pressure placed on services through an increasingly ageing population, and policy orientations to keep people in their own homes, there has been a move to a more active social care intervention for people who have acute health care needs, with improving communication and coordination between hospital services and social services. This has resulted, for example, in the creation of joint LA/NHS posts in many hospitals with the brief to assess needs urgently for people who are about to be discharged, the creation of new, short term re-ablement packages of domiciliary social care and health care and the development of short-term residential step-down care facilities, managed either by the local NHS or by Social Services departments. Community health services, provided both by General Medical Services (including General Practitioners and nursing teams working together) and Primary Care Trust community nursing services, contribute to the rehabilitation and long-term health needs of clients through usual health care routes and through personalised care packages.

#### 4.4 Actors and human resources in home care

##### *Actors in home care*

The following organisations are involved in home nursing and personal care:

- Department of Health for England (DH); develops policy under parliamentary statute and issues regulations and guidance to the organisations charged with providing home care, particularly to Local Authorities (Councils) and to the NHS through Strategic Health Authorities and Primary Care Trusts.
- Strategic Health Authorities (SHAs). Ten SHAs are responsible for regional guidance and coordination of the NHS through management of PCTs, which hold NHS budgets and commission care from NHS providers. Thus SHAs have an 'arms length' management and monitoring influence on primary and community care services which play a part in home care.
- Care Quality Commission (CQC); has regulatory overview of all home care provider agencies, whatever their ownership or allegiance.
- Local Authorities (Councils); those with social services responsibilities (CSSRs) play a key role in home care in England by assessing client needs and commissioning or managing effective services. They are responsible to the government for the effective provision of services and are monitored by the national Audit Commission. LAs are also responsible for adaptations to housing to help to maintain people in their homes.
- Primary Care Trusts (PCTs); commission local health services and, sometimes, through a local provider arm which also provides health services. Together with the CSSRs they are responsible for the safe and effective provision of home care and expected to use resources in support of the Council's work in this field. PCTs are also responsible for managing primary care/general medical services to enable client needs to be met. Note that Primary Care Trusts will be abolished by April 2013 (HM Government (*Equity and excellence: liberating the NHS*. 2010).
- Home Nursing and Domiciliary Care provider agencies, mainly in the independent sector. NHS Community Care Services, (sometimes in collaboration with LAs) are the main providers of technical aids.
- Local housing providers. There has been a growth in the investment in 'Extra-care' housing, to which clients may re-locate and rent or purchase and which provides on-site access to personal and nursing care in the home while retaining a domestic environment (dhcarenetworks 2-6-10).
- Skills for Care. This company is a social enterprise which develops educational and practical skills frameworks to assist the training of the overall non-professional social care workforce.
- Voluntary and Charitable (Third Sector) organisations, which may contribute to national policy debates, act on a clients behalf and also provide services (which are sometimes subsidised through public funds). The largest of the organisations is Ageuk (2-6-10).

##### *Human resources in home care*

According to the OECD health database in 2008 there were 8,088 formal personal carers employed by Local Authority Social Services Departments working in home care. In England in 2006/7 Councils reported that there were approximately 270,000 directly employed workers in domiciliary care (212,000 of whom were care workers). Of these 29,000 worked in day care. Additionally, many of the 90,000 professional staff involved in social care overall were working in home care, including nurses, social workers and occupational therapists. Additionally, there a very significant number of workers who are not directly employed (those who are on short-term contracts or who are self-employed), such as 'pool' staff, other agency staff and volunteers and staff from Community Health Services and General Medical Services. Furthermore, these figures do not include the many people who are employed privately to provide domestic help services, such as cleaning or shopping, by clients who do not meet the means tested criteria for state help. Nor do the figures include the estimated 100,000 people who are being employed through Direct Payments to Local Authority clients. Overall employment figures are therefore also almost certainly an underestimate.

**Table 1:** Home care human resources

Staff (excluding those working in Community Health Services and General Medical Services)	Directly employed in 2006/7
Domestic help staff	No data available
Care workers	212,000
Community health nurses	34,000

Source: *The Health and Social care Information Centre 2009a, Mickelborough, 2010.*

#### 4.5 Use of tele-care

The use of tele-care is increasing quickly in social care in England, driven by the perceived value of tele-care systems in reducing hospital admissions and the role of tele-care in assisting people to remain longer in their own homes. Personal alarm systems are commonplace (1.3 million in the UK by 2003). Usually a means-tested charge is required (around €15/month). Some LAs have gone much further with assistive technology and are providing extensive tele-care systems, with bed monitors, water and gas monitors, ‘wandering’ alarms, door monitors and GPS systems for monitoring movements outside of the home. One city authority has demonstrated a fall in numbers of people entering residential care associated with the establishment of a comprehensive tele-care system.

#### 4.6 Monitoring the adequacy of care

Monitoring is performed by a social service case manager or by the community nurse, the GP or specialised palliative care nurse, depending on the home care needs. The frequency of monitoring is dependent on the complexity of the client needs, but is usually the basis of a short report every six months or after a change in needs.

### 5 Clients and informal carers

#### 5.1 Home care recipients

A total of 1,521,000 services were provided to people over 18 years by Local Authorities during 2006/7. All clients had been assessed, though not all through the national standard framework. About 35% of clients were aged 18–64. Table 2 indicates the total number of services (1,512,000) provided by CSSRs in a year in England, together with totals of each type of service. Many clients receive more than one service and thus the total number of services is greater than the number of clients.

It is estimated that an additional 145,000 people are privately accessing services, either prior to assessment or because they do not meet their Local Authority funding criteria (Mickelborough, 2010). Some among this group of people may, as a matter of personal choice, decide to spend their own resources on home care and to purchase it privately. Others may be just outside of the state-funded threshold and may find the purchase of home care services burdensome.

Councils and the NHS are now providing short term ‘re-ablement’ packages of up to six weeks for people who have short term needs, often on discharge from hospital. In 2007/8, 225,000 people received these services free, an increase of over 30,000 from the year before.

#### 5.2 Coverage and unmet needs for care

Usually, only people with substantial or critical needs are now able to access state support for home care, with some exceptions (e.g. tele-care), hence a large group of people depend to a large extent on their own means. Furthermore, geographical divergence in met needs also exists. Social care coverage depends on funding available to Councils and the annual report on the state of social care in England for 2007–08 (CSCI 2009) highlighted the current variation between Councils, particularly in the ways in which personal choice was being enhanced, a problem especially for people with complex needs.

Furthermore, the report noted that individuals did not always seem to be getting individualised help to make decisions on their care, whether they were accessing public funds or were self-paying. The Commission expressed concern that some people who were assessed as self paying were ‘lost to the system’ (sometimes by choice) and no-one follows up to ensure that they have appropriate interventions. Tensions also remain at the policy and practice level between targeting support for people with the highest level of needs and the provision of

**Table 2:** Recipients of primary home care service provision England 2006/7

Total client services	Home care and Home respite	Day care	Meals	Direct payments	Equipment and adaptations
1,512,000	586,000	237,000	150,000	48,000	491,000

Source: The Health and Social care Information Centre 2009a, Mickelborough, 2010.

a universal, open access service. Interviews with experts identified the challenge of providing appropriate packages of care when budgets were constrained.

A national User Experience survey in 2006 targeted those who received Social Services funded community equipment or adaptations. Over 90% of people replied that they were satisfied or very satisfied with their recent service (The Health and Social Care Information Centre, 2006). A national home care clients survey carried out in 2008 found that 58% of respondents were extremely or very satisfied with the service they received (The Health and Social Care Information Centre 2009c).

### 5.3 Empowerment of clients

As mentioned, there are some perceived problems with the empowerment of clients. Even so, the position of clients is beginning to change in England. New policies on 'personalising' and increasing choice in determining the need and type of care are designed to empower clients (Department of Health 2008) and to assist in the provision of services according to the client's wishes. However, there is evidence that progress has been variable across the country (CSCI 2009). With the personal choice agenda, the introduction of direct payments and, not least, the estimated 145,000 older people who fund their own personal care, the voice of clients is slowly becoming stronger and may be a key change in the future development of home care services.

Information is available to support choice from a number of sources. The Government Public Services website (Directgov 2-06-2010) provides information on home care assessments and direct payments (including on responsibilities of the client as an employer). Additionally, the Government Office for Disability Issues (2-06-2010) provides data and information for all adults who (may) have disabilities. Most Councils have information desks that are open access and during assessments information and advice designed to help client choice is provided.

Many charities provide information for adults who have a particular health problem. For older people, the major charities are important sources of information, advice (for example on direct payments and personal budgets) and advocacy, together with direct assistance such as day care, lunch clubs, home help and 'handyperson' schemes (for example, Age UK). The Care Quality Commission provides assessments and ratings of all registered providers in England and the Citizens Advice Bureau offices are accessible in the 'High Street' and via the internet (Citizens Advice 2-06-2010), providing advocacy and guidance. In general, clients do not usually have a choice of preference of residential care over home care, although they may choose home care over residential care, even if their needs are high. For a more recent update on the clients' choice, please see section 7.

### 5.4 Informal carers

There is no legal expectation on family or friends to provide informal care in the UK. Where informal carers are involved, there are a range of support services available and the CSCI (2009) reports that over 4 million carer's breaks were funded during 2007–08. Carers are now able to access direct payments to buy support (about 7,000 did so in 2007), help around the home or other support such as a course or leisure activity. In 2008, around 900,000 people in Great Britain were receiving or were eligible for Carers Allowance (approximately € 60 per week), although there has been criticism that this allowance is too restricted (CarersUK 2-06-2010).

## 6 Disparities in the process of home care in England

Differences in the provision home care across England relate to the availability of funding, variation in the interpretation and application of eligibility criteria and the extent of provision of new types of service. As the main providers of public funding for home care, CSSRs have many calls on their resources and make choices on where funds should be prioritised. As a

result, demographics, community needs and other local conditions, Councils do therefore vary in the support they provide for state-funded home care.

These differences in funding, allied to variation in policy, also influence the levels at which Councils will support assessed need. The criteria for home care assessment are less stringent than those for residential care and until recently some Councils have been providing home care services free to people with low or moderate levels of need, while others are exclusively provided to people assessed to have critical or substantial needs.

The process and extent of social care provision also varies across Councils. Some Councils lead on the personalisation and choice agenda, exploring outcomes based commissioning and progressing on direct payments to clients, while others are making progress at a rather slower rate. Many Councils, some with NHS partners, are building more extensive extra-care housing facilities to support people with more complex needs – again, however, there is variation between Councils, while out-of-hours services provision seems to differ considerably.

## 7 Current concerns and new developments in home care in England

The main concerns with regard to home care are:

- Funding does not match needs. Since many Councils only provide services to people judged as having substantial or critical need, many people may have to make their own funding arrangements. The CSCI (2009) indicated that such people may be lost to follow-up and be disadvantaged as a result.
- Strain on the domiciliary services due to a policy focus on prevention of institutionalisation, while at the same time facing increasing constraints on financial resources.
- People accepting personal budgets without an understanding of the attendant legal responsibilities as an employer (which are considerable), due to pressure on them to take the budgets.
- Many services are still being formulated and chosen by the assessors:- this runs counter to the policies on personalisation and choice (Department of Health 2008).

The most important new developments relating to home care are:

- Outcomes based commissioning of services offers a new approach to changing services from a process based commodity, although there are concerns that the required transformation in services is a steep challenge (Paley 2007).
- Tele-care is being promoted widely, with a wide range of functions on offer, although there remains a need to ‘use the simplest technology that fulfils the purpose of the intervention’ (Roulstone 2007).
- Coordination between social and health services appears to have improved following the recent change towards co-terminosity of health care and social care boundaries and Government policy directives to promote better integration. This has, for example, resulted in coordinated approaches to support people in the move back into the community following hospital admission.

In mid 2010 there was a change of Government in the UK and the new Government’s health and social care policies for England, as outlined earlier, will have a profound effect on the means by which social care – as it relates to home care – is regulated and delivered (HM Government. *Equity and excellence: liberating the NHS*. 2010). Responsibilities currently taken by PCTs and by SHAs will either disappear or will be shifted elsewhere, possibly to Local Authorities, or even to the proposed GP commissioning groups. Interfaces between the NHS and social care will change radically. Until the current systems are put in place, and have bedded down, there is real and serious risk that home care services will become less effective, to the detriment of users.

### *Recent developments 2011*

In late 2011 a report by the UK Equality and Human Rights Commission on the quality of home care has caused serious public and political concern and prompted urgent regulatory action (UK Equality and Human Rights Commission, 2011). This section on recent developments has been added here as a result of the report’s findings that, with over 1200 respondents from among users, carers, providers and local authority commissioners, presents a stark picture of unequal provision and poor external regulation.

Almost 500,000 people receive essential home care in the UK, supported financially in whole or part by their local authority. Many others pay for services themselves. Around 85% of publically funded home care is now provided by private or voluntary sector agencies, together with significant numbers of private individual providers. About half of the user respondents and families expressed satisfaction with home care in the Commission report, and there were examples of quality service and good practice in commissioning, even in local authorities where there were severe financial constraints. But about 75% of authorities now limit access to public funds to people with either critical or substantial needs and services are increasingly being offered on the basis of lowest cost rather than quality, with staff being paid at minimum wage or less (see also section 2.2 above).

Quality concerns which flow from these constraints include examples of people not being given adequate support to eat or drink, neglect due to tasks in the care package not being carried out (lack of time is cited as one of the causes) and risks to personal security with frequent changes of care workers (section 2.3). Despite the 'personalisation' of home care, with a Government emphasis on choice and support for personal budgets, in many instances users have little or no choice and very little support in decision making (section 5.3).

In a properly regulated environment these systemic, structural and quality issues should already have been identified and addressed by the Care Quality Commission (CQC) and the Department of Health for England. But, with the support of the Government, the CQC stopped a system of inspections previously in place and has instead relied on using metrics or serious complaints to identify providers at the greatest risk of non-compliance with essential standards.

As a result of the publication of the Commission's report, the CQC has now been required by Government to undertake a series of 250 inspections in a year and to raise the priority given to the regulation of home care services. However, there is also clearly much more to be done at both national policy level and at local authority level to bring home care up to a universally acceptable standard.

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# Estonia

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## 1. The context of home care

### Country, population and health

Estonia is the smallest of the Baltic countries, covering an area of 45,227 km<sup>2</sup>. Since 1990 the number of births has been diminishing, the number of deaths has been growing and the population decreasing. In January 2009, the population of Estonia was 1,340,415 and the average density was 29.6 inhabitants per km<sup>2</sup>. About two thirds of the population are Estonians and one third is made up of Russians and other ethnic groups. The urban population accounts for 69.4% of the total population. The proportion of people aged 65+ has increased from 11.6% in 1990 to 17.1% in 2009 (Statistical Office of Estonia 2009). Between 2010 and 2030 those 65 years and older are expected to increase from 16.7% to 20.6% and those 80 and older from 3.9% to 5.1% of the population (eurostat 2008). The female and male life expectancies at age 65 were 18.3 and 13.2, respectively, in 2006. The healthy life expectancy at age 65 was 4.0 years for males and 3.9 for females (2006), which is lower than the EU average (eurostat 2008).

### Characteristics of health and social services

Health services are funded mainly by social health insurance and by public taxes. In 2006, 62.5% of the health care expenditures were financed by health insurance, 11% by state and municipal taxes, and 25.6% by the private sector (including 23.8% by out-of-pocket payments). In 2006, the health expenditures were 5% of GDP (Koppel et al. 2008). The primary health care (PHC) system includes a partial gate-keeping function – patients need a family doctor's referral to see

most specialists. Since the early 1990s family doctors have taken over a number of responsibilities that earlier belonged to the area of specialized outpatient care, including management of the care of chronically ill and elderly people (Pölluste et al. 2007 & 2009). The number of acute hospital beds has decreased and the number of long-term care beds increased. However, the fall in the number of acute care beds has not been accompanied by a sufficient increase in the volume of nursing care services. Even though the volume of home and day nursing services, including personal care, has risen year on year, these services are not being developed to the necessary extent (Koppel et al. 2008).

The social services are funded mainly by public taxes, and mostly through the budgets of the municipalities (in case of counselling, home care services, personal assistance, social housing, adapting a dwelling, social transportation). When one is no longer able to live independently, one can apply to the general care home which provides 24-hour care. Care in these social welfare institutes is mainly paid out of pocket, or possibly by the providers and local governments. Only the care costs of those who were already living in general care homes as at 1 January 1993 are covered by the state.

### Social indicators and conditions related to old age

About one third of Estonian elderly people are at risk of poverty, which is extremely high in a European context. The availability of informal carers is rather low as labour market participation among women is high, with 65.9% between 15 and 64 being employed (eurostat 2008). According to the Family Law Act in Estonia an adult child is required to maintain his or her parent who needs assistance and is incapacitated for work.

### Attitudes related to old age

Estonians are pessimistic about their social welfare system. Few (10%) believe it could serve as a model

for other countries in this respect, or that it provides enough coverage (23%). European citizens are much less negative (42% and 51%, respectively). The opinion that the welfare system is too expensive is shared by a relatively small proportion of Estonians (30%) compared to the European average (53%) (TNS Opinion & Social 2007a). About half of Estonian people (49%) find care for dependent elderly people to be a task for close relatives even if the career would be affected. Eighty percent of the Estonians think that professional care at home is the best solution for a dependent elderly parent, while 12% hold the opinion that moving to a nursing home would be the solution (TNS Opinion & Social 2007).

## 2. Policy and regulation on home care

### 2.1 Governance on home care

Policy for elderly people's care in Estonia focuses on issues such as the family and its environment, non-governmental organisations and self-help, but also on health and social welfare, including home care. Home care is a rather new service in Estonia and is divided between the health and social welfare systems. Although both areas are the responsibility of the Ministry of Social Affairs (MoSA), they are relatively separate, which causes problems when people need to switch from one system to another (Koppel et al. 2008). Home nursing, geriatric assessment, home care for cancer patients and inpatient nursing care are provided by the health system, while domestic aid and personal care are provided by the social welfare system. Domestic aid is defined as helping individuals to carry out and manage everyday activities such as cleaning their home, supervising clothing and buying food and household commodities. It does not necessarily cover repair work. Personal care is helping an individual with daily activities related to health and hygiene, including washing, dressing, eating, moving and exercising and general hygiene issues. Domestic aid and personal care are provided by municipalities (MoSA, 2009) and most social welfare services are also provided by municipalities. The Estonian Nursing Care System Strategy of Estonia for 2004–2015 states that they aim to have home nursing services costs covered by health insurance for 100% (2010).

### 2.2 Eligibility for home care services

#### *Home nursing & personal care*

There are no uniform criteria of eligibility for home nursing. The need for the service is usually decided by the patient's family doctor. It is mostly needed by immobile patients or those with restricted ability to move. Furthermore, home care is provided to patients suffering from (end stage) cancer. The only assessment with agreed criteria is geriatric needs assessment. It is based on a single assessment system for health care, nursing care and the country's welfare systems. Usually the primary assessment of needs is carried out in geriatric departments of hospitals but it is also possible at the person's place of residence (Koppel et al. 2008).

#### *Domestic aid and technical aids*

Domestic aid is provided by municipalities and there are no common criteria for eligibility. Domestic aid services aim to support elderly people to manage their household if they, or their families, are unable to do so. Technical aids are allocated by the MoSA and eligible people are to purchase or hire technical aids at a discount or to have the costs of services related to such equipment compensated. These include the purchase of glycometers for people with insulin-dependent diabetes and old-age pensioners for whom technical aids improve their ability to manage. The need for small technical aids is assessed by a person's family practitioner or another attending physician. For more complex technical aids or prosthetics the need for such aids is determined by a specialist or a rehabilitation institution.

### 2.3 Quality of process and output

#### *Availability of quality criteria and assessment of quality of services*

Quality criteria for nursing care, like for other health services, are affirmed by regulation of the Minister of Social Affairs. These criteria are used by managers and providers to organize the care process, to maintain the quality of the nursing care and to optimize the use of resources. Nevertheless, the quality of nursing care differs considerably between care facilities. There is a lack of common understanding of quality criteria and the evaluation of service quality is complicated. Some supervision on the quality of services is made by the Estonian Health Insurance Fund (EHIF), the financier of the services, but usually the process and outcome of home care services are just observed by the service providers.

### *Accreditation and clients complaint procedures*

Compulsory registration exists for agencies providing home nursing financed by the EHIF. Individual providers of home nursing services need a licence, to be renewed every 5 years, from the National Health Board. Services can be provided only by registered nurses. According to the quality requirements, providers of health services and home nursing have to have a complaint procedure in place. However, there is no information to what extent these are used.

## 2.4 Quality of input

Responsibilities of home nurses and the description of the home nursing services are set by regulation of the Minister of Social Affairs. The definition of home nursing was developed by the Estonian Nurses Association and accepted by EHIF in 2005. It reads: 'a home nurse is a nurse who has passed 3.5-years vocational training, undertaken obligatory continued training in home nursing and has at least 3-years working experience. A home nurse must be able to perform all nursing procedures'. In addition to home nurses, auxiliary nurses (with 1–2 year vocational training) can be involved in the provision of home nursing, in particular for personal hygiene and simple procedures. Senior nurses (with higher vocational training or university at Master's level) are involved as case managers.

Non-medical and non-nursing home care is provided by social care workers (with short training courses or with 2-years vocational training), and social workers with higher education (3-years higher vocational training or bachelor's or Master's degree). Social care workers help clients with household work, shopping and some caring (eating, dressing, etc.), but also organise medical services and to get technical aids (including instruction for use). Social workers may provide direct help, but their main task is to support self management through counselling, rehabilitation, etc.

No regular satisfaction surveys are carried out in the home care sector.

## 2.5 Incentives for providers

Health and home nursing services are provided by organisations or foundations who are acting according to private law. Providers compete for contracts with the EHIF. Other home care services are provided by the state

and municipalities and there is no competition, except in cases when the state or municipalities purchase specific services from private providers (for profit or non-profit).

## 3. Financing

### 3.1 General funding

In 2007, 0.45% of the total health expenditures were for home health care (including medical and nursing services provided at the patient's home; curative rehabilitation home care and long-term nursing care at home) (NIHD, 2007). Not covered in this percentage are social home care services provided by the state and municipalities. As home care is partly health care and partly social care, funding is from these two sources. Health services are paid from obligatory health insurance premiums paid by employers' (13% from employees' salary). Health insurance contributions for some groups of people are covered by the state (e.g. unemployed people) or municipality (e.g. carers of disabled persons). The obligatory health insurance system is managed by the EHIF. Insured people are entitled to free-of-charge health services at home. However, patients pay part of the costs of medicine and some nursing materials. In 2007 the private expenditures for long-term home care were 0.0015% of total health expenditures.

Social welfare services are funded from central taxation. Domestic aid is funded by municipalities from resources received from a central fund, fed by taxation; with possible co-payments. Common is also paying informal care givers money directly through care givers' allowance. It depends on the municipality whether this funding is available (Paat & Merilain, 2010). Technical aids are financed from the state budget with co-payments by clients. Private payment or co-payment depends on the type of service, but they mostly apply (excluding health services). In 2007 1.7% of all social home care services were financed by such private payments (Ministry of Social Affairs 12-4-2010).

### 3.2 Financing of home care agencies

Licensed providers of home nursing services are contracted by EHIF and are financed on the basis of fee for services (the unit of payment is a visit). Payment methods, service prices and benefits package are included and regulated in a single government-approved health

service list; so, they are not part of a contract negotiation process. All providers are paid the same prices. Municipalities have a fixed budget for home care.

### 3.3 Price setting of home care services

Prices for home nursing as well as for other health services are approved by the government in the list of health services. Health service prices should cover all costs related to providing services. The prices are fixed, but only the upper limit of prices. In theory it is possible that EHIF and the provider will agree with lower prices, however, in practice it has not yet happened. If the maximum level of prices will not cover the service-related costs, the parties may initiate the revision of the prices. And if agreed and the health insurance has resources for that the maximum level of prices could be increased and the new price should be approved by the government. For domestic aid price setting is left to the municipalities. Most services are provided in kind by social care workers or personal helpers, without financial calculation.

## 4. Organisation & delivery of home care

### 4.1 Access and needs assessment

Clients' needs for home nursing, personal care and domestic aid are usually assessed by family doctors, other doctors or by a social worker. Nursing care and personal care is usually provided to elderly people with several chronic illnesses, who need support with treatment procedures and activities of everyday life; and to adults with multiple conditions and partial incapacity to cope with everyday life (Koppel et al. 2008). Usually there is a unified assessment system for health care, nursing care and the country's welfare systems. The primary assessment of needs is usually carried out in geriatric departments of hospitals but it is also possible at the person's place of residence. Geriatric assessments can result in a referral for home nursing, personal care, domestic aid or technical aid, but this assessment is not available to every client who may need the services mentioned.

### 4.2 Delivery of services

Domestic aid is provided by municipalities. In 2009, home nursing services are provided by 65 licensed health organisations. The number of practising home nurses is

estimated at about 150. Data on the number of home nurses are missing in the register of health professionals as home nursing can be provided by nurses having different specialties (e.g. family nurse, health nurse, clinical nurse, etc.) and who have passed special training. Home nursing services are provided both by nurses employed by health organisations and by self-employed home nurses.

### 4.3 Coordination and integration of services

As described above, home care services in Estonia have their roots both in the health care and the social welfare system. Home nursing services are provided and coordinated by licensed health organisations and the home nursing units or centres closely cooperate with family doctors and hospitals. Besides, in the social welfare system the domestic help which can be provided by different providers is coordinated by a local social worker (the so-called single entry point). But the systems of health care and social welfare are relatively separate from each other, and it causes problems in the transfer of people between systems. It has been suggested that accessibility and quality of nursing and personal care services suffer from the split financing of the welfare and health care systems – from the state budget and through the EHIF, respectively (Koppel et al. 2008, p.194). The Development Plan of Primary Health Care for the years 2009–2015, has stressed the need for cooperation between primary health care and the social welfare system (MoSA, 2009).

### 4.4 Actors and human resources in home care

#### *Actors in home nursing and personal care*

- The Ministry of Social Affairs develops the policy, development plans, legislation and regulation.
- The Health Board is responsible for licensing, registration of health professionals and supervision of the quality of care.
- The Estonian Health Insurance Fund (EHIF) is a public institution setting prices for health services, contracting service providers and financing services according to the contract.
- Home care providers, varying from self-employed home nurses to large organisations.
- The clients or patients (and their informal carers).

**Table 1:** Human resources in home care in 2008

Functions	Estonia (est. number)
Social workers	705
Nurses	550

Sources: Health Board, MoSA.

#### Actors in domestic aid and supportive aids

The Ministry of Social Affairs also holds prime responsibility for domestic services and supportive aids. As most of tasks are delegated to municipalities these can also be considered as major actors, together with their clients.

#### Human resources in home care

In the beginning of 2010 the licence for home nursing services was issued to just 64 independent providers (hospitals, out-patient clinics, self-employed nurses). The number of nurses being employed of those providers is 550 (Health Board, 2010). The previous number of home nurses (150) referred to year 2007 and was based on the estimation of one of the experts. Today the number of nurses providing the home nursing services has increased, however, there is no information about how many of them have passed special training in home nursing. The number home nursing services providers includes only qualified home nurses (with medical background – nurse who has passed the special training for home nursing; their services are financed by health insurance), not personal carers nor family members or friends employed under a formal contract. Formal personal carers (19,322 qualified social workers and social carers without medical background) are working in social welfare system. In 2008 domestic care was provided by 705 social workers (MoSA) who are employed by municipalities. Working conditions, payment, duties and responsibilities for salaried staff are defined in contract of employment and job description. In general, salaries of home nurses and social workers are below the average wage.

#### 4.5 Use of tele-care

Tele-care is still sparsely used in Estonia. So-called safety buttons are used – equipment based on a mobile phone connection – but it is not very common. Costs related to the use of safety buttons are partly covered by local government and partly paid out-of-pocket by the clients.

#### 4.6 Monitoring the adequacy of care

There is no uniform national record system to monitor the adequacy of care. The process of care is monitored and (re-)assessed mostly by service providers themselves.

### 5. Clients & informal carers

#### 5.1 Home care recipients

In 2008, there were a total of about 6530 recipients of long-term homecare in Estonia (0.5% of the population) (MOSA: 2009). This was just below the number of recipients of long-term care in institutions 2008: 7,413 (0.6% of the total population). Of all services, 84.5% were provided to people over 65 years of age; 46.1% to those aged 80 and more.

#### 5.2 Coverage and unmet needs for care

In general, home care in Estonia is under-delivered. Even though the volume of home nursing services has risen year on year, there are still a lot of people who need nursing care but who do not have access to services they need. There continues to be a lack of qualified staff (nurses, social care workers) and appropriate financing. Experts who responded to the vignettes also pointed to under-delivery. Services may not be sufficiently available. The Eurobarometer survey showed the relative appropriateness of home care in Estonia: 88% responded that services were appropriate or partly appropriate, which was around the EU-27 average (TNS Opinion & Social 2007).

#### 5.3 Empowerment of clients

If more providers are available, clients can usually choose the provider they want. If eligible for care, clients can freely choose to have this care at home or in an institution. Information about care options and other aspect of the organisation of home care (for instance to be able to compare services and providers) is mostly available on the websites of those organisations. Elderly people can find

information on special websites for senior citizens (e.g. <http://www.delfi.ee/eakad/>), which includes information about home care. Furthermore, there are organisations offering information and help to choose the best option for home care (e.g. The Self-Help and Advisory Centre for Senior Citizens, Estonian Association of Gerontology and Geriatrics; local organisations of senior citizens). There are no systematic client satisfaction surveys in the field of home care. However, people are concerned about the low affordability and quality of nursing and personal care, which mainly result from poor public financing (TNS Opinion & Social 2007b, Koppel et al. 2008).

#### 5.4 Informal carers

Clients' partners and others adult co-habitees are expected to provide everyday care and help in client's home. If the client needs continuous care and help, a partner or other family members acting as carers can be paid by the municipality.

### 6. Disparities in the process of home care

There are usually different ways in which the client or his/her family members can apply for care, such as via the GP or via specialists for nursing and personal care, as well as municipalities for domestic aid, home adaption and other social services. The assessment and monitoring of individual needs can be designed by the providers of services in simple cases (GP, nurse, social worker) or in more complicated cases by the team of geriatric assessment or team for assessment of rehabilitation services.

There is formally no gap between the needs of clients and care received. However, the range of services provided and financing of services depend essentially on the possibilities (human and financial resources) of local municipalities. The following disparities have arisen from the vignettes:

- The receipt of different services like meals-on-wheels, tele-care, social transportation, social housing, etc. depends on the municipality. The situation is more favourable in bigger (and wealthier) municipalities and in urban areas where the population density is high. But in rural areas with low population density and shortage of qualified specialists people's needs may partially be unmet. Still, there is little information available how much these matters vary across municipalities.

- The level of co-payment for domestic aid and guidance varies across municipalities.

### 7. Current concerns and developments in home care in Estonia

Home care in Estonia is developing but, despite initiatives taken, the need for home care continues to grow due to the growing number of elderly people in the population. There are concerns about insufficient number of qualified staff – both in home nursing as well as in domestic help, but also about scarcity of financial resources. Furthermore, there is a lack of common understanding of various requirements to quality of services and the evaluation of service quality is often complicated. Finally, cooperation is poor between the health and social sectors which may cause difficulties in access and transition.

The following developments are relevant to home care in Estonia:

- Increase of the share of outpatient nursing care services.
- Development of human resources and appropriate financing schemes for home care services.
- Development of quality assurance mechanisms in home care.
- Need for integration between the PHC and social welfare systems, as has been stressed in the Development Plan of Primary Health Care for the years 2009–2015.

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# Finland

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## 1. The context of home care

### Country, population and health

Finland has an extremely low population density (15.5/km<sup>2</sup> in 2009 – Eurostat 2009), especially in the North and East. Almost two-thirds of the population lives in urban areas. Compared to other countries in the EU there are relatively few immigrants. The country's nominal GDP per capita in Euros is 32,100 Euro in 2010 and in purchasing power it is comparable to the EU15 average (Eurostat, 02-08-2010). Governmental responsibilities in Finland have been strongly decentralised to the 20 regions and 342 municipalities in 2010. Municipalities are legally responsible for providing welfare services to their residents. So, municipalities have a strong role in education, health care, social welfare services, planning and construction (Leskinen, 2005). Like in other countries the Finnish population is aging. In 2008, 4.3% of population was over the age of 80 and about 16.5% was over the age of 65, which is in line with the EU average (Eurostat, 2009). For women the life expectancy at the age of 65 (in 2006, 21.2 years) is higher than the EU15 average, while for men it is much below (in 2006, 16.9 years). With a healthy life expectancy at 65 of 7.4 years for women and 6.1 for men, the Finnish remain below the EU15 average (Eurostat, 2008). In 2008, about 89.4% of the persons over the age of 75 lived at home (THL, 2010).

### Characteristics of health and social services

Finland has an extensive system of care services. Care options include home care, service housing and

institutional care, which differ in the care intensity provided and in the division of financial responsibility between clients, municipalities and the Social Insurance Institution (Parkatti & Eskola, 2004). Institutional care can be short-term, continuous day or night care as well as 24-hour care (Raassina, 29.7.2010) and can be provided in nursing homes, old age homes, inpatient wards of municipal health centres, specialised care units and special institutions for the handicapped (Mälly, website visited 29-07-2010). Services for people with disabilities under the Disability Act (for people under the age of 65) include personal care services. In 2008, about 11.2% of persons over the age of 75 received regular home care, i.e. home help and nursing (THL, 2010). The share of persons over the age of 75 receiving regular home care has declined over the past years (in 1995 it was still 13.8%), just as the share living in residential homes for the elderly (from 6.5% in 1995 to 3.8% in 2008). The share of persons over the age of 75 receiving sheltered housing with 24-hours assistance has increased from 1.7% in 2000 to 4.6% in 2008 (THL, 2010). The public and private home care provision and service housing has been growing because these were prioritised to substitute for institutional care. In addition to home care workers (primary nurses), people can also be home visited by specialized nurses and in special needs general practitioners (GPs). In many municipalities these different professionals (primary nurses, specialized nurses and GPs) have been organised in a care team structure based on spatial areas. The density of GPs in Finland, 0.7/1000 inhabitants, is relatively low, but the task area of primary nurses and specialized nurses is quite wide especially in the home settings.

### Social indicators and conditions related to old age

The employment rate in 2008 was 71.1%; one of the highest in the EU. As part-time working is not widespread, the availability for informal care is relatively low. However, the municipal support system for informal care is partly broadening. Informal care giving is supported by municipal support system, through cash

or in-kind benefits especially for informal care. In 2008, these benefits were received for 4.1% of clients over the age of 75 (THL, 2010).

The Finnish pension system consists of a national basic pension and an income related occupational pension. Compared to other countries a very high percentage of GDP was spent on pension contributions (11%) and spent on pension benefit (9.2%) in 2006 (OECD, 2008). Still, about 23% of the population of 65 years and over is at risk of poverty, while the EU average is 19% (Eurostat, 29-01-2010). There are however some means-tested allowances for pensioners and people with disabilities to cover part of dependency costs.

### Attitudes related to old age

The Finnish people consider care for dependent elderly people primarily as a professional affair. Just 20% (compared to 34% in Europe) found it the responsibility of close relatives even if the career might be affected (TNS Opinion & Social 2007). About half the Finnish population (against 27% of Europeans) see professional care at home as the best solution for a dependent elderly parent, while 13% indicated to think that moving to a nursing home would be the solution (against 10% of Europeans) (TNS Opinion & Social 2007).

## 2. Policy and regulation on home care

### 2.1 Governance on home care

The national government aims to enable elderly people to live at home as long as possible and to stay in their own social environment (Holma, 2008). This should be achieved by easy access to health and social services. Central theme is to safeguard a good quality of life, self-determination and independence (Holma, 2008). By 2012 the target is that 91–92% of the 75-year-old-and-over population should live in their own home and that 13–14% of them should receive regular home care (Ministry of SAH, 2008). Regular home care means home help (usually including supportive services such as meals-on-wheels, cleaning, bathing, shopping, personal alarm systems, etc.) and home nursing, provided to those holding a care and service plan or receiving these services at least once a week. *Home help* consists of helping in daily activities, domestic help and personal care (Parkatti & Eskola, 2004). *Home nursing* encompasses taking care of illness, medicines and of wounds provided by nurses

(Hammar, et al., 2008). Occasional home health care means nursing care at home for a short period mostly after hospital care period. In that case the care mostly happens after some operation. As the length of stay at hospitals is shortening, consequently this kind of home health care is increasing.

Municipalities, who are primarily responsible for home care, can organise home help and home nursing in separate or combined units. Nowadays the number of combined, so called home care units has increased (Tepponen 2009).

Health and social services should be organised on a scale of at least 20,000 inhabitants (following the Act on the Restructuring of Local Government and Services 169/2007). Many (smaller) municipalities cooperate with other municipalities to deliver home nursing care. This is also becoming more and more the case with home help services. The national government holds its supervisory role mainly by law and information steering systems. Different laws are related to home care and its organizational and financial structures. However, the most important laws are the Social Welfare Act (including a general description of home help services for which municipalities are responsible), the Primary Health Care Act, and the Act on the Status and Rights of Social Welfare Clients (including clients' right to participate in the care planning). The Primary Health Care Act and Social Welfare Act are in transition process at the end of 2010.

Besides the laws, the national information and supervision steering systems have affected the practices of home care on the municipal level in Finland. The current national 'Development Programme for Social Welfare and Health Care' gives guidelines for service provision also in elderly care. In addition, the national government obliges municipalities to develop a municipal policy and service plan for care for older people (Holma, 2008). Regional State Administrative Agencies observe the government's supervision in the regions.

Policy documents on home care focus on the elderly but home care regulations are not age related, except that people over the age of 75 are eligible to receive a needs assessment without an urgent problem and can receive a needs assessment within 7 days. Care for the handicapped has been more specifically regulated than for elderly people, i.e. in the Services and Assistance for the Disabled Act. For severely disabled persons a range

of services is available, such as transportation, home conversions, service housing, personal assistance and help with administration. 'Service housing' also encompasses a personal assistant with activities of daily life or home help and home nursing (Ministry of Social Affairs and Health, 2006).

## 2.2 Eligibility for home care services

The 'pallet of services' provided differ across municipalities. Detailed national requirements for the extent and content of statutory services do not exist. Only recommendations exist about eligibility. The availability, scope, structure and quality of services may thus vary somewhat from one municipality to another as well as between units of provision. However, social and health care benefits do not depend on the financial situation or the availability of informal care (Blomgren et al. 2008). Eligibility criteria usually relate to the medical history, the physical, mental and psycho-social impairments, the possibilities for ADL, and the social environment. The level of need is then scaled into 3 or 4 categories, which is the basis for the assignment of care. Although home help is generally meant for clients who need support in routine daily activities it has become in certain municipalities increasingly targeted on those with low incomes and very high needs. Preventive home visits, available to those over the age of 80, include a check of possible health and social needs and providing information about available services. Also GP's can prescribe occasional home health care for their elderly patients consisting of e.g. the care of pressure ulcers or some kind of medication. In that case, elderly clients do not have to make many short time visits to the health care centre.

'KELA', the Social Insurance Institute of Finland offering home care allowances, has issued requirements for these allowances. Such allowances require a referral by a physician and can be used to cover costs for public or private home help (incl. supportive services) and home nursing. Another requirement is that the illness or injury should have resulted in a need for (weekly) assistance, guidance or supervision with personal activities of daily living or in continuous expenditures at least equal to a certain amount (Website KELA, <http://www.kela.fi>, English version available).

## 2.3 Quality of process and output

### *Availability of quality criteria*

Insight in the quality of services is said to be insufficient and concern is growing that recommendations and guidelines are insufficiently observed. Therefore quality of care has come high on the policy agenda. The state encourages projects enhancing the development and quality of home care services (Salonen, 2009). In 2008, the Association of Finnish Local and Regional Authorities and the Ministry of Social Affairs and Health have updated a framework for the quality of care for the elderly (Ministry of Social Affairs and Health, 2008). It is intended to be used by providers and decision makers to develop and monitor the quality of their services. It puts forward values, ethical principles and strategies that increase quality and effectiveness. However, it does not include quality criteria. State agencies set minimum requirements for registration of private providers. To stimulate quality provision the Ministry and Association of Finnish Local and Regional Authorities jointly present good practices, which are available on a website.

Municipalities are responsible to organise the services as well as the quality of care. For contracted providers quality criteria are included in the contract (for instance, on the educational level of staff; evaluation of client satisfaction; availability of a quality system; and how prices are set). It is unclear, however, whether municipalities explicitly formulate quality criteria for their own services. Guidelines for activities of nurses do exist, but these guidelines are said to be scarcely used by nurses.

### *Assessment of quality of services*

Municipalities differ in the way they monitor the service quality (Tepponen 2009). A usual way is by client satisfaction surveys; about the availability, adequacy and functionality of the services (Parkatti & Eskola, 2004). Registered private providers who deliver services through vouchers are monitored to some extent by the municipality providers. Compared to three other countries with cash-for care programmes, in Finland services paid through 'service vouchers' were subject to a high level of quality control (Timonen, Convery, & Cahill 2006).

### *Accreditation and clients complaint procedures*

No accreditation scheme applies. Client complaint procedures are at the national level. A recipient of private or public home care can either complain to the municipality or to the regional agencies of the Ministry. Each municipality must have a health or social official ('ombudsman') who handled and helped with the complaints. Complaints can also be received and dealt with by the State Inspectorate.

## 2.4 Quality of input

### *Education and job description*

Some years ago, the educational system for home care has changed. The present situation is a mix of the new and the old professions. The following professionals are active in home care:

- Registered nurse: 3.5–4.5 year polytechnic education; specialised care/technical nursing and coordination and supervising service provision.
- Primary carer/home care assistant (new system): 1.5–3 years of education (depending on the basic education) or shorter re-educated of former home helps and primary nurses (of the old system); e.g. personal care, supervising intake of medicine; less attention for social care such as accompanying clients and counselling.
- Housekeeper: (since August 2010) a one year training. Holders of a Vocational Qualification in Household and Cleaning Services plan, assess and develop their own work and services based on quality standards. In addition to basic competences, holders of a Vocational Qualification in Household and Cleaning Services have specialist skills in domestic services or cleaning services tasks determined by their selections. They work in meal services, cleaning and textile care tasks and help clients in their daily routines and errands.
- Primary/practical nurse (old system): 2 years upper secondary education with medical orientation; personal care, guidance, advice, help with medicine intake and monitors health.
- Home helper (old system): 6 month socially oriented education by the employer; assistance, personal attendance, accompanying clients and counselling. Since August 2011 there is also less than one year new education dealing with home help.
- Auxiliary (old system); no education; provide meals on wheels, maintenance of clothes, bathing, cleaning, transportation and services promoting social interaction.
- Social worker; university master level education, but some may be unqualified temporary workers; perform preventative home visits, coordinate care and transfers from hospitals to home. Social worker performs also different kinds of benefits for poor and disabled people in home care and support systems for informal carers.

Educational requirements for social workers are laid down by the Act on Qualification Requirements for Social Welfare Professionals. Professional requirements for home nursing personnel are set in the Act of Professionals in Health Care and the National Authority for Medicolegal Affairs. However, in the absence of a nationally established nursing curriculum, nursing schools (polytechnics) are relatively independent to develop their programmes. The government just recommends what home care professionals (nurses and home helpers) should learn. The Regional Agencies of the Ministry inquire about the provision of continued training, but do not monitor it.

### *Accreditation*

Both nurses and primary carers need to be centrally registered. They need to be certified/qualified to get a permanent job in home care (Parkatti & Eskola, 2004). The educational requirements for technical nursing tasks are laid down on national level. This is in contrast to other types of tasks, which are not officially linked to certain educational levels. Municipalities can rather independently decide upon job descriptions. Whether a nurse or a home help is providing simple personal care usually depends on needs of the recipient (e.g. if nursing care is required, simple personal care may be provided by a nurse too).

### *Recertification*

- There is no obligation for relicensing, and so there are no norms. However, further education is based on the law. Furthermore, employers of professionals, such as municipalities, are supposed to monitor the continued quality of home care professionals. The Ministry of Social Affairs and Health has given Recommendation for further education for health care staff (STM 2004) and for continuing professional education in social welfare (STM 2006).

The aim of these recommendations is to maintain, develop and deepen the professional skills and knowledge of personnel based on their education needs and the fundamental task and development of the operations of the organisation. For instance, in health care particular attention should be paid to the provision of further education and training within primary health care. This means for instance, that every three years nurses must pass a knowledge test on certain topics, such as medical drugs. The nursing association recommends spending 6 days per year on courses and other continuing education. Furthermore, municipalities do receive a budget from the Ministry for external training.

### 2.5 Incentives for providers

To increase efficiency, some municipalities have chosen to separate the role of purchaser and service provider in their organisational structure. In this way the purchaser can also choose another provider. There are also other efficiency incentives. Private services and partnerships between public, private and third sector have become the accepted solution for the increasing demand of care. Competition between private providers, although not an explicit policy aim, has consequently grown, also under the influence of EU regulation. NGOs that previously had a protected position and were exempted from paying taxes, now have to compete with private companies.

To safeguard that competition does not harm quality, there are laws on Monitoring of Private Social Services and Health Services. This act lays down requirements for the organisation, staff and availability of services. A private provider needs to be licensed by the central government in order for private home care recipients to be eligible to tax reductions. Municipalities furthermore set quality norms in their contracts with private providers.

## 3. Financing

### 3.1 General funding

The main sources of public funding are municipal and national taxation. Although municipalities receive resources from the central government the larger part is funded from local taxation. The budget of the central government is not earmarked for home care specifically but only more general for social welfare and health care. The compulsory health insurance funds ‘care allowances’

for elderly and severely disabled persons. These allowances are means-tested and are bound to a maximum. As no home care services are without co-payment, private payments are an important source of funding. They are either full-payments by private household (e.g. in case of supportive services) or co-payments. Only 10% of the private social care recipients was estimated to pay the complete fee themselves (Rissanen et al., 2010). The height of the co-payment is related to the financial position of the client and the prevailing regulation of the municipality where he or she is living.

So most home care services (also respite care and technical aids) are – at least partly – publicly funded by the municipalities. Frequent exceptions are extensive home cleaning help, shopping and psycho-social counselling. In 2006, the total expenditures on home health care amounted 1.6% of the total health care expenditure (OECD/HD, 2009). Over half of this amount was spent on long term care at home. In 2007, almost 699 million Euro was spent on home help for the elderly (website NIHW, <http://www.thl.fi>), which is threefold the amount for home nursing (Knape, 2009). The proportion of private expenditures, excluding purely privately purchased services, was 6.4–7%. The average cost in 2003 for municipalities per client for home nursing and home help were estimated to be 67 Euro and 223 Euro respectively (Hammar, Rissanen, & Perala 2008).

Simple technical aids, like walkers can be borrowed by elderly persons from their health centre and more advanced aids (e.g. electric wheelchairs and special beds) can be borrowed from hospitals for a short period of time (Alzheimer Europe, 27-07-2010). Government loans for basic renovations and repairs, and grants such as the pensioners allowance can pay for home adaptations (e.g. of toilets and bathrooms and widening of doorways). In case of severely disabled persons municipalities can reimburse home adaptations but also technical aids.

### 3.2 Financing of home care agencies

The municipal home help and home nursing departments are assigned a budget by the municipality (or by a cooperation of municipalities). In some municipalities home care budgets are split between home help and home nursing and in others they are merged together. Municipalities receive an amount from the state depending on the number and age of inhabitants, and morbidity structure; but municipalities may ask in some

cases for more financial funds when needed. In larger cities, like Helsinki, there are several service regions. Each region is assigned a budget. If this would not be sufficient the municipality may shift resources from one region to another in case of shortages.

Private providers (NGOs and commercial agencies) are usually paid directly by clients, either out-of-pocket or with vouchers that clients received from the municipality. If private providers are contracted for certain services by a municipality they are paid by the municipality according to the contract.

Although its use is growing, service vouchers still have a limited role in home care. Only a minority of municipalities is working with service vouchers. The use of vouchers is means-tested, and they are bound to a maximum per month. Municipalities may choose to offer vouchers instead of providing home help, service housing and supportive services and (since 2009) home nursing themselves. In 2009, 7% of all older home help recipients received service vouchers (data THL website). The vouchers are means-tested and they are bound to a maximum per month. They are mainly used for private providers and self-employed individuals (Timonen, Convery, & Cahill 2006). As the value of service vouchers is not enough to buy services up to the number of eligible hours, co-payment by clients is required.

### 3.3 Price setting of home care services

Although the Ministry issues guidelines for the prices of home care services, municipalities are free to set prices as well as the proportion to be co-paid by recipients, depending on their income, in regular care. The cost of occasional home nursing or home help does not depend on client's income. Recipients of public home care clients usually need to pay an amount per hour related to the type of service. The price setting by private providers varies; most apply hourly tariffs, irrespective the mix of services, while others calculate service related fees. If contracted to municipalities they obviously must comply to what has been agreed with the municipality.

## 4. Organisation & delivery of home care

### 4.1 Access and needs assessment

Publicly provided home care can be applied in different ways, depending on the situation of the applicant

and the municipality where he or she is living. After hospitalisation the hospital will usually contact – for instance via electronic exchange – the municipality to prepare home care. In other situations it is likely that either the client, their family, the GP or other primary care providers will contact the municipality, after which an assessment visit will be made. Some municipalities have an integrated application procedure for both home nursing and home help services run by the municipal department for care for the elderly or a home care centre. In other municipalities applications must be made to the health care centre and social welfare office separately. Sometimes, for technical aids or home adaptations still another department needs to be addressed. For home nursing a GP referral is required. For other home care services, a physician's referral is only necessary if one aims to receive a home care allowance.

For the assessment of care needs municipalities use a standard form by which the medical history, physical and social abilities and psycho-geriatric status are described. Many municipalities use for instance the standard RAVA-assessment instrument to measure functional abilities. The organisation of the needs assessment depends on the municipality and can either or not integrate social and health care needs and either or not be integrated with the provision of services. The assessment procedure ends with a personal service plan for the client, including all services provided, the available informal care, private care and voluntary services. For personal assistance a comparable path to access is followed.

Those wanting to purchase care privately usually find providers through advertisements or are informed about them by the municipality. Then the client is visited and a contract is agreed with the provider about the services to be provided and the price.

### 4.2 Delivery of services

In 2001, service recipients at home received on average 7.5 home help visits and 1.7 home nursing visits per week (Hammar, Rissanen, & Perala 2008). Lately visits more and more focus on those clients who need intensive care. For instance 2008, 30% of regular home care clients aged 75 and over were visited more than 40 times in a month. The comparative percentage was 25% in 2001. (THL, 2009). Services in the peoples' homes are also delivered by personal assistants, physiotherapists and social workers. Smaller municipalities may deliver services jointly with other municipalities. Public home nursing can either

be provided by health centres or by an integrated home care service unit (incl. home help). If the home help and home nursing is not merged, the home help is provided by the municipal social welfare departments. In a few larger cities, home hospital services are offered for people in need of technical nursing, such as intravenous antibiotic treatment or treatment of asthma (Hujanen 2003, 32). While municipal home care is often provided by geographically bound teams, this is not the case for private care providers.

As a result of a general increase of needs and costs of welfare services, certain services are increasingly removed from the public package of home care. This particularly applies to domestic aid. As a consequence, the share of privately provided home care is growing. The number of private companies providing home help has increased with one third between 2000 and 2006 (Rissanen et al., 2010; THL, 2010). All together it is estimated that private-sector service providers, that is, organizations and business enterprises, accounted for nearly a third of the provision of all social services. Private health-service providers account for about a fifth of the provision of all health services (THL, 2009).

Among private providers of home care are those organised on a national scale as well as very small local firms. Private providers usually work more flexibly than the municipal services. However, the more complex provision of home care to patients with high care needs (for instance with terminally ill) is usually left to municipal service provision. Clients of private providers are usually more affluent and have lower levels of care needs than those of public home care services. Higher costs related to larger distances make that rural areas are less interesting for private providers. As a consequence rural municipalities have focused more on public home care services.

Also NGOs and voluntary organisations, such as the Central Union for the Welfare of the Aged and the Finnish Red Cross, are involved in the delivery of home help and assistance. Voluntary providers, but also hospitals, tend to be more involved in home care for handicapped persons.

#### 4.3 Coordination and integration of services

Tepponen (2009) found that across Finland integration between home help and home nursing had increased between 2004 and 2007, in particular at the structural

level. Structural integration means that there are home care units, boards, responsible for 'home care', and that health and social welfare departments were combined. Integration at structural level was associated with more multi-professional teamwork and other integrative tools, like shared client information systems. In 2006, about half the Finnish municipalities had completely integrated their home help and home nursing services, while in others usually there was some form of coordination, for instance by combined care plans for both types of care (Tepponen, 2009). Additionally, municipalities increasingly work with teams of home helps and home nurses responsible for designated geographical areas.

Case coordination is usually in the hands of a nurse. In some municipalities 'home care GPs' take over the function of the GP/family doctor when the patient is in long-term care at home. In some regions information technology, such as portable patient information systems, is used to improve coordination. However, information exchange systems jointly used by both public and private sector are unknown until now. New legislation aims to facilitate this exchange of patient information.

Coordination between hospitals and public home care services is quite often well developed, including uniform electronic patient records and direct communication during needs assessment. Home hospitals (hospitals providing technical nursing such as dialyses, mainly to physically disabled persons) usually work in close cooperation with night teams of the home nursing providers. Finally, home care providers also often provide care in service homes, elderly homes and nursing homes.

#### 4.4 Actors and human resources in home care

The main actors in home care are:

- Ministry of Social Affairs and Health: in charge of general planning, guidance and supervision of services aimed at older people and disability policy and law.
- Municipalities: in charge of the provision and (to some extent) the financing of home help, supportive services and home nursing.
- Social Insurance Institution of Finland: provides allowances to buy home care and monitors rehabilitation services
- Regional State Administrative Agencies: coordinates the implementation of social and health services

**Table 1:** *Human resources in home care*

Functions	Employed by municipalities	Employed by private enterprises	Employed by NGO	Total number
<i>Home help (2007)*</i>	<b>16473</b>	<b>2830</b>	<b>444</b>	<b>19747</b>
<i>Home nursing (est.)</i>	–	–	–	<b>5000 (est.)</b>
Est. total home care workers	–	–	–	20,000–25,000

Source: *Yksityinen palvelutuotanto sosiaali- ja terveydenhuollossa. Suomen virallinen tilasto. Sosiaaliturva. Helsinki. Terveyden ja hyvinvoinnin laitos.*  
 Source: total number of home care workers: Home carers total: Salonen, K., Home care for older people. Turku University.

(check adherence to legal requirement) and monitors and evaluates home care provision (Website Regional State Administrative Agencies, visited 30-07-2010). They license private social and health care providers and client complaints are handled by them.

- Private providers: mainly self-employed or small companies; mainly for supportive services at home but, to a lesser extent also home nursing and home help.

#### *Human resources in home care*

There are around 20,000–25,000 home carers in Finland, usually working full-time. Most home care professionals are employed with a salary by municipalities or private providers; self-employment is still infrequent. There is shortage of home care nurses, especially in the cities. As a consequence, nurses in large cities are better paid than those in rural areas due to a shortage of nurses. Many nurses leave the profession due to tough working conditions. Working conditions and payments of nurses in the public sector are subject to regulation. Interestingly, the municipality of Helsinki has deployed unemployed people to provide supportive home care services in return for their welfare benefits.

The working conditions for providers of social and nursing services the working conditions have been laid down. Nurses in the private sector have their own collective agreement, usually including more favourable working conditions. Work in the private sector is also said to be more attractive due to better equipment and facilities. For social services working conditions in the public and the private sector are comparable. Nevertheless, working with private providers seems to offer more freedom of choice and better career chances. The practice nurses earn on average 2,370 and the registered nurse about 2,860 per month at end of 2009 (Colombo et al., 2011).

#### 4.5 Use of tele-care

The use of alarm buttons is quite usual in Finland. Alarm systems are partially provided and funded by municipalities and also offered by NGOs and private companies, including alarm call centres that may send home nurses and helpers when needed. Tele-care services, which are usually not publicly funded, include screen-to-screen equipment, distant signalling devices and wireless tracking.

#### 4.6 Monitoring the adequacy of care

Although the monitoring of care needs and possible changes may differ between municipalities, some common elements can be identified. Firstly, relatives can ask for a re-assessment if they think the situation has changed. Furthermore, most municipalities have a routine of updates every six months. Finally, home care nurses informally monitor the situation and will take action if needed (Timonen, Convery, & Cahill 2006). As soon as a client would need care for more than 80 hours per month admission to a residential setting is considered. This can be for instance a private service home, or an old age home (run by the municipality or private organisation hired by the municipality) or a public nursing home (or long term care hospital). In all cases, like with home care, income-related co-payment applies.

## 5. Clients & informal carers

### 5.1 Home care recipients

Home care is more frequently used than institutional care (see Table 2). As defined by the OECD home care is available to almost four times as many recipients as is institutional care. In 2008, 11.2% of the Finnish population over the age of 75 received regular home care (THL, 2009). Home help is mainly provided to

**Table 2:** Recipients of long term care provided at home and in institutions

Recipient groups	Total home care service recipients (30 Nov 2009)	Regular <sup>1)</sup> home help and home nursing recipients (30 Nov 2008)	Support for informal care recipients (2008)	Personal assistants (2009)	Long-term care recipients at home (2006; OECD def)	Institutionalised long-term care recipients (2006; OECD def)
Total	88,950	65,383 <sup>2)</sup>	n.a.	6,598	79,454	21,378
Total over 65 years old (% of total population 65+)	n.a.	55,800 (6,3%)	23,000	1,071	63,532	18,707
% 65+	n.a.	88%	n.a.	16%	80%	88%
% 80+	n.a.	74% <sup>3)</sup>	n.a.	n.a.	50%	63%

Sources:

Long-term care recipients: OECD, OECD Health Data 2008. Data 2009: Väyrynen, R., 2010, Count of Regular Home-Care Clients on 30 November of 2009, Helsinki: THL.

Others: THL, Statistical Yearbook on Social Welfare and Health Care 2009, 2009.

Notes: <sup>1)</sup> See footnote 34; <sup>2)</sup> data for 2009; <sup>3)</sup> data for 2009 and for 75+.

the elderly. In 2009, municipalities have financed home help for 103,656 elderly persons and to only 6,039 persons with a handicap (THL data, 07-08-2010). This number does not include home care provided by private organisations. In 2008, there were for instance 353 private units providing home help (THL, 2010).

Home care recipients are mostly older women, living alone with various co-morbidities. Most of those above 70 receiving formal care also receive informal care or voluntary help. For this group, receiving formal care was associated with increased age, cognitive and functional disabilities (IADL and PADL). One-third of these home care recipients received both home help and home nursing (Hammar, Rissanen, & Perala 2008). Over half of the regular home care clients needed repetitive care, just 6% needed continuous care and about 9% of recipients was totally or nearly totally independent (Väyrynen, 2010).

## 5.2 Coverage and unmet needs for care

In general, unmet needs were not reported to be a major problem. This could change, however, since the reduction of institutional and residential care is insufficiently compensated by a growth of the home care volume. At present the financing of supportive services, like cleaning, was said to be marginal. Furthermore, the focus of home care is strongly 'instrumental', which means that the

attention for social and emotional needs has not been developed. Informants expected there is a lot of loneliness and lack of activation.

As parts of the country are very sparsely populated services may not be easy to reach.

## 5.3 Empowerment of clients

Efforts have been made to increase clients' influence in the process of care, e.g. through the increasing possibilities of service vouchers and allowances from a public social insurance scheme (called KELA). KELA allowances provide compensation to those with a medical certificate for loss of income in case of illness and for costs of care services not covered elsewhere. Service vouchers allow clients to purchase care services under their own conditions from whomever they wish. However, service vouchers are not available everywhere and only to a limited extent.

Furthermore, the Act on Status and Rights of Social Welfare Clients and the Act on Status and Rights of Patients formalises the rights of the clients or patients in health and social care. For instance the Act on Status and Rights of Social Welfare Clients support the idea, that the wishes of clients must be taken into account in the planning and provision of social welfare services. In addition, there is voluntary older people's councils in 279

municipalities, which role is to support positive progress of elderly care services in municipality (<http://www.kunnat.net>). Voluntary handicap councils have the same role, but concerning services for disabled persons.

Although dependent persons are in principle free to choose their provider, in practice this choice is hampered in several ways. Private providers are not always an option as they are not available in many municipalities. Furthermore, private providers are free to decline a care request from a patient. Secondly, it is mainly the nurse and physician deciding upon the setting of care based on assessment scales.

#### 5.4 Informal carers

Respite care, regulated in the Act on Informal Carers, aims to alleviate the burden of informal carers and thus to postpone the clients' need for more intensive forms of care (Parkatti & Eskola, 2004). The law enables informal carers to leave two or three days a month. During these holidays the client can be cared for in an institution. Respite care can also be provided at home. However, this type of respite care is not widely available (Alzheimer Europe, 27-07-2010). Financial compensation for informal carers does exist in the form of home care allowance. Their tasks are taken up in a care contract.

### 6. Disparities in the process of home care

Although there is no conclusive evidence for differences in service coverage, it seems that municipalities in Northern and Eastern Finland face a lack of resources due to population ageing, migration and decreasing tax revenue. Furthermore, there are differences between municipalities, in particular in the needs assessment procedure and how service delivery has been organised. Some municipalities provide home care jointly with other municipalities. Another difference is between municipalities where home help services and home nursing are integrated and those where this is not the case.

- No differences were reported in the access to home help and nursing between categories of recipients. However, (the coverage of) some related services may differ between elderly persons and adult disabled persons. For example, transportation is better covered for people with a handicap and personal assistants and service housing are a subjective right for them.

### 7. Concerns and new developments in home care in Finland

Current concerns in relation to Finnish home care are:

- *Possible future unmet needs.* The realisation of the 2012 target, that 13–14% of people over the age of 75 receive home care services, is doubted (YLE, 2010). Institutionalised care is decreasing, but faster than home care provision is increasing.
- *A lack of trained home care professionals.* There are enough trained nurses, however due to low salaries and unattractive working conditions many have changed to other jobs. It seems they are sometimes replaced by lower educated staff ('de-skilling'). It is estimated that currently 10,000 persons with a nurse education do not work as a nurse.
- *Financial shortages in some areas.* In some municipalities, especially in Northern and Eastern Finland, almost one third of the population is over the age of 65. This negatively influences tax revenues and available financial resources in situations where the demand for home care is rising. Even though poor municipalities are obliged now to combine their service provision with other municipalities, they are no attractive partners to other municipalities.
- *Inequalities in the quality of services, in the financial conditions for the use of services as well as in staffing of home care services result from the different financial position of municipalities as mentioned above. This situation tends to worsen by the financial crisis.*
- *Lack of focus on social needs.* Home care in Finland was said to be strongly focussed on the physical needs, and much less on the social needs of people (e.g. prevention of loneliness and insecurity).
- Some informants reported the public home care system to *lack flexibility and efficiency*. It would be difficult to quickly respond to changing needs or provide an integrated mix of services. Procedures may be bureaucratic and time consuming.

Current developments in Finnish home care are:

- *Further expansion of home care and service housing.*
- *Reorganisation of home care in municipalities.* Several municipalities are splitting up the provider units and the needs assessment and purchasing units in municipalities. Furthermore, municipalities aim

to increase the efficiency of home care services in an attempt to cope with growing demand and shrinking budgets.

- *Further opening up of the market for private providers* (i.e. through service vouchers). It is expected that joint mixed networks of private and public providers will develop with the municipality in a coordinating role, rather than straight competition between these sectors. At the same time large commercial service companies explore the home care market by employing nurses and extending their range of products with housing, shopping, alarm and other services in the homes of elderly and handicapped people. Some municipalities contract these services.
- *Integration of home help and home nursing* has increased over the past years. Several publicly financed projects aim at integrating home help and nursing into one municipal department.
- *Growing attention for the quality of home care.* Next to the introduction of the framework for quality services, some projects have been developed to increase its quality (Salonen, 2009).
- Some hospitals have developed outreach home care services, for instance for people with a handicap, severe illness (needing injections also at night) or palliative care.
- The education level of care workers is being debated, i.e. whether the lower level education (e.g. 6 months) will be reintroduced.

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# France

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## 1. The context of home care

### Country population and health

France is a “central south” European country with a population of 64.6 millions (2010) and a population density of 118/km<sup>2</sup>. Its GNP is worth over 2 trillion US dollars (2009) and average purchasing power is 8% higher than the average in Europe. Demographic state and trends are relatively good with, in 2010, 16.5% of the population being over 65 and 5.2% being 80+ and a 2009 old age dependency ratio of 28%, projected to be 45% by 2050 due to a relative high birthrate (2.05) when compared to European countries. Female life expectancy at age 65 in 2009 was 23 and 18.9 for males, while healthy life expectancy at 65 respectively are 22.7 and 18 years, thus one of the highest for men in the EU and the highest for women. About 36% of women and 33% of men aged 65+ declared (2006) having a long-standing illness or health problem, which is about average for the EU.

### Characteristics of health and social services

Health services are funded by obligatory social insurance. The expenditures on health of about 11.8% of the GNP are far above the EU15 average (8.9% in 2005: (OECD 2009). Also with regard to other health resources, France is above average, i.e. the number of acute beds and beds supply in nursing homes and homes services for the elderly population (OECD 2009). The average length of stay in acute care hospitals is however near the European average. Quality of long-term care is a point of concern, especially regarding home care. The availability of self registered nurses, GPs and specialists (in and out hospital)

is relatively high but with a very high geographical variation (OECD 2009). The frequency of home visits by GPs is sharply declining and transfer of tasks from medical to nursing professionals, although an important theme, is still in its infancy as multi-professional group practices have only recently been on the forefront of the health agenda and solo practice remains dominant. Long term care services are provided either in nursing homes (Ephad) with medical services funded by the National Sickness Fund (CNAM) or at home by Home help and Care Agencies (SAD) or/and by Nursing Agencies (SSIAD). Social services (home help and personal care) are (partially) publicly funded through a care attendance allowance called APA (Allocation Personnalisée d'Autonomie). Also various but still not sufficient types of respite care are available.

### Social indicators and conditions related to old age

According to a 2010 report from HCAM (advisory council for the health insurance agency) about 20% of health expenses was devoted to old age (+75), with individual average health expense per year for an 80+ being about 6,000 Euros. The average monthly pension is worth € 1,000 for women and € 1,600 for men, with only 13% of people aged 65 years or older being at risk of poverty (20% in the EU). The low employment rate of the 55–64 year old cohort shows that aging is considered as a negative rather than a positive status. The employment rate of women, 60% of females between 15–65 being employed (Eurostat, 13-01-2010), is in the middle range, hence an average resource for informal care is available. According to civil code, children have the legal obligation to furnish economic support in case their genitors are financially needy. The “family and social action code” stipulates that the state shall assume responsibility and substitute for the family only if the latter can demonstrate its inability to pay. To benefit from social welfare, older persons must first use 90% of their revenue to pay residential costs (with a minimum remainder of €75/month) while the other family member must have a minimum amount to live of €620.

## Attitudes related to care for elderly people

When it comes to a dependent elderly parent in need of care, the French respondents to the Eurobarometer (2008) survey consider professional home care the best option, more than do Europeans overall (46% of the French compared to 27% of all respondents). Informal care was the second most popular option (36%; in their home or that of their children). However, just 17% (compared to 34% of Europeans) finds care for a dependent elder a task for close relatives even if the career of the carer is affected (TNS Opinion & Social 2007). The state is considered as having the main responsibility to insure access to LTC services. As “voices” informal carers are not politically very strong, Only Alzheimer families have attracted public compassion and are driving most of the financial efforts to find innovative tools to support families (Alzheimer plan, <http://www.plan-alzheimer.gouv.fr/>).

## 2. Policy and regulation on home care

### 2.1 Governance on home care

Even if the “Laroque report” in 1962 defined main principles of a policy targeting the 60+ disabled elderly population called ‘dependent’, it was not until 1995 that it became a political priority. Before 1975 policy consisted mainly of giving limited financial resource to poor elderly retirees with very restricted access to home help services. This changed only slightly during the 1975/1995 period during which actions targeting frail and/or disabled elderly people at home remained rudimentary due to a chronic lack of funding and because residential care even if poorly staffed seemed more adapted. This was in opposition to the policy addressing the needs of the disabled population below 60 and called “handicapped”; the latter are receiving quite generous compensation even after turning 60. A public Personal Autonomy Attendance allowance for non-disabled 60+ (APA – in kind or in cash) was introduced in 2001 (52). A national agency (CNSA: National Agency for Autonomy and Solidarity) was set up to be strategically responsible for the overall “disabled” policy at national level (49). The “General Council” (executive body of the “département” which is a political entity located between region and municipalities (could be coined county) is responsible for organising and regulating home care at local level (50). The law for “equality of rights and opportunities, participation and citizenship of disabled persons” (11 February 2005; (52)) stressed the necessity to begin a convergence process in the assessment, organisation and financing of the care

of the two previously segmented disabled populations. The main principles are treating disabled persons equally, independent of age and geographical equity in access and distribution of care (14,35). This policy was put in action through two successive plans (57,58) setting targets. This evolution has also to be placed in the general context of a labour policy pushing for the development of a personal service’s market in general (meaning not targeting only old persons) and which entails, through competition, giving more choices and options for consumers. In this regard, policy gave financial incentives for people to hire home helpers directly as this is considered a promising way both of creating new job opportunities and cleaning up the grey market (48, 25).

### 2.2 Eligibility for home help and care services

Access to IADL and ADL services and other technical services such as respite care or housing accommodation (see also Section 5.3) delivered at home is not means-tested. That is, in order to benefit from APA any elderly 60+ can directly ask for a needs assessment, as can a handicapped person regarding their specific attendance allowance (called PCH). For handicapped persons younger than 60 years of age, a specific assessment instrument called Geva is used. For 60+ persons, the the Aggir instrument applies. in order to classify an applicant in one of the 6 levels groups ranging from 1 (totally disabled) to 6 (not disabled) each being statistically related to an average volume of services. Only groups 1 to 4 are entitled to APA. APA funded services such as personal care, domestic aid and technical aids can thus be financed. When needed and acknowledged by a medical prescription, technical nursing services are funded through the health sickness fund (HSF) and are thus universally covered. If ranked at disability level 5, an old person has the right to simple home help, funded by the CNAV (National Agency for Ageing) and also from specific financial benefit coming from the Social unit of the National Health Fund. Next to the assessment of disability level, the care plan takes into account the availability of informal carers, the housing situation and (unrelated) medical conditions in assigning care. For in-kind services, client co-payments for the services are dependent upon the client’s disability level and revenues while the older person choosing in cash benefits to hire a home helper is entitled to fiscal exemption or reduction in social charges.

### 2.3 Quality of process and output

#### *Availability of quality criteria*

Regarding personal care and domestic aid, no developed body of national criteria regarding home care quality exists. The National Agency for Evaluation of the Quality of Medical-social residences and Services (ANESM), created in 2005, is beginning to develop such indicators and related criteria. Its first report issued in 2008 deals with “ill treatment”. No national system setting quality standards exist for nursing agencies (home nursing care providers).

#### *Assessment of quality of services*

For the delivery of help and care services to frail elderly persons, home help and care agencies (SAD) financed through APA (2) are subject to different national external regulations: “Authorisation” (delivered on behalf of the health minister applying only public and non-profit agencies) and “Quality agreement” (for all types of home help and care agencies) delivered by the Ministry of Labour. Both systems enable people who are eligible to care to benefit from tax and social contribution exemptions. Both require that care providers prove that they employ staff with expertise corresponding to the agency’s missions and have set up a quality management system and a complaint management procedure. Criteria used are roughly similar if not common with regard to regulating bodies (the local general council or the region). Furthermore, agencies are responsible for monitoring the work of their employees, which occasionally involves home visits (33). But the monitoring does not always appear in the annual report supplied to the General Councils (40). Also SAD, unlike nursing agencies (SSIAD), are legally obliged to set up an annual satisfaction survey, which they do not have to disclose.

With regard to nursing agencies (SSIAD), delivering technical nursing services or personal care, no obligation exists for quality assessments of the care delivered by nurses or nurse’s assistant. Legally, Nursing Agencies are under the control of the Regional Health and Social Affairs department (DRASS) but controls are far from systematic. Each nursing agency is free to establish its own quality control procedures, which they do in a limited way and criteria are proprietary and not public.

#### *Accreditation and clients complaint procedures*

A new obligatory certification scheme has been launched by ANESM for all home help and personal care agencies.

Other forms of private certification such as AFNOR quality certification for personal services (NF X50-056 standards) are increasingly sought after. For nursing agencies, no accreditation scheme exists. Hospital at home agencies (HAH) caring for patients with sub acute pathology or/and complex chronically ill with disabilities are regulated as traditional hospitals and are thus subject to accreditation procedures.

Internal complaint procedures exist and are obligatory for home help and care agencies, but as they are not well known they are infrequently used. Furthermore, there is no national data about the functioning and impact of the complaint procedures.

### 2.4 Quality of input

Professionals in home care are:

- home helpers/home aids (level 1); provide mainly IADL related tasks; possibly having attained an ‘Assistant de Vie Familiale’ diploma.
- Auxiliaire de Vie Sociale (AVS) (level 2/3); additionally performing personal care services (same tasks as a nurse assistant, but not to people with disabilities linked to chronic illness).
- Nurse assistant, providing help with IADL, and allowed to perform personal care but under nurse’s supervision, two years training leading to national diploma.
- Registered nurses, providing personal care but mostly technical services licensed after a 3½ year training).

Services designed to maintain or restore individuals’ autonomy (primarily ADL and IADL services) are legally defined at the state level. Education and training courses for any type of home worker are defined *jointly by the labour and health and social ministry and candidate* may apply for at least 6 different types of qualifications, the most frequent being the AVS diploma (38). Still despite policies aiming at enhanced training programmes for home help and care sector, 75% of people working in SAD had no professional qualifications in 2005 (68). The control on staff’s professional expertise is higher on non-profit agencies than on intermediate agencies (which only provide home workers to old persons).

The profession of registered nurse is legally protected by their diploma; and their diploma has national trade

references on behalf of the Ministry of Health and Social Affairs. Some overlap and/or substitution between nurse assistant and home helpers regarding “simple” personal care may exist and also between self employed nurse and nurse assistant working in SSIAD for ADL relating to ill old persons. No recertification scheme exists for either nursing profession.

## 2.5 Incentives for providers of home care

There is no competition between home nursing agencies (SSIAD), nor between them and home help and care agencies (SAD), as neither are particularly numerous or fast-expanding and also because, in principle, they each address a different public. In rare cases requiring complex nursing and technical care, nursing agencies may be in competition with hospital at home agencies. But competition mainly exists between different types of home help and care agencies: as they may be public or private (for and not-for-profit). Private for profit agencies are beginning to penetrate the market (20%) and to compete with the more numerous (60%), long-standing, non-profit ones. But up to now no studies have demonstrated any positive impact in efficiency. Some local authorities through their tariff setting power are trying to lower their expenses. Competition entails provider’s obligation to secure a balanced budget while keeping staff’ working conditions at an acceptable level. Services differ according to staffs working conditions. Operating agencies (employing home care workers) are at a financial disadvantage with intermediary agencies or direct employers, while being the most able to guarantee the quality of the services (expert opinion).

## 3. Financing

### 3.1 General funding

Public funding of long-term care was estimated to be averaging €23 billions in 2008 (IGAS) (1.20% of the GBNP, with about €6 billions being spent on home care (to compare with 2.5% of health care expenses in 2005 spent on the ambulatory sector (OECD, 11-05-2010). Home care is financed by a mix of social insurance premium and general and local taxation, i.e. resources stem from the National Health Fund (NHF) (60 %); from CNSA specific funds (15 %); from general council contribution (20 %); and direct state contribution (2 %). All these resources transit to CNSA, which redistributes the funds to General Councils which allocate these funds

to all providers of non-medical home services, while technical nursing services are directly paid by the NHF. An important fraction of personal and home help care is financed by the clients and/or his family via co-payments (for publicly covered services) or directly out of pocket money (for non-covered services). The average overall financial out of pocket contribution for home care is estimated to be around 800 Euro per year. However, it may range from zero to 80% of the total costs for services included in the care plan, according to the client’s position regarding disability level, revenues and entitlement for fiscal exemption or reduction or social welfare benefits (39). Additionally, in 2008 3 million different types of private disability insurance contracts existed but only 0.5% were activated (<http://www.ces-asso.org/sites/default/files/Courbage.pdf>, 23/12/2011).

Day care, technical devices and housing accommodation are also financed jointly by CNSA and NHF. The client either has to pay out of pocket for uncovered services or the General Council may allow an extra legal financial contribution for poor people, on a voluntary basis.

### 3.2 Financing home care agencies

Only authorized or agreed home help and care agencies delivering both home help and personal care to frail elderly persons or disabled persons younger than 60 are financed by public money. In this case, most of them can apply to receive extra funds for patients under social welfare. Each year they negotiate their budget with the General Council that sets hourly tariffs applying to services delivered by their salaried staff. Nursing agencies and hospital at home have also to be registered with their regional regulating bodies (DRASS) in order to receive public funding. Agencies providing hospital at home care are financed by the NHF through a specific case mix system based on activity with tariffs fixed at national level. Nursing agencies receive an annual overall budget coming from NHF based on the number of allowed day cases decided by the health regional authority (DRASS) and a national day price.

### 3.3 Prices setting of home care services

Services have fixed prices determined through different technical bargaining processes according to their type. ADL and IADL services provided by qualified professional are each classified in terms of a standard time and the tariff of a personal carer is fixed at national level

through negotiations. Each medical service and technical nursing service listed in the NHF classification of services has been priced taking into account direct and indirect costs, capital costs and its complexity. For technical devices such as infusion pumps or respiratory machines the costs are fixed by the NHF according to specific rules, after negotiations with firms. All APA recipients need to co-pay unless they are below a certain threshold (€650 per month) according to their income. There is an APA ceiling amount for each disability category/level; in 2009 the average amount was 28% below this threshold.

## 4. Organisation & delivery of home care

### 4.1 Access and needs assessment

The individual needs assessment is usually performed at home by a nurse or a social worker approved by the General Council, depending on the existence or not of an associated illness. A GP's referral is not necessary, but in the case of a pre-existing disease the referral can also be done by a nurse on behalf of GP orders or by the GP themselves, but the General Council staff will then have to confirm it. For handicapped persons below 60 a similar process exists but with a different assessment tool (GEVA) and performed by multi professional staff of the resource centre for handicapped person (MDPH), which is managed by the General Council. Either at the same time or separately, the General Council staff will set up the care plan. It is then up to two separate commissions of the General Council to decide the type and level of services the older person or handicapped person will be allowed after the corresponding care plan has been agreed by the GP.

### 4.2 Delivery of services

There also exist about 10,000 home agencies (providing domestic aid and personal care; SAD) working in the market of care for frail elderly people, with different labour status: 10% are public; 70% are private non-profit and 20% for-profit, but the latter are growing. Home help and care agencies are managed by organisations which may also run nursing agencies (providing technical nursing and personal care by certified nurses and nursing assistants) and sometimes run nursing homes. Each of these organisations belongs to an umbrella organisation, while employees are regulated by umbrella labour agreements. These agencies may have salaried staff (and are then called 'operating agencies') or act as

intermediary organisations by providing clients with home care professionals, but it is the old person who is the employer. According to unpublished data of 2008, around 2300 nursing agencies exist, 70% being not for profit, 5% public and 25% for profit. Nursing agencies, whether they are freestanding or belong to a common organisation with SAD, are covered by the same umbrella organisations but with a different labour agreement from SADs.

### 4.3 Coordination and integration in home care

There are some rare cases of efficient geriatric networks. However, nursing agencies (SSIAD) and home help and care agencies (SAD) usually operate independently. Hence, coordination within the home of the recipient is usually weak. Even when both agencies operate under the same organisation coordination is usually not optimal, as integration between staff does not really exist. Also coordination between home and residential care is weak, even when one organisation runs both, as types of staff are managed completely separately. Case managers who may bridge the gap are rarely involved (with the exception of some experimentation (see section 6). Structured links with hospitals are rare. Discharge management is not frequent and the employment of nurses called "liaisons" is an exception. Links between all types of home help and care agencies on one side and self-employed nurses and/or GPs on the other side are not formally organised. So the variation may go from no link at all to a complete integration in very rare networks. Due to new financial regulations by the NSF, GPs' home visits have sharply declined in number while contact with agencies may be required more.

### 4.4 Actors and human resources in home care

#### *Actors*

The main organisations involved in home care are:

- The Ministry of Health with its central administration (department for health (DHOS) and for social services (DGAS)) develops national legislation, and regulation for access, quality and efficiency of all type of home care.
- The General Councils; regulate home agencies in term of access to the market, setting tariffs, financing all settings and monitoring quality.

**Table 1:** *Human resources in home care in 2007*

Functions	total number (est.)
Domestic aid (aide ménagères) level 1	390,000
Home workers (AVS) level 2–3 not necessarily licensed	460,000
Assistant nurses in nursing agencies	30,000
Registered nurses (contracting with nursing agencies)	29,000

From Ecosante 2009, <http://www.ecosante.fr/>

- The Ministry of Labour is responsible for setting help and care services prices and in regulating social workers.
- The NHF is responsible for defining the types of nursing care services to be delivered at home, and in pricing them with their respective co-payment levels. It also reimburses all medical services delivered at home by free (or independent) nurses, working on their own.
- The CNSA (National Agency for Autonomy and Solidarity); responsible for funding, professionalization of home workers (together with the National Agency for user's services) and for stimulating innovation in home care organisation and research.
- The Anesm (National Agency for Evaluation of the Quality of Medical-social residences and Services); responsible for setting quality indicators and criteria for good practise and also of the certification process.
- The Regional Health and Social Affairs authorities (DRASS); planning location and number of nursing agencies and in monitoring their activity.
- The CNAV (National Agency for Ageing), together with the social department of the NHF, also funding some simple domestic work and extra legal social welfare measures (meaning not coming directly from the state).

#### *Human resources*

As becomes clear in Table 1, the majority of the people working in formal home care are domestic aids.

Home helpers may be salaried by operating agencies or employed by clients directly or through an intermediate agency. The working conditions of home workers depend on their labour status. A licensed home worker's full time salary is about 1.2 the minimum salary. The financial advantage of having a diploma and working in

an operating agency is weak and in order to work full-time they have to care for 3 to 4 clients. So, licensed care workers prefer to work directly employed or through intermediate agency as they will care only for one or two older persons (and sometimes get extra money from their clients). Others leave to go to nursing homes for a better working environment and again others move to more socially recognised sectors such as mother and children care. While assistant nurses (AS) are always salaried, most registered nurses are self-employed and paid fee for service as are those working under contract with nursing agencies. They are socially well considered and have a high support from the population but have to work more than 50 hours on average to get a fair income (average salary is €2200 – 2.2 times minimum salary compared with 1.4 times for assistant nurses).

#### 4.5 Use of tele-care

The use of alarm systems and other telecom applications are applied on a limited scale, but the use is slowly. Most common are personal alarm systems. Internet based facilities (e-domotica) and home telemedicine applications are still rare despite the pressure of firms working in this field. And video based communication and counselling still do not seem to match real needs of recipients and their carers (with the exception of some recent ones using smart phones) (12,19).

#### 4.6 Monitoring the adequacy of care

Care assessment is legally supposed to be reviewed at least once a year. This renewal process should be adapted according to the changing needs of clients and monitored by home care workers and nurses under the supervision of the agency's coordinator. But no uniform procedure exists, and there are neither local nor national data.

**Table 2:** Long-term care provided at home and in institutions 2007/2009.

Recipient groups	Recipients of home care 2009 (60+)	Recipients of care in institutions 2007 (60+)
% females	74%	75%
% 60+	686,000 (APA only)	657,000 (84% with APA)
% 80+	Not available	74%

Source: from Drees (23, 32).

## 5. Clients & informal carers

### 5.1 Home care recipients

For home care, data concerns only APA recipients who are all 60+. For institutions, data concerns all residents among which 84% are entitled to APA. In June 2009 more than 1,170,000 persons over 60 were entitled to the APA care attendance allowance, among which 61% left home. Among the 75+ population 17% were entitled to the APA. Also 300,000 people aged over 60 years, assigned a GIR5 level, receive home help financed by CNAV and the Social Department of NHF. From these figures, and adding the 170,000 persons receiving the ACTP/PCH allowance (with an estimate of 50% receiving home care), the overall disabled population in 2010 can be estimated at around 1.6 million, which roughly corresponds to data coming from a recent estimation based on data in the general population (HESM 2008 survey).

### 5.2 Coverage and unmet care needs

Surveys have also shown that for APA recipients with the highest disability level the care plan does not cover the real needs. So some services may not be delivered unless gaps are filled by subsidies (e.g. from General Councils) other than APA. Next to a lack of financial resources are also shortages in professional resources, entailing unmet needs for people with no informal carers in their family or/and in the community. In some areas there is also a lack of home help and care agencies, leading to obstructions in timely hospital discharge.

### 5.3 Empowerment of clients

In theory the clients can choose their own home care providers. In practice, choice may be distorted for several reasons. It may result when their 'voices' (or those of their informal carers) are not taken into account during needs assessment and the care planning process. Or it may arise

from a lack of information, although more and more, there exists a unique point of entry to services whether at municipalities level (CCAS, CLIC) or at "department" level (MDPH, MAIA) that such as CCAS, CLIC, or MDPH, where an older person and/or her family can find all the required information regarding the availability of home help and care agencies. However, no national assessment has been done regarding these organisations' efficiency. Also the possibility to choose among various providers may be limited by the assessment team which may favour operating agencies against others types or against direct employ (experts). In some areas there is a shortage in home care workers, forcing clients to move into a nursing home, or conversely in some areas there is a delay in hospital discharge due to the lack of nursing homes or nursing care agencies. Finally, an APA recipient needing many hours of personal care may, for financial reasons, directly hire a home worker, for example by using prepaid vouchers linked to social and fiscal incentives to pay him ('Cheque emploi service universel'), or indirectly through a contracting agency because of differential costs. Even if there are no data to provide evidence, many experts believe that there exist high risks of poor quality for delivered services, due to weak control over the workers directly hired. So there is a risk that financial empowerment may leave to negative outcomes. Control is much more stringent for the PCH and, furthermore, the level of the PCH allowance is about twice the amount for APA recipients with a similar level of disability. Low socio-economic status and age are also a strong barrier at the individual level. At a political level, contrary to the empowerment of the handicapped population below 60, where advocacy groups are powerful, advocacy groups defending the position of informal carers of old people are numerous but not powerful at national level, having low financial resources and degree of expertise. In this regard also the 2005 law calling for a convergence between the two populations (disabled persons below 60 and those over) did not bring substantial changes to the power of informal carers' advocacy groups.

#### 5.4 Informal carers

Informal carers are called “natural helpers” so they are considered more as “co-workers” than clients whose needs and preferences should be acknowledged and answered. They have no voice in the assessment process and cannot apply directly or respite care. Even if it is acknowledged that their health may be at risk, they are “morally blamed” if they refuse to intervene in the caring process. Consequently, little support used to be given especially to help them reconcile work and caring. In general, flexible working arrangements are not formally authorised or favoured by firms, even if carers may take work leave in order to care (46). Only recently (2010) and in case of terminally illness, informal carers are entitled to a paid work leave (47 Euro/day), but only for 3 weeks. The care provided by formal carers is also usually not coordinated so the family will frequently be forced to take the role of “informal coordinator” with a weak legitimacy and thus with very little support coming from professionals.

#### 6. Disparities in the process of home care

Discrepancies between theory and reality are relatively important in France as evidenced by the vignettes:

Even if any client can apply (in many ways) for home care, there are important differences in the information people have regarding their rights but also in how the overall system functions. Furthermore, the process of assessment is not done reliably at nation level though teams use the same instrument. So old person with comparable needs may be granted different level or type of care while not all clients generally receive the care that they are entitled to as some restrictions apply when informal carers are potentially present. Also:

- The receipt of home care services depends on the general councils that may disclose differences in resources or in home care policy. Regarding person with low resources, some GCs may cover specific services not covered by APA like respite care or public transportation or technical aids while other will not. This correlates with acknowledged strong variations in GC expenses for social policies at large.
- The level of co-payment varies with revenues.
- Quantitative reductions of care may exist due to shortages of personnel in some areas but also qualitative due to the use of untrained staff or unrealistic time restrictions for specific activities

due to biased tariffs. Furthermore, it is not easy for recipients to change home care agency when dissatisfied.

- The amount of the APA allowance reported to be insufficient in some cases to pay for the entitled care (because the prices for services included in care plan are higher).
- There exist large social inequalities in home care as financial incentives are biased toward the rich and the latter are also more flexible in using services at their will.

#### 7. Concerns and new developments in home care in France

Current concerns are numerous and relate to at least six domains:

- *Insufficient funding*: The ongoing and second ministerial plan for elderly people (‘Plan solidarité grand âge’) clearly needs more funding than is currently reserved for long-term care in order to achieve its goals. (68).
- *Poor assessment instrument*: The national assessment tool (AGGIR) is seen as having poor validity, reliability and reproducibility. Also it may be that the amount of care accessible through APA does not allow real care needs to be met, and/or that the care plan does not correspond to needs. (32).
- *Lack of equity* due to territorial disparities in home care services provision and financial access. A high level of out-of-pocket money is needed despite the use of prepaid vouchers to pay for directly employed home care worker (‘Cheque emploi service universel’). Additionally, social welfare benefits are unfairly distributed, i.e. not only are APA co-payments relatively higher for the poor, but also the fiscal incentives have anti-redistributive effects as they do not target the elderly population enough and favour the better off. (15, 38, 40).
- *Shortage of qualified workers*, related to difficult working conditions and low levels of remuneration and social recognition. Not only is the number of jobs in the home care sector far from reaching expectation, but the quality of these employees is poor (13, 24).

- *Lack of quality monitoring*: The quality monitoring system is still in its infancy, despite the effort of CNSA to stimulate innovative practices and the work done by national agencies such as CNSA, Anesm and ANSP (National Agency for User's Services). Crucial moves to increase the quality include controlling commercial agencies and better regulating direct employed workers (40, 31).
- *Lack of informal care support*: informal carers are still supposed to care while the oldest generation is itself ageing and the younger ones have to balance between caring and working, especially those who are middle aged women caring still for their children and for their ageing parents (sandwich generation). (43,53, 60).

**Several developments** can be discerned with regard to home care. First of all, a core policy element between 2001–2007 has been transcending the age barriers. The CNSA has been created, whose mission was not only to consolidate long-term care funding but also to facilitate reconciliation of care processes of the previously segmented population of the 60- and 60+, while enhancing research and speed up the creation of new tools and innovations in long-term care organisations. The transcending of the age barriers was planned to begin with the convergence of the respective assessment tools and care planning process (in 2013). Assigning a high position on the political agenda, political and appropriate financial provision to universal access for long-term care (and thus home care) was the second step. But the financial and economic crisis has led to a more “budget” than “socially” led approach. Not only the assessment tools and the planning of the care are still to converge, but the public financial resources will remain in separate silos on the (disputable) conception that disability linked to ageing is under the individual responsibility contrary to the one linked to life accidents. This view in combination with the financial crisis, as lead government in order to prepare the debate for a structural change planned for 2012 to propose through a parliament report (<http://www.assemblee-nationale.fr/13/rap-info/i2647.asp>) that individual buy privately a long-term care insurance – access to being improved by fiscal incentives (21, 28) with a mutualisation into a fund in order to secure the collected premiums, with limiting access to publicly funded services only to the more precarious ones and/or to the most disabled ones (GIR level 1, 2 and 3). Reinforce the age barrier with the handicapped population regarding universal access as (30, 38 bis). Also a person considered as ‘wealthy’ (threshold to be fixed

between 100,000 and 150,000 euro per year) would only receive the full APA corresponding to their disability level if they accept that after their death, the state recovers a fixed percentage of the funded amount, otherwise they will get only 50%. But after a hot debate in the mid 2011 and under the pressure of the financial crisis, all reforms were postponed to the end of the presidential election (May 2012) Another development is that policy makers claim the need for a dedicated policy to support informal carers. However, directed to secure their availability, this claim has not been yet followed by many practical measures, with the exception of Alzheimer sufferer's families. Also the issue related to the illegal employment of immigrants (which real scope is unknown as “ethnic” statistics are forbidden).

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# Germany

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## 1. The context of home care

### Country, population, and health

In 2006 82.54 million people lived in Germany in a territory of 352,022 square kilometres (approximately 230 persons per km<sup>2</sup>). Of these 15.4 million inhabitants had a foreign ethnic background. Increasingly, Germans live in single-person households (39.4% in 2009) (Statistisches Bundesamt 2009a).

About 20% of the population are 65 years old or older and by 2050 up to 40% of Germans will reach or exceed 65 years of age (Statistisches Bundesamt, 2006a, 2009a). Differences in life expectancy represent the “heritage” of the German division (Hoffmann et al., 2009). On average, the life expectancy at birth amounts to 76.1 years for men and 82.1 years for women. But in the territory of the former GDR it is still 1.4 years (men) and 0.3 years (women) lower than in the territory of the former Federal Republic. Currently, every other male German survives at least his 79th, every other German woman at least her 85th birthday. The linear increase of life expectancy will amount to two years per decade (ibid). The current group of 85+ year-olds (3.7 million people) will increase to 6 million by 2020, and to 10 million by 2050. This means that the oldest population will become almost three times larger than it is today (ibid.). One reason for this is the continuously low birth rate.

As a consequence of societal aging, health problems have changed in Germany, even within the aged population, in particular of the “young old” up to the age of 75 years of age. Health status has been improving for years. At the same time, huge socio-economic differences in health

status have become obvious (Birg & Flötmann, 2002): It is evident that only the better educated persons with a higher income benefit significantly from the increase in life expectancy and from the related health improvement. Nevertheless, other circumstances prevail as far as the oldest old are concerned. A large proportion of them suffers from multi-morbidity. The micro-census of 2005 has shown that 17% of the population between 65 and 69 years of age suffered from more than one disease. This status was found in 24% of the group between 70 to 74 years of age, and in 28% of those 75 years of age and older (Statistisches Bundesamt, 2006). A high percentage exhibited functional loss (Menning & Hoffmann 2009).

### Characteristics of health and social services

Around 51 million Germans are members of the statutory health care insurance required by law that covers their dependents as well. Additionally, 11% of the population (e.g. civil servants, persons running their own business) are privately insured. Only 211,000 individuals did not have any health insurance coverage in 2007. Approximately 10.6% of the GDP are spent on healthcare for the German population each year (245 billion Euros in 2008) (Statistisches Bundesamt, 2008a).

A variety of health services are available and frequently used by the majority of Germans: 2,083 hospitals treated 17,520,000 cases in 2008. The average length of stay amounted to 8.1 days. In the same year, 319,700 physicians worked in hospitals, practices, and other facilities. Of these, 71,262 physicians had a single person practice, 19,152 worked in group practices, and 6,647 in 1,378 Centres for Health Care (Kassenärztliche Bundesvereinigung, 2008).

Elderly persons constitute the largest group of health care clients. According to the micro-census survey, up to 3% of the 65+ year-olds, but only 1.5% of persons under 65 years of age were hospitalized within the last four weeks before the completion of the micro-census survey (Statistisches Bundesamt, 2006b). The highest

hospitalization rates were found within the group of 80 to 89 year-olds, that also has the longest stays. Hospitals are increasingly relevant as an instrument for the regulation of streams of the aged health care clients. The decision whether a person will be referred to a nursing home, or whether he/she will stay in community care mostly is accomplished in a hospital – 19% of nursing home residents were admitted from hospitals in 1994, but in 2004 this proportion increased to 24% (Schneekloth, 1995; Schneekloth et al., 2006). The utilization of GPs or physician-specialists by elderly people is very frequent as well. Even persons, who do not have urgent health problems, are among the frequent visitors of doctors because general practitioners and physician-specialists are not only responsible for their treatment, but also for their referral to health care services, such as home nursing. The insurance data have shown that 81% of the women between 65 to 69 years, and 92% of the women between 85 to 89 years visited a general practitioner or practicing physician-specialist within a time span of three months. The figures for men are similar. The frequency of contacts was high as well (Garms-Homolová & Schaeffer, 2010).

The geriatric infrastructure within the health care sector is still not well developed. About 10,600 places for so-called “acute geriatric treatment” are integrated into general hospitals in Berlin, Hamburg, Bremen, Hessen, Schleswig-Holstein, and Thuringia. Another model exists in the remaining federal states with 6,512 places available in specialized geriatric rehabilitation facilities. However, elderly people are overrepresented even in those rehabilitation clinics that do not specialize on geriatrics, but are dedicated to the general population – 31% of all users of in-patient rehabilitation were 65 years and older (ibid).

Long-term care represents a separate pillar of the care system. It means that a special insurance (Social care insurance – *soziale Pflegeversicherung* – Social act XI) is responsible for the allocation and reimbursement of long-term care in institutions or in the community. In 2007, 710,000 persons lived in long-term care facilities (Statistisches Bundesamt, 2008b). The number is steadily increasing, and the infrastructure of long-term care facilities is expanding: up 4.8% from 2005 to 2007 (Bundesministerium für Familie, Senioren, Frauen und Jugend, 2009). The average age of the residents was 82 years. Most were suffering from chronic diseases, 50% to 80% of the resident were mentally impaired, or suffered from dementia or psychiatric disorders (Wingenfeld & Schabel, 2002; Garms-Homolová

& Schaeffer, 2010). Persons whose functional status is not severely impaired only rarely live in long-term care facilities (Garms-Homolová & Theiss, 2007a,b) that have increasingly become a place for care in the end stages of life. Many long-term care facilities provide services of low quality. This may also be one of the reasons why the nursing home is almost never a “free choice.” But the market of alternative forms of housing and care is growing e.g. multi-generation communities, care apartments, group housing, assisted living. The residents of all of such kind of housing are frequent users of the home care.

The home care sector is divided into two parts:

- home nursing that belongs to the health sector and for which the health care insurance is responsible,
- home care that belongs to the long-term care and for which the long-term care insurance is responsible.

However, the existing 11,529 home care agencies (Statistisches Bundesamt, 2008b) mainly provide both home nursing and ‘home care’ (only about 22% of clients use long-term home care without simultaneous utilization of home nursing – Garms-Homolová & Roth, 2004).

Details on both services (their eligibility, provision, and payment) are presented in the following paragraphs.

#### Social indicators and conditions related to old age

In 2008, 38.73 million Germans were in the labour force. They earned a total GDP of € 2,489.40 Million (Statistisches Bundesamt, 2009b). In 2008, the average annual gross income of full time employees amounted to €41,465 in the “producing branches” and to €33,802 in the service sector. An extreme inequality between men and women has been found: The hourly income of women was €4.39 lower than the income of men, on average. Around 15% of the population were at risk of poverty in 2008 (classed as income lower than €764 a month for a single person household, and €1,605 a month for a two-person household). This was the case for 36% of all women aged 65 years and over, but only for 12% of men of this age category (ibid). The risk of poverty differs based on the place of living; it increases from the south to the north, and from the west to the east.

### Attitudes related to home care for elderly people

Family care is very important in Germany. Surveys have shown that many elderly people are expecting to be cared for by their children, if care should become necessary (Garms-Homolová & Theiss, 2007a,b). The official policy counts on the relatives as well. For this reason, the long-term care insurance has been established as a subsidy, but not as a substitution of informal care. Care-giving relatives can use a number of advantages:

- benefits in money to compensate a part of their efforts,
- relatives and informal caregivers take courses in care giving, and use counselling free of charge,
- work as a family caregiver can potentially increase the retirement benefits.

The newly introduced update of the social insurance for care (*Pflege-Weiterentwicklungsgesetz*) aims at further improvement of the situation of family caregivers:

- Care centres were created to provide persons in need of care and their relatives with information, advice, and case management to make accessibility to professional care easier;
- Relatives can take unpaid leave to organize care for their impaired family member.
- Generally, children are committed to support their old parents in need. The amount of support depends on their income. The decisive criterion is that of “reasonableness”, meaning that children have the right to keep a sufficient amount of money for their own purposes. A single child must pay only, if his/her income exceeds € 1,400 per month, a married child can keep € 2,450 per month at his or her own disposal. If adult children have children themselves, care for them has priority.

## 2. Policy and regulation on home care

### 2.1 Governance on home care

In Germany, home care has precedence over the institutional care in facilities: everyone ought to stay at home as long as possible but the benefits provided by the long-term care insurance are not currently supporting this principle. The amount of money for institutional care

is much higher than for care in a private household. The new *Pflege-Weiterentwicklungsgesetz* (care extension law) introduces a gradual increase of benefits for home care.

### 2.2 Eligibility for home care services

Members of the long-term care insurance (SGB XI) or their dependents are eligible for benefits, if they are recurrently unable to fulfil basic ADLs (to a part also IADLs) for at least six months. This home care consists of ADL care, to a certain part IADL care and some basic nursing and light supervision of simple medication. Two forms of benefits for home care are available: benefits in kind and benefits in money (that only can be allocated if informal care by relatives amounts at least to 14 hours/week). If a person is recognized as eligible, he/she is classified into one of three degrees of benefits according to his/her need:

- Degree 1 is for persons who need 90 minutes of help in at least three ADLs (once a day) and with IADLs (once a week). This help is provided for at least 45 minutes). About 60% of beneficiaries are classified as needing Degree 1.
- Degree 2 is for persons who need help in three ADLs (three times a day) and in IADLs (once a week). The time needed daily amounts to at least three hours (including at least two hours of basic care). About 30% of beneficiaries are classified as needing Degree 2.
- Degree 3 is for persons who need help in three ADLs (around the clock) and in IADLs (once a week). The time needed daily amounts to at least five hours (including at least four hours of basic care). About 10% of beneficiaries are classified as needing Degree 3.

Eligibility for “home nursing” is regulated differently. It is inseparably connected to “need for treatment” out of hospital (§§ 37 SGB V). A prescription by a GP or another physician is required, and possible, if the home nursing:

- makes medical treatment at home possible.
- helps to shorten the hospital stay.

#### Technical aids

Claim entitlement is defined in § 33, Section 1 of the Social Act V (SGB V, Health Care Insurance). Insured individuals can receive visual and auditory aids,

prostheses, orthopedic aids, and other devices that are necessary to ensure the success of the treatment or to compensate for a handicap. The following requirements must be met:

- A medical prescription is necessary.
- The devices are needed directly for the treatment or prevention of an illness.
- The allocation of devices must be reasonable from an economic point of view.

The entitlement to technological devices and consumables for persons receiving long-term care benefits is regulated by the long-term care insurance (Social Act XI). Technical devices include, for example, care beds and equipment, wheelchairs, walkers, orthopaedic devices, such as prostheses, lifting devices to help with personal hygiene, emergency call systems, and electric kitchen devices (that compensate IADL disability). These devices require a co-payment of 10% up to €25. Consumables are covered by the long-term care insurance for up to €31 per month; the client must pay costs above this amount.

### 2.3 Quality of process and output

The long-term care insurance law (SGB XI) offers a general regulation of quality management and quality assurance. The Medical Service of the Leading Organization of Health Funds (MDS) is responsible for the development and specification of the concept and its implementation into actual procedures. This institution is the most important consultant of the Health Funds on the quality issue. On the local or regional level, the so-called MDK (Medical Service of the Health Insurance Institutions) is in charge. Its tasks are control of the quality rules and monitoring according to a treaty that has been agreed upon by all partners involved: the LTCI-institutions, representatives of care providers on the federal level, and finally, regional providers of social subsidy.

Care providers are obliged to introduce an internal quality assurance in their agencies (§ 72, section 2, SGB XI). The regional MDK examines, whether the requirements are fulfilled (§ 112 SGB XI). The purpose of the examination is the quality of life of clients. Two kinds of examinations are possible. On the one hand, the MDK is committed to reacting to complaints of clients. On the other hand, random samples of agencies are examined. Recently, it was decided that the examination would take

place without advance notice. The summary of results is published. A regular benchmarking is in preparation. Additionally, many home care agencies use the audits and certifications by commercial agencies certifying quality (EFQM, DIN, ISO, EN, etc.).

### 2.4 Quality of input

The existing law (SGB V and SGB XI) uses the term “*Pflegefachkraft*” (expert in care). This term that has to signal some professional expertise is general and is not congruent with the officially recognized titles resulting from professional training. Usually, qualified nurses provide medically-oriented nursing covered by the health care insurance; otherwise, the insurance institutions would refuse reimbursement. Home care has to be provided by fully qualified “nurses for the aged” (Altenpfleger), the IADL-care by home-helpers whose training lasts between one year and three months only. The law also describes requirements regarding the leadership of home care agencies (SGB XI, § 71, 3). Most often, a fully qualified nurse is the head of staff (a total of 10,100 persons held such a function in 2007). Other home care agencies are lead by fully qualified nurses for the aged (Statistisches Bundesamt, 2008b, Bundesministerium für Gesundheit, 2008).

## 3. Financing

### 3.1 General funding

In 2007, spending for home care amounted to €7.9 billion, an increase of 6.7% (€500 million) over the course of one year. The cause of the increase was medically-oriented nursing (Statistisches Bundesamt 2008a). Selected “payers” in 2007 were:

- The public budget (states and communities): €444 million,
- The statutory health insurance institutions: €2,374 million,
- The statutory long-term care insurance institutions: €2,808 million,
- Private insurance institutions: €108 million,
- Private households: €2,024 million (Statistisches Bundesamt 2008a).

As the long-term care insurance benefits are said to be generally insufficient to cover home care costs, co-payments are usually required (Rothgang, 2010).

### 3.2 Financing of home care agencies

The development of a market for home care and the privatization of services were among the most important aims proclaimed when the long-term care insurance was introduced in the mid-1990s. Therefore, public involvement with the funding of agencies or providers remained limited. It is available only in eight federal states; communities of some of them subsidize the agencies on a voluntarily basis. In some states, the contribution is dedicated to the staffing; in other states, the purpose is the development of the infrastructure (Bundesministerium für Gesundheit, 2008). The main income of the agencies comes from the “selling of care and other services” to their clients. The insurance institutions reimburse the expenses for individual cases (benefits in kind in the area of long-term care – according to SGB XI or in the area of home nursing according to SGB V). Some of the money is given to the clients to purchase the necessary care on their own (benefits in money).

### 3.3 Price setting

The price setting is regulated by law in the act on long-term care insurance (SGB XI, §§ 89, 90, 91) according to the following principles:

The price is negotiated between the long-term care insurance institution and care providers. Some exceptions are possible for those care providers who must negotiate directly with clients (§ 91). In such cases of “direct payment”, the amount of benefits must not exceed 80% of the benefits in kind. The criteria of the price setting must not be different for individual clients. The partners that have to be involved in the negotiation are the long-term care insurance institutions, and the local or regional representatives of the care providers. The time needed for the service provision can be taken into account. For some activities, a flat rate is possible. Each care provider gets an individual contract with the long-term care insurance institution.

The federal ministry on health is authorized to set a price list for long-term care at home (ADL care, to a certain part IADL care and some basic nursing and light supervision of simple medication), in particular for

tasks that obligatory belong to home care. The price has to correspond with the effort, and can be adjusted to regional differences.

## 4. Organization & delivery of home care

### 4.1 Access and needs assessment

Mandatory rules for the assessment of needs have been set down in the guidelines of the association of care insurance institutions for assessment of need for care as outlined in the Social Act XI on March 21, 1997 (updated in 2009).

A person who wants to get benefits in money or in kind has to send his/her application to the long-term care insurance institution. A range of additional information is needed (on existing diagnoses, on the use of home nursing, on treatment by a physician, and on hospitalization). These documents are evaluated by the MDK that visits the applicant at home (or in the hospital, if the person is currently hospitalized) to complete an assessment. An expert (nurse or physician) working in the MDK or an assessor authorized by the MDK usually completes this task. The choice between a physician or a nurse depends on the complexity of the individual case.

The Social Act XI (SGB XI §§ 17 and 53) sets up the rules for the eligibility and the assessment that is the basis of the claim entitlement. The rules have been in place since the introduction of the long-term care insurance and are based on the mandatory guidelines of the association of care insurance institutions for assessment of need for care as outlined in the Social Act XI on March 21, 1997. The guidelines are being adapted continuously (last updated 2009).

Criteria of eligibility that are applied are described under 2.2.1 above. Additionally, the following aspects are assessed:

- availability and capability of informal caregivers,
- time that was/will be needed to provide care giving in the individual case,
- location of the apartment and equipment,
- the fact that rehabilitation has priority over care and that home care has priority over institutional care.

As a next step, the MDK prepares a recommendation that is directed to the long-term care insurance institution responsible for the final decision on eligibility, entitlement to benefits in money or in kind, and for the allocation of home services or admission to an institutional facility.

#### 4.2 Delivery of services

- 504,000 individuals in private homes use organized professional home care services. They are served by 11,529 home care agencies, 57.6% of which are owned by private (commercial) organizations that are working “for profit.” 40.6% are owned by charity organizations, and 1.8% by public institution (communities). The development of home care infrastructure is progressing; the number of agencies increased by 5% between 2005 and 2007 (Statistisches Bundesamt, 2008b).

The number of clients per agency varies considerably: 9.8% of the agencies are very small caring for up to 10 clients only, while 17% of the agencies have between 36 and 50 clients. Only 7% of services have more than 100 clients. Agencies under private (commercial) ownership are smaller than those run by charities or communities – 13% of the private agencies only have up to 10 clients, a quarter of all private agencies served up to 15 clients, and the median is 18 clients, and only 3% of these agencies provide care for more than 100 clients. Agencies run by charities have considerably more clients (30% have more than 70 clients, one third has between 36 and 70 clients) (ibid.).

#### 4.3 Coordination and integration of services

A sharp dividing line exists between home health care (especially nursing) and home long-term care. Funding, the law, the provision, the organization within the agencies, and the clients are all affected. This division has negative effects on the continuity of care, for instance, after the discharge from the hospital or when rehabilitation is needed. Often, the MDK or physicians do not recognize that persons who are eligible for long-term care benefits also need rehabilitation or special treatment (in other words, health services). In this respect, the beneficiaries of the long-term care insurance are disadvantaged systematically. The comparison of European countries has shown that the level of integration is extremely low in Germany (Henrard et al., 2006). The newly introduced law on the development of the long-term care insurance (PFWG = *Pflege-*

*Weiterentwicklungsgesetz*, March 2008) promises some changes. The aims are more continuity and intensified care and case management. It regulates the collaboration between the home care agencies and the hospital during the period of the patients’ discharge. So-called “clearing points” (*Pflegestützpunkte*) will be established.

In some regions, networks of institutions (hospitals, nursing homes, and home care agencies, and sometimes general practitioners) have been established to integrate care of the old/frail population. Mainly, such networks organize the admission and discharge according to common protocols, and their member facilities use common criteria for the management of quality.

#### 4.4 Actors and Human resources in home care

The following professions belong to the total of 236,000 staff members in the home care agencies:

- 33% are fully qualified nurses
- 19% are fully qualified nurses for the aged (*Altenpfleger*)
- 4.3% are aids of the fully qualified nurses
- 2.9% are aids of the fully qualified nurses for the aged.

The remaining staff represents different professions such as family care and social work, with 6.4% in vocational training (Statistisches Bundesamt, 2008b). Some 26.4% of the staff have a full-time job, 33% a part-time job with more than 50% of the hours of the full-time job; the rest work less than 50% of the time of a full-time job. Additionally, 1% of the staff are persons in civil service (a substitute for military service).

For employees of agencies that are owned by communities or other public institutions, and by charities, the salaries are based on fixed salary scales that differ in the Eastern and Western states. So-called “indirect salary scales” for leasing companies and “time limited work” are in place. The Federal Commission on Minimum Wages set minimum wage for home help, domestic aid, and other similar professions at the beginning of 2010. Around the middle of the year 2010, the minimum salary amounted to €8.50 per hour for nursing aids in the West and €7.50 in the East of Germany. The hourly salaries will increase to €8.75 (West) or €7.75 (East) in 2012, respectively, and to €9.00 or €8.00 in 2013, respectively (for more information see <http://gesundheit-soziales.verdi.de/>).

#### 4.5 Use of tele-care

The home emergency call (*Hausnotruf*) has been available since 1982 and the service is provided in more than 350 communities with about 250,000 clients (<http://www.bagso.de>). The price for the equipment is about €380, but many care agencies offer the call equipment for rent for about €6 per month. The installation costs about €20, but the connection to dispatchers costs €17.90 per month. An additional fee of €20 must be paid for the deposit of the key at the helping organization that offers 24-hour surveillance and help. Altogether, the expenses are too high for some people, and therefore, only 1.9% of the population of 65+ year-olds is among the clients. However, the expenses can be covered by the long-term care insurance (if the person is eligible for long-term care benefits), or as a social subsidy by the social office (means test is required).

There is a large variety of similar products and services, e.g. phone service, GPS-systems that can search for the person, a fall detector, “sound watcher” (that reacts to the voice of the person), and “Wrist Care” for persons at risk of medical crisis (it transmits data on vital functions to the emergency department).

#### 4.6 Monitoring the adequacy of care

The MDK is responsible for the monitoring of clients status. For this purpose reassessments are required. The schedule of the reassessment has to be adjusted to the prognoses for the individual.

### 5. Clients & informal caregivers

#### 5.1 Home care clients

Among the total of 1,537,508 persons entitled to long-term care insurance benefits in 2007, 504,232 used professional home care; of these, 69% were female and 52% were eligible for benefits degree one, 35% for benefits degree two, and the remaining group was eligible for benefits degree three (Statistisches Bundesamt 2008b). According to a European comparative study “AD HOC”, German users of home care were more severely impaired than clients from most other countries (Garms-Homolová, 2008).

#### 5.2 Empowerment of clients

The Charter of Rights for People in Need of Long-term Care and Assistance is intended to strengthen the role and the legal position of long-term care users, and of their relatives. It also provides information for caregivers and assistants. The Charter is a result of the work of the “Round Table for Long-term Care” initiated by the Federal Ministry for Family Affairs, Senior Citizens, Women, and Youth in the autumn of 2003.

#### 5.3 Unmet needs

- Long-term care insurance benefits are not intended to be a full coverage, but are only a subsidy. As a consequence, only the needs of a relatively small part of the population can be satisfied.
- The focus of the assessment for the purpose of eligibility is still physical impairment. Persons suffering from depression or dementia are disadvantaged systematically.
- Support of family caregivers has to be intensified.

#### 5.4 Informal caregivers

Even persons who received professional home care needed a great amount of care by informal caregivers. In Germany, the home care-clients received on average an additional 34.23 hours of informal care in one week (Garms-Homolová, 2008). Therefore, support of the informal caregivers is considerable and important. According to the law, care giving members of families are entitled to being consulted. If employed, they are eligible for a “leave from work” for up to six months; however, payment of salaries stops during the leave. Additionally every care giving family member can get a contribution to their retirement insurance. In total, €0.9 billion was spent for this purpose in 2008. The contribution is dependent on the degree of benefits that the receiver of the long-term care insurance benefits is entitled to.

### 6. Disparities in the process of home care

Home care services are expanding, but the quality of care has not improved much (Schaeffer et al., 2008). In particular, the specialization of the services that was promised by the policy makers has not been realized yet. The opposite development can be observed: a homogenization of the work of agencies. Almost all of

them offer the same services and have equal profiles of care provision (Schaeffer & Ewers, 2002). In this way, needs of certain client groups cannot be met satisfactorily. For instance, persons suffering from dementia and mental health problems, people suffering from very serious diseases, persons in need of end of life care, migrants, and persons living alone are all chronically underserved (Landtag NRW, 2006).

## 7. Concerns and new developments in home care in Germany

Until today, reliable concepts of domiciliary long-term care have not been developed. The goals of prevention, health promotion, and maintenance, as well as of rehabilitative care have not been reached yet:

- For the future, a considerable shortage of staff is expected. Even today, the recruitment of staff is extremely difficult, particularly in some federal states. Highly qualified nurses that would like to work in home care are almost not available at labour market. Important tasks are the legalization of the work of migrants in home care and diversity management;
- The nursing staff cohort is aging rapidly. Therefore it becomes unavoidable to improve working conditions and to introduce health promotion programmes for aging professional caregivers;
- The results of the quality assessment by the MDK will be published. In this way the potential clients and their relatives would get information on the achievements of different providers;
- The law of the further development of the Long-Term Care Insurance (PFWG – Pflege-Weiterentwicklungsgesetz) dated 14th of March 2008, enforced 1th of July 2008, brought some changes: It regulates the collaboration between the home care agencies and the hospital during the period of patients' discharge. Also the so-called "support points" for persons in need of care or for their relatives (Pflegestützpunkte) have been established recently. The aim is to achieve more continuity, and to intensify care and case management;
- Graduation of benefits for home care: each year the amount of benefits will increase.

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# Greece

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## 1. The context of home care

### Country, population and health

Of the Southern European countries, Greece is the least densely populated with large variations between urban areas and remote mountainous or island areas. Currently, Greece's population is ageing rapidly and already relatively old compared to the rest of Europe. In 2008 18.6% compared to 17% in the EU27 was over 65 years old and between 2005 and 2030 the proportion of the population over 80 is expected to double (Eurostat 2008, age structure trend). The life expectancy of Greeks at 65 is about average for the EU27, but the proportion of these years lived in relative health is higher than the EU average (Eurostat, 2006). When looking at the national health interview survey (used by Eurostat), Greek persons seem relatively healthy, i.e. 20.7% and 24.5% of respectively males and females reported having a long-standing disease or health problem in 2008, compared to 29.4% and 33.5% in the EU27 (Eurostat, 28-01-2010).

### Characteristics of health services and social services

The Greek health care system is mainly financed through general taxation and social insurance funds, which provides for insured members. Primary care is free of charge though non-declared private payments for services in primary health care are high (Siskou et al. 2009). There are very little human resources available in health care: the number of practicing GPs per 1000 inhabitants is about one third of that in the EU15, par for nurses or midwives (OECD, 2008). But there is a huge number of specialised doctors – nurses are

generally missing at primary health care level. GPs are relatively recent phenomenon in Greece – 15 years max. The number of beds in hospitals and their usage is around the EU average (WHO, 15-09-2009). Public social services are also funded through general taxation, though overall provision is poor and funding is at a very low level, compared to the EU average. Responsibilities for social services are increasingly being moved to local authority level with partnerships between central and local government some NGOs, and between the public and private sector.

### Social indicators and conditions related to old age

Greek elderly are at a slightly higher risk of poverty than the average European elderly person (in 2008 22% compared to 19% of the persons over 65, Eurostat, 29-01-2010). Pension replacement rates are high, but they vary considerably (50–200%). In 2006, the percentage of GDP spent on care for elderly people was one fifth of the EU27 average (Eurostat, 12-02-2009). Children have a formal legal liability to maintain their parents, which is, in practice, unenforceable. In the context of inadequate public and non-profit services (residential and help at home) and insufficient financial resources for private care costs of those in need and their family members, family members are expected to provide care. For women, the main informal carer, the employment rate is the third lowest in the EU27 (Eurostat, 21-01-2010).

### Attitudes related to old age

When compared to nursing home care and professional home care, informal care (whether taking in a dependent elder or visiting them) was most popular; much more popular than with the average European (preferred by 87% compared to 54%). Home care is over five times as popular as a nursing home as the first choice for a dependent elder.

## 2. Policy and regulation on home care

### 2.1 Governance on home care

Pilot initiatives regarding home care started in 1989 using EU Structural Funds in approximately 101 Local Authorities (Law 2082/92) expanding to 1064. The laws currently governing home care services date from 2001 with a major revision in the Law of May 2009 which are now implemented (September 2009). The Law sets out beneficiaries of the service, home care services offered (health and social services and domestic care) and job tasks of some professions involved. Home care services are politically popular – serving the local dependent population and providing local employment. The recent law (May 2009) foresees an increase in the numbers of clients to be budgeted though strictly limited. No explicit links are made to health care services, yet 62% of services (from EETAA 2008 survey) have a strong health element.

The initiation and regulation of home care services is the responsibility of the *Ministry of Health and Social Solidarity* though some funding comes through the *Ministry of Employment*. This funding is then transferred to the agencies providing home help services, in the case of the *local authorities* this occurs through the *Central body of the Local Authorities* (KEDKE) run by the Ministry of the Interior. Services are run either by local authorities (LA) owned social enterprises or under the budgets and organizational structures of the local KAPIs (*Open Care Community Centres for Older People*). 91 Units of (Social) Home Care (nursing, personal care and domestic aid) are funded by the National Governmental Programme and 880 Units sponsored from the Third Social Support European Programme. (Kirkoglou et al., 2010).

### 2.2 Eligibility for home care services

Eligibility for the services offered is covered by the Law and covers those who are dependent, poor, and without family carers; those whose family carer (usually women) needs to find employment; or those who need help to live independent lives, in the case of the disabled. Home care services are *exclusively* oriented to these groups. This holds for those with temporary or permanent social, health or disability problems. However, eligibility is not absolutely standardised. In most areas there is a greater demand than supply. There are significant variations in case loads between Local Authorities owned services. The social worker decides on the personal care and nursing care services needed using her own non-nationally

standard method of evaluation, which may be used throughout the Local Authority. This is supposed to change as of 1st September 2009 when those wishing to provide services will have to tender to the Regional Authorities for the funding of the clients they are able to serve. Eligibility to technical aids depends on whether the specific Social Insurance Fund provides such help to its insured members: the largest fund, IKA does.

### 2.3 Quality of process and output

There is no assessment of the substantive quality of the service either for home nursing and personal care or for home help. Only bureaucratic criteria are used, e.g. staff, hours, activities, numbers served. A Law (4035/27-7-2001) on evaluation and monitoring of these criteria does exist. Quality standards may become elaborated in September 2009 but there are no details as yet. Other instruments of quality control such as accreditation based on outcome or obligatory complaint procedures for services are also absent. No data are available on clients' complaint procedures but these are almost certainly voluntary, depending on the interest of the relevant organization and social worker. However personal report back from the EETAA suggests that the requirement for those receiving the service to sign that they did receive it, has changed the quality of the service in many cases.

### 2.4 Quality of input

The recently introduced system (Sept. 2009) provides exact descriptions of all tasks that a *home care service* must or may provide to clients, broken down by time and task. Some variations within a home care service will allow additional services (e.g. doctor, driver) depending on local funding, staffing and political commitment.

The laws governing home care provide work descriptions and required educational levels for the three main categories of personnel employed: social workers (legal responsibility for assessing needs and coordination), nurses and home helps (a variety of professionals providing personal care and domestic aid, e.g. social carers and personal care assistants). All professionals employed are supposed to have the specified levels of education, normally university degrees or equivalents for social workers and nurses. The specified levels are supported and enforced through professional unions and linked to conditions of work. Educational standards for home helps are secondary education (until age 18)

or equivalent. The body responsible for vocational training standards (ELKPIS) sets precise descriptions of vocational training and tasks for personal care assistants (the equivalent of home helps). However, in many cases these standards are not enforced either when individuals are recruited or subsequently through training. A large proportion of home helps have received no vocational training. There are just three occupations – but the actual levels of qualification does not always match that supposed by the law e.g. secondary education for home helps will be waived if none applies with such qualifications, e.g. in remote areas.

Tasks for social workers, nurses and home helps, described under the law, are subject to the state inspectorate, but the inspectorates have not intervened in the essentially illegal (under Greek Law) process of giving temporary contracts repeatedly or in the prolonged non-payment of staff. The main difficulties of staff concern their non-permanent work contracts, making it difficult for them to obtain compensation or leave for continuing education. If employed as full-time civil servants they are entitled to training leave. However, reported by social workers was the fact that those given permanent jobs as public service employees, often seek transfer from home care service provision.

Nurse recruitment remains a problem in seeking for an improvement in standards or certification. Home helps are often untrained, despite the availability of a training course to make them into a profession with an improved status.

### 2.5 Incentives for providers of home care

The May 2009 Law makes Home Care services open to competitive tender to be partly funded under National Strategic Reference Framework – 2007–2013. The provision of the majority of services will continue to be by those already running services (Local Authority owned social enterprises). NGOs and the Orthodox Church may be new applicants, as well as a limited number of private suppliers. It is unlikely that many private home service providers will be interested in tendering. The extent of competition will be entirely unknown until the process of evaluation is completed.

## 3. Financing

### 3.1 General funding mechanism

The major sources of funding are national taxation and EU funding, originally covering 75% of all costs. The core home care services (social work, nursing and home help) are not subsidised through the social insurance funds nor are private payments allowed to the publicly funded home care services. Some supplementary services delivered at home can be partially funded through social insurance funds [e.g. physiotherapy, home medical visits] and clients (usually 50% or less reimbursement). In private home care services clients pay the full costs, which are non reimbursable. There are hardly any privately funded services. The only solution for those with money is to buy home care from private people or migrant workers; however this is not part of a service and there are no mechanisms to ensure supervision of workers. Therefore, private resources are also of great importance. The few NGOs/Church linked bodies that exist have funded services by insecure donations.

The Ministry of Health and Social Solidarity reported home care annual expenses of 834,000,000 Euros serving 9,500 people, (unpublished EETAA 2008) but figures probably refer to the 91 services they run directly and not to the overall budget. For technical aids one has to be member of a social insurance fund. It depends on the fund to what extent these are funded. Home adaptations were not publically financed before September 2009, and current problems in public finance mean they are unlikely to be developed. Meals “on wheels” services may be provided free of charge by and funded by some Local Authorities, voluntary and church based groups. Local Authorities maximised the numbers – now will be given a fixed budget – but it is still unclear whether financing has changed in any way and at the moment there are again terrible delays in payments in the public sector

### 3.2 Mode of financing home care providing agencies

LA controlled home care providing agencies apply for funding to KEDKE (Central Body of Local Authorities). Home care services have been funded through the Ministry of Health and Social Solidarity while a small percentage comes from the Ministry of Employment and Social Insurance’s budget.

Publicly financed home care providers are paid for the number of clients they serve. Under 2009 legislation home care service clients who meet the eligibility criteria will be given a nominal personal care budget of 1,200 Euros per year, enabling some limited choice in service tasks. It is not allowed to use the personal budget to reimburse privately employed care workers or family carers. As each service will operate independently it is unclear if those needing more hours of care will be allocated services beyond their assigned budget limit, or whether the service will make a total budget based on the total number of clients it can handle by client budget totals. Existing publicly owned and NGO run home help services, as well as any private services, will be able to apply to be publicly funded but have to demonstrate the number of clients they can and are serving in their area. In all of the areas served there was more demand for services by those eligible than available resources.

### 3.3 Price setting of home care services

From 1st September charges for home care are fixed, and are set by:

- Time unit (10 minutes to 60 min units).
- Type of work for client (details all tasks and includes weight of task, complexity of care needed).
- Level of staff person used (qualification, type of job). New tasks have been added to the Home Care service (e.g. handyman, physiotherapist), enabling a home care service to offer more than the basic three elements.

Under the 2009 Law service costs are Social Worker and Nurse: 11 Euros per hour, an Assistant Nurse – 9.5 Euros per hour, Personal Care Attendant 8.5 Euros per hour. There are no details on the current costing of home care services by non-publicly funded NGOs/Churches. In the only private home care service found, an unqualified care worker for an older person employed 6 days per week – 8 hours per day, costs 700 Euros plus 140 Euros social insurance; a private nurse working 6 hours and 40 minutes per day costs 60 Euros per day and 75 Euros for night care. Non-registered/illegal migrant care workers with no social security payments – for as far as could be found – cost from 700 Euros upwards (depending on their experience, levels of dependency and command of Greek) for a 6-day week, residing with the older person.

## 4. Organisation & delivery of home care

### 4.1 Access and needs assessment

Applications are normally made to the Local Authority through its social work department. There is no local or central reference or information point on the criteria used for acceptance onto the programme and on services available to older people. A GP's referral is not necessary. Also no standard or uniform measurement tools are used for needs assessment. Those needing home help come to the social worker, undertaking needs assessment in a variety of ways, e.g. local doctors, neighbours, kin, etc.

### 4.2 Features of delivery

The government currently reports 1,163 Units of (Social) Help at Home (home care providers). They operate in 849 Municipalities and Counties. Local Authorities' owned social enterprises are the main providers with 1,064 centres nationally (unpublished EETAA study 2008). Additionally public KAPIs and NGOs provide home care. Local monopolies are the norm and there is virtually no competition amongst home service providers because of the lack of staff, e.g. home helps, nurses, makes staffing services in some areas difficult. Clients do not have the funding to choose alternative providers even if these were available. Those with private means are not eligible to use the publicly funded services. Private care solutions rarely include an organised home care service. Usually they are provided by independent non-professionals. One common practice amongst those with adequate incomes is to use privately employed legal and illegal migrant care workers for care work at home. The Eurofamcare National Report for Greek (Triantafyllou et al. 2006) study indicated 7% of those with a family member as informal carer also employed a migrant care worker, a figure which increases where a family member is not available to care.

### 4.3 Coordination and integration in home care

The home care services are coordinated by the social workers belonging to the service. Some primary health care units work closely with home care services, though this is not an institutionally structured link. Home care services are reported to be working closely with local primary care services in practice. Doctors or health visitors attached to a local KAPI may be instructed by the Local Authority to work with the home care services.

**Table 1:** *Human resources in home care*

Functions	Estimated number 2009
Domestic aids	1500–2000
Personal carers at home	50.000–70.000
Home nurses	n.a.

Outreach home nursing is rare in the primary health centres. There are no District Nurses. Agricultural doctors, undertaking an obligatory year of service in a rural area, normally pay home visits but their relationship with the home care service depends on personal rather than institutional arrangements.

Hospitals bear no responsibility for patient care after discharge. In practice hospital social workers seek care solutions for dependent people whose families cannot take on responsibility for providing or paying for care. Residential clinics take the dependent elderly when discharged and costs are funded through the social insurance funds or the pension of the patient. One or two large private hospitals work with private home care services mainly for health care.

As yet nursing homes and private residential homes do not provide home care services. There are no known structured links between nursing homes and home care agencies. Day care for the dependent elderly and the disabled is provided by some NGOs and the Church, though rarely on a 5-day week basis.

#### 4.4 Actors and human resources in home care

The most important actors to home care in Greece are:

- Ministry of Health and Social Solidarity; initiation and regulation of home care services;
- Ministry of Employment; partially funding home care;
- Central body of the Local Authorities (KEDKE); run by the Ministry of the Interior; assigning public funding to home care providers;
- Social insurance funds; funding some supplementary home care services such as home physiotherapy;
- Municipalities are the main providers of domestic aid through their social enterprises.

Local Authority owned social enterprises; providing home nursing and home help. 34.95% of the staff works as home helps. (unpublished EETAA study 2008):

- Local Authority run Open Care Community Centres for Older People (KAPIs); providing home health care;
- NGOs (e.g. Alzheimer societies); providing home care services for members and some day care.

#### *Human resources in home care*

Table 2 shows the number of home care professionals. The number of personal carers at home is much higher than the number of domestic aids. The absence of data on care workers reflects the lack of long-term care, of registration and supervision, and the reliance on private provision, especially families, for a majority of older people in Greece. (EETAA study 2008).

The employment status and required level of education of care workers are regulated by the legislation for Home care services, but may not be adhered to in practice. There is an absence of qualified nurses in specific locations and there are inadequate numbers of applicants for work as home carers/domestic aids. National legislation also covers the working conditions of home care providers. In difficult working conditions, such as squalid environments, the staff is not insured for accidents or work related infections. In many cases, some may not continue working in home care services if given permanent contracts as they prefer working in other departments and positions.

Payment levels are set out under the relevant national Laws on a par with those in the public sector. There are basic minimum levels of pay and increases with levels of qualification and years of service and depends on being married and knowledge of a foreign language. It is unclear whether these accrue to staff on temporary contracts. The basic salary of a social worker with a degree, married, knowing some English and with 5 years of experience,

would be 1176 Euros per month. A home care worker would receive a minimum salary of 760 Euros per month plus increases for years of service.

#### 4.5 Use of tele-care

Experimental tele-care is used for remote small islands and communities, mainly for health care (e.g. provided by hospitals). These are usually EU funded projects. After EU funding ends, no follow up takes place and there is no indication that these practices are being absorbed into long-term programmes, including home care services. Until now the main focus is on patients with chronic conditions and/or in remote areas. Two NGOs run Life line services providing social support to the isolated (Red Cross, Life Line Hellas) but this is not part of a home care service.

#### 4.6 Monitoring the adequacy of care

The social worker in charge monitors the care process, as services are under tremendous pressure of staff resources. The social worker would also ask about the problems from client's perspective and staff's difficulties. This would be seen as a normal part of monitoring the operation of the service. Apart from administrative reports there are no criteria set out for quality standards or the frequency with which the services should assess their effectiveness. Systematic client evaluations or satisfaction surveys are not available or mentioned.

## 5. Clients & informal carers

### 5.1 Home care recipients

No national figures are available about the number of LTC recipients at home. The 2008 EETAA study reports that a sample of 297 Home Care services from 1,064 LAs serve an estimated 100,000 clients. In addition small numbers served by services run by NGOs and Church.

### 5.2 Coverage and unmet care needs

There is a substantive gap between needs and coverage for, e.g. 24 hour or weekend care and there are inadequate numbers of care workers. All experts stressed the inadequacies of current services. However, of those clients receiving services 98% reported being satisfied

(unpublished EETAA study 2008); in a country that offers so little and where these people would otherwise receive no care, this response makes sense.

### *Empowerment of recipients of home care*

Care choices are few or non-existent especially in rural areas. Nevertheless there are private solutions for those with money. The only alternative for those with low incomes to home care services are residential care units, mainly run by the Church or philanthropic bodies for the poor. In the private sector home care services are rare, partly because those needing services and having adequate incomes tend to prefer using private home care workers – especially live-in migrant care workers.

There is no information available to (potential) clients to compare services. Some of the disabled organizations act to provide support and information to their members and families. NGOs (e.g. Disabled Now, 50+Hellas) provide some information and links to existing services and entitlements, however the problem lies in the lack of services and staff and funding.

Disabled people have a private care budget but this is often inadequate to cover their needs. The budget is the same for disabled or older people and is managed by the social worker. Under the 2009 Law each person eligible for home care services will have a personal budget of 1200 Euros per annum allocated, to be used for a wide range of services e.g. health care, domestic work, physiotherapy, odd jobs, etc. The social worker will manage the allocated budget for each client. As yet there is no specification on the quality of input, and how to evaluate this by clients; nor of outcomes and processes. Since the staff will remain the same, the recipient will find it difficult to evaluate the staff – though there is now some capacity to control hours worked and tasks performed. It is unclear if there will be real choices for either clients or even the services themselves given the almost certain large scale of unmet needs among qualifying older people and disabled people.

### 5.4 Informal carers

There is no formal recognition of informal carers. The Eurofamcare study of 1,000 Greek carers, showed that 10.3% had given up work to care; 12.6% reported stopping their careers or education because of caring

demands, 12.2% felt only able to work occasionally. 19.2% had reduced the hours worked by a mean of 9 hours per week.

## 6. Disparities in the process of home care

- The way in which a client received home care and the services, varied by geographical location and age of recipients. The available services depend on the provider (Local Authority) and there is a higher likelihood of a shortage in (qualified) personnel in rural areas. Young adult disabled persons may be entitled to a disability grant which has to be applied for from a regional medical committee who decide on the amount of help needed with ADL. It appears that the new budget allocation of 1,200 Euro per home care recipient may be supplemented, where necessary by an additional disability grant to cover the need for more extensive care.

## 7. Concerns and new developments in home care in Greece

Important developments related to home care in Greece are:

- Reduction of EU funds for home care. The expansion of the home care services occurred opportunistically with funding from the Structural Funds, and has continued in this manner. As more Local Authorities took the opportunity to obtain state and EU funding, budget requirements and problems in long term structure and funding of these programmes has come under scrutiny. The EU has reduced its contribution to 50% (for 2 years until 2011) on condition that plans exist for their long-term financial viability and that services would become increasingly client centred;
- Introduction of 'theoretical budget' for clients. Each home care service will be able to juggle the type and amount of services given to each person on their client list; how this will operate in practice is unclear;
- Increase private nursing care services. In the past 2–3 years private nursing care services (2–3 institutions (?)) have opened usually linked to private health insurance. These serve the 8% of the population covered by private insurance or those willing to pay the full costs;
- The implementation of the new law. It is said that despite the limited ways in which some of the reforms were actually introduced (by March 2010), the focus on ensuring that older people sign that work was done has changed the atmosphere in the service and the relationship of the client to the services, enabling more client control.

The main problems are:

- Lack of long term funding. Currently, programming and funding periods depend heavily on the EU and depends on the yearly negotiations with KEDKE. Central government has not prioritised home care funding. Alternative sources of funding are scarce. Firstly, clients and their families are not allowed to pay for or contribute to the costs of the state subsidised home care services. Second, the major social insurance funds (e.g. the IKA) do not fund home care as they have inadequate financial or research data bases to allow them to calculate the economic benefits accruing from subsidising home care services. Finally, the National Health Service does not pay for those home care services linked to health;
- Staff shortage. The absence of adequate staffing, especially domestic aids in rural areas or where there are high proportions of dependent older people and the absence of other specialists within the home care service e.g. physiotherapists, occupational/ergo therapists, chiropodists, psychiatrists, psychologists, (this may find some resolution under the new law);
- The absence of legal obligations and any necessary funding to establish formal co-operation with other local services, e.g. KAPI, local health centres, local hospital, and the private sector;
- Bad working conditions of home care professionals. Insecure funding leading to insecure work contracts and the non payment of staff for several months; transport and reliable drivers;
- The lack of common tools in client evaluation, service quality monitoring, in data recording and processing, and use of new technologies to facilitate communication and service capacity are significant problems.

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# Hungary

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## 1. The context of home care

### Country, population and health

Hungary is a medium-sized Central-European country with 93 thousand km<sup>2</sup> and a bit over 10 million inhabitants. The total GDP of the country was estimated to be \$198.2 billion USD in 2008 (CIA World Factbook, 16-06-2010), and the per capita in Purchasing Power Standard was relatively low, with 16,100 compared to 25,100 on average in the EU27 (Eurostat, 16-06-2010). The socio-demographic context in Hungary is characterised by population ageing and a general decrease in the population size (-2.17% in the last decade, -5.26% since 1989). The population over 65 and 80 is currently 15.9% and 3.7% respectively and is expected to reach 20.9% and 5.3% by 2030. Currently, the share is just below the EU average. The old-age dependency ratio can rise even above 50% by 2050 according to estimations (Ageing report 2009).

Life expectancy at birth is still far below Western European average, but has increased significantly since 1990. In 2007, it was about 69 years for men, and 78 years for women. (Eurostat 2009 data). Healthy life expectancy at the age of 65 is estimated to be 5.5 years for females and 5.0 for males.

### Characteristics of health services and social services

Hungary has an insurance-based public health care system funded by income-related social health insurance contributions. Primary care is mostly based on private

practices having a gate-keeping role. Thus, a referral is needed to visit a specialist except for some services. Primary care is reimbursed on a capitation base. The vast majority of polyclinics and hospitals are owned by municipalities or the state, and are financed by the National Health Insurance Fund Administration (NHIFA), the only health insurance fund in Hungary. Hungary is divided into 20 counties, each of them having a county hospital and many smaller city hospitals. County hospitals serve as a county centre providing complex diagnostic and treatment services for patient with a large variety of diseases (the size of the catchment area is approximately 0,3–06 million population). At regional level regional centres provide more specialized care including treatments (catchment area is approximately 2–3 million people).

Health care expenditure was 5.8% of GDP in 2007 and its share is expected to increase with 1.3% until 2060 (OECD, 2008). Long-term care's importance in the health system is increasing (European Communities, 2009). In 2007, just 0.3% of GDP was spent on long-term care, while this share is expected to be at least doubled by 2060 (European Communities, 2009). In 2005, about 29.2% of the total expenditures on health was privately paid, most of which, 86.8%, out-of-pocket (WHO 2008). The share of private spending on health, including the traditional under-the-table payments, is among the highest in the EU (OECD 2010). NHIFA has been facing continuous deficit since its foundation in 1994 (e.g. in 2005, 31.2% of the total revenue). In 2005, the cumulative deficit was equal to the yearly budget of the fund. Focusing on cost-effectiveness would be essential in the Hungarian health and social care.

After the political changes of 1990, the responsibility of providing health care services was transferred to local governments in each level of the health care system such as primary care, out-patient care, and inpatient care. Only a few exceptions were made such as university clinics and national medical institutes, which represent the highest level of health care services (tertiary care). Performance-

related financing was introduced. As a general rule, the NHIFA finances the running costs from its separate budget (Health Insurance Fund), whereas covering capital costs is the duty of the owner of the given health care institution, mainly the local governments. The Health Insurance Fund consists of more than 15 sub-budgets for different types of services (primary care, out-patient care, acute and chronic in-patient care, etc.), capped with a national budget ceiling.

Regarding the social sector, local and regional differences exist. The smaller local authorities are partly or entirely unable to provide the compulsory basic services set out in the Social Welfare Act since the capitation received is not sufficient to cover the costs. This is the case mainly in smaller settlements where there are strong ties to family members and neighbours. No up-to-date information is available for the Ministry on those receiving social services, the potential claimants, their social circumstances, health and on their income. There are no reliable data on the conditions of the buildings of social institution system, on the personnel and physical conditions (expert opinion). The current system of statistical data provision does not provide the information necessary on managerial level.

Based on the Social Act it is mandatory for the metropolitan and county local governments to harmonise the specialised social services (including home care) in their area. However, the establishment of the necessary powers for executing the harmonisation activities is said to not have happened yet.

As a substitute for home care, there are the long-term residential social institutions. These institutions provide continuous care on a permanent basis, day and night accommodation, nursing, care or rehabilitation for people who are in need of social support.

#### Social indicators and conditions related to old age

Elderly Hungarian people seem to have the lowest risk of poverty in Europe, in 2008 just 4% of the population over the age of 65, compared to 19% on average in the EU. However, as mentioned the PPP is very low in Hungary as a whole but also the material deprivation is one of the highest in Europe (Eurostat, 2010). The employment rate of women (42%) is below the EU average of 59.1% in 2008. In Hungary, 50.6% of people between the age of 15 and 64 were employed. There is no formal liability for children to pay for the care of their

dependent elderly parents. However, in some cases the opportunity of informal care is taken into consideration while deciding the eligibility of home care provisions.

#### Attitudes related to old age

Hungarians are relatively positive towards informal care. About 48% (compared to 34% in Europe) find care for a dependent elderly a task for close relatives even if the career might be affected (TNS Opinion & Social 2007). Well over two thirds of the Hungarian respondents of the Eurobarometer prefer either that a dependent elderly would live with their children (36%) or be visited at their own home by them (35%). Both are more popular with Hungarians than with Europeans in general. Just 12% of Hungarians compared 27% of Europeans think that professional care at home is the best solution for a dependent elderly parent. Care in a nursing home is just as popular as home care (TNS Opinion & Social 2007).

## 2. Policy and regulation on home care

### 2.1 Governance on home care

There are several laws regulating the home care provision. It is established what the conditions and activities in home care should be. After the political changes of 1990, several health care reforms were made that had long-lasting effects on the Hungarian health care system up until now. The responsibility of providing health care services was transferred to local governments, with a few exceptions. The responsibility of financing health care services was given to the National Health Insurance Fund Administration (NHIFA), the health insurance fund in Hungary ('Országos Egészségbiztosítási Pénztár', OEP) and performance-related financing was introduced. Employees in home care are represented by the 'Magyar Egészségügyi Szakdolgozói Kamara Közösségi és Hospice Szakápolási Tagozata' (Chamber of Hungarian Health Care Workers, Community and Hospice Professional Care Department) and employers by the Hungarian Home Care and Hospice Association.

### 2.2 Eligibility for home care services

A wide range of services/care are available and granted, including domestic aid, personal care and home nursing, social catering („meals on wheels”), physiotherapy, medical devices shipment, tele-care, home adaptations.

These services are not included for everybody. Whether this service is covered depends on the given self-government's financial ability and decision. In any case, the coverage is less than 100%. In order to benefit from publicly funded home care services – only applicable to those services that are part of the social system – one needs to be in need of two to four hours care a day. However, what 'need of care' means remains undefined at national level (Czibere & Gal, 2010). Still a uniform procedure is used to measure 'need'. The procedure looks at dependency in ADL, self-reliance (dealing with household administration, following therapy), walking, mental functions (orientation in space and time, communication), eyesight and hearing, the need for health care, the need for supervision, and social network (Czibere & Gal, 2010).

Rules on eligibility to home services are laid down by law (formal welfare minister decree 20/1996. VII.26. NM). Both in health care and social care eligibility criteria are explicit and published – in various ministerial orders – in the Official Gazette of the Ministry of Health and Ministry of Social Affairs and Labour. Eligibility to home care services is decided by a professional committee (or by the provider itself). The client's financial means are a major factor taken into consideration in the social care field. In the health care sector home care is covered by the National Health Insurance Fund Administration, this is universal and not income-dependent. Home nursing is provided for patients having a diagnosis that can be cured at home, shortening or substituting hospital stay. Eligibility is decided by the GP (but not obligatory, just recommendation) and the notary. Every service is standardised at national level. The family doctor can "order" the following provisions: professional care, therapeutic gymnastics, physiotherapy, speech therapy, according to own decision or specialist's recommendation. 14 Visits can be granted at once that can be exceeded by further 3 with medical recommendation (by control visit) (Banai 2009).

'Home care' as defined in Hungary includes the following forms of care: – Domestic care: basic social service provided to persons being unable to care for themselves in their home as well as to psychiatric patients, disabled persons and addicts who, due to their condition, need help in performing the tasks necessary for independent life. – Club for the aged: provides day care for elderly people who are partially capable of looking after themselves and in need of social and mental support, and enables them to maintain social relations, satisfy basic

hygienic needs and to get daytime meals upon request. – Day home for disabled: enables disabled or autistic people over three years of age living in their own homes and not needing supervision to find daytime shelter, maintain social relations and satisfy basic hygienic needs and to get daytime meals upon request.

### 2.3 Quality of process and output

#### *Availability of quality criteria and assessment of quality of services*

Home services and their operation are regulated by law (formal welfare minister decree 20/1996. VII.26. NM). The material and human conditions, eligibility, number of visits are also regulated here. Furthermore, according to Law Act '20/1996. (VII.26.) NM. Rendelet' the operating rules of the home care services are fixed. There's an annual reporting obligation for the institutions about the major figures of home care activities. The following have to be included in the reports: number of home care patients, visits by gender, age group and by form of funding.

#### *Accreditation and clients complaint procedures*

Most of the home care service providers are licensed. Some of them have got ISO certification and all of the health care providers have to operate an inner quality assurance system. For patients' complaint procedure a lawyer, Health Insurance Budget (connected to NHIFA), National System of the Public Health Officers (ÁNTSZ; licensing the providers and health insurance is paying for the services) are available.

### 2.4 Quality of input

#### *Education*

For the home care staff general nursing qualification (BSc, MSc in nursing) is enough. Their education is built in the official education structure. Diplomas and degrees are accepted by governmental supervision. At BSc level home care is a course, like in MSc level degree, which exists as Community based nursing. In professional secondary (called OKJ, in English ISCED) qualification it is an option to learn nursing but home or community nursing is educated only in further studies, BSc and MSc level.

For home nursing upper level education is required but in domestic aid there are no such criteria. Publicly funded companies usually pay for the continuing education

**Table 1:** Expenditures on home health care as a% of total health care expenditures (source: expert)

Expenditures on home health	0.2 %
Expenditure curative rehabilitation home care	0.1 %
Expenditures on long-term nursing care at home	0.1 %
Private expenditure (home care and day care)	0.0 %
Expenditures on day care as % of total expenditure on health, all amount for curative rehabilitative day care	0.8 %

obligatory for the workers. Private companies rarely pay these educational costs. However, the provider itself doesn't pay for further courses beyond the obligatory continuing education.

#### Job description

It is set in the law act what professional/educational level the employees need. There is no existing difference among workers' competence. Two levels of home care activities are distinguished, the law acts differentiate the home nursing (*otthoni szakápolás*) and home domestic aid (*házi segítségnyújtás*).

#### Recertification

There is no separated re-registration for home care workers. Similarly to other caring/nursing activities a 5-year recertification is required, while they have to participate on different further training activities like attending acknowledged conferences, participating on trainings and workshops, publish paper, or participate on study trips. The content is regulated in ministerial decree.

### 2.5 Incentives for providers

At any settlements several providers can work with NHIFA-funding. However, funding is limited by a given number of visits. Competition among different providers is allowed.

## 3. Financing

### 3.1 General funding

In Hungary home care within the health care sector is financed by the National Health Care Fund since 1996, while social care (domestic aid, catering, day provisions, etc.) is financed by state reimbursement. Social and health care sectors have a lot of parallel functions but

they work isolated from each other regarding their organisation, provision and financing. The share of health care sector is less in long-term care services than the social sectors.

The financing of home visits is entirely different by the funder. In professional home nursing the visits are free (paid by NHIFA) until a determined number of visits. But in case of domestic aid (funded by the social sector) the financing comes from three different sources: governmental state budget (fixed; irrespective of costs), co-payment from the patient and contribution from the financer (local government). In social home care the co-payment is significant, and set according to the income of the recipient and family and real estate of the recipient (Czibere & Gal, 2010). The calculation method of co-payments for social home care services is set at national level; the maximum co-payment is 20% of the total costs (Czibere & Gal, 2010).

Home nursing visits are funded in 98.16% by NHIFA. This excludes expenditures on operating costs. About 37.7% of the home care services consists of specialised provision, like therapeutic gymnastics, physiotherapy and speech therapy. Tending decubitus is with the second highest share (35.4%), followed by tending open and closed wounds (8.9%) and educating the use of special therapeutical equipment (7.0%). The average total expenditures per home care recipient funded by NHIFA is 270 Euro per year (taking into account the duration of care).

Funding comes from the central source only. NHIFA has the responsibility for funding some home health care services, then at local levels the County Health Insurance Budget. The providers are contracted by the Regional Health Care Budget. Funding is set for a preliminary determined monthly number of visits. Laid down in law act 43/1999. The rules of financing home care are regulated by Ministerial Decree No. 20/1996. The Health Insurance Fund includes more than 15 sub-budgets for

**Table 2:** Home care cost data in year 2007 (Banai 20009, NHIFA data)

	counted by visit	counted by patient number
Average cost per case (visit) or per patient (EUR)	10.4	10.4
Total cost for all visits/patients (EUR)	203.9	270

different types of services (primary care, outpatient care, acute and chronic inpatient care, etc.), which are capped with a national budget ceiling. According to its financing regulation home care is considered to be outpatient provision. Home Care Budget of NHIFA is determined annually at state budget level. The NHIFA divides the Home Care Budget between its Regional Health Care Budget institutions according to the number of inhabitants of regions.

While the responsibility of delivering health care is decentralized and local authorities (city and county councils) have a strong influence as the owners of health care institutions, financing health care is highly centralized at the NHIFA. Although the NHIFA has local offices (branches) in each Hungarian county, they do not have the opportunity to make independent decisions. (Boncz 2004).

### 3.2 Financing of home care agencies

The Regional Health Care Budget institutions divide the financial sources for home care among providers according to inhabitant number of their catchment area also. The financing basis of the provisions is the daily visit fee (that depends on the annually determined home care assigned state budget). Payments are matching the exactly reported number of visits. There is no weighting according to age, etc.

As a general rule, the NHIFA finances the running costs from a separate budget (Health Insurance Fund), while covering maintenance and depreciation costs is the duty of the owner of the given health care institution, mainly the local governments.

Additional to client-copayments private domestic aid providers contracted by the local authority, e.g. civil organisation, may use their own revenues or donations (Széman, 2004).

### 3.3 Price setting of home care services

Prices for NHIFA financed home care are fixed and set by the annual governmental budget as normatives. The basis is not the real cost of the provisions but the planned volume of activities.

## 4. Organisation & delivery of home care

### 4.1 Access and needs assessment

In case of social care, a member, usually social worker, of the committee of the given municipality headed by the notary. In case of home health care, the patient can apply to GP's offices for the home care provider (nursing home care). Home care is granted on the basis of GP's assessment in the patient's home or residence. The needs assessment is completed by an independent committee, on basis of GP's or nurse's opinion. Guidelines are uniform for the whole county and cover an explicit procedure, in needs assessment and in monitoring as well. Financial monitoring is implemented, professional monitoring is on ad hoc basis and by unspecified players. The main aim is to shorten or substitute hospital care in case when no continuous supervision is needed. The GP's recommendation is needed to get home care funded. The GP and the representative of the home care provider's organisation assess the needs and decide what kind of services the patients are eligible for. The GP can initiate a package of a 14 care episodes (30–180 minutes per event). If further care is needed, out-patient or hospital specialists' recommendation is needed, in this case three more packages of 14 care episodes can be used by the patient.

### 4.2 Delivery of services

Home care provision is rather segmented so far. There are institutions run by social sector for home care/ domestic aid, etc. others are covered by the health care budget and work separately. However, as some provided tasks are parallel there are overlaps in the provisions, but not formally. Providers are mainly public, non-

**Table 3:** Volume of funded professional home care between 1996–2005 funded by the NHIFA (Banai 2009)

Year	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005
Nr of providers	10	210	320	340	350	330	325	325	330	335

profit. Most of the providers are funded by NHIFA, competition is allowed among them. If there are several providers available for the patients they can freely choose from them.

In practice, home help, meals on wheels, cleaning, shopping are provided only on working days. Patients are eligible for these provisions but the municipalities cannot provide the services continuously. Home adaptations are not necessarily covered, this heavily depends on the decision of the local self-government. Consequently, in Hungary there are existing gaps between eligible and available provisions as well as the organisation and access probability among different geographical regions.

#### 4.3 Coordination and integration of services

As mentioned, there is a lack of integration between social home care and home health care, i.e. there is some overlap in their work. Furthermore, community care is not directly part of home care, but in many cases they complete the tasks like aftercare, etc. Visits done by community care nurses do not belong to home care visits, but rather to the visits of GP practices.

Structured links with primary care exist as the GP determines whether the patient is eligible and can recommend utilizing home care. According to experts about 84% of all home care visits are ordered by the family doctor.

Coordination between home care and hospital is usually not structural. The exception is rehabilitative care where the end of the hospital stay induces the need for rehabilitative care and this provision can be continued immediately after the patient goes home. Home nursing aims to shorten or substitute hospital care. Hospitals namely also provide long-term care. In 2006, they had 189,498 long-term care recipients. There are remarkable overlaps in functions: within the inpatient and outpatient care but most typically within social and health care provision that makes home care coordination more difficult (organization, financing, etc.). Hospital care

can't be relieved in enough share by home care because of the different logic of financing outpatient and inpatient care and the lack of availability.

#### 4.4 Actors and human resources in home care

The main actors in personal care and home nursing are the patient, the family doctor, professional nurses in medical care, nurses and social workers in the social sector care, physiotherapist, and logopedist. Recently, the dietitian expert has become also an actor in the field of home care. Regarding domestic aid and supportive aids the patient, family doctor, notary, social worker and the family are the main actors. There are altogether around 5,095 nurses working in home care (Hungarian Statistics year 2005). According to the OECD health database, there were 10,928 formal personal carers and nurses working in home care in 2008. But this figure also includes professionals working in day homes and clubs for the aged. It is thus an overestimation. The Central Statistical Office (2008) shows that in 2006 there were about 5,100 carers in home care services.

Nurses/caregivers are in most of the cases part-time employees or health care free-workers (*'egészségügyi szabadfoglalkozású'*). People who provide domestic aid are not part of home care workers. (Separated home nursing and personal care) Nursing home care is provided by highly educated professionals, while domestic aid belongs to basic provisions and social care. In lots of cases they are confused and not separated. Workers for domestic aid and personal care can be full- and part-time employees as well. The minimum conditions are laid down in a law act (Ministerial decree 20/1996). The payments are also regulated for the health care providers. (Ministerial decree 43/1999.) The provider decides the salary level. Being employed in public providers, home care workers' salary is determined by the valid public servants' salary-list. This is the same for social care workers. Working conditions are uniformly documented at country level. For different jobs there are different rules (nurses, caretakers). Material requirements are set as well, and the usage of equipments, e.g. some equipments can be used only by professional nurses. The fluctuation of employees

**Table 4:** Long-term care recipients at home and in institutions (Source 2008: OECD, 2010)

<b>LTC recipients (OECD definition)</b>	<b>At home in 2008 absolute number*</b>	<b>In institutional care in 2008 absolute number**</b>
Total (% of total population)	142,627 (1.4%)	76,622 (0.8%)
% Females	68%	61%
% 65+	73%	62%
% 80+	24%	32%

\* Data include people receiving domestic care, services at clubs for the aged, day homes for the disabled and special nursing homes.

\*\* Data includes people in the homes for the aged, homes for psychiatric patients, homes for disabled people, and homes for addicts.

**Table 5:** NHIFA funded home care utilization data in year 2007; and municipality-funded social home care year 2006 (respectively: Banai 2009, NHIFA data; Central Statistical Office, 2008)

	<b>NHIFA funded counted by case</b>	<b>NHIFA funded counted by patient number</b>	<b>municipal funded counted by patient number</b>
Number of people	59,411	44,869	(60+) 48,000
Number of visits	1,166,580	1,166,580	–
Average number of days of care	19.6	26.0	–
Average unit cost (EUR)	10.4	10.4	–
<b>Total cost (EUR)</b>	<b>204</b>	<b>270</b>	–

is low. There is no separated law act for payment of home care workers, the general rules for employees are valid (public servants).

Regarding financing home care the main actors are the NHIFA that provides funding for the health care provision. For social home care, central government and also local municipalities are the main actors as they commonly finance and organise the provision. Also, the families of the patients are important actors as typically they have to involve some complementary contribution in the financing because of the existing provision gaps.

#### 4.5 Use of tele-care

The only form that is available connected to tele-care is the bell-alarm systems used typically in the social care. It is publically funded, the same way as other social care provisions. The use of it isn't widespread rather complementary.

#### 4.6 Monitoring the adequacy of care

The process of home care is continuously monitored. Completed visits can be reported only after monitoring by Public Health Officers and staff of the National

Insurance Fund Administration. Also, the system has a valid uniform reporting system for the whole country (towards NHIFA). The head of the home care service and the GP controls the nursing activity after every 14 visits and it is an obligation for the carer/nurse to set up an updated nursing plan. According to Ministry Decree No. 20/1996. the operating rules of the home care services are fixed.

For home nursing care the National Health Insurance Fund Administration is checking the reimbursement, like in other fields of the health care. The National System of the Public Health Officers (ÁNTSZ) is responsible for supervising the professional part of the care. In social care monitoring and professional responsibility is problematic.

## 5. Clients & informal carers

### 5.1 Home care recipients

There has been a sharp decline in home care recipients in the last two decennia: almost half as many recipients in 2006 as in 1990 (Czibere & Gal, 2010). The long-term care data on home care recipients by OECD covers home nursing and personal care, while NHIFA data here show just the health care sector (home nursing) provision

data (funded by NHIFA). There are more people receiving home care than institutional care in Hungary. Furthermore, the OECD data shows that home care services are more targeted towards elderly people between the age of 65 and 80 than are institutional care services. However, according to the Hungarian Statistical Office, 2.1% of the 60 year olds and over received home care from professionals in 2007 (Central Statistical Office, 2008); a very low share. Comparing the NHIFA data with the OECD health data shows that NHIFA funded care is just a small part of home care. The Social care at home, services at clubs for the aged, day homes for the disabled and special nursing homes are the other home care services included by the OECD.

### 5.2 Coverage and unmet needs for care

A coverage gap may occur in the smallest settlements in the rural area (local authority does not have enough financial sources to complete this social care obligation). Regarding the basic, medical provisions over the country, coverage gaps are not typical. The limitations are rather typical in the social care. Home care services are not organised in over a quarter of the municipalities in Hungary (Central Statistical Office, 2008).

According to vignettes, there are however limitations in the frequency of the visits. The amount of time the carer can spend in the recipient's home is limited and less than needed, e.g. 24 hour care is usually not provided and limited number of specialised home care events are available (maximum 4 hours and 14 times of social care provisions, i.e. domestic help, catering, social work, etc.). The smaller the local government the less frequent and shorter the care provided and services may be provided only once a day. The chance of receiving help (at least partial coverage) for home adaptations is very low.

### 5.3 Empowerment of clients

Patients are free to choose a provider. The most typical limitation of their decision is the lack of non-public providers in most of the services. Having insurance at the NHIFA is an obligation and patients then have the right for publically funded provisions (if available). Choice for care setting is also free (according to GP's recommendation). Personal care budget is restricted. NHIFA's annual report on home care services and

provider data are mainly aggregations, there is no detailed lists about providers where individual provider data are also shown.

### 5.4 Informal carers

There is no formal recognition of informal carers if they don't do the care in full time. There are very strict rules laid down by law that the nursing fee ('ápolási díj') can be given to one of the family members of relatives who stay at home. It is a quasi employment status because it counts to the working-years of the carer.

## 6. Disparities in the process of home care

The following disparities could be found in home care in Hungary:

- Home help (social care) is usually available for the people in need. The limitation is the frequency of the visits. Furthermore, the amount of time the carer can spend in the recipient's home is limited and less than needed. More than one visit per day is practically impossible. This leads also to quality problems.
- There is a gap between social and health care funding. In social care the co-payment is significant, and set according to the income of the recipient and family. For specialised home health care no co-payment is required.
- The size (budget and number of professionals employed) of the local government is the major limitation. In Hungary there are more than 3 500 municipalities and the financial capacity of them is usually low.
- 24 Hour care is usually not provided. The smaller the local government, the less frequent and shorter of the care provided. There are huge variations between local governments in the kind of care provided, what is covered and in what extent, and how frequent is the care.

## 7. Concerns and new developments in home care in Hungary

There are several current concerns in relation to Hungarian home care. It has been not explicitly determined what cases need hospital treatment or nursing at home. So there can be situations when the

Health Insurance Budget will withdraw the already completed payment for the visit afterwards, after the control. According to practical experiences it is difficult to divide and define what belongs to the health and what to the social sector's responsibility. Summarizing the main problems about financing and regulation: the health care and social care provisions are partly parallel, but a progressive and complementing system where the levels of provision are well-structured and built on each other is absent. As shown the financing of home visits are entirely different by the funder.

Hospice at home services have recently been introduced. On average people receiving this type of nursing (financed by NHIFA) receive 24 days of this care (Central Statistical Office, 2008).

The current financing system does not take into account the real living conditions and reason of care of the patients (age, health condition), nor their income conditions (Banai 2009). Providers undertaking the tasks voluntarily can usually select from the waiting list; while those performing mandatory tasks are not allowed to choose, despite the fact that these institutions have the scarcest available resources. That is why elderly people, whose income conditions do not allow to choose other institutions have less chance to care-taking of a high standard fulfilling up-to-date conditions (State Audit Office 2003).

Both the patients and other health care organisations such as out-patient care providers and hospitals are mainly satisfied with home care. However, according to the experts regarding the professional activities defined in the Ministry of Welfare statutory rule (20/1996. VII. 26) there is a great need for change in order to meet the real residential and medical requirements: improve the availability and develop the educational background of the nursing staff. (Banai 2009).

The further steps in developing home care in Hungary should be to work out the problem of overlaps, parallel functions within health and social care; establish a better progressive system; and set up appropriate incentives for the providers.

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# Iceland

*Author: Allen Hutchinson*

## 1. Context of home care

### Country, population and health

Iceland is one of the smaller European countries with a population of about 320,000 and the one of lowest population densities in Europe. There have recently been some fluctuations in population size because of the arrival of new immigrants, many being economic migrants. There are only two urban areas in the country and a significant proportion of the population live in isolated communities.

Compared to most other European countries, the GDP was on a high and rising trend until 2007, but recent economic circumstances have curtailed this growth.

The country currently has a high proportion of young people, with only 12% over the age of 65 and around 3.5% aged over 80 years (OECD 2008). It is expected that the population structure will change significantly by 2030 when 5.5% are expected to be aged over 80 (OECD 2008). Although only about 12% of the population are currently aged over 65 years, this proportion is expected to rise to 27% by 2050. At 17.6, the old-age dependency ratio is among the lowest in Europe.

Life expectancy is among the highest in the world, female life expectancy at birth in 2006 being 82.9 years and male life expectancy being 79.5 years. Female healthy life expectancy at the age of 65 in 2006 was 12.8 years while that of males was 13.6 years.

### Key characteristics of health and social care services

Iceland spends about 9.9% of GDP on healthcare, including private health care costs of about 1.6% GDP. Health and social care services are funded through general taxation. Health services are provided by the Ministry of Health through health centres and their staffing, including general practitioners, health centre nurses and some home nurses. Funds from general taxation are also transferred from the Ministry of Social Affairs and Social Security to Municipalities (Local Authorities) which run social services and social care services and, in a large sector of the population, now also run home nursing services (Halldorsson, 2003; Suppanz, 2008). There is an element of co-payment for primary care and social care provision, which is means tested for those on lowest incomes.

Nursing home and residential care homes are also funded through taxation and until recently there has been quite a high occupancy rate with about 8% of people over 65 years in such accommodation. Residential care and Nursing Home care, and long term care in community wards and hospitals, is paid for by the Ministry of Health, through direct payments to the organisations which are providing care. These may be health service providers, or not-for-profit organisations, or private providers.

### Social indicators and conditions related to old age

Iceland has one of the highest proportions of working population aged over 65 years – 20% in 2005. This is partly because the pension age is 67 years and also because there has been a low unemployment rate. Many people, including those in the public sector, are encouraged to continue working until they are aged 70 and 5% of the population are economically active at age 75. In addition to state pension provision, mandatory occupational pensions have been required since 1970 and people have been strongly urged to provide additional private pensions (UN Economic Commission for Europe,

2007). Because of the high employment rate to later age, the risk of poverty for people aged over 65 is relatively low at 15%.

## 2. Policy and regulation on home care

### 2.1 Governance on home care

Two Government Departments take the major responsibility for home care in Iceland. The Ministry of Social Affairs and Social Security takes the lead on the affairs of older people in terms of overall policy making and planning. A Joint Committee on the Affairs of the Elderly brings together policy makers from the Ministry of Social Affairs and the Ministry of Health, the senior Citizens Association of Iceland, the Senior Citizens Council and the Union of Local Authorities, under the workings of the Act on the Affairs of the Elderly (1999) (UNECE, 2007). The Act is the main policy instrument for the care of older people, published first in 2000 and the subject of amendments up to 2004. Although there have been no more policy documents published, recent working papers indicate an active consideration of the challenges of an ageing population.

The Ministry of Health takes responsibility for the health of older people and has included a set of targets for the health of older people in the National Health Plan (2004), although the Municipalities now have increased responsibilities for home nursing for people of all ages. The targets set in the National Health Plan do not include targets regarding home care.

### 2.2 Eligibility for home care services

Needs assessment for nursing in the home is assessed by home nursing staff who work from health centres or, in the urban areas, by nurses who are employed by the Municipalities. There is no formal, structured process for assessing need. Eligibility for domestic aid support is established by members of Municipality Social Services departments and these criteria may vary between Municipalities and are dependent on the availability of funds. There is an element of co-payment for most services, based on means testing.

### 2.3 Quality of process and output

There are no formal quality assessment methods for home care, nor is home care quality assessed externally. However, Iceland is unusual in being one of only a few European countries to use the Resident Assessment Instrument (RAI) (Jónsson, 2003) to assess pre-admission needs and the needs and outcomes of people living in residential and nursing care accommodation.

In home care, there are client complaint procedures in place and, depending on the type of complaint, may be directed to the Medical or Nursing Director of the primary care facility or to the local Social Services department (Act on the Rights of Patients 1997). There is no central collection of these data. For very serious clinical complaints, there is a process for making a complaint to the national Medical Director of Health.

### 2.4 Quality of input

Senior community nurses manage staff and also undertake initial needs assessment on behalf of the multi-disciplinary assessment teams. Community (home) nurses provide care in the home. Their work includes a full range of nursing care and a 24-hour community service is also provided in the urban areas. Community nurses also provide a service to day care centres and Serviced Apartments, mainly of a personal advisory nature. Health care assistants provide basic personal care services both in the community and in residential and step-up care housing such as Serviced Apartments. Home help staff provide domestic aid to people in the community and in step-up care housing.

The primary nursing degree in Iceland is a four-year university course, provided in two university faculties. There are regulations in statute that cover the registration of nurses and their educational attainment level. Although there are update courses available for continuing education, including specialisation in community nursing and continuing professional development courses on the care of older people, there is no requirement for this. There is no re-certification programme.

There is no formal task differentiation between home nursing and home help grades, except that nurses must hold professional registration. Thus nurses undertake the more technical tasks and domestic aid staff perform some personal care tasks.

Where staff are employed by public bodies and require continuing education, they are compensated for this.

### 2.5 Incentives for providers of home care

State funding is the main basis for financial support of home nursing providers so there is little commercial competition in the home nursing sector. Domestic aid services are usually provided by the Municipalities or by non-profit organisations so there is no real commercial incentive.

## 3. Financing

### 3.1 General funding mechanism

Data on other aspects of expenditure on home care are not currently available. A wide range of home care services are provided and are either fully funded or are provided on a means tested basis. These services include home nursing, rehabilitation, domestic aid and adaptations to housing. Under the Act of the Affairs of the Elderly the facility requirements for Serviced Apartments are closely defined, including 24 hour surveillance, a security system in each apartment, and services such as catering, laundry, cleaning and social and recreational facilities. Facilities are also available for nursing, medical aid and rehabilitation.

While taxation is the general funding mechanism for funding home care (both home help and home nursing) there are also elements of co-payments and private payments. Co-payments are means tested and tend to apply to social care costs such as home helps, Day Centres and other services. There is a means tested co-payment for a range of primary health care services, including visits to a General Practitioner or General Practitioner visits to the home. Some elderly citizens may cost share when they live in Serviced Apartments that may be privately owned or rented. For those who rent, their contribution is means tested. Where people have the resources, the costs of living in a Serviced Apartment may be fully covered by the resident, although home nursing charges may be on a co-payment basis.

### 3.2 Mode of financing home care providing agencies

Funding is provided through two Government ministries. Domestic and social care help, and home nursing in the larger urban areas, is funded by the Ministry of Social Affairs and Social Security, through the Municipalities which act as the agents for the Ministry. Currently, in smaller communities, the Ministry of Health pays for home nursing through the services of health centres. All of these services are provided to people who live at home and to those who live in Service Centres. Budgets for the main providers are related to the amount of particular services delivered, as a block payment from the relevant Ministry. As the Municipalities take more control of services, decisions on budgets will become part of the overall budget setting process of the authority, which may result in variation of service level between Municipalities.

Although it is possible to hold a personal budget this happens relatively infrequently and is mainly a service used by younger people who have disabilities. Those who hold personal budgets may use them for a wide range of purposes which extend beyond those usually offered by the main service providers. There are no regulatory requirements on the providers of services funded through personal budgets.

### 3.3 Price setting of home care services

Prices are mainly set by the public sector, since the State is the main funding body for home care services and the great majority of services are provided by state or not-for-profit organisations. For services provided by Municipalities, there is some variation between prices.

## 4. Organisation and delivery of home care

### 4.1 Access and assessment

For social care and domestic aid provision there are informal methods of assessment that do not use a standardised instrument. Professionals working in health centres, home nursing services or social services can initiate the assessment, which may be undertaken by a home care nurse or social worker, according to the client's needs. For nursing support at home there is a more formal assessment either by the municipality social services department or the home nursing service, although no assessment tool is used. The organisation of

the assessment process may vary in rural communities, when staff from a local health centre may undertake the assessment.

The strict assessment process for institutional care mean that more people with needs continue to live in the community and need home care. Needs assessment is much more formalised for residential homes and nursing homes and wards (for which the RAI is used) (Jónsson, 2003). Referral to hospital based assessment teams for institutionalised care may be made by hospital staff, for people who are in-patients, or by social workers or home nursing staff and by primary care staff from health centres, including general practitioners.

#### 4.2 Features of delivery

For clients who live in the community, including Serviced Apartments, provision of home care is mainly by public or not-for-profit agencies based at the Municipality level [for example home help services] or at local health centres. Providers of community care services may be managed by the Municipality, for example through a Social Services department, or perhaps a non-profit agency, which might provide specialist nursing or domestic services. A limited number of private companies have emerged more recently. For those providers who receive support from the Ministry of Health [such as health centres], the organisation is developing into a regional level, with the recent establishment of four health regions that cover the country.

The responsibility for developing home care services lies with social services departments working with home care nurses, on behalf of the Municipalities. Domestic aid services are either provided by the Municipality or are commissioned from not-for-profit or, occasionally, private organisations.

Home care nursing is organised by teams and team leaders function as case managers, co-ordinating the daily services and managing the staff who are providing assistance. Team leaders also provide direct care themselves and are in close contact with day care centres and places offering respite care for clients.

Care for older people with problems of frailty, physical illness or mental is usually managed by the partnership of social services, home nursing and primary care teams in the health centres. This approach uses the range of services available and may include care in the home,

care in Serviced Apartments or care in residential and nursing homes. Although there is some choice available in terms of place of residence, the service providers tend to be limited, not least because the total population of the country is small at around 320,000 people.

#### 4.3 Coordination and integration in home care

Recent changes in the organisation of home nursing services in some areas of the country have been made with the intention of improving integration between nursing and social care services, improving 24-hour cover and seeking best use of resources. Thus home nursing services and domestic aid services are increasingly being managed by Municipalities, rather than the home nursing services being offered through health centres managed by the Ministry of Health. For example, commencing in 2009 in Reykjavik, home nursing services previously based in health centres were clustered into a home nursing service providing 24-hour care under the management of the Municipality, rather than the health service. This has enabled more vertical integration between the parts of the nursing service and domestic aid service but it is not yet clear whether the previous lateral integration will be retained with other health centre staff, such as general practitioners and practice nurses. The changes may need time to settle in and attempts are now being made to re-strengthen relationships with primary care.

However, in the smaller communities the home care nurses and general practitioners and other health centre staff still work closely together so that there is cooperation across the team. There is also contact, but less coordination, with social workers.

Some specialist home care services are provided by hospitals – for example where people need long-term therapies, but this is a limited feature of the services.

Respite care, day care and day centres are closely integrated with the home care services because much of the management responsibility of all of these services falls to the Municipalities. Home care nurses visit day centres and Serviced Apartments and day care is often provided by centres run by the Municipality. Other day care is provided in nursing homes and residential homes which have financial support from the Ministry of Health. Here, coordination is managed by social workers.

#### 4.4 Actors involved in home care

The main actors in home care are:

- The Ministry of Social Affairs and Social Security takes the lead policy responsibility for home care for all adults and makes funding available for social care and (increasingly) for home nursing care.
- The Ministry of Health develops health care strategy for the population, including older people and people with disabilities, and provides funds for primary health care through health centres.
- Municipalities develop local policies for home care eligibility and services and provide funds from general and local taxation. The greater part of home care services are now provided by Municipalities.
- Health centres provide primary care services, including home visits by General Practitioners, although home visit rates in Iceland are very low (around one visit per week per doctor).
- Not-for-profit agencies may provide home nursing services or domestic aid services, paid for by Municipalities. There are a few for-profit agencies entering the market.
- There are no data available on the number of home care staff (nurses, personal carers and home helps).

Most home care workers have established contracts of employment with agreed payment rates, although these may vary to some extent for agency staff. Nurses have a national professional agreement on rates of pay. There are no publicly available documents in English that set out pay rates for nurses, but a recent survey by the International Council of Nurses (<http://www.icn.ch>, accessed 12-07-2010) indicates that although rates are similar to other Nordic countries, purchasing power is rather lower than that of colleagues in other countries.

#### 4.5 Use of tele-care

There appears to be limited use of tele-care in Iceland, beyond personal alarms and door security systems. Although some health professionals are aware of the range of technologies available, there currently seems to be little enthusiasm for the range of personal and home sensors and mobility alarms.

#### 4.6 Monitoring the care process

Monitoring of the care process falls to the care manager for care of the individual client and to the managers of the different professional groups. For nurses working in the community the managers with responsibility for nursing care process are either the Nursing Directors in the health centres or in the Reykjavik primary care centre. Changing needs are documented by the nursing team leaders/care managers.

### 5. Clients and informal carers

#### 5.1 Coverage and unmet care needs

No data are available on the number of home care recipients in the country. There appears to be only a limited coverage gap for home care services. The main difficulty raised by professionals was that there can be a waiting list for respite care (mainly to support relatives). Until relatively recently there was a significant waiting list for people who wished to be admitted to nursing or residential homes. However a change in policy to providing step up care facilities through Serviced Apartments, associated with a much more stringent pre-admission assessment, appears to have considerably reduced this waiting period.

#### 5.2 Empowerment of recipients of home care

In the past there was a tendency in Iceland for older people to place themselves in residential and nursing homes through choice. More recently there has been a strong national policy and practice move to place people according to need. In this sense, there is some limitation of choice but it is a limitation found in many countries as a result of the need to reduce costs. There is some choice of provider in the larger communities but this is more limited elsewhere because of the small size of the 'market'.

The Icelandic Ministry of Health (2004) identified long waiting times to nursing homes for people aged over 80 in 'dire need' of admission during the year 2003. Although the state target for length of wait was no more than 90 days, waiting time from first pre-admission assessment to admission was 213 days. It is said that this waiting time period has been reduced by 2009 as a result of more community based facilities such as Serviced Apartments.

The use of personal budgets is increasing but these are mainly used by younger people with complex needs. There are no formal requirements on providers in terms of process and outcome. Younger people with complex needs tend to be able to choose options of care using personal budgets and may use these funds in many different ways, including choice of residential settings and of social affairs, such as arranging swimming lessons.

Support for making a decision regarding type and receipt of home care comes through the assessment process (usually undertaken by the home nursing service or social workers), but there are no publicly available data on which to make a comparable choice. Councils for the Affairs of the Elderly may provide advice to local communities.

### 5.3 Informal carers

There is some formal recognition of the role of spouses. Financial compensation may be available if a spouse has suffered a loss of income as a result of stopping full-time employment to provide care at home, has incurred extra expenses linked to care or if the spouse has a low income.

## 6. Disparities in the process of home care

Care for is usually managed by the partnership of social services, home nursing and primary care teams in the health centres. Access is usually quite similar across the nation but some service providers are concerned about delays in access to day care centres and to respite care for older clients.

Although there is some choice for older people with problems of frailty, physical illness or mental available in terms of place of residence, the service providers tend to be limited, not least because the total population of the country is small at around 320,000 people. In very rural communities there is less access to the full range of home care services, with the result that some people may have to enter residential care or nursing homes earlier than if home based services had been available.

## 7. Current trends and developments in home care

Recognising that there was a societal view among older people that they should spend the last part of their lives in state funded residential accommodation, with the consequent impact of quite high levels of residential

care among people over 65 and long waiting times for admission, the Government introduced standardised residential eligibility criteria. This has increased the pressure on the home care services. However, a broad range of step-up/extra-care accommodation has been developed, especially, which have a care framework and level of service provision established under the Act of the Affairs of the Elderly [1999].

These developments appear to be having the effect of reducing the numbers of people seeking admission to residential or nursing accommodation and reducing waiting times for admission. As the population ages, it is likely that there will be further moves to encourage people to stay in their own homes or in Serviced Apartments, rather than in nursing home accommodation. Although assessment and eligibility criteria for home care services has tended to be un-standardised, future increased demands and resource constraints are likely to require a more managed process.

While the organisation and delivery of home care is reasonably stable in the larger communities, there remains a difficulty of what to do in very rural communities where it is difficult to provide professional 24 hour cover. In view of recent financial constraints, progress in this area of provision is likely to remain difficult.

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# Ireland

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## 1. The context of home care

### Country, population and health

Ireland is one of the smaller states in the EU with a population of approximately 4.2 million people. Against this baseline population there have been recent significant fluctuations as a result of migration movements. The current population density [60 persons per km<sup>2</sup>] is lower than the European average, with the lowest density to the west of the country [33 persons per km<sup>2</sup>]. Until 2008 there was a steeply rising trend in GDP, although this rise has now fallen back.

Although the population of people aged 65+ is a lower proportion of the total than in most other European countries, the age structure is expected to change considerably by 2041 with the numbers of people aged 65+ increasing from 500,000 to 1.5 million in the context of a total population change of 4.2 million to 6 million. As a consequence the old age dependency ratio will increase from among the lowest in Europe [18% in 2009] to 36% in 2041 – although these figures are consistently lower than the EU-27 averages [45% in 2041], principally because of the relatively large population of younger people.

Life expectancy of people 65+ in Ireland has now risen to 77.3 years for males and 82.1 years for females [2006], slightly above the EU-15 average. Around 9% of the total population report a longstanding health problem or a disability. Public health concerns include the high rate of accidental deaths and the overall health and lower life expectancy of the migrant population (McDaid 2009).

### Key characteristic of health and social care services

According to OECD data (2009) Ireland spent 7.6% of its GDP on health care in 2007. Health service financing remains a mix of public and private provision (McDaid, 2009). Hospital services are mainly financed by the state, although there is a large private sector and co-payment is common in primary health care and social care.

Access to a medical card, which entitles the adult holder to free access to health care, including long term care, is based on means testing and there is now no upper age limit at which health care becomes free (a change introduced in 2008 as a result of financial constraint). General practitioners who provide services to people holding medical cards are paid on a variable annual fee for service. Access to General Practitioner care for those who do not hold a medical card costs around €60 per consultation. There are 0.5 practising GPs (EU 15 average 1.0) and 15.4 practising nurses (EU 15 average 9.8) per 1,000 inhabitants (OECD/HD, 2008). The average length of stay in acute care hospitals, 6.12 days, is just below the EU average (WHO/HFA, 09-07-2010). There is mixed provision of nursing home and residential beds between the state (about 11,000 beds, provided by the state and voluntary sectors) and about private sector (about 17,000 beds, some of which may be leased to the state sector). Provision of home care personal and domestic services is tripartite, with the public health services providing health and personal care (McDaid, 2009), the voluntary sector playing a long-standing role in domestic care and the recently introduced private sector offering more flexible personal and domestic care packages (Timonen, 2007).

### Social indicators and conditions related to old age

Expenditure on care for older people was 0.225% of GDP in 2005 and expenditure on old age was 3.8% of GDP. Pensionable age in Ireland is currently 66 years, preceded by a one year period in which a 'retirement pension' payment is made at 65 years. The pension

scheme is a mixture of state non-contributory and contributory schemes and people are encouraged to also seek employment-related and private provision. Increasing employment rates among women have led to a rising need for formal care rather than the traditional family based care of earlier years (Timonen, 2007).

In general people in Ireland consider that the state should provide for long term nursing care although most consider this is not likely to be the case. Nevertheless, the recent so called 'Fair Deal' scheme on residential care does seek to limit the liability of older people who must make a means-tested contribution to their care, by discounting the value of the domestic home until after death and then limiting the contribution to 5% of the value. A medical card is not required to access support under the Nursing Home Support Scheme.

While the proportion of people aged 65+ in Ireland is currently lower than many other European countries, the proportional change over the next 40 years is a considerable policy and financial challenge. Although there have been a number of policy documents outlining the nature of the challenge, there has not yet been an overarching public policy debate that addresses future options.

### Attitudes related to old age

Irish people see care for dependent elderly people primarily as a professional affair. About 31% (compared to 34% in Europe) find this a task for close relatives even if the career might be affected (TNS Opinion & Social 2007). When having to choose a care option for a dependent elderly parent, between moving them to a nursing home, letting them move in with their children, their children visiting them and providing care or professional home care, many Irish respondents (30%) of the Eurobarometer survey chose professional home care. Moving to a nursing home is chosen by only 9% of them (TNS Opinion & Social 2007).

## 2. Policy and regulation on home care

### 2.1 Governance on home care

The principle Government department with responsibility for home care is the Department for Health and Children, relating to the Ministry of Health and Children, with some support also from the Department of Social and

Family Affairs and the Department of Finance. Senior civil servants from these Departments produced a document known as the Long Term Care Report, made available in 2008. Whilst not officially endorsed as a government publication, the Long Term Care Report (Long-Term Working Group, 2008) reviews many of the challenges in relation to meeting future need and appears to have influenced policy such as the recent Fair Deal on Long Term Nursing Care. In addition to identifying the rapid demographic changes in the country and the need to review pension support, the Report identifies gaps in provision at the community level, particularly in respect of step-up housing, with additional care support that is short of long term residential and nursing care. In practice, the vision and strategy is increasingly the domain of the Health Service Executive (HSE), which employs significant numbers of health and social care staff, commissions Home Care Packages and supports the Voluntary sector (Doyle, 2007; McDaid, 2009).

Although there are now moves to regulate quality in hospital and residential care, there are currently no national moves to regulate the home care sector, despite its increasingly diffuse and mixed economy and provision. However the HSE has recently proposed 'Quality Guidelines for Home Care Services' with a view to agreeing a national implementation plan.

### 2.2 Eligibility for home care services

There appears to be variation in the eligibility criteria for home nursing services, at least until the recent past. Information from Care Alliance Ireland suggests that eligibility has varied within and between regions. This may continue to be a problem while there is no standardised means of assessment being used to determine care needs. Recently a national task group within HSE has been examining eligibility for the 'Home Help' service including personal care and domestic aid and for Home Care Packages and a standard approach to eligibility may be implemented in late 2010. Guidelines for the standardisation of the operation of the Home Care Package scheme are also being developed.

While some aspects of home nursing are fully funded for all people, much of the service provision is provided on a means tested basis, with significant or full co-payments paid by many people in receipt of personal and domestic services.

Domestic aid and personal care provision is extensive and is provided by the state through the regional offices of the Health Service Executive, with means tested co-payment for those without a medical card.

### 2.3 Quality of process and output

There are currently no input, process or outcome requirements placed on providers, other than those arising from statutory standards for younger people with disabilities. There is no quality inspection of home care services at present (2009). The Health Information and Quality Authority is mainly concerned with hospital provision. Quality improvement of Health Service Executive (HSE) funded services appears to be mainly the domain of the (so far relatively few) Primary Care Team development officers working at a Local Health Office level, covering populations of about 30,000 people. Although this is a useful development, commentators have raised concerns about the quality risks in an unregulated, complex, sector such as home care (Doyle, 2007).

In contrast, during the past five years there have been significant improvements in quality assurance of residential care and nursing home services. The Social Services Inspectorate (SSI) now publishes reports of its triennial mandatory visits to nursing and residential homes, with associated, time bounded, recommendations for improvements, where required. Standards of care against which provision is judged have recently been published, and a version has been published which is accessible to clients and their families. From July 2009 all provision of residential care – public, voluntary and private – is subject to accreditation, registration and inspection.

### 2.4 Quality of input

Professionally trained staff in home care include community and public health nurses, community nursing assistants and health care assistants, therapists and social workers. Personal care staff have shorter training requirements.

In 2009, An Bord Altranais, the Irish Nursing Board, developed nurse training further by publishing a set of generic minimum standards that all nurses are expected to meet when delivering care to older people. The standards are also linked with those in use for the

registration of nursing and residential homes. Nurses, who now must graduate through a four year university course, are encouraged to seek additional skills in the care of older people but there is no mandatory requirement for such training.

Unlike in the nursing home and residential home sector where there are national care standards regarding training level, there is no task differentiation in the home nursing, personal care and domestic aid sectors set out formally by the state, other than An Bord Altranais regulations regarding the title and role of nurses.

Although HSE staff have financial support for training, evidence suggests that private sector providers are reluctant to pay for training, and that many voluntary sector providers recruit untrained staff as personal carers (Doyle, 2007).

### 2.5 Incentives for providers of home care (including possible competition)

Until the past decade there has been no competition in the home care sector, where providers comprised public health nursing and (mainly) locally based voluntary sector providers. There is already a significant and long standing private market in the residential care sector. There has been a recent emergence of the private sector in home care, with policy maker support though without formal policies in opening the market. This group of providers with more flexible services, may prove to be a longer term competitive challenge to the voluntary sector (Doyle, 2007). The inspection reports from the SSI on residential care, which are absent in home care, could act as an incentive in the home care market when regulation of this sector is finally put in place.

## 3. Financing

### 3.1 General funding mechanism

A wide range of home care services is available supported by a mix of public and private (means tested) resources. Some services such as rehabilitation and home and public health nursing are provided free or at low cost to people who hold a medical card, but at a cost to those who don't. For social services such as domestic help the client has to pay full cost or make a co-payment. This mix of funding sources should be seen in the context of the long-standing policy of mixed funding in the Irish health care system.

There are few data on the different expenditures outside of those directly from the state system, although there is a drive to collect more statistics to support policy making.

Funds from general taxation are the main source of revenue used for home care. This is principally managed through the HSE, and its four regional offices, by a variety of means such as direct service provision by Health Care Assistants, purchase of home care packages from the private sector, purchase of (mainly) domestic care services from the voluntary sector (McDaid, 2009) and, to a modest extent, provision of cash payments in lieu of Home Care Packages (Timonen, 2008). Means testing results in a considerable co-payment or private payment component for all forms of community care for older people, at all ages, who do not hold a medical card.

### 3.2 Mode of financing home care providing agencies

Most state funding for the care of older people is managed through the HSE and its four regional offices. Local Health Offices are responsible for managing a local budget which is distributed to Primary Care Teams (PCTs – a team providing primary care). Home help services are provided by the state through long term payments to voluntary or faith groups, paid retrospectively on a historical basis (McDaid et al., 2009). Where agencies are providing the service, this may be a block contract or fee for item of service.

Home Care Packages (HCPs) comprise a set of services assessed as being those required to meet the client's needs and are primarily provided through the Primary Care Teams. They may attract an element of co-payment. Around 11,000 Packages are provided each year, in some cases for only short periods. The overall budget for HCPs is managed through an allocation to each PCT network and is capped. This means that there can be a waiting list across the network, new clients waiting until current clients no longer require the service. About 2,000 people, often in the younger age groups, choose to take cash payments instead of a HCP, but there is no information at present as to what this money is spent on since there is no reporting mechanism. There is an increasing provision of mixed, 24 hour, services being provided by the private sector, on a care package basis. Commentators have remarked on the increasing 'grey' market, in which clients pay for home care themselves and where training and skills of providers have little oversight (Doyle, 2007).

### 3.3 Price setting of home care services

Price setting and co-payments appear to differ across regions, with the highest prices being in Dublin and surrounding areas.

## 4. Organisation & delivery of home care

### 4.1 Access and needs assessment

The initiative to seek care may come from the client, relatives or health professionals providing care, either in secondary or primary care. Needs assessment for people who might require some element of home care is undertaken either by professional teams in hospital before discharge or by members of the multi-professional PCT. The whole package of rehabilitation, home nursing and personal care and home help services is considered. There is no one member of the team who is identified as the initiator of the assessment. Rather, a PCT member (usually the person judged to have the most relevant skills) will receive the referral, either from the acute services or the GP, and that person will complete the initial assessment. Applications for home help services can be made directly by clients or relatives to the Public Health Nurse (also a member of the PCT). The assessor may then pass this to the Local Health Office or regional HSE office for approval of funding and assessment of level of co-payment.

Until recently there has been no standardised or uniform assessment process or tool in use in Ireland so that needs are assessed by hospital or primary care teams using subjective, non standard criteria. However, there is currently a national 'Single Assessment Tool Group' seeking to identify methods of assessing suitability for residential care and also for the assessment of need for community service and support.

PCTs can also assess the needs of people for day care activities (there are approximately 21,000 publicly funded day care places in Ireland) and for respite care, although there appears to be an element of under provision of the latter with waiting lists in some network areas.

### 4.2 Delivery of services

There is mixed provision although at PCT network level, where Home Care Packages are delivered, there are often only a single public sector or Voluntary sector home care

provider for services delivered in the clients own residence, or in sheltered housing. In many areas of the country the HSE provides personal care and domestic aid since there is no alternative provision. Private sector provision is changing this pattern and may improve flexibility in some cases by providing multi-functional teams over a 24 hour period, where traditional provision has tended to be restricted to day-time hours [Doyle 2007].

#### 4.3 Coordination and integration in home care

New configurations of Health Service Executive Primary Care Teams, including attempts to integrate General Practitioners [who are private practitioners], provide the opportunity for good integration between the components of the service available to all adult age groups in need of home care. Essentially, home care is the domain of the Primary Care Teams and their linked General Practice Teams and, critically, the teams include a social worker who can often lead in the assessment of need. Social worker team members are also often the linkage with hospital teams when specialist care is required, while the community nurse and the public health nurse make contributions to the care of people with more complex care needs. The introduction of Home Care Packages that are provided by the private sector may be a threat to integrated HSE services. On the other hand, private provision of combined personal and domestic care may improve coordination for individual clients.

#### 4.4 Actors and human resources in home care

Organisations that are concerned with home care include:

- The Department of Health and Children (DoHC) is concerned with national strategy and overall budget, and reports to the Minister for Health and Children.
- The Health Service Executive [HSE] is now the operational arm of the DoHC and responsible for operationalising strategy agreed by Government, through four regional offices.
- Provider organisations, including health services directly managed by the HSE, the large voluntary or non-profit sector, with traditional links to the DoHC, and the recently emerging private sector. HSE also provides direct funding to support GPs in some practices.

- Charities and voluntary bodies providing advice and support for clients and families, including Care Alliance Ireland.
- Professional organisations which influence standards and integration, including the Irish Nursing Board [An Bord Altranais], the Irish Medical Organisation and the Irish College of General Practitioners.

#### *Human resources*

There is a range of professional actors providing domiciliary home care. These professionals are members of the PCT, and include the staff of the associated General Practices. A typical team would therefore include General Practitioners and practice nurses, a social worker, occupational therapist and physiotherapist, community nurse and community nursing assistant and public health nurse. The PCT staff may work across more than one general practice team, since PCTs are being developed on a geographical basis of 7–10,000 people and general practices often see patients from a much wider area.

Other than General Practitioners and their staff, PCT staff of all grades are salaried staff paid for by the HSE (McDaid, 2009). Where the home help service (including domestic aid and personal care) is paid for by the HSE, staff may be paid on a salaried basis. However, there is evidence that staff in the voluntary sector and the private sector have less comprehensive contracts and many in the voluntary sector have no contracts of employment and may lack holiday pay (Doyle, 2007; Timonen, 2008).

Current home help salaries are approximately €25,000 p.a. and a senior nurse salary is approximately €35,000 p.a.

As mentioned, there have been recent reports of a 'grey market' in home care, funded by people who have to make full contributions to domestic and/or personal care, with many of the staff being from immigrant communities and often untrained [Doyle 2007, Timonen 2008].

#### 4.5 Use of tele-care

There appears to be limited use of tele-care in Ireland. There is extensive use of personal alarms and telephone alerts, with co-payment on means testing. Although private companies are promoting door monitoring, in-house sensors and remote wandering sensors, there

appears to be little publicly funded use of these. There do not appear to be any video monitoring systems being used, other than on a pilot scale.

#### 4.6 Monitoring the process of care

Care process monitoring in domestic and personal care is undertaken on an occasional basis by the PCT network development officer, who usually has clinical training. This process is not formulated. There are voluntary complaints procedures. There are no systematic client evaluations or satisfaction surveys, other than one major survey undertaken in 2007 by Boilson et al. (2007), which showed that respondents rated only 3% of General Practitioner services and 11% of community services as fair or poor.

### 5. Clients & informal carers

#### 5.1 Recipients and coverage and unmet care needs

There are approximately 19,500 long term care recipients in Ireland. There were around 54,000 Home Help recipients. Gaps between assessed needs and services available result from constrained budgets for Home Care Packages, limited availability of respite care and limited resources available for the adaptation of houses. Care Alliance Ireland [2009] indicated a probable growing gap between the number of Packages available during a year [about 12,000] and previous estimates of requirements of up to 15,000 per annum. This possible gap in care may increase pressure for residential care. Because of budgetary and provision constraints, and because of the availability of free access to health care and residential care for medical card holders, there is evidence that people may enter residential care with only modest levels of need [Long-Term Working Group]. Irish respondents to the question on satisfaction with allocated care were among the least to be totally satisfied.

#### 5.2 Empowerment recipients of home care

Many voluntary providers are paid through block contracts paid for by HSE on an historical basis, which often precludes choice. Furthermore, little comparative information is publicly available to help potential clients compare services, other than those available from the private sector. Home Care Packages offer the opportunity

for closer monitoring [Doyle 2007] but there is usually little choice of provider from a client perspective. For people who have enough resources to pay either for residential or home care there is full choice. Until recently it was also the case that people holding medical cards could access residential care without an eligibility review. However, following the recognition that lack of policy and standardised practice was leading to variation and a high number of residential care placements (Long Term Care Working Group 2008), eligibility criteria development will standardise the practice and may reduce choice.

Personal care budgets, in the sense of cash payments, are not very common and are mainly offered to younger severely disabled people. In practice, there is little choice of personal care budgets or approaches to provision of personal care that are offered to older people, often because of the established patterns of local personal and domestic care [McDaid 2009, Doyle 2007, Timonen 2008].

#### 5.3 Informal carers

The availability of informal carers may be taken into account because there is financial support available for those who, for instance, have to give up work to care. However the sums available to support informal carers are relatively small. Despite the increase of recent times in the proportion of women working, informal [family] care remains an important area of provision. Support for carers, and the promotion of the cause of care is provided by Care Alliance Ireland, which among other things undertook a survey of the health and well-being of family carers [O'Sullivan 2008]. The study found that a random sample of carers who were recipients of the Carers Allowance reported a lower quality of life than the general population.

### 6. Disparities in the process of home care

There is some evidence of variation in access and in unmet need. Ireland has a large rural community and there is variation in primary and community care staffing, with more limited access in some rural areas. New developments in PCTs (see 7 below) are aimed at reducing these disparities.

Data from the recent (small) SHARE study in Ireland (Delaney, 2009) indicate that over one third of

respondents aged over 70 reported that the help they received did not meet their need for care. Some experts have also indicated that access to respite care varies across networks because of limitations in funding or provision, leading to local waiting lists.

## 7. Concerns and new developments in home care in Ireland

There are several concerns in Ireland concerning home care. They are:

- Lack of regulation and quality assurance in community services appears to be so far unaddressed. With the increasingly complex social care system now developing, lack of an effective regulatory framework may lead to problems with quality and safety.
- In common with many nations, providing adequate funding for community services, such as Home Care Packages, may prove to be a challenge. Yet this must be addressed in order to reduce the number of people being admitted to residential homes with only limited need.
- Standardised assessment methods are not being used in Ireland. This may lead to variability in eligibility to state support and in some cases inefficient use of resources.
- Limited alternatives to residential care are currently available, so that there is little alternative to residential care for people with disabilities who need more intensive levels of care.

Future trends are difficult to foresee at present. The largest gap in provision seems to be in step-up housing with additional support for people who wish to continue to live in the community ('sheltered housing' in Ireland does not usually have such support). Although the Long Term Care Report (Long-Term Working Group, 2008) recognises and supports the need for a coordinated approach to providing enhanced care in community residences, there are as yet no public policy moves to enhance this form of residential provision and public financing still appears to be targeted at nursing home and residential care.

One area of development is increasingly clear. The Government has made a policy and financial commitment to developing 530 Primary Care Teams across the country which will be the basis for the provision of health care and home nursing care (McDaid, 2009). Well resourced

Primary Care Teams, with investment in community based rehabilitation close to communities, offer an important opportunity to improve the effectiveness of post-event care and to maintain people in their own homes for longer. New premises are also being built and examples are showing how well furnished teams can be integrated to provide high quality public health nursing services to communities. Increased integration between PCTs and the hospital sector (known as Integrated Service Areas) for older people is being enabled through the active creation of networks based around clinical problems.

Increased private sector provision of personal and domestic care may also increase care options, particularly for people who live in rural areas or for those who need care 'out of hours', although this might be at the risk of employment in the sector becoming 'precarious' (Doyle, 2007).

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# Italy

## Characteristics of health services and social services

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### 1. The context of home care

#### Country, population and health

In 2009 Italy had almost 60 million inhabitants (198 persons per square kilometre (ISTAT, 2009)). Italy is one of the countries in which the ageing society is most problematic. Between 2009 and 2050, the old age dependency ratio is expected to increase from 31 to an extreme 61 (less than 2 persons of working age for one elderly person), and the mean age will increase from 43 to 49 years (central scenario, ISTAT 2008, 2009, 2009b). The most intense growth, certainly compared to the rest of Europe, is in the age group of 85+ which will more than triple, up to 7.8% of the total population in 2050.

Information available on the health status of Italians is contradictory. At age 65, men can expect to live further 18.2 years and women 21.9 years (data 2009 – ISTAT 2009b), both living longer than an average European at that age. However, the years lived in the absence of limitations in functioning/disability at that age falls down to 9.4 years for men and 9.7 for women (data 2005 – EUROSTAT, 2008). Hence, the need for care may be relatively large. However, the share of persons over 65 reporting a long-standing illness or health problem is much lower than for Europeans (40.5% of women and 37.9% of men for the age group 65–74 years, and 58.9% of women and 57.3% of men for those aged 75 and over in 2008 – EUROSTAT, 19-03-2010).

Expenditures on health care per capita in 2007 was 2,414 US dollars, 8.7% of the GDP (OECD, 2008). Italy has a governmental medical service financed through general taxation, SSN (Servizio Sanitario Nazionale, as established by Law 833/1978). All citizens are entitled to receive hospital admissions and general practitioner care free of charge. All health care provided within SSN is free of charge for some particular categories (i.e. people 65+). In Italy in 2007 there were 4 hospital beds and 3 acute care beds per 1000 population (OECD, 2009). The average length of stay for acute care, on 2005, is 6.7 days (OECD, 2008). Concerning residential care in 2006, available nursing home beds were 308 per 100.000 inhabitants, 81% for the elderly (Ministry of Health, 2008). The percentage of GDP spent on in-kind benefits of social protection is higher in the EU27 (8.7%) than in Italy (6.9%) (Eurostat, 2008). Besides home care there are also semi-residential facilities for elderly people, who are mainly for those with more intense health care needs. Integrated health-social home care (ADI) is also very important, combining both health and social services. However, the Italian care system is mainly cash-oriented, through disability/invalidity pensions, attendance allowance and care allowances.

#### Social indicators and conditions related to old age

The purchasing power of Italians is about the same as for an average EU-citizen (in 2008 the GDP per capita in ppp US\$ was 25.200 – Eurostat, 2009) and also the share of Italians 65+ at risk of poverty is about average (in 2007 22% – Eurostat, 2008). In 2006, in Italy a very large share of GDP, 26.6%, is spent on social protection, 13% is spent on old age as pensions, attendance allowance, other financial benefits (EURISPES, 2006). This is relatively high compared to other European countries. Italy has had a very generous pension system. In

combination with the demographic problems this would lead to a tremendous problem. Hence, the system has been changed recently.

Italy had the second lowest employment rate for women in 2007 strengthening the resources for informal care (ISTAT, 2009c). Regarding children's formal liability to maintain their parents, in Italy any person who is unable to live independently has the constitutional right to receive public support, but at the same time the legal right to ask for alimony from relatives (up to the second degree, such as grand-children, children-in-law, etc.), in accordance with Art. 433 of the Civil Code (Polverini et al. 2004).

### Attitudes related to old age

Care of the elderly is felt to be a social duty for families (Polverini et al., 2004), mainly by female members. However, the increased female labour market participation has been curbing informal care. According to the findings of the Eurobarometer study (TNS Opinion & Social, 2007), many Italians believe elderly people should stay at home and receive regular care visits either from a public or private care service provider (30%) or from their own children (22%). Only 7% believe that elderly people should move to a nursing home.

## 2. Policy and Regulation on home care

### 2.1 Governance on home care

Law 833/1978 (SSN) stated the importance of preventing elderly isolation and home care has been an official policy since the beginning of the 1990s. The National Health Plan since 1998–2000 and the Legislative Decree 229/1999 envisaged an integrated home care scheme. Law 328/2000 aimed at promoting an integrated system of health and social services (Battistella, 2002) and the document “New definition of home nursing” in 2006 defined and updated the Essential Levels of health Assistance (LEA) (Ministry of Health, 2007), stating three categories of home nursing care: occasional, integrated and palliative. Home nursing care includes the home nursing service (SID), integrated social-health home care (ADI), home hospitalisation service (OD), patient control analgesia (PCA) and programmed home care assistance by GPs (ADP) (Polverini et al., 2004).

Home help includes housework and personal care (hygiene, getting up and going to bed, dressing, eating, administrative tasks, etc.).

The main ministries involved in home care are the Ministry of Health for home nursing and the Ministry of Work and Social Policy for home help. Additional governing organisations in home nursing care are the regional government and local health centres, while municipalities are involved in home help. However, the growing labour market participation of women has led to many privately hired foreign immigrants as live-in caregivers of older Italians (Lucchetti et al., 2003). Hence, a large part of home care falls outside of these legislative realms.

### 2.2 Eligibility for home care services

#### *Home nursing*

The document “New definition of home nursing” (Ministry of Health, 2007) defines uniform eligibility criteria. Home nursing is needs-tested. The availability of informal carers is also taken into account. These services are free of charge for people with minimum income and aged over 65, and also for those with recognised chronic disabling diseases, for terminal cancer patients and during an intensive post-acute phase (protected discharge from hospital). Otherwise a ticket for co-payment is requested (Ministry of Health, 2010).

#### *Home help*

Eligibility for home help (domestic aid and personal care) is means-tested and there are means-tested co-payment by clients. Home help is also needs-tested (home visit by a social assistant). In the absence of national/regional guidelines, municipalities define their own criteria of eligibility (Pesaresi, 2007a).

### 2.3 Quality of process and output

#### *Availability of quality criteria*

The rules ‘UNI EN ISO 9004-1’ (on Quality Management) describe the elements for managing and set the quality of the integrated home care (ADI) (Becchi, Bernini Carri, 2000). Also the regulations of ADI and home help (SAD) sometimes contain references to quality assurance (Pesaresi, 2007a).

### *Assessment of quality of the services*

*De facto*, the evaluation of the results, and also the recording of operational data (type of client, problems, solutions), are little practiced in Italy. There are difficulties in the assessment of outcomes (to measure the effects of the treatment on the client), Re-evaluation of people after the allocation of services is rare, as are attempts to record the outcome of interventions at distance (Guaita, 2009). Audits of the service, when made, are executed by the Social Services of the Municipality, and by the managers of integrated health services involved in the home (Regional Health Service). Evaluations of client satisfaction do take place, but cannot be used for choosing a provider (no individual organisation information is available). The second “Report on Integrated Home Care” presents and makes public the satisfaction of clients concerning hours of home care received, continuity-discontinuity or interruption of service, quality and waiting lists (Cittadinanzattiva, 2009).

### *Accreditation and clients complaint procedures*

Some Regional Authorities require accreditation (Polverini et al. 2004), thanks to which agencies acquire the status of subjects qualified to deliver home care (Legislative Decree, 502/1992).

Law 328/2000 art 13 states that all providers of social services must adopt a publicly available service chart. Charts must indicate the organisation of services and the existing procedures to ensure clients’ protection and complaints. Local Health Authorities and Municipalities also have specific offices called URP (Public Relations Office) for complaints.

## 2.4 Quality of input

### *Education*

In Italy, nurses provide technical home nursing. Home help (domestic aid and personal care) is provided by social-sanitary operators (basic assistant), private home assistants (“badante”), social workers and professional educators. Mainly, a social worker checks the needs, activates the procedure and coordinates the operators (basic assistants) which in general help with housework and ADL, without a rigid distinction of tasks. A professional educator sets up and works in educational projects to promote the balanced development of recovery and the social reinstatement of persons with cognitive and physical impairments; with persons having

difficulties in, and need for support with, performing everyday tasks (ADL-IADL) and persons with economic/ financial difficulties.

Concerning home nursing, university courses in nursing, rehabilitation and prevention (three years degree, First level, four degree classes) are provided by the Faculties of Medicine. The Ministry of Health defines the professional profiles to educate, while the content of the degree programme is defined by the Ministry of University and Scientific Research (Legislative Decree, 502/1992). Concerning home help, the Social-Sanitary operator (OSS) has a (compulsory) training course of 1,000 hours after the secondary school certificate; the social worker (Law 84/1993) and the professional educator (Legislative Decree, 502/1992) have a first level degree with three years of education; the psychologist has a second level degree with five years of education.

### *Job description*

The Document “New definition of home nursing” describes all home nursing tasks (general and specialist medical care, nursing and rehabilitation care, functional recovery) (Ministry of Health, 2007). Home help (SAD) includes housework and help with personal care (hygiene, getting up and going to bed, dressing, eating, administrative tasks, etc.), although there is no rigid distinction of tasks (Polverini et al., 2004). Which professional provides what is specified in the municipalities’ own rules concerning home help.

### *Recertification*

Many national collective employment contracts (CCNL) of different categories refer to sector-specific training (Perticaroli et al., 2006). Both regarding home nursing and home help, long-life-learning is compulsory. The employees having a regular-permanent contract in the public sector may have compensation or leave for continuing education. Continuous updates are obligatory in accordance with the national ECM programme (continuous medical education) concerning all health personnel working in the health sector (Perticaroli et al., 2006).

## 2.5 Incentives for providers

The accreditation schemes, with consumerist clients’ orientation and protection, creates competition among suppliers through the establishment of a quasi-market for the provision of social and health care, where clients

**Table 1:** Funding of home care services

<b>Publicly funded home care services</b>	<b>Publicly funded</b>	<b>Restrictions</b> (age, income)	<b>Co-payments</b>
<b>Home help services</b> Housekeeping activities Shopping (for daily needs)	<b>Municipality</b>	<b>Income</b>	<b>Charges</b> depending on <b>income restriction</b> and <b>Municipality/Region own rules</b>
<b>Personal care services</b> Assistance with washing and going to the bathroom Assistance with dressing and grooming Assistance with eating	<b>Municipality</b>	<b>Income</b>	<b>Charges</b> depending on <b>income restriction</b> and <b>Municipality/Region own rules</b>
<b>Home nursing services</b> Education and information about health related issues (such as diet) Paramedical care such as occupational/physiotherapy (learning to deal with consequences of illness) Assistance with putting on prostheses elastic stockings and other aids, etc. Assistance with movement and transfer from one place to another (incl. in/out of bed) Changing stomas and urinal bags and help with bladder catheter and the like Help with skin care, disinfecting, preventing bedsores Help with using medicines/treatments	<b>LHA</b>	<b>Age/income, disease, phase of cure:</b> Free for over 65 (and <6) years and low income, recognised chronic-disabling disease, terminal cancer patients, during intensive post-acute phase (i.e. protected discharge from hospital)	<b>Tickets</b> depending on <b>restrictions/exemptions</b>
<b>Technical aids</b> Adaptation of dwelling (like stair lifts, wheelchair ramps) Providing a walker frame/rolators Providing simple aids (like canes and crutches) Special transport against reduced fares (like wheelchair taxi) Personal alarm/telephone alert Door entry monitoring Video/web cam monitoring Personal monitoring external to home	<b>LHA</b>	<b>Civil disability level:</b> Free for people with a disability >34%	In case the <b>TA is not included in the list provided in the Ministerial Decree, 332/1999</b> (economic difference between the admitted fee and the cost of the device)
<b>Respite care</b>	<b>LHA</b> <b>Municipality</b>	<b>Income</b>	<b>Charges</b> depending on <b>income restriction</b> and <b>Municipality/Region own rules</b>
<b>Other support services</b> Meals-on-wheels (home-delivered meals) Assisting with social activities Help with household administration Psycho-social (Counselling, conflict mediation)	<b>Municipality</b>	<b>Income</b>	<b>Charges</b> depending on <b>income restriction</b> and <b>Municipality/Region own rules</b>
<b>Preventive home visits</b>	<b>not available</b>	<b>not available</b>	<b>not available</b>

get vouchers allowing them to buy services and to choose their provider (Grusol, 2009).

### 3. Financing

#### 3.1 General funding

- In 2005, the total expenditure of Municipalities for home care (ADI, SAD, tele-care, allowances-voucher, meals on wheels, home laundry, other) was €706 million (ISTAT, 2008a). The percentage of public health expenditure dedicated to integrated home care in Italy in 2006 is 1.08%; €924 per recipient (Gori, Casanova, 2009). With regard to day care/day centres, the amount spent has reached €332 million, i.e. €1.450 per client.

The National Health Service is financed by 95% through direct taxation (on income) and indirect taxation (on consumption). The National Health Fund (NHF) is divided among Regions and Local Health Authorities. The remaining costs are covered by revenues of Local Health Authorities and client co-payment. Concerning home nursing services, the client co-payments are related to age, income, disease, and phase of cure. Home help co-payments are only necessary for those with high income. The National Fund for Social Policies (FNPS) represents a specific funding source for social support and assistance to individuals and families. (Law 328/2000). Home help is publicly funded by regions, mainly by funds received from the NHF.

The technical aids are funded by the Local Health Authorities, taking into consideration the civil disability level; a co-payment of the client is due in case the technical aid is not included in the list provided in the Ministerial Decree, 332/1999 (as economic difference between the admitted fee and the cost of the device).

#### 3.2 Financing of home care agencies

Home health care is publicly funded by Regions through Local Health Authorities – LHA (ASL) – budgets (derived from NHF), based on a capitation formula and by fees paid by non-exempt clients (Ministry of Health, 2010). With regard to home help, municipalities are funded through the regions (Pesaresi, 2010). Municipalities pay the accredited ADI providers per client based on the intensity of care provided (actual days of care/number of days of care provided in the Care Plan);

average length in days; the mix of professionals involved; average time in minutes for each professional and time period of operation of the service (i.e. night) (Ministry of Health 2007). Some regions (e.g. Lombardy) opted for other funding mechanisms and issued vouchers for entitled individuals, that can only be used for purchasing of specific services provided by providers authorized (accredited) by the public authority (Battistella A., 2002). Additionally, care allowances (by Municipalities or more rarely by Local Health Authorities) are used to pay family members for informal care. The client is free to spend the allowance as desired (Lamura, Principi, 2009).

#### 3.3 Price setting of home care services

Home nursing services have a fixed price for non-exempt clients (Ministry of Health, 2010). Regions define the principles for the definition of fees that the municipalities have to pay to accredited providers of home help services. Municipalities can set their own charges (depending on income restrictions) (Ministry of Health 2007).

## 4. Organisation & delivery of home care

#### 4.1 Access and needs assessment

Some Regions have dedicated separate “access points” for home help and home nursing services. In other regions or single Local Health Authorities the Single Access Point is already operative (Ministry of Health 2005). With regard to home nursing, the GP, by himself or on request from others (hospital doctor, ASLs’ services, etc.) activates the service and the social worker organizes a home visit in order to verify the actual needs. In case of integrated home care (ADI), a client needs assessment is performed by a Multidimensional Assessment Unit (UVD) composed of social and health professionals which agrees the PAI (Individual Care Plan). Social evaluation scales and ‘multidimensional evaluation scales’ (standardized and validated) are used. There is no country-wide assessment instrument (Pesaresi, 2010). With regard to home help, the client, family or social services may activate the service. In order to calculate the co-payment and possible exemption it is necessary to obtain a GP’s certificate assessing the dependency level of the client and documents on the client’s financial means.

## 4.2 Delivery of services

As indicated in section 2.1, the responsibility for home care is shared between the Regional government (Local Health Authority/Districts) and the Local government (Municipality). The local governments accredit private providers of home help. Law 328/2000 stressed the importance of decentralising the management of services (Ministry of Work and Social Policy, 2006) to for profit/non-profit organizations, social cooperatives, volunteer organizations and other private organizations, through the authorization to deliver the services by Municipalities. In Italy, delegation and tendering are the most traditional forms used by public authorities to develop the provision of home care services (social and health sector) through the externalisation of tasks to non-profit organisations, especially to (social) cooperatives. Privately paid home social care is largely an informal market and often out of public regulations (Pesaresi 2007a). Also private home nurses may be informal and unregulated. In order to find a professional nurse for care at home, clients must refer to the College of nurses (Ipsavi) to obtain a list of which professionals to contact (all enrolled on the Public Register of Nurses).

## 4.3 Coordination and integration of services

There are concerns with the integration of social and home health care services. Usually they are provided by different organisations. Only in some regions (mainly in the Centre-North of Italy) are there agreements between Municipalities and Local Health Authorities for an integrated provision (ADI) (Pesaresi 2007a, 2010). In integrated home care (ADI) the GP has the responsibility of the care process. In planned home care (ADP) the GP provides medical home care at the patient's home (Pesaresi 2007). Another role of GPs in home care is that they certify the dependency of the client. Also hospitals can be involved in providing home care. Hospitalisation at home (OD) is requested by GPs, organised by a hospital and dedicated to cancer patients and dependent patients (Pesaresi 2007). In a few cases, home nursing services (SID) and Integrated social-health care (ADI) are also assured, free of charge, for intensive post-acute phase (protected discharge from hospital). Additionally, liaison nurses coordinate transfer from hospitals. Often there is a professional nurse as coordinator, but always with the collaboration of the GP.

Coordination between home care and nursing homes is also structured when it comes to integrated home

care (ADI). Indeed the Multidimensional Assessment Unit assesses whether home care recipients may need temporary or permanent admission to residential care (Ministry of Health 2007). In case of other types of home care the coordination is less frequent. Overall, it should be noted that although Law 328/2000 aimed at promoting an integrated system of services, many Regions (mainly in the South of Italy) still haven't set the rules for organizational and financial integration.

## 4.4 Actors and human resources in home care

### *Actors in home nursing*

The following are the main actors in home nursing:

- The Ministry of Health develops the national legislation, national minimum standards and the criteria for using the National Health Fund;
- The Region is responsible for planning and implementing services through the local health units. It is also in charge of defining the main organizational and managerial features of services, including control and supervision; also plans and organises the professional training of the care personnel;
- The Local Health Authority organizes and delivers home nursing services (SID), integrated social-health home care (ADI) and home hospitalisation service (OD). The ADI service includes as explicit members of the care network both a Case Manager (supervisor of integrated home care) and the relatives who provide care to the patient (the presence of such relatives is a prerequisite for receiving ADI) (DGR 606/2001);
- GP is the care professional in charge for deciding whether the patient needs home health care;
- Specialist doctors, physiotherapists, professional nurses provide the direct treatment to the patient.

### *Actors in home help (personal care and domestic aid)*

The following actors are involved in home help:

- The Ministry of Work and Social Policy develops the national legislation, national minimum standards and the criteria for using the National Fund for the Social Polices;

**Table 2:** *Human resources in home care 2009*

Functions	Estimation total number
Domestic aids	n.a., +/- 90% immigrants
Personal carers at home	1.5 millions, 71.6% immigrants
Home nurses	n.a.

Sources: *Personal care* : CENSIS, 2009 *Domestic aids*: Chaloff, 2008.

- The Region is responsible for planning and implementing home help services through the municipalities; monitors the implementation and integration among the planned interventions (social and health services); defines the criteria for the authorisation, accreditation and monitoring of residential structures;
- The Municipality defines the local rules regarding the provision of home help, contracts home help agencies, sets prices and reimburses home help agencies (or grants voucher directly to the clients);
- Public providers, Social cooperatives, Volunteer associations provide domestic aid and personal care;
- Private home assistants (“badanti”) provide domestic aid and personal care;
- Family and other informal carers (Mauri, 2007) provide domestic aid and personal care.

#### *Human resources in home care*

Regarding formal long-term care (see Table 2), data for Italy do not include nurses working at home (Fujisawa, Colombo 2009). Foreign workers are estimated to account around 90% of home help in Italy but there is no exact numbers available (Chaloff, 2008). There are 1.5 million personal carers at home (private home assistants (colf and “badante”), 72% of whom are immigrants (CENSIS, 2009). Nurses mainly have a salary from Local Health Authorities or are employed in the private sector. Social workers mainly have a salary from municipalities. Sometimes their contracts are temporary. Domestic aids are often migrants, without contract and unregulated, but the Law Bossi Fini (189/2002) has increased regulation. Nevertheless, the most recent “legalization campaign” for foreign domestic aids (Law 102/2009), during September 2009, recorded only 114,000 requests (less than expected). It is of note that in case of co-residence, “badante”, cared-for clients, the “regular” expense for the family is 30–50% higher than the corresponding sum in a black market

(Gori 2009). In the case of ADI there are also the Case Manager and the cared-for person’s relatives (DGR 606/2001).

So far as working conditions are concerned, private care supply is associated with a low qualification and a weak position of workers, and a very reduced professional protection (Pesaresi 2007a). Home helpers and nurses having a regular-permanent contract may have better working conditions and professional protection. The levels of payment are set out under the National Contract of Category (CCNL public sector). There are basic minimum levels that increase with levels of qualification and years of service. Night or weekend work increases the cost impact. There are also regional Tariff Nomenclatures for job categories (Conti, 2006–2007), in which a nurse has a net monthly salary of about €1.300/1.800 (depending on shift, night work, length of service) (LABORSTA, 2009). Publicly provided domestic care, guaranteeing 24 hours/day medical, nursing and social home services, costs €200 per day per recipient; the least qualified-expensive home care visit still costs no less than €16–20/hour; an illegally-employed live-in foreign caregiver costs €6–7/hour (Chaloff, 2008; Pasquinelli 2009). A private personal carer at home earns on average €930 net/month (CENSIS, 2009).

#### 4.5 Use of tele-care

Tele-care is mainly used for the elderly (72,951 clients and 153 euro per client in 2005) and the disabled people (2.050 clients and 260 euro per client in 2005) (ISTAT, 2008a). The client using a tele-care service may ask for help through a dedicated phone connected with a medical unit.

#### 4.6 Monitoring the adequacy of care

In many regions home nursing services provided are periodically monitored for the clients’ needs and evaluated at the end of the intervention plan, but there is no home help (SAD) information system (Pesaresi 2007).

**Table 3:** Long term care provided at home and in institutions 2005 <sup>1)</sup>

Recipient groups	Recipients of home care		Recipients of care in institutions	
	Number	% of the elderly	Number	% of the elderly
<b>Total</b>	<b>585,027</b> <sup>3) 5)</sup>		<b>244,304</b> <sup>4) 5)</sup>	
ADI	78,708 <sup>5)</sup>			
SAD	246,469 <sup>5)</sup>			
65+				
<b>Total</b>	<b>476,223</b> <sup>3)</sup>	<b>4%</b>	<b>110,341</b> <sup>4) 5)</sup>	<b>2.0%</b> <sup>2)</sup>
ADI	70,271	0.6%		
SAD	188,959	1.6%		

Source:

<sup>1)</sup> ISTAT, 2008a.

<sup>2)</sup> ISTAT, 2008b, data for 2005/2006.

<sup>3)</sup> This value includes: ADI (Home nursing and rehabilitation integrated with home care/help), SAD (Home help services), tele-care, allowances-voucher, meals on wheels, home laundry. The ADI value in this table refers to the "really" integrated ADI, whereas in many cases older people receive as ADI only nursing home care not integrated with social services (e.g. when also a family carer is available).

<sup>4)</sup> Residential Structures.

<sup>5)</sup> Own calculation.

The only information available is on an aggregate level and only provides data on expenditures and the territorial coverage of service (ISTAT, 2008a). There is said to be insufficient involvement of the patient and family in the definition, implementation and monitoring of home care (with satisfaction questionnaires) (Pesaresi, 2007).

The Ministry of Health and the Italian national institute of statistics (ISTAT) carry out periodic surveys on home care (Ministry of Health, 2008; ISTAT, 2008a).

## 5. Clients & informal carers

### 5.1 Home care recipients

In 2005 (see Table 3) about 1% of the Italian population received home care (mainly home help – SAD). About 81% of them were over 65 years old (however this is just 4% of the elderly population). Of those people in residential care only 45% were aged over 65 (2% of the elderly population). Home nursing is mainly provided to elderly people and those with terminal illness, those with severe illness, with high levels of disability or who have been discharged early from hospital. Home help is provided to people without adequate support networks and with low income, mainly older people (Pesaresi, 2007).

### 5.2 Coverage and unmet needs for care

According to the EUROFAMCARE survey (Lamura et al., 2008), 28% of interviewed informal carers were unsatisfied with bureaucratic/complicated procedures in accessing services, and 10.6% with long waiting lists. Italian informal carers were however reasonably satisfied with home nursing and governmental home help (95 and 94% respectively). However, according to the EURHOMAP vignettes on which home care professionals and experts were interviewed, rural areas are hard to reach, there are many differences among regions, and problems of long waiting lists exist. Other problems identified were the difficulties in accessing tele-care and home nursing for psychological support and pain therapy.

### 5.3 Empowerment of clients

Clients can choose among accredited suppliers through vouchers (Gori, 2004). With the care allowance, the informal carer is free to spend the allowance as desired (Melchiorre, 2006). Residential care units/nursing homes and the private paid assistant or "badante" may be an alternative to home care services (Polverini et al., 2004). Clients are 'forced' to choose home care, over institutional care, by (high) costs of both nursing homes and badante. They are furthermore assigned home services according with eligibility criteria for home care. Concerning the choice for funding, the Italian care system is mainly cash-oriented, through disability/invalidity pensions, attendance allowance and care allowances (Lamura, Principi, 2009). With regard to support for making a decision, Service Charts of the providers indicate

the organisation and the characteristics of the services supplied, and help for clients in their choice for services mainly comes from physicians and nurses (50%), less from social services (9.6%) (EUROFAMCARE study). Voluntary associations may also support them in this decision (Polverini et al., 2004).

#### 5.4 Informal carers

There is no formal recognition of informal carers at a state level as co-workers, but there are forms of monetary support (such as allowances and vouchers) addressing family caregivers directly, measures for working caregivers (flexible working times, part-time, paid and/or unpaid care leaves) and deductions from income tax (for costs of assistance) which are intended as an economic acknowledgement of the role of family care (Polverini et al., 2004). Therefore, in home care, family carers are fundamental to the implementation of care services and ensuring continuity (Ministry of Health, 2007). Carers are considered as co-clients with needs to be taken into account only partly. Measures for supporting family caregivers include day centres, self help groups, relief/respite services, telephone and dedicated internet services (Mauri, 2007). Concerning opportunity costs of informal carers, the EUROFAMCARE Study (Lamura et al., 2008) highlighted that 14% of employed family carers reduced the amount of their working hours and 7% gave up their work. The Special Eurobarometer Survey in 2007 showed that 5% of European citizens gave up work in order to take care of elderly parents.

### 6. Disparities in the process of home care

Some discrepancies between practice and theory in Italy have arisen from the vignettes. In fact, different treatment can be granted to similar situations, as follows:

- There are significant differences between North and South Regions: the rules of admission to home help are different between Regions and even within the same Region;
- There are long waiting lists in urban areas, and rural areas are hard to reach;
- The quality of services varies a lot among Local Health Authorities and Municipalities;
- The method and level of co-payment of home help are different among Municipalities;

- Explicit monitoring procedures of delivered services, in order to solve problems in the case of a worsening of the clinical situation, are not widely used.

### 7. Concerns and new developments in home care in Italy

*Current concerns in relation to Italian home care are:*

- Problems with long term funding and cuts in social spending and hence fewer future possibilities of supplying the service of home care;
- Difficult integration between health and social services in many regions, mainly in the South of Italy;
- Lack of common tools in client evaluation and quality monitoring;
- Lack of care continuity after hospital discharge: in many cases the continuity of care from hospital to the home of older people is not assured, since home care services might not be delivered in a timely fashion;
- Finally, the in a European context relatively high occurrence of mistreatment of dependent elderly people by staff working in the person's home (Europe 30%, Italy 37% according to the Special Eurobarometer in 2007) is seen as a problem.

*Future developments:*

- Increasing need of home care;
- Increasing provision of home help by private foreign assistants;
- Increasing use of vouchers as prepaid entitlements to care and market oriented care services;
- The attempt to combine money transfers with services delivery to families, a 'cash and care' option in order to support the informal care of family. Current public debate in Italy is focused on the development of home-based services (both ADI and SAD) and of local care allowances in order to prevent institutionalisation. This "cash and care" solution might be applied, for instance, to the national care allowance (Law 18/1980), a non means-tested benefit granted to the totally disabled person who is unable to perform the routine actions of daily

life and thus requires continuous assistance (Lamura, Principi, 2009a). This allowance might become a composite “basic care package” (“Prestazione Assistenziale di Base”), made up partly by cash and partly bound to the use of local services. In the long run, this solution might promote the transformation of the Italian welfare state into a more integrated and equitable care system;

- Integration of the foreign private assistants (“badanti”) within the network of local services, through coordination and collaboration between local and national levels of governance (Lamura, Principi, 2009a);
- Increasing use of technology.

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# Latvia

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## 1. The context of home care

### Country and population

Latvia is a Baltic state with 2.3 million inhabitants. The share of population over 65 and its expected increase until 2030 is comparable to the rest of Europe (Eurostat, 20-12-2008). The life expectancy and the healthy life expectancy at 65 years are relatively low, the latter even the lowest in Europe (Eurostat, 2008). In 2008, the life expectancy at age 65 was 12.7 years for men, while the European average is 15.8 years. A relatively large proportion of the population, especially women, claims to have chronic conditions (Eurostat, 2008).

### Characteristics of health and social services

Home nursing is a process where the health care services are performed by certified nurses' or doctors' assistants at the patients' place of residence. The patient is provided with health care services at home if he needs a regular outpatient treatment, but he is not able to arrive to the medical institution to receive a treatment according to the medical indications. Social care is help with ADL and IADL and domestic aid.

In 2008, an estimate of 6.5% of GDP was spent on health care (HFA, 2010), and just about 3,9% was spent by the public sector. The share is below the estimated average in the EU of 9.1% and 3.9% respectively. The main source of funding is a tax based social health insurance (NCHI). The supply of active nurses (5.3 per 1,000 inhabitants), is far below the European average (Eurostat, 2008). The hospital sector was extensive in 2008. The supply of beds was far above the EU-27 average (WHO/HFA, 2008)

and the average length of stay in acute care hospitals was also comparatively long (7.2 compared to 6.7 days in the EU-27 in 2007 – WHO/HFA, 2010). Social services are primarily financed through municipal taxation; 0.3% of GDP was spent on social services by the government (Jakaite 2007). Services include long-term social care and social rehabilitation institutions, day care and social work. Recently, an administrative reform has resulted in larger local administrative entities where tax is collected and care is organised.

### Social indicators and conditions related to old age

Latvia's share of GDP spent on old age is half the average in Europe. One third of the population over 65 is at risk of poverty, which is among the highest in Europe (19.5% on average for available countries) (Eurostat, data for 2008). The 2009 economic crisis has created a fragile context for public funding of home care.

### Attitudes related to old age

Latvians are financially liable for their parents' care costs and their ability to care is taken into account. Almost half of respondents (46%) answered that care should be provided by close relatives, even if it would affect their career, versus 37% of Europeans (TNS Opinion & Social 2007a). Home care provided by professionals is perceived less favourable, even compared to nursing home care. Asked about preferred options for their dependent elderly parents, only 10% mentioned professional home care, compared to 27% of the Europeans (TNS Opinion & Social 2007b).

## 2. Policy & regulation on home care

### 2.1 Governance on home care

Governance on home care in Latvia is split between “medical or health care at home”, on the one hand and

personal care and domestic aid on the other called “social home care”. Health care at home (further to be called home nursing care) is performed by certified nurses’ or doctors’ assistants at the patients’ place of residence. The municipalities regulate personal care and domestic aid conjointly. Since 2009, regulation and funding of health care at home is a national affair. The Regulation of the Cabinet of Ministers of the Republic of Latvia No. 1046 “Procedures for the Organisation and Financing of Health Care” (adopted on 19 December, 2006) prescribes the procedures for the health care services provided at home. It regulates for what diagnoses health care at home should be provided, the duration, the professional to provide the service and their duties (Regulation No. 1046). Regarding health care at home, both the Ministry of Health (MoH) and the Health Payment Centre (HPC, formerly the State Compulsory Health Insurance Agency – ‘VOAVA’) have an important role. The MoH aims to substitute hospital services with outpatient services, including health care at home. In September 2009 the turbulence of the economic crisis resulted in reduced financial resources for health care and many hospitals were reorganized to day hospitals, care hospitals and other. This led to the closure of 72 hospitals at the beginning of 2009, and another 40 hospitals at the beginning of 2010.

The government’s aim to also deinstitutionalise social services has led to a stronger focus on home care, which is mainly governed at local level. At the national level the Law on Social Services and Social Assistance is of greatest importance to social home care. It defines home care as services at home to satisfy basic needs of those with functional problems who are unable (according to objective criteria) to take care of themselves. The Law specifies the kind of services that can be provided, to whom and the requirements for providers of social services.

## 2.2 Eligibility for home care services

Health care at home requires a referral from the GP or hospital. Furthermore, access to health care at home is universal for persons with mobility problems and at the same time having certain diagnoses; oncology patients; mental care patients; decubitus patients; and patients after surgical intervention in hospital and those needing respiratory therapy (Regulation No. 1046). After surgical treatment in hospitals, patients have the right to five days of health care at home if prescribed by medical specialist (Regulation No. 1046). This can be extended up to one month by the GP (Regulation No. 1046). If care is

needed longer than one month, it can be extended by the patients’ general practitioner (expert opinion). After the one month (s)he should visit the patient within two days and give a new referral to the provider of health care at home (Regulation No. 1046). Next to this, persons with any of the before mentioned diagnoses, palliative care patients, and persons under the age of 18 or above 80 with other than the specified diagnoses or with a first order disability, should receive free visits by their GP or practice nurse. These visits are part of primary care, not health care at home. Otherwise they should pay these services themselves (Cabinet Regulation No. 1046).

Local assignment procedures for social services need to be laid down in local government regulations. The local eligibility criteria and assessment forms for personal care and domestic aid need to conform to national requirements, for instance it needs to take into account the subsidiarity to informal care (Rules of the Cabinet of Ministers Nr. 288). Payment for social home care is means-tested, also family means (Law On Social Services and Social Assistance). Exact criteria and the extent of means-testing are left to the municipality but need approval of the Cabinet of Ministers. Social home care can be as expensive as private home care for those with higher incomes but also of lower quality and without the possibility to choose the professional or have additional services. Hence, the large majority of social home care recipients (80% in Riga) are the very poor.

For technical aids adults should have a chronic physical disability; and a referral from a physician is required (Law On Social Services and Social Assistance). Otherwise, they need to be either heavily disabled (group 1–3) or have an anatomic defect (e.g. need of prosthesis).

## 2.3 Quality of process and output

*Process and outcome quality criteria for home care*  
Some formal criteria for various services have been laid down by the government in the “Requirements for social service providers” (Republic of Latvia, 2003). These only have a limited relevance for the quality of services. For example, they formulate norms for the adequacy of the number of professionals and the obligation of social service providers to have a contract with the client or family, specifying the type and scope of services to be provided (Republic of Latvia, 2003). Some municipalities have developed quality criteria. In Riga a short questionnaire for professionals is used to check the quality

of social services. Like for personal care and domestic aid, for health care at home services quality criteria do not exist at national level; just some general process criteria e.g. about registration of visits made by home care nurses. In order for health care at home providers to be registered and thus receive funds from the insurance, they need to comply with requirements set in the Regulation of the Cabinet of Ministers of the Republic of Latvia No. 60. 'Regulations on the compulsory requirements for medical institutions' (adopted on 20 January, 2009). The health care inspection checks whether these requirements are met.

#### *Assessment quality of home care*

The assessment of quality is more regulated for social service providers than health services. There are three possible checks on the quality of *personal care and domestic aid*. Firstly, the Ministry and until recently their Social Service Board may check (in complex cases); secondly, the Municipal social (care) office and, thirdly, the care provider (in some cases). In theory, at central level basic requirements are set for all social service providers, and good practices are presented to the field and financed. Practically, however, the focus of national quality control is only on contracted providers. The role of municipalities in assessing quality is set in the Law on Social Services and Social Assistance, stating they are obliged to "*assess the quality of social services and social assistance administered by the social service office and financed by the local government*" (Law on Social Services and Social Assistance, 2006). Procedures and frequency have not been specified. In general, municipal quality specialists (social workers) visit recipients once a year. Furthermore, clients are visited after they have delivered a complaint. One quality expert for every 2000 inhabitants is required. In Riga a client satisfaction questionnaire has been developed.

The quality control over *health care* is exerted by the clients' GP and the Health Care Inspection. The Health Care Inspection controls quality of health care at home in two ways: firstly by follow up of complaints, and, secondly, by planned visits to care providers looking at things like certification and documentation. The GP is supposed to (informally) check the quality of health care at home.

#### *Accreditation and clients' complaint procedures*

All health care at home providers are required to be contracted by or in case of social care providers by

municipalities in order to provide governmental financed home care. However, as the number of providers is still too small (although health care at home is provided in all regions), accreditation schemes are absent. Complaints are an important source for quality control. Official complaint procedures for home help recipients are set by law. Clients can submit complaints to the Social Services Agency. Municipality must specify the timing and procedures for appeals against the care assignments. Municipalities are free to develop additional procedures. Complaints related to the assignment of health care at home should be delivered at HPC, while complaints on the quality of health care at home should be filed to the Healthcare Inspection.

## 2.4 Quality of human resources

### *Education*

The following positions and educational levels exist in home care (just the first three positions named hereinafter refer to social home care):

- Carer: no education is required, but usually trained by the provider; mainly providing personal care services;
- Social carer: two years of mainly higher professional education providing personal care services and coordination;
- Social worker; four years degree obtained at any type of higher educational establishment; involved in coordination with other care providers;
- Certified nurses (three years education) or doctor's assistants (three years education): providing medical care at home, informing and instructing clients and their families, and supporting the GP when necessary.

In order to integrate coordination and practical social tasks the government aims to combine the functions of social worker and social carer.

Professional education falls under the inspectorate of the Ministry; it sets the contents and terms of the courses and checks certification of professionals.

### *Job description*

The tasks of carers, social carers and social workers are set in formal job descriptions. For the large number of providers who are paid as 'informal carers' no task

description exists. However their tasks have been specified in the individual contract with the patient. Nursing tasks are set in the ‘professional standard for nurses’ and more generally in governmental regulation.

#### *Recertification schemes for nurses*

Certification and recertification of nurses is the responsibility of the Latvian Nurses Association. Home care nurses must recertify every 5 years which requires a minimum number of credits attained through courses and passing a written exam. They are then included in the Register of Medical Persons.

### 2.5 Incentives for providers of home care

In theory, competition to be contracted is possible in home help (social home care), but usually the municipality contracts all providers since there is a shortage of providers. For health care at home providers are required to be contracted by the Health Payment Center in order to be financed by the state. As clients have little information on social care providers even competition among private providers is said to be low.

## 3. Financing

### 3.1 General funding mechanism

The expenditures on social care were 0.03% of the GDP in 2008. Expenditures on home social care were 5,490,204 lat (about 7.7 million Euro) in 2008 for the whole country. Expenditures on home nursing in the first month of 2009 was 50,000 lats (about 71,000 Euro) and was at the start of the year aimed to be 300,000 lat (about 0.4 million Euro), although cuts have been announced by mid 2009. Health care at home was very limited available and so, expenditure data provided showed to be extremely low. In the European context expenditures on long-term care at home were very low (in 2005, 0.01% of GDP) in comparison with the average in Europe (0.4%) (Eurostat, 2009). However, currently health care at home is provided in all regions of Latvia and funded by the state budget.

Health care at home is funded by national revenue including income and consumption tax revenue and for services outside the benefit package by private payments. Home help services are funded through the municipal budget (consisting for 83% out of the total income tax of its inhabitants) and client co-payments. Municipalities

decide how much to spend on home care and, within nationally set limits, what clients need to contribute by co-payments. The national limit states that, after co-payment the remaining financial means of the client may not be lower than half of the official minimum wage (now 90 lat, about 126 euro). But municipalities may decide to put a higher limit, e.g. in Riga at least the official minimum wage (now 180 lat, about 253 euro) should remain. Cohabiting family members of the client should then pay the remaining amount; only if this is not enough or impossible the municipality must pay. Privately hired services are paid completely out-of-pocket.

### 3.2 Mode of financing home care providing agencies

Activities of health care at home providers are limited by volume of health care budget. Health care at home providers are generally paid *per visit*, irrespective of the service. Medication, such as injections provided during the visits, is paid per ‘dosis’.

Private providers of social care have three or four sources of income: payments from the municipality (fixed amount *per hour*, irrespective of the service); a budget from the state for health care services; income from private services and possibly private donations. Private providers that also work for municipalities (social home care), use their income from private clients to compensate the very low amounts they receive from municipalities for their poor clients. As fixed costs of municipalities are paid from the municipal fund, it is cheaper for municipalities to delegate the provision of services to private organisations.

### 3.3 Price setting of home care services

Prices for health care at home provider’s visits and primary care visits by general practitioner or his nurse are set by Regulation No. 1046. In the price of home health care visit, administered by HPC, are included salary, transport, basic medicine and medical goods and additional (indirect) costs. When home visits are not part of ‘health/medical care at home’ or belong to the other groups mentioned in the eligibility section the patient must contribute an amount per visit by family doctor, except for visits to children up 18 years of age, severely disabled persons, persons older than 80 years of age; visits to patients who need sustained artificial pulmonary ventilation; patients who receive palliative

**Table 1:** *Distribution of home health care visits by type of provider*

Types of providers of medical care at home	% of medical care at home visits
Hospitals	38,3%
Home care specialised institutions	35,9%
Health centres (polyclinic)	19,9%
GP practice	4,6%
Rural municipalities	1,3%

Source: *interview HPC, 2010.*

care (recumbent patients with particular diagnoses) and medical care at home, persons with cases of influenza during influenza pestilence.

The prices of domestic aid and personal care are fixed per municipality and usually they do not cover transport costs.

## 4. Organisation & delivery of home care

### 4.1 Access and individual needs assessment

In case of needs for domestic aid and personal care, people with lower incomes directly apply to the municipal social care office, without a doctor's referral. Municipalities do require a physician's referral if technical aids are applied. The social care office's social worker will make the needs assessment. Details of the procedure and organisation may differ per municipality. As affluent people are not eligible for publicly funded home help these will apply and purchase it from private providers.

Health care at home can be received if there is a referral from the general practitioner or hospital (after discharging from the hospital) that contains information about the health care services that should be provided, the statement of providing and the duration ( Regulation No. 1046). Specification of care, frequency, etc. is provided based on referral of GP or specialist and paid by HPC. The information about patient: family, age, gender, identification code, diagnosis, number of visits are fixed in special form and sent electronically to HPC. Home health care administered by HPC is provided without special agreement between patient and provider. A contract is set up between the health care at home provider and the HPC, containing a specification of services, the price, the frequency of care and possible sanctions if not complied with conditions of contract.

The health insurer's agreement is obligatory. Some municipalities have combined the assessment for home health care and social care as they provide both.

### 4.2 Features of delivery

By mid 2009, 69 home health care providers are contracted by HPC (source: VNC) – GP practices, health centres (polyclinics), hospitals, in home care specialised institutions and doctor's assistants. By first half of 2010 there were 156 contracted providers (source: VNC). More than 90% of GPs in Latvia are self-employed. Hospitals are public, except in Riga where the majority is private. Nurses and physicians providing medical care at home are either contracted with a salary from a medical institution or self-employed. In 2009, there were about 400 social home care providing organisations. These are a mix of public providers (municipality agencies or social workers employed by municipalities), private contracted home help agencies (incl. NGOs), and private providers contracted by the patient. In cities, social home help is usually provided by the municipalities (with the exception of Riga, where there are only NGOs and private providers), while in rural areas NGOs are more involved. In big cities the supply of home care providers is short to demand. Hence, competition among them is practically absent.

### 4.3 Coordination and integration in home care

The organisation of health care at home and social care at home is usually apart. Also the organisation of institutional and social home care is usually split, in contrast to health care at home which may be provided by hospital employed nurses. In the capital Riga only two out of five contracted agencies is providing both home care and institutional social care services. The administrative split is said to be an obstacle to consolidate these services.

If nursing care is provided at home the GP is the coordinator of care, if necessary contacting a social worker and checking the provision of health care services by nurses. Nurses can also contact social services on behalf of clients to apply for social home care services. Structural coordination and cooperation between medical/health care at home and social home care is absent.

As mentioned, hospitals have an important role in providing health care at home.

#### 4.4 Actors involved in home care

For home help the following actors are relevant:

- The municipality. Regulating, financing and some provision of domestic aid, personal care, assistance and some technical aids (Riga municipality also provides adaptation of dwelling, such as stair lifts and adaptation inside of the apartment for wheelchair users). Municipalities with more than 3,000 inhabitants are obliged to have a social care office. This office organises social home care;
- The Welfare Ministry. Setting minimum regulatory standard (e.g. maximum co-payment, assessment);
- Professional home help (domestic aid and personal care) providers. Municipalities and private providers (NGOs as well as for profit);
- Informal carers. Their number is growing (also because pensions of elderly parents are currently used to replenish the family income).

For health care at home the following organisations are relevant:

- The Ministry of Health. Financing, organising and regulating health care at home and technical aids. Provision of technical aids basically is state responsibility;
- The HPC (formerly VOAVA). Administration of health home care including planning of financial resources from the state budget for health care sector, contracting, payment, collecting and analysis of statistics;
- The Health Care Inspection. Evaluating quality health care providers and checking complaints;
- Home health care providers. Their tasks are (Regulation No. 1046): care planning; providing care prescribed by GP or medical specialist (incl.

palliative care and assistance to emergency teams); preparing the patient for home nursing, including informing and instructing the patient and his/her family for providing health care at home; if necessary, assisting the GP in his medical treatment; reporting about care provided;

- Nurses, employed by a contracted health care institute such as hospitals;
- GP assistants and nurses. Providing health care at home.

In 2008 there were 1,906 carers (see section 2.4) and an estimated 524 social carers in Latvia working for registered providers (either municipalities or private) or contracted by a patient or family member. Working conditions of carers, social carers and social workers are set at municipal level but salaries are set by Cabinet of Ministers. Carers' and social carers' salary usually is around the minimum wage. In contrast to social carers and workers, who receive salaries, carers are paid per hour or for the type of care.

At the beginning of 2009, there were just 75 home nurses in Latvia, of which 10 work in Riga. This shows that the national system was still in its infancy. However, by the end of 2009 there were 472 medical persons (certified nurses and doctor's assistants) who performed health care at home (HPC data). Home care nurses usually work part-time in health care at home as they are employed by hospitals and outpatient clinics. As with social care professionals, no national working conditions are set. The salaries of nurses are set on a national level; they are paid per visit, i.e. their income fluctuates according to their productivity.

#### 4.5 Use tele-care

Tele-care is not (yet) an issue in Latvia. Alarm buttons are currently only provided by one private home care agency in Riga, and about two third of it is financed by the municipality. The provider has created a special needs assessment form for these alarm buttons. Not all municipalities can afford such services; tele-care is not seen as a must. Therefore, municipalities with less financial means may decline to provide it.

**Table 2:** *Estimated care provided at home 2008–2009*<sup>1)</sup>

Recipient groups	Social home care recipients 2008	Health/medical care at home at the end of 2009	Adult institutionalised long-term care recipients in 2008
<b>Total</b> (% of pop)	<b>10,633 (0.30%)</b>	–	–
	5,298 (0.15%)	+/_ 5,700 (0.16%)	–
% women	75,8% <sup>2)</sup>	n.a.	–
% 62+	69,6%	87% <sup>3)</sup>	–

<sup>1)</sup> Source social home help and institutionalised care: expert opinion and for% women: Purne, 2008. Source health care at home: interview HPC and VOAVA.

<sup>2)</sup> 2007.

<sup>3)</sup> 60 years and older.

#### 4.6 Monitoring of adequacy care

At the end of providing health care services at home, the providers must send a report, including the result of the indicated care, to the patients' general practitioner or local doctor. If home nursing services are necessary for a longer time than one month, it can be continued by the patients' general practitioner who should visit the patient not later than two days after the end of the one month term and pass the decision to the health care at home provider. In practice, monitoring of the adequacy of health care at home takes place about once a month by the GP or an assigned nurse, irrespective of diagnosis. Nurses are obliged to constantly report to the HPC on the actions they perform.

For social home care a monitoring plan is obligatory, but frequency and procedure have not been defined. In Riga, it is performed every six months by an assigned social carer, except for those having short-term care. Each social care office should register their visits to enable possible adjustments. After six weeks of care providers can ask the social care office to re-evaluate the situation.

### 5. Clients & informal carers

#### 5.1 Number of home care recipients

In 2008, about 4% of the Latvian population received social home care. In Riga long-term care in institutions is less popular compared to social home care, e.g., in 2009 in Riga only 1,664 persons received long-term care in institutions, compared to 3,941 persons which received social home care (from these persons, 2,792 received social home care services, and 1,149 a financial allowance for home care). Compared to other countries the share of retired people among these recipients is low. The scope of health care at home is limited with only 0.1% of the

population receiving it. The number of 'health/medical care at home' recipients has been growing vastly since the start of 2009. In the first four months there were just over 2,000 recipients and at the end 5,298. For health/medical care at home, 87% of patients is older than 60 years, 72% older than 70 years – in reality home health care is elderly care.

#### 5.2 Coverage and unmet care needs

Only municipalities having more than 3,000 inhabitants were obliged to have a social care office. So, small municipalities are not obliged to organise social care, though this does not mean that they do not provide social home care at all: services may be contracted from neighbouring municipalities. However, in a number of villages home care needs may not be adequately met. The situation may improve due to an administrative reform through which municipalities may unite.

A ground for unmet needs is that clients can only have health care at home once a day.

Especially in rural areas conditions for home care are poor. There is a lack of both informal carers and formal carers. Distances are large. The availability of mobile social and health services, which existed in rural areas, was said to be insufficient. It is unclear to what extent shortages still exist in these areas after the introduction of health care at home.

#### 5.3 Empowerment of home care recipients

People who need *health care at home* theoretically can choose between institutional care and home care. However, whether health care at home or institutional care (financed by the state) is provided, is decided by the

**Table 3:** Distribution of home health care visits in 2009 by diagnosis groups

Diagnosis ICD-10	% of home care visits
Patients with decreased mobility due to one diseases or ailments specified by HPC	67,6
Patients with malignant carcinomas	14,6
Patients with pressure ulcers	6,9
Patients with psychiatric disorders	3,0
Other	7,9

Source: HPC, 2010.

GP or medical specialist who is contracted with HPC. Furthermore, GPs usually choose the health care at home provider.

Those needing *social home care* can choose between private home care and social home care, depending on the number of providers available. For the patient it is cheaper to stay in an institution: they can keep 15% of their pension and everything is covered. However, a referral to a long-term care institute is only possible when they need more than the 4th level of home care (i.e. more than 35 hours of home care weekly).

Personal budgets are no option for either health/medical care or social care in most municipalities. A client can choose to pay an informal carer, but the amount is so low that it cannot be considered a personal budget. Some municipalities with shortage of home care workers replace the benefit in kind with these budgets. There are no restrictions on how these payments are spent.

#### 5.4 Informal carers

Informal carers are considered as co-workers. It is the duty of GPs and health care at home providers (certified nurses and doctors' assistants) to provide the informal carers with necessary information and instructions for providing health care at home. Home care started in 1992 with neighbour-to-neighbour care, where these non-professional carers were trained by social care offices. Later professional carers were introduced. According to the law informal carers (family or neighbour) may be paid for their services. The pay is very low. Informal carer can only be paid if they earn less than a certain amount, which is below the minimum wage. The working conditions of these paid informal carers have not been formalised, although the recipient and informal carer make a contract. In Riga about 1,207 recipients in 2008 receive this type of financing.

- Finally, there are signs that informal carers are perceived as clients. The Law on Social Services and Social Assistance states that “if family members are caring for the person, the local government shall support these family members psychologically, by consulting and training them and, if necessary, also materially.” No information is available to what extent psychological help, consultation and training are provided in practice.

#### 6. Disparities in the process of home care

Many geographical disparities exist. Some services are not available in rural areas (home care in general, physiotherapy, alarm buttons, etc.) due to the municipal financial situation or the lack of home care providers. Furthermore, the organisation of individual needs assessment differs and whether care is monitored also depends on the municipality. Furthermore, differences in care pathways are strongly related to the income of the recipient and his or her family.

#### 7. Concerns and new developments in home care in Latvia

Current concerns in relation to home care are:

- Poor efficiency due to split between social and health care. This creates problems for providers as financing is provided through two different sources and accounting needs to be separated;
- The budget for social home care is insufficient (both from municipality and the state). As a consequence new service providers have little or no interest in entering the market;
- Lack of financial resources for private social care providers. They rely on Latvian or foreign donations;

- Low and decreasing payment for home care professionals. For instance, in June 2009 the pay per nurse visit was said to have decreased by 10% in one month time. The shortage of nurses is related to poor payment;
- Quality of home care providers. Social care is mainly provided by non-professionals and no specific training for social home care is available;
- Use of the open method of coordination of policy development at local level as regard social home care. This results in differences in quality of services between municipalities and obstacles for providers to work in multiple municipalities;
- Frequency of monitoring care. Many clients should be re-evaluated for medical care at home more frequently than the current practice. Currently, changes in these procedures for health care services provided at home are planned.

The following developments relevant to home care can be mentioned:

- Closing of hospitals and stronger focus on ambulatory and home care, and hence continued development of health care at home (extending number of recipients). The Ministry of Health of the Republic of Latvia aims to substitute hospital services for outpatient services, including health care at home;
- Changing the home health care system. Some basic proposals for improvement of home care have been laid down by a working group under HPC to be included in Regulation from January 2011. These may further change the field of home health care. These proposals are: changing clinical criteria for home care so that impairment of functional ability will be an eligibility criterion independent from diagnosis. Furthermore, professional qualification criteria for carers are planned to be laid down: the obligation of documentation of the care process (by a care plan and care protocol) will be introduced and there will be two tariffs of home health care visits, one for simple cases and one for complicated cases.

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# Lithuania

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## 1. The context of home care

### Country, population and health

According to the size and population, Lithuania is the biggest country of the three Baltic States with a population of around 3.33 million inhabitants (data of 2010, Department of Statistics to the Government of the Republic of Lithuania, Statistics Lithuania). Due to rapid changes in economic situation, a negative population increase and emigration to other countries after Lithuania regained its independence in 1990, a constant decrease in population from 3.67 million inhabitants in 1990 to 3.35 million inhabitants in 2009 is being observed (Department of Statistics to the Government of the Republic of Lithuania). Around 83.9% of the population are Lithuanians, followed by 6.6% of Polish, 5.4% Russians and 4.1% other ethnic groups. As compared to other European countries, the current population density is much lower, around 52.06 inhabitants per km<sup>2</sup>. The percentage of population above 65 years in 2005 was 15.3% and is expected to increase to 21.9% in 2030. Between 2005 and 2030 the proportion of inhabitants aged 80 years and more will increase from 3% to 5.4%. The life expectancy for females at age 65 was 17.98 years and 13.34 years for males in 2008 (Statistics Lithuania). In 2006, the healthy life years at the age of 65 years was 5.2 years for females and 5.8 years for males (Eurostat, 2009 edition). The prevalence of longstanding illness or disease was 65.1% for females in age group of 65–74 and 80.5% in age group of 75 years and over. The corresponding numbers for males were much lower, i.e. 55.7% and 72.6%.

### Characteristics of health services and social services

Health services are financed both by public and private sectors, with compulsory health insurance fund being the main source of health care financing. In 2007, public expenditure on health care accounted for 72.8% of total expenditure on health care. In private sector, 98.3% of private health care expenditures consisted of out-of-pocket payments. In 2007, the total expenditures on health care were 6.22% of GDP (Health Information Centre).

There is a three-tier system for the provision of health care in Lithuania. The primary services are provided by general practitioners or family physicians, and nursing hospitals. The second-level services are provided by county or municipal hospitals, and there are 2 third-level hospitals with highly specialized departments (Lesauskaite et al., 2006). According to the data of the Lithuanian Health Information Centre, in Lithuania during the period of 2002–2008, the number of practicing physicians remained stable, being 36.89 practicing physicians per 10 000 population in 2008, and the number of nurses per 10 000 population decreased from 77.74 in 2002 to 74.36 in 2008 (Lithuanian Health Information Centre). Currently, one GP provides health services to 1800–2000 citizens. The number of hospital beds per 10 000 population was 81.67 in 2008, showing a 20% decrease from 2002. The mean length of hospital stay was 9.6 days in 2008. In hospitals providing nursing services (so-called nursing hospital), in general it is possible to stay for 4 months per year at longest. In 2006, the number of nursing home and elderly home beds per 10 000 population was 43.73. However, the number of beds in nursing hospitals is insufficient, and patients, except those with ontological diseases, are included in a waiting list and they are informed when a free place occurs. Other problem encountered in Lithuania is a lack of hospices. In 2007, the Law on palliative care addressing issues of palliative care was adapted by the Ministry of Health. The alternative to hospices is support-treatment hospitals.

Social care services are financed by public and private sectors: from funds of the state and municipal budgets, EU structural funds, foreign foundations, sponsorship (donations), person's (family's) payments for social services, etc. Social services are granted for all residents in need. The need for social services is determined by taking into consideration the level of independency, which is fixed on the evaluation criteria for person's social and physical independency. Social services are of the following types: social services of general interest and special social services. Social services of general interest are provided to a person (family) whose abilities to independently care for his/her private (family) life and to participate in society may be developed or compensated for by the specific services provided without permanent assistance by specialists (includes information, counselling, mediation and representation, social and cultural services, organisation of transportation, organisation of catering, provision of necessary clothes and footwear). Special social services are provided to a person (family) in respect whereof social services of general interest are insufficient to develop or to compensate for the abilities to independently care for his/her private (family) life and to participate in society (includes social attendance and social care).

#### Social indicators and conditions related to old age

According to the Department of Statistics to the Government of the Republic of Lithuania and Eurostat, expenditures on old-age pensions were 7.4% of GDP in 2008. The old-age pension is comprised of (i) the main (or base pension) and (ii) the supplementary part. The amount of the base pension depends only on the insurance period and if a person has the required social insurance period (now 30 years for men and 29 years for women), he/she receives the full amount. The supplementary part depends on both the insurance period and the contributions paid. The old-age pensions are very small and it makes up less than 50% of a working age income level (Lesauskaite et al., 2006). Due to this above-mentioned reason, even 29.8% of total Lithuanian population aged 65 and over was at risk of poverty in 2007 (Statistics Lithuania). Employment rate of the female population aged 15–64 increased from 58.2% in 2000 to 62.2% in 2007 (Eurostat, 2007). In Lithuanian law, there is no concept of legal maintenance obligation for children to maintain their parents. However, it is reasonable to conclude from the rules governing maintenance that the obligation covers an adult child's maintenance obligation towards parents

who are unable to work and who require support. Adult children are required to maintain parents who are unable to work and who need support. Maintenance is paid on the basis either of a mutual agreement or of a court decision (European Judicial Network).

#### Attitudes related to old age

About 46% of Lithuanian people totally agree or tend to agree that care should be provided by close relatives of the dependent person even if they have to sacrifice their career to some extent. This might be caused by fact that a close relationship among family members exists – couple generations live together in the same house especially in rural areas. Almost every second Lithuanian believes that the best option for the elderly parent is to live with one of their children (47%); 10% and 27% of Lithuanians believe the elderly should stay at home and receive regular care visits either from a public or private care service provider or from their own children, respectively. Nursing homes as a preferable option for care provision for elderly and dependent people were seen only by 10% of Lithuanians (Eurobarometer, 2007).

## 2. Policy and regulation on home care

### 2.1 Governance on home care

Home care is a rather new area of services in Lithuania. Only in 1992, after changes in economic and political situation took place, the health system was started to be reorganized, including the sector of home care. Until 1990, outpatient departments were integrated part of hospitals, and later outpatient departments became independent sectors. Internal medicine physicians and some paediatricians were recertified to general practitioners (GPs); a new qualification for nurses was introduced – the community nurse. Particular colleges and universities started to prepare new specialists – social workers. The Ministry of Health of the Republic of Lithuania prepared medical norms for GPs and nurses. Home care covers health care and social welfare systems especially in rural areas. Both these areas are the responsibility of two Lithuanian Ministries – the Ministry of Health and the Ministry of Social Security and Labour. Services for geriatric patients, cancer patients and persons with physical, mental disabilities and palliative care patients are provided by health care and social welfare systems. The provision of nursing services at home is combined with services of social welfare

according to the general order of provision of services, which was approved by the Law of the Minister of Health and the Minister of Social Security and Labour (Law No. V-558/A1-183).

The National Health Board together with the Lithuanian Association of Physicians and the Organization of Lithuanian Nursing Specialists have formed a vision of home care, which was presented to the Government.

The National Health Board in 2004 addressed the issues of development of home care and pointed out that little attention is paid to activities of community nurses, development of outpatient nursing, integration of nursing and care, and insufficient financing is given to home care. All these issues were addressed to the Committee on Health Affairs of Parliament, the Government of the Republic of Lithuania and both ministries.

## 2.2 Eligibility for home care services

### *Home nursing & personal care*

No general criteria for eligibility to home care services exist. After evaluation of patient's clinical situation, his/her level of independence and disability, the need for home care services is determined by a family doctor. Additionally, conditions at home are evaluated. Most frequently home care services are provided for geriatric patients and patients with chronic diseases and advanced cancer.

There is a nation-wide document providing clear guidelines where all the criteria for home care eligibility are listed for patients who need special long-term nursing. The criteria are uniform at national level and approved by common law of the Ministry of Health and the Ministry of Social Security and Labour. Palliative care at home is provided to patients according to the Law of the Ministry of Health, where disease codes, Karnofsky scale and Barthel index are indicated. The Karnofsky scale is a tool for grading a patient's functional status and ability to carry out daily activities. The Barthel index is a tool designed to measure skills such as activities of daily living and mobility. However, these criteria are not holistic. These services are financed for all patients by the Territorial Health Insurance Funds. Additional financial support for nursing does not depend on family income and on whether one has children.

Special needs are considered in respect to age, level of disability and capacity for work. Client's special needs are set by the Disability and Working Capacity Assessment Office at the Ministry of Social Security and Labour and a consulting commission of doctors at the institution to which the person is referred. A family can apply for an additional target compensation for patient's nursing at home. In this case, the family should apply to the Social Care Department by the place of residence.

### *Domestic aid and technical aids*

Domestic aid is provided to the elderly, persons with disabilities, children from families with social problems, and persons from risk groups with the aim to establish normal living conditions. After evaluation of independence level, the following services can be provided: house cleaning, personal hygiene and care, supply of food and its preparation, washing, buying of medicines, calling a doctor, etc.

The Law issued by the Ministries of Health and Social Security and Labour sets criteria for technical supportive aids. A family doctor, after evaluation of health status of a person and confirmation that his/her disease and status fulfils the criteria for special needs set in the Law, presents his/her conclusions for technical aid supply to the consulting commission of doctors.

Technical aids can be provided by the NGO Society of the Physically Disabled too.

## 2.3 Quality of process and output

### *Availability of quality criteria and assessment of quality of services*

In 2002, the Ministry of Health issued the Law on the Endorsement of Conception for Health Care Quality Assurance (State News, 2002, Nr. 10-355). This law outlines what quality management should be developed based on European quality policy generated in 1994. Health care quality is evaluated by external quality estimators, consultants, personnel staff and patients. The Ministry of Health approved the requirements of delivering nursing services at home, which regulate activities of community nurses, social workers and their helpers, and specialists in other fields in organizing and implementing patients' nursing at home. In medical norms for family doctors and community nurses, their functions, competency, responsibilities and subordination are described and the provided personal health care

services are listed. An institution holding a license for provision of personal health care services is responsible for high-quality nursing services at home. Some institutions providing amongst others home nursing have implemented quality system according to ISO 9000 standards.

#### *Accreditation and clients complaint procedures*

In 1999, the Ministry of Health issued the Law on Accreditation Regulations for Health Care Institutions. Accreditation is performed by the State Health Care Accreditation Agency at the Ministry of Health. This Agency selects accreditation experts and senior experts who take a decision to accredit or not to accredit a health care institution. An institution to be accredited has to apply to the director of the State Health Care Accreditation Agency and then has to fill in the Agency's internal evaluation questionnaire. The State Health Care Accreditation Agency's expert group analyses and evaluates the activities of the institution and takes a decision to accredit or not to accredit this institution.

A person (or family members or other persons concerned) may complain about an inappropriate provision of social services of general interest and social attendance to a municipal administration's director. If violations of the provision of social services are determined, a municipal administration's director must require elimination of shortcomings within a set time limit. If elimination of shortcomings fails, the municipal administration's director has the right to initiate the suspension or discontinuation of the provision of the social services by the social services establishment, i.e. a provider of social services (Law on Social Services, 19 January, 2006, No. X-493).

Complaints about an inappropriate provision of nursing services at home are analysed by a commission compiled by a primary health care centre. If a patient applies to the Ministry of Health, then the commission for the investigation of a complaint is formed by the Ministry. The commission, while analyzing a complaint, follows the Law on the Rights of Patients and Compensation of the Damage to Their Health (Ministry of Health).

## 2.4 Quality of input

### *Education*

Nursing at home is provided by community nurses (general practice nurses who have specialised in

community nursing and who are working 50% of their time together with a family doctor) and Red Cross' nurses (persons without special education in nursing, who completed specific courses; they can perform just patient hygiene procedures). Since 1990, studies are organised considering the Western European experience and the EU directives. To become a nurse, college (3 to 3.5 years) or university education (4 years) is needed. Both receive a bachelor in nursing degree after graduation (State News, 2009, No. XI-242). Additionally, those planning to work at a primary health care institution and to provide nursing services at home, have to complete 3-month courses at colleges, universities or the Development and Specialization Centre for Nursing Specialists at the Ministry of Health. Courses are financed by a primary health care institution and lead to a license enabling them to deliver home care services.

Graduates from colleges can enter two-year studies at a university and they are granted a university bachelor's qualifying degree in nursing; bachelor's studies are financed by the student himself/herself. Graduates with higher university education can continue their studies at a university in master's programmes. The master's studies take two years, and a master's qualifying degree is granted; master's studies are financed by the Ministry of Education and Science.

Students who study extramurally (graduates from colleges with non-university bachelor's qualifying degree in nursing) have to pay for their studies by themselves or expenses of studies can be covered by the health care institution where they work (Law on Higher Education).

Some nonspecialised nursing, such as feeding, personal hygiene, help with activities in daily living or technical procedures not requiring special training, can be provided by untrained family members as well.

Home care services are also provided by social workers and self-employed house cleaners; the latter is hired by family members. More seldom, lonely persons are helped by neighbours, friends or volunteers. Social workers at client's home help with personal hygiene, housecleaning, preparation of meals. Domestic aid is provided by volunteers too: Samaritans, Caritas' volunteers and Student Volunteer Organization 'Patrica'. Courses of one to two months in duration are organized for volunteers; courses are obligatory. Most frequently volunteers provide help with activities of daily living and not with nursing and medical support.

### *Social care workers*

Social workers are trained in colleges and universities. The graduates of the study programmes in colleges acquire non-university higher education and the professional qualification of social worker. At universities, students acquire Bachelor or Master degree and professional qualification.

### *Recertification*

Every 5 years community nurses have to renew their license. During this period, they have to complete the 60-hour courses: to participate in studies improving qualification, conferences and traineeships. Such training is financed by a health care institution, where a nurse works or by a nurse himself/herself.

### *Job description*

The legal document describing the rights, duties, competence and responsibility of a general practice nurse is the Lithuanian Medical norm MN 28:2004 “General practice nurse. Rights, duties, competence and responsibility” (adopted by the Ministry of Health, 2004). The corresponding document setting the rights, duties, competence and responsibility of a community nurse is the Lithuanian Medical norm MN 57:1998 “Community nurse. Rights, duties, competence and responsibility” (Ministry of Health, 1998). The legal document defining the areas of activities and qualifying requirements of a social worker was enacted by the Ministry of Social Security and Labour in 2006 (Ministry of Social Security and Labour, Law No. A1-92).

## **3. Financing**

### 3.1 General funding

In 2008, 4.87% of health care expenditures was spent on home health care, that is, on long-term nursing care at home (Eurostat, 25-06-2010). This is a sharp increase from 2004 where it only accounted for 1.18%. Almost all was funded by the government. Home health care is financed by health care and social service systems and covers nursing and social services provided at home.

Personal care services, home nursing and medical means are paid from the Compulsory Health Insurance Fund in accordance with the Law on Health Insurance of the Republic of Lithuania. The budget is approved for one

year. Health care services are funded from compulsory health insurance contributions paid by employees (6% of personal income) and employers (3%).

The compulsory health insurance is transacted by the Compulsory Health Insurance Council, the National Health Insurance Fund at the Ministry of Health and the Territorial Health Insurance Funds. Budget revenue of the Compulsory Health Insurance Fund consists of the following incomes:

- Compulsory health insurance contributions of the insured as well as contributions paid on their behalf;
- State budget contributions for the insured covered with state funds;
- Earnings of the institutions transacting the compulsory health insurance;
- Additional allocations from the state budget;
- Voluntary contributions of natural and legal persons;
- State Budget appropriations to compensate the expenses of acquisition of orthopaedic devices;
- Funds extracted from or returned by health care institutions or pharmacies for individual health care services which have been illegally provided or illegally presented for reimbursement, for medicines and medical aid equipment which have been illegally prescribed, issued or presented for reimbursement.

The compulsory health insurance contributions are transferred to the account of the budget of the Compulsory Health Insurance Fund of the National Health Insurance Fund. The National Health Insurance Fund has the right to use budget resources of the Compulsory Health Insurance Fund to control the quantity and quality of individual health care services, covered from the budget of the Compulsory Health Insurance Fund.

Nursing services at home for persons with special long-term nursing needs are paid to outpatient personal health care institutions by the Territorial Health Insurance Funds from the allocations of the Compulsory Health Insurance Fund (benefits in kind). In 2008, 23 million litas (6.7 million Euro) were assigned for nursing services at home (around 800 litas (232 euro) per patient). In addition, nursing services at home can be financed from municipal budget funds and personal patient's funds. Target compensations for nursing expenses (benefits in cash) can be requested by those in need (the special

need for long-term nursing must be established by the Disability and Working Capacity Assessment Office at the Ministry of Social Security and Labour). Target compensations for nursing expenses (765 litas (222 euro) per month) are paid from target subsidies allocated to municipal budgets from the state budget.

Social care services for elderly people and adults with disability (with the exception of persons with severe disability) are covered from municipal budget funds. Social care services for persons with severe disability are financed from target subsidies allocated to municipal budgets from the state budget (benefits in kind). Target compensations for care (assistance) expenses (benefits in cash) can be requested by those in need (the special need for long-term nursing must be established by the Disability and Working Capacity Assessment Office at the Ministry of Social Security and Labour). Target compensations for care (assistance) expenses (306 or 153 litas (89 or 44 euro) per month depending on the level of a loss of working capacity for adults) are paid from target subsidies allocated to municipal budgets from the state budget.

### 3.2 Financing of home care agencies

Home care agencies providing home care services can be private or public. All public and part of private home care agencies have contracts with patient funds and are funded by the Territorial Health Insurance Funds.

### 3.3 Price setting of home care services

Prices for personal health care services, which are covered by the Compulsory Health Insurance Fund, are set by the Ministry of Health after the evaluation of opinions of the Board of the National health Insurance Fund and Compulsory Health Insurance. Methodology for setting the prices for personal health care services, which are covered from the budget of the Compulsory Health Insurance Fund, is approved by the Ministry of Health.

Every nursing service at home is estimated based on levels of complexity of service (level I, level II, level III) and by applying a formula, every service is expressed in terms of money. The prices set for nursing services at home slightly differ among providers of nursing services at home.

For domestic aid, every municipality establishes the order of domestic aid organisation and approves the list of

services provided as well as their appraisements (tariffs). Financial contribution to the provision of these services depends on family income, family composition, client's health status, nature of services, etc.

## 4. Organisation & delivery of home care

### 4.1 Access and needs assessment

The Ministry of Health approved the requirements for the provision of nursing services at home (also in personal health institutions). Criteria for the assessment of patient's needs for nursing services are set in these requirements. The criteria are based on vital bodily functions, which are assessed by a community nurse: maintenance of safe environment, communication, breathing, eating and drinking, urination and bowel movement, personal hygiene and clothing, regulation of body temperature, movement and transportation, leisure activities, and need for palliative care. A family doctor decides about the need for medical procedure (for example, catheterization). To receive nursing services at home, the patient submits an application to his/her family doctor. A community nurse acting in accordance to competence set in medical norms for a community nurse provides nursing services at home.

In case of social care needs, the clients' needs for social services are described in detail by family members, by patients themselves or social workers who submit a request to a social care department of the municipality to receive social care. A representative of the Society of the Physically Disabled takes part in a decision.

### 4.2 Delivery of services

Home nursing services can be delivered by public primary health care centres, private health care institution cooperating with a family doctor and a community nurse, and private nursing agencies. A client, based on his/her wishes and affordability, can choose the provider of home nursing services; however, this choice can be limited in rural areas.

Municipalities and primary personal health care centres employing social care workers provide social care services. The choice of these services is based on availability.

Domestic aid services can be offered by private cleaning companies.

### 4.3 Coordination and integration of services

The transfer of a patient from hospital to home is coordinated by a senior nurse or ward nurses. Later on, the role of a coordinator for nursing at home is taken by a family doctor with participation of a community nurse. The family doctor determines whether a referral to another specialist, for example to an urologist, is needed.

Social care needs are coordinated by the social department of the municipalities and the Society of the Physically Disabled.

A community nurse, in accordance with medical norms for a community nurse, works closely in a team with other health care specialists, social workers, their assistants and specialists in other fields in organising and realising nursing services at patients' homes.

### 4.4 Actors and human resources in home care

#### *Actors in home nursing and personal care*

- The Ministry of Health is responsible for the development of nursing at home, legislation of regulating nursing at home, supervision of nursing quality, supervision of nursing quality, assurance of specialists' qualification, organization and structure, subordination, allocation of finances;
- The Ministry of Social Security and Labour is in charge of the development of social care, legislation of regulating social care, supervision of social care quality, assurance of specialists' qualification, organization and structure, subordination, allocation of finances;
- Municipalities are in charge of development of personal care and social care, quality assurance of nursing and social care, accessibility, allocation of human resources and finances;
- Primary personal health care centres and private clinics provide medical, social and nursing services, ensure the quality of these services, manage human and financial resources, assure specialists' qualification;
- The Compulsory Health Insurance Fund and the National Health Insurance Fund: the goal of the National Health Insurance Fund is to implement the budget of the Compulsory Health Insurance Fund (five Territorial Health Insurance Funds belong to the National Health Insurance Fund; the

latter supervises the activities of these Territorial Patient Funds and The State Patient Fund distributes finances to the Territorial Patient Funds);

- Voluntary organisations provide services to patients at home according to the set and approved legal norms;
- The Lithuanian Association of Palliative Medicine initiates legislation of laws and amendments, development of palliative care in the country and establishment of palliative care system;
- Home care providers, clients or patients (and their informal carers).

#### *Actors in domestic aid and supportive aids*

Some of the above-mentioned actors are involved in providing domestic aid and supportive aid services. The Ministry of Social Security and Labour, holding the major responsibility for these services, as well as municipalities are essential actors in assessing client's needs for these services. The Society of the Physically Disabled helps to adapt facilities within the house with supportive aids.

#### *Human resources*

The number of nurses providing long-term care at home is not known in Lithuania. Part of these nurses are community nurses working 50% of time together with a family doctor; other 50% of their time is spent on visiting patients at their home. Community nurses are employed and receive a fixed salary; however, an additional payment would be granted for the nurses providing palliative care at home.

According to the data of the Lithuanian Social Workers Association, there are about 6,000 social workers in Lithuania (Lithuanian Social Workers Association). Social workers at client's home help with personal hygiene, housecleaning, and preparing meals.

### 4.5 Use of tele-care

No tele-care system has been established in Lithuania.

### 4.6 Monitoring the adequacy of care

Nurses document their actions in so-called 'Form of Patient's Nursing at Home', uniform for the country. Nursing problems, objective of nursing, nursing strategy and services provided are registered in this nursing

**Table 1:** Social help and care provided at home in 2009

Recipient groups	Recipients of social help and care at home	Recipients in care institutions for the elderly and disabled persons
<b>Total number (% of total population)</b>	<b>13,554 (0.40%)</b>	<b>10,242</b>
Females (% of total female population)	10,039 (0.56%)	5,483
Elderly and disabled females of retirement age	8,495	–
Males (% of total male population)	3,515 (0.23%)	4,759
Elderly and disabled males of retirement age	2,345	–

Source: calculated from data of Department of Statistics to the Government of the Republic of Lithuania.

form by a community nurse during every visit to a patient at his/her home. Therefore, a uniform form is used to document services provided, but there are no standards how to perform a particular clinical procedure (i.e. standards for actions) approved and a uniform monitoring system of the adequacy of care in Lithuania does not exist.

## 5. Clients & informal carers

### 5.1 Home care recipients

See Table 1.

### 5.2 Coverage and unmet needs for care

In general, under-delivery of home care exists in Lithuania. There are an inadequate number of home nurses and social workers for the high demand for these services. In addition, such a high demand cannot be met because of insufficient financing for these services. With sufficient financing, more clients could receive a wide range of home services and get the reimbursement for these services.

### 5.3 Empowerment of clients

Clients have the rights to choose providers of primary health care services as well as a family physician and community nurse connected to him/her. The same applies for nursing services at home. However, this choice is limited in rural areas where usually only one provider of health care services exists. For any type of health care services, clients can use a personal budget for paying to any provider, if he/she can afford paying for health care services from out-of-pocket payments.

### 5.4 Informal carers

Most frequently client's family members provide everyday care or additionally family hires a self-employed person. Long-term care can be financed by the decision of a consulting commission of doctors at a primary health care institution.

## 6. Disparities in the process of home care

In urban areas, medical and social services provided are in accordance with the requirements set. Discrepancies appear in cases when the number of persons referred to a particular health care institution is rather high, but only one community nurse provides home nursing services; she has to spend a 50% of working time together with a family doctor.

Greater discrepancies exist in rural areas. Not all rural areas can provide social services as there is no social worker; patients are visited more rare because of long distances.

## 7. Concerns and new developments in home care in Lithuania

### Current concerns

Home care in Lithuania is still underdeveloped. An increasing elderly population causes greater needs for home care. Shortage of nurses and social workers exists. One of the biggest problems is an extremely low appraisalment (tariff) for home nursing and home care services. Another important issue is that only a very limited number of domestic aid services is included in the valuation list and many of the nursing services are not separated from the medical care appraisalment provided by a general practitioner. Medical and social services are still being not integrated.

### Current trends

Regarding development, it is important to note the current plans of the Ministry of Health and Lithuania Catholic Church, which actively participates in providing spiritual and social support for patients with chronic diseases and their family members. The current plans of the Ministry of Health are as follows:

- To accelerate development of nursing at home, integration of nursing and care;
- To assign several community nurses to a family doctor;
- To allocate more social workers, especially in rural areas;
- To expand rehabilitation services at home;
- To develop day-stay services;
- To increase the extent of personal health care services at home;
- To establish units at nursing hospitals for palliative care at home;
- To improve the financing for nursing care at home;
- To decentralize personal health care institutions in order to improve access to the services;
- To give a special attention to medical care services in rural areas;
- To increase financing, to promote preventive measures, to improve the quality of nursing;
- To develop long-term monitoring system for patients with chronic diseases;
- To promote scientific research related to home nursing.

The Lithuanian Catholic Church plans are the following:

- To built an ambulatory centre of nursing, psychosocial and spiritual services (an initiator is the Bernardinai monastery);
- To encourage volunteers to provide nursing, social and spiritual services at home in all the parishes (Caritas Lithuania);
- To establish voluntary palliative care centres, where treatment, nursing and spiritual help are intended to be provided.

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# Luxembourg

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## 1. The context of home care

### Country and population

Luxembourg is one of the smallest countries in Europe with just under half a million inhabitants; a large share of which is foreign (almost half in 2008 (eurostat, 2009)). The population over 80 years old, 3.4% in 2008, is expected to increase with 1.2% from 2005 to 2030 ((eurostat, 2008). This growth is less pronounced than in most other EU-15 countries, partly due to the high level of labour immigration (STATEC, 2009).

### Population's health

The average life expectancy is just over the EU15 and well over the European average for both women and men. For a most wealthy country it is noticeable that the average healthy life expectancy for those over 65 is below the EU15 average (9.1 and 8.6 compared to 9.7 and 9.3 for women and men respectively) (eurostat, 2008).

### Characteristics of health services and social services

Luxembourg has the highest expenditure per capita on health care of all EU countries. It is funded by compulsory health care insurance, additional voluntary insurance and co-payments. A shortage in nurses is a relatively small problem in Luxembourg as the number of nurses relative to the population is around two thirds higher than the average of EU15 countries (OECD, 2008). The picture is reverse with regard to physicians (2.8 physicians compared to 3.5 in the EU15) (OECD,

2008). The average length of acute care stay is relatively long; consistently the number of hospital beds is relatively high when compared to the EU15 (OECD, 2008). Other social services complementing home care are Integrated Centres for the elderly (homes for the elderly), nursing homes, senior clubs (leisure activities) and day care. Admittance to a nursing home requires that the informal carers and home care providers are not able to secure an independent life at home as described in the Dependency Insurance (Ferring et al., 2005).

### Social indicators and conditions related to old age

As Luxembourg has the highest GDP per capita in Europe elderly are relatively well off and the proportion at risk of poverty is well below the average in the EU15 countries. There is no duty for children to finance the care for their dependent elderly parents. But the Civil Code does state that children should help their parents in case of need. In practice however, the children will not be asked to pay for the care of their parents.

### Attitudes related to old age

In Luxembourg people are less positive towards providing informal care than on average in Europe. When asked whether care is a task for close relatives even if this would affect their career, 84% of respondents in Luxembourg disagreed, compared to 58% in Europe (TNS Opinion & Social, 2007). Like in most EU15 countries, professional home care is most frequently mentioned as an option in case of a dependent elder (TNS Opinion & Social, 2007).

## 2. Policy & regulation

### 2.1 Governance on home care

Home care is almost completely governed at the national level. The Ministry for the Family and Integration

(MIFA) is the primary responsible for home care, but the Ministry of Health and Social Security is involved as well. Legislation on home care is split between the Long-term care Insurance (AD), the Health Insurance (AM) and a subsidy called 'Tarification Sociale'. The governmental vision on long term care is to enable citizens to remain living in their own homes as long as they desire and it is medically possible (CEO, 2005). Home care is prioritised to institutional care and therefore the quantity and quality of home care providers is promoted (Le Ministère de la Santé et de la Sécurité Sociale, 2006) (Ministère de la Famille et l'Intégration, 2008). Prices for home care services are set by the Caisse National de Santé (the umbrella of health insurance funds), while its quality is supervised by the 'Cellule d'Evaluation et d'Orientation' (falling under the Ministry of Social Security). Furthermore, the umbrella organisation of providers and associations for prevention, assistance and care of dependent persons (Confédération des organismes prestataires d'aides et de soins – COPAS) has an advisory role and sometimes is a negotiation partner.

The 2004 coalition declaration of the Luxembourgian government stated about home care to further develop geriatric and gerontological rehabilitation, establishing the rights of psycho-geriatric clients and to continue developing palliative care (Ferring et al., 2005).

## 2.2 Eligibility for home care services

As the long-term care law states unconditional entitlement to (cash) benefits, there is no means testing for care financed through the Long-term care Insurance (AD). However, the following eligibility criteria do apply:

- rehabilitative measures should precede entitlement to the AD-financed care;
- care can only be applied for in case of a physical, psychological or mental illness or deficiency;
- there must be a need for assistance with ADL (related to: nutrition, personal hygiene and mobility);
- a specified threshold of need for care must be reached;
- minimum duration and intensity of the required care (ADL care for at least 3½ hours per week for a period of at least 6 months).

Some specific conditions, e.g. Spina Bifida, are exempted from the above criteria. No dependency assessment is

needed for technical aids provided by the AD, but the clients must have an illness, deficiency or handicap limiting independence (CEO, 2005).

Those in need of care but who do not meet the AD-criteria, a 'Tarif Social' can be obtained for ADL and IADL related help under the condition that there is a contract signed by a care network (for which a medical indication is needed) and that the income is below a certain threshold. National criteria are set for the 'tarification social' and the insurance; besides, at local level criteria may exist for additional resources offered by municipalities.

Finally, qualified nursing acts are financed by the Health Insurance (AM) if prescribed by a physician. No eligibility criteria apply beside this referral.

## 2.3 Quality of process and output

### *Availability of process and outcome quality criteria for home care*

At present no process or outcome criteria are in place. However, they are considered for the long-term care insurance. An inter-ministerial quality commission ('Commission de qualité des prestations') is working out such quality criteria (Le Ministère de la Santé, 2009).

Home care agencies are subject to a legally binding agreement with the Ministry for Family and Integration (MIFA), including safety and quality clauses, for instance, on educational requirements and hours of service (Commission Sociale, 2009). However, many care providers voluntarily implement quality assurance measures (self-evaluation). This may even include explicit values and standards and quality audits (Ferring et al., 2005).

### *Regulation on assessing the quality of services against these criteria*

The overall responsibility for insuring the quality of services lies with the "Cellule d'Evaluation et d'Orientation" (CEO), which may undertake quality audits but has not done so until now. Client evaluations are not obligatory; however, care providers do so voluntarily. Information from evaluations undertaken by care providers is not public. An independent national client satisfaction survey was conducted

(CEPS/INSTEAD, 2007). Results from the national study are public. However, results are not linked to individual providers.

#### *Accreditation and clients' complaint procedures*

At present, no accreditation for care providers is available in Luxembourg (although plans exist). Providers need to be registered with the MIFA (CEO, 2005). The AD has a complaint procedure for decisions of the CNS. Clients can also complain with a care provider, with the patient representation organisation ('Patientenvertretung') or with the relevant Ministries (MIFA and MISA). No data is available on the use of complaint procedures.

## 2.4 Quality of human resources

### *Education*

The following main occupations with educational requirements can be distinguished in home care:

- 'Aide ménagère' (domestic aid): no qualification needed; assigned when just domestic help is needed;
- 'Aide socio-familiale' (personal carer1): 2 years certificate; for ADL help, supervision and adjusting to new attributes;
- 'Auxiliaire de vie' (personal carer2): 3 years certificate; for domestic help and ADL and supervision;
- 'Aide-soignant' (nursing aid): 3 years certificate; for more intensive ADL care ('comprehensive assistance'); for nursing tasks (e.g. help with stomach bags, prosthesis; protection of the skin) and supervision of clients, by checking their temperature and heart rhythm;
- General qualified nurse: diploma for 3 years education; for nursing tasks mentioned in the 'nomenclature des actes infirmiers' (e.g. injections, disinfecting wounds and preventing bedsores, help with a feeding tube, taking blood and perfusion) and for case management;
- Specialised nurse; e.g. palliative care nurses.

All qualifications are subject to Luxembourg homologation by the relevant ministries (MIFA or MISA) and/or the Ministry of Education. Also specific additional courses for home care professional are

available, for instance, 'Kommunikation in ambulanten Pflegediensten'. For home care professionals there is an obligatory 40 hour continued education per year.

### *Formal task-differentiation*

The services are defined within the framework of the long-term care insurance and contain prescribed times and "relevé-type" (CEO, 2006). Here the minimal levels of education required are laid down. Besides, tasks of personal carer-2, 'Aide socio-familiale' and nursing aides are laid down in governmental regulations, e.g. 'Organisation de la formation de l'auxiliaire de vie'(Education Nationale et de la Formation Professionnelle – Sports, 2005). Acts to be exclusively performed by qualified nurses and specialisations have specified in the general government regulation (Le Ministre de la Sante et de la Securite Sociale, 1998) and specifically for Social Health Insurance financed services (Ministère Sécurité Sociale, 2000).

### *Recertification schemes for nurses*

No official recertification scheme applies. However, nurses not having practised for 5 or more years need to do an internship before re-entry ('stage de réinsertion') (Ferring et al., 2005). Besides, employers are obliged to have their nurse employees follow at least 20 hours of advanced training per year (Ferring et al., 2005).

## 2.5 Incentives for providers of home care (including possible competition)

Out of the current 3 main home care agencies in Luxembourg, two are non profit: Stéftung Hëllef Doheem and HELP. The third one CAMILLE is a commercial provider. As all three work under the same financial conditions and have no exclusive working areas, they are competing to a certain extent. However, MIFA ensures, via a legally binding agreement with providers, that the competition does not harm access to services and safety. All services must be available to all people equally. Another restriction to competition is that the payment of home care professionals is regulated through the collectively negotiated work contract (COPAS, 2002; COPAS, 2002). Finally, care agencies need to be formally licensed. In prices for home care services are set at national level and care providers are paid per service provided. So, home care agencies in this way lack incentives to decrease their prices.

### 3. Financing

#### 3.1 General funding mechanism

Compared to nine older EU countries, with 6% in 2007, Luxembourg spent a relatively high share of their total health care expenditures on home health care. On the other hand, the expenditures on day health care were relatively low (1.3% versus 2.1% in 10 older EU countries). Most of the expenditures on home care were on long-term care (about 95%) and only a small fraction (less than 1.3%) of the home care expenditures were private expenditures (OECD, 2009).

Home care is mainly financed through a compulsory long-term care insurance (Assurance Dépendance; AD) and a compulsory health insurance. Other sources are national and local general tax revenue and client co-payments. The National Health Fund (CNS) financing qualified nursing care and some technical aids through the compulsory health care insurance (AM), and personal care, domestic aid, respite care and borrowable technical aids through the long-term care insurance (AD). Both insurance funds consist of a mix of taxation and insurance premiums. The premiums are paid jointly by employees, employers and the state.

Co-payments are not required for AD-financed care, but clients need to contribute 20% for the costs of (AM-financed) qualified nursing (Le Ministre de la Santé, 2009).

For home care services not financed by the long-term care Insurance the 'Tarification Sociale' is an alternative. Unlike AD and AM, this scheme is means-tested and funded completely through taxation by the Ministry for the Family and Integration. The alternatives for unfinanced nursing services are the additional voluntary health insurance such as CMCM and DKV. Finally, there is also an unknown although considerable number of privately hired home care professionals. They are completely privately paid.

The Ministry of Family and Integration financially supports the organisation providing tele-care, but the recipient still needs to pay for the aids. There is individual (usually means-tested) financial support for this.

#### 3.2 Mode of financing of home care agencies

In the case of IADL, ADL or nursing care financed by the long-term care Insurance (AD), the National Health Fund (CNS) directly pays the home care agencies on a fee-for-service basis. Other nursing acts are paid by the CNS either directly to the care agency (if the patient also receives personal care through the AD) or are reimbursed to the patients, also on a fee-for service basis. In the case of the 'Tarification Sociale' the Ministry (MIFA) pays the provider part of the price (the remaining part is paid by the recipient) again on a fee-for-service basis (HELP, 2009).

#### 3.3 Price setting of home care services

A fixed hourly tariff (valeur monétaire) for AD-financed home care is negotiated between CNS and the association of providers (COPAS). In 2009 the tariff was 57.62 Euro (Ministère de la Sécurité Sociale, 2009). The tariff is based on the costs of home care, including staff costs, travelling, overhead and collective wage agreements. Cash benefits are half this hourly tariff. Real prices for home care services depend on the 'valeur monétaire', the time to perform the task and the qualification level required. For qualified nursing acts a yearly fixed method is used. It is based on a different method of calculation than for AD-financed home care. The real prices also take into account the intensity of the care needed as well as the level of competence (qualification) required. Both the 'valeur monétaire' and 'lettre clé' are binding for all home care service providers in the country.

## 4. Organisation & delivery of home care

#### 4.1 Access and individual needs assessment

Home care financed from the long term care insurance (AD), must generally be applied for at the 'Caisse Nationale de Santé' (CNS) with a standard form and a medical report of a physician. Valid applications are subsequently forwarded to the Evaluation and Orientation Unit (CEO) for assessment. CEO undertakes a medical assessment and a basic needs assessment. The basic assessment, using a standard questionnaire, focuses on the help needed with activities of daily living. On the basis of this multi-disciplinary assessment CEO concludes on the type, intensity, period and frequency

of care, including what will be done by informal carers. Everything is included in a care plan that CEO presents to CNS, which takes the final decision.

For reimbursement of qualified nursing services a prescription of a physician is required. The ministry's 'Controle Medicale de la Sécurité Sociale' has to see to the compliance to specific types of home care, e.g. palliative care. In case services not financed by the AD but financed by the subsidy 'Tarification Sociale' the assessment is carried out by the home care agency. Agencies decide about an application on the basis of information on income and a care plan. Provided subsidies are then checked by the Ministry for the Family and Integration on a yearly basis.

#### 4.2 Features of delivery

All three home care agencies in Luxembourg are private national organisations providing home nursing, personal care, domestic aid and care provided by physiotherapists, occupational therapists, psychologists and dieticians. They cover various diagnostic groups. One is for-profit, while the other two are not for profit. In addition, in 2005, 23 foundations existed which provided domestic aid and personal care on a voluntary basis (CEO, 2005) and a number of categorical organisations aiming at specific patient groups. Furthermore, an unknown number of private professionals is active in home care.

#### 4.3 Coordination and integration in home care

Most home care agencies provide the full range of home based services, which is facilitated by a multi-disciplinary approach in the individual needs assessment for long term care financed under the AD scheme.

There is no structured cooperation between home care professionals and GPs (who also see patients during home visits). Mutual contacts usually depend on whether the GP favours such contacts or not.

One home care agency has developed the routine that coordinators and special nurses (*infirmières de référence*) contact the client's GP whenever necessary. Hospitals do usually not provide home care. In general, no formal link is organised by the hospital to ensure the continuity of care from hospital to the community, although some hospitals do cooperate by means of a collaboration contract whereby liaison nurses employed by the agencies

are formalised. Some hospitals have a collaborative agreement by which the agencies' liaison nurses organise a smooth transfer. Conditions for integration with nursing homes service provision is better as one home care agencies also provides nursing home care and agencies may provide standard "fiches de transfer" for nursing homes. The "fiche de transfer" is a tool developed by the foundation to assure the seamless continuation of care when transferring clients from the different care settings. As such it is not a compulsory document.

#### 4.4 Actors involved in home care

##### *Actors*

The following actors are involved in policy making, financing and delivering home care in Luxembourg:

- The Ministry of Social Security is responsible for the AD system and the Ministry of for the Family and Integration, for the tarification sociale, registration and inspection of care providers, supporting and financing of local initiative, for instance on elderly care;
- The "Caisse National de Santé" (CNS) is the financing body responsible for granting services; managing the budgets of insurance schemes; developing nursing contracts; negotiating with providers of nursing aids; and setting the home care services prices (together with other actors);
- "Cellule d'évaluation et d'orientation" (CEO) is an interdisciplinary needs assessment agency for AD-financed care (under the Ministry of Social Security);
- Local governments are involved in providing and financing services such as meals-on-wheels, tele-care, etc.;
- The Consultative Commission is an advisory body consisting of representatives of long-term care insurance beneficiaries, providers, social partners and UCM. It advises on how to assess the clients' state of dependency, issues related to evaluation and reporting, experiments, appliances to be covered, etc.;
- COPAS is a confederation of nearly all home care and institutional care providers in Luxembourg and is a negotiation partner for the state;

**Table 1:** Estimated long-term care provided at home and in institutions 2006

Recipient groups	Recipients at home	Recipients in institutes (other than hospitals)
<b>CEO: Total</b> (% of pop)	<b>6,489 (1.3%)</b>	<b>3,300 (0.7%)</b>
OECD: % females	61.1%	77.9%
OECD: % 65+	68.6%	96.9%
OECD: % 80+	37.8%	73.6%

Source: CEO; OECD/HD June 2009.

- Home care agencies and other organisations providing home care (e.g. Stéftung Hëllef Doheem, Camille), including physiotherapists, occupational therapists, psychologists and dieticians;
- The clients or patients (and their informal carers).

#### Human resources

It is estimated that about 2,500 personal carers and nurses provide care at home. Most nurses are employed by agencies, but a small number are self-employed. Self-employed providers are generally not allowed to work in the AD-system. However, there is one exception for self-employed nurses. If they are an “*infirmière libérale*” and work under a subcontract with one of the agencies they can be reimbursed by the AD-system. However, self-employed nurses may also work within the ‘Assurance Maladie’ System nursing activities are prescribed by a doctor and regulated by the AM. No statistics are available on the self-employed cleaning aids.

Working conditions and salaries of employed home care workers are set in collective agreements, which are the basis for individual contracts (COPAS, 2002a; COPAS, 2002b). Nurses contracts are also based on the “*Convention collective de l’entente des hôpitaux*”. Working conditions are controlled by law. Nurses in Luxembourg earned €2,589 at the start of their career and €4,906 a month as a final salary in 2004 (Ferring et al., 2005). Currently, aide-soignants earned €2,028.- at the start and €3,487.- as a final salary (source: interview with expert).

#### 4.5 Use of tele-care

The tele-care service in Luxembourg is called ‘Secher Doheem’ (safe at home). It covers around 4,000 households per year. It is subsidised by MIFA and run by one home care agency, but is available to all inhabitants. The second is the municipal subsidised ‘SOS Senior’ covering Luxembourg City (about 1,000

recipients per year). Tele-care is purchased directly from ‘Secher Doheem’. Individual client’s financial support, usually means-tested, may be obtained from the local governments. Examples of commonly used tele-care by ‘Secher Doheem’ are the normal alarm button; breathe sensor; bed and/or chair detectors (reacting on late return in the bed or chair). At present no telemedicine technologies are reported.

#### 4.6 Monitoring of adequacy care

Care plans specify the duration of services, after which re-evaluation is required. Benefit changes before the elapse of the care plan can be initiated by the client, family members, the agency, the CEO and the CNS. However, requests for re-evaluation can normally only be made after six months (CEO, 2009). CEO is entitled to monitor all services at any time, but no rules exist on the frequency. Re-evaluation for services covered by the subsidy called ‘*Tarifification Sociale*’ is up to the providers.

### 5. Clients & informal carers

#### 5.1 Number of home care recipients

In 2006, the Long term care insurance scheme (AD) had 6,489 home care recipients, which is double the number of those receiving institutional care. No data is available on the home care recipients through the ‘*Tarifification Sociale*’ and the obligatory health insurance.

#### 5.2 Coverage and unmet care needs

A satisfaction survey on AD beneficiaries at home showed that 89% of the beneficiaries was satisfied with the provided care (CEPS/INSTEAD, 2007). Most of the experts consulted for the EURHOMAP study indicated that no gap existed between indicated and received care. CNS tries to prevent such gaps by operating in

a flexible way. In acute cases care is provided first and only afterwards financing and formalities are settled. Nevertheless, some specific services turned out not to be available (e.g. routine blood measuring, intake medicine, help with social relationships and daily administration). Also, working times of the agencies were reported not always to fit with the time clients needed care.

### 5.3 Empowerment of recipients of home care

According to the government's vision on community care clients are free to choose their care provider (CEO, 2005). Clients also have the choice either to stay at home or to live in an institution, although they are advised by CEO. For an informed choice, no comparative information on the quality of services of individual agencies is available. Usually physicians, social workers or other professionals recommend which provider to choose. Clients eligible to AD-financed care can opt to hire an informal carer instead of a professional. Informal carers then receive 25 EUR for one hour and additionally a contribution to their pension. CEO decides how much and what type of care is to be provided by the informal carer (the upper limit in 2009 was 10.5 hours per week).

### 5.4 Informal carers

The position of informal carers in the Luxembourgian home care system has been formalised, not just through the financial arrangements, but also as tasks of informal carers set in care plans. Furthermore, they can be trained in caring; are entitled to get counselling and advice on how to stay healthy themselves; and have possibilities of respite care services (e.g. night care), relaxation, etc. (Ferring et al., 2005).

## 6. Disparities in home care

Discrepancies between theory and practice of home care do not seem to be significant. Still care plans, which normally follow national criteria, can be adapted by care coordinators during their visit of clients. Until 2009, it depended upon one's GP and the nearest hospital (with out-reach services or not) whether specialised palliative care was available. The Dependency Law provides special provisions for people with blindness, impaired hearing and people with Spina Bifida. These individuals receive an amount of EUR 650 per month, solely because of the disability they are suffering. Furthermore, for patients with specific conditions, such as in need of palliative

care, client pathways may differ. For people who require palliative care, care is prescribed by the attending physician and provided by the 'Controle Medicale de la Sécurité Sociale'. They are paid through the insurance budget but the CEO does not grant or refuse care to them, the Controle Medicale de la Sécurité Sociale' does.

## 7. Concerns and new developments in home care

The home care sector in Luxembourg is growing, despite continuing building of residential homes. The positive development of home care is congruent with the satisfaction of recipients with the provided care at home (CEPS/INSTEAD, 2007). Trends in care provision that can be mentioned are the increase of palliative care at home; care during the night; quality assessments; and the rapid growth of tele-care. The community alarms system of SHD ('Secher Doheem') won a price for quality, the "Prix Luxembourgeois de la qualité", in 2005, for providing a number of a tele-alarm system and signalling devices (e.g. GPS detectors, smoke detectors and epilepsy mattresses).

The following problems in the home care system in Luxembourg were mentioned:

- Reported deficits of the Caisse Nationale de Santé (CNS);
- The introduction of the Long-term care insurance (AD) had resulted in too high commitments. Staff has tripled in ten years time and services were restructured fundamentally and were increasing in number. A large number of new home care workers was needed. This has put a strain on the quality of staff and flexibility of services;
- Limited choice for clients as there are only three providers, one of which has a large market share;
- To enlarge the home care workforce also people from neighbouring regions were hired (they were partially drawn by higher salaries). This is said to have led to a shortage of care professionals in neighbouring regions and in Luxembourg it has led to language and cultural problems between professional and recipient;
- Gap between on the one hand the required practical skills and time for nursing care tasks and on the other hand the remuneration given by the CNS; the "valeur monétaire" is said to be a mathematical

calculation which insufficiently takes into account elements such as quality, safety, transparency or the level of skills and qualifications required;

- Several preventative, curative and secondary services are not covered by the AD, e.g. routine blood measuring, intake medicine, help with social relationships and daily administration.

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# Malta

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## 1. The context of home care

### Country, population and health

Malta, with 410,290 inhabitants in 2007, has the highest population density in Europe (1,298 persons per square kilometre). By 2060 the country's total economic dependency ratio is expected to be as high as 1.99 – one of the EU's highest. The proportion of inhabitants over 65 years old is expected to increase from 13.8% in 2007 to 32.4% by 2060 (and the mean age has already increased from 35.73 to 49.43 between 1995 and 2005 (NSO, 2007)). This clearly illustrates the ageing of the population. In 2007, the average life expectancy at birth and at 65 years was around the EU-average (Eurostat, 27-02-2010). In 2006 the healthy life expectancy at the age of 65 in Malta was longer than the EU25 average; 9.7 healthy life years for females and 9.9 for males (compared to 8.8 and 8.7 years for the EU25 respectively) (Eurostat, 25-08-2009).

### Characteristics of health services and social services

The share of GDP spent on in-kind social security benefits is much lower than the EU27 (5.2% compared to 8.7% respectively in 2007). Even so, health services are highly developed with free hospitalization. All residents have access to personal health services, preventive, diagnostic, curative and rehabilitative services in government health centres and hospitals. In 2005, 8.4% of GDP was spent on health care, below the EU15 average (WHO/HFA, 10-12-2008). In 2007, there were about 0.78 GPs per

1000 inhabitants (Eurostat, 13-01-2010). The density of nurses (0.56 per 1000) is considerably lower than the EU27 average (0.75 – WHO/HFA, 15-09-2009).

Those aged 75 and over with a disability frequently use outpatient clinics and hospitals, residential homes and community services (National Commission Persons with Disability, 2003). The service spectrum includes domestic aid, personal care, day care, government-owned residential homes for elderly people (serviced apartments, including provision of meals, laundry, etc., limited individual assistance and social activities), the Handyman Service, the Incontinence Service, social work units providing elderly with guidance and assistance, long-term health care facilities (a residence for the elderly, long-term care units in hospitals and homes for the elderly run by private or charity organisations) and meals-on-wheels (Triosi & Formosa, 2004).

### Social indicators and conditions related to old age

Just 16% of the population over the age of 65 is at risk of poverty, one of the lowest proportions in Europe. In Malta there is a basic pension (obligatory and earnings-related, and minimum around 50% of average wage) and in the near future there will be a private (voluntary and mandatory) pension. Children have a formal liability to maintain their elderly dependent parents, although the first responsibility lies with the spouse. In line with this the employment rate of Maltese women is the lowest of the EU, with just 35.7% in 2007 (Eurostat, 10-12-2008). Hence a large source of informal carers is available.

### Attitudes related to old age

The concept of active ageing lies at the heart of the public policy on elderly people; hence the Maltese government strives to promote a positive self-perception among the older persons themselves. At the same time, it aims at eradicating any form of ageist attitudes by instilling positive attitudes towards older persons by the general

population. Relating to attitudes towards the care of the elderly, the Eurobarometer 2007 showed that only 23% of the Maltese thought that care is a responsibility for close relatives even if their career might be affected, while this is 37% of the EU-citizens. Interestingly, when respondents were asked what should happen with a dependent elderly person who is not able to take care of him or herself, moving elders to a nursing home (25% of respondents) is more popular than professional home care (16% of the respondents). This is unique in the EU.

## 2. Policy and regulation on home care

### 2.1 Governance on home care

The main legislation on home care is the Social Security Act, laying down benefits and assistance for, among others, elderly and disabled persons. The responsibility for publicly funded home care is highly centralised. The Ministry of Social Policy's (MoSP) health department is responsible for financing and regulating home nursing (technical nursing and some help with ADL) and its Elderly and Community Services is responsible for home help (help with ADL as well as IADL). Regulation on privately financed home care is scarce.

Since 1987 the Maltese government has been appointing a Parliamentary Secretary directly responsible for the country's older persons. In this way the various issues of older persons, including home care, are being dealt with holistically. The government revolutionised its concept of caring for the elderly. It started planning a wide range of policies and programmes to respond to the unique needs and requirements of older persons and aimed at socially integrating them within their society. For elderly people, but also for their carers and disabled persons, more than 30 services are available which are aimed at improving the quality of life of the dependents while maintaining them in their own homes, community and environment. In this way they seek to avert or delay institutionalisation. These services include amongst others Domiciliary Nursing and Home Care Help. Formal care is seen as complementary to informal care, rather than substitutive. Hence, the majority of policies in the field of ageing, including home care, are family-focussed (Troisi & Formosa, 2006).

### 2.2 Eligibility for home care services

There is a difference between home care/help and home nursing. Home nursing is carried out by the Memorial District Nursing Association (MMDNA). Service is given to members who pay a annual membership (12 Euro) and to those who are referred by a general practitioner. The recipient is not means tested. It is given free of charge. The service is largely "procedure oriented". The home care beneficiaries are to be those persons over the age of 60 and persons with disability who are housebound or nearly housebound, and who have difficulty in managing the practical household chores or looking after themselves.

#### *Home nursing*

The Malta Memorial District Nursing Association (MMDNA) – a non-governmental nursing association – has been contracted by the Health Division of the Maltese government for co-ordinating all government general home nursing services. Access to nursing by MMDNA is universal. The range of services provided by the MMDNA can be classified under 4 main categories, namely: 1) general care which includes blanket baths, prevention and treatment of bed sores, enemas, wash-outs, dressing of wounds, stoma care, and toe nail cutting, 2) surgical dressings; 3) injections (other than intravenous); and 4) diabetic care. Home nursing is also offered at a cost by a number of private organisations.

#### *Home help: domestic aid and some personal care*

Home help service includes a wide range of services such as daily shopping needs, running small errands, laundry, limited personal attention such as bathing, procurement of medicines from government dispensaries and cooking. A person's application form has to be accompanied by a medical report. The applicant's home is visited by a social worker and the request is judged by the Board of Allocation of Service. Availability of informal care is taken into account. But there are no national explicitly laid down eligibility criteria: it is to the discretion of the Home Help Allocation Board (Quality Service Charter of the Department for the Elderly and Community Services). The policy is that formal care does not substitute informal care but supports it. This influences the number of hours provided by the Home Help Services. The needs assessment also takes into account the levels of social capital. When the service is received at a cost from a private organisation the availability of the informal carers is not taken into account.

### 2.3 Quality of process and output

#### *Quality criteria*

There are no national quality criteria on care process and output laid down in Malta. A Quality Service Charter has been set up to ensure a high quality level of publicly financed home help services. This is a list with services which are to be expected, under what conditions, when they can be contacted, how clients can be expected to be treated and where to file a complaint. The quality service charter handbook is a guide and manual both for home care recipients and home care providers considering developing their own quality service charter (Troisi & Formosa, 2006).

#### *Measuring quality*

The service is regularly supervised by specially appointed persons to ensure the quality of service and to examine complaints received both from the receivers and also from the care givers. The quality of home care provision is evaluated regularly through visits by local Welfare Officers to the beneficiaries' homes (Troisi & Formosa, 2006). There are different monitoring systems for different services. The MMDNA has its own system to monitor the process of care.

#### *Accreditation and complaint procedures*

Home care services are mainly provided by the government. Of late a few private organisations are also providing home care services. The privately run home care services are not subject to an obligatory accreditation scheme as they are not heavily subsidised by government. Complaints by the home helps (Part Time Social Assistants), and by the beneficiaries, are dealt with by the Welfare Officer (in the Department for the Elderly & Community Care) and, if the need arises, this is taken up to the Officer in Charge of the Home Care Service. Complaints by clients using privately run home help services can also be sent to the Department for the Elderly and Community Care.

### 2.4 Quality of input

#### *Education*

The following professionals are working in home care:

- Qualified nurses: providing technical nursing as well as some personal care (e.g. bathing). Under- and

post-graduate degree programmes in nursing studies are available within the Institute of Health Care, University of Malta;

- Home helps (part-time social assistants) providing domestic aid: There is no required level of education. A clean conduct certificate by the police authorities is required. Moreover given the fact that given the fact that school attendance between the ages of 5 and 16 is compulsory, the majority of home helps have a minimum level of education.

The government of Malta believes that education and training should be made available at all levels and for different functions (also volunteers and informal carers). To meet this need, in 1993, in collaboration with the Parliamentary Secretary for the Care of the Elderly, the University of Malta initiated in-service training programmes for para-professionals and primary care workers working in the care of older persons in the statutory sector. A number of short training programmes are also held in conjunction with the MMDNA. Other programmes, although not on a compulsory basis, are organised by various voluntary organisations.

#### *Task description*

The tasks for the home helpers are described and explained to all those who apply for such a position, although the tasks are not set out in regulations. The beneficiaries of both publicly financed home nursing and home help are also informed of the tasks which they are expected to receive from their carers.

### 2.5 Incentives for providers of home care

Although the private sector has of late also started providing home help, till now the question of competition, and hence its incentives, has not arisen. This is perhaps due to the fact that while the state home help service is heavily subsidised, the one provided by the private sector is at a cost.

## 3. Financing

### 3.1 General funding mechanism

Home care is highly subsidised by government, with steadily increasing costs, as shown in Table 2. Not all needs are met by Government support, especially for those with complex or high dependency needs.

**Table 1:** Expenditures (in Euros) on home care/Help Services and Meals on Wheels, 2005, 2006 and 2007

	2005	2006	2007
Home nursing	1,195,000	1,223,000	1,255,000
Home Help Services	1,297,500	3,803,300	4,234,200 (0.08% of GDP)
Meals on Wheels	53,000	123,000	123,500

Source: Ministry of Finance, 2006, 2007, 2008.

At present, expenditure on social programmes catered for by the Ministry of Social Policy absorbs a relatively large share of the Maltese government budget. An increase in Social Protection Benefits at Function Level was mainly due to the Old Age and Sickness/Health Care Functions, which together contribute around 70% of expenditure on benefits and include home care expenses.

The Maltese National Health Service, including home nursing, is funded through the National Insurance, made up of national general taxation. All workers and employers pay National Insurance contributions on a weekly basis, but this money goes to finance welfare services in general (e.g. pensions) and not health services in particular. Home help services are also paid from this budget. Domestic aid and some personal care, but also technical aids and home adaptations, require a nominal client co-payment. If a client wants to make use of a service given by privately owned organisations, he/she has to pay for it. Hence such services are self-funded. The private company providing such a service sets the cost of the service. Private providers of home help services are solely financed from the client's own resources and this may be required in cases where people feel they need more support than government agencies can provide. As pointed out, one has to distinguish between services offered by government and services offered by privately owned profitable organization. The former is financed through general taxation while the latter is covered by the client out-of-pocket or by his private insurance if (s)he has one.

### 3.2 Mode of financing home care providing agencies

Although the MMDNA offers services to a certain number of paying members, the majority of beneficiaries receive the service free. In the case of the latter the Association is contracted by the government and works under a specific budget which is discussed and amended as needed. Home care costs are highly subsidized by the

Government through general taxation, thus allowing the provision of domiciliary nursing totally free of charge for most people. MMDNA members pay an annual membership charge of €12 and financing of non-member services is negotiated annually with the Government.

### 3.3 Price setting of home care services

Prices of publicly financed home help services depend on the time at which they are provided. Other services are not time-bound e.g. home nursing and meals on wheels. If these latter two are carried out daily in the morning except on Sundays and public holidays, are provided against a nominal weekly fee of €2.3 for a single person (€3.5/couple), irrespective of services provided. Other home care related services also only require nominal fees which are deducted directly from the recipient's pension. Other services such as domiciliary nursing and meals on wheels are not time bound.

During the past decade, a number of for-profit organisations within the private sector have started providing care for the elderly especially in the areas of residential care, domiciliary nursing and home care. There are no price limits set by government for these services, but each private provider has its own criteria to guide pricing of the home services.

## 4. Organisation & delivery of home care

### 4.1 Access and needs assessment

A social worker can apply in the name of the individual for various home care services and the older person can apply individually for various services at various 'windows'. All applications for the Service for the Care of the Elderly are received in the appropriate Government Department within the Ministry for Social Policy, Health and Care for the Elderly. However, since there is no coordinated case management system, these applications

are then farmed out according to the needs and type of service applied for. Consequently, most of the services have separate boards who decide how much service can be given to a particular request. Home nursing services are given to those who are referred by a general practitioner. In the case of home nursing a GP or senior nurse of the MMDNA assess the needs using a standard assessment form and assigns the care.

In the case of home help, a person's application form has to be accompanied by a medical report (of GP) which is then sent to the specific unit (called "Internal Board of Allocation of Service") within the Department for the Elderly and Community Services. Then a social worker from the Social Work Unit within the same department visits the applicant's home to assess the applicant's effective needs. The internal Board of Allocation of Service then discusses the case. If accepted, the case is sent to the area supervisor in which the applicant lives. The allocation of hours of service to the beneficiary is based on the applicant's needs.

#### 4.2 Features of delivery

Public home help services are managed and supervised by the Department for the Elderly and Community Services of the Ministry for Health, Elderly, and Community Care. There is no formal relation between health centres (primary health care centres), welfare officers and MMDNA. However, General practitioners from the primary health care centres can refer patients in need of home nursing to the MMDNA. The Maltese Islands are divided into areas which are supervised by a Welfare Officer appointed by the Department. There is no formal relationship between primary care centres (which are managed by the Ministry of Health, the Elderly and Community Care) and home nursing services that are provided by the private non-profit MMDNA. MMDNA employs around 55 nurses and carers. Some patients e.g., those who need insulin injections are visited twice a day, in the morning and in the evening. Through its carers, MMDNA offers also bathing to patients.

Both for-profit and non-profit organisations provide home care. Of late a number of private profit-making organizations have been organized offering at a cost home nursing and home help. There is no indication regarding their share of home care provision. This is due to the fact that statistics are not made available. Rehabilitation services are provided free, often at home to older people.

An important role is also played by a number of voluntary organisations, especially through Caritas Malta. They encourage the creation of social clubs for the elderly within a village or town. Members are also encouraged to visit residents in government run homes for the elderly. The Good neighbour scheme is aimed at giving company to persons who are home bound and living alone. Others keep a friendly and unobtrusive watch on their elderly neighbours observing their normal habits so that any possible signs of trouble are immediately recognized and action taken. Under the guidance of a fully qualified staff, the volunteers are prepared and trained to provide support to elderly people at home, and to encourage the elderly persons' participation and involvement. The hiring of foreign carers, mainly from the Philippines, has recently begun, whereby these carers live in with the person in need and help in the caring process. This is at a cost and is not always affordable.

#### 4.3 Coordination and integration in home care

Different agencies offer different services. The MMDNA offers only nursing services; domestic aid and some personal care, tele-care, handyman service, etc. are offered by other organisations. There are no case managers but there are structured links of home care providers with hospitals and nursing homes relating to the provision of medicines and the accompaniment of patients to hospital appointments. Residential care homes also offer respite care for both clients and families for short convalescence periods and short holidays.

#### 4.4 Actors involved in home care

Several actors are involved in home care:

- The Ministry of Health, the Elderly, and Community Care (through the Department for the Elderly and Community Services) provides home help through the employed home help service and its Internal Board of Allocation of Service assesses the needs for home help (personal care and domestic aid).
- The MMDNA, a non-profit organisation, assesses the needs for home nursing and provides and coordinates nursing services and employs nurses. There are other private organisations providing domiciliary nursing but their number is very small.
- Health Centres are managed by the Ministry of Health, the Elderly and Community Care, and provide primary medical and nursing care.

**Table 2:** Human resources in home care

Human resources in home care	Total number in 2009
Number of home helps	310
Number of home nurses MMDNA	31–60

Source: MMDNA.

**Table 3:** Number of Tele-care beneficiaries during 2004–2007

Year	2004	2005	2006	2007
Total number	8,855	9,031	9,260	9,414

Source: Department for the Elderly & Community Care.

**Table 4:** Number of home help and home nursing beneficiaries during 2005–2008

	2005	2006	2007	2008
Home help	2,371	3,201	3,553	–
Home nursing (all providers)	–	–	–	8,654

Source: NSO, 2008b.

The MMDNA service is provided by a staff complement of about 60, the majority of whom are qualified nurses. There are much more home helps than qualified nurses, see Table 1. The home help workers are now called part time social assistants. Formerly they were called casual social assistants. They are now in the process of being upgraded to full time workers having full time employment with government. Their nomination will be social assistants. To this effect a call for applications have been made already and applicants will be interviewed. The Government finds no difficulties in recruiting home helps (part-time social assistants) – the number of applicants always exceeds the available positions. One of the reasons behind this is the fact that, being a part-time job, married women and mothers do not find it very difficult to combine their traditional family role with their work and the contact hours are very convenient. To date the part time social assistants work 30–35 hours a week. They are paid Euros 5 per hour. Besides they enjoy pro-rata all other employment benefits which full time government employees enjoy including among others, sick leave, vacation leave, maternity leave, marriage leave, death leave, etc. These staff currently earn around €600–700 per month. However, these part time posts are currently being upgraded to full time posts with full Government contracts.

#### 4.5 Use of tele-care

The Department for the Elderly and Community Services provides a Tele-care service, i.e. a telephonic lifeline system (an alarm button automatically dialling a Control Centre and providing them with the personal details of the caller such as medical history) aimed at helping those older persons living alone in their homes by reassuring them. This service has also been instrumental in helping the elderly overcome the feeling of loneliness, as well as their family carers, so that these could leave their elderly relatives and even go to work. Although this system has been extended to persons with disability almost 98% of the clients are older persons. By the end of 2007 there were 9,414 older persons benefiting from this service, the majority being female.

#### 4.6 Monitoring

There are different monitoring systems for different services. For home help services, regular checks are made to the beneficiaries' homes through the local Welfare Officers to see whether the needs of a client have changed. The MMDNA has its own systems to continuously monitor the process of domiciliary nursing care. There is no official re-assessment once in a while.

**Table 5:** Provision MMDNA of home nursing to those through contracts with the health division and to those who are member

Health Division	2005	2006	2007	2008
General Care	2862	4099	3710	3493
Surgical Care	2179	2221	2285	2688
Injections	2373	4497	1423	2168
Diabetics	1199	1272	1293	1382
<b>MMDNA Members</b>				
General Care	196	386	205	108
Surgical Care	103	216	101	67
Injections	118	346	191	61
Diabetics	190	318	56	42

## 5. Clients & informal carers

### 5.1 Home care recipients

As can be seen in Table 4 there are more home nursing recipients than home help recipients, although the number of recipients has risen somewhat over the past four years. The majority of recipients are elderly people, who took up 86% of all the services offered by MMDNA in 2008. MMDNA nurses offer services to their own paid members and also to those under the contract between the government health division and MMDNA.

### 5.2 Coverage and unmet care needs

The number of hours allocated for the government run home help and nursing services is limited. They are not available during the night. Hence, clients need to hire private providers at a cost.

Sometimes, especially in the case of caring for persons who are not bedridden or wheelchair bound, caring primarily involves surveillance. In the case of fully dependent and frail older persons, regular and full-time care is needed and mainly consists of nursing care for people who are bedridden or wheelchair bound. When this constant care and nursing help are required difficulties may arise, because older persons who require help to perform personal activities of daily living need more care hours daily than those usually provided. In the case of fully dependant and frail older persons, however, regular and full-time care is needed. The Maltese government has two schemes as a result of which family carers of dependant older persons can receive financial benefits. These are 1) the Carer's Pension and 2) Social Assistance for Females taking care of a sick or elderly

relative. Although there are services to help family carers of older persons needing full-time care there is still a shortage of such full-time carers and hence the need has arisen of importing foreigners to do such work. These are paid by the family members concerned.

The Maltese government has, especially during the past two decades, enacted various policies, programmes and services benefiting dependent older persons. However, it results in the majority of older people preferring their personal needs to be met by their relatives. Hence, one finds that many older persons living in residential homes are not having their personal needs met.

### 5.3 Empowerment recipients of home care

In the case of the state run home care providers, clients are assigned to home carers. Personal care budgets are not available in Malta, only disability allowances (not a substitute to care in kind). Those clients who are availing themselves of such a service provided by a private for-profit organization, the person receiving care has an opportunity to choose the carer.

There are several organisations supporting eligible people in the choices they need to make, and with applications. Voluntary organisations can help the client buy the equipment he needs and social workers often help with the clients' choice for home care. Although comparable information on client's satisfaction is missing as an instrument for choosing a provider, there is ample information for clients in folders and websites on the services available.

To change from home care to Government-run institutional care one requires an extra assessment: choice

between the two is not up to the client. There is freedom of choice for people who choose and pay for privately run facilities. Furthermore, publicly funded care is time limited during the day and weekends, so for heavily dependent persons home care may not be a feasible option, unless family members are able to make use of Government incentives for carers.

#### 5.4 Informal carers

Care for the elderly is mainly provided by the family in Malta. In times of need, older persons turn first to their own families for help, then to friends and neighbours and finally to the governmental agencies. In spite of this, family carers in Malta are not officially registered and they do not have any representative organisations. Still there are a number of programmes and services directly and/or indirectly aimed at supporting the family carers of older persons. Examples of such programmes are: the Carer's pension; Social Assistance for Females taking care of a sick or elderly relative; the Social Work services and Training. To be eligible to the first two schemes, one has to be taking care of a dependent elderly relative on a full-time basis. At the end of 2003, there were 715 family carers benefiting from these schemes. Finally, reduced working hours and responsibility breaks for carers of children and the elderly, as well as pro-rata benefits for part-time employees, have been adopted to support informal carers.

### 6. Disparities in the process of home care

Malta is a very small country where no distance by car is greater than 45 minutes and where the majority of children live in the same or neighbouring areas of their parents. So differences between rural and remote areas do usually not arise. In the case of palliative care, there is a special voluntary service (the Malta Hospice Movement) that provides extra care and additional technical aids.

### 7. Concerns and new developments in home care in Malta

Care of older persons in the community has, especially during the past two decades become a focus in the policy of the Maltese government. In recent years, the traditional care provided by the family to its elderly members has been subjected to a considerable strain. Given the rapid changes which Maltese society is undergoing, carers are becoming more vulnerable than before. In this light,

various public policies and programmes have sprung up to supplement family support to the growing elderly population so as to enable the elderly to remain within their family environment for as long as possible.

Malta is very rapidly seeing an increase in its 'old old' residents, many of whom are dependent and requiring constant care. At the same time, filial responsibility is decreasing. Although a number of incentives for carers have been introduced, this has proved insufficient to manage the caring load increase, resulting in a number of immigrants providing privately funded caring services to older dependent family members.

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# The Netherlands

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## 1. The context of home care

### Country, population and health

The Netherlands is small but its 16.5 million inhabitants make this country extremely densely populated. It is also a wealthy country with a Gross Domestic Product per capita significantly above the EU15 average. Almost 20% of the population has foreign roots. The proportion of persons over the age of 65 (pensionable age) is currently below the average in Europe but is expected to grow strongly. Between 2005 and 2030 those 65 years and older will increase from 14.2% to 24.1% and those 80 and older from 3.6% to 6.8% of the population (Eurostat, 2008). The life expectancy in good health at age 65 was 10.9 years for males and 11.2 females (2006), which is considerably above the European average (Eurostat, 2008). The prevalence of longstanding illness or disease was around the average, with 36.6% for females and 27.9% for males (Eurostat, 2008).

### Characteristics of health services and social services

Health services are funded by a mix of obligatory social and private insurance, with additional co-payments for long-term care. The percentage of the Gross Domestic Product that is spent on health expenditures (9.7%) is just about the EU15 average (which was 9.2% in 2006) (OECD/HD, 2009). The number of acute beds is below the EU15 average but the length of acute hospital stay is relatively long (OECD/HD, 2009). In contrast, bed supply in nursing homes and homes for the elderly is well above the average (OECD/HD, 2009). The quality of long term care facilities in the Netherlands is an issue

in Dutch policy, that is, much is being done to control quality in the nursing and home care sector (website Ministry VWS 2010). House calls are a normal task of for Dutch GPs. Chronically ill and disabled people are eligible for cash payments and tax reductions ('Wet tegemoetkoming chronisch zieken en gehandicapten'). The availability of active general practitioners is relatively low in the Netherlands (OECD/HD, 2009). Currently, transfer of tasks from medical to nursing professionals is an important theme.

The share of GDP spent on in-kind social protection benefits (including home care) is relatively high, i.e. 8.7 in the EU27 and 10.4 in the Netherlands (Eurostat, 29-10-2009). The same holds for the expenditure on social services in LTC (aimed at persons with functional limitations), although these data are only available for 12 countries. With regard to social services, counselling and guidance are important services. General social work, which is free of charge, provides counselling and guidance in complex problems. Guidance is also provided by home care agencies. Many social services with a focus on promoting the participation of disabled persons in society are financed from municipal funds.

### Social indicators and conditions related to old age

Elderly Dutch people are at a relatively low risk of poverty compared to other European countries. Labour market participation among women is high compared to other European countries, with 69.6% between 15 and 64 being employed (Eurostat, 2008), but most women have part-time jobs. Dutch law provides for a collective care obligation, which means that the state is responsible for the provision of care (Pommers et al. 2007). Partners bear the primary responsibility for 'usual care' and co-habiting children need to perform some household chores, but children are not liable to financially maintain their parents.

### Attitudes related to old age

Only 13% (compared to 34% in Europe) of Dutch Eurobarometer respondents consider the care for a (hypothetically) dependent elderly person a task for close relatives even if the career might be affected (TNS Opinion & Social 2007). Well over half of the Dutch population (as against 27% of Europeans) think that professional care at home is the best solution for a dependent elderly parent, while for 18% moving to a nursing home would be the solution (against 10% of Europeans) (TNS Opinion & Social 2007).

## 2. Policy and regulation on home care

### 2.1 Governance on home care

Home care has a long tradition in the Netherlands. Policy documents have considered home care in the context of an aging population, of autonomy and of the independent living of clients. Recurrent themes have been a more integrated provision of home and institutional long-term care services, tailored to the clients' needs. In 2006, government and stakeholders have developed a quality framework and norms for effective, efficient, safe and client-centred home care (Zichtbare Zorg, 2010). In 2008, a governmental statement stressed the need for transparency to the public in regard to the quality of care services (Bussemaker 2008). Additionally, affordability and cost control in home care have been addressed repeatedly.

The prime responsibility for home care is with the Ministry of Health, Welfare and Sport, but decision-making has been largely decentralised and steered by market forces. The allocation and contracting of nursing and personal care services at home has largely been delegated to regional 'care purchasing offices' linked to the health insurance companies. Municipalities are responsible for domestic aid and some technical aids. Municipalities decide on the eligibility of these services and negotiate prices with providers.

### 2.2 Eligibility for home care services

#### *Home nursing & personal care*

The Centre for Care Indication (CIZ) assesses the needs for home care. They apply nationwide uniform criteria for most home nursing and personal care, related to: 1. the demand of the candidate client; 2. the clinical situation

(somatic, psycho-geriatric or psychiatric problems or those with mental, physical and sensory disabilities and for e.g. personal care: not being able to provide personal care to oneself – Ministry of Health, Welfare and Sports 2010a) and disabilities; 3. the personal situation (including what 'usual care' can be provided by members of the household, depending on the age of co-habitants); 4. possible alternatives and already received benefits. For standard 'indications' protocols for assessment (with standard questions) are publicly available for providers to fill in. Eligibility is independent of income, but co-payments for nursing and personal care services depends on income, household composition and age of the client (divide between the group of 18 years and over and the younger group). In case of home nursing financed by the compulsory health insurance (for a specification see the financing section), a small part of home nursing, eligibility is completely universal.

#### *Domestic aid and technical aids*

Municipalities set their own criteria for access to domestic aid and supportive aids. Many municipalities use an algorithm like the one used for nursing and personal care. Eligibility for domestic aid is independent of income, but co-payments are general and dependent on income and the type of services. The personal situation (possibilities of other inhabitants providing 'usual care') is taken into account in the decision to allocate domestic care (Noordhuizen, et al., 2007). Technical aids, like crutches and wheelchairs, can be borrowed when needed for up to 6 months, or otherwise provided via health insurer or municipality (either or not with co-payment).

### 2.3 Quality of process and output

#### *Availability of quality criteria*

Patient organisations, stakeholders and the Health Care Inspectorate (IGZ) have jointly developed measurable norms for the quality of care that are used for assessment and benchmarking (for instance the 'Consumer Quality-index for Home care' – CQI Home Care – is available). A quality framework has been laid down for the nursing and caring sector (see paragraph 2.1). It lays down norms for effective, efficient, safe and client-centred home care (Arcares et al. 2006). This framework is the basis for the consumer quality index but also includes quality of actual care indicators, which are measured by the care providers themselves. Additionally, a set of quality criteria for domestic aid is available and used (LOC et al. 2008). The

regional purchasing offices, which purchase nursing care for provision in-kind, use quality standards in contracting care providers.

#### *Assessment of quality of services*

The Health Care Inspectorate (IGZ) is responsible for supervision on the quality of services. By law, home care agencies are obliged to systematically monitor and improve the quality of their services and staff and to annually report on it. These reports and possible complaints can give rise to closer investigation by IGZ. Home care agencies organise client evaluations using the CQI Home Care every two years. Municipalities are obliged to annually assess their clients' satisfaction with domestic aid services. There is a special CQ index for domestic aid (household chores) as well. On a voluntary basis results of quality assessments are made publicly available on a website (<http://www.kiesbeter.nl>). Furthermore, the two umbrella organisations covering home care agencies, i.e. BTN and ActiZ (also including residential elderly care institutions) hold quality requirements for members.

#### *Accreditation and clients complaint procedures*

No obligatory accreditation applies to individual providers of any type of home care (Zichtbare zorg 2008). However, compulsory registration does exist for agencies providing home nursing or personal care financed through the Exceptional Medical Expense Act. Registration requires these agencies to comply with standards of accessibility of emergency care and transparency of administration and management. The Law on Complaint Rights of Clients in the Care Sector forces all agencies providing any type of publically funded home care to maintain a complaint procedure. Umbrella organisations of providers in home care have voluntary accreditation schemes.

## 2.4 Quality of input

### *Education*

The following professionals (including their educational requirement) are involved in the provision of home care:

- Domestic workers with no specific training: involved in household work, daily shopping etc;
- Auxiliary helps (level 1); no training is necessary but a one-year vocational training is available; involved in household work, plus signalling function;
- Home help (level 2), two years vocational training: involved in some personal caring tasks and sometimes may be involved with household tasks (but for efficiency reasons they are just like nursing aids usually used as little as possible for household chores);
- Certified nursing assistants (level 3): three years vocational; involved in caring, some household tasks and drawing up and evaluating care plans; some nursing aids help with basic nursing tasks (catheter; skin care);
- Nurses (level 4): three years vocational training; involved in nursing, planning and coordination of care;
- Nurses (level 5): four years (higher) vocational training; involved in (technical) nursing and supervision of other home care professionals;
- Nurse specialists (sometimes also called nurse practitioner; master level): relatively new function; academic education at master's level; involved in independent treatment and follow-up of specific (chronic) conditions, and in some cases including drug prescriptions (this latter is not laid down legally though – it is still on an experimental basis).

The Ministry of Health, Welfare and Sport has formally established minimum criteria for the education of all home care professions for which qualification is needed. Educational institutes are subject to government inspection.

### *Job description*

Required expertise and the discretionary power of nurses, nurse specialist and certified nursing assistants have been legally defined and protected by the Health Care Professionals Act (BIG). Additionally, informal descriptions of job profiles have been developed for use by professional associations and care agencies.

### *Recertification*

Re-registration under the BIG act, applicable to nurses of level 4 and 5 (and part of the nursing assistants performing nursing acts as well), is required every 5 years. For re-registration a minimum number of 2080 working hours during the previous 5 years is required. Additionally a voluntary quality registration for nurses does exist, requiring to have completed 184 hours of continued education during the previous 5 years.

## 2.5 Incentives for providers

The home care system is largely driven by regulated competition among providers of services and to that end the following regulation has been developed.

- Since 2003 clients are no longer assigned to a type of care provider, but a care indication is assigned by an independent organisation (CIZ) to a client, by which client can choose a provider (NZa 2009b). An indication states how much and what type of care a person needs. This has facilitated the entry of new competitors to the home care market (such as nursing homes);
- The introduction of personal care budgets, allowing clients themselves to contract providers (NZa 2009b);
- The introduction of payment per type of service provided, instead of payment per type of client and not being fixed to a certain amount of hours;
- The separation of financing schemes for nursing and personal care services on the one hand and domestic aid services on the other hand. This allows commercial cleaning agencies to provide domestic services;
- The establishment of the Dutch Care Authority (NZa) as a ‘market watchdog’ to safeguard access, quality and affordability and to avoid providers or insurers undermining competition (e.g. by monopoly or abuse of significant market power);
- The introduction of selective contracting and bargaining on price and quality, instead of the obligatory contracting of home care agencies by the regional purchasing offices.

## 3. Financing

### 3.1 General funding

In 2006 home care providers were contracted for 3.760.000.000 Euro (NZa, 2007). This is about 7% of the total health care expenditures. As regards health care at home, in 2002, 3.5% of the total health expenditures were spent on home care, a high figure compared to other EU countries. Additionally, 2.5% was spent on day care and 11.7% on care in nursing homes. Home care is financed by a mix of funding mechanisms. Home nursing and personal care are funded by a combination

of income dependent social insurance premiums and by co-payments of clients (related to age, income and household composition). Domestic aid, certain technical aids and most respite care are funded by municipalities from resources received from a central fund, and from income dependent co-payments. Finally, part of home care is funded by compulsory health insurance (CVZ 26-08-2010). This contains all home care that should be provided by the GP also if provided by their practice nurse, e.g. blood pressure measurement, taking blood and instruction on use of medicine. It also contains ‘Continued hospital care’. Continued hospital care is:

- home nursing prescribed by a medical specialist (e.g. haemodialysis at home);
- all other care and activities that are coordinated by the medical specialist;
- and instructions and information directly related to the treatment.

Whether home care is seen as specialist care depends on complexity, the risks involved and level of needed interference by the medical specialist.

### 3.2 Financing of home care agencies

Home care agencies are contracted by regional care purchasing offices, municipalities or (in some cases) directly by clients if they hold a personal budget. The agencies are paid a fee for service (SER 2008). Payment is calculated by ‘functions’ and ‘performance’, as specified in the needs assessment. Functions refer to the mix of services provided, while performance refers to client characteristics and terms of provision (either ‘basic’, ‘extra available’, or ‘special’) (NZa 2009a). Clients receiving a personal budget for nursing or personal care must give account of their expenses once or twice a year. Accountability rules for personal budget recipients for domestic aid are set by municipalities and may differ.

### 3.3 Price setting of home care services

Prices for home nursing and personal care are not fixed but a maximum is set by the Dutch Healthcare Authority (NZa 2009a). These maximum prices are calculated by combining the provided functions and the performance level needed in particular cases. They take into account labour costs; level of expertise required; productivity and overhead (like material costs and capital) and usually are subject to indexation (VWS 2006). The Regional Care

Purchasing Offices, who buy mainly home nursing care and institutional care, agree on a price per service with the providers keeping to this maximum. For domestic aid price setting is left to the municipalities and therefore no uniform maximum prices apply.

## 4. Organisation & delivery of home care

### 4.1 Access and needs assessment

Clients' needs for home nursing and personal care are generally formally assessed by agencies falling under the Centre for Care Indication (CIZ), who operate formally independent from the care providers. CIZ uses a uniform assessment instrument in line with the International Classification of Functions (Francke & Peeters 2007). In simple cases the assessment can be delegated to the service provider with use of a standard protocol and checks by CIZ. There is a growing number of indications which are called 'simple indications', so the role of providers is growing. Partially this is caused by a concern over the disadvantages of bureaucratic procedures within CIZ. Anyone can take the initiative to apply for needs assessment. However, in case of home care financed by the compulsory health insurance the GP or medical specialist will assess the needs (CVZ 26-08-2010). In that case there is no role for the CIZ. Municipalities are responsible for the needs assessment for domestic aid, although many municipalities have contracted it out to CIZ. Additionally, it is in this context important to refer to a recent development. Currently clients themselves are able to define their own 'indication' (as they think is fit) in their application letter. But care is only assigned after it is checked by the CIZ.

### 4.2 Delivery of services

Home care services are provided by almost 1,000 admitted private agencies operating locally or regionally in competition (NZa 2007). Most agencies are still not-for-profit, with roots in voluntary organisations, but the share of commercial agencies is growing (Van der Boom 2008). Among suppliers of domestic aid services, commercial cleaning companies are now able to join traditional home care agencies. Currently, there is a revival of neighbourhood-centred home care services ('Buurtzorg') by small-scale autonomous professional teams is; resulting from dissatisfaction of professionals with current modes of service (De Veer et al. 2008). At the moment more than 200 of such small-scale

autonomous teams are available across the country and these autonomous teams seem to influence standard providers to be more neighbourhood-centred.

### 4.3 Coordination and integration of services

Since purchasing of domestic services is separated from nursing and personal services, integration is less evident. An important recent development is the re-introduction of community nurses as an important link in home care. They coordinate care, living and wellbeing within one neighbourhood. For coordination with (primary) health care services, home care nurses and GPs need to cooperate. Currently, there is a strong focus on increasing coordination within primary care, including coordination between home care and family practitioners. House calls are a normal task for GPs in the Netherlands and the Dutch College of General Practitioners (LHV) and professional associations of community nurses and other workers have developed interdisciplinary protocols on specific conditions, such as bedsores, palliative care and dementia care made by e.g. the Scientific Association of GPs (NHG) (see e.g. Vriezen et al. 2004). Eight percent of Dutch GPs are working in a multidisciplinary health centre that includes home care workers. One quarter of GPs have a structured cooperation with home care agencies (Hansen, Nuijen, & Hingstman 2007). To promote the smooth transition to care at home many hospitals nowadays have a liaison nurse to prepare and coordinate care after discharge, while home care agencies often employ 'transmural nurses' who work both in hospital out-patient departments and in the patients' homes. As many nursing homes and homes for elderly people also provide home care services and run day care facilities, conditions for coordination between these services are good. For the coordination of domestic aid and other social services most municipalities have organised an integrated single-entry point of access for all services, including domestic aid, social work, support for informal carers, meals on wheels and home adjustments (Beun 2006). In case of home nursing financed by the compulsory health insurance, the GP or the medical specialist has to coordinate and monitor the home care.

### 4.4 Actors and human resources in home care

#### *Actors in home nursing and personal care*

- Ministry of Health, Welfare and Sport develops legislation and regulation and supervises access, quality and efficiency;

- The Dutch Healthcare Authority (NZa) is a public body overseeing the proper functioning of the regulated market and is involved in cost control at macro level, setting maximum prices, and safeguarding compliance with care insurance laws and advising the government;
- The Health Care Insurance Board (CVZ) is responsible for the implementation of the Exceptional Medical Expenses Act (AWBZ), the management of the AWBZ-fund and distribution of personal budgets to the regional purchasing offices;
- The Dutch Healthcare Inspectorate (IGZ) is the regulatory and supervising authority for quality of care;
- The Centre for Indication of Care (CIZ) and its regional branches are in charge of needs assessment among care applicants for nursing and personal care and can be contracted by municipalities for needs assessment for domestic services;
- The Central Administration Office (CAK) sets co-payments individuals have to pay and is involved in the collection of co-payments. Furthermore, it is responsible for paying care providers;
- Regional Care Purchasing Offices help clients to find a provider to deliver nursing/personal care that conforms to the outcome of the needs assessment. Additionally, the Offices manage any possible waiting lists and inform CAK what to pay to contracted care providers;
- Umbrella organisations of home care providers (ActiZ and BTN). ActiZ is an umbrella organisation that represents care agencies and institutions. It is a partner in discussions and deliberations with the government, patient organisations and health insurance companies. ActiZ is also an employer organisation that negotiates labour agreements. BTN is the other umbrella organisation, but represents exclusively home care providers and is also involved in negotiating labour agreements;
- Home care providers, varying from single-handed workers to large organisations;
- The clients or patients (and their informal carers).

#### *Actors in domestic aid and supportive aids*

Essential actors specifically for domestic aid and supportive aids are the municipalities, which develop local regulation on eligible services, organise needs assessment,

finance providers and decide on prices and providers. Part of domestic care (through the municipalities) is provided by home care agencies and part by commercial cleaning enterprises. For the procurement of home care, municipalities are obliged to write a tender, but they also have to observe that clients are able to make a choice between providers.

#### *Human resources in home care*

With around 160,000 workers the home care sector is a vast source of employment in the Netherlands. Most numerous are 'domestic aids' ('Alfa helps' and level 1 helps) whose number are around 90,000. The number of personal carers (level 2 and 3) was estimated at 61,000 in 2008. A very large share of home care workers are working part-time and are female. A large majority (89% in 2005) is employed with a salary by an agency (Van der Kwartel et al. 2007). This is expected to increase after 2010 as care financed through the Social Support Act should from then on be provided by professionals employed by an agency (not by a client). In domestic aid, flexible contracts are on the rise at the expense of permanent contracts (Van der Windt 2008b). In contrast, in the sector of home nursing and personal care, permanent contracts are usual. Working conditions and payment for home helps and home nurses are set at national level in collective labour agreements. Home nurses' salaries are around the median wage, while the salaries of home helps are below it.

#### 4.5 Use of tele-care

Although the use of alarm systems and other telecom applications is expanding, they are still applied on a limited scale (Mandemaker & Van der Leeuw 2007). Most common are personal alarm systems and, to a lesser extent, internet based facilities (e-domotica), in total there were 3,000 users of these applications in 2007 (RIVM 2008). Another development is video communication. That is an audiovisual connection between the home care agency and the client at home. Through this connection a part of the care is provided. According to an evaluation study on 'distant care' in 2008–2009 video communication was used by 10 home care agencies and tele-counselling in five organisations (Peeters & Francke, 2009). On the whole, managers, workers, clients and informal carers were positive about the possibilities of video communication and the government has developed stimulating policy measures (Peeters & Francke 2009).

**Table 1:** Human resources in home care

Functions <sup>1</sup>	Estimation total number
Domestic workers <sup>2</sup>	49,941
Auxiliary helps	39,200
Personal carers at home (home helps and certified nursing assistants)	61,000
Home nurses (level 4 and 5)	13,600

<sup>1</sup> For 2008 (Van der Windt 2008a).

<sup>2</sup> For 2005 (Van der Windt, Keulen, & Arnold 2007).

**Table 2:** Long-term care provided at home and in institutions 2006/2007

Recipient groups	Recipients of home care during 2007	Recipients of care in institutions 2006
Total over 18 years old (% of pop. over 20 years)	610,180 (4.8%)	232,640 (2.5%)
% females	71.3%	64.4%
% 65+	81.3%	74.8%
% 80+	44.8%	53.8%

Source: calculated from data Statistics Netherlands (CBS 2008).

Some obstacles were unclear needs and wishes of clients, discontinuity among providers of technical aids and financing (Peeters, de Veer & Francke, 2008).

#### 4.6 Monitoring the adequacy of care

Indications for care, made by CIZ, are usually valid for a fixed period and need to be observed by the care provider. For patients with certain chronic diseases, such as dementia, indications are assigned for an indefinite period. If the client's situation changes, the type and intensity of care can be adapted by the provider within margins set by CIZ. Otherwise re-assessment can take place. Care professionals are responsible for monitoring the clients' needs for care.

Municipalities decide about monitoring systems for domestic aid services, but usually clients or care professionals are supposed to take action. For nursing and personal care a national monitoring system is in place containing data from CIZ, Regional Purchasing Offices and providers (Zorggegevens 2009).

## 5. Clients & informal carers

### 5.1 Home care recipients

In 2007, 4.8% of the Dutch population above 20 years of age received home care. Almost three quarters were women. Well over 80% of the clients were 65 years or older, and of these almost half of them were 80 years or older.

### 5.2 Coverage and unmet needs for care

Both under- and over-delivery of home care occurs. A study among patients with chronic illness showed that 10% did not receive all types of home care that were indicated (Algera 2005). Another 22% received the right types of care but in smaller volumes than indicated. Over-delivery in types of care occurred with 8% of the clients, while 15% received more hours of care than indicated. Experts who responded to the vignettes also pointed to under-delivery. Especially lack of personnel and therefore time-limits and the financial cuts in 2009 in guidance provision may lead to unmet need. Finally, the personal budget is said not to be sufficient for the entitled services. The Eurobarometer survey among EU citizens showed the relatively high perception of the appropriateness

of home care in the Netherlands: 93% responded that services were appropriate, compared to an average of 89% in EU-27 (TNS Opinion & Social 2007).

### 5.3 Empowerment of clients

Clients being eligible to nursing or personal care can freely choose among admitted providers in their region. Those being eligible for domestic aid may have a more limited choice now than some years ago, since many municipalities have contracted a limited number of agencies for these services (ActiZ 2009). If care in a nursing home is indicated, clients can still opt for home care (be it under the responsibility of a nursing home) (Van Bennekom 2008). For any type of care clients can opt for a personal budget by which any provider can be contracted.

Clients are supported to make a balanced choice in a number of ways. A government initiated website (<http://www.kiesbeter.nl>) publishes benchmark information on the quality of an increasing number of home care agencies. Via another government-sponsored website (<http://www.regelhulp.nl>) disabled, chronically ill and elderly people can find information how to arrange care or financial support. Furthermore, most municipalities run information desks for domestic aid, technical aids and respite care and all regional purchasing offices have websites for those seeking nursing and personal care. IGZ (Health Care Inspectorate) publicises evaluations of care providers. Also client organisations offer information on how to choose a care provider. Finally, there is an organisation to inform those opting for a personal budget ('Per Saldo'). Mediating agencies have been established to support personal budget holders in their relationships with contracting providers (Knollema 2009).

### 5.4 Informal carers

Clients' partners and other co-habitants are expected to provide 'usual' care, the content of which has been specified in a protocol (Ministry of Health, Welfare and Sports, 2010b). Informal carers can be paid from a personal care budget, and to prevent cases of overburdening they are eligible for respite care.

## 6. Disparities in the process of home care

There are many ways through which the client can apply for care, such as through the home care providers,

nursing homes, municipalities (for domestic aid) and through the CIZ. Furthermore, the processes of assessment and monitoring of individual needs can be designed by the *municipalities*. The *type of care* required also influences which organisations are involved in the processes of application, assessment and monitoring, e.g. in simple cases the home care provider may be the only organisation with which clients come into contact. Many geographical differences are said to be explained by objective criteria such as age, income and gender.

Discrepancies between practice and theory are relatively small in the Netherlands. Clients generally receive the care that they are entitled to. However, clients with comparable needs may receive different care. The following disparities have arisen from the vignettes:

- The receipt of services like meals-on-wheels, discounts for public transport, respite care, specific forms of guidance and technical aids depends on the municipality. Little information is available how much this varies across municipalities;
- The level of co-payment for domestic aid and guidance varies across municipalities;
- Possible qualitative and/or quantitative reductions of care due to shortages of personnel in some areas and sometimes unrealistic time restrictions for specific activities (e.g. 20 minutes for bathing). However, recipients may change home care agency if they are dissatisfied;
- Personal budgets are reported to be insufficient in some cases to pay for the entitled care (because the prices for services are higher than calculated in the personal budget).

## 7. Concerns and new developments in home care in the Netherlands

Current concerns in relation to Dutch home care are:

- Insufficient time for clients resulting from staff shortage. Shortage may grow as the care workforce ages;
- Many agencies (mainly for domestic aid) have suffered losses after reform of the system towards more competition (CBS 2009b);
- Poor control on new types of providers. Some new providers are subcontractors which are not subjected

to various legal obligations. The focus on making a profit in some of these cases is said to lead to a lack of focus on quality of care;

- While the costs of long-term care are rising rapidly, it seems there is insufficient insight and grip on the financing of this complex system (Herderscheë 2009);
- Many auxiliary helps (level 1) have been replaced by cheaper and less qualified domestic aids.

Future developments:

- Sharply increasing use of home care: personal care will rise by 36% between 2006 and 2030; home nursing by 39% and domestic aid by 18% (Jonker et al. 2007);
- Privately hired home care services will rise by 58% and informal care by 12% (Jonker, Sadiraj, Woittiez, Ras, & Morren 2007);
- Increasing need for integrated provision of primary care and cooperation between nurses and GPs, especially on specific areas such as dementia care;
- Promotion of the quality of home care services;
- More freedom of choice for clients as the diversity of providers in a region increases;
- Supply of services needs to adapt to the rapidly growing numbers of elderly people with foreign roots (CBS 2009a);
- A revival of neighbourhood-centred home care services ('Buurtzorg') by small-scale autonomous professional teams; resulting from dissatisfaction of professionals with current modes of service (De Veer et al. 2008). At the moment more than 200 of such small-scale autonomous teams are available across the country and these autonomous teams seem to influence standard providers to be more neighbourhood-centred;
- Increasing use of supportive technology, such as tele-care and video-communication, in home care settings (Zorgbalans 2009).

The development of 'transmural care' arrangements paid by the ministry's budget for 'transition'-experiments. An example is the introduction of dementia expertise teams in certain neighbourhoods to identify dementia in an early stage. (Zorggroep Almere, 2009).

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# Norway

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## 1. The context of home care

### Country population and health

Norway is sparsely populated with only 4.8 million inhabitants (13.8 inhabitants per square kilometre). Most people live along the coast and the largest population is in the south. The average income is €3880 per month. About 15% of the population is over 65 years and 4.5% is older than 80 years. It is estimated that in 2050 41.4% of the people will be 65 years or above, an exceptionally high percentage even in a European context. At the age of 65 the life expectancy is 17.7 years for males and 20.2 years for females, with relatively long healthy life expectancies of 12.4 years for males and 11.9 years for females.

### Characteristics of health services

Primary care is financed through taxation, both at central and local level. Norway currently spends 9% of its GDP on health care. Eighty four per cent of the health care costs are publicly financed, which is high compared to the OECD countries (average 73% publically financed). There is a fixed budget related to characteristics of the municipality: number of inhabitants, age structure, ethnic structure, health and social indicators. In some cases there is a fee for services like domestic aid, day care centres, short-time nursing home stay and nursing home residency. The number of physicians is 3.7 for every 1,000 persons and the corresponding number for nurses is 31.6. The average length of stay at a hospital is 5.0 days. There are 865 nursing home beds and elderly home beds for every 100,000 persons. The expenditures on care for elderly people are 1.6% of GDP.

### Social indicators and conditions related to old age

The general retirement age is 67 years and there is an income related public pension schemes. Expenditures on old age, mainly pensions, are 6.6% of GDP, which is rather high. Also the rent for a nursing home is income dependent. The system as a whole is thus solidarity based. Hence, just 14% of persons aged 65 years and over is at risk of poverty. Compared to the rest of Europe this figure is rather low. About 74% of the women aged between 15–64 years are employed; hence resources for informal care are in this respect low.

### Attitudes related to old age

In Norway children have no liability to pay for their parents. Unfortunately, no comparable data on the attitude towards informal care is available.

## 2. Policy and regulation on home care

### 2.1 Governance on home care

Several policy documents show that the importance of home care will increase in importance in the Norwegian care and health care sector. In 2008, the Norwegian Ministry of Health and Care Services published the “Care Plan 2015 – Long Term Care, Future Challenges” giving an overview of the main future challenges and outlining measures to achieve stated goals. An important goal is that all citizens, regardless of health status, shall live in their own homes as long as possible and, if needed, receive advanced health care at home. This means that the home care services are likely to be enhanced in the future (Ministry of Health and Care Services 2009).

Due to the establishment of new disability groups the Ministry expects new ways of working, a shift in expertise and a considerable expansion of the services offered for elderly people. The report mainly focuses upon preventive measures and operational efficiency measures

(through long-term development efforts with the focus on expertise, organisation and management). For home care, these aims pose great challenges, as home care will become a core service in the Norwegian Health Care system. The Norwegian government further accentuates the importance of the inhabitants' own contribution and joint responsibility for community schemes, arranging their own housing and participation in civil society.

The new Coordination Reform will give the municipality increased responsibility and new tasks when it comes to treatment, nursing and care of elderly persons. The reform is aimed at decreasing hospital admissions by treating patients in their own homes, or in nursing homes. Due to the considerable pressure that will be put on the home care sector, this sector will have an increased need of health care professionals, especially nurses. The focus on research and professional development has increased, especially in the area of care for the elderly in municipalities. Hence, the Department of Health has established "Teaching Home Care" in all counties, after the model of the establishment of "Teaching Nursing Homes" that have been active for 10 years in Norway.

Municipalities are responsible for all health care performed in the municipality. According to national laws, the municipalities are obliged to provide health care of good quality, ensuring patient participation, provide care according to the patients' needs and to provide it with respect.

At the national level home care and home health care is regulated by several laws and regulations; the Act relating to the municipal health services (1982:66), Patients' Rights Act (1999:63), the Health Personnel Act (1999:64), Social Services Act (1991: 81), and Regulations concerning quality in health care (1982:66).

## 2.2 Eligibility of home care services

The health service shall, as far as possible, be formulated based on the individual's wishes and needs, regardless of social status, personal finances, place of residence or way of living. The need for service is assessed in accordance with the general health care criteria in laws and regulations. Care is assigned based on this assessment of needs. However, some local differences may occur. Health care laws and regulations are general, allowing freedom for the municipalities to some extent. The municipalities decide the service criteria according to the national laws and regulations.

There is a national assessment system in use, IPLOS, which is a national health statistics system. It can be used to assess the needs of patients and those who apply for health care. Other systems used locally are, for example, the Barthel Index and the Resident Assessment Instrument (RAI). These locally used systems are, however, not required.

Domestic aid services are available to those who are in need of such services, and are regulated by the Social Services Act (1991:81). The need is assessed by general criteria formulated in the laws and regulations, but also due to the person living alone or not. The receiver pays a fixed price per hour, based on his or her income. Some local differences may occur.

With regard to home adaptations and technical aids, public funding is only available for those most in need. In some cases the social services may partly fund the renovation of the home, but not extensively. If the client does not own the house where he/she lives, the social service will provide a new home.

## 2.3 Quality of process and output

Several laws contain criteria on process and outcome of health services in general and are applicable to home care. There are also regulations specifically concerned with the quality of health care (1982:66). The Norwegian Board of Health Supervision (NBHS) continuously assesses whether the institutions, home care district or other services have good quality systems for providing health care.

There is a legal obligation to have complaint procedures. Client complaints are addressed to the municipality first, and then, if needed, to the County Board of Health Supervision. When it comes to domestic aid the complaint procedure is the same, but the second step is the County Governor, because domestic aid services are regulated by the Social Care Act. The use of satisfaction surveys is widespread in the municipalities, mainly on client and employee satisfaction. These surveys are, however, voluntary. The municipalities make public the results on satisfaction outcomes on their web sites. The surveys are often part of the quality system, required by the municipalities.

The information about the home nursing service varies among the municipalities. The most common approach

is to inform the public through a press release; however it is possible to ask for the whole report. There is no public ranking system.

## 2.4 Quality of input

The following educational levels are required for the different home care professions:

- Registered Nurse (RN): a three year university or college degree;
- Assistant nurse (enrolled nurse) (EN): a three year upper secondary school education;
- Health worker: a three year upper secondary school education which is based on the education of an EN and that of the former care workers;
- Care worker: no further education requirements now exist. Care workers provide domestic aid and nursing assistant activities;
- Domestic aids can undergo a one-year local course based education in the municipality;
- A personal assistant is a person who assists the person with his or her daily life. No further education is required.

The education of RNs, ENs and health workers is regulated by a general plan, which is formulated by the government. The content is regulated in terms of core and subject curricula. Local variations occur but only within the above mentioned curricula. One of the obligatory areas of knowledge that RN and EN students must go through is home health care and home nursing, but there is no specialist education for home health care nurses/district nurses. The nurse does not need to recertify.

There is no legal obligation to compensate for continuing education. However, in some cases agencies pay for specialist education if the nurse agrees to stay at her position for a set period of time. In most cases the agencies pay for shorter courses. Paid additional training of domestic aid workers rarely happens, and when it does it is determined locally.

## 2.5 Incentives for providers

In some municipalities there is a mix between private and public providers (domestic aid), but in most of the municipalities the public provider has monopoly.

Therefore competition incentives are usually absent. With the Coordination Reform there will be more incentives for the municipalities to provide home care. The Reform is not yet active, but one of the intentions is that the municipalities shall be required to pay the hospitals for patient admissions. The idea is that the municipalities shall keep and treat their own patients as long as possible (within medically justifiable limits), avoiding unnecessary hospital admissions.

## 3. Financing

### 3.1 General funding mechanism

Expenditures on home health care make up 9% of the total health care expenditure. Expenditures on curative rehabilitation home care amount 0.2% and expenditures on long-term nursing care at home 8.8%. Private expenditures on home health care and curative rehabilitation care are 0.3% (Statistics Norway).

All home care services, including technical aids, are financed by the municipalities. Part of the budget is transferred from the National budget to municipalities based on allocation conditions set by the Norwegian Parliament. The other part stems from municipal taxation, which is a major factor when it comes to differences between municipalities. There are differences between poor and rich municipalities, and these differences may affect some services that are not statutory, such as transportation services, day care centres, amount of domestic help, etc. However, the health care is not affected.

Home health services, including help with ADL, medical services, nursing and personal care, require no private payments. Services from doctors and physiotherapists require excess payment by the patient. Domestic aid (e.g. cleaning the house, food delivery, grocery shopping, etc) has to be paid partly by the individual, i.e. through a fixed price based on the personal situation, mostly income. In some cases if domestic services are considered to be crucial for the person's health situation, the service may be considered a health service and is free of charge. Personal alarm/telephone alert, door-entry monitoring, video/web-cam monitoring and personal monitoring external to home are not normally publicly funded. However, if these devices are considered crucial for the person's functional ability, they are considered technical aids and are free of charge, as are all technical aids.

### 3.2 Financing of private home care agencies

The municipalities pay the private home care agencies for performing home nursing and personal care services per hour. The patient does not pay for nursing and personal care. The municipalities always assess the patients' needs, which the provider, either private or public, performs. Depending on which provider the patient prefers, the patient can choose between a number of providers in Oslo and soon Bergen, and can also change the provider, if preferred. In case of private domestic aid agencies they are paid by the same principles – from the municipality, but the patient pays a price based on their income. The patient can choose to pay the private domestic aid agency for extra services not provided by the municipality.

### 3.3 Price setting

For domestic care services, prices are based on income, and they are fixed within each income group.

## 4. Organisation and delivery of home care

### 4.1 Access and needs assessment

Applications for domestic aid as well as for personal care and home nursing care are submitted to the municipality, where there is one window or entry point for all homecare services, usually an independent formal assessing agency in the municipality. This is called the “purchaser–provider split” (Vabø 2006). The purchaser unit assesses individual needs, formulates contracts, orders services and checks outcomes; the provider unit delivers care specified by the purchaser. However, sometimes it is a representative of the home care provider, which also assesses the needs, i.e. in some municipalities the organisation, the financing, the assessments and the accesses are attained by the same department in the municipality.

Older people's needs for home nursing are always assessed by health personnel, most commonly a nurse, but sometimes a nurse in collaboration with the GP, physiotherapist or others medical staff depending on information about the situation and apparent needs beforehand. The older people's needs for domestic aid are assessed by a lead person from the service unit or the executive unit.

### 4.2 Service delivery

Home nursing services are provided by the municipalities. However, if there is a lack of nurses working for the municipality, private agencies can assist in providing nurses. Home nursing is decentralized and is not meant to profit. Public domestic aid and private domestic aid agencies are decentralised and not for profit. In some municipalities there is a mix between private and public providers (domestic aid), but in most of the municipalities the public provider has monopoly.

Voluntary organizations can provide help (escort to the doctor, domestic chores, keeping company, etc.) for elderly people.

### 4.3 Coordination and integration of service delivery

District nurses and home helpers are not integrated into health centres with GPs. Instead they cooperate, often through regular meetings. Hospitals and home care have a structured cooperation. The cooperation is regulated by a formal agreement between the hospital and the municipality. The hospitals are required to give professional guidance in cases where the health care professionals in home care ask for it in order to acquire competence, for instance in the treatment of patients with a home ventilator or in complicated procedures. The cooperation between the community nurses and hospital nurses is often well organised. There are usually no special liaison nurses; all nurses are required to assure a good transfer between hospitals and for example home care. The hospital gives notice some time before discharge (Paulsen & Grimsmo, 2008) and the municipality assesses the patient's needs before the patient returns home. Research has shown that home nurses need and want more information than the hospital nurses provide (Paulsen & Grimsmo, 2008), e.g. on a functional level (as different interventions are required than provided at the hospital).

In some small municipalities, nursing homes and home care are integrated in one organisation called “The Big Integration Model”. Otherwise, when it comes to nursing home discharge, there is regular, systematic contact and cooperation between the nursing home and the home care. They cooperate when the patient is admitted and when he or she is discharge.

**Table 1:** Human resources

Functions	Estimation total number: municipal health care (Statistics Norway) 2008
Care workers	9 000
Assistant nurses	36 000
Registered nurses	28 000
Domestic aid workers incl. assistants	32 000

#### 4.4 Actors and human resources in home care

The most important organizations for home nursing and domestic aid care:

- The Government: regulating home nursing at a national level;
- Norwegian Directorate of Health: a specialist body, regulatory administrator and implementer in the areas of health and care policies improving social security and health through comprehensive and targeted efforts across services, sectors and administrative levels;
- Norwegian Board of Health Supervision: ensures that health and social services are provided in accordance with national acts and regulations;
- The municipalities: provide health and domestic aid services to the population in accordance with laws and regulations;
- Home care professionals in personal care (1) and domestic care (2) are: (1) nurses (RNs), psychiatric nurses, geriatric nurses, assistant nurses (ENs), care workers, assistants (no health care education), occupational therapists, physiotherapists, (2) domestic aids, assistants, care workers.

The number of employees in home care and community care is approximately 55,000 (Dahl et al. 2009). Registered nurses are employed and paid by the municipalities, but there is an increasing number of self-employed nurses, working on commission for the home care service. The number of registered nurses from health personnel consultant firms has also increased. Domestic aid workers are either employed by the municipal service or by an agency that provides services for the municipality. The working conditions for the nurses are in general regulated by law, i.e. the Working Environment Act, 2005:62. The conditions are supervised by The Norwegian Labour Inspection Authority. Working conditions specific to home care

should be set in documents in the local Internal Control System which is required by law. Payment is set in documents following collective agreements both by the local and the central government, i.e. agreements between employer and labour unions. In all municipalities in Norway the monthly salary of a nurse with 4 years experience is € 2,805 (higher in Oslo). Domestic aid workers have a salary of about € 2,103. The average salary in Norway is about € 4,037, so the pay is relatively low.

#### 4.5 Use of tele-care

In home care, the most commonly used tele-care device is a personal alarm called the “Safety alarm”. It is partly financed by the municipality and partly by the receiver through a fixed monthly amount. There is however a great interest in tele-care solutions and the use of PDA’s (Personal Digital Assistance) for electronic communication, WEB 2.0 (internet application) and TV-conferences are some examples of tele-care used in Norway. When in use these devices are financed by the municipality.

#### 4.6 Monitoring of provided care

The monitoring is to be done systematically and collaboratively by the health care services involved at least twice a year. The nurses are obliged to document their assessments and actions, and assess the care provided. A uniform national record system is in place: IPLOS – National statistics linked to individual needs for care. IPLOS is an information system which provides a standardized set of information about any recipient of health care or social help (nursing and care sector) from local authorities. Private providers must also register in the systems.

## 5. Clients and informal carers

### 5.1 Home care recipients

In Norway on the 31st of December 2006, there were about 171,226 persons had long-term care at home, approximately 112,000 were women, 60,000 of them were between 18–64 years, 76,000 of them were over 80 years. Statistics Norway (StatBank Norway, visited 01-09-2010) shows that 56,547 persons received only home nursing, 48,121 only home help and 66,558 persons received both home help and home nursing in 2006.

### 5.2 Coverage and unmet needs

The Norwegian home services, both health care and domestic aid are based on laws (see section 4.4), but local differences and economic matters may influence the amount of services. Rich municipalities are more likely to give extra services while poor municipalities give adequate services as required from them according to the law.

### 5.3 Informal carers

Formally, informal carers (next of kin) are considered to be an important resource as co-workers to ensure continuity. Next of kin is mentioned in the Patients Rights Act as a person who is to be involved if the patient approves, i.e. the health personnel should also cooperate with the next of kin if the patient wants them to be involved. Informal carers can be paid by the municipality if they give considerable service/help to the patient. This matter is assessed by the municipality.

## 6. Disparities in the process of home care

As mentioned there may be differences in the services available across municipalities. Based on responses to the study vignettes there appear to be some other disparities between ‘theory and practice’. The time spent on a patient may be limited and there may be a lack of competence of those providing the services, as in some localities there are (nurse) staff shortages. Furthermore, there are differences between the assessors between municipalities. In some municipalities there is a separate assessment agency (a team of health professionals), while in others there is only one assessor (a nurse).

## 7. Concerns and recent developments in home care in Norway

The main concerns in Norway are:

- Geographical inequality with regard to receiving home care;
- Lack of quality of professionals. Many young persons working with older people did not plan on working within that field. Instead they got their jobs by chance;
- Social needs usually remain unmet. Home care does not provide for someone visiting or accompanying a person;
- 24-hour attendance is usually not provided. Only in Oslo is there a voluntary organisation, which attends severely ill and dying persons in order to relieve the next of kin’s burden and to ensure that dying people do not die alone;
- Due to the Care plan 2015 there has been a shift of attention towards home care services and more resources will be allocated to these services and research on these services. The home care services will perform more advanced nursing care and medical treatment to avoid unnecessary patient admissions to hospital. The need for professional competence will increase;
- Electronic patient record systems, which provide information exchange between organizations such as hospitals and home care and primary doctors are being developed, aiming at providing inter-organizational continuity of care;
- Teaching Nursing Homes have been active for 10 years. In 2009, Teaching Home Care Services were established to meet the challenges and to provide services of higher quality facilitate research and disseminate and spread new knowledge.

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# Poland

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## 1. The context of home care

### Country, population and health

Poland is a country in central Europe with a population of 38.2 million and an area of 312,685 square kilometres. In 1989 democracy was re-established after more than forty years of communist rule. The economic reforms that followed entailed social costs, including rising unemployment and poverty levels. Since the mid-1990s Poland's economics showed steady growth (Kuszewski et al. 2005). In 2008 Polish GDP per capita stood at US\$ 15,989, 57 per cent of the 27 EU average. Unemployment has been a serious problem since the economic transformation, reaching 18% in 2002 but going down to 10.5% in 2008. Polish people make up 97.5% of the population. Year 2008 was the first year for 11 years with a positive natural population growth (Central Statistical Office Poland). The proportion of elderly people (aged 65 and over) will increase from current 13.5% to 24.1% in 2030 and proportion of those 80 and older will increase from 3.0% to 5.7% of the population (eurostat 2008). Average life expectancy at birth, after years of decline during the 1970s and 1980s, began to increase after 1991 reaching 79.8 years for women and 71.3 years for men in 2007. The healthy life expectancy at age 65 was 6.5 years for males and 7.0 females (eurostat 2008).

### Characteristics of health and social services

Health services are paid from an obligatory health insurance premium contribution. The system of obligatory health insurance is managed by the National Health Fund (Narodowy Fundusz Zdrowia – NFZ)

and its 16 regional branches (Law on Universal Health Insurance with the National Health Fund 2003). Long-term healthcare can be delivered at patients' homes and patients can also choose to stay at long-term care residential institutions. Health services which are financed from NFZ are generally free of charge for insured people (Law on Health Care Services Financed from Public Sources 2004). However, within the health care system there are residential long-term care facilities (not classified as hospitals), which are co-financed by the payments of people staying there. With 6.8% of total expenditure on health care Poland is below the EU15 average (8.9% in 2005) (OECD 2009). The number of acute beds is 4.7 per 1000 people and the average length of acute hospital stay is 6.1 days. The number of long term care beds in nursing homes is 2.4 per 1,000 population. In Poland there are 2.2 working physicians and 5.1 practicing nurses per 1,000 people (OECD, 2008). Making home visits is a routine task of Polish family physicians (Marcinowicz et al. 2007).

Social assistance in Poland is organised by units of central and local administration in cooperation with organisations such as foundations, associations, churches, religious groups and employers. Units of social assistance include: in municipalities and communes – social assistance centres; in poviats (districts) – poviat centres for family support, in voivodships – regional social policy centres (voivodship is an administrative area equivalent to province in France, there are 16 voivodships in Poland). Social assistance consists of various categories of cash benefits as well as different forms of non-financial support e.g. services in the form of social work, care services and specialist counselling (Prekurat et al. 2007).

### Social indicators and conditions related to old age

According to Eurostat (12-10-2008) elderly people in Poland remain at lower risk of poverty than the average elderly population in Europe with 8% of those 65+ falling

below 60% of the median income after social transfers. Among women between 15 and 64 years, 50.6% are in employment (Eurostat).

### Attitudes related to old age

The family is the main source of care for elderly and/or disabled people. Traditionally, older family members help their adult children with raising grandchildren, whereas the family is obligated to help in the case of a disability. Simultaneously, changes in the family model have been observed – family ties, which form natural support resources, are diminishing. Additionally, changes in values, especially individualism and separate living arrangements, are causing a decline in children's or grandchildren's feeling of responsibility for care. When asked if care should be provided by close relatives of the dependent person, even if that means that they have to sacrifice their career to some extent – 61% agreed (compared to 27% of Europeans) (TNS Opinion & Social, 2007). Also 59% of respondents stated that elderly parent who live alone and are dependent should live with one of their children (TNS Opinion & Social, 2007).

## 2. Policy and regulation on home care

### 2.1 Governance on home care

In Poland, home care is situated within the health care and social assistance systems. There are several care forms available within healthcare system as well as different types of support from the social assistance sector. The Ministry of Health is responsible for regulations and shaping health policies, and the Ministry of Labour and Social Policy is responsible for shaping social policy and for supervision of its implementation. NFZ is responsible for signing contracts for the delivery of a fixed number of services of a specified quality within health care (Law on Health Care Services Financed from Public Sources 2004). The rules on contract proceedings are legally specified and define equal treatment of all potential providers. NFZ is obliged to lead the contract proceeding openly, in the way that secures legal competition and respect of the legal provisions.

There are no clearly defined standards of collaboration between healthcare and social sectors. Health services financed from NFZ are free of charge (with some exceptions) for insured persons (Law on Health Care

Services Financed from Public Sources 2004), and services from social assistance are financed by local authorities and are frequently co-paid for by people using them (Law on Social Care, Prekurat et al. 2007).

Until recently home care within the healthcare system has been provided almost exclusively by primary care (family physician and family nurse). Nowadays there are new forms of home care services, financed from health insurance: long-term home nursing care (Decree of the Minister of Health regarding the guaranteed services in the field of nursing and caring services in long-term care 2009), home hospice, home care for people with complex needs and medical rehabilitation at home.

### 2.2 Eligibility for home care services

#### *Home nursing & personal care*

Forms of nursing health services contracted by the NFZ and delivered at the patient's home include care provided by a primary care nurse and care provided by the long-term home care nurse. The *primary care nurse* plans and delivers comprehensive nursing care in a primary care practice and at a patient's home. All insured patients are eligible for primary care nurse services and are free to choose their primary care nurse. A primary nurse's tasks include the identification and assessment of the patients' health needs, health promotion, nursing care and collaboration with other agencies (Decree of the Minister of Health regarding the range of tasks of doctor, nurse and midwife in primary care 2005). However, in practice, the goal of home visits most often is the execution of short-term doctor's orders (Marcinowicz et al. 2009). In 2004, the NFZ introduced a new form of nursing care directed only towards the needs of any chronically ill and handicapped patients staying at home, namely the *long-term home care nurse*. A referral from a doctor is necessary. Eligibility is assessed using the modified Barthel index, with monthly reassessments (Decree of the Minister of Health regarding the guaranteed services in the field of nursing and caring services in long-term care 2009). Although nationwide uniform criteria are applied when granting long-term nursing care services, limitations occur due to demands exceeding supply of services contracted by NFZ.

#### *Domestic aid and technical aids*

Domestic aid (but also basic personal care) is accessible from the social sector. Within the system of social assistance, the scope of services at home depends on

a persons' needs and their personal situation and may include: basic personal care, house cleaning, shopping, being brought to a doctor, etc. Financial participation of the client depends on his/her income and only persons with income below social assistance criteria are entitled to free services. Services are mainly provided to persons without family support, or when family care is ineffective (Law on Social Care 2004, Prekurat et al. 2007).

Orthopaedic equipment and assisting means, which according to regulations might be prescribed by a doctor of a particular specialization, are subject to a refund from the NFZ (up to a certain price). They are, among others: orthopaedic apparatus, artificial limbs, orthopaedic footwear, crutches, wheelchairs and hearing aids. If the patient is not able to pay the costs over the price limit or if the equipment is not refunded by the NFZ, the social assistance centre at the district level – the District Centre for Family Support (Powiatowe Centrum Pomocy Rodzinie) – may grant money from the National Disabled Persons Rehabilitation Fund (PFRON) budget. The most important indicator when trying to receive financing for a disabled person (with confirmed disability status) is his/her income.

### 2.3 Quality of process and output

#### *Availability of quality criteria*

The NFZ places some quality indicators (requirements for staff qualifications, standard equipment, and standard of premises) in contracts with service providers and has the authority to control provision of services in accordance with the NFZ contract. In the social assistance sector the authority responsible for the quality control is a voivode (the governmental administration on regional level) whose activities focus rather on organizational and legal aspects than on the outcome of care.

#### *Assessment of quality of services*

Nurses perform a self evaluation of the services provided in long-term home nursing care, using NFZ documentation, which requires making a nursing diagnosis as well as a care plan. Moreover, patients confirm the services carried out by the nurse. An external audit from the payer (NFZ) is possible but relates mainly to fulfilment of contract conditions, not quality of services. Provider must meet and comply with a set of NFZ criteria to be awarded and retain a contract.

The job of the voivode is to carry out supervision of the role of local government with regard to social care, assessing social assistance units run by local government and units run by private entities against contracts with local government (Law on Social Care 2004). This supervision is mainly focused on the quality of structure.

#### *Accreditation and clients complaint procedures*

There is no obligatory accreditation scheme for either social care or health care providers, but the latter do have to fulfil the NFZ criteria to obtain a contract.

The complaint procedure is uniform in all healthcare institutions. Each health care unit, functioning within the frameworks of health insurance should put in place visible information about the days and hours at which the patient may lodge complaints and petitions. Complaints may be lodged orally or in writing. If the complaint concerns the inappropriate conduct of staff (doctor, nurse, receptionist, etc.), the first step to be taken is to report to the immediate superior of the employee. Insured may also refer to a branch of NFZ, where Patients' Rights Advocate operates, or to the NFZ headquarters. In the absence of due diligence in medical practice, mistakes in treatment or unethical conduct of medical professionals, patients may apply to the Professional Responsibility Ombudsman's, which operates both at the District and Supreme Board of the Medical Chamber and at the District and the Supreme Chamber of Nurses and Midwives (Nurses' and Midwives Chamber).

There are also formal procedures for reporting complaints in the social care system. They are addressed in the Rules of Procedure of Social Assistance Centres.

### 2.4 Quality of input

#### *Education*

##### Health Care Sector

Currently, in order to practise as a nurse, it is necessary to have a nursing bachelor's or master's degree. Additionally, long-term home care nurses should have a qualification course and/or specialization in fields such as long-term care, family care, chronically ill and disabled people's care or internal or geriatric nursing (Decree of the Minister of Health regarding the guaranteed services in the field of nursing and caring services in long-term care 2009).

### *Social Assistance Sector*

The social worker may be a person who meets at least one of the following conditions: 1) has a diploma from the College of Social Service Workers, 2) graduated from university in the area of social work, 3) graduated from university with a specialization preparing for the profession of social worker (Law on Social Care 2004). Until recently, there were no criteria for the professional qualifications regarding who may provide formal care services. However new occupations are starting to replace unskilled workers in the field of home care (i.e. the 2001 introduction of education for ‘community carers’ (or domicile guardian opiekun środowiskowy) and ‘assistant to the disabled’ (asystent osoby niepełnosprawnej) (Szczerbińska 2006) and in 2007 the profession of ‘medical guardian’ (opiekun medyczny). This education takes one to two years depending on the previous education level. Currently non-governmental organizations delivering social assistance services (e.g. the Polish Committee of Social Services, the Polish Red Cross), in agreement with Social Assistance Centres (Centrum Pomocy Rodzinie), employ persons that do not possess the above qualifications. Candidates are trained internally by these organizations. Private agencies employ and train individuals performing services at people’s homes.

### *Task descriptions*

#### *Nurse*

The profession of nurse is defined in law (Law on Nurse and Midwife Profession 1996), and by the Decree of the Minister of Health on the matter of type and extent of care services rendered by a nurse or midwife independently without a doctor’s order (Decree of the Minister of Health regarding the type and range of preventive, diagnostics, therapeutic and rehabilitative services provided by nurse or midwife independently without doctor’s order 2007). This Decree also describes the area of competence of the nurse, for example dressing of burns and wounds, treatment of bedsores (up to 3rd degree), etc., on condition of additional training.

#### *Social worker*

Social workers work in social assistance centres. They maintain professional relationships with clients, acting as guides to the social assistance system. Tasks typically involve: conducting interviews with clients and their families to assess and review their situation, offering information and counselling support to clients and their families.

Assistant to disable people, medical guardian and community carer

Roles of assistants to disabled people, medical guardians and community carers involve assistance with personal, domestic and social tasks.

### *Recertification*

There is no existing system of nurses recertification. Only if a nurse remains out of the job for five years s/he is required to undergo training and pass recertification exams.

## 2.5 Incentives for providers

In the social home care sector there is limited competition. With regard to home nursing, the system is largely driven by NFZ regulated competition among providers, for example by pricing services. The price for services is set by NFZ and the number of contracted services is limited.

## 3. Financing

### 3.1 General funding

In 2008, Poland spent 5.8% of total health care expenditures on home health care (personal care and home nursing, OECD/HD 2010). Home health services are paid from an obligatory common health insurance premium contribution. The obligatory contribution constitutes 9% of personal income (7.75% is deducted from income tax, whereas 1.25% is paid by the insured). Contributions for some groups of people (e.g. unemployed) are covered by the government. The system of obligatory health insurance is managed by NFZ. Health services which are financed from NFZ are free of charge for insured people. However, in home care, co-payments apply to the costs of medicine, dressings and other specialised supplies (Law on Universal Health Insurance with the National Health Fund 2003).

Taxation is the main source of funding of social assistance services such as basic personal care, house cleaning, shopping and supply of meals. Services from social assistance are financed by local governments (community “gmina” and district “powiat”), the central budget (very limited role) and by client co-payments proportionate to their income. On the community (gmina) level assistance is provided in the place of residence of the beneficiary and day care homes (half-institutional assistance).

Assistance may include financial help (mainly permanent, temporary and intentional benefits) and services – (e.g. home aid and some personal care). At the district level some specialized services (e.g. counselling, rehabilitation) and social care homes are organized. An additional source of financing is the National Disabled Persons Rehabilitation Fund (PFRON), created from obligatory payments of employers. The role of governmental administration and local governments is described in the Law on Social Care (2004). Recently, a consistent shift of responsibility for financing of social service tasks to local governments (communities, districts) has been observed, and simultaneously, the number of ordered tasks financed centrally has decreased.

### 3.2 Financing of home care agencies

Healthcare is financed by the NFZ, based on contracts with healthcare providers. Primary care (family) nurses may form their own practices (collecting a capitation fee) or alternatively are employed by family physicians (capitation fee collected by the employer, nurse receives a salary). A nurse can take care of no more than 2,750 persons (the same as family physician). The services of the long-term home nurse are remunerated by the NFZ with a rate for a day of care provided to a patient (person-day-fee). A single nurse can look after a maximum of 6 patients. A rate per “person-day” may differ between NFZ branches.

Services from the social sector may be carried out directly by local authorities but can also be delegated to other organizations (profit and non-profit). The local authorities organize tenders for caring services, which are financed from the municipality’s budget as well as co-paid by the patient. Services of social care are paid per hour of care. Non-profit non-governmental organizations (Polish Red Cross, Caritas, Polish Social Care Committee) mostly take part in tenders and the majority of employees are salaried workers.

### 3.3 Price setting of home care services

The capitation level for services provided by primary care nurses is set by the NFZ and is corrected by a factor appropriate for the age group of the clients – the highest for people over 65 years of age. Also the prices for a person-day are fixed. The hourly rates of social care services are set by the municipalities and thus can

be very different across the country. Client co-payments for social assistance services are left to the discretion of municipalities.

## 4. Organisation & delivery of home care

### 4.1 Access and needs assessment

In order to obtain long-term nursing care services a referral from a doctor is necessary. Then, long-term nursing care nurse assesses the activities of daily living (ADL) using the modified Barthel scale (nationwide eligibility criterion). After the patient’s registration, the long-term care nurse assesses the patient’s individual needs. There are no precise rules for needs assessment.

Services of social assistance are granted at the request of the interested person or his or her guardian or other institution made in the Social Assistance Community Centre (Gminny Ośrodek Pomocy Społecznej). The scope of necessary tasks is determined by a team consisting of: individual/family member, social worker (a representative of Social Assistance Community Centre), and a representative of the organization providing the services (non-profit non-governmental organizations like Polish Committee of Social Service, Polish Red Cross or for profit organizations). The final decision about granting services of social assistance is taken by the Community Social Assistance Centre based on a community interview conducted by a social worker.

### 4.2 Delivery of services

Long-term home nursing services are provided by public (local authorities) and private providers. Most often it is a private healthcare institution providing medical services at a patient’s home. Usually, the former are independent structures in legal and financial terms, but cooperating with a family (primary care) doctor and family (primary care) nurse. They are often formed by nurses. Many nurses that work full-time in hospitals, work additionally in long-term home nursing care on a contract basis. There are also special palliative care teams which provide care at home to those in the final stage of neoplastic disease. Primary care nurses providing home care work either in a team with GPs, form a non-public healthcare centre or a group nursing practice under a contract with the NFZ. Competition between providers of nursing home care is limited due to high demand for their services.

Social assistance is organized by units of local (community “gmina” and district “powiat”) and central administration. The majority of social services are organized by community social assistance centres and district centres for family support which cooperate with providers of social assistance (for example NGO’s). Competition between these providers is generally absent. There are additionally private providers providing all kinds of home care services, completely paid out-of-pocket by the recipients.

#### 4.3 Coordination and integration of services

Most institutions that provide health and social services work separately. In the private market there are agencies that offer a wide range of services at the patient’s home (both household and nursing) – these services are paid entirely by the patient. The institution of case manager does not exist. There is insufficient cooperation between the social service and health care sectors mainly due to separation of the two sectors. The role of a coordinator is in most cases performed by a healthcare professional (family nurse, family doctor or long-term home care nurse) or by an informal carer. Long-term home nursing care usually functions as a separate provider from primary care. Some primary care institutions have a simultaneous contract for services from the field of primary care (family medicine) as well as long-term nursing care. The family physician and the primary care (family) nurse play a key role in directing patients to long-term nursing care or palliative care at home. The family physician remains in charge of the medical care. There is no active involvement of hospitals in home care. Hospitals usually do not communicate with primary care. Some hospitals employ a social nurse who helps patients find residential care in case of an inability to remain at home. Generally also the residential facilities operate independently from long term home nursing care providers.

#### 4.4 Actors and human resources in home care

In home health care the following organisations are involved:

- The Ministry of Health – develops legislation and regulation;
- National Health Fund – is involved in signing contracts with healthcare providers;
- The Chamber of Nurses and Midwives is the organisational entity of the self-government of midwives;
- The National Consultant in the field of Nursing of the Chronically Ill and Handicapped is a medical professional in the respective field appointed by the Minister of Health, in an advisory role to the Minister of Health;
- The National Consultant in the field Family Nursing medical professional in the respective field appointed by the Minister of Health, advisory role to the Minister of Health;
- The Polish Society of Gerontology – society for professionals in the field of aging. Focuses on promoting the scientific study of aging, dissemination of the results;
- The Blue Umbrella Association, an NGO acting for the benefit of chronically immobilized patients;
- The Government Plenipotentiary for Disabled Persons: Supervises the performance of tasks specified by the relevant legal acts;
- Private health care institutions: providers of long-term nursing care at home;
- Public providers: providers of long-term home nursing;
- Primary care institutions: providers of primary care at home.

#### *Actors in domestic aid and supportive aids*

Related to domestic aid the following set of actors is involved:

- The Ministry of Labour and Social Policy – is responsible for shaping the social policy and the supervision of its implementation;
- Voivode – is a governemental representative responsible for supervision of social care on the regional (voivodship) level;
- Community Social Assistance Centres;
- Community “gmina” administration, provide majority of services in the place of residence of the beneficiary and day care homes;
- District “powiat” administration, provide specialised services (counselling, rehabilitation) and organize social care homes;

- The National Consultant in the field of Nursing of the Chronically Ill and Handicapped, medical professional in the respective field appointed by the Minister of Health, advisory role to the Minister of Health;
- The Polish Society of Gerontology, society for professionals in the field of aging. It focuses on promoting the scientific study of aging;
- The Blue Umbrella Association NGO, Association acting for the Benefit of Chronically Immobilized Patients;
- The Government Plenipotentiary for Disabled Persons. Supervises over the execution of tasks specified by the relevant legal acts;
- NGOs – provide domestic aid and simple personal care on the basis of the contract with social assistance centres.

#### *Human resources in home care*

The number of long-term home care nurses in Poland is unknown since, for most home long-term care nurses, home care is additional work next to their work in the hospital.

In order to provide long-term home nursing services, nurses that are already employed full time at hospital are employed on a contract job agreement by the private nursing institutions. In social service most employees are employed on the basis of an employment contract and receive a fixed salary.

In health care, payments of healthcare workers are subject to negotiations with employer and are established individually. In social care home aid workers' payments are set within a certain range locally. It is very difficult to give precise monthly salary of home care nurse because most nurses working at hospital treat it as an additional source of income, not as a primary work place. Gross median income in Poland in 2009 is 3,332 PLN (€758) per month (Main Statistical Office). Primary care (family) nurses earn about 2,200 PLN (€500) per month before tax and it could be assumed that full time working long-term home care nurse gets about the same. A domestic aid receives about 1,700 PLN (€390) per month (gross median income) (expert estimations).

#### 4.5 Use of tele-care

Remote health care (tele-care) is not financed, either by health or social care. The possible use and purchase of them is only done on the initiative of the caregiver and paid by own resources.

#### 4.6 Monitoring the adequacy of care

Services for patients of long-term home nursing care are periodically assessed (modified Barthel index). Monitoring of the care process is based on medical records, uniform across the country. Long-term home care nurse keeps a charter of nursing activities divided into different categories. Execution of each operation is acknowledged by the signature of the patient or guardian. Monitoring is mainly focused on the care provision. A social worker is required to periodically monitor the patient's care at home. The standard uniform national document "community interview" is filled in by a social worker periodically and is used to assess whether the care is still needed (rather than whether it is appropriate) (Maciejko W et al. 2009).

### 5. Clients & informal carers

#### 5.1 Home care recipients

In 2002 81,200 persons received care services from the community (Błędowski et al., 2004) and it was estimated that in 2008 92,500 persons were granted care services and specialist care services at home (Wapiennik, 2009). Those services typically included domestic aid, some basic personal care and meals services. Within the current healthcare system only severely disabled people are eligible for long-term home nursing care (those with a low score in activities of daily living).

#### 5.2 Coverage and unmet needs for care

In Poland there is high demand for long-term healthcare and high restrictions to access. Hence, many home care needs remain unmet. Despite recent developments like the introduction of long-term home nursing, in most situations informal caregivers remain the major source of care. At the same time there is low support for family caregivers.

### 5.3 Empowerment of clients

In Poland, there is a freedom of choice between primary care nurses usually connected with choosing the family doctor. The patient has the right to change the family doctor as well as the family nurse. In practice, the freedom of choice concerns only large cities because in smaller localities there is often only one service provider. Clients who are eligible for long-term home care nursing are free to choose among providers who have signed a contract with the NFZ in the particular region. However, because of a large demand and at the same time an insufficient amount of service providers, the possibilities of an option are limited. Clients who need the care of social services often have a limited choice since many municipalities have contracted a limited number of agencies for these services. Furthermore, there is no quality data available on comparing providers. Although in theory a client is able to choose between institutional care and home care, in the absence of family support (which plays a major caring role), a patient may have no alternative but to stay in an institution. All persons over the age of 75 receive a caring allowance from the Social Insurance Company (ZUS) (without any other conditions). Additionally a caring allowance is also given to a person entitled to a pension or annuity (regardless of age), provided that the person has been declared totally unfit to work and unable to lead an independent life.

### 5.4 Informal carers

Studies carried out within the European multicentre project Carers of Older People in Europe – COPE, show that care for the elderly disabled people in their home environment is mainly based on informal networks of family carers, and usually the immediate family members. The needs of carers are not assessed. Informal carers are taken for granted. They are mostly supported by other family members (Bień et al. 2001, Błędowski et al. 2004). In larger cities, there are support groups for carers of disabled and terminally ill people, or people with learning disabilities (such as the Society of Alzheimer Families) and day care centres for those suffering from Alzheimer's disease (in some cities in Poland).

## 6. Disparities in the process of home care

A limited and unequal availability of various forms of home care is claimed. This particularly concerns rural areas. Health and social services are harder to obtain for persons living in villages and small towns due to the

underdevelopment of a proper infrastructure in these areas. There are also obstacles in the utilization of various forms of residential care: financial (partial co-payment for stay at social assistance and certain health care institutions) administrative (shortening of time of stay at the healthcare institutions) as well as clinical (limitation of indications of admission to hospitals), which force faster transfers of patients to either their homes or a social assistance centre. Only individuals with severely limited activity of daily living (0–40 points on the modified Barthel scale) are eligible for long-term home care nursing. An insufficient development of home physical therapy is emphasized.

In the social assistance system, free-of-charge services are only available for those with a very low income.

## 7. Concerns and developments in home care in Poland

Separate organization and financing of health care and social assistance, as well as lack of cooperation between these sectors, are the main problems. At the same time, patients and their families are not adequately informed about the possible forms of help and the places where it can be received. Some organizations postulate the integration of nursing services (health) and caring services (social) into one group of services, coordinated and supervised by a nurse (Szwalkiewicz et al. 2006).

There have also been positive changes in Poland in recent years. A separate healthcare sector for chronically ill and disabled people living at home (e.g. long-term nursing care, home hospice, mechanically-ventilation at home) has been created. Moreover, new day care facilities, for example day care centres for people with Alzheimer's disease, have been created. Sometimes, municipalities organize programmes supporting disabled persons independently. There are still plans for introducing mandatory disability insurance (against the risk of dependence) as a way of financing benefits. Funds from premiums would be deposited to the insurance fund. The insurance is to be of a solidarity character – therefore, there will be no individual accounts for each person.

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# Portugal

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## 1. The context of home care

### Country, population and health

The population of Portugal is approximately 10.6 million people (Eurostat, 2008) and has been steadily increasing. Even so, the number of births has been declining and the crude birth rate has been below the EU15 average since 1990 (WHO Regional Office for Europe, 2007). The population growth results from an increased life expectancy, by returning citizens from emigration in the 1970s and by immigration from Brazil, Africa and Eastern Europe. In 2006, life expectancy at birth was 82.3 years for females and 75.5 years for males.

The proportion of elderly people is currently below the average in Europe but is expected to grow strongly. Between 2005 and 2030 those 65 years and older will increase from 16.9% to 23.3% and those 80 and older from 3.7% to 6.4% of the population (eurostat 2008). The healthy life expectancy at age 65 (6.8 and 5.9 years for males and females respectively in 2006) was below the European average (eurostat 2008). The prevalence of longstanding illness or disease was just above the average (eurostat 2008).

The Portuguese economy has faced a period of a low or negative growth over the past few years and the GDP per capita remains one of the lowest among EU countries.

### Characteristics of health services and social services

In 2006, the total expenditures on health amounted to 9.9% of GDP, above the EU15 average (OECD, 2009). Portuguese health care is financed through three overlapping systems (Barros & Simões, 2007). The (largely) general tax based NHS provides universal coverage of care provided in public hospitals and health centres. Private funding is essential to the Portuguese health care system. Client co-payments are required for hospital admissions, secondary care consultations, diagnostic exams and medication prescriptions. Additionally, special social health insurance schemes (health subsystems), based on employee and employer contributions and including State contributions as an employer, cover (totally or partially) care provided to certain professions (e.g. civil servants, military, banks and insurance companies employees). About a fifth to a quarter of the population is covered this way. Employers must register their employees with the *Segurança Social* (the Social Security fund), and contribute with regular payments to it. Self-employed persons need to get additional insurance in order to cover family members. Approximately 7% of the population is covered by mutual funds, which are funded through voluntary contributions. These are non-profit organizations that provide limited coverage for consultations, pharmaceuticals and, more rarely, some inpatient care. In 2005, 28% of the expenditures on health per capita was paid by the private sector, mainly private household out-of-pocket expenditure (Van Mosseveld, Kawiorska, & de Norre, 2008).

In 2007 the length of acute hospital stay was relatively long (6.8 days) (OECD 2009). In order to make a specialist or a hospital appointment (emergencies are an exception) a general practitioner (GP) referral is necessary. GPs' long waiting lists have consequently led to an overuse of emergency rooms, i.e. about 25% of visits did not require immediate care (Barros & Simões, 2007). The 2004–2010 National Health Plan aims to decentralize primary care facilities by creating family

health units to increase accessibility to primary care units. There is still some concern over regional disparities, particularly between urban-coastal and rural-interior regions (Barros & Simões, 2007).

Health services available for elderly people include acute and geriatric hospitals and home care, with integrated home care in a few settings. Social care is provided at residential homes for the elderly, day centres and at home. The bed supply in nursing homes and homes for the elderly is increasing, as a result of the launch of the RNCCI (*Rede Nacional de Cuidados Continuados Integrados* – National Network of Long-Term Integrated Care) in 2006 and significant investments are being made by the State, through the social insurance fund and the private non-profit sector. Since then, accessibility and quality of care provided for those in need of long-term care have increased.

#### Social indicators and conditions related to old age

In Portugal, 22% of the population over 65 years old were at risk of poverty in 2006 – above the EU15 average. In 2008, the old-age dependency ratio was below the EU average, but varying across the regions. Labour market participation among Portuguese women was high (Eurostat, 2008), partly explaining the decreasing availability of informal carers. Descendants to the 2nd degree are responsible for providing care in terms of sustenance, housing and clothing to their parents (Civil Law Code). If the family cannot provide such care, the Social Security takes over the responsibility. For a long time, institutionalisation was considered a third response to the population ageing (Jacob, 2002), as the family is traditionally involved in care (Duarte & Paúl, 2006/2007) and as the technical cost in a nursing home run by a Social Solidarity Private Institution (*Instituição Particular de Solidariedade Social* – IPSS) is much higher than for the Domiciliary Support Service (*Serviço de Apoio Domiciliário* – SAD) – in 2000 it was 87% higher (see section 4.4 for a description of the activities of IPSS and SAD) (Jacob, 2002).

#### Attitudes related to old age

In 2007 (Eurobarometer, 2007), the Portuguese declared themselves worried about the idea of becoming dependent due to a physical or mental health condition but few had taken practical measures regarding such a situation. The Portuguese are less optimistic than Europeans in general

regarding the probability of being provided with the appropriate help and long-term care in the future, as 65% estimate this to be certain or probable against 71% for EU (27) (Eurobarometer, 2007).

The family is always perceived as the preferred caregiver for dependent elderly parents. Only 20% of the Portuguese Eurobarometer respondents preferred a professional home care service for dependent elderly parents, compared to 27% of the other EU-citizens.

## 2. Policy and regulation on home care

### 2.1 Governance on home care

The responsibility for home care is split between the Ministry of Health (home nursing) and the Ministry of Employment and Social Solidarity (personal care and home help).

For several years, there were official documents defining, discussing and regulating SAD and defining the roles and criteria for co-payments of clients and their families for the services provided. More recently, the Decree Law that creates the RNCCI assumes home health care as part of a set of health and/or social sequential interventions and defines the “*equipas domiciliárias*” (domiciliary teams).

In each region, elders and dependent persons receive benefits in kind (personal care and home help) and cash from *Segurança Social*, at the council (*concelho*) level. However, service implementation is mostly made via IPSS and *Misericórdias*, most of which have the status of IPSS. As family support has been decreasing, the State considers home care provided by non profit social solidarity institutions a strategic part of the care system.

A number of SAD's places are contracted between the State and each institution, through *Segurança Social*. These places will be financed mainly by the State. Without a signed protocol and contract with the State, the institution is not permitted to operate. Moreover, institutions are not allowed to operate places outside the contract with *Segurança Social* (Despacho Normativo 62/99). *Segurança Social* has developed regulation and norms regarding efficiency, effectiveness, price and safety of home care, which institutions must follow.

An increasing number of for-profit entities are entering the market of home care, providing health care, personal

care, domestic help or a mix of them. To be able to operate, a company needs to have a licence (*alvará*) from *Segurança Social*, which implies meeting all the associated requirements. Municipalities' participation in home care is being stressed by the national government, but it is not yet very common or significant.

In the late 1990's, attempts were made to extend the Domiciliary Support Service to the field of health care, through setting up the Integrated Home Support (ADI), though with little result. Long-term care was identified as one of the gaps in the Portuguese NHS. For this reason and in order to reduce costly acute care, the National Network for Long-Term Integrated Care (RNCCI) was created within the scope of the Ministry of Health and the Ministry of Employment and Social Solidarity. Home care is supposed to be one important element in this network, but monitoring reports issued in 2007, 2008 and 2009 show that there is a lot to be done in this particular field (Santana, 2010). In 2009, the execution rate of the budget for home care previewed in the Implementation Plan (6,100,000 €, to be funded by the MoH) was around 8%.

This new attempt to develop integrated home care is being made through partnerships between regional health administrations and non-profit institutions. As the level of financing depends on whether home help or home nursing is being provided and State control over private providers, including non-profit and for-profit, seems to be underdeveloped, access, affordability, patient centeredness, cost control and quality assurance are major current issues.

## 2.2 Eligibility for home care services

### *Home nursing*

Nationwide uniform criteria are applied, related to the needs of the client, the clinical situation and disabilities, the personal situation (e.g. access to transportation, informal care available) and possible alternatives. The informal caregiver (e.g. wife/husband, children) has to agree to home care. Eligibility does not depend on income. A physician, either the client's family doctor or a hospital or rehabilitation centre's doctor must provide written support and evidence of need for home care.

Nurse's home visits are free of charge; doctor's home visits may be subject to a co-payment, or be free of charge in

the case of exempt clients (e.g., patients with chronic disease). The situation within RNCCI regarding health home care is still unclear.

### *Domestic aid, personal care and technical aids*

The Domiciliary Support Service, offered by IPSS and *Misericórdias* (see section 4.4), is intended mainly for individuals/families that are not able to meet their own basic needs associated with daily life, because of illness, disability or other impediment. Eligibility is not income dependent, but the amount of clients' co-payments depends on the type of services requested and family income. The limit established by law is the operational cost of the service declared by the institution in the previous year. IPSS and *Misericórdias* set their own criteria for access to the services they provide, including prices. Criteria are based on indications issued by *Segurança Social* and obligatorily stated on their *Regulamento Interno*, a public document usually published on the Internet. Prioritization of criteria is made by each institution (e.g., based on their stated mission). They might include family aspects (whether informal care is available), area of residence, age of the potential client and dependency profile. Additionally, there may be a preference given to members of the institution. This usually happens with *Misericórdias*. For these services the informal caregiver (e.g., wife/husband, children) also has to agree to home care.

Clients using day care services are not eligible for SAD. This implies that those benefiting from social activities during the day lose the right to support if institutions do not provide day care services over the weekend, possibly leading to institutionalization of the client.

Concerns have been raised regarding the discretionary power of these institutions and the State ability, capacity and will to control their action and outputs, including their freedom to decide who are eligible for the services (Ferreira, 2003). However, the situation seems to have changed recently following the development of quality models and comprehensive and very detailed procedures and rules for each of the services that might be provided, followed by more frequent and rigorous assessments.

Technical aids, like crutches and wheelchairs, can be borrowed from a health centre or an IPSS when needed. Some patients, e.g. disabled people, can ask for funds from Social Security to buy more specialised technical aids, such as electric wheelchairs.

### 2.3 Quality of process and output

#### *Availability of quality criteria*

Quality criteria have been defined for the services provided by health centres (mainly nursing care), by ADI (only implemented in some parts of the country) or by Domiciliary Teams of Long-term Integrated Care, in the context of the RNCCI. There are also process and outcome criteria for services provided by IPSS. They have been defined recently by *Segurança Social* the State agency that oversees the providers of SAD. The extent to which the requirements are already being applied is unknown. However, the general feeling is that implementation of requirements and assessment of compliance with requirements have increased significantly.

#### *Assessment of quality of services*

The Regional Health Administration plays an important role in the assessment of quality of health care. It is able to monitor and audit quality of providers, and adherence to legislation. A specific institute has been created to ensure and monitor the quality of health care provided – the IQS (Institute for Health Quality).

For services provided by ADI or Domiciliary Teams of Long-term Integrated Care, the process of care (e.g. adherence to the care plan, execution of tasks according to the established rules) is explicitly assessed from time to time by the coordination team, involving the health centre, Social Security and the entity providing homecare. However, criteria should be more objective and results should be more related with actual performance of each professional.

IPSS self-assess the quality of services they provide but the extent to which this is made varies between providers. Theoretically, all the IPSS with protocols with *Segurança Social* should implement a quality management system but certification is not mandatory so far. The Quality Manual, the Processes Manual and the Client Satisfaction Manual are published on the website of *Segurança Social*. Some institutions are making huge efforts to implement all the requirements and meet all the criteria of a very detailed and complex model and regret not being able to certify due to the high cost of the certification process. *Segurança Social* is responsible for quality assessment (overall quality and processes quality) and is now making periodical evaluation of the institutions.

#### *Accreditation and clients complaint procedures*

Certification is possible for all IPSS services, including SAD. The Portuguese Institute for Social Security (ISS) has developed a quality model derived from the ISO 9001 standard and the EFQM (European Foundation for Quality Management) Model of Excellence and adapted to the different types of services provided by social care entities. The certification is to be made by independent entities accredited within the Portuguese Quality System. The Portuguese Institute of Accreditation (*Instituto Português de Acreditação*) defines the requirements of accreditation. Three levels of accomplishment have been defined and while certification is not mandatory so far, the revalidation of the protocol with *Segurança Social* depends on meeting a certain level of requirements.

### 2.4 Quality of input

#### *Education*

The ADI (*Apoio Domiciliário Integrado*) teams usually comprise a medical doctor, a nurse and a social worker. In well-implemented settings, these teams usually visit patients at home from time to time and meet regularly at the health centre to discuss current cases. With the launch of the RNCCI, many of these teams disappeared. The general understanding among professionals is that they will be replaced by the Domiciliary Teams of Long-term Integrated Care, but in most part of the country these teams have not been implemented yet. Domiciliary Teams of Long-term Integrated Care that are expected to provide health care at home will include a medical doctor, a nurse and a social worker, but might also comprise an occupational therapist, a physiotherapist, a psychologist and an undifferentiated auxiliary. The medical doctor and the nurse are the patient's family doctor and nurse, some of them already integrated in the *Unidades de Saúde Familiar* (Family Health Units) that have been recently created in the context of an ongoing restructuring of the primary care in Portugal. At least for now, experience is that these professionals are not routinely visiting patients receiving home care at their homes.

RNCCI is providing professional training for those involved but auxiliaries have not been included. However, prior education is required. They require the following training:

- Medical doctors: at least seven years of studies. Doctor's tasks related to home care include needs assessment, home visits, and drug prescription;

- Nurse: four years resulting in a graduate degree. There are no nursing auxiliaries or equivalents in Portugal. Nurses may specialise through postgraduate programmes such as psychiatric nursing and community nursing. Nurses' tasks related to home care include needs assessment, nursing care (e.g., injections, catheter care) evaluation of patient condition and articulation with other professionals. Historically, in Portugal, nurses with specialization in physiotherapy have been responsible for physiotherapy care;
- Social worker: university courses on social work last for four years. Social worker's tasks related to home care include signalling function, making a social diagnosis, needs assessment, help with getting other services (e.g., domestic help and personal care) and articulation with other professionals;
- Physiotherapist; university courses last for four years. These professionals should provide physiotherapy at home according to the best practice of their profession.

National legislation establishes that SAD's personnel, either technicians or auxiliaries, must have the necessary and adequate training to perform the tasks they undertake (Ministry of Employment and Social Security, 1999). Rules conditioning the implementation, localization, installation and functioning of SAD determines the number and capabilities that the staff of a unit providing SAD has to include. Generically, the following professions work in SAD:

- The Director of the service, most often a social worker. The Director has management and social tasks;
- Technicians (knowledge in areas of social services or gerontology, e.g., social worker, gerontologist, psychologist). Gerontologists, social workers and psychologists all must complete four years university courses;
- Family auxiliaries; their tasks include, for example, providing personal hygiene and comfort; house cleaning; help with meals; help with administration of medicine not in the exclusive competence of a health professional and observing changes in the global situation of the patient in order to allow the reassessment of the Care Plan. There is little formal training for family auxiliaries – they may have had a short introductory course or have been trained on the job. The State is facilitating vocational training

opportunities in areas such as domiciliary care and informal health care as part of a job-creation scheme. Nowadays, the required minimum for auxiliary staff is the 9th year of education (end of elementary/basic school); however, the great majority has only the 4th or the 6th year (before diploma at elementary school). The workforce in home help services is large, but the level of required education has been relatively low.

The domiciliary support services provided by IPSS and *Misericórdias* are managed by a technical director with training in human and social sciences areas.

#### *Job description*

Required expertise and discretionary power of doctors, nurses, physiotherapists, occupational therapists and psychologists are legally defined. The individual professional is authorized by the health authorities.

Processes, tasks and roles for the services provided by RNCCI are described in internal manuals aimed to be used by professionals (nurses, physiotherapists, psychologists among others). Job profiles as well as all the tasks and roles for SAD personnel are described within the Quality Manual to be applied by IPSS.

#### *Recertification*

The National Health Plan 2004–2010 accentuated the need for reform in order to improve the quality of medical staff available. A 2002 change introduced two classes of career – nevertheless promotion is based only on years of service, without including factors such as education, professional training or achievement (Giannakouris, 2008). There is no need for recertification.

### 2.5 Incentives for providers

Health centres are the only public providers in their geographic area. Clients in need of personal care and domestic aid are also supposed to choose an IPSS in their geographic area. To be able to operate, a non-profit social solidarity organization must have an agreement signed with *Segurança Social*.

Even if at a restricted geographic level, IPSS compete on price and increasingly on quality. The client is increasingly more aware of quality issues and the general feeling is that certification will soon become very

important in terms of competition. Also, it will become mandatory, since the establishment of new contracts already depends on certification.

An increasing number of for-profit entities is entering the market of home care, providing health care, personal care, domestic help or a mix of them. To be able to operate, a company needs to have a licence (*alvará*) from *Segurança Social*, which implies meeting all the associated requirements. For-profit entities might succeed in making a contract with the State in which case the services they provide are partially financed by the State. The client pays the remaining fraction of the cost. Apparently, *Segurança Social* is demanding certification of the companies applying. This situation is very recent and disparate information has been collected in different parts of the country.

### 3. Financing

#### 3.1 General funding

Services provided by health centres and the RNCCI are mostly funded by the Ministry of Health but co-financing from the Ministry of Labour and Social Solidarity is due when there is a component of social care. Client co-payments are required for social services within the RNCCI. Services provided by SAD are funded by the Ministry of Labour and Social Solidarity, through the *Social Security* and clients' income dependent co-payments or membership's fees and donations.

In 2006, 2.5% of total health expenditures were for home health care, including medical as well as paramedical care at home. From this, 2% were spent on curative rehabilitation and 0.5% on long-term nursing care at home. In addition, 3.8% was spent on day care. There is no information available on expenditures with home help, including family expenditures.

A characteristic feature seems to persist in most of the inclusive measures taken so far within the Portuguese social system: "although the system is inclusionary and updated in terms of coverage the levels of benefits are considerably low." (Ferreira, 2003).

#### 3.2 Financing of home care agencies

The government, at central or local level, and IPSSs may establish Cooperation Agreements regarding a

particular area (Despacho Normativo nº 75/92, Norma I, nº 4). Co-financing by the *Segurança Social* depends on social responses developed by the IPSS (Giannakouris, 2008). It is defined in the *Protocolos de Cooperação* (Cooperation Protocols) and consubstantiated in the corresponding "Cooperation agreements" that used not to be open to clients or public opinion. Protocols are deliberated annually between the Ministry responsible for *Segurança Social* and the three Unions representing IPSSs. A typical agreement defines a value per client/month. This presupposes the provision of services indispensable to the satisfaction of basic needs, regarding meals, personal hygiene, house cleaning and laundry. In 2008, the value stipulated to be paid by *Segurança Social* to IPSS for SAD was €230.17 per client per month. This figure may increase to a maximum of 50% of the established amount, with the provision of other services or if the services are provided outside working days. In 2006, the mean co-payment from *Segurança Social* was €191.3 per client per month, while institutions declared a mean operational cost of €251.6 per client per month. Nowadays, information on State financing and other issues by institution is published in the Internet, in the so-called *Relatório Único* (Single Report).

Families' co-payments are defined by a Governmental order and have been redefined by documents emanated by *Segurança Social* but these dispositions are not compulsory to IPSS. Theoretically, family co-payment for basic services should be 50% of the income per capita of the household. The provision of other services may increase the co-payment to a maximum of 60% of the income per capita of the household. The inability to provide some of the basic services reduces the co-financing. In practice, some IPSS follow the norm while others establish their own prices and co-payments, always indexed to the income per capita of the household. The general understanding is that the State funding will most probably evolve to payment by service provided to the individual client.

Home-based nursing and rehabilitation provided by health centre teams is funded through the NHS primary care budget. As regards the RNCCI (the long-term care network), in 2006 the Government defined the prices to be paid for health care and social care provided within the pilots of the newly created network (Article No. 12 of Decree-Law No. 101/2006, of 6 June 2006). The costs of health care provision were to be paid by the Ministry of Health, while the Ministry of Labour and Social

Solidarity is responsible for a possible component of social care. The patient has to pay the co-payments for social care she/he receives.

Clients may apply to the Dependency Subsidy (formerly, Third Person Subsidy) from *Segurança Social* and buy some services in the market. This subsidy can be received additional to SAD.

### 3.3 Price setting of home care services

Some IPSS have fixed prices for the services while others charge prices that are fixed between upper and lower limits. These prices are settled by internal regulation. Some IPSS do not establish prices and follow SAD's rules. In such cases, the client is asked to pay a contribution based on the cooperation agreement between a given institution and the Social Security bearing in mind a monthly income and possible deductibles (e.g., house rent, monthly expenses for water, transportation, medicine).

When stated, prices are set at an individual level. Monthly cost increases with the provision of services at weekends and free days. The values of family contributions are calculated upon the existing laws, considering a monthly income and possible deductibles.

According to previous studies, the mean client co-payment is around 30% of the operational cost, with the remaining costs being supported by *Segurança Social* (Instituto da Segurança Social, 2006).

Some institutions are providing all the services defined in the *Manual da Qualidade* without additional costs to the client.

The prices of services provided by companies are usually too expensive for most of the Portuguese families. A small study conducted in the region of Lisbon among five companies (Instituto da Segurança Social IP – Departamento de Planeamento/Núcleo de Estudos e Conhecimento, 2009) showed that when the base for pricing is the hour, the price might vary from €6.5 to €20, depending on the conditions. Some companies charge a minimum number of hours (e.g., 3 or 6). The criteria for pricing might be the number of daily visits per month, in which case a daily visit for personal hygiene seven days a week might cost between €280 and €480 a month, depending on the company; two daily visits might cost between €480 and €840 a month. When a 24-hour permanence in the house is requested, prices

rise significantly and may vary from €2,200 to €4,600 per month. In all of the modalities available, medical, nursing or rehabilitation tasks are not included in the prices, being paid separately.

## 4. Organisation & delivery of home care

### 4.1 Access and needs assessment

For home health care, needs assessment may first be done in an acute care hospital by an EGA (*Equipa de Gestão de Altas* – Discharge Management Team), which would refer the patient to a Local Coordinating Team of the RNCCI located in a health centre. The Local Coordinating Team would validate the need for home care and give continuity to the process. When there is no Domiciliary Team of Long-term Integrated Care available, the hospital (usually a social worker) would send the client to her/his health centre to have needs evaluated. Needs assessment might also be done in a nursing home working within the RNCCI. Otherwise, needs assessment might be done by a social worker or a family doctor/nurse in a health centre. Depending on the person making the assessment, the need for home help might not be assessed. Another possibility co-existing in some parts of the country is that the ADI (Integrated Domiciliary Support) assesses the clients' needs. In this case, clients' needs would be integrally assessed. IPSS always assesses home help needs. The person in need of personal care and domestic aid (or her/his family) will usually approach a provider. Needs assessment is mandatory for determining co-payment made by the client/clients' family.

### 4.2 Delivery of services

Health centres, which traditionally provide home nursing and now should provide integrated home care in the context of RNCCI, are public entities. Health centres are the only public providers in their geographic area. There are also an increasing number of private providers of home nursing in Portugal, some of them affirming they provide integrated home care.

Entities providing personal care and domestic aid are usually either private non-profit (some affiliated to charity, the Catholic Church or the Portuguese Red Cross), such as IPSS and *Misericórdias*, or for-profit – many companies are now entering the market in Portugal.

### 4.3 Coordination and integration of services

Where different types of home care services are provided from one agency, coordination will be promoted. This might be particularly effective and efficient in cases where an IPSS provides personal care, domestic help and rehabilitation care at home. Within Integrated Domiciliary Support, coordination would be also assured because teams integrate medical and social care through protocols between hospitals, health centres, Social Security and IPSS. However, both cases are not very common.

Within the RNCCI, home care is the weakest and the least cared for link of the network. In most parts of the country, *Equipas Domiciliárias de Cuidados Continuados e Integrados* (Domiciliary Teams of Long-term Integrated Care) have not yet been created. Efforts are being made, namely, by establishing partnerships between regional health administrations and non-profit institutions, but it is too soon to report on the coordination and integration of services between the health care network and the social care network.

There are structured links between primary care and home care, particularly, home health care. Family doctors and social workers in health centres are referral agents to home nursing and members of Domiciliary Teams of Long-term Integrated Care work in health centres. The links between primary care and entities providing personal help and domestic help are much less developed, relying mostly on informal relationships. Usually, acute care hospitals are not active in home care directly. Social workers in hospitals might cooperate with SAD units or individual home care workers but not in a structured way. Nursing homes in Portugal are also involved in supportive day care and respite care.

### 4.4 Actors and human resources in home care

#### *Actors in home nursing*

- MoH coordinates and finances public health care provision, develops health policy and oversees and evaluates the implementation, regulation, planning and management of the NHS. It is also responsible for the regulation, auditing and inspection of private health services providers;
- The High Commissariat for Health provides technical support on policy development and strategic planning in the health sector;
- The General Inspectorate of Health-related Activities (IGAS, Inspeção-Geral das Actividades em Saúde) performs the disciplinary and audit function for NHS institutions and services;
- The General Directorate of Health (GDH, Direcção – Geral da Saúde) plans, regulates, directs, coordinates and supervises all health promotion, disease prevention and health care activities, institutions and services, whether or not they are integrated into the NHS;
- IQS (Institute for Health Quality) ensure and monitors the quality of care provided;
- Central Administration of the Health System (ACSS, Administração Central do Sistema de Saúde) is in charge of the management of financial and human resources, facilities and equipment;
- Regional health administrations (RHAs) are responsible for the regional implementation of national health policy objectives and coordinating all levels of health care. They work in accordance with principles and directives issued in regional plans and by the Ministry of Health. Their main responsibilities are the development of strategic guidelines; coordination of all aspects of health care provision; supervision of management of hospitals and primary health care; establishment of agreements and protocols with private bodies; and liaison with government bodies, Misericórdias, other private non-profit-making bodies, and municipal councils. They are in charge of the development of the RNCCI;
- Health Centres are responsible for delivering primary health care, participating directly in the provision of home nursing and other health care services at home. They also run banks of technical aids, such as wheelchairs, special beds and crutches;
- Ministry of Labour and Social Solidarity (Ministério do Trabalho e da Solidariedade Social) is responsible for social benefits such as pensions, unemployment benefits and incapacity benefits. The Ministry's collaboration with the Ministry of Health has improved in recent years, giving rise to the RNCCI, that aims to improve continuity of long-term care for older people and people with disabilities;
- Social Solidarity Private Institutions (IPSS, Instituições Particulares de Solidariedade Social) provide personal care and often provide home nursing and other health services.

- Santas Casas da Misericórdia (independent charity organizations), provide home nursing and other health services beside personal care and domestic aid; they usually have the statute of IPSS;
- Private home health care providers, varying from single-handed workers to larger organisations;
- The clients or patients (and their informal carers).

#### *Actors in domestic aid, personal care and supportive aids*

- Ministry of Labour and Social Solidarity is responsible for social benefits such as pensions, unemployment benefits and incapacity benefits;
- Social Security, the Portuguese social security fund;
- Social Solidarity Private Institutions provide personal care and domestic aid and, often, home nursing and other health services. They might lend supportive aids;
- Santas Casas da Misericórdia (independent charity organizations), provide home nursing and other health services beside personal care. They might lend wheelchairs, special beds and crutches;
- Private providers, varying from single-handed workers to larger organisations;
- The clients or patients (and their informal carers);
- The role of municipalities in the Portuguese health system is still marginal. No published, formal information is available on the subject, but daily experience seems to show that the involvement of municipalities in health promotion and improvement programmes has not expanded beyond a few specific projects.

#### *Human resources in home care*

No data is available on the number of professionals working in home care, but there is regulation on it. Minimum requirements for the number of professionals working in a unit providing SAD and respective competencies are set on national level (e.g. one social worker for each 60 clients and one family auxiliary for each six clients). Even so there are enormous differences in the availability (number and qualification) of home helpers.

Nurses and domestic aids might be self-employed (a rare but increasing situation), or be employed with a salary,

either annual or indexed to the hour or the task. Some might have the two modes from different employers. Working conditions are usually set in documents, at national and sometimes organisational level. Individual contracts are becoming more common, as well as payment per task.

Healthcare employees are contracted by healthcare services providers under different kinds of contracts. Primary care home care nurses and social workers might be civil servants or people working under contract. Their salaries are always based on a Salary Table settled by the national government. In Portugal, the wage of a full time, averagely experienced nurse is above the level of the average wage.

The situation in the private sector is diverse and not very well documented. Professionals providing SAD are contracted by IPSS at local level. In both the profit and non-profit sectors a minimum salary is defined but many professionals are nowadays paid on an hourly base and work under conditions that are not very motivating.

Home care workers, such as domestic aids, are paid below the average wage, but there is no reliable information published about the overall situation. However, IPSS follow a Salary Table defined within a contract between CNIS, the *Confederação Nacional das Instituições de Solidariedade* (National Confederation of Solidarity Institutions) and the three syndicate associations. Family auxiliaries have to be paid by level 13, corresponding to a monthly salary of €543, to which a meals subsidy is added. Some institutions also pay a “function subsidy” (e.g., €75).

#### 4.5 Use of tele-care

The use of alarm systems and other telecom applications, such as tele-monitoring, is still limited but increasing. The service of tele-alarm is considered a component within the Program of Integrated Support to the Elderly. Equipment installation and maintenance are free of charge, but there is a monthly payment (€12.5) and communication costs due and co-participation from the State is available only to those with very low income (below €386).

**Table 2:** Growth rates in long-term care provided at home and in institutions 1998/2007

Type of care	Growth from 1998 to 2007 (%)
Domiciliary Support Service (SAD)	79.3%
Day Centres	40.6%
Residential Homes for the elderly population	33%

Source: (Ministério do Trabalho e da Solidariedade Social, 2009).

#### 4.6 Monitoring the adequacy of care

The changes in the needs of a client are probably monitored during and at the end of a service by a care provider. However, practices vary a lot from provider to provider.

### 5. Clients & informal carers

#### 5.1 Home care recipients

In 2007, 71,663 persons received services from the SAD, about 0.7% of the total population (Ministério do Trabalho e da Solidariedade Social, 2009). Domiciliary Support Service represents high utilization rates. From 1998 to 2007, the Domiciliary Support Service (SAD) had the highest growth rate (79.3%) in terms of number of facilities, followed by Day Centres (*Centro de Dia*) (40.6%) and Residential Homes (*Lar e Residência*) for the elderly population (33%) (Ministério do Trabalho e da Solidariedade Social, 2009). In the case of SAD, the number of places available more than doubled, corresponding to a growth rate of 111%. In 2007, the utilization rate of the SAD was 89.3% (Ministério do Trabalho e da Solidariedade Social, 2009).

#### 5.2 Coverage and unmet needs for care

The Eurobarometer survey among EU citizens showed the relative appropriateness of home care in Portugal: 64% responded that services were completely appropriate, compared to an average of 58% in EU-27 (Eurobarometer, 2007). Evaluations conducted by or on behalf of the authorities supervising the RNCCI and the social network and published in the RNCCI 2008 monitoring report (UMCCI, 2008) and the *Carta Social* (Social Chart) (Ministério do Trabalho e da Solidariedade Social, 2005) also show high levels of satisfaction with the services provided (Santana, 2010). The problematic aspects in the Portuguese home care system seem to be

availability and affordability of long-term care services (Eurobarometer, 2007) (Ministério do Trabalho e da Solidariedade Social, 2005).

#### 5.3 Empowerment of clients

The State tends to be regarded as responsible for population health status and health care delivery, which reduces responsibility in relation to patients' choice. While legal documents do refer to the possibility of patients having choices in health care, the mechanisms needed for citizens to acknowledge their possibilities are not developed.

Regarding home care, clients with an indication for nursing care are assisted by professionals from the health centre serving the area of their residence. For those in need of personal care or domestic aid, choice might be an option but first always in the area of their residence. Only in case of no vacancy, or when the service is not being provided, might the client approach an IPSS outside the area of residence. If care in a nursing home is indicated, clients can still opt for home care provided that a possible co-habiting family member agrees on homecare. Clients cannot choose to take a personal budget and contract their preferred provider but those with needs might apply to the Dependency Subsidy and buy some services in the market.

No comparative information on the quality of home care providers is available in Portugal so far. Social workers are probably the professionals more active in providing information and help to clients and *Social Security* is an important organization, regarding this aspect. Professionals agree that social workers in institutions are usually more client-centred than *Segurança Social*. Often, a social worker in a health centre or a hospital will contact IPSS and *Misericórdias* in order to find a suitable place for the client and help her/him making the approach to the institution. Municipalities have started to open

information desks for some aspects of home care but most of the time they limit their action to the provision of leaflets.

#### 5.4 Informal carers

Clients' partners and other adult co-habitants are considered as co-workers to ensure continuity of care, as home services are not provided overnight or sometimes during the weekend and also because SAD services are not provided during extended periods of the day. However, a description of usual care is not laid down in formal documents. Informal carers are also considered as co-clients, in the sense that their needs are taken into account. They are eligible for respite care if needed, might receive meals-on-wheels when delivered to the recipient of care and benefit from other services, such as laundry and house cleaning. However, often the care they receive might be too basic or insufficient to cover their needs. Clients with an informal carer providing six or more hours of daily care may apply to the Dependency Subsidy.

### 6. Disparities in the process of home care in Portugal

There are many ways in which the client can apply for care, such as through IPSS, her/his health centre (family doctor, social worker), rehabilitation centres and the *Segurança Social*. Acute care hospitals are the entities that refer more patients to the RNCCI.

The type of care required determines what organisations are involved in the processes of application, assessment and monitoring. In simple cases the provider of domestic aid may be the only organisation with which clients come into contact.

There might be some discrepancies between practice and theory. Moreover, clients with comparable needs may receive different care. The following disparities have arisen from the vignettes:

- Decentralized implementation implies different conditions between providers, e.g., not all the IPSS provide all the services at home, the mix of services provided is defined by internal regulation; SAD admission criteria are settled by internal regulation and may vary. Little information is available how much this varies across providers;
- No permanent help: SAD professionals do not provide help on a continuous base, they only make one or two (in special cases, may be three) short visits during the day; usually, SAD services are not provided during the night; some of the providers of SAD do not provide domiciliary support services during the weekends; there is no provision of domiciliary health services from the RNCCI during the night and the weekend;
- Shortages of personnel or unrealistic time restrictions for specific activities might lead to service reduction (qualitative and quantitative) in some valences (e.g., help with shopping, physiotherapy). Recipients may change home care provider if they are dissatisfied but sometimes it is not easy to find a replacer in the area of residence;
- In most districts, the *Equipas Domiciliárias de Cuidados Continuados e Integrados* (Domiciliary Teams of Long-term Integrated Care) have not yet been implemented;
- Providers of home help might refuse more problematic cases. They might decide not to provide some of the services, such as help with shopping based on internal regulation. They might limit the service (e.g., confine house cleaning to the area surrounding the patient's bed);
- In cities, waiting lists for homecare services are probably longer than in rural areas. However, in cities it is probably easier to find answers to complex needs.

### 7. Concerns and developments in home care in Portugal

Current concerns:

- Willingness of families to take care of their sick relatives at home seems to be decreasing rapidly, especially after the launching of the RNCCI;
- Poor control on private providers, even on those funded by public money;
- Innovative services might be discouraged, "due to the difficulties raised by special regulations in the case of services that fall outside the framework for typical cooperation agreements nationally framed with the peak associations through the Co-operation protocol." (Ferreira, 2003);

- The system of quality assurance proposed by Segurança Social is so complex that it might be very difficult to implement by most IPSS;
- Not all the IPSS provide all the services at home: the mix of services provided is defined by internal regulation;
- No permanent help, as SAD professionals do not provide help on a continuous base;
- Usually, SAD services are not provided during the night and some of the providers do not work during weekends;
- There is no provision of domiciliary health services from the RNCCI during the night and the weekend;
- Shortages of personnel or other situations might lead to service reduction in some valences (e.g., help with shopping, physiotherapy);
- Waiting list might be long;
- Supply of services needs to adapt to growing numbers of elderly people with foreign roots, comprising not only immigrants from Brazil and developing African countries, but also Eastern Europeans that have come to Portugal to work and other Europeans that have chosen Portugal as place to live after retirement.

The following developments relevant to home care include:

- Increasing use of home care;
- Increasing integration of health and social care services;
- Increasing need for integrated provision of primary care and cooperation between nurses, GPs, social workers and other health professionals;
- Promotion and evaluation of quality of home care services, with the implementation of Total Quality Management Systems;
- Increasing drive to structured evaluation of both nursing home care and social home help;
- More freedom of choice for clients, due to increased diversity of providers in a region;
- Increasing use of supportive technology, such as tele-care, in home care settings;
- Increasing use of technology to support the integration of care;

- Information systems able to integrate clinical and administrative information (e.g., for insurance companies) need to be developed. This implies the development of strategies, policies, procedures and systems not only at country level, but also at European level.

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# Romania

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## 1. The context of home care

### Country, population and health

Romania has one of the lowest GDP per capita in the EU 27; 9,291 USD (IMF 2008), in 2005 GDP per capita in PPS was 35% in Romania compared to EU-27 data (Eurostat). Since 1989 Romania is undergoing major change in every sector of the economy. The so-called transition has its negative effect as well, it caused an increase of the poverty rate, between 1989 and 1998 from 7% to 33.8%. Compared to the Western European countries the health status of the population is rather poor (WHO 2007). In this period there has also been a continuous population decline, due to emigration, declining birth rate and increasing mortality rate (Vladescu 2008). In 2002 life expectancy in Romania was 71.4 while healthy life expectancy was estimated to be 63.1. Both data is lower than the figure for the Eur-B+C: 68.1 and 60.5, respectively. (WHO 2005) However, the healthy life expectancy at age 65 as a percentage of the total life expectancy was higher than the EU25 average in 2007, at the time of the last wave of the EU enlargement (Eurostat, 25-08-2009). This means a shorter average span of time in which care may be provided. The old age dependency ratio (21.3) in 2010 is estimated to be higher than the EU-27 average, that is 25.9. (Eurostat, 10-12-2008).

### Characteristics of health services and social services

The share of GDP Romania spends on health care was a bit higher than the half the average in the EU15 in 2005. A current issue related to the health care system

is its accessibility, both from financial and geographical point of view. A relatively high private payment is required for health services, there is limited possibility of transportation, low number of GPs and nurses (the latter just over half the average in the EU, WHO) and badly equipped medical centres. In general, the quality of health care depends on social situation, because the share of out-of-pocket expenditures is getting high.

The social health insurance covers services such as care by family doctors and medicines for certain diseases. According to the law regarding social assistance for old persons, old dependent persons are provided with care in homes for older people, day centres, clubs for older people, homes for temporary attendance and at home. Furthermore, there are 49 nursing homes for chronic diseases and 20 nursing homes for neuro-psychiatric disorders (WHO/HFA, 15-09-2009). The number of hospital beds per 100,000 inhabitants is higher than the EU average in 2006 (WHO/HFA, 15-09-2009).

### Social indicators and conditions related to old age

There is a high risk of poverty in old-age in Romania, 26% of 65 year-olds and over is at risk compared to 19% in the EU27 in 2008 (Eurostat, 06-04-2010). Only 6% of GDP is spent on old age (pensions) in 2006 (Eurostat, 10-12-2008). There is no formal liability laid down in law acts for children to pay for care of their dependent parents.

### Attitudes related to old age

Romanians have relatively traditional attitudes and values regarding the support family should offer each other (UNFPA, 2008). However, the Eurobarometer survey (TNS Opinion & Social, 2007) showed that still almost half of Romanians thought care was not the responsibility for close relatives if their career might be affected. Just 10% of the respondents thought that the care of a

dependent elder should be provided professionally to their elder's home, instead of care in a nursing home and informal care.

## 2. Policy and regulation on home care

### 2.1 Governance on home care

No explicit national vision or policy plan on home care has been laid down by the Romanian government. In Romania there is no well-established long-term care policy. Social services do not have enough financial resources and provision is organized badly. Furthermore, current social care could be defined just as institutional care for orphans and long-term psychiatric care. Most health care is still provided within hospitals and 30–40% of cases in acute care hospitals are elderly social cases – a less cost-efficient way of caring. The demand for community-based social and home care is very high because people prefer to stay at home within family boundaries; 95% of the patients die at home. These services are not sufficiently developed. Still, the *“Strategic National Report Regarding Social Protection and Social Inclusion 2008–2010 Romania”* points at the aim to further develop home care (Popa, 2010).

Home health care and home help are regulated separately (Popa, 2010). The Law 95/2006 on Health Reform lays down the principles of the national social health insurance system covering home health care (Popa, 2010). Next to general legislation on health care, the main regulation affecting home care is the Law regarding Social Assistance for Old Persons No17/2000. It states that there are three types of community services to people in their own home (social, medico-social and medical services) and regulates supportive measures for family members. Furthermore, it sets general eligibility criteria for the services described under this law. In 2006, a Law (47/2006) on National System of Social Assistance was introduced for adult disabled persons (Popa, 2010). Hence, there is a split in legislation regarding home care for the elderly and the disabled (Popa, 2010).

One of the current government's main goals is to integrate the long-term medical and social services (laid down in the *“Strategic National Report Regarding Social Protection and Social Inclusion 2008–2010 Romania”*). Regarding integration two policy documents are also of importance: National strategy on the social protection, integration

and inclusion of the disabled persons 2006–2013 and the National Strategy regarding the integrated system of social services 2008–2011.

Since 1997, elderly people in need of care are the responsibility of the National Authority for People with Disabilities, a governmental agency. The local and provincial representatives of the Department of Social Assistance and Familial Policies of the ministry of Labour, Family and Social Solidarity and the Ministry of Health (the local and the county council) are responsible for the provision of home care. Next to county councils there are also the governmental General Directorates of Social Assistance and Child Protection, which are responsible for assessing the quality of services (Popa, 2010). Municipalities and local councils play an important role in needs assessment of home care to those in need and providing and financing services. With regard to health care the District Health Insurance Funds (DHIFs) and Romanian College of Physicians (CoPh) are prioritising and listing services to be covered by health insurance, including home care services. The delivery of home care is separated between that for elderly and that for persons with an illness.

### 2.2 Eligibility for home care services

Home care services for elderly people that are publicly financed are (see Vladescu et al. 2008):

- Social services (mainly preventing of social marginalization or reintegration): domestic aid (cleaning of the home), preparing meals, assistance with administrative work and legal issues and some financial support;
- Medico-social services: personal care, home adaptations, help with developing work, social and cultural activities, day/night care services;
- Attendance to medical services: medical consultations at home, medical devices and sanitary materials and medicine administration.

The main type of home care services provided, are help with IADL (Popa, 2010). According to the 17/2000 law social providers should provide home medical care, including personal hygiene and social medical care (physical rehabilitation, dwelling alteration, and help in social and cultural activities). The services can be temporary or permanent. However, these services are publicly financed only for a limited number of hours

and weeks, depending on the condition of the patient (maximum 56 days per year, eight hours per day). This time limitation has been introduced in 2007 (Alzheimer Europe, 15-07-2009). The Law N. 17/2000 states that the beneficiaries are persons that (Panait-Rodriguez 2007):

- Do not have family or someone with care obligations towards them;
- Do not have a dwelling or the possibility to ensure housing conditions based on their own resources;
- Do not have their own income or this is insufficient;
- Cannot care for themselves, or they require specialized care or they cannot satisfy their socio-medical needs because of their illness or physical or psychological condition.

The services are means-tested and dependent upon the available informal care (children and wider family). The services are offered to persons with a certain level of disability. There are three levels of disability that are eligible for receiving different amounts of benefits. The client co-payments are also means-tested. Although the exact eligibility criteria may differ across the country, in case of some diseases standard nationwide eligibility criteria are used.

Medical care at home requires a referral from a family doctor or specialist (contracted with the National Health Insurance Company) and requires that a person has previously been hospitalised for their disease. 23 types of medical interventions are listed and available for the patients. (Alzheimer Europe, 15-07-2009).

### 2.3 Quality of process and output

#### *Availability of quality criteria*

No quality criteria have been established yet. Only some quality standards of long-term care exist, referring to the structure of the organizations and administration processes, as well as human resources, access to services, service provision, rights and ethics (Vladescu et al. 2008). In 2006, with Decree 246 some minimum specific quality standards were laid down for home care services for the elderly (Popa, 2010). But they mainly focus on input and process, i.e. administration, human resources and access to services.

#### *Assessment of quality of services*

The quality of long-term care is regulated by Decree 246 of 27 March 2006, issued by the Ministry of Labour, Social Solidarity and Family. Care provided by personal assistants is monitored by the Social Protection Departments who also set the standards. (Alzheimer Europe, 15-07-2009), although it is unclear to what extent and how service ‘quality’ is taken into account. (Alzheimer Europe, 15-07-2009).

#### *Accreditation*

Medical care providers need to be contracted by the National Health Insurance Company. No accreditation scheme has been established yet however it would be necessary in order to improve the quality of care.

## 2.4 Quality of input

#### *Education*

There are four ‘professions’ working in home care in Romania. The educational level that is required for them and the task performed by them are:

- Uncertified carers: in practice many carers are uncertified;
- Personal assistants: they usually follow training programmes offered by local authority, but no specific educational requirements;
- Certified carers for elderly: they usually complete a six-month training programme (620 hours) on care for elderly, and receive a certificate;
- Certified carers for ill people: they attend a six-month training programme (720 hours), and are certificated.

The latter two are laid down in the Romanian Occupational Code and receive certification from the Ministry of Employment. The content of education is controlled through the National Council for the Professional Training of Adults, which has to accredit the educational institutes. However, the training is only provided by NGO’s. It is seen as too expensive by private companies and the authorities have not been involved yet. The private companies only act as intermediaries between carers and those in need (Alzheimer Europe, 15-07-2009).

### *Job description*

Personal assistants are employed by municipalities. As for the personal assistants of disabled persons, the approval of Methodological norms for working and the rights and responsibilities are specified officially in the Government Decision no. 427/2001 (Alzheimer Europe, 15-07-2009). They are laid down on national level. There is no further information available on the regulation of professions.

## 2.5 Incentives for providers

Institutions are mostly (contracted) NGOs or run by the church. Competition is not typical and the number of institutions is quite low.

## 3. Financing

### 3.1 General funding

Home care services are funded through the central public administration's social health insurance fund, private payments (e.g. by NGOs), client co-payments (depending on provider and municipal taxation). Home nursing as medical care provided by the GPs is funded by the health insurance fund, but home care as social provision has different sources: the insurance fund, by municipalities (the salaries) and also by patient co-payment.

Home carers (also called social carers) are employed and paid by local authorities/councils. Municipalities receive funding from the central fund. The services funded through the insurance, laid down in the benefit package, payments and conditions of service delivery are set up based on the framework contract between the Romanian College of Physicians (CoPh) and the district health insurance funds (DHIFs). Co-payments are allowed (but up to the providers) for these services. Also coverage of home care services are laid down in the framework contract (home care and help with housekeeping during illness and disability). In 2008, municipalities spent about €6,104,350 on long-term care home care to non-disabled elderly in Romania, NGOs spent about €2,701,522 (Popa, 2010).

### 3.2 Financing of home care agencies

The medical home care providers are contracted with the National Health Insurance Company. These home care providers are reimbursed on a fee-for-service

basis (Vladescu et al. 2008). Local municipalities hire personnel and employ them by the hour. Some additional financial support can also be available for the relatives but only occasionally.

### 3.3 Price setting of home care services

There is no information available on the prices of home care services. Co-payments depend on the providers.

## 4. Organisation & delivery of home care

### 4.1 Access and needs assessment

Family doctors (gate keepers) or specialists should write a referral for medical home care. They take into account the state of health of the person in need and the person's dependency (Alzheimer Europe, 15-07-2009). Commissions of medical expertise for adults with disabilities establish the degree of handicap of a person (United Nations Human Rights, 2009). After, the assessments are performed by home care service's local representative or by the Social Service of the municipality. They usually use their own standard assessment form. Then, they set up the nursing plan.

If a patient turns to the county-level social institution for social support – than the professionals from the institution will prepare a preliminary needs-assessment about the patient. According to this assessment they determine what services the patient needs. If the institution is not able to provide all of these services they direct the family towards other specialised institutions (e.g. non-governmental social care organisations, local authorities/institutions). The social care organisations prepare their own assessment, on the basis of their criteria.

### 4.2 Delivery of services

Generally, the family provides care at home. Professional home care services are almost completely missing in rural areas (but the relatives usually live together with patients).

Home care (help for self care, housekeeping services, shopping and preparing meals) is usually provided by local government carers, by personal assistants (in case of first level disability) or by NGOs or volunteers. Thus, there is a mix of public and (not-for-profit) private

provision. Usually there is no competition between providers, as there is a lack of supply (The Relief Fund for Romania website).

An important group of providers of home care to add are the by the family informally hired carers (Alzheimer Europe, 15-07-2009) (as public and NGO provision is not adequate). The carers remain unregistered and hence their income is untaxed.

#### 4.3 Coordination and integration of services

No information on this was identified.

#### 4.4 Actors and human resources in home care

##### *Actors in home nursing and personal care*

Even though the network of home care is not well established, there are a number of organisations that are officially involved in home care:

- The Ministry of Labour and Social Solidarity;
- Ministry of Health;
- National Authority for People with Disabilities;
- District Health Insurance Funds (49), responsible for collecting health care contributions, contracting services with public and private providers and reimbursing providers;
- National Health Insurance Company;
- County Councils; providing and financing care;
- Municipalities; providing and financing care.

##### *Human resources in home care*

There is a remarkable lack of data, especially about nurses' numbers and workload. Hence it is difficult to estimate the extent of home care in Romania. The home care workers are usually employed by local government for a given period or by NGOs. Local councils hire them either on a part time or full time basis. Carers can also be self-employed, but need an authorisation (Alzheimer Europe, 15-07-2009). Family members taking care of a dependent elderly person may receive either an additional sum to their salary when they are still part-time employed somewhere or a payment that is similar to a minimal salary of a social assistant with medium level training (Vladescu et al. 2008). They work as personal assistants but not officially in that function.

#### 4.5 Use of tele-care

No tele-care services have been implemented yet.

#### 4.6 Monitoring the adequacy of care

Monitoring of the appropriateness of care provided is going on but has not been explicitly executed yet. The Commissions of medical expertise for adults with disabilities **are in charge of periodically revising the patient's condition (Alzheimer Europe, 15-07-2009). The Municipal's** Social Protection Department representative is in charge of monitoring the care provided by personal assistants, but the process and results of monitoring are not publicly available.

### 5. Clients & informal carers

#### 5.1 Home care recipients

There is no data available on home care recipients. As mentioned earlier there are two types of recipients, namely the ill or disabled adults and the elderly. Medical care at home is only provided to persons that have just recently been treated in hospital. As there are very strict eligibility criteria for all home care services, there are expectedly many persons in need which do not receive home care. In 2008, there were estimated to be on average 7,318 recipients of home care paid from local budgets per month and on average 10,192 recipients of home care paid by NGOs per month (Popa, 2010).

#### 5.2 Coverage and unmet needs for care

As several documents state that the home care network is not sufficiently developed, needs remain unmet. According to general expert opinion, home care is hardly available in rural areas and continuous nursing/supervision not available at all. Services are partial, continuous care is not available, and the numbers of days that care is available is limited (56 days per year) as well as the total hours of care per day.

#### 5.3 Empowerment of clients

No such policy paper or section was identified.

## 5.4 Informal carers

The Romanian elderly care is mainly informal care based, although the extent differs between rural and urban areas. Most Romanians think that young people should assume the responsibility for taking care of their parents (89%), offer them financial support when they face difficulties (82.5%) and take them to live at their place when they cannot look after themselves anymore (71.1%) (UNFPA, 2008). Only when there are no family members (also wider family) to take care of the dependents, the government will finance professional care. Informal carers are taken for granted. Respite care is not available.

## 6. Disparities in the process of home care

Although persons may be eligible to home care, in rural areas home care facilities are often not available since providers are mainly in cities and surrounding areas. In this case a private home caregiver may be paid by the family. Furthermore, it is usual that reductions are applied (for instance in number of hours of care) in the provision.

## 7. Concerns and new developments in home care in Romania

The main problem with regard to home care is the unavailability of services (across the whole country, all types of services required and the time it is required for). Causes are the lack of infrastructure as well as financial resources. Furthermore, Crawford (2006) states that one of the challenges related to social care in Romania is organising national structures in such a way so as to “assist the effective and efficient implementation” at the local level (Crawford, 2006, p.490.) and at the same time to involve local communities and institutions in the service delivery systems.

A new development is that a client co-payment system has been introduced since 1st January 2010, both for social and health care system. At the moment (2009), there is a very low number of people who pay social insurance but the biggest share of the population is covered by public provision (where available) (Simion, 2009). For the sustainability this is hence necessary. The introduction of a client co-payment system is intended to define a basic care provision for the insured people (Simion, 2009).

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# Slovakia

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## 1. The context of home care

### Country, population and health

After Czechoslovakia ceased to exist, Slovakia became independent in 1993. In 2008, the share of population over 80 was the lowest in the EU27. The health status of the population is relatively poor compared to average in the older EU countries. In 2006, the life expectancy of 65 year old Slovaks was 17.3 and 13.3 years for women and men respectively compared to 20.6 and 17.2 in the EU15 (eurostat 2008). The same goes for the healthy life expectancy, which is 3.8 years for women and 4 for man compared to 9.7 and 9.3 respectively in the EU15 (eurostat 2008).

### Characteristics of health and social services

In 2006 Slovakia spent 7.7% of GDP on health care (OECD 2009), two thirds of which were public expenditures, stemming from compulsory health insurance and national taxation. Those unable to pay for their compulsory health insurance are covered by governmental contributions. The supply, in 2006, of 6.3 nurses and 0.4 general practitioners per 1,000 inhabitants is relatively low in the European context (OECD 2008). The length of stay in acute hospitals is relatively high, i.e. on average 7.2 days compared to 6.2 days in the EU15 in 2006; (OECD 2009). Social home care services are financed from general taxation (mainly municipality and regional budget) and client co-payments. Home care is supported also through direct payments (e.g. care allowance and personal assistance benefit).

### Social indicators and conditions related to old age

The Slovak GDP per capita is much below the EU-27 average in 2008 (eurostat 2008), but the economic growth is the highest. The population over 65 at risk of poverty is extremely low, with 8% compared to 19.6% on average in the rest of the European countries in 2007 (eurostat 2008). The female labour market participation of 53% is just below the average in the EU in 2007 (eurostat 2008).

### Attitudes related to old age

Slovaks are relatively positive towards informal care, as 48% of Slovaks interviewed for the Eurobarometer thought that care should be provided by close relatives, even if this would affect work (compared to 37% in Europe) (TNS Opinion & Social 2007). Furthermore, according to 47% of the Slovaks the best option for dependent elders would be living with one of their children (TNS Opinion & Social 2007). Formal home care is the second most favoured option (others were institutional care and a child visiting the home of the elderly).

## 2. Policy and regulation on home care

### 2.1 Governance on home care

Governance on home care is split between home nursing (which belongs to health care) and formal home care i.e. personal hygiene and household chores (which is part of social services, provided by professionals carers from municipalities). Although no integrated vision has been developed, both types of home care have the attention of policymakers. One of the government's main priorities is supporting recipients of social services to remain in their own environment or local community and to 'increase independent living' (Brichtova et al. 2009). Since 2003, regarding health care the accent was shifted from hospitals to out-patient services, including home

nursing. In Slovakia, nursing care at home aims to maintain and improve the quality of lives by alleviating suffering, rehabilitation and counselling, prevention of health complications and health education (Lezovic et al. 2007). In contrast to personal care provided at home, home nursing is poorly developed. In addition to services cash-benefits are possible under certain conditions (for example, personal assistance benefits for people whose disability started before the age of 65).

The Ministry of Health is developing national legislation and defines the package of benefits, safeguards access to home nursing and supervises the private insurers (via the Office for Supervision in Health Care) (Hlavacka, Wagner, & Riesberg 2004).

At national level the eligibility to personal care and domestic aid/formal home care has been defined in the 'Act on Social Services' (Act N 448/2008) and legislation on 'Direct payment of Compensation of Disability' (N447/2008). Home nursing has been regulated in the 'Act on healthcare providers, health workers and professional organisations in the health service' (Act No 578/2004) and the 'Act on the scope of healthcare covered by public health insurance and on the reimbursement of health care-related services' (Act No 577/2004).

Municipalities and self-governing regions are responsible for local regulation in the area of social services (including professional home care). Offices of state administration (Offices of Labour, Social Affairs and Family) are responsible for the provision of personal care (e.g. care allowance, personal assistance), technical aids and home. Furthermore, municipalities should establish (public) health care agencies (providing home nursing); secondary nursing schools; and license private health care providers (Hlavacka, Wagner, & Riesberg 2004).

## 2.2 Eligibility for home care services

Eligibility criteria for all home care have been set at the national level. Assessment is based on the level of 'self-sufficiency' or functional ability. A person is considered to be severely disabled if his/her rate of functional impairment is 50% and over. For each level of self-sufficiency detailed criteria have been laid down and, in case of domestic aid and personal care, these are related to a number of hours that care is needed. General eligibility criteria and conditions for social services can be further elaborated at municipal level (e.g. exemptions to co-payments). For social services the family situation and

capacities to care are often taken into account. In general, client co-payments for these services are means-tested (Brichtova et al. 2009).

For the (obligatory) approval of medical care at home (including nursing) the insurance companies only consider the level of disability (Lezovic, Raucinova, Kovac, Dzungova, Moricova, & Kovac 2007). In addition to services contained in the general 'solidarity package', individual health insurance companies can cover additional services to their insureds against their own criteria of eligibility.

## 2.3 Quality of process and output

### *Availability of quality criteria*

The Act on Social Services has defined obligatory conditions for social service providers on procedures, clients-per-employee and human resources development (Brichtova et al. 2009). An evaluation scheme has been developed, using set quality standards and a scoring system.

Health care providers are obliged to maintain an approved quality system and to keep to it. Requirements aim at controlling the quality of input, such as qualification of professionals and quality of medical instruments. Besides, the Ministry of Health and stakeholders, jointly decide on quality criteria for contracted providers; mainly on the process quality (e.g. management of chronic care). Ultimate sanction is ending the contract with the provider. Health insurance companies should produce a quality ranking of providers, but this has not been effectuated yet.

### *Assessment of quality of services*

The Act on Social Services regulates supervision over social services. Since 2009, social service providers are legally obliged to evaluate the quality of their services. Inspection bodies check the set standards. The quality of health care providers is yearly assessed by medical reviewers or inspectors of the insurance companies (Hlavacka, Wagner, & Riesberg 2004).

### *Accreditation and clients complaint procedures*

Accreditation is not obligatory but possible for home nursing providers on a voluntary basis with the Slovak National Accreditation Service. Home nursing providers are contracted by insurance companies and need to

register with the municipality where they work. Providers of social services must register with a self-governing regional authority, which implies they work conform the conditions laid down in the Social Services Act. Home health care providers are not obliged to maintain a complaint procedure. Complaints on home nursing are usually submitted to health insurance companies or to the Office for Health Care Supervision. For social services having a complaint procedure is voluntary.

## 2.4 Quality of input

### *Education*

The following professionals with their obligatory education are working in home care:

- Social worker: higher education in social work (first and second degree);
- Carer: full secondary vocational training with a focus on home care (nursing) and health care or accredited course (220 hours) for carers;
- Health care assistant: supervised by a nurse, providing elementary nursing, assisting in diagnostics, prevention and administration. Education: four years basic vocational training;
- Nurse: bachelor or masters education; performing injections, infusion, wound care, ulcer treatment, etc.

The educational curriculums for nurses and health care assistants have been regulated nationally (by Government Regulation 296/2010) and the educational programmes must be accredited by the Ministry. Qualification requirements have been defined, along with further education required to perform specific social services activities.

### *Job description*

General job descriptions for all home care providers are set at national level (regulation N: 341/2004). Social services organisations are obliged to have job descriptions for their workers.

### *Recertification*

- A recertification scheme for nurses does not exist. Nevertheless, many nurses take additional courses even though these are usually not paid by the employer.

## 2.5 Incentives for providers

As in most areas providers of social services hold a monopoly, competition is of little significance in this sector. However, competition among health care providers (on price and quality) is more prevalent as in most regions several agencies provide these services and insurance companies can selectively contract agencies.

## 3. Financing

### 3.1 General funding

In 2007, 0.5% of the total health care expenditures was spent on home nursing (OECD/HD, 12-11-2009). The main sources of financing home nursing are:

- Compulsory health insurance (with premiums jointly paid by employers and employees) covers most services. Care outside the insured package needs to be privately paid (unless covered by voluntary insurance). For privately purchased care client and purchaser can negotiate prices;
- National taxation. Health insurers are compensated by the government for specific groups like pensioners and people with disability benefits (Hlavacka, Wagner, & Riesberg 2004).

For social care services at home cash benefits are much more important than benefits in kind. In 2007, 7.5 times more was spent on cash payments than on in kind services (Brichtova et al. 2009). State offices at local level make direct payments for help with ADL and IADL and personal assistance.

In kind personal care and domestic aid are financed through:

- Municipalities (e.g. respite care and formal home care) by their tax revenues;
- The state budget: the Ministry of Finance subsidises approximately 90 municipal establishments that had lost financing after decentralisation;
- Social insurance pays informal care givers;
- Co-payments by clients. Compensation for care provided by or via municipalities and self-governing regional authorities depends on the financial position of the client. If, after paying for social services, the remaining income would be below 1.3 times the life minimum there will be compensation.

Technical aids are financed either through the compulsory health insurance (e.g. wheelchairs, crutches and prostheses) or from state budget through Offices of Labour, Social Affairs and Family. Home adaptations are paid by Offices of Labour, Social Affairs and Family (state administration).

### 3.2 Financing of home care agencies

Insurance companies contract home nursing agencies (ADOS) and pay them a fee for the services they provide. The client is paying for services that are not covered by health insurance. Independent qualified nurses are paid an equal fixed amount per patient they serve.

Municipalities pay social workers a salary from their budget. Number of inhabitants older than 62 years is one of the criteria for creating municipality budget from taxes. Private providers hired by a municipality or self-governing region, receive a fee for the services they provide and a lump sum for care for dependency costs. Fully privately hired social care providers usually work on a fee-for-service basis.

### 3.3 Price setting of home care services

Insurance companies agree on prices of home nursing with providers in a contract. In general, prices are related to the case-weight (the level of disability and the hours needed).

For home social services maximum prices are set by municipalities and self-governing regions. Municipalities choose their own mode of price setting (e.g. an amount per hour or per ADL activity). The amount of client co-payment is usually established per service. If private providers are hired maximum prices are specified in the contract. Limits of co-payments by clients are set by the Law on Social Services (Brichtova et al. 2009).

## 4. Organisation & delivery of home care

### 4.1 Access and needs assessment

Access to home nursing care formally requires a physician's referral. Thereafter, an agency's nurse will assess the client's degree of mobility, draft a treatment

plan and assign the intervention nurse. The plan needs approval from the health insurer. In practice this procedure may not always be followed.

One can apply to the municipality for social services, while for personal assistance and paid informal home care one needs to apply to a Local Office of Labour, Social affairs and Family, a public organisation. In the municipality a municipal assessment teams performs the needs assessment. A social worker will assess the social situation, while a physician will examine the patient's health status. Medical devices and technical aids are prescribed by GPs and paid by the public health insurance agency. Other devices and technical aids are paid from state budget via financial allowance for severe disability compensation.

### 4.2 Delivery of services

Although GPs (or their nurse) are legally obliged to visit patients at home, this only occurs sporadically. Home nursing (but personal care as well) is primarily provided by 162 Home Nursing Agencies (ADOS) (Lezovic, Raucinova, Kovac, Dzundova, Moricova, & Kovac 2007). These are private non-profit organisations bounded to a region. They also provide nursing care in institutional settings. Usually, several agencies are active in one region.

Home care services are provided by municipalities and self-governing regions or, on their behalf, by private providers (either for profit or non-profit, such as charity organisations, Red Cross). However, most providers are public, although the revised Act on Social Services is said to have complicated financing of private providers and thus to make private provision less attractive (Brichtova et al. 2009). Public as well as private providers of social home services may provide services to several municipalities.

### 4.3 Coordination and integration of services

Continuity between social and health care is problematic in Slovakia, according to research commissioned by the Ministry of Labour, Social Affairs and Family and self-government regions (Bednarik et al. 2009). Although GPs are legally responsible for care coordination, cooperation between GPs and home care providers is lacking. In fact, ADOS are substituting for the home visits no longer made by GPs. As home nursing requires a GPs referral some coordination would be possible. However,

**Table 1:** Human resources in home care

Functions	Estimation total number
Carers employed by municipality (2009)	7,085
Home nurses (2008)	381

Source Carers: Brichtova et al. 2010.

Home nurses: NCZI: Health statistics yearbook of Slovakia 2008. Bratislava 2009.

with social services this is not the case. Although direct cooperation between hospitals and home care providers is rare, some coordination does exist. Hospital specialists usually advise GPs or home nursing agencies on the recommended services. Hospitals also inform patients about social care.

Between institutional care and social home care social workers are the formal liaison. They must arrange the smooth transfer of patients from an institution to their home. Home nursing agencies may provide care in nursing homes and homes for the elderly.

#### 4.4 Monitoring

A GP and nurse review every three months the nursing care plans. Furthermore, ADOS-nurses need to report possible improvements monthly. In practice, the monitoring is irregular, and GP referrals are not always asked. No rules exist for the monitoring of social services, but if performed it is done by social workers visiting clients at home.

#### 4.5 Actors and human resources in home care

##### Organisations

The following organisations are involved in home nursing:

- Ministry of Health: safeguarding equitable access, overseeing insurers and defining the benefit package;
- Office for Supervision in Health Care: supervising the financial situation of the private insurance companies;
- Private health insurance companies: insuring basic benefit package and additional packages;
- Home nursing agencies: providing nursing care in various settings;
- Municipalities: establishing home care agencies, issuing licenses for health care providers and participating in health prevention programmes.

The major actors for personal care and domestic aid are:

- The Ministry of Labour, Family and Social Affairs: setting general eligibility and quality criteria, controlling providers of social services, preparing new legislation in the area of social services and direct payments (including personal assistance);
- Local Offices of Labour, Social Affairs and Family or local social welfare offices: administering and deciding on direct payments (e.g. cash benefits to buy technical aids, care allowance for ADL care, transport and home adaptation);
- Municipalities: providing/ensuring home care, lending technical aids and providing respite care;
- Self-governing regions: providing home care;
- Private providers of personal care and domestic aid.

##### Human resources in home care

Among long-term carers there are those educated for the job and those without such specific training. No further information is available on their educational level. The number of personal assistants is 9,340 (from that 212 are family members) and the number of untrained informal family carers, is 56,434 (June 2010). Most carers employed by municipality are employed with a salary, but some are employed through a work performance agreement (paid for a certain number of services to be provided instead of hours) (the Labour Code). Home nurses and assistant nurses are contracted by ADOS, which in turn are contracted to health insurance companies. However, nurses may also be physician's employees.

Working conditions of home care professionals are set in the general Labour Code and individual agreements. Salaries of municipal employees are set according to national regulation. Salaries in the private sector are free. Home carers earn €300–€500 per month, which is just about or just above the minimum wage. The nurse's monthly salary in social services is €652 (2009), which is below average (€766).

**Table 2:** Long-term care (LTC) provided at home and in institutions 2007

Recipient groups	In kind recipients (% of pop.)
LTC recipients at home in 2007 (excl. IADL, including Personal Assistance)	81,617 (1.5%)
LTC recipients in institutions in 2007 (excl. IADL)	31,540 (0.6%)
Recipients of municipality home care in 2007 (incl. help with IADL and ADL)	22,760 (0.4%)
Recipients of residential social care services in 2007	35,055 (0.7%)
Personal Assistance recipients	Over 6,000 (0.1%)

Source: OECD/HD, 2009 for LTC recipients.

Brichtova et al., 2009 for other.

#### 4.6 Use of tele-care

Equipment for distant monitoring is on the market, but not widely used as public funding for it is missing (Ministry of Labour Social Affairs and the Family 2008).

### 5. Clients and informal carers

#### 5.1 Home care recipients

Recipients of long-term home care services make 1.5% of the Slovak population. In contrast a negligible proportion is receiving home nursing (technical nursing) by ADOS. Personal assistance benefits are aimed at disabled persons up to 65 years of age. Only when receiving it before turning 65, the disabled will continue to receive it. Home care recipients are almost triple the number of institutional long-term care recipients, which is considerable compared to the other countries.

#### 5.2 Coverage and unmet needs for care

It has been reported that not all who are in need of home care do receive it, for instance by lack of financial resources. The network of social service facilities are said to be insufficient to provide those who are eligible with the proper services. Furthermore, municipalities are insufficiently equipped, in terms of personnel, expertise, material resources and technical outfit. Long waiting lists for institutional social care, 16,800 persons waiting for admission by mid 2009 (Brichtova et al. 2009), put pressure on home based services.

#### 5.3 Empowerment of clients

The Act on Social Services has enabled clients to freely choose between home care and institutional care and among service providers (Brichtova et al. 2009). The right

on information on service providers also has a legal basis. Information on social services is available on websites of the Ministry and regional bodies. Health insurance companies must publish quality scores of health care providers. Furthermore, clients with a serious disability below the age of 65 can choose their own personal assistant for which they personally receive a financial allowance for up to 20 hours a day (Brichtova et al. 2009). Details of the work relationship between the disabled person and the personal assistant are settled in an agreement (Brichtova et al. 2009). Personal assistance clients can be supported by local support groups and a national organisation; for instance to draft contracts and organise payment (Brichtova 2009). Lack of resources may limit the formal freedom of choice in practice.

#### 5.4 Informal carers

Informal carers are formally recognized. According to the Act on direct payment of Compensation of Disability (N447/2008) they can receive an income dependent care allowance. As the basic amount is around €200 per month it does not cover full-time involvement. In addition to being a worker, informal carers are also in the position of clients. Since 2009, they are eligible for respite care (up to 30 days a year, 8 hours per month) and free counselling (Brichtova et al. 2009).

### 6. Disparities in home care

- Indeed, discrepancies exist between theory and practice of home care. Eligible home care services are not always provided and only very few people do receive nursing care at home. Furthermore, in practice General Practitioners will not always be asked to write a referral for home nursing. Besides informal payments are being made for receiving services.

- Also differences between different types of clients exist. Those under the age of 65 may receive services from personal assistants, while those becoming disabled after this age may not. For applying for public financing clients need to go to a different organisation than when applying for home care from the municipality. Finally, access to social services is unequal between different areas because of considerable differences in policies of self-governing regions and municipalities.

## 7. Concerns and developments in home care in Slovakia

The following problems in the home care sector have been reported:

- Unmet needs: Those eligible do not always receive the indicated care. Very few people receive home nursing;
- Insufficient financial resources: The largest health insurer only spent 0.22% of all expenditures on ADOS. Most of the budget is spent on nursing homes (Lezovic, Raucinova, Kovac, Dzundova, Moricova, & Kovac 2007);
- Inequality: Access to social services strongly varies by local and regional policies;
- Poor housing conditions of housing and living environment restrict people to stay independent in their own environment;
- Unequal funding of public and private providers (Brichtova et al. 2009), which is an obstacle to competition and, therefore, lack incentives for good services;
- Inefficient assessment procedure: For instance, applications for cash grants may take three months and multiple overlapping assessments (for each type of service again);
- Inefficiencies as a result of lacking competition between health insurance companies. New insurers entered the market but the largest still has a 64% market share (Lezovic, Raucinova, Kovac, Dzundova, Moricova, & Kovac 2007);
- A benefit trap due to means-testing of direct payments: the higher the family income, the lower the benefit, so much that there is a disincentive to work for family members (Brichtova et al. 2009).

Home care is a dynamic sector in which the following major developments can be mentioned:

- The role of GP practice nurses in home care is slowly being replaced by ADOS-workers;
- Increasing attention is being paid to issues of quality of care, by introducing the new Act on Social Services and by introducing quality ranking of contracted home nursing providers;
- The accessibility, affordability, financial sustainability of social services and independency and social inclusion of clients in social services have got a boost by the new Act on Social Services.

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# Slovenia

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## 1. The context of home care

### Country and population

Slovenia's just over 2 million inhabitants are ageing rapidly compared to other EU countries (eurostat 2008). The group above the age of 80 is expected to grow from 3.1 to 6.6% between 2005 and 2030.

### Population's health

Compared to other countries that accessed the EU in 2004 the Slovenian (healthy) life expectancy is good. The healthy life expectancy at 65 years of age is only just below that in the EU15 (eurostat 2008).

### Characteristics of health services and social services

The expenditures on health care (in 2005 8.5% of the GDP) are high compared to the other countries that accessed the EU in 2004, but somewhat below the EU15 average of 9.3%. The main financing mechanism of health care is by compulsory health care insurance. Other sources of financing are private payments (about 27.8% in 2006) municipal and national taxation (Albrecht et al., 2009). Supply of physicians and nurses is relatively low, with 2.4 physicians and 7.6 nurses per 1000 population in 2006. The same goes for hospital bed supply, which amounts less than 5 hospital beds per 1,000 population.

### Social indicators and conditions related to old age

Although below the European average, the GDP per capita is high compared to other 2004 new EU Member States (OECD 2008). The share of elderly living at risk of poverty is about average for Europe with 19% in 2007 (eurostat 2008). Compared to the other new EU countries the female labour participation is high (eurostat 2008).

### Attitudes related to old age

Compared to Europeans in general, Slovenians attach much value to informal care, as 44% find care a task for close relatives even if this would affect career perspectives, compared to 37% in Europe (TNS Opinion & Social 2007). However, asked about the most preferable option for their dependent elderly parents, a nursing home is most preferred; by 32% of the Slovenes, compared to 10% of Europeans (TNS Opinion & Social 2007). So, institutional care is more popular among Slovenes than home care. The reason lies in the accessibility of home care which is still scarce (only 1.7% of people 65+ received social home care in 2009), it covers only 20h per week, and it is not equally accessible around the country.

## 2. Policy & regulation

### 2.1 Governance on home care

In Slovenia, governance on home care is fragmented. One reason for this is the existence of many different types of home care, i.e. domestic aid, social servicing, home nursing, family care assistance, personal assistance and tele-care (social alarms). Furthermore, the responsibility is split over two ministries. Home nursing falls under the Ministry of Health and is governed by the Law on Health Care Provision and Health Care Coverage, and Health Insurance Act. Personal care, domestic aid and social care, encompassing all other home care services,

are the responsibility of the Ministry of Labour, Family and Social Affairs (MLFS) and are governed by the Social Security Act.

Home care is a policy objective in Slovenia as far as personal care and domestic aid are concerned. The Slovenian government aims to stimulate programmes and services enabling old people to stay in their own environment as long as possible (Ministry of LFSa 2006). Home care is aimed to increase. By 2010, at least 3% of people aged 65+ should receive *social* home care. Another aim is to enhance the coordination between different types of care providers, i.e. individuals, family, the third sector, the market and the state (Ministry of LFSa 2006). No vision or targets have been formulated on home nursing.

Apart from the ministry, other important players in home nursing are the national and regional offices of the Health Insurance Institute and municipalities. They collect premiums, distribute funds, contract providers of care and technical aid and they co-decide on the publically funded services. Municipalities are involved with granting concessions to private providers and, in theory, with managing primary health care facilities (Albrecht et al., 2009). Municipalities are more important with regard to the other types of home care; they elaborate national legislation into ordinances; and organise individual needs assessment, financing and delivery of home help.

## 2.2 Eligibility for home care services

The four main types of home care are called ‘*social home help*’ (public home help that is officially called help to the family at home – consisting mainly of housekeeping, personal care and social contacts), *social servicing*, the ‘*completely private home help*’ (mostly meals on wheels) and *home nursing*. The general eligibility criteria for these publically financed *home help* services are set in the national ‘Rules on Standards and Norms of Social Security services’. Municipalities can elaborate on these criteria (and decide to provide additional services). Eligibility is not means-tested, but those with a low income can pay less. Availability of informal care can be taken into account, but uniform criteria do not exist.

Slovenes or permanently residing foreigners are eligible to *social home help* if they are able, with the occasional organized help of another, to maintain the mental and

physical well-being and can function in his/her home environment, as described by the Ministry (Ministry of LFSa 2009a).

Home care (help with ADL and IADL) may also be provided in the form of home social services (called social servicing). Recipients are by law liable to pay the service (Hvalič Touzery 2007). These are privately paid, but may be co-financed by municipalities (Touzery 2007). *Private home helpers* are private individuals *without* a concession of the Ministry. As no legislation applies to them formal criteria for eligibility do not apply.

To be eligible to a *family assistant* (paid informal carers providing personal care, medical care, social care and domestic aid) one has to be severely physically impaired or have a severe mental or development disorder. According to the Act Amending the Social Security Act (SSA-C) only family carers who are either unemployed or work part time are entitled to this status.

Eligibility to *home health care* is universal, i.e. it is independent of income, age or available informal care (the Health Care and Health Insurance Act, 2006). The criteria used for needs assessment are to the discretion of the GP.

## 2.3 Quality of process and output

### 2.3.1 Process and outcome quality criteria for home care

Social service providers should provide the prescribed quality and use effective professional methods (Social Service Act). According to experts no detailed quality criteria exist. However, one policy regulation has specified ‘elements’ on the basis of which providers and municipalities can be judged, in particular access after working hours, methods of service provision and availability of explicit organisational procedures (Official Gazette of the Republic of Slovenia 2004).

Supervision of home nursing is carried out by the Health Insurance Institute of Slovenia (ZZZS), using process quality criteria, for instance, instructions on how to perform prevention at the primary care level. Next to criteria on volume and prices of services, quality criteria may be laid down in contracts between regional ZZZSs and health care providers. A study in general practice,

however, reported that no quality criteria were formulated in the contract between community health centres and ZZZS (Boerma et al. 2008).

### 2.3.2 Regulation on assessing the quality of services

Regulation on quality assessment of social service providers is laid down in the 'Social Security Act' (SSA) and the 'Rules on Professional and Administrative Control in the Field of Social Assistance and Social Services'. Social home help and social servicing providers are controlled professionally and administratively by a special commission (at least every three years). Furthermore, according to these Rules, family members of eligible persons may also ask for a quality evaluation. Family assistants are, at least yearly, obliged to report about their care to the social work centres (Ministry of LFSA 2009b). Social work centres must annually report about information on or opinions of the disabled person.

Quality evaluation and control of home nursing is in its infancy in Slovenia. Monitoring data collected by the National Institute for Public Health seem not to be used for quality improvement in primary care (Boerma et al. 2008). The Nursing Chamber is formally in charge of professional auditing of nurses in the context of the Medical Service Act services (Albrecht et al., 2009). But external audits are rarely performed in primary care (WHO, 2008). Administrative and financial control is performed by the Health Insurance Institute (ZZZS), for instance on evidence-based prescribing (Boerma et al., 2008). Finally, some community health care centres perform internal audits, voluntarily gather data on the quality of their services and perform client satisfaction studies.

### 2.3.3 Accreditation and complaint procedures

No accreditation schemes exist for any type of home care. Ministerial (administrative) concessions/permissions are required for all nursing providers and for others as far as working in the public sector. Complaint procedures are obligatory for nursing care providers (Patients' Rights Act). Health care providers must appoint someone to receive and process client complaints. Complaints usually deal with the quantity of services and with lay helpers. If clients are dissatisfied with personal care and domestic aid, they may appeal against the provider at the council of the social welfare institution, and against a private undertaking at the Social Chamber (Social Security

Act, Article 94). Next to the Social Chamber, the Social Inspection is also taking an important part in handling complaint procedures.

## 2.4 Quality of human resources

### 2.4.1 Education

The Social Chamber decides about the educational requirements of professional workers, home helpers and family assistants. The following providers of domestic aid and personal care can be distinguished with their educational level:

- Professional workers (SSA, article 69): higher or high degree schools for social work or university degree (e.g. in sociology or psychology) with one year social welfare work experience; coordinates social care at home; provides counselling; helps with social problems (Peternelj et al. 2006);
- Home assistants (professional assistants by law): with a qualification called 'National Vocational Qualification Social Home Care Worker' – 120 hours training for 'home assistant' (Smolej et al., 2008), help with IADL (meals, basic cleaning of the house, etc.) and ADL (dressing; washing; help with catheter; care of orthopaedic instruments, etc.) and maintaining social network, contact with volunteers and family; accompanying a client; liaison to institutions;
- Family assistants (also called home care assistants); training stipulated by the Social Chamber; help with ADL and IADL;
- Laymen (without required qualification); assisting professionals.

The National Vocational Qualification Social Home Care Worker was the first NVQ in Slovenia under the National Vocational Qualification Act in 2000. This makes it the oldest publicly recognised qualification recognised and validated under APEL procedure (Hrovatič, 2009).

For community nurses a state registration exam is compulsory after graduation and fulfilling an internship. Diplomas of home nurses and assistants are subject to legal recognition by an inspectorate.

For home nursing the following educational levels are required:

- Nursing assistants (second largest group): three year secondary vocational education (Hvalič Touzery 2007); ADL-help and some community nursing tasks;
- Nurses with higher non-university education (80% of community nurses): technical nursing tasks;
- Nurses with a university degree specialized in community nursing care: coordinating primary health care.

#### 2.4.2 Formal task-differentiation.

Tasks of professional workers and assistants tasks are set in the Social Security Act and the Rules on Standards and Norms of Social Security Services. Tasks of the family assistant are laid down in the Social Security Act. They provide personal care, medical care, social care and organisation of leisure and housework assistance. The SSA (Article 73) states that some individual welfare services may be provided by unqualified persons (also called laymen) as long as they are under the supervision/guidance of a professional worker.

Tasks of nurses are set in the national ordinances ‘list of professions in health care’ and additionally in the ‘Instructions for the implementation of preventive health protection at the primary level’. Nurse assistants only carry out those tasks mentioned in the ‘Instructions’ that have been delegated to them by registered nurses.

#### 2.4.3 Recertification schemes for nurses

To practice independently nurses and nursing assistants need to be licensed and recertify every 7 years (Nurses and Midwives Association of Slovenia 9 A.D.).

#### 2.4.4 Incentives for providers of home care

The lack of supply and the mainly public nature of providers of personal care and domestic aid create little incentives for good quality and efficiency through competition. Such incentives are also lacking for home nursing providers. Although they need to keep to the agreements on prices and possibly quality in the contract with the ZZZS, competitive pressure from other providers is absent as new organisations can only enter the system if the ZZZS raises the funded nursing capacity.

### 3. Financing

#### 3.1 General funding mechanism

In the first half of 2008 over eight million Euro (about 0.02% of the total GDP) was spent on social home help. About one quarter was reported to be paid by recipients themselves (Smolej et al., 2008). However, the clients’ real contribution to personal assistance and social servicing may be higher. No expenditure data is available on home nursing and home care other than social home help. Home nursing and social home care (social home help, social servicing, personal assistance, family care assistance) are financed separately. Home nursing (also preventive home visits) and technical aids are funded through a compulsory health insurance and through co-payments, in case of some technical aids. Basic costs of municipal health care centres are partially paid by municipalities.

Social home care is mostly financed through out-of-pocket payments and additionally through municipal budgets, the state budget and by charitable organisations (through donations and voluntary contributions). Municipalities are legally obliged to subsidise *social home help* for at least 50%. In 2008 they paid about 60% of the total costs (Smolej et al., 2008). *Family care assistants* are financed by municipalities and the client and/or a liable person, e.g. family member (means-tested). Municipalities may decide whether and to what extent they will contribute to *social servicing*.

#### 3.2 Mode of financing home care providing agencies

Providers of home nursing and social home care are differently financed. Health care centres are paid by ZZZS once a year based on the number or items of services to be provided. social home help services are financed by clients and municipalities, usually per hour. Agencies hiring people through the governmental active employment policy programme are paid for these employees. In the context of home care, many types of financial benefits for recipients exist, for instance: disability benefits, disability pensions, compensation of travel costs, and attendance allowances.

### 3.3 Price setting of home care services

Prices of home nursing services are set nationally and for social home help by municipalities. In 2008 the average total costs for social home help per hour were € 15.- (Smolej et al., 2008), but they differ significantly across the country. In 2008 the total costs ranged from €6.40 to €39.90 and the co-payments ranged from €2.60 to €12.10 (Smolej et al., 2008). The calculation of prices of social home help services are set in the 'Slovenian Rules on Methodology for Social Service Price Formation' (including direct and indirect costs).

## 4. Organisation & delivery of home care

### 4.1 Access and individual needs assessment

The initiative to seek care is usually taken by those who need it or their families, and otherwise by district nurses, GPs or the hospital social worker. For home nursing the GP or the district nurse needs to be contacted for an assessment. Although only a GP's prescription is enough for most technical aids, some technical aids require the insurance company's consent. When in need of personal care and/or domestic aid one applies to the providers of such services (in many cases the Social Work Centre); in some cases to a physician for a proof of severe handicap. Help of family assistants can be applied for to the municipal Social Work Centre. A special Disability Committee will then assess the need and advise the Social Work Centre.

### 4.2 Features of delivery

The provision of social home help is organised at the local level, and provided by a mix of public and private providers, mostly non-profit. In the first half of 2008 there were 77 social home help agencies, of which 88.5% was public (mostly Social Work Centres). In each municipality, there is only one provider of social home help within the public department network.

Private providers, also providing social services, are those with concessions and may be either profit or non-profit (Smolej et al., 2008). In larger municipalities social service providers offer a broader range of services, (e.g. home repairs, shopping, accompanying the client, care for home pets). Home helpers without concessions are private mainly for-profit providers of which many are individual domestic helpers paid informally. The number

of family assistants is very low (in 2007: 1.349; 59,9% persons cared for were 65 years of age or older – Ministry of LFSA 2009b) compared to actual family carers of old people in the country (ca. 25–30,000 – but there is no official data – Hvalič Touzery 2007: 25–26). Family assistants are paid informal carers to one person. They are family members or share a household and should not be registered in the unemployment register (as this is part of an employment policy).

Home nursing provision is organised regionally by public (e.g. the municipal (primary) health care centres) or non-profit private providers (self-employed community nurses with concessions, or charities such as the Red Cross and Caritas). Municipal health centres have health and nursing teams that also provide care at home.

### 4.3 Coordination and integration in home care

Formal coordination is well developed between health care services but practically absent between different types of home care services. GPs assess the needs and appoint a district nurse. Furthermore, in health centres nurses and nursing assistants work together in teams and general nurses and specialist and generalist physicians work in health teams. Coordination between hospitals and the centres takes place via hospital employed social workers referring patients to home help or home nursing services. In small municipalities some old people's homes provide social home help. Social home help providers are obligated to prepare the recipient for institutional care when this is needed.

### 4.4 Actors and human resources involved in home care

#### Actors

Home nursing and home help are separately organised in Slovenia and therefore different actors are involved in policy-making, financing and provision. Major actors regarding home nursing are:

- Ministry of Health is responsible for legislation;
- Health Council defines the professional basis for health policy, e.g. by defining relevant issues and priority tasks and proposing programmes (Hvalič Touzery 2007 p.17);
- Health Insurance Institute of Slovenia and its regional offices: collecting insurance premiums

**Table 1:** *Human resources in home care*

Functions	Total number of professionals in 2007
Home assistants (in 2008)	780
Family assistants	1,349
Nursing assistants	154
Nurses	647
Nurses with a university degree or specialised	14
Other health care professionals in community nursing	6

Sources: *Home helps:* (Smolej et al. 2008). *Family assistants:* (Ministry of LFSA 2009b). *Nurses and nursing assistants:* (IVZ 2007).

- and distributing funds; contracting home nursing providers and negotiating the scope of the home care programmes and the necessary funds;
- Health centres: providing health care at home. In each of the more than 55 health centres (and their sub-units) in Slovenia district nurses visit ill people at home;
- Private individual nurses (holding a concession); providing home nursing in accordance with Instructions for the Implementation of Preventive Health Protection at the primary level.

In home help the following actors are involved:

- Ministry of Labour, Family and Social Affairs: responsible for legislation and part of financing;
- Municipalities; setting prices, co-payment levels, exclusion criteria and types of services provided: financing of services; and giving concessions to home help providers;
- Public social welfare institutions (mainly Centres for Social Work): providing social home care;
- Private institutions without concessions; providing privately financed personal care and domestic aid.

For social care in general additionally, these organisations are involved:

- Council for Social Security and Specialist Council (SC); monitoring health developments and policies and advising on directions in the field of social security;
- Community of Centres for Social Work (CCSW); defines tasks of municipal centres for social work; sets prices for unified social care services; and is involved in development of standards (CCSW, 2009);

- Disability committee of the Pension & Disability Insurance Institute: assessments for family assistant;
- Social servicing providers; providing privately financed domestic aid and personal care;
- Family assistants providing paid personal care and domestic aid to one family member.

#### *Human resources*

Experts reported a shortage of home care professionals. In 2008 (see Table 1) there were 780 home assistants. About 60% of them were employed by social home help organisations (Smolej, Nagode, Jakob, Ziberna, Jerina, & Kenda 2008). The other 40% of them were paid by the Employment Service of Slovenia through one of the active employment policy programmes and are working on fixed contracts (Smolej, Nagode, Jakob, Ziberna, Jerina, & Kenda 2008). There are a large number of family assistants, which are paid informal carers; either family members or persons who share the same permanent residence. Each takes care of one person. Nursing assistants and nurses are the other two important professions in home care. Hardly any of them had a university degree in community nursing. They are a mix of employed (by health centres) and self-employed nurses. Working in home care is relatively unappealing. Home assistants as well as family assistants are badly paid (the former just over half the female average). Although the wage of a nurse in general is around the average for women (Brnot 2008), a community nurse earns less (around 20% less). There are no collective agreements on wages for home nurses or home helpers, neither are there any such agreements on the working conditions. Family assistants' rights and obligations are established by the decision on 'granting the right to a home care assistant' but descriptions of working conditions are absent.

**Table 2:** Care provided at home (estimations)

Categories	Social home help recipients (2008)	Family care assistant recipients (2007)	Community nursing visits (2007)
<b>Total (% of pop)</b>	<b>5,780 (0.3%)</b>	<b>1,245 (0.06%)</b>	<b>1,156,638</b>
% female	n.a.	62%	n.a.
% 65+	88.2%	59.9%	85.2% <sup>1)</sup>
% 80+	53.4%	–	53.5% <sup>2)</sup>

Sources: home help (Smolej et al., 2008); Family care assistant (Ministry of LFSA 2009b); Community nursing visits (IVZ 2007).

<sup>1)</sup> % 60+ of first curative visits, <sup>2)</sup> % 75+ of first curative visits.

#### 4.5 Use of tele-care

Home help centres in 12 municipalities offer distance support, mainly by use of lifeline phones, which connect home living disabled people to a central facility where relevant information about this person is available and a response on emergencies can be organised quickly. Costs are only partially covered and not in all municipalities (Smolej et al., 2008). Tele-care services are in principle available in four of the Slovenian regions. There is no exact figure on take-up; however, it is extremely low, as the use of sensors in the home is very rare. Trial activities have recently been initiated in the context of the IRIS Smart Home project. No specific policy has yet been developed for tele-care. However, an Act on Long-term Care and Insurance for Long-term Care that is still in preparation and reconciliation, promises to include tele-care (Nagode et al., Forthcoming)

#### 4.6 Monitoring the adequacy of care

Every three months, before the contract between the *home nursing* provider and the client is renewed, care needs are monitored. *Family assistants* must report only once a year, but changes in the client's situation need to be reported immediately to the social work centre. *Social home help* and *social servicing providers* must inform institutions about the state and needs of the beneficiary. However, no regulation does exist on when and how needs should be re-assessed.

### 5. Clients & informal carers

#### 5.1 Number of home care recipients

As shown in Table 2, 0.3% of the Slovenian population received social home care in 2008. For 2010 the government aims that at least 3% of people aged 65+ would receive *social* home care; in the first half of

2008 this proportion was still 1.5%. With regard to social home care, the most frequently provided types of care were domestic aid (46%) and personal care (45%) (Smolej et al., 2008). As the number of family assistants exceeds the number of recipients, it may be concluded that recipients may have more than one assistant. As the family assistant scheme was originally meant for younger disabled persons, elderly people still make a modest share of all recipients. The number of home nursing recipients is not available, but statistics show that 40% of all visits were for wound care and 20% were preventative home visits (IVZ 2007). The share of those over 60 and 75 years old is comparable to social home help.

#### 5.2 Coverage and unmet needs for care

Attempts to reduce the pressure on institutional care by increasing the number of people receiving home care may turn out to fail. Access to eligible home care is problematic (Smolej et al., 2008). Home help, social servicing, alarm systems, physiotherapy, volunteer services and sheltered housing are not available in all municipalities and not to the same extent. In rural areas, professional help is less available, but the need for these services is also lower as people still live in enlarged families.

Several services are in general insufficiently accessible. Firstly, personal assistance (providing help with ADL and IADL), for which demand is rapidly growing, is only financed on a project basis and only in certain areas. Legislation or regulation on personal assistance is absent. In 2010 the first draft on Personal Assistance Act for disabled was prepared, but it has not passed yet. Secondly, physiotherapy services are only available at home if privately paid. Thirdly, hospitals and primary health care centres do not provide comprehensive palliative care in the absence of sufficiently trained workers. Comprehensive palliative home care is provided only by an NGO, the Slovenian Hospice Association.

Finally, home adaptations are not publically financed. Therefore, in many cases staying at home continues to be problematic.

Another reason for unmet needs is that services have time restrictions, i.e. social home help is maximised at 20 hours and four days a week. In 2008 over 40% of the municipalities provided no care in the weekend and holidays (Smolej et al., 2008). Night care is unavailable. Workloads are high as a result of staff shortage. While home assistants should have no more than 5 clients, in 2008 they had 7.3 on average (Smolej et al., 2008). The problem aggravates because of the diminishing traditional role of the family and the neighbourhood in the care for old people (Ministry of LFSA 2006) and the trend of decreasing home visits made by GPs.

### 5.3 Empowerment of recipients of home care

Clients usually have very limited choice as in many municipalities there is only one social home help and one community nursing provider. Home nursing providers are assigned to clients based on clients' place of residence.

Clients are free to choose between residential and home care. However, long waiting lists for homes for the elderly obstruct the freedom of choice.

### 5.4 Informal carers

Informal carers assigned as family assistants can be compensated for lost income, build up a pension and get a health insurance. Compared to other countries, respite care is hardly available in Slovenia (Mestheneos & Triantafillou 2009). Support services partially funded by the government are counselling and advice for family carers and self help support groups (Hvalič Touzery 2007).

## 6. Disparities in the process of home care

Client pathways to home care depend on the type of care needed. The application process for home nursing differs from the one for social home care. Furthermore, patients leaving a hospital may be helped with application while in other cases they may not. Next to different pathways due to different client situations, there may also be differences across municipalities. Some services, as stated

above, are not available (to the same extent or price) in all municipalities. Especially in rural areas these services may not be available.

## 7. Concerns and new developments in home care in Slovenia

The following major problems can be identified on home care in Slovenia:

- Inability to cover the currently defined needs;
- Lack of public funding for essential services;
- Geographical inequality in prices for social home help and social servicing;
- Lack of structural coordination between types of home care, in particular between the social and health care sector. These are governed by different organisations and programmes;
- Insufficient quality of care as a result of lack of human resources and overburdened workers (Hvalič Touzery 2007). This lack of human resources is significant mainly in Ljubljana. In Slovenia in general the lack of human resources is not found as problematic fact. Social home care sector is actually facing with main imbalance between social care needs and lack of jobs for qualified social care workers. In another words, there are enough qualified workers but not enough regular jobs;
- Another mentioned concern is maintaining employment for actual social home care workers (nearly one third of them are losing the jobs each year). Next to that also increasing job creation for newly qualified social care workers has become an issue.

Important developments with regard to home care are:

- The further implementation of the personal assistant scheme. In some parts of the country this programme, which is run by disabled people themselves and funded by the national government, is available. As personal assistant services are related to an employment programme, applications must be addressed to the Employment Service. This service, however, has not yet been made a standard provision;
- The planned introduction of an integral system of long-term care, including home care. The preparation of a law on long-term care and long-term insurance started in 2005. The law on long-term

**Table 3:** Publicly funded home care services

Publicly funded home care services	Publicly funded	Restrictions (e.g. age, income)	Co-payments
<b>Home help services</b>			
Housekeeping activities	X	Income. Income is a restriction only if the person would like to have extra exemptions for payment of costs for home help. This service is part of home help.	X
Shopping (for daily needs)	X	Income ***	X
<b>Personal care services</b>			
Assistance with washing and going to the bathroom	X	Income ***	X
Assistance with dressing and grooming	X	Income ***	X
Assistance with eating	X	Income ***	X
<b>Home nursing services</b>			
Education and information about health related issues (such as diet)	X		
Paramedical care such as occupational/physiotherapy (learning to deal with consequences of illness)	X		
Assistance with putting on prostheses elastic, stockings and other aids etc.	X		
Assistance with movement and transfer from one place to another (incl. in/out of bed)	X		
Changing stomas and urinal bags and help with bladder catheter and the like	X		
Help with skin care, disinfecting, preventing bedsores	X		
Help with using medicines/treatments	X		
<b>Technical aids*</b>			
Adaptation of dwelling (like stair lifts, wheelchair ramps)			
Providing a walker frame/rollators	X		
Providing adjustable beds; wheelchairs, patient lifter	X		X
Wheelchair	yes		
Anti bed sore cushions	X		X
Providing simple aids (like canes and crutches)	X		
Special transport against reduced fares (like wheelchair taxi)			
Personal alarm/telephone alert	*	*	X
Door entry monitoring			
Personal monitoring external to home			
<b>Other support services</b>			
Meals-on-wheels (home-delivered meals)	**	**	X
Assisting with social activities	X	Income ***	X
Psycho-social (Counselling, conflict mediation)	X	Income ***	X
Help with household administration			
Psycho-social help of family	X	Income ***	X
Respite care			
<b>Preventive home visits</b>			

\* Just in some municipalities there is the Red-button service. \*\* Just if meals-on-wheels are part of home help service package. If the client receives only meals-on-wheels, then this kind of service is commercial (paid by client). \*\*\* The same comment that in the first line.

X means: Yes.

care and long-term insurance is still in a process of discussion. There is a great need for long-term care law, because people are not treated equally with regards to the access to services. The law is said to introduce personal co-payments and voluntary insurance for long-term care. With passing the Long Term Care Insurance Act the home care sector will be included in an integral system of long term care.

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# Spain

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## 1. The context of home care

### Country, population and health

When looking at the Spanish home care system, it is essential to note that Spain is one of the most decentralised countries in Europe. There are 17 autonomous regions, with differing but high levels of autonomy. These regions may be responsible for health care (and home care), education and taxation. Spain is a country of 45 million of inhabitants. The prevalence of longstanding illness or disease is around the European average, with 26,2% for females and 22,2% for males (Eurostat 2008). The dependency ratio in 2050 will reach 58,69, one of the highest in Europe.

Another important contextual factor is the major economic crisis leading to 18% unemployment in 2009 (Eurostat, 10-04-2010). Regarding demographics, the percentage of the population over 65 is currently below the EU average (in 2008 16.6% compared to 17%; Eurostat, 10-04-2010). Nevertheless, ageing is problematic as the old age dependency ratio is expected to be 58.7 in 2050 (compared to 50 in the EU). The life expectancy (as well as the healthy life expectancy) is about one year longer than that of the average European, for both males and females.

### Characteristics of health services and social services

The public health system is tax financed within the universal National Health Service scheme. Home care visits are included in Primary Health Care services.

Human resources in health care are around the European average, with 3.6 practising physicians and 7.3 practising nurses per 1000 inhabitants in 2006 (OECD/HD, 10-12-2008). The number of GPs and nurses working in primary care are 0.9 and 0.6 respectively. The relative number of hospital beds (330 per 100,000 inhabitants) was below the EU average in 2005. Over 75% of the beds were for acute care.

Health services and social services are separately organized and function independently; health services are organized by the Department of Health, while social services are organized by the Department of Welfare. There is no integrated model that coordinates the two services.

The national level government discusses policy issues related to health and welfare. But most competencies in social services (allocating budgets, governing health care facilities, implementing national policy) lie with the regions and local authorities.

Social services (personal and domestic care) are organised by the municipalities. The Dependency Law recognises moderately and highly dependent people and finance some services under a co-payment scheme.

### Social indicators and conditions related to old age

Over a quarter of the Spanish population over 65 is at risk of poverty. Compared to the EU average in 2007, Spain spent very little on old age (just 6.5% of GDP compared to 10% in the EU; Eurostat, 07-04-2010). Also the share of GDP spent on care for the elderly, 0.36% in 2005, is relatively low. Hence, informal care is common in Spain.

The low employment rates in women between the age of 15 and 65 (55%) are probably related to this. Since the introduction of Dependency Law of 2006, there is no legal obligation for children to pay for the care of their dependent elderly, as occurred in the past when children were responsible for taking care of and giving financial support to their parents if they did not have sufficient economic resources.

### Attitudes related to old age

The attitude towards informal care is comparable to the EU average. About 53% of Spanish Eurobarometer respondents (TNS NIPO, 2007) think that care is the responsibility of close relatives, even if their career might be affected. Regarding care options, 39% think it would be ideal for a dependent elderly person to live with one of their children. Home care is rather unpopular, as only 15% of Spanish respondents thought that formal home care was the favourable option, compared to 24% in the EU.

## 2. Policy and regulation on home care

### 2.1 Governance on home care

There is a separate area of competency between home health care and social home care. Different home health services are organised by Primary Health Care centres and hospitals (hospital at home initiatives) under Department of Health schemes (3, 6). Social home care (personal and domestic care) is related to the Welfare Department which, by means of independent subcontracted agencies, assesses and determines the level of dependency. Subsequently, the responsibility to organise and provide services is transferred to governments of the autonomous regions and municipalities.

Regarding home health services, there is no framework home care programme that regulates home healthcare care on a national level, and there are some home care eligibility criteria. Primary Health Services are responsible for organising home nursing care as one of the activities organised and delivered by Primary Care after professional assessment.

The main national regulation in Social Care is set through the Dependency Law and national policy. Municipalities

contract external private providers to provide social home care services to people protected by the publicly financed Dependency Law (17).

### 2.2 Eligibility for home care services

Home health care is a universal service. The health organisations (mainly public owned) have established inclusion/exclusion criteria and a list of services for home health care. The different possibilities for choosing services are, through objective and standard criteria, subject to evaluation performed by the different professionals applying existing programmes/guidelines.

The PIA (Individual Care Plan) is an instrument used by Social Services to provide personal and domestic care, through which an agreement is made with the dependent person and their family. For social home care there are also exhaustive evaluation criteria that amplify the services in the application of the Dependency Law. Eligibility is based on an assessment of needs of the client (level or severity of disability). The Dependency Law does not currently cover moderate and mildly disabled people but increasing coverage is expected, although low mild dependency will be excluded after at the end of the law's implementation. The co-payment is based on income. Although there is a common national objective needs assessment form, each local authority determines the final set of services after an agreement with the client/family. Hence, a great deal of variability exists in whether one receives domestic aid depending on the client's place of residence. There is a ceiling amount of hours of care per month corresponding to the degree of dependency. (4)

There is no common objective assessment instrument which results in a score to assess eligibility criteria to receive home health care as in the Dependency Law model.

### 2.3 Quality of process and output

#### *Quality criteria*

There are process and outcome quality indicators of home health care services linked to home-based care by different service providers. These indicators are established in the contract between the regional department of health and health providers.

There are no quality criteria for domestic aid providers, as in the majority of the cases it is not offered directly by the

public services, and some of the help provided at home is delivered by family caregivers. The term family caregivers constitutes that they receive some financial help through the the Dependence Law. Therefore, they constitute a kind of formal provision of home care.

#### *Regulation on quality assessment and complaint procedures*

The regulatory process in place to assess the quality of health services is in the form of contracts between autonomous health bodies and service providers, with assessment criteria. Assessments of quality for home health services are voluntary and non-specific to home healthcare. Some autonomous regions carry out annual satisfaction surveys using external companies, although these surveys are for all of the services and not specifically directed towards home health care services. Satisfaction data for the healthcare system are published by the autonomous region's health care boards and are available to clients. In some autonomous regions, satisfaction data are part of the results of the Assessment of Primary Care Team Programme-Contracts. The Catalonian Health Services, for instance, launches a satisfaction survey every two years for Primary Care services, but there are no specific surveys for home care services. Satisfaction data for the healthcare system are published by the autonomous region healthcare boards and are available to clients. In some autonomous regions, satisfaction data is included as part of the results of the Assessment of Primary Care Team Programme-Contracts. A client complaint procedure is available for clients in the health centre, and it is compulsory to give an appropriate answer to the client/family in a timely manner (2, 13, 15).

Primary Health Care services are monitored and evaluated but a certification for home help care is not required. For home nursing, a primary care computerized medical history system is used. Feedback on some health outcomes is returned to health professionals; however, this feedback represents a wide range of health indicators, not only home health care indicators.

For personal care, there is regulation in place to assess the quality of services using objective eligibility criteria for assessment. For services funded through the Dependency Law, the government establishes inspection controls every six months to one year at minimum. With regard to social services, in general, there are no assessments or satisfaction surveys carried out (10).

A complaint procedure office is available to receive client complaints in Social Services. The organisation providing the services is obligated to give an appropriate answer in timely manner to these complaints. An objective assessment may be reviewed if a client's situation has changed through time.

With regard to social services, in general no assessments or satisfaction surveys are carried out. But In Dependency Law, it is possible to perform inspections to review good practice and adequacy of public funding related to care services.

#### *Accreditation*

For the purpose of accreditation, provider agencies are regulated by the different autonomous regions. The process to accredit health services is not the same throughout the country, as there are differences among autonomous communities. In the case of social services, it is expected, but not compulsory, that an agency is accredited.

## 2.4 Quality of input

### *Education*

The following professions provide home care:

- Primary care nurse. There are different types of nurses that have the same university education. Nurses do not need a specialization for home care, although training is taken into account in work bank merits when appointing someone to the post. There are no Primary Care Nurses that are specialists in home care working in the home health care sector. Primary Care Nurses perform home health care in addition to other Primary Health care tasks (chronic care, preventive care, etc.). They are not responsible for providing help in Activities of Daily Living (ADL). Nurses improve their knowledge and skills through continuous professional development in the form of courses, conferences and clinical sessions and attendance at courses, seminars and conferences. It is a common practice for providers pay for continuous training for their employees; however, it is not a legal obligation. Nurses who are advancing in their professional career obtain extra payment. Currently nurses do not need recertification and it is not required to work in Primary Health Care;

- In some regions, the role of a nurse case manager has been introduced, with specific advanced competencies and practice in home care (11);
- Public personal care staff (family carers and/or staff from home help agencies): They provide help with ADL and with putting on prostheses, elastic stockings and other aids, assistance with movement and transfer from one place to another, help with taking medications and shopping. They are expected to follow a basic minimum training course for home helpers or health aides, but this is not always achieved. The *Servicio de Atención a domicilio* (SAD: Home Help Service for personal care and domestic care) is also regulated and minimum educational requirements are needed although in practice there are differences among regions and within regions;
- Private sector domestic aid workers (contracted by clients) and personal care staff: No training is required. Domestic service workers are not usually included among the resources assigned, and some domestic tasks must be performed by the family caregiver. There is no type of continued training for domestic care workers. In some cases, clients prefer to receive money instead of services and he/she independently contracts a caregiver.

Universities, professional colleges and autonomous communities establish some competency frameworks. There is a professional pathway within health organisations which assesses and recognizes training in general (not specifically in home care). Currently there is no certification and recertification required for nurses because home health nursing is a service within Primary Care services that is monitored and evaluated.

#### Tasks

Competencies have been laid down by universities, professional colleges and the health organisations.

### 2.5 Incentives for providers of home care

Public Health Service provision: These are public, non-profit statutory institutions that are contracted by the national healthcare system. Although competition between care providers is allowed, in practice there is no competition as each provider covers a specific territory; each Primary care centre is responsible for its catchment's area. There is competition, however, in private healthcare and social services.

Privately funded services (companies but mainly individuals) operate according to free market principles. Public services or publicly funded private organizations are contracted by the Department of Health and operate within a delimited area. Public services are put out to tender.

In Social Care, there are also those belonging to the public network, centralized at the local level and private for profit providers and non-profit providers (NGOs). The last two are an increasing tendency in the social care sector.

## 3. Financing

### 3.1 General funding mechanism

All expenditure estimates include medical and nursing care at home, as well as other health professionals at home. Expenditures on personal and domestic aid are excluded.

Expenditures on home health care comprise of 2.8% of total expenditures on health care (2006, OECD/HD, 10-12-2008), two-thirds of which is on long-term care. The funding of healthcare services is charged to the Department of Health budget and paid for from general taxes (3).

Personal and domestic aid are financed jointly by local, autonomous and state governments by both taxes and client co-payments. Social assistance is financed by local, autonomous and state governments from general taxes, as well as by client co-payments. Since the Dependency Law was approved, social services (help with ADL and meals on wheels) for severely disabled people are funded under this law, although it does not cover reimbursements to adapt homes or to help with cleaning homes. Financial support and allowances to adapt homes are funded in some autonomous regions through the Family Support Plan (PAF). NGO activities are financed by public and private funds. Most technical aids are completely funded.

### 3.2 Mode of financing home care providing agencies

Home health care services (except home-based rehabilitation, which is financed by Department of Health specific budget) are paid from the fixed primary healthcare and hospital care budget. There is thus no

specific budget for home care. In the healthcare field, primary healthcare and hospital care are covered by the public budget.

Some domestic aid and personal care services are funded by either the Dependency Law or by local governments (especially for mild dependency excluded by Law).

Dependency Law needs a previous assessment and recognition but not cover mildly dependant individuals. Local governments can establish co-payments for mildly dependant individuals with higher incomes. Municipality contract private or non-profit companies to deliver care, paid on a fee-for-service basis related to the amount of hours provided and agreed with patient/family.

Under the Dependency Law, an objective needs assessment of needs of clients (level or severity of disability) and income (co-payment) is performed by agencies/teams contracted by the government.

### 3.3 Price setting of home care services

There is no system regulating prices for public home health care services, and it is difficult to establish the average cost. After the needs assessment, the Primary care team establishes the amount of time to be dedicated to home healthcare, and costs are included in the overall budget at the primary care centre. This is a problem because it is a cost for public providers that is not recognized by any financial scheme

In the case of social services, rates are regulated in the private sector by municipalities, and the companies agree upon rates with their clients. Regarding the personal contract with the client, the rates are agreed between the parties; in these cases, it is normal for the rate to be below the minimum established in agreements and other labour provisions. Under the Dependency Law, an objective needs assessment is performed. Three possible degrees are established: very severe dependency, severe dependency and moderate dependency. Low dependency cases are excluded and not covered, although some patients apply for some service to the local Social Services. If the client is recognised as “dependant”, some amount of money is devoted to care or reimbursed to the informal carer.

This amount of money is based on the income level of the client, and a level of co-payment is established according to this principle. Payment is reimbursed by both central

and regional authorities. Providers agree upon a price per hour or package of care; however, this can vary among municipalities (17).

Healthcare services are universal and free at the point of service. Social care is universal but with co-payment based on the individual’s income.

## 4. Organisation & delivery of home care

### 4.1 Access and needs assessment

The application for care is submitted to the care provider. Primary Care teams (general practitioners, nurses and social workers) perform the individual needs assessment with regard to the home healthcare programmes. No referral by the GP is required. Patients can be assessed directly by community nurses. Evaluation is based on nursing models and the nursing diagnostic classification system (NANDA-NIC-NOC). Validated instruments/tools are used to assess functional status (i.e.: Barthel scale) and Instrumental Activities of Daily Living, anxiety and depression assessment, cognitive deterioration and pressure sore risk (1, 14). The Primary Care teams also assess social care needs; however, regarding the Dependency Law, the level of dependency is assessed by agencies contracted by the Welfare Department in each autonomous community (17).

### 4.2 Features of delivery

Primary Health Care centres are the home health care providers that provide home nursing care. They are public (statutory agencies) and, non-profit network institutions and are contracted by the National Health System. Each Primary Care centre is responsible for its catchment-area, and there is no competition (6).

ADL help and domestic aid are covered within the social sector. The public services are put out to tender, and there is also a free market made up of companies and individuals. In some cases these are contracted by the municipality to deliver services; it is possible that different organizations compete for the service in a territory or municipality. In some municipalities, services related to home care are called SAD (Home Help Services for personal care and domestic care), although in some cases separate companies can be contracted for personal and domestic care, on an outsourcing basis.

### 4.3 Coordination and integration in home care

Primary Care teams are the main provider in the home health sector. Doctors, nurses and social workers all work together in the same healthcare centre. It is possible to organise coordination meetings between health providers (case managers, primary care professionals, palliative home care services).

There is a growing trend to provide hospital services at home (Hospital at Home schemes) and for hospitals to see the home as an alternative to hospitalisation. Admission and discharge evaluation units may be placed in acute hospitals. Shared electronic records may be viewed by both hospital and primary care staff. Hospital discharge liaison nurses and case management is used by an increasing number of hospitals. In some cases, new liaison nurses have been posted to assure a better discharge planning between hospital and primary health care (5, 8).

Most nursing homes are separated from home services, although they provide support and there are some companies that offer a range of services such as temporary stays and day care facilities.

After an agreement between client/family and municipality is recognized and funding is determined by the Dependency Law, services by these organisations can be provided up to a ceiling amount of hours per month related to degree of dependency. An increasing level of coordination would be desirable to deliver a more integrated care approach. Social home care agencies should not act isolated and should coordinate services with Primary Care teams to deliver a more comprehensive package of care.

### 4.4 Actors involved in home care

#### *Actors*

The main actors in home care are:

- The Ministry of Health and Social Affairs: Sets main legislation for both home nursing as well as personal care, but not for domestic aid. Competencies in health have been decentralised to the regional Department of Health which is responsible for planning health services and home healthcare (3);
- Autonomous regions: Responsible for regulating personal care, implementing health policy and governing the Primary care centres. They should assess and recognize the dependency level of applicant. The autonomous Department of Welfare or Social affairs are responsible for planning and financing social services, including personal and some domestic aid;
- Local governments: Responsible for planning and providing personal care and domestic aid;
- Primary health care centres (GPs and community nurses): Provide technical nursing;
- SAD (“Servicio Ayuda a domicilio”) municipal agencies: Provide personal care as well as domestic aid;
- Dependency Agencies: Responsible for assuring objective needs assessment and “dependency recognition” (17);
- Community Nurses: All workers are waged, although employed under different kinds of contracts. Nurses are paid by salary, and their extra payments depend on professional career level. Healthcare employees: We have described above why Community Nurses are the main professionals that work in Primary Care and home health care. They are contracted by healthcare service providers. Conditions are not known for nurses in private services, as there is a great variety. There are no specific home care nurses; community nurses are responsible for a wide range of Primary Care services (chronic care, preventive care, acute care, group education, community care and also home care);
- Social workers: Contracted mainly by public service providers (local governments) and private service providers (home care service companies) too. Social workers contracted by municipal social services are responsible for operationalising the Intervention Plan for individuals with the right to receive services. There are also social workers in primary health care centres, but the competency in home health is attributed to municipal social workers;
- Home help: This is governed by a Special Domestic Employment Regime legislation that dates from 1969, although in most cases they operate in the underground economy ruled by the law of supply and demand and have no employment or wage guarantees. As an individual can receive money instead of services, occasionally this money is used to contract carers without formal qualification;

**Table 1:** *Human resources in home care*

Human resources in home care in (2008)	Number of home care workers
Number of home helps (12)	358.078
Number of personal carers at home	Not available
Number of home nurses (20)	26.709 primary care nurses

- Domestic help: Although a contract between employer and employee is not mandatory, the employee must be registered under the Special Domestic Employment Regime legislation. Conditions and wages for employees who provide services through publicly subsidised private bodies or through a public body (core social services) are explicitly documented;
- Family carers.

As shown in Table 1, there are more home helps than nurses. Furthermore, Community Nurses are responsible for a wide range of Primary Care services (chronic care, preventive care, acute care, group education, community care and also home care); it is estimated that around 20% of the time is dedicated to home nursing care.

#### 4.5 Use of tele-care

There is a trend towards coverage of all the population that needs the service. Current tele-care coverage in Spain is 4,72% for people over 65 years, with large differences between autonomous regions (11,9%–1,2%) (12).

There is growth of home-based tele-health care to monitor chronic patients, to check blood pressure, oxygen saturation or other parameters at distance (9,12).

#### 4.6 Monitoring the adequacy of care

A continuous re-assessment of the allocated resources and possible changes that could occur in the needs of home help takes place. The different programs of homecare also make periodic visits together with the health services to re-assess the situation. In social dependency there's an objective assessment based on an objective instrument common for all the autonomous communities.

In health services every provider does it differently. In Catalonia, for example, the evaluation and re-assessment through nursing care plan is very important. It is an

individualized method of intervention that includes technical aspects related to the patient's clinical condition and information, ethical aspects as commitment and respect for patient's preferences and instrumental aspects such as providing the appropriate documentation to incorporate the participation of the patient in making decisions about clinical attitudes and to re-assess the attention model.

## 5. Clients & informal carers

### 5.1 Home care recipients

Around 4.7% of individuals over 65 years of age receive long term care at home, and about 62% of those who receive long-term care in institutions have 80 or more years. A 2004 study showed that receivers of home help services were frail, highly dependent and suffered from numerous geriatric problems (21).

### 5.2 Coverage and unmet needs

Generally, fewer hours are provided than have been assigned, and many people are on a waiting list for home care. All this is due to capacity problems. Furthermore, services are only provided for 4 hours a day maximum. Home adaptations and home care equipment may not always be funded. Extra subsidies for this are means-tested. A 2003 study on unmet needs showed that unmet home care needs among community dwelling elderly were associated with low income, lower education, living alone and symptoms of depression (22).

In general, the share of publicly funded services are lower than other countries (ie. Germany and Austria) which have introduced Dependency Law scheme. It is difficult to have a good estimation of unmet needs in home health care. Unmet needs are expected to increase due to the economic crisis in Spain and also because of lack of funding.

**Table 2:** Long-term care (LTC) recipients in Spain

Recipients	LTC at home in 2008	LTC in institutions	
		Social home care 2008	Home health care 2007 (*)
Global coverage	358,078	–	–
(7,8%)	1%	n.a.	–
Coverage in 18–64	n.a.	0–64: 0,84%	n.a.
Coverage in 65+	4,7%	4,7%	4,44%
Coverage in 80+	n.a.	8,5% (in >75)	n.a.
Females	67%	–	–
% of 80+ over total attendees	51%	–	62%

Source: expert (with exception of Total coverage home help: Gutiérrez et al., 2010).

(\*) Data from one region, Catalonia (12, 9, 16).

n.a.: not available.

In the case of personal care and domestic aid, the new Dependency Law will be deployed until the year 2015. Currently, only very severe dependency and severe dependency are covered by this law. It is expected that new clients will be included in the future (mild and less severe dependency). There are some financing problems to fund this scheme because of the current economical situation. This raises a sustainability problem.

Better coordination between Health and Social Care could improve the complete package of care. Aside from guaranteeing a minimum of services, coordination between social and health services is important; currently, there is no model that guarantees this coordination.

### 5.3 Empowerment recipients of home care

In primary health care, in most areas, clients have a free choice of centres and professionals. A client may change his or her assigned Community Nurse or General Practitioner if he or she is not satisfied with the services provision, after a complaint or under free decision (18, 19).

For social services, there is no free choice of provider or type of care (both in institutional or at home care), although these are planned jointly with the patient and the carer. The family can decide to receive the money instead of services because a family carer is available to give care at home. The family can also receive some part in money and the other part in services under agreement with the municipality. The Dependency Law assigns a maximum amount of money (financed by national government, regional government and co-payment scheme); however, the client does not have full autonomy in choosing the service or provider. The Dependency Law

indicates dependency recognition, but services are agreed upon between the municipality and the client together (17).

### 5.4 Informal carers

There is an extended tradition in which the family copes with the patient's caring at a very high rate. The situation is changing but informal care is an extended model.

The family has an important role and is very involved and committed in the care of the patient compared with other European countries.

The primary care services portfolio (which includes home care services) recognizes the informal carer. In some autonomous regions, informal carers are a target population in the services portfolio; this implies having certain specific services, such as options for breaks or day care services (6).

With regard to social services, in general there is no formal recognition of informal carers, although among the provisions of the Dependency Law is it possible, in certain cases, to obtain a carer's allowance.

## 6. Disparities in the process of home care

As already mentioned, there are large disparities between regions, especially regarding the types of services assigned. There are also differences between what should happen in theory, according to regulations, and what actually happens. Due to resource shortages, there are waiting lists in personal care and domestic aid, as well as in home-based rehabilitation. Regional financial contributions

have not been the same everywhere, resulting in different service packages and personal payments when confronted with similar dependency levels. Recognition is valid for the whole country; however, services are organised at the local level.

There are significant discrepancies between practice and theory in Spain. Clients generally receive different care than what they are entitled to due to differences in how the Dependency Law is applied in each autonomous community. Clients with comparable needs may receive different care:

- The allocation of services (personal and domestic care, respite care, technical aids) depends on the municipality. Little information is available about discrepancies;
- The level of co-payment for services can vary across municipalities;
- Possible qualitative and/or quantitative reductions of care due to new financial situation under public budget constraints;
- Personal budgets are reported to be insufficient in many cases because less money was received than expected when the Dependency Law was designed;
- In the case of home health care, differences in coverage exist across professionals, as services are based on each professional's previous evaluation and not all professionals evaluate and provide services in the same way. In many cases, more attention is paid to other Primary care services rather than to home care.

However, since the implementation of the Dependency Law, major changes have been produced and there is a significant evolution from the previous situation, with more hours of care dedicated to personal and domestic care.

## 7. Concerns and new developments in home care in Spain

The following problem areas have been reported in home care in Spain:

- Inadequate funding in some autonomous regions, with great differences between them;
- There is a need for acceptable ratios in human resources. More home care resources should be

deployed, and Primary Care teams should prioritize home health care services compared with other primary care services;

- There is poor coverage in social care for persons to whom the dependency law does not yet apply;
- The administrative procedure to obtain formal recognition under the Dependency Law is slow and bureaucratic and varies according to the autonomous region. A number of reports have been issued by the ombudsperson on the subject of elderly people and the application of the Dependency Law;
- Apart from increasing the number of hours of care, a more integrated care approach based on cooperation between health and social services should be adopted, since much of the dependant population suffers from chronic diseases as well.

Trends in home care in Spain are:

- Further introduction of case management for complex chronic patients (7);
- Liaison nurses to guarantee continuity after hospital and residential discharge;
- ESAD (home care support teams for end-of-life patients and complex chronic patients) for palliative care. These teams are composed of a doctor, nurses and a social worker in most cases;
- Service integration. There an increasing call to integrated care and improved coordination between primary and hospital care, as well as between social and health care;
- Universal access to tele-care (slow development) to monitor chronic patients (COPD, Heart failure) at home;
- Development of out-of-home tracking systems (GPS tracking devices).

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# Sweden

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## 1. The context of home care

### Country population and health

Sweden has a population of 9.1 million people, with 22 inhabitants per square kilometre. Most people live in the middle and southern parts of the country. In 2004, the average income was € 1,510 per month for women and € 2,100 per month for men (SCB, 2006). Sweden has one of the oldest populations in Europe (OECD, 2006). Currently 18.4% of the population is older than 65 and 5.3% is older than 80 years. In 2050, about one fourth of the population will be 65 year or above (Statistiska centralbyrån 2006).

At the age of 65 the remaining life expectancy is 17.7 years for males and 20.9 years for females. Healthy life expectancy for males is 12.9 years and for females 13.9 years. About half of the people over 65 years have a long standing illness or health problems, among males 44.3% and among females 50.6% (Eurostat, 2008).

### *Characteristics of health care and social services*

The total cost of elderly care in Sweden in 2005 was SEK 80.3 billion (€ 8.4 billion) (Sweden Institute, 2007). The total expenditure on health care is 9.2% of the Swedish GDP and health care for older people accounts for 1.6% of the GDP. In 2006, there are about 3 to 4 physicians and around 10 to 11 nurses serving 1,000 people, the former is about average and the latter is double the European average. The average length of stay in hospital is 4.6 days, which is the second lowest in Europe. There are about 27 beds in special housing (i.e. nursing homes, sheltered accommodation, group housing and residential homes) per 100,000 inhabitants, the lowest for all 18

European countries for which this data is available. Health care and services in nursing homes are accounted for the bulk of elderly care costs in 2005. The cost per care recipient is more than twice as high in special housing as in regular housing (Swedish Institute, 2007).

### Social indicators and conditions related to old age

The pension system is based on life-time earning on the one hand and residence on the other (Forsakringskassan, 2009). To redistribute the wealth several compensations are in place (e.g. for lost income due to having small children, studying or receiving certain disability benefits). The good old-age protection leads to only 11% of the people above 65 years being classified as poor (Eurostat, 2008). About 72% of women between 15- 64 years old are employed, which is a high number compared to the rest of Europe. In this regard informal care sources are low.

### Attitudes related to old age

Since 1956 there is no legal obligation for children to take care of or pay for their parents. The proportion Swedes positively answering on the questions whether care is a responsibility for close relatives even if their career might be affected, is only about one fifth of that in the whole of Europe (TNS Opinion & Social 2007). Attitudes towards older people may vary among nursing staff (Häggström, et al. 2005; Fagerberg & Kihlgren, 2001; Tornstam, 2005).

## 2. Policy and regulation on home care

### 2.1 Governance on home care

Since 1992 care for older and disabled people (except medical treatment) is the responsibility of municipalities ("The Ädel reform"). The same holds for simple assistive devices in a particular living arrangement. The Health

and Medical services Act (1982) includes fundamental regulation of health care. The goal of this outline law is a good health and health care for everyone, with equal access to health care, irrespective of age (Health and Medical services Act, 1982). The home care recipient who has the greatest need for health care is prioritised. The County Council has responsibility for health care and care prevention at home. In agreement with the regional County Council, the municipalities could be responsible for the health care at home. This is the case in about half of the Swedish municipalities (Alzheimer Europe, 2009).

The Social Services Act (2001) is also an outline law in the Swedish elderly care and established to obligate municipalities to set up activities to service, take care of people with special needs, domestic and personal care and ensure that special housing are built, renovated and available. However, the main intention is to offer people with functional impairments to continue living at home. Municipalities should ensure that those with impairment be able to participate in society, influence their own lives and feel secure and independent as they grow older. People with impairment should have access to quality care and be informed about their treatment.

People with functional impairment who are younger than 65 years of age are also covered under the Act 'Support and service for certain disabled persons', LSS (1993).

## 2.2 Eligibility for home care services

Publicly financed home help (social home care) service is a universal right; no means-testing takes place and it is independent of available informal care. Publicly financed home help service cover domestic and personal care and practical assistance (household duties such as cleaning and doing the laundry, shopping, bank office errands, and help with cooking or the delivery of ready-cooked meals) and personal care (help with eating, drinking, hygiene, dressing and to be a guarding company during walks). Additionally, the social home service cover methods to prevent isolation or help to feel safe and secure at home. People who are functionally impaired and in need of home help service are able to get help 24 hours per day. There is a standard formula of options, but the municipality has to consider the person's functional status and the situation in which the person lives. The eligibility of social home service can differ slightly from municipality to municipality.

## 2.3 Quality of process and output

### *Availability of quality criteria*

The Health and Medical services Act (1982) and the Social Services Act (2001) both refer to the obligation to provide home health care and help service of good quality. A way to measure quality has been developed by the Swedish Association of Local and District Health and Welfare. It has developed a national system for public comparisons of quality (and cost and efficiency) in health care and services for disabled people. Municipalities are responsible for the registration. The system includes, for instance, questions about participation, food, continuity, accessibility, physician's assistance and frequency of staff. Results of these evaluations are used by policy makers.

### *Assessment of quality of services and clients complaint procedures*

The municipalities are obliged to continuously monitor and ensure qualitative outcomes. The home care recipients' opinions are seen as an important part to increasing the quality. For instance, one common way of evaluating the quality of the services is to keep records of the home care recipients' satisfaction and experience with the service. Further, the supervision of home care quality is monitored by the National Board of Health and Welfare (NBHW), a governmental agency. One way in which it also ensures quality is to oblige home care staff to report blunders or neglects and to discuss them with their colleagues. The introduction of the person's freedom of choice in home health care and home help service is expected to increase the quality in the long term. Furthermore, if home care recipients are not satisfied they have the opportunity to complain to the County Administrative Court.

### *Accreditation*

No obligatory accreditation applies to individual providers of any type of home care. However, compulsory registration does exist for agencies providing home health care or/and home help service.

## 2.4 Quality of input

### *Education*

The aim with regard to Swedish home care is that all staff should be trained. Educational programmes are

legislated by the Ministry of Education. The following professionals with their educational backgrounds are involved in the provision of home care:

- An assistant nurse, a three year upper secondary school education;
- Home help assistant, a three year upper secondary school education;
- A registered nurse (RN), a three-year education on university/advanced level;
- A primary nurse, a four year education on university/advanced level, including a certificate to prescribe drugs from a limited list;
- Home help officer, a three year education at university level including education in management and service assessment;
- Personal assistant, at least a short course focused on the role of being a personal assistant but often the person has a three year upper secondary school education.

#### *Recertification*

None of these professions needs to be recertified, but the employer often offers short courses with the intention of improving home care quality.

#### *Job description*

Each profession is in charge of different tasks in home care, laid down by national legislation. The nurses are responsible for the home health care (i.e. home nursing), including assessment, planning and evaluating the outcome of activities such as bandaging, different tests such as blood tests and urine tests, giving medication by injection, terminal care, etc. The home help officer is responsible for the assessment of home help service and has to make sure that indicated home help service is being provided. Finally, the home help assistants and the personal assistants do both provide home help services i.e. domestic aid and personal care (bathing, dressing, etc.), and activities such as socializing or going for a walk.

### 2.5 Incentives for providers

The home care is mainly driven by regulated competition among providers of services. The home care recipients are able to choose if they want to get help from the local authority or private providers; the latter is now becoming more common. The municipal and the private providers

in the area are competing. Besides the public municipal home health care and home help service providers, the home care recipient can, even if it is relatively unusually, also get help from the church, the Red Cross or other voluntary organizations. These are not involved as regular home nursing providers.

## 3. Financing

### 3.1 General funding mechanism

In 2007, Sweden spent about 0.4% of GDP on home health care (Wolff, 2009), which is comparable to the European average. Where adults, under 65 years of age, having a severe functional impairment according to LSS, the municipality has the responsibility for the first 20 hours of home help assistance. If the person needs assistance and home help for more than 20 hours per week, the Social Insurance will take care of the costs for the extra hours. (Forsakringskassan, 2009). Non means-tested co-payments are usually required, but some municipalities offer their services for free.

### 3.2 Financing of home care agencies

Mostly health care and social home care (the ‘home help’) service are financed by municipal taxes and government grants. The financial resources for home care are usually gathered through municipal tax. In half the municipalities home health care is funded through County Council tax. Regarding social home care service, the people themselves also have to pay a part of the cost depending on their individual financing situation, although only 4% of the financing came from patients’ charges (Sweden Institute, 2007). Prices for home care are not fixed but a maximum is set by each municipality. For instance, in a municipality in the southeast of Sweden there is a uniform fee system depending on amount of hours’ social home care service delivery (<http://www.karlskrona.se>). About 90 percent of all social home care services for older people were provided by the municipalities in 2005. Some have contracted out their social home care services. In certain areas, older people are allowed to choose whether they want their social home care services or special housing to be managed by public or private operators (Swedish Institute, 2007). In those cases the local authority determines the price, which is the same for all providers, so the competition

between them is one of quality. If the person wants to use private home help service besides the regulated social home care service they have to pay for it themselves.

### 3.3 Price setting

Since 1992 there has been a national maximum price for social home care services (Alzheimer Europe, 2009). The fee of home care is decided by the municipality and based on the recipient's financial situation. In situations when the person is not able to pay, the fee for home care (for instance, domestic aid and personal care) can be reduced or cancelled. In counties in which the county council has the responsibility for the health care at home the health care is usually free of charge. For meals on wheels, personal alarms and technical devices, each service has a unique and fixed price for all services and the person's financial situation is not considered.

## 4. Organisation and delivery of home care

### 4.1 Access and needs assessment

To access home care one can apply to one of the Home help officers in the municipality. In case of a young adult, under 65 years of age, the application is submitted to the municipal home care officers in LSS. It is this officer who makes the needs assessment and the decision of home care service in consultation with the home care recipient and/or her/his relatives. The needs assessment is based on information from, for instance, the home care recipient, the relatives, the nurse and the GPs. The assessment and the plans are performed together with a primary nurse and/or a GP as well as other health care professionals if needed. In some cases the medical treatments in the health care plan need to be prescribed by a GP. Staff in the home care team delivers home care based on the decision in the needs assessment and the health care and service plans. The home care officer has the responsibility for the delivery of the health care and social home care service and for following up of the decisions of home care services.

### 4.2 Delivery of services

Home care service is mainly provided by salaried staff working for the municipality or private agencies. Home care from a municipality is provided by a home care team in which the medical interventions are made by

the primary health care (i.e. the district nurse and GP) and the home help service are performed by the home help assistant or the home assistant nurse. Medical interventions such as advance home health care, including palliative care are usually provided by staff working for the County Council.

In 2003, about 9% home help service was provided by private providers. They often offer more kinds of services (e.g. extensive cleaning, window-cleaning). Voluntary agencies have been increasing in number over the past year, but are still in the minority. Sometimes they are affiliated to religious organisations or the Red Cross, which usually provides social activities for people with disability.

### 4.3 Coordination and integration of services

If there are many providers involved in the person's home health care, the coordination is managed from a home help officer or a primary nurse. Independent of housing, the health care and home help service providers are integrated in the same organization. Also the need of special housing is need assessed and provided by the home help assistant in the municipalities.

In case of advanced health care at home for a disabled person there is coordination between the ward at the hospital and the health care at home. In some Swedish hospitals there is coordination of care called "hospital associated home health care" and this advanced home health care includes several health professionals working at the hospital nearby.

### 4.4 Actors and human resources in home care

#### *Actors*

The main actors in home care and their responsibilities are:

- The Ministry of Health and Social Affairs composes rules and regulations recommendations and the parliament makes the laws;
- The National Board of Health and Welfare works out statute and principles from the rules;
- The County Administration and the National Board of Health and Welfare are responsible for supervision

**Table 1:** *Human resources in home care*

Functions	Estimated total number 2007
Home help assistants with 3 years of education	90,000
Home help assistant with shorter courses 1	70,000
Home help officer 2	n.a.
Registered nurse	14,000
Primary nurse in the whole health and service sector 3	9,000
Personal assistant	20,000

*According to the National board of Health and welfare there are about 140,000 formal carers who have insufficient or are without education in the care of the dementia persons and some of them might be included in this group.*

*Data not available for Swedish context since in Sweden there are different names on this profession, like home help officer, manager, or need assessment manager.*

*Data not available about numbers of primary nurses working in the home care.*

of home care services. The County Council is responsible for home health care and the National Board for health care (Johansson, 2004);

- The municipalities are always responsible for financing and organising home care services, technical aids and housing and some of them also for health care services. They also employ professionals providing these home help services;
- The County Council is mainly responsible for financing and organising home health care. They employ professionals providing this health care;
- Private home care agencies. They mainly provide social home care service at a basic level, window-cleaning, cleaning and bank services. The number of private providers is growing and will probably be of great importance in the future;
- Voluntary providers provide social activities, go for a walk, etc. This social service is based on the person's wishes and is performed in relatively little extent.

The registered nurse, the primary nurse and the assistant nurse can be employed by the county council or the municipality. The home care officer, the home help assistant and the personal assistant are employed by the municipality. Working conditions and payment of home care workers are regulated by the local and central governments. A Swedish nurse and a home care officer has an average income of about €2,600 per month and a home help assistant about €1,800 (SCB, 2006).

#### 4.5 Use of tele-care

Personal alarms are commonly used. Other tele-care innovations are still being set up. One example of this is a project about TV-monitoring to increase health care in

a city in South East of Sweden. In this project the home care recipient are able to choose a “host channel” on their own TV. The purpose is that the home care recipient can be able to see the district nurse and her-/himself in the small image and talk over the channel about actual health care problems of the home care recipient (Larsson & Lundberg, 2009).

#### 4.6 Monitoring of care

According to the Patient Data Act (2008), staff have the obligation to document the tasks of health care and social home care services which have been performed. The home care officer has the responsibility of making follow-ups of home care services. The monitoring of adequacy of home care is to be done systematically by the home care professionals involved (in collaboration) once a year or when necessary. However, a uniform record system to monitor the whole care process is not available.

### 5. Clients and informal carers

#### 5.1 Home care recipients

In Sweden, the number of home care recipients has declined by about 40% between 1980 and 2005 (Swedish Institute, 2007). One of the reasons why the number of home care recipients has fallen is that more and more people in old age are in good health. In 2006 about 4.6% of the population receives home care services and most of them were women (Socialstyrelsen, 2007). Among those who were 65 years or above the amount who got social home care services alone was about 140,300 (Socialstyrelsen, 2007) and those who got health care alone at home was about 14,000 (Socialstyrelsen, 2008), whereas it was about 34,500 persons who got both social

**Table 2:** Estimation care provided at home and in institutions

Recipient groups	Recipients of social home care in 2006	Recipients of home nursing 2006
<b>Total</b> (% of pop)	<b>421,351 (4.6%)</b>	<b>178,282 (1.9%)</b>
% Female	+/- 70%	n.a.

Source: Socialstyrelsen, 2008.

home care service and health care in this age group in the year of 2006 (Socialstyrelsen, 2008). The amount of older people with social home care services is especially increasing among the oldest old, i.e. 80 years and above (Socialstyrelsen, 2007).

### 5.2 Coverage and unmet needs

The Swedish law about social security states that nobody should have any unmet needs and that there should be no differences in the ability to receive home care regarding to where the home care recipients lives (urban vs. rural areas). In practice there are differences across Sweden but only in non-essential needs. Furthermore, a 1996 study showed that older people or their families are rarely denied formal home help services (Johansson et al., 2003). According to the study authors, few appeals to courts concerning total denials were made no association was found between local variation in home help service coverage and unmet needs among older people. Nor did Salva et al. (2008) find clear evidence for the existence of inequality in their study about home care service.

### 5.3 Informal carers

Many receive assistance from family members and social home care services which indicates that overlaps of assistance occur and about one third receives assistance from both social home care service and informal carers (Swedish Association of Local Authorities and Regions, 2009). There are signs that the informal care is increasing in general, but the true extent depends in part on how the care is defined. There is no recognition of informal carers but sometimes informal carers are taken for granted as a co-worker. Government support for informal care is possible. For instance, in 1999–2001, SEK 300 million were allocated to stimulate development of different support for informal carer. Types of support or pursuing improvement efforts such as: respite via short-term care, respite via day activities, respite in the

own home, individual talks, family support group and centres, educations and recreation, well-being activities are available for informal carer (ibid).

## 6. Disparities in the process of home care

People with functional impairment who are younger than 65 years are covered under the Act ‘Support and service for certain disabled persons’ (LSS 1993:387) whereas those who are 65 years old or older are covered by the Social Services Act (SFS 2001:453). However, there can be local differences in selection of social home care service, such as the ability to receive housekeeping, accompanying with going for a walk, and go shopping. The home health care (nursing) is the same across Sweden, though the organisation may differ. There is also a difference in social home care recipients pathways related to age. Applications are submitted to different municipal departments and different assessment criteria exist.

## 7. Concerns and developments in home care in Sweden

There are lots of discussions in Sweden about different trends of home care in the future; about the high mean age of the employed staff and the need of new employments, the responsible authority and the opportunity of more privatization. Currently, the responsibility of home health care and social home care service is shared between the municipality and the county council. In the future it is likely that all the responsibility will be under one responsible authority, most likely the municipality. The informal caregivers’ role is another subject that has been discussed. More and older people will need support at home. Combined with earlier discharges from hospital, health care providers in the community will provide more and more advanced health care at home, home health care as well as home help services in the older people’s own homes. In several cases this results in that relatives also will be informal

caregivers on advanced level and be put under pressure. By this follows an increased risk of need for emergency admission to hospital.

The major problem is that in most Swedish municipalities there are two employers (county council and municipality). Both organizations are financed by taxes but with different rates. This problem brings both financing, organization and delivery problems. A typical example of this is that older people sometimes get confused by the home care organization and do not get the health care and home help service they need.

Several research and development projects are going on in Swedish home care. For instance a Swedish research group has been participating in a European project about “Improving independence, choice and quality of life for older people across Europe (WEL HOPS)”. The purpose of the project was; to establish common guidelines for the design of senior citizens’ homes, to establish guidelines for renovation of senior’s homes and to create a European Network of Experts to assess new schemes and promote the sharing of information and good practices (<http://www.welhops.net>). The project belongs to the “the SeniorForum concept” in which the idea is to create co-operative housing for older people with access to premises for activities and other facilities that contribute to a secure, pleasant living situation. IMMODI – Implementing Digital Development in Mountain and rural areas project is another project in the same area. The aim of this study is to capitalizing results and good practices developed by the partners in the field of e-government and e-health, which strongly contribute to the development of mountain and rural territories. Italy, France, Greece, Bulgaria, Germany, Finland and Sweden are included in this study (<http://www.interreg-immodi.net>).

Another innovative project is the Nurse Gudrun’s Full-scale Lab in Blekinge, which is using modern technology to make health care more accessible and efficient (see paragraph 4.5. *Use of tele-care*). The project includes a full-scale lab at the hospital which is connected to research lab at Blekinge Institute of Technology (BTH) to develop and test tools and technology before using them in health care. The project is divided into several subprojects such as i) the care Channel, in where the home care recipients access the health care facilities at home through their TV and computer. ii) e-learning for staff, iii) need-assessment on distance iv) virtual health arena, etc.

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# Switzerland

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## 1. The context of home care

### Country population and health

Switzerland has an average population density of 176 per km<sup>2</sup> and a population of 7.6 Millions (2008) among which 20% are non-citizen residents (8). It is a federal state with 32 cantons and 4 linguistic areas: French, German, Italian and Romanche. Its GDP is worth USD 4,450 billion dollars (2009) and the country's purchasing power is higher than the EU average. The demographic balance is relatively good with 16.4% population being over 65 in 2008 and 4.9% over 80. The old age dependency ratio is 24.1% (Eurostat) but is projected to be 45% (almost 2 persons of working age for every person of 65+) in 2050, due to a low birth rate. Life expectancy at birth in 2009 was 84.2 years for women and 79.4 for men with respective figures 21.9 and 18.5 at age 65 while healthy life expectancy at birth respectively was 70.3 and 69.4 (Spitex 2009), above the EU average, especially for women. Finally, about 42% of women and 44% of men aged 65+ declared having a long standing illness or health problem, which was much higher than the average for the EU in 2008 (Eurostat, 01-16-2010).

### Characteristics of health and social services

Health related services are made available through a mixed system of mandatory public insurance, financed through social contributions and individual premium payments to competing private insurance companies which are regulated at federal level through LAMal (Law for medical insurance). Also tariffs of ambulatory and residential care services are defined and publicly reimbursed according to rules defined in the Department

of Interior's (OPAS) legislation (federal legislation regarding health provided services: Ordonnance sur les prestations de soins). Other federal social security agencies also intervene for financing social services (Complementary pension (PC)) for poor retirees and disability allowance (AI) for handicapped persons. Cantons partly finance social services and about 55% of hospital and nursing homes, through local taxes. Only in-kind provision for health related services is available, while home based social services may be provided in cash by using PC and AI payments. Health expenses amount to 10.9% of the GDP in 2009, far above the EU15 average (8.9% in 2009 (OECD 2009)). The number of acute beds in acute hospitals is above the EU15 average with an average length of stay of 8.2 days in 2006 (OECD, 12-10-2008). Bed supply in nursing homes and home service for the elderly are well above the average but with dramatic variation between cantons. Quality of long-term care facilities is a point of concern (see section 2). The availability of both active nurses and general practitioners is relatively high but goes with important geographical disparity (OECD 2009). Home visits by GPs are rapidly declining. Solo practice remains dominant so transfer of tasks from GPs to nurses although an important topic is still controversial.

### Social indicators and conditions related to old age

The situation of old retirees is fairly good even when compared to other EU15 countries as supplementary benefits (PC) combined with old age pension covered by insurance (AVS) represents a real guaranteed income for pensioners, amounting on average to CHF 1,800 (€ 1,475) per month, while people with disabilities who retire before 60 endure a much worse situation, with a 13% risk of poverty for over 65 (OFS 2007). A legal basis for children's liability exists (civil code), but this does not entail covering home care expenses if their parents are unable to do so. Only if personal wealth has been passed on to children to avoid self pay can children be considered as being liable. Women's experience a relatively high unemployment rate (10.8% by the end of 2009), and

for those in the labour market full time employment rate is at middle range while being low in regard to part time (8).

### *Attitudes on informal care*

The family is “morally” supposed to care for their elderly relatives but is not legally forced to put “hands on care” as it is legally up to the local authority to plan and provide professional services to the elderly citizen, based on their needs. A population-based survey in 2003 showed that the preferred elderly care scenario for all generations is care at home but delivered by trained professionals (17).

## **2. Policy and regulation on home care**

### 2.1 Governance on home care

Since 1990, long-term care policies that were previously focussed on institutional care (16) now concentrate on delivering services at home, but with substantial variation by cantons regarding the trend and the prevailing situation. Home care is not defined in official documents as a target for a specific and global policy at federal level, as Swiss home care is heavily decentralised. In fact, the federal medical insurance law (LAMal: 11) sets only main respective responsibilities for long-term care policy and organisation of the three political powers: the federal state, the cantons and municipalities and between them and the private insurers. The health insurance legislation of 1996 (article 101bis) states that the federal state must subsidize services for elderly people at home, but gives to Cantons the main responsibilities with regard to planning and providing home care services. The federal state also defines the general conditions for entitlement to health and social services for old persons and the training, education and responsibilities of all health professionals delivering their services at home. Furthermore, it is also responsible for setting the overall share to be paid by the federal state, cantons/municipalities and insurers for social services (16). In this legal framework, it is up to the canton, (sharing these responsibilities with municipalities) to plan services according to the population needs; to acknowledge (and sometimes run) home care agencies; to coordinate, regulate and assess the delivery of nursing/ personal care and home help/aid; to fix tariffs of care provided by home helpers and negotiate tariffs of nursing and the nurses’ remunerations with other stakeholders health (insurers and Social Security Fund such as AVS and AI).

As not all cantons moved at the same speed regarding deinstitutionalisation, big differences in the relative share of home care to residential care are mainly explained by differences in policies across cantons and municipalities, rather than by demographic or epidemiologic data. These differences in policies have thus led to dramatic heterogeneity between cantons regarding the number of people receiving home care services and also in the way it is organised and provided (6).

### 2.2 Eligibility for home care services

Each canton has developed its own tool for assessing the social needs of the disabled person. Personal care and access to ADL services is never means-tested, but a doctor’s prescription is mandatory in order for health related services to be reimbursed. For home help and aid (IADL services), entitlement rules depend on canton’s specific rules. But it may be that these rules are applied diversely even within them, a reality acknowledged by home care agencies. So the level of uniformity inside a canton depends on the numbers of agencies and also on the stringency of their supervision (17). Home help services are partially reimbursed by cantons using a sliding scale linked to revenues (10). Next to this, there are supplementary benefits for indigent people, but depending on need and on the availability of informal care, meaning that allowed benefits are lower if they live with their family.

### 2.3 Quality of process and output

#### *Availability of quality criteria*

No system of quality criteria exists at federal level, whether for health or social related services. The only legal obligation regarding quality comes from LAMal (Law on health insurance). Federal regulation states only that in each canton an explicit quality system must exist, covering some key topics, and professional’s qualifications must comply to professional norms coming from OPAS (professional classification of AMAL, the Swiss health insurance fund). The association of the directors of the public health committee of each canton can also give advice, but this is not mandatory (20).

#### *Assessment of service quality*

Assessment of service quality only exists at the canton level. The canton’s public health department controls the activity of accredited/provided home care agencies,

but the assessment criteria are not publicly available and may be different between cantons. They mostly focus on administrative and hygiene rules and level of staff salaries, and thus cannot be considered criteria strongly linked to service quality. In the best cases (e.g. in the canton Vaud), after being checked for their capabilities, home helpers work is supervised by a referent (social worker or a nurse), sometime in the home, but nothing is known about the real impact of such control (14). But huge variations exist in the frequency and stringency of the control. Because competition is not considered as an efficient tool in this sector, benchmarking procedures and publication of care results do not exist even within the cantons. Even if home agencies are sometime encouraged to run a survey for their population, such surveys are not frequent at the level of the canton and no data exist about the frequency of these and how the results are used.

#### *Accreditation schemes and clients complaint procedures*

There is no certification at the national level. But many agencies are certified according to ISO 9001 norms. Cantons authorize agencies but their criteria for authorisation are not publicly available. The federal state only recommends (so not mandatory) that home agencies report on the existence of a client complaint procedure scheme. Thus it is only up to the cantons to assess whether complaint procedures are working, with no obligation to make it public or to assess it. But usually complainants, in line with the Swiss tradition of direct democracy, prefer to use a different procedure which is frequently to write to his/her canton representative (22). Also it is not known how complaints are processed in order to correct potential deficiencies.

#### 2.4 Quality of input

Two levels of diplomas exist; one for nurses and one for nurse assistants (ASSC). All legal frameworks for the course diplomas are set up by regulations under the responsibility of the Labour Ministry. Even if national diplomas do not exist, all cantons have about the same level of requirements. Cantons are not subject to a formal state inspectorate as it is legally up the cantons to put in place the education and training process as well as the follow up. It is also up to the canton to decide about practice authorization. There is no formal description of nursing tasks at the national level, although the OPAS catalogue of AMAL lists all health related services, whether technical or personal care nursing, that can

be reimbursed when delivered on behalf of GP order's by a nurse working in a authorized agency (21). Also Lamal enforces a 5 years recertification process for nurses that the canton is responsible for organising. No specific federal requirements exist regarding home helpers training and education, which may be different according to cantons: it may go from a basic training of 80 hours by the Red Cross to a fully certified diploma of "family helper", usually given to a person with less than a secondary education level. It is also up to cantons to decide whether a home helper can practice and to define regulations about their continuing education. IADL services are listed in a specific federal catalogue but with no detailed description for each task or about who should perform them. So there may be some crossing over between tasks performed by home helpers, nurses and nurse assistants regarding services related to IADL.

#### 2.5 Incentives for providers of home care (including possible competition)

Competition is not considered as a good driver for enhancing quality and access in the long-term care sector (16) as most home agencies inside a canton are not for profit and are strongly regulated by the local authority. Only a few, rather small, organisations of self employed nurses located in specific areas of the German speaking region are competing against canton's agencies, but their influence is weak as they have no market power (17). There is also no shortage of home workers that exists, through which competition between providers would increase in that sense. Experts consulted during this project suggest that this is because most of home workers belong to the high (and still growing) volume of migrant community and because home helpers are usually somewhat better paid than workers performing similar tasks in other sectors. Hence, they may compete for positions in this sector. However, benefits in terms of quality are not known.

### 3. Financing

#### 3.1 General funding

Social home care (domestic aid and personal care when delivered by social workers) is financed by the County through subsidies based on local taxes (cantons/municipality) while home technical and personal nursing care is financed through insurance premiums. Also a small (2%) federal contribution exists. According to the

2007 health care survey of the federal office for statistics (OFS), the relative contribution of AMAL (health insurance fund) through social income contributions amounts to 43% of the total home care expenditures while 16% come from Cantons/municipalities (through local taxations) with relative contributions from cantons and municipalities set between 0 to 100 (Blum 2008), meaning resources devoted by cantons to home and institutional care may vary in proportion from 1 to 2 (Spitex 2008).

About 9% of total financing comes from private disability insurances while other direct client contributions amount to 31% (8), related to deductibles, co-payments and extra out of pocket money (see below). Additionally, there are several subsidies and/or payment exemptions for poor recipients to cover the home care costs, these funds stemming from general taxation.

### 3.2 Financing home care agencies

For health related services, cantons receive their budget from the health insurance fund based on the volume of delivered services and negotiated tariffs (with local insurers) (see paragraph below). Cantons finance all infrastructure costs, administrative staff and subsidise home help workers and their salaried nurses.

### 3.3 Prices setting of home care services.

For social home care services, it is up to the canton to set the hourly tariff, which they do in order to at least cover their costs. In this case, the agencies directly, or through their umbrella organisation, negotiate about prices with the cantons, resulting in huge variations between cantons in this regard (24). However, national tariffs are foreseen in coming legislation.

Regarding the reimbursement scheme for health related services, for each “health” service on the list OPAS of AMAL, each canton negotiates tariffs with the nurse’s representative organisations and the regional insurers. The latter, according to LAMal, should cover each delivered health related service at a 100% level. But as insurers increasingly called for an overall ceiling per patient per year for the total amount of reimbursed services, this has been put in place by the new LAMal passed in 2009 (see section 6). A universal (not income related) obligatory deductible of CHF 300 (€246) exists, but the client then may choose deductibles up

to CHF 1,500 (€1,230) per year with a lower premium for higher deductibles. Also once the deductible has reached CHF 800 (€660), the beneficiary pays only a 10% co-payment of the tariffs for delivered services, while above the chosen deductible ceiling, (s)he has nothing to pay. Conversely, clients with an income below a certain threshold (CHF 2,200 (€1,800) per month) does not pay for health-related care services and in cases where he can not cover obligatory costs, he will receive subsidies (extra money) coming from either from the retirement pension fund (AVS); or from the AI (invalidity insurance fund) for younger disabled persons. Regarding social home care services, these are partially reimbursed by cantons using a sliding scale linked to revenues (10). Next to this, there are supplementary benefits for indigent people, depending on need and on the availability of informal care, i.e. the benefit will be lower if they live with their family. The average cost of nursing homes amount CHF 4,500 (€3,700) per month with big inter-canton differences, meaning that for more than 15% of the population, AVS has and will to cover these costs.

## 4. Organisation & delivery of home care

### 4.1 Access and needs assessment

No national scheme exists, as each canton has its own assessment tool. For more than ten years the umbrella of home care agencies (at federal level) has been pushing for a uniform assessment instrument. Also for the past five years the national association of home care directors has recommended the use of the ‘RAI’ (resident assessment instrument) as the common tool to assess disability. But only three cantons in the French area, after “customizing” it according to their needs, are using it extensively. Any person can directly ask the agency of their canton whether (s)he is legally entitled to care and at this stage no a priori referral by a doctor is necessary. According to the person’s situation a nurse employed by the authorised agency will perform the assessment if health related services are expected but usually it is done by a social worker if only help with cleaning of the home is expected. Rarely an occupational therapist, or very rarely a multi professional team may be involved.

### 4.2 Delivery of services

In this federal and highly decentralised system, it is the responsibility of each canton to plan the number and the location of agencies according to the population’s

need, political choices and budget, and give them authorization to practice. In 2007 there were 639 home agencies delivering domestic aid and/or nursing care. Those delivering more comprehensive services were being less numerous. Most of the domestic aid and/or nursing care agencies are run by independent not-for-profit organisations that are approved or directly managed by the cantons. Among them, 88% are private non-profit organisations, 5% are for profit, and 5% are publicly run by municipalities. The remaining 2% are public and managed at another level (28). Inside a canton there is no competition as a person is usually related to his/her closest agency and usually will not try to go elsewhere, although he/she is formally allowed to contact them.

#### 4.3 Coordination and integration in home care

Home care agencies may also be united through an association on a cantonal basis, like in the Vaud canton (50 agencies run by 7 associations) but supervised by the canton (e.g. Vaud) or the municipalities (e.g. Zoug). Agencies may integrate nursing and domestic help and/or meals on wheels service so, as Spitex statistics 2007 show, services delivered by Home Agencies are much more comprehensive in French Switzerland (Romande) than in the German area (9). And in general, inter-organisational arrangements are rare and the degree of integration not high whatever the canton. A few of them (e.g. Vaud) have “integrated teams”, encompassing home helpers, nurses, rehabilitators, social workers (see section 6). Case management is partially in place in some of the German-speaking cantons (18). But there is no uniform conception of the roles of case managers and thus they have different scopes of activity and types of tasks (according to experts). There is no national formal arrangement with acute care hospital. Only in some cantons and only in some hospitals has a discharge management programme with a liaison nurse been set up (18, 4). Also links between nursing homes and home care agencies seldom exist. Only a few nursing homes provide supportive day care but, usually, the type of provided care is not targeted (specific) to the recipient’s needs. Some provide also short (temporary) stays as respite care with special staff but generally have no liaison nurse. GPs are not integrated in home care agencies, even if the GP can act as a referral by prescribing either home or residential care. Also, if after assessment, health related services are deemed necessary, then a medical order is necessary to be reimbursed by LAMal (6).

#### 4.4 Actors and human resources in home care

##### *Institutional actors in home care and their responsibilities*

The following organisations are involved in home care:

- The federal level: defines the general principles of regulation and organisational framework for all involved organisations;
- The health insurance fund (AMAL): defines all reimbursable basic health services (nursing care);
- AVS (pension fund) defines regulation for entitlement to subsidies (complementary pensions (PC) for poor retired people and AI for disabled people before retirement) to pay for the costs of home social services;
- Independent professional (Drs, nurses) umbrella organisations negotiate tariffs with insurers at canton level while national tariffs are expected in the new LAMal;
- The cantons and municipalities: jointly, through a great diversity of arrangements, organise, regulate and assess the provision and delivery of home care services. They also intervene in negotiating non-health related service’s tariffs;
- Insurers together with the cantons: at macro level they are part of the bargaining with the professionals unions (nurses, doctors) about price fixing for health related services but also at the micro level in the arbitrage to be set between health and social services regarding the reimbursement of services included in the care plan;
- Home care agencies: they provide either social home care or home nursing or both. Home agencies are run by independent not-for-profit organisation and approved by cantons or are directly managed by cantons. In case on non-health related home care, agencies directly or through their umbrella organisations negotiate about prices with the cantons. National tariffs are also foreseen in coming legislation.

##### *Human resources in home care*

All nurses working in home care agencies are salaried as are home helpers. Most of the home helpers are working part-time (see Table 1). Usually each canton or home agency has a document which sets up the working conditions for the main types of workers. A ten years

**Table 1:** Home care human resources in Switzerland

Human resources in home care in 2007 and 2008	Switzerland
Number of home helps (domestic aid and personal care)	27,945 workers (11,960) (FTE)
Number of home nurses	16,619

According to Spitex 2007 and 2008 (28, 29).

**Table 2:** Number of home care recipients compared to recipients of long-term care (LTC) in nursing home care

Recipients in 2007/2008	Number of recipients at home (% of total population)*	Number of LTC recipients in a nursing home (% of total population)
Total	211,000 (3%)	134,992 (2%)
% of recipients being female	69%	n.a.
% of recipient between the age of 65+ and 80	74.7% (estimation)	94.5%
% of recipients over 80 years old	46.5% (estimation)	75.2%

\* Recipients of OPAS, AD and other home care services, according to Office fédéral de la statistique, *Statistique de l'aide et des soins à domicile, 2008*  
Source: (28, 29, 33).

experienced nurse gets an average salary of €4,000. The profession of nurse is socially well recognised. Home helpers, even if not located high on the social scale, are better paid than workers with comparable qualifications (cleaning worker in the service industries for example). A further characteristic of the home care workforce is the large share of “qualified migrants” continuously fuelling the sector. Accordingly, there is no shortage.

#### 4.5 Use of tele-care

Tele-care is not much developed, as Cantons are not eager to use this. Most of the device's costs are perceived as being too high and there is a lack of proof of improvements. Only télé-alarm is fairly often used (according to experts).

#### 4.6 Monitoring of care need

It is up to the team or on the request of the client and/or his family to make the reassessment. Even if not formally defined, dependant person should be reassessed at least on an annual basis.

## 5. Clients & informal carers

### 5.1 Number of home care recipients

As shown in Table 2, on average those receiving long-term professional care more often live at home than in a nursing home (69% of long-term care clients receive home care). However, as mentioned earlier, there are large discrepancies between the cantons in their relative weight. It may be difficult to receive home care in cantons where home care has not been chosen as a priority by local authority, mainly in the German speaking areas (15, 17). Also means of focusing elderly care may vary extensively. No distinction is possible between social home care and home nursing recipients. Activities of home care agencies are not limited to chronically dependent elderly persons; almost one quarter of clients are under 65 years of age (24).

### 5.2 Coverage and unmet care needs

Rationing of home care services happens in Switzerland even if it is not well documented. Rationing comes mostly from the unavailability of professional resources stemming from the canton's policy regarding the long-term care budget and the relative preference given to home care. The lack of professional home care services may be aggravated by the absence of an informal carer. Also, and even in some well provisioned cantons, some specific services such as a 24-hour care customarily may not be made available by cantons because of their high

costs and must be paid with private money. Also few nursing homes deliver respite care (temporary residency) and/or day care.

### 5.3 Empowerment of home care recipients

Even if they are not legally assigned to one agency, in practice any person eligible to home care usually has no choice and will be directed to the nearest one, as cantons plan their activity according to a definite population in a specific territory. Regarding care setting, the client is also not completely free to choose. His/her choice may not be followed either because it is not considered by staff as the most suitable solution according to his/her needs and/or quality of life, or because of a lack of professionals. Furthermore, it may be because the recipient lacks financial resources to pay, for example for residential care which usually involves more private costs than home care. But it may also be the consequence of the following specific regulation: according to a previous judgment delivered by the TFA (federal insurer's legislative authority), an insurer is not obliged to pay for a service delivered at home if the same services in another setting cost less. Finally, neither a personal budget scheme nor care attendance allowance exists in order to empower clients in their choice, as only people below a certain income threshold receive subsidies from the local authorities which they will use for their basic needs, rather than for their long-term care needs.

Regarding information on home services, no national ranking system is available for, as stated, choice is not really an option. Nevertheless there may exist, at the municipality level, some small organisations with volunteer staff supporting the recipient in finding and organising the care delivery. But they are operating in an informal mode rather than being rationally organised and managed and the cantons very seldom support them (5,9).

### 5.4 Informal carers

Family and “affinity” helpers are more and more caring even if their contribution usually stops when technical or heavy care is necessary (15). In a household, the main carer is almost always the second member of the couple when the cared for person is a man while, in the contrary case, tasks are divided with children and are gender driven. In the vast majority of the situations, the daughter will be involved in delivering help and personal care, even if women's participation to labour market is growing, and

the spouse will provide more the paper work tasks. But as the number of very small (one or two persons) or small (three persons) households is growing, due to children's growing mobility, using them as a free resource may prove difficult in the future. Also neighbour's solidarity is becoming weaker compared to the more extended personal network. Already 32% of old people above 80 need health or personal care and more services coming from professionals will be mandatory. Practically, at the level of the cantons and even if some variation may exist, it appears that informal carers are considered more as co-workers than as clients with needs to be addressed by home workers and nurses. And as co-workers they rarely benefit from the in-kind or cash support that their major contribution would justify but which does not exist as they work is not formally recognised (16). And as clients, their voice and needs are not taken into account at different phases of the caring process (assessment of needs, care planning and monitoring).

## 6. Disparities in the process of home care

- As cantons are the main operating instances in financing and delivering home help services and regulating health related services for the disabled population, independently of age; as they are free to organise at their will the care needs assessment process and the care planning; to negotiate tariffs for home help services to set the level of dedicated funds (through the level of taxation and policy priorities) and the balance between residential and home care, it seems “evident” that this variation should entail large geographical and social disparities regarding access and the way home services are delivered and reimbursed. But no cross comparison surveys exist in order to collect more scientific based evidence regarding this outcome.

## 7. Concerns and new developments in home care in Switzerland

### Major problems

- Problems are numerous.
- First, in term of financial equity, the insurance funding scheme based on a regulated competition (through LAMal) between private health insurers at the level of cantons is financially unfair, as the level of the mandatory health insurance premiums,

health services deductibles and co-payments are not linked to income. Also the structure of governance entail in particular that availability and service prices are uneven on the territory (cantons), raising the question of fairness in access to services. The building of a more egalitarian insurance scheme at the federal level was pushed by some stakeholders (both at policy and social level). In order to counter it, insurers kept the premium level almost fixed over the last two years by consuming their guarantee funds, despite the fact that this was not a legal action. But the federal level regulators did not react to it. This manoeuvre proved to be successful as the new LAMal is more favourable to insurers.

- The second issue is the lack of policy aiming to support informal carers while they still provide the vast majority of the services delivered at home, substituting for the lack of professional services.
- The third problem is the failure to measure the quality and the efficiency of the formally provided services.
- The fourth is the escalating cost of home health care services, even if growth rates are (still) in line with the growing economy. But the financial crisis is beginning to change the picture, because this growth is more driven by health related service prices. These are growing in absolute and relative volume for epidemiological reasons (more chronic illnesses) but also because they are more costly than social services and are also better reimbursed by health insurers, since the law requires that health insurers cover each health service at a 100% level.

### New developments

On the basis of the non-sustainability of costs growth and in order to reduce the cost of all long-term care services, insurers have pushed for a new reform of the LaMaL which would free them from the constraint of reimbursing all basic health services according to full costs (10). Insurers succeeded, as the new law (passed in 2008, but to be formally established only in 2011) states that AMAL should only “contribute” towards covering long-term care costs. Also services prices are to be set in such order that they respect a national norm, thus avoiding inter-canton discrepancies. More importantly, practical measures regarding the reimbursement process by insurers for health based services are the following: The client mandatory co-payment level above the first

CHF 800 (€ will rise from 10% to 20% and the annual ceiling for co-payment could reach CHF 7,000. Above this threshold, neither health insurers nor the client are supposed to pay. Also the boundaries between services, respectively AMAL and other “social insurers” (AVS and AI), will change through their complementary contribution cover and reimbursement. As funds coming from the AVS and/or AI are also going to be more means-tested and as they are financed through taxes (and not by social contributions as are health services), this suggests that some new financial gaps will be created that need to be compensated by Cantons through more local taxes, with the overall result of more out of pocket money for the eldest and their family.

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# Appendix I:

## *Terminology used in this book*

**Activities of daily living (ADL):** both personal activities of daily living (PADL) and instrumental activities of daily living (IADL).

**Delivery:** activities organized within public and privately owned agencies and institutions which are meant to deliver social and health care services in clients' homes.

**Domestic aid:** help with instrumental activities of daily living (IADL), such as using the telephone, shopping, food preparation, housekeeping, transportation, taking medication and financial administration.

**Financing:** process by which revenue is collected from primary and secondary sources, accumulated in fund pools and allocated to provider priorities.

**Governance:** policy development, supervision of a good functioning of the system and regulation to steer where necessary.

**Home care system:** an integrated and interdependent set of elements that produce actions with the primary purpose of allowing people to live at home despite functional disabilities. Its functions are 'governance', 'financing', 'service delivery', 'needs assessment', 'safeguarding the quality of services' and 'human resources'.

**Home care:** care provided at home by professionals after a formal needs assessment. 'Care' means domestic aid services, personal care and supportive, technical and rehabilitative nursing.

**Home health care:** technical, supportive and rehabilitative services and possibly personal care services depending on the characteristics and boundaries of both systems in a country.

**Informal care:** care provided by family members, friends and volunteers, usually unpaid.

**Instrumental activities of daily living (IADL):** help with IADL relates to services such as help with using the telephone, shopping, food preparation, housekeeping, transportation, taking medication and financial administration.

**Needs assessment:** systematic exploration of the physical and financial possibilities of a person living independently, according to specified rules.

**Nursing:** activities of nurses that are of a technical, supportive or rehabilitative nature (see rehabilitative nursing, supportive nursing, technical nursing).

**Personal activities of daily living (PADL):** help with PADL relates to services such as assistance with dressing, feeding, washing and toileting, getting in or out of bed.

**Personal care services:** providing assistance with dressing, feeding, washing and toileting, and getting in or out of bed (also known as PADL).

**Privately/publicly funded organizations/services:** providers or the activities of home care services that are funded through tax revenue or social insurance (publicly funded) or *only* through a person's or his/her family's own financial resources or through private insurance schemes (privately funded).

**Privately/publicly owned organizations:** organizations that are legally owned mostly by the government (publicly owned) or by other organizations (privately owned).

**Rehabilitative nursing:** occupational therapy or physiotherapy.

**Respite care:** short-term care (e.g. help with ADL) aiming to relieve informal caregivers, i.e. providing the caregiver with time away from the patient.

**Social home care:** domestic aid and (depending on the country's system) personal care services.

**Supportive nursing:** provision of health information and education.

**Technical nursing:** Activities such as assistance with putting on prostheses or elastic stockings; changing stomas and urinal bags; help with bladder catheter/catheterization; skin care; disinfection and prevention of bedsores; oxygen administration; and giving intravenous injections.

# Appendix II:

## *Four case narratives ('Vignettes') & related questionnaires*

### Vignette 1

#### **Accompanying letter for the experts**

Dear Madam, Sir,

We are glad with your preparedness to contribute to this European home care study. The study aims to describe and compare the organisation and provision of home care services in Europe. One of the approaches to gather information is based on *vignettes*, which are (hypothetical) descriptions of situations of elderly or disabled people living at home in need of care. In all European countries, experts are asked to answer the questions related to two vignettes. Comparison of the answers will show the diversity of home care in the countries of Europe, in particular from a users' perspective.

Some of the questions to the vignettes can be answered by simply ticking a box, while others are open-ended. Since we attach great value on explanations that further clarify the situation in your country, you are encouraged to use the possibilities to expand on your answers or attach an annex to this questionnaire.

If you would not know an answer, you can tick the option 'I do not know' or, in case of open questions, just move on to the next question.

As a check of the information, the draft report concerning your country will be fed back to you.

For all your questions, please contact one of the undersigned persons.

Thank you very much for your cooperation in this important study.

### Name(s) from Eurhomap partner

Wienke Boerma ([w.boerma@nivel.nl](mailto:w.boerma@nivel.nl))

Nadine Genet ([n.genet@nivel.nl](mailto:n.genet@nivel.nl))

Research Institute NIVEL (Netherlands)

<http://www.nivel.eu>

- If you would like to be acknowledged in the country report, please provide your details here:

#### Name:

.....  
 .....

#### Function:

.....  
 .....

#### Organisation:

.....  
 .....

#### Address:

.....  
 .....  
 .....  
 .....  
 .....  
 .....

### Background

A couple, both 84, are physically relatively healthy, but the wife has symptoms of early stage dementia which is an increasing obstacle in her management of the household. For years they have hired a cleaning lady on a private basis twice a week, who also helps with preparing meals. The children are committed and give support as far as possible beside their jobs and other obligations. One daughter with 3 children under the age of 20 is living nearby, while another, widowed with two grown up children, and a single son are living at half an hour travel distance.

### What happened

The lady falls and breaks her hip. She is hospitalised for an operation and subsequently admitted to a nursing home for recovery and initial rehabilitation. Her situation develops well and returning home, which is her preferred option, is possible if precautionary measures are taken. Measures should also focus on safety issues related to expected increase of dementia problems.

### Care needs

At home, at least for some time, she will need help getting up, washing herself and going to bed. Furthermore, the lady will temporarily need continued rehabilitation to further improve walking. Since she will no longer be able to oversee household and daily activities, more help will be needed for cleaning the home, shopping and preparing meals. Timely intake of medicines should also be taken care of. Since there is no bathroom at the ground floor of the house, a solution needs to be found for her to get upstairs.

**(Format of the questionnaire has been slightly compressed)**

**Please answer the following questions**

To what home care services would this lady be entitled according to current criteria and rules in your country (so, this is about the ‘theory’; the practice may be different!).

*She is **entitled** to the following services:* .....

Which of the needs of this lady would be covered by the services for which she is (‘theoretically’) entitled, and for which of her needs other solutions should be found (or remain unmet)?

*Entitled services cover the following needs of the lady:* .....

*The following needs **cannot** be met according to rules of entitlement:* .....

Do financial consequences for the client apply to the acceptance of the eligible services in this case (for instance co-payments or other financial contributions)?

*(please explain):* .....

Does a gap exist between the services to which the lady is entitled and the services she will effectively receive? (This gap may result from possible shortages and other imperfections in your country).

*(You may tick more than one box)*

Normally all services to which she is entitled will be provided without reduction.

Usually, reductions are applied (for instance in number of hours of care) in the provision of the following type(s) of services.

*Please fill in:* .....

Usually the following type(s) of services are not available at all.

*Please fill in:* .....

I do not know

*Please further explain your answer:* .....

Would some tele-care application be used in this situation in your country? (Examples of tele-care are personal alarm systems, distant observations and other ICT applications in home care).

*(please, tick the most applicable box)*

No tele-care applications will be used in this case.

Yes, the following tele-care applications can be used (also indicate the probability of use).

*(fill in a tele-care application):* .....

How often this will be used in cases like this?  
*(tick a box)*

often    occasionally    infrequent/rarely

*(fill in another application, if applicable):* .....

.....  
.....  
.....  
.....

I do not know

*Please further explain your answer:* .....

.....  
.....  
.....  
.....

In your country, who would most probably take the initiative in this case to apply for care?  
*(please, tick the most applicable box).*

The couple or family.

The nursing home.

The GP of the couple.

Someone else, namely.

*(please fill in):* .....

.....  
.....  
.....  
.....

It depends on the situation who will take the initiative *(please explain below).*

I do not know

*Please further explain your answer:* .....

.....  
.....  
.....  
.....

In your country, is there usually ‘one window’ for all services relevant to this application for care (as the start of the care process) or are different bodies to be approached separately?

*(please, tick the most appropriate box).*

There is one window or entry point for all home care services needed.

Each service has its own entry point.

The situation is different, namely.

*(please fill in):* .....

.....  
.....  
.....  
.....

I do not know

*Please further explain your answer:* .....

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Who will usually assess the needs and the personal situation of the lady? Needs assessment is done by:

An independent formal assessing agency.

A representative of the home care provider.

A governmental organisation.

Another type of organisation, namely.

*(please fill in):* .....  
.....  
.....  
.....  
.....

It depends.

I do not know

*Please further explain your answer:* .....  
.....  
.....  
.....

Are explicit (written and publicly known) eligibility criteria used in needs assessment in this case? ***(please, tick the most appropriate box).***

In this case nation wide used criteria are applied.

Criteria are used, but these are not used everywhere and not uniformly.

No explicit criteria will be used.

Another situation, namely.

*(please fill in):* .....  
.....  
.....  
.....  
.....

I do not know

*Please further explain your answer:* .....  
.....  
.....  
.....  
.....

In your country, who would take the decision about the granting of the requested services?

*The granting decision will be taken by:* .....  
.....  
.....  
.....

In this case, will the availability of informal carers (children) be taken into consideration in the decision to grant services? If yes, in which way? ***(please, tick the most appropriate box).***

No, the availability of informal care is not taken into consideration.

Yes, availability of informal care is taken into consideration, as follows:

*(please fill in):* .....  
.....  
.....  
.....

I do not know

In this case, will the financial situation of the couple be taken into consideration in the decision to grant services? If yes, in which way? ***(please, tick the most appropriate box).***

No, the financial situation is not taken into consideration.

Yes, the financial situation is taken into consideration, as follows:

*(please fill in):* .....  
.....  
.....  
.....

- I do not know
- Which care providers (professional and other) will probably be involved in home care for the couple?

*(You may tick more than one answer)*

- Home help (domestic aid)
- Nurse
- Social worker
- Physiotherapist
- Occupational therapist
- Family doctor
- Children of the couple
- Volunteers
- Neighbours
- Friends
- Others, namely:

*(please fill in):* .....

.....

.....

.....

.....

- I do not know

*Please further explain your answer:* .....

.....

.....

.....

.....

- Will the process of care to this couple be explicitly monitored from time to time to assess whether the provided care is still appropriate in relation to the couple's needs? ('explicitly' meaning that it is done by a formal procedure at regular intervals)  
*(please tick one box).*

- Services to this couple will not be explicitly monitored (monitoring procedures do not exist in this country).

- Services to this couple will not be explicitly monitored (existing procedures are not widely used).

- Services to this couple will be monitored according to an explicit systematic procedure.

- I do not know

Please further explain your answer (including who will do the monitoring):

*Please further explain your answer:* .....

.....

.....

.....

.....

- If, in your country, formal home care would probably not be an option to this couple, what would likely be their situation or what would be the solution?  
*(you may tick more boxes, but limit to 'most probable')*

- Not applicable, because home care is the most likely option in this case

- The lady would be in a home for the elderly (separated from her husband)

- The couple would be in a home for the elderly

- The couple would live with one of the children

- The widowed daughter would reduce her job to care for them

- The couple would hire private care (paying 'black')

- The couple would hire private care (paying tax, etc.)

- The couple would suffer from unmet needs (health and social threats)

Another situation, namely.

*(please fill in):* .....  
.....  
.....  
.....  
.....

I do not know

*Please further explain your answer (and distinguish which of the children would have which role):* .....  
.....  
.....  
.....

Related to the situation and the needs of this couple, what are frequently occurring difficulties, possible unmet care needs or other peculiarities, if they would live in your country? Would it make a difference in home care for them to live in a city or in a rural area?

*Please explain the possible difficulties, peculiarities or differences:* .....  
.....  
.....  
.....

## Vignette 2

### Background

A 91 year old widow is living independently in a single family dwelling. None of her 6 children, two of which are retired, is living nearby. She is getting her meals from a meals-on-wheels service. Once a week a privately hired cleaning lady is doing domestic work. Additional care is provided by her children on a rota basis.

### What happened

Her major health problem is increasing poor walking, which restricts her mobility and ability to cope with daily living and household tasks. Even in-house she cannot walk without a Zimmer frame (rollator). Going up and down the stairs is becoming extremely difficult. Sometimes she is found to be slovenly and she sometimes has problems structuring her days, especially at occasions when she has taken too much alcohol. The only formal care she receives is the occasional home visits from her GP, with whom she has good contact. Since the situation is expected to further deteriorate and the children feel they are at the limit of their possibilities, they all agree that measures need to be taken.

### Care needs

Institutionalisation is no solution, since she strongly wants to stay at home. Having her bed in the living room and building a basic bathroom facility at the ground floor would make the use of the upper floor superfluous. Besides, on working days she would need help with getting up, washing and dressing and getting to bed. Since she is unable to clean the house and shop, more support will be needed for these tasks.

**(Format of the questionnaire has been slightly compressed)**

**Please answer the following questions**

To what home care services would this lady be entitled according to current criteria and rules in your country (so, this is about the ‘theory’; the practice may be different!) (also consider the bathing facility).

*She is **entitled** to the following services:* .....

Which of the needs of this lady would be covered by the services for which she is (‘theoretically’) entitled, and for which of her needs other solutions should be found (or remain unmet)?

*Entitled services cover the following needs of the lady:* .....

*The following needs **cannot** be met according to rules of entitlement:* .....

Do financial consequences for the client apply to the acceptance of the eligible services in this case (for instance co-payments or other financial contributions)?

*(please explain):* .....

Does a gap exist between the services to which the lady is entitled and the services she will effectively receive? (This gap may result from possible shortages and other imperfections in your country).

*(You may tick more than one box)*

Normally all services to which she is entitled will be provided without reduction.

Usually, reductions are applied (for instance in number of hours of care) in the provision of the following type(s) of services.

*(please fill in):* .....

Usually the following type(s) of services are not available at all.

*(please fill in):* .....

I do not know

*Please further explain your answer:* .....

Would some tele-care application be used in this situation in your country? (Examples of tele-care are personal alarm systems, distant observations and other ICT applications in home care).

*(please, tick the most applicable box)*

No tele-care applications will be used

Yes, the following tele-care applications can be used (also indicate the probability of use)

*(fill in a tele-care application):* .....

How often this will be used in cases like this?  
**(tick a box)**

often    occasionally    infrequent/rarely

(fill in another application, if applicable): .....

.....  
.....  
.....

How often this will be used in cases like this?  
**(tick a box)**

often    occasionally    infrequent/rarely

(fill in another application, if applicable): .....

.....  
.....  
.....

How often this will be used in cases like this?  
**(tick a box)**

often    occasionally    infrequent/rarely

I do not know

Please further explain your answer: .....

.....  
.....  
.....

In your country, who would most probably take the initiative in this case to apply for care?  
**(please, tick the most applicable box)**

The lady or her family

The GP of the lady

Someone else, namely:

(please fill in): .....

.....  
.....  
.....

It depends on the situation who will take the initiative (please explain below)

I do not know

Please further explain your answer: .....

.....  
.....  
.....

In your country, is there usually 'one window' for all services relevant to this application for care (as the start of the care process) or are different bodies or agencies to be approached separately?  
**(please, tick the most appropriate box)**

There is one window or entry point for all home care services needed

Each service has its own entry point

The situation is different, namely:

(please fill in): .....

.....  
.....  
.....

I do not know

Please further explain your answer: .....

.....  
.....  
.....

Who will usually assess the needs and the personal situation of the lady? Needs assessment is done by:

- An independent formal assessing agency
- A representative of the home care provider
- A governmental organisation
- Another type of organisation, namely:

*(please fill in):* .....

.....

.....

.....

.....

- It depends
- I do not know

*Please further explain your answer:* .....

.....

.....

.....

.....

Are explicit (written and publicly known) eligibility criteria used in needs assessment in this case?  
***(please, tick the most appropriate box)***

- In this case nation wide used criteria are applied
- Criteria are used, but these are not used everywhere and not uniformly
- No explicit criteria will be used
- Another situation, namely:

*(please fill in):* .....

.....

.....

.....

.....

I do not know

*Please further explain your answer:* .....

.....

.....

.....

.....

In your country, who would take the decision about the granting of the requested services?

*The granting decision will be taken by:* .....

.....

.....

.....

.....

In this case, will the availability of informal carers (children) be taken into consideration in the decision to grant services? If yes, in which way?  
***(please, tick the most appropriate box)***

No, the availability of informal care is not taken into consideration

Yes, availability of informal care is taken into consideration, as follows:

*(please fill in):* .....

.....

.....

.....

.....

I do not know

In this case, will the financial situation of the lady be taken into consideration in the decision to grant services? If yes, in which way?  
***(please, tick the most appropriate box)***

No, the financial situation is not taken into consideration

Yes, the financial situation is taken into consideration, as follows:

*(please fill in):* .....

I do not know

Which care providers (professional and other) will probably be involved in home care for the lady?

*(You may tick more than one answer).*

Home help (domestic aid)

Nurse

Social worker

Physiotherapist

Occupational therapist

Family doctor

Children of the woman

Volunteers

Neighbours

Friends

Others, namely:

*(please fill in):* .....

*Please further explain your answer:* .....

I do not know

Will the process of care to the lady be explicitly monitored from time to time to assess whether the provided care is still appropriate in relation to her (changing) needs? ('explicitly' meaning that it is done by a formal procedure at regular intervals)  
*(please tick one box)*

Services to this lady will not be explicitly monitored (monitoring procedures do not exist in this country)

Services to this lady will not be explicitly monitored (existing procedures are not widely used)

Services to this lady will be monitored according to an explicit systematic procedure

I do not know

Please further explain your answer (including who will do the monitoring):

*(please explain):* .....

If, in your country, formal home care would probably not be an option to this lady, what would likely be her situation or what would be the solution?  
*(you may tick more boxes, but limit to 'most probable')*

Not applicable, because home care is the most likely option in this case

The lady would be in a home for the elderly

The lady would live with one of the children

One of her daughters would reduce her job to care for her

The lady would hire private care (paying 'black')

The lady would hire private care (paying tax, etc.)

The lady would suffer from unmet needs (health and social threats)

Another situation, namely:

*(please fill in):* .....  
.....  
.....  
.....  
.....

I do not know

*Please further explain your answer:* .....  
.....  
.....  
.....  
.....

Related to the situation and the needs of this lady, what are frequently occurring difficulties, possible unmet care needs or other peculiarities, if she would live in your country? Would it make a difference in home care for her to live in a city or in a rural area?

*Please explain the possible difficulties, peculiarities or differences:* .....  
.....  
.....  
.....  
.....

## Vignette 3

### Background

A 65 year old married man, with two young adult children who have left the parental home, was early retired two years ago. The family used to be religious, but contact with the church has faded.

### What happened

Almost half a year ago the man was diagnosed with stomach cancer in a late stage. No operation has been done, but he has received chemo therapy to reduce the growth of the generalised carcinoma. He has strongly weakened and become increasingly confined to bed, but major complications have not yet occurred. So far, his 58 years old wife, who works part-time, has been able to provide the daily care to her husband, supported by the children and some friends. Medical support is provided by the GP, who is regularly paying visits. Pain is controlled by morphine plasters, but it is expected that soon the use of a morphine pump will be needed. The man and his family are aware of the terminal stage of the illness and they have decided that he will be at home as long as possible.

### Care needs

The man has not accepted the situation emotionally and his mood fluctuations are hard to cope with, in particular for his wife. She is dreading the future. On a short term, intensive nursing and drastic pain control will be required and her husband can no longer be left alone. His current bed has become impractical and he will not be able to go to the toilet and the bathroom. Although she fully supports the idea of having her husband at home, the wife feels she is at the end of her tether, both physically and emotionally.

**(Format of the questionnaire has been slightly compressed)**

**Please answer the following questions**

To what home care services would this man and his wife be entitled according to current criteria and rules in your country (so, this is about the ‘theory’; the practice may be different!).

*They are entitled to the following services:* .....

.....  
.....  
.....  
.....  
.....

Would eligibility of the needs of the woman be considered explicitly?

*(please fill in):* .....

.....  
.....  
.....  
.....

Which of the needs of the man and his wife would be covered by the services for which they are (‘theoretically’) entitled, and for which of their needs other solutions should be found (or remain unmet)? (also consider emotional support and care to alleviate the women’s burden).

*Entitled services cover the following needs of the two:* .....

.....  
.....  
.....  
.....

*The following needs cannot be met according to rules of entitlement:* .....

.....  
.....  
.....  
.....

Do financial consequences for the client apply to the acceptance of the eligible services in this case (for instance co-payments or other financial contributions)?

*(please explain):* .....

.....  
.....  
.....

Does a gap exist between the services to which the man and his wife are entitled and the services they will effectively receive? (This gap may result from possible shortages and other imperfections in your country).

***(You may tick more than one box)***

Normally all services to which they are entitled will be provided without reduction.

Usually, reductions are applied (for instance in number of hours of care) in the provision of the following type(s) of services.

*(please fill in):* .....

.....  
.....  
.....

Usually the following type(s) of services are not available at all.

*(please fill in):* .....

.....  
.....  
.....

I do not know

*Please further explain your answer:* .....

.....  
.....  
.....

Would some tele-care application be used in this situation in your country? (Examples of tele-care are personal alarm systems, distant observations and other ICT applications in home care).

*(please, tick the most applicable box)*

No tele-care applications will be used

Yes, the following tele-care applications can be used (also indicate the probability of use)

*(fill in a tele-care application):* .....

.....  
.....  
.....  
.....

How often this will be used in cases like this?

*(tick a box)*

often    occasionally    infrequent/rarely

*(fill in another application, if applicable):* .....

.....  
.....  
.....  
.....

How often this will be used in cases like this?

*(tick a box)*

often    occasionally    infrequent/rarely

*(fill in another application, if applicable):* .....

.....  
.....  
.....  
.....

How often this will be used in cases like this?

*(tick a box)*

often    occasionally    infrequent/rarely

I do not know

*Please further explain your answer:* .....

.....  
.....  
.....  
.....

In your country, who would most probably take the initiative in this case to apply for care?

*(please, tick the most applicable box)*

The man and/or his wife

The GP of the couple

Medical specialist by which he is treated

Hospital

Someone else, namely:

*(please fill in):* .....

.....  
.....  
.....  
.....

It depends on the situation who will take the initiative.

*(please explain below):* .....

.....  
.....  
.....  
.....

I do not know

*Please further explain your answer:* .....

.....  
.....  
.....  
.....

In your country, is there usually ‘one window’ for all services relevant to this application for care (as the start of the care process) or are different bodies or agencies to be approached separately?

*(please, tick the most appropriate box)*

There is one window or entry point for all home care services needed

Each service has its own entry point

The situation is different, namely:

*(please fill in):* .....

.....  
.....  
.....  
.....

I do not know

*Please further explain your answer:* .....

.....  
.....  
.....  
.....

Who will usually assess the needs and the personal situations of the man and his wife? Needs assessment is done by:

An independent formal assessing agency

A representative of the home care provider

A governmental organisation

Another type of organisation, namely:

*(please fill in):* .....

.....  
.....  
.....  
.....

It depends

I do not know

*Please further explain your answer:* .....

.....  
.....  
.....  
.....

Are explicit (written and publicly known) eligibility criteria used in needs assessment in this case?

*(please, tick the most appropriate box)*

In this case nation wide used criteria are applied

Criteria are used, but these are not used everywhere and not uniformly

No explicit criteria will be used

Another situation, namely:

*(please fill in):* .....

.....  
.....  
.....  
.....

I do not know

*Please further explain your answer:* .....

.....  
.....  
.....  
.....

In your country, who would take the decision about the granting of the requested services?

*The granting decision will be taken by:* .....

.....  
.....  
.....  
.....

In this case, will the availability of informal carers (the wife) be taken into consideration in the decision to grant services? If yes, in which way?  
*(please, tick the most appropriate box)*

No, the availability of informal care is not taken into consideration

Yes, availability of informal care is taken into consideration, as follows:

*(please fill in):* .....  
 .....  
 .....  
 .....

I do not know

Will the woman be considered as an informal carer only, or also as a client entitled to care?

No, she will not be entitled to home care

Yes, she will be entitled to the following services

*(please fill in):* .....  
 .....  
 .....  
 .....

I do not know

In this case, will the financial situation of the couple be taken into consideration in the decision to grant services? If yes, in which way?  
*(please, tick the most appropriate box)*

No, the financial situation is not taken into consideration

Yes, the financial situation is taken into consideration, as follows:

*(please fill in):* .....  
 .....  
 .....  
 .....

I do not know

Which care providers (professional and other) will probably be involved in home care for the man and his wife? *(you may tick more than one answer)*

Home help (domestic aid)

Nurse

Social worker

Physiotherapist

Occupational therapist

Family doctor

Medical specialist

Priest or spiritual worker

Children of the couple

Volunteers

Neighbours

Friends

Others, namely:

*(please fill in):* .....  
 .....  
 .....  
 .....

I do not know

*Please further explain your answer:* .....

.....  
 .....  
 .....

Will the process of care to the man and his wife be explicitly monitored from time to time to assess whether the provided care is still appropriate in relation to their (changing) needs? ('explicitly' meaning that it is done by a formal procedure at regular intervals)  
**(please tick one box)**

Services to this couple will not be explicitly monitored (monitoring procedures do not exist in this country)

Services to this couple will not be explicitly monitored (existing procedures are not widely used)

Services to this couple will be monitored according to an explicit systematic procedure

I do not know

*Please further explain your answer (including who will do the monitoring):* .....

.....  
 .....  
 .....

If in your country, formal home care would probably not be an option in this situation, what would likely be the alternative arrangement?  
**(you may tick more boxes, but limit to 'most probable')**

Not applicable, because home care is the most likely option in this case

The man would be admitted to a hospital

The man would be admitted to a nursing home

The man would be admitted to a hospice

A private nurse would be hired by the couple

The hospital would provide outreach services in the home of the patient

The man would suffer from unmet needs (reduced pain control; more emotional distress; poor coordination, etc.)

Another situation, namely:

*(please fill in):* .....

.....  
 .....  
 .....

I do not know

*Please further explain your answer:* .....

.....  
 .....  
 .....

Related to the situation and the needs of this man and his wife, what are frequently occurring difficulties, possible unmet care needs or other peculiarities, if they would live in your country? Would it make a difference in home care for them to live in a city or in a rural area?

*Please explain the possible difficulties, peculiarities or differences:* .....

.....  
 .....  
 .....

## Vignette 4

### Background

A 23 years old man, living with his parents, is severely disabled since his birth as a result of a Spina Bifida. He is wheelchair dependent and has severe bladder problems, for which he has been frequently hospitalised in the past. However, since he is using a bladder catheter his situation is stable and no more hospitalisation is foreseen. In and around his parental home he uses a wheelchair. For the longer distances he frequently uses transport by his parents, whose car is adapted for wheelchair access. Sometimes he uses a special taxi service.

### What happened

Although the relationship with his parents is fine, the man's desire is to live on his own and to be able to support himself as much as possible.

### Care needs

Independent living will firstly require an adapted dwelling. Furthermore, his current hand-powered wheelchair is not sufficient to safeguard the required range of action and mobility. He continues to need help with his bladder catheter. In his new situation he will also need help for cleaning the house and washing. He will be able to shop and prepare meals, but he needs additional support and guidance to run his own household, especially in the beginning.

**(Format of the questionnaire has been slightly compressed)**

**Please answer the following questions**

To what home care services that allow him to live independently, would this young man be entitled according to current criteria and rules in your country (so, this is about the ‘theory’; the practice may be different!). (In particular, consider the adapted dwelling, electric wheelchair; guidance, etc.)

*He is entitled to the following services:* .....

.....  
.....  
.....

*Please further explain your answer:* .....

.....  
.....  
.....

Would the man be eligible to receive a personal care budget to purchase his own care?

No

Yes, under the following conditions

*(please explain):* .....

.....  
.....  
.....

I do not know

Which of the needs of this young man would be covered by the services to which he is (‘theoretically’) entitled, and for which of his needs other solutions should be found (or remain unmet)?

*Entitled services cover the following needs of the young man:* .....

.....  
.....  
.....

*The following needs cannot be met according to rules of entitlement:* .....

.....  
.....  
.....

Do financial consequences for the client apply to the acceptance of the eligible services in this case (for instance co-payments or other financial contributions)?

*(please explain):* .....

.....  
.....  
.....

Does a gap exist between the services to which the man is entitled and the services he will effectively receive? (This gap may result from possible shortages and other imperfections in your country).

***(You may tick more than one box)***

Normally all services to which he is entitled will be provided without reduction.

Usually, reductions are applied (for instance in number of hours of care) in the provision of the following type(s) of services.

*(please fill in):* .....

.....  
.....  
.....

Usually the following type(s) of services are not available at all.

*(please fill in):* .....

.....  
.....  
.....

I do not know

Please further explain your answer: .....

Would some tele-care application be used in this situation in your country? (Examples of tele-care are personal alarm systems, distant observations and other ICT applications in home care).

*(please, tick the most applicable box)*

No tele-care applications will be used

Yes, the following tele-care applications can be used (also indicate the probability of use)

*(fill in a tele-care application):* .....

How often this will be used in cases like this?

*(tick a box)*

often    occasionally    infrequent/rarely

*(fill in another application, if applicable):* .....

How often this will be used in cases like this?

*(tick a box)*

often    occasionally    infrequent/rarely

*(fill in another application, if applicable):* .....

How often this will be used in cases like this?

*(tick a box)*

often    occasionally    infrequent/rarely

I do not know

Please further explain your answer: .....

In your country, who would most probably take the initiative in this case to apply for care?

*(please, tick the most applicable box)*

The parents of the man

The man himself

The hospital where he was treated in the past

The GP of the man

Someone else, namely:

*(please fill in):* .....

It depends on the situation who will take the initiative.

*(please explain below):* .....

I do not know

*Please further explain your answer:* .....

.....

.....

.....

.....

In your country, is there usually 'one window' for all services relevant to this application for care (as the start of the care process) or are different bodies or agencies to be approached separately?

***(please, tick the most appropriate box)***

There is one window or entry point for all home care services needed

Each service has its own entry point

The situation is different, namely:

*(please fill in):* .....

.....

.....

.....

.....

I do not know

*Please further explain your answer:* .....

.....

.....

.....

.....

Who will usually assess the needs and the personal situation of the young man? Needs assessment is done by:

An independent formal assessing agency

A representative of the home care provider

A governmental organisation

Another type of organisation, namely:

*(please fill in):* .....

.....

.....

.....

.....

It depends

I do not know

*Please further explain your answer:* .....

.....

.....

.....

.....

Are explicit (written and publicly known) eligibility criteria used in needs assessment in this case?

***(please, tick the most appropriate box)***

In this case nation wide used criteria are applied

Criteria are used, but these are not used everywhere and not uniformly

No explicit criteria will be used

Another situation, namely:

*(please fill in):* .....

.....

.....

.....

.....

I do not know

*Please further explain your answer:* .....

.....

.....

.....

.....

In your country, who would take the decision about the granting of the requested services?

*The granting decision will be taken by:* .....  
.....  
.....  
.....  
.....

In this case, will the availability of informal carers (the man’s parents) be taken into consideration in the decision to grant services? If yes, in which way? **(please, tick the most appropriate box)**

No, the availability of informal care is not taken into consideration

Yes, availability of informal care is taken into consideration, as follows:

*(please fill in):* .....  
.....  
.....  
.....

I do not know

In this case, will the financial situation of the man be taken into consideration in the decision to grant services? If yes, in which way? **(please, tick the most appropriate box)**

No, the financial situation is not taken into consideration

Yes, the financial situation is taken into consideration, as follows:

*(please fill in):* .....  
.....  
.....  
.....

I do not know

Which care providers (professional and other) will probably be involved in home care for the young man?

**(You may tick more than one answer)**

Home help (domestic aid)

Nurse

Social worker

Physiotherapist

Occupational therapist

Family doctor

Medical specialist

Volunteers

Neighbours

Friends

Others, namely:

*(please fill in):* .....  
.....  
.....  
.....

I do not know

*Please further explain your answer:* .....  
.....  
.....

Will the process of care to this man be explicitly monitored from time to time to assess whether the provided care is still appropriate in relation to his (changing) needs? (‘explicitly’ meaning that it is done by a formal procedure at regular intervals) **(please tick one box)**

Services to this man will not be explicitly monitored (monitoring procedures do not exist in this country)

Services to this man will not be explicitly monitored (existing procedures are not widely used)

Services to this man will be monitored according to an explicit systematic procedure

I do not know

Please further explain your answer (including who will do the monitoring):

*(please explain):* .....  
.....  
.....  
.....  
.....

If, in your country, formal home care and independent living would probably not be an option to this man, what would likely be the alternative solution? ***(you may tick more boxes, but limit to 'most probable')***

Not applicable, because home care is the most likely option in this case

The man would continue to live with his parents

The man would be in an institution for disabled people

The man would suffer from unmet needs (in particular his desire to live independently)

Another situation, namely:

*(please fill in):* .....  
.....  
.....  
.....  
.....

I do not know

*Please further explain your answer:* .....  
.....  
.....  
.....

Related to the situation and the needs of this man, what are frequently occurring difficulties, possible unmet care needs or other peculiarities, if they would live in your country? Would it make a difference in home care for them to live in a city or in a rural area?

*Please explain the possible difficulties, peculiarities or differences:* .....  
.....  
.....  
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.....



Demand for long-term care, of which home care forms a significant part, will inevitably increase in the decades to come. Despite the importance of the issue there is, however, a lack of up-to-date and comparative information on home care in Europe. This volume attempts to fill some of that gap by offering a country-by-country study of the situation in Europe.

Not all countries have an articulated policy on home care and in most countries, the available formal home care schemes fail to meet current demand for home care. Ambitions to develop and expand the home care sector in Europe will be restricted by prevailing financial constraints; unconventional solutions will need to be tried to bridge the gap between growing need and shrinking budgets. Retreating governments and the growing role of the private sector may be drivers towards a new balance between regulation, efficiency and flexibility of service delivery.

Home care is important for policy-makers because basic principles are at stake, including the protection of frail dependent people against quality failures and unaffordable care. This volume presents 31 case studies looking at the financing of home care, the organization and provision of services, and some of the challenges being currently faced or likely to be encountered in coming years.

## The editors

**Nadine Genet** is a researcher at the Netherlands Institute for Health Services Research NIVEL in Utrecht.

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“My congratulations for this truly impressive publication. The scope of the analysis offered in this book sets new standards and will set the mark high for future studies.”

*Manfred Huber, Coordinator, Healthy Ageing, Disability and Long-term Care, WHO Regional Office for Europe.*

