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**Freedom of choice and dignity for the elderly**

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## Contents

<b>Introduction .....</b>	<b>1</b>
<b>Discussion Paper: Freedom of choice and dignity for the elderly.....</b>	<b>3</b>
Part A: The policy debate on long-term care at European level.....	3
Part B: Description of the main elements of the Swedish policy on long-term care .....	13
Part C: The results of the Swedish policy on long-term care and its European Implications .....	21
Part D: The policy debate – Good practice and open questions.....	29
<b>Synthesis Report: Freedom of choice and dignity for the elderly .....</b>	<b>37</b>
Part A: The policy debate on long-term care at European level.....	37
Part B: Policy and situation in the host country – Sweden.....	41
Part C: Policy and situation in the peer countries Austria, Czech Republic, Ireland, the Netherlands, Portugal .....	45
Part D: Issues Discussed.....	54
Part E: Lessons Learned .....	55



## Introduction

Peer Reviews are a key element of the Open Method of Coordination (OMC), a central policy instrument of the European Union (EU). Peer Reviews are mutual learning processes based on the systematic evaluation of good practice and assessment of selected policies or institutional arrangements coming under the various NAPs. Peer Reviews are based on existing evaluation or early monitoring data and are thematically linked to common EU objectives for combating poverty and social exclusion. Every Peer Review is hosted by a Member State which will present the selected "good practice". These reviews will be carried out by a group of decision makers from peer countries, representatives of the European Commission, independent experts and stakeholder representatives with a special interest in the experience and transfer of the policy. Alternatively, other scenarios can also be considered. For instance, host countries can use the Peer Review seminars as an opportunity to gather expert advice from other countries in order to inform the process of preparation of a major policy reform in the field of social inclusion (or new programme or institutional arrangement). Their aim would be to take advantage of "good practices" existing in other EU countries to improve the efficiency of their reforms. Host countries could be identified on the basis of the common indicators endorsed by the Laeken European Council as the countries showing best performance in a number of areas (e.g. risk of poverty, in general or for specific categories, early exit from school, illiteracy, etc.). Peer Reviews allow for an open discussion between EU member states on social inclusion policies. They are intended to ascertain whether and how each reviewed policy, regarded as effective in a national context, can be effectively transferred to other Member States). More information can be found at the website on "Peer Review and Social Inclusion" ([www.peer-review-social-inclusion.net](http://www.peer-review-social-inclusion.net)).

In 2007, a peer review with the topic "Freedom of choice and dignity for the elderly" was conducted taking Sweden as a point of reference. The starting point of this peer review was a brief summary of the Swedish policies on long-term care, as given by the Swedish government<sup>1</sup>:

*In Sweden, policy for the elderly aims at enabling older persons to live independently with a high quality of life. Elderly care is provided in accordance with democratic principles and is mainly financed out of taxation revenue. The Swedish Parliament (Riksdagen) has defined the following objectives for national policy for the elderly. Older persons shall*

- *be able to lead active lives and have influence in society and in issues affecting their daily lives,*
- *be able to age with security and with their independence preserved,*
- *be met with respect and*
- *have access to good health care and social services.*

*One of the most important principles of Swedish policy for the elderly is that society's initiatives are to be framed in such a way that older persons can continue living in their own homes for as long as possible,*

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<sup>1</sup> see [http://www.peer-review-social-inclusion.net/peer-reviews/2007/freedom-of-choice-and-dignity-for-the-elderly/view?set\\_language=en](http://www.peer-review-social-inclusion.net/peer-reviews/2007/freedom-of-choice-and-dignity-for-the-elderly/view?set_language=en)

*even when in need of extensive care and social services. An accessible society, good housing, transport services and home help services are examples of important measures to realise that principle.*

The present report contains two documents from the 2007 peer review: A discussion paper which served as the basis for the discussion among participants and a synthesis report which contains the results of the review process. More information can be found on the website [www.peer-review-social-inclusion.net](http://www.peer-review-social-inclusion.net).

I am extremely grateful that Anna Hokema supported me in writing the discussion paper and, especially, the synthesis report. Without her help it would have been impossible to finish the two papers in a rather brief time span. Thanks for the reliable and excellent input to these papers!

# Discussion Paper Freedom of choice and dignity for the elderly

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## Summary

Life expectancy has increased in the past and will be increasing in the future. Especially European societies are witnessing the presence of an ever-rising number of very old persons, many of them in need of support and long-term care. This paper discusses European policy approaches which aim to support freedom of choice and dignity for older people with needs for long-term care. In the context of the Open Method of Coordination and, specifically, the procedures of the Peer Review, the Swedish national social protection policy has been chosen as point of departure. First, the policy debate on long-term care on the European and international level is treated. Secondly, the Swedish policy on long-term care will be described: its goals, resources, and implementation strategies. Thirdly, the results of the Swedish policy on long-term care are presented and its implications for the member states of the EU are discussed (The contribution of good practice in Sweden to the European policy debate and its transferability to European member states will be in the focus of this section, as well). Fourthly, the policy debate on long-term care in Sweden will be discussed. Open questions and areas of debate on the policy within Sweden and on the European level will be presented.

## Part A: The policy debate on long-term care at European level

### A.1 The policy framework at European level

#### *A.1.1 Demographic change and long-term care in Europe*

The population in developed countries is ageing rapidly (European Commission, 2005a). As a result of increasing life expectancy and the ageing of the baby boom generation the age group over 65 years of

age (2005: 79 million) will grow to 107 million in 2025 and to 133 million in 2050. Within this age group the largest growth is to be expected for people over 80 years of age (2005: 19 million, 2050: 51 million; Münz, 2007, p.5). Although age does not cause dependency, and may not even be the best indicator of need for long-term care services, the probability of dependency is raising with advancing age. Dependency is defined as the need for help with basic and instrumental activities of daily living over an extended period of time. Such basic activities of daily living include bathing, dressing, eating, getting in and out of bed or a chair, moving around and using the bathroom. Dependency often develops in individuals with longstanding physical or mental illnesses. Long-term care (LTC) services bring together a range of supports and services for dependent persons.

Individuals in the highest age groups of the population present the largest proportion of LTC services users. The overall proportion of older people in need of LTC in Europe was estimated to have been 12.6 million persons in 2004, which is 17 percent of the total population aged 65+ (Tsolova & Mortensen, 2006, p.3). The degree of dependency, however, shows a considerable disparity between European countries, ranging from only 15 percent of those aged 65+ in Austria and Sweden to more than 30 percent in the United Kingdom. Disability rates are higher for older women than for older men. Among those aged 80 and older, 27.7 percent of men and 36.3 percent of women reported at least one limitation in activities of daily living which can be explained at least partly by gender differences in living conditions (while men quite often live together with a partner even in late adulthood, women are more often widowed and living alone).

The effect of demographic ageing on the LTC sector might be modulated by several societal developments. The number of very old people affected by age-related illnesses will increase in the future with high probability. However, because of improving health in subsequent cohorts, it is uncertain how much the proportion of very old people with the need for LTC services will increase. The ageing of the population is accompanied by a growing number of old people living alone, because of changing family dynamics, and a higher female employment participation rate, which means that men have to be more active in informal care work in the future as women are carrying the main part of this task at present. Hence, there is a need for well-planned and sustainable policies on long-term care which integrates policies on health care, housing and social services.

### *A.1.2 Common objectives*

Following the Lisbon and Gothenburg European Council meetings, the European Commission identified three principles that serve as a basis for the development of health and long-term care systems which could meet the challenges of demographic ageing. These principles refer to accessibility, quality, and financial sustainability of medical and social care: "Member states are committed to accessible, high-quality and sustainable health care and long-term care" (European Commission, 2007b, p. 78). From the perspective of old people in need of care, access to and quality of services are intertwined principles. High quality services which are accessible to a small share of the population only are as unacceptable as



broad access to services with low quality. Hence, successful policies have to reach the two goals of accessibility and quality of services concurrently (under consideration of financial sustainability). Lately, it has been suggested to focus on human rights in order to evaluate the adequacy and efficiency of services to older people: "Human rights instruments offer the hope ... of using resources more appropriately and generously, according to the severity of need" (Townsend, 2006, p. 177). Hence, human rights might be used to develop indicators of good care

Two European documents may demonstrate this claim. In the Charter of Fundamental Rights of the European Union (European Union, 2000) the right for adequate medical and social services is mentioned several times. A counterpart of this document is the European Social Charter, which includes rights to provision for health care, social security, welfare services and care for old and disabled persons (cf. article 23 "The Right of Elderly Persons to Social Protection"). The European Charter describes political goals which are to be reached in cooperation between public and private organisations. These European charters are important in setting important goals for securing adequate long-term care. However, because of their broad scopes, these charters are highly abstract, and it is not easy to spell out what freedom of choice and dignity for the elderly in the context of dependency and long term care means. For instance, the general right of older people "to remain full members of society for as long as possible" (European Social Charter) has to be explained in more detail.

An example for the attempt to define the rights of older people in need of care in simple and concrete terms is the "Charter of Rights for People in Need of Long-Term Care and Assistance" which has been published by the German Government (German Federal Ministry of Family Affairs Senior Citizens Women and Youth & German Federal Ministry of Health, 2007) in 2007 (see Box 1, containing the eight articles which are described in detail in the charter itself). This charter specifies universal rights (and entitlements based on national social policy of Germany) for the particular situation of frail and dependent persons. Although this charter has grown out of the German national context, the specifications of rights might apply to European societies in general. Because the charter has been introduced only recently, there is no systematic evidence on the impact of this document so far. However, one may assume, that this charter improves the information of old, dependent persons and their care givers. In addition, it establishes a broadened framework for the definition of quality of care. While traditional outcome measures of quality of care are health oriented (like incidence of pressure sores, malnutrition, restraints, and tube feeding), this charter allows to define – and eventually measure – quality of care on wider terms, including fundamental aspects like freedom of choice and dignity when facing dependency. At the moment, several projects develop quality indicators based on this charter which might be used in quality management systems.

**Box 1: Charter of Rights for People in Need of Long-Term Care and Assistance****ARTICLE 1: SELF-DETERMINATION AND SUPPORT FOR SELF-HELP**

Everyone in need of long-term care and assistance has the right to support for their self-help efforts to enable them to live a life which is as self-determined and independent as possible.

**ARTICLE 2: PHYSICAL AND MENTAL INTEGRITY, FREEDOM AND SECURITY**

Everyone in need of long-term care and assistance has the right to protection against any physical or mental threats.

**ARTICLE 3: PRIVACY**

Everyone in need of long-term care and assistance has the right to the safeguarding and protection of his or her private and intimate sphere.

**ARTICLE 4: CARE, SUPPORT AND TREATMENT**

Everyone in need of long-term care and assistance has the right to qualified, health-conducive care, support and treatment tailored to his or her personal needs.

**ARTICLE 5: INFORMATION, COUNSELLING, EXPLANATION**

Everyone in need of long-term care and assistance has the right to be fully informed of the possibilities and opportunities available for counselling, care and treatment.

**ARTICLE 6: COMMUNICATION, ESTEEM AND PARTICIPATION IN SOCIETY**

Everyone in need of long-term care and assistance has the right to esteem, interaction with others and participation in the life of society.

**ARTICLE 7: RELIGION, CULTURE AND BELIEF**

Everyone in need of long-term care and assistance has the right to live according to his or her culture and belief and to practice his or her religion.

**ARTICLE 8: PALLIATIVE SUPPORT, DYING AND DEATH**

Everyone in need of long-term care and assistance has the right to die in dignity.

The entire text of the charter can be obtained at  
[http://www.dza.de/allgemein/Charta\\_English\\_Final\\_Draft.pdf](http://www.dza.de/allgemein/Charta_English_Final_Draft.pdf)

## A.2 A summary of the related policy debate at European level

Although member states of the European Union have agreed on common goals regarding the development of care systems, there are large differences between member states in a variety of dimensions. Several typologies of welfare regimes have been described. In a classic distinction, residual welfare states assume responsibility only when families or the market fail, while institutional welfare states offer universal transfers and services (Titmuss, 1987). Esping-Andersen (1999) identified three types of welfare state regimes: liberal welfare states as in the United Kingdom, the United States and Australia provide means-tested benefits at a low level; conservative/corporatist welfare states as in Germany, France and Italy provide benefits based on insurance principles; and social-democratic welfare states as in Sweden and Norway guarantee universal benefits and services at high levels based on taxation. Lately, the increased diversity of European societies has been acknowledged by introducing five types of "elder care country-clusters" (Lamura et al., 2007). Based on the distinction between demand for care (e.g. share of oldest-old population, economic wealth), provision of informal care (e.g. diffusion of extended households and informal care), and provision of formal care (e.g. public expenditure on elder care, share of older people receiving formal home care or residential care) five care regimes are distinguished:

- *Standard-care mix countries* (like Germany, Austria, France, Italy, UK): medium to high demand for care, medium to low provision of informal care, medium provision of formal care
- *Public-Nordic countries* (like Sweden, Denmark, Netherlands): medium demand for care, low provision of informal care, high provision of formal care
- *Family based countries* (like Spain, Portugal, Ireland, Greece): high demand for care, medium provision of informal care, low provision of formal care
- *Transition countries* (like Hungary, Poland, Czech Republic): low demand for care, high provision of informal care, medium to low provision of formal care
- *Baltic countries* (Estonia, Latvia, Lithuania): low demand for care, high provision of informal care, very low provision of formal care

In the current context, not the choice of a specific welfare state typology matters, but the fact that differences between countries are multi-dimensional. For instance, in the Nordic countries the demand for care is relatively low, but the generosity of public formal care rather high, whereas in the family based countries the demand for care is high, but provisions of formal care rather low. In addition, and sometimes overlooked are cultural differences between countries: While in some countries informal support of families is seen as a matter of course, in other countries it is much more common to rely on formal services for personal care (and this is also seen as a legitimate option to choose). However, welfare states are changing, partly because of convergence in the European context, but it seems unlikely that all differences in national care strategies will disappear in the near future (Bettio, 2004).

Although there is no comprehensive system for the provision of long-term services in the EU, the member states are committed to ensure universal access to quality care. Responsibility for funding and organisation of long-term care rests primarily with the member states. Long-term care provision varies across member states, both in terms of coverage of the population and extent of provision and also in terms of the schemes used. As instruments are used in-kind benefits or cash allowances and personal budgets or a mix of the two. Several countries have a mixed financing system (e.g. Belgium, France), combining resources from insurance schemes and taxes, with different budgets and institutions responsible for the provision and purchasing of long-term care. Some countries provide comprehensive public programmes financed through social insurance (e.g. Germany, Luxembourg, Spain), whereas others fund their programmes through taxation (Sweden, Denmark, Lithuania) or means-tested schemes (e.g. United Kingdom, Cyprus)

The task of the “Open Method of Coordination” (European Commission, 2005b) and, specifically, the peer-review process is to analyse the present situation of long term care in European societies, to describe the diverse solutions implemented by the member states, and to evaluate the results in respect to the criteria mentioned above: accessibility, quality, and sustainability of care services. The intention of benchmarking processes like the Open Method of Coordination is to learn about good (or poor) practices, in order to support steering the regulations and framework of care systems. However, as pointed out above differences between European countries not only exist in respect to care policies, but also in mortality and morbidity structures as well as cultural beliefs and societal structures. These complexities have to be taken into account when comparing European countries in respect to care policies.

### **A.3 European and international comparative aspects**

Early in 2007, the European Commission published a supporting document to the “Joint Report on Social Protection and Social Inclusion” which is based on national reports of the European member states and discusses the current state of long-term care in Europe thoroughly (European Commission, 2007b, pp. 100-110). Hence, whenever it is appropriate the key messages of the supporting document will be presented briefly in the following paragraphs.

#### *A.3.1 Ageing and health: The needs for support and long-term care among old people in Europe*

Although the increase in life expectancy will mean a higher share of old and very old people in the future, this does not necessarily mean more old people in need of care. Moreover, it is well known that aspects of the living situation, like co-residence with a partner or family members play an important role in the development of the need of care. Women often outlive their partners and therefore lack the support of a

spouse in old age. European countries differ in the extent of older persons with the need of help and support.

With the current steady increase in the life-expectancy of Europe's population, the number of people with dementia and related disorders is forecast to increase in the future. Dementia affects memory, intellectual abilities, emotion regulation, and behaviour. As the disease progresses, practical difficulties with daily tasks such as dressing, washing and going to the toilet gradually become so severe that the person becomes dependent on others. For carers, changes in personality, e.g. emotionally disruptive and aggressive behaviour, as well as the loss of identity can be very straining. Nevertheless, in many European countries, the majority of people with dementia live at home and are cared for by their relatives and friends. Hence, medical and social care has to take into account not only the special needs of people with dementia, but also those of their carers.

If healthy life expectancy is growing faster than general life-expectancy, this could mean that the rate of old people in need of care grows slower than the share of very old people in general (this assumption is also known as "compression of morbidity"). If such a compression of morbidity occurs over time, that should be seen also in a decreasing portion of the oldest old suffering by functional disabilities. However, the development in the proportion of severely hampered persons in the age group of 80 years and older does not give a clear picture (see table 1). Between 1994 and 2001 there is no clear trend in the share of severely hampered persons in this age group. The share changes from one year to the next, but there is no decisive trend discernible, at least for the six European countries selected. Hence, although the positive implications of morbidity compression are emphasized (Fries, 2005), the scientific debate still continues to weigh up the hypotheses of compression versus expansion of morbidity.

Table 1: Severely hampered person in the age group 80 years and older in selected European countries 1994-2001. Source: ECHP (Schulz, 2004, p. 69)

	1994	1995	1996	1997	1998	1999	2000	2001
<i>Belgium</i>	30.4	27.3	27.6	21.1	23.1	18.9	17.6	21.6
<i>Germany</i>	n.a.	38.4	41.0	33.2	41.3	44.2	37.9	41.0
<i>Denmark</i>	20.8	21.6	24,9	22,9	24,5	23,3	27,8	29,6
<i>Netherlands</i>	25,5	21,9	26,7	21,1	25,1	20,3	26,2	27,4
<i>Spain</i>	30,1	27,8	24,5	24,5	27,8	23,8	24,7	24,8
<i>France</i>	36,2	40,7	38,8	42,7	41,2	40,3	33,4	34,5

### *A.3.2 Accessibility of care*

The need to call into question the adequacy of long-term care systems in the light of population ageing, socio-demographic developments and changing needs has been recognized in many European societies. One issue effectively acting as a barrier to access for long-term care may be the cost of long-term care services. High private costs act as a barrier to access, particularly for low-income groups. Women are more often affected by the high costs of long-term care than men, because they have lower incomes in old age, due to unpaid caring activities, interrupted employment careers and part-time work during their life course. The lack of public long-term care services can also result in substantial waiting times for care services, particularly residential care. Uneven geographical provision (across regions, urban versus rural, within cities) can also be observed as social services are typically the responsibility of local authorities or regions. In general, many member states want to expand long-term care services.

In the European discourse, other aspects of accessibility are discussed as well. Even if long-term care services are available, they may not be known to potential users. Long-term care policies must therefore develop care systems which are sufficient and well adapted to the needs of the population – and which are easy to identify and to find. “Single entry” solutions seem to support the accessibility of services. Finally, a general problem in European societies seems to be the lack of well-trained and competent staff, which might stem from the low salary and prestige of positions in the long-term care sector. Hence, it seems important to improve the education and career opportunities for personnel working in the LTC sector.

### *A.3.3 Quality of care*

Defining, monitoring, and improving quality of services: Although quality of care belongs to the central objectives in the European debate, there is a lack of definition. Clearly, there is no gold standard of good care. Quite often, quality of long-term care is defined on three levels: quality of structure, process, and outcomes. Examples are building characteristics or staff qualification (quality of structure), procedures of resident assessment, care planning, and existence of quality management (quality of process) and results of the care process on the individual level, like incidence of pressure sores, malnutrition, restraints, and tube feeding (quality of outcome). As outlined above, it might be useful to consider fundamental human rights as a basis for defining and measuring quality long-term care (Townsend, 2006). Two examples from residential care may show that there may be problems in quality of care in European countries. The percentage of residents living in single rooms varied between 49 percent (Germany, 2001) and 84 percent (UK, 2003) (OECD, 2005, p. 77). Evidence of quality deficits in nursing home care has been reported in OECD countries in different domains, e.g. pressure sores, malnutrition, pain management, and physical/pharmaceutical restraints (OECD, 2005, p. 68). Hence, improving quality of care plays a major role in the European debate. A basic requirement for quality assurance, of particular relevance for long-term care, is the active deterrence of maltreatment or abuse. Uniform quality

assurance mechanisms can address regional inequalities in provision and deter arbitrary discretion application in users' needs assessment at local or regional level.

Consumer direction and choice: Highly important for the concept of quality of services is the degree to which the provision of services meets the demand for patients and their private network. Three types of arrangements can be distinguished which allow long-term care users more choice: (a) personal budgets and consumer-directed employment of care assistants, (b) payments to the person which can be spent as the persons wishes under the condition of acquiring sufficient care services, (c) payments to informal care givers as income support. There is a clear trend in the European discussion that, where available, home or community care is preferred to institutional care as older people prefer to live at home. However, institutional care provision will continue to be important for patients with severe disability. Arrangements which increase consumer choices should lead to improved empowerment, autonomy, and independent living. However, there is not always solid evidence if (and how) these intended effects can be reached.

Establishing continuum of care: Care needs of older people tend to be complex and call for co-ordinated approaches to provide a continuum of care. In many instances, acute health care, rehabilitative services, long-term care, support with household chores and advisory services may be fragmented, not only because of different institutional organizations, but also because of different funding schemes. This is especially true for home care, but can be problematic in the case of residential care as well. Coordination problems at the interface between medical, social services and informal care can result in negative outcomes for users and in inefficient use of resources. This seems to be a problem in many European countries, and a variety of different solutions have been developed. Examples for policies which intend to establish a continuum of care are: coordination and combination of health and social budgets, development of common assessment schemes for multidisciplinary teams, establishing an infrastructure of case and care management which supports long-term care users and their carers.

Using technology: Currently, technological progress has a deep impact on the health sector, but not so much on the long-term care sector. However, this may be changing with new generations of ageing and old consumers who have grown used to handling technological devices and services, like the computer and the Internet. Hence, using technology to improve the quality of care will be a task for the next future. Using not only intelligent technology, but using technology in an intelligent manner will be a challenge. Information and communication technology (e-health solutions such as tele-monitoring, telemedicine and independent living systems) can help to ensure independent living and more user-oriented services. For example, information and communication technology (ICT) can offer better self-management of chronic conditions and can support informal carers in their role. Finally, technology plays also a role in information on the accessibility and quality of care services, e. g. via the Internet.

### *A.3.4 Financial sustainability of care*

Financial sustainability of care systems for old people is at the moment often discussed in terms of “burdens of care”, “future risks of demographic change” and “generational equity”. Hence, continuing to offer accessible, high-quality care without taking funds away from other sectors or political priorities is a major challenge. In Europe, a large proportion of spending for health and social care comes from public funds. However, there are large disparities in the proportion of GDP spent for health and social care, and also in respect to increasing or decreasing spending in this area over the last decade. However, so far there is a discussion about the adequate mix between public and private sources of finance. In general, appropriate measures should be taken to ensure sound management of public funding for health care and long-term care, concentrating on the need to improve the quality and effectiveness of public expenditure. In detail, this could mean to develop prevention and guidance policies to reduce the need for expensive treatments, but also to offer cost-effective care and improve the effectiveness and efficiency of the care system.

## **A.4 An assessment of measuring the results of the policy under review**

In order to comparatively evaluate the impacts of policies on long-term care, it is necessary to define adequate indicators which measure the commonly agreed objectives – accessibility, quality, and financial sustainability of long-term care. Hence, indicators should be available which can be used in monitoring the overarching objectives specified earlier. The European Commission has published a portfolio of overarching indicators on social inclusions, pension, and health (European Commission, 2006b). These commonly agreed indicators and context information will continue to be calculated and regularly updated by Eurostat on the basis of the commonly agreed definitions and presented on the Eurostat website.

However, the indicators listed in the portfolio of overarching indicators in the health domain are mainly covering the area of medical services. The only indicator referring to long-term care and social services refers to financial sustainability (HC-C8: projection of public expenditure on long-term care as percent of GDP). Clearly, the areas of accessibility and quality of care services are not covered with the existing scheme of indicators. Hence, it could be useful to add indicators which would allow a better assessment of policy impact in the area of long-term care and social services. Table 2 shows some suggestions for indicators which would allow to measure results of policies on long-term care in an European comparative perspective.



Table 2: Indicators which allow to measure results of policies on long-term care in an European comparative perspective

	<i>Access</i>	<i>Quality</i>	<i>Sustainability</i>
<i>Primary Indicators</i>	Self-reported unmet need for social care services	Outcome indicators based on dignity, free choice, privacy, and physical integrity	Projection of public expenditure on long-term care as percent of GDP
<i>Contextual Indicators</i>	Number of home care services or number of beds in residential care on 100.000 inhabitants	Structural indicators, e.g. proportion of single rooms in residential care facilities or proportion of qualified staff	Willingness of population to adapt public spending on long-term care to the needs of the ageing population

## Part B: Description of the main elements of the Swedish policy on long-term care

The following description of the Swedish policy on long-term care has been based on several official papers from the Swedish Government, the Swedish Association of Local Authorities and Regions, and the European Commission (European Commission, 2007a; Swedish Association of Local Authorities and Regions [SALAR], 2007; Swedish Ministry of Health and Social Affairs, 2006, 2007a, 2007b, 2007c, 2007d). Hence, this brief discussion by no means claims to be comprehensive.

### B.1 Background

The Swedish welfare state model can be described by several characteristics: wide-ranging social sector, active employment policies, universal rights for benefits or services, citizenship as basic criterion for support, taxation as the main source of financing, and a combination of income related and flat rate benefits. Equality between women and men is a highly important goal: This entails efforts to reach equal employment opportunities, equal pay, and the provision of day care services for children. In the 1950's and 1960's the Swedish welfare state expanded and had its peak in the 1980's. The 1990's were a decade of economic crisis, not only for Sweden, but also for other Nordic welfare states as well. During this period, many social services have been curtailed. Nevertheless, compared to other European countries, Sweden still has the highest gross expenditure on overall social protection in relation to GDP (32.9 percent in 2004). In terms of social inclusion policy, Sweden is very successful. For instance, risk of poverty (9 percent in 2004) and income inequalities are low as compared to other European countries.

Sweden is projected to face less challenging demographic trends in comparison to most EU member states: the old age-dependency ratio in Sweden will increase from 26 percent in 2004 to 41 percent by 2050 while the EU25 average will increase from 25 percent to 52 percent (European Commission, 2007a, p. 235). It should not be withheld, however, that the welfare state in general, and Sweden, too, has been criticised, because its financial basis may be not sustainable. Before this background, the main elements of Sweden's policy on long-term care will be described in the following sections.

## B.2 The goals, objectives and target groups of the policy and its reform

In respect to the policy for the elderly, the overarching goal is "enabling older persons to live independently with a high quality of life" (Swedish Ministry of Health and Social Affairs, 2007b, p. 1). The Swedish Parliament has defined the following objectives for national policy for the elderly. Older persons shall

- be able to lead active lives and have influence in society and in issues affecting their daily lives
- be able to age with security and with their independence preserved
- be met with respect and
- have access to good health care and social services

One of the most important principles of Swedish policy for the elderly is that society's initiatives are to be framed in such a way that older persons can continue living in their own homes for as long as possible, even when in need of extensive care and social services. The basis for the provision of long-term care services for old persons are two national acts, namely the Health and Medical Act (Swedish Ministry of Health and Social Affairs, 1982), and the Social Services Act (Swedish Ministry of Health and Social Affairs, 2001), which have seen several reforms since their enactments. These acts refer also to the main objectives of the European debate, namely accessibility, quality, and financial sustainability of long-term care. When comparing the Swedish system with other countries one has to be aware of the terms used.

In Sweden, the term *special housing* (former service houses, old people's home, group-home, nursing home) is used as official term while in other European countries terms like residential care or long-term care facility may be used. One could debate, of course, if only the words differ (and the places people live in are very similar) or if the terms reflect also differences in structure, organisation, and attitude of long-term care. However, in the following, for the Swedish situation only the term "special housing" will be used (and for other European countries, the terms "residential care" or "long-term care facilities" may be employed where appropriate).

### *B.2.1 Accessibility*

Health and social services in Sweden are open to all those in need of care. "Health and medical services are aimed at assuring the entire population of good health and of care on equal terms (SFS 1982:763, ch. 1, sect. 2). In addition, they should be "readily available" (SFS 1982:763, ch. 1, sect. 2a). In respect to social services, the responsibility for "ensuring that persons staying within the boundaries [of a municipality] receive the support and assistance they need" lies with municipalities (SFS 2001:453, ch. 2, sect. 2). The municipality takes care to "ensure that older persons obtain good housing" and to "provide support and assistance in the home and other readily available services for those in need of the same" (SFS 2001:453, ch. 5, sect. 4). Specifically, the following services are part of Sweden's LTC policy: home care services, adult day care, personal safety alarms, short stay housing, home health care, assistive devices, home adaptations, transportation services, special housing, support for family carers, and dental care (Swedish Ministry of Health and Social Affairs, 2007b). Although the Swedish welfare policy has a universal perspective, special attention is given to particularly vulnerable groups. For instance, the special needs of old persons with dementia or of persons with certain functional impairments are taken into account on the level of the municipalities (Swedish Association of Local Authorities and Regions [SALAR], 2007). Also the situation of elderly who migrated to Sweden during their life course is considered in respect to access and use of social services.

### *B.2.2 Quality*

The quality of health and social care is of central importance in Swedish social policy law. The Swedish Health and Medical Services Act states that the aim of Swedish health care is for the whole population to have access to good care services on equal terms. Health and medical services must "be of good quality and cater to the patient's need of security in care and treatment" (SFS 1982:763, ch. 1, sect. 2a), and "measures within social services shall be of good quality" (SFS 2001:453, ch. 3, sect. 3). Government policy for tackling current problems and supporting positive future development has been set forth in the National Development Plan for Health Care and Social Services for the Elderly (Government Bill 2005/06:115). Over the next ten-year period, the Swedish Government intends to raise the level of aspiration and quality in medical care and social services for the elderly (Swedish Ministry of Industry Employment and Communications, 2005, p. 46).

### *B.2.3 Sustainability*

The Swedish economy is growing at the time being. Growth is expected to be 3.0 percent in 2007. The public finances are also developing well. The Swedish government anticipates that central government debt will decrease in 2006, both in proportion of GDP and in monetary terms. However, financial sustainability of long-term care requires long-term strategies. The Swedish Government's National

Development Plan for Health and Social Services for the Elderly contains several initiatives to support municipalities and county councils in their efforts to combine both better quality and improved efficiency in delivering long-term care services. Good quality and good efficiency are essential if legitimacy is to be secured for long-term care services among the public. However, it is difficult to predict the future development of the demand for long-term care services as a variety of factors have to be considered, like demographics, trends in health, income, technologies, changes in expectations and values and the relationship between the efforts of the public institutions and those of family members (Swedish Ministry of Health and Social Affairs, 2006).

### **B.3 Legal, financial and human resources provisions to implement the policy**

#### *B.3.1 Legal Resources*

Overall responsibility for care of the elderly in Sweden rests with the state. There are three tiers of the state in Sweden: The national level (Parliament and Government), the regional level of 21 counties with county councils, and the municipality level with 290 municipalities. The three levels have different roles and responsibilities in respect to health and social care. On the national level, legislation governs the general framework for health and social care in Sweden, like for instance over the Health and Medical Service Act or the Social Services Act. The national authorities – the National Board of Health and Welfare (focusing health care issues) and the 21 county administrative boards (focusing social services issues) – are responsible for supervision, follow-up and evaluation of municipal and county council caring services. The county councils operate the hospitals and out-patient clinics, while the responsibilities of municipalities include health care in special forms of housing, e.g. nursing homes. Finally, the responsibility for social care rests with the municipality. The social welfare committee, a municipal institution, plays a central role in ensuring adequate social infrastructure at the community level. Within the broader framework of national legislation, county councils and municipalities are autonomous, i.e. local politicians are elected at general elections, and both municipalities and county councils levy taxes (Swedish Ministry of Health and Social Affairs, 2007b).

The coordination between health services (county level) and social services (municipality level) has been re-organized in a reform about 15 years ago. Up to this reform, responsibility in health care and social care of the elderly was divided between county (health care) and municipal level (social care). However, as during the 1970's and 1980's more persons with extensive needs of health care and social care could stay on in their ordinary homes because of improved home care services, the division of responsibility for health and social care became unclear. In 1992, a major national reform of policy for the elderly ("Ädel reform") came into force. Under this reform, the municipalities were given overall responsibility not only for social care (special housing accommodation and home care), but also for health care for the elderly and disabled person who live in special housing. Responsibility for the work of physicians in hospital and

primary health care in out-patient clinics remained under the responsibility of county councils. However, the county were allowed to transfer this responsibility to the municipalities which has been done in half of the 290 municipalities. This is a good example of integrated care, e.g. in order to provide targeted services. The municipalities were also given financial responsibility for patients whose medical treatment in hospitals has been completed and who are staying in long-term care facilities. Evaluations of this reform showed that more elderly could live at home even if there was need for extensive care and that the former problem of "bed-blockers" in hospital care had been reduced. Although the standard of special housing for the elderly had increased through the reform, in some municipalities waiting lists exists. Evaluations also show some other deficiencies, for example in respect to the supply of physicians in care of the elderly or the cooperation between municipalities and county councils (Swedish Ministry of Health and Social Affairs, 2007b).

Finally, it has to be emphasized, that freedom of choice for individuals has become a strong part of the Swedish policy on health and social care (Swedish Ministry of Health and Social Affairs, 2007b). Since the early 1990s an increasing number of municipalities have chosen to make elderly care subject to competition. In 2006, about 30 municipalities had introduced client choice or some similar activity. Client choice primarily applies to social home care in ordinary housing, including practical services. Since 2003 people everywhere in the country have been entitled to freedom of choice in health care. Free choice means that patients can seek out-patient care anywhere in the country on the same terms as in their own county council area. When a county council decides on a course of treatment, such as hospital care, the patient is free to choose a hospital anywhere in the country.

### *B.3.2 Financial Resources*

In 2005, Swedish municipalities spent about SEK 80.3 billion on long-term care (about EUR 8.6 billion; (Swedish Ministry of Health and Social Affairs, 2007c). Special housing accounts for 64 percent of this amount, home care for 34 percent and preventive activities for 2 percent. Care for a person living in special housing is approximately twice as costly as care in ordinary housing. If health care services provided for the elderly at county council level (i.e. hospital care and out-patient care) are included, the total cost for health and social care approximates about SEK 160 billion (about EUR 17.1 billion). Municipal health care and social care services for the elderly are mainly (more than 80 percent) financed by taxes levied by municipalities on their residents. A smaller part of this elderly care is financed by government grants to the municipalities. About 4 percent of the costs are financed privately by fees. In 2002 new rules under the Social Services Act came into force about charges for the care of the elderly. The new rules set limits for the highest charge which can be made for home-help services (in both ordinary housing and special housing accommodation), daytime activities and certain outpatient health care (Swedish Ministry of Health and Social Affairs, 2007d). The financial resources devoted to long-term care in Sweden are exceptionally high, much higher than in all other countries in Europe and the OECD. Sweden spends about 3.8 percent of its total GDP on long-term care (Finland which holds the second place in Europe spends 1.7 percent of its GDP on long-term care). This generous spending is not

explained by the demographic composition of the Swedish population alone: It is higher than would be predicted from the proportion of old people (OECD, 2005).

### *B.3.3 Human Resources*

The general principles of the Swedish policy on long-term care of the elderly are the same throughout the country, namely that social care and health care for the elderly are primarily public sector tasks and that care is to be provided by trained and qualified staff. Knowledgeable and engaged personnel are key prerequisites for achieving and maintaining high quality in care services. All older people in need of health and social care must be able to meet skilled staffs who work in a well-functioning organisation. In order to respond to people on the basis of their unique life situation and background, medical knowledge needs to be combined with social and cultural skills. "Steps for Skills" is a national initiative appointed by the Swedish government to support municipalities' long-term quality and skills development in health and social care for older people. The purpose of "Steps for Skills" is to improve the internal quality of health and social care. This will be achieved by developing the skills of the staff working with older people. In the period 2005-2007 a total of more than one billion SEK (about EUR 107 million) will be awarded to municipalities that want to enhance staff skills (Swedish Ministry of Health and Social Affairs, 2007d). Staff in long-term care services are mostly women like in many other European countries. A study is planned to present proposals for a national system concerning professional qualifications, education and training for care occupations, and to propose actions to enhance future personnel recruitment (European Commission, 2007a).

## **B.4 Institutional arrangements and procedures of implementation**

As long-term care lies in the responsibility of Swedish municipalities, the institutional arrangements and procedures of implementation of services will be discussed using Nacka, a municipality near Stockholm, as an example ([www.nacka.se](http://www.nacka.se)). Nacka has about 80.000 inhabitants and expects to grow in the next years (Nacka Kommun, 2006). The proportion of children is higher and the proportion of people 65 years and older is lower than the national average. The average yearly income in Nacka (SEK 268.800 in 2004) is above the national average for salaries in the private sector (about SEK 230.800, according to <http://www.worldsalaries.org/sweden.shtml>). Hence, when looking at the institutional arrangements of long-term care services in Nacka, it has to be kept in mind, that the proportion of old people is below and the economic prosperity above national average in this municipality.

### *B.4.1 Providing access*

In order to increase the freedom of choice of citizens, Nacka has been operating since 1992 a customer choice system for both home care and care in special housing (Nacka Kommun, 2002a, 2002b). Residents who apply for home help (personal assistance and care in the home), companion services (helping the disabled to take part in various activities) or respite services (service aimed at people caring for relatives) will be assessed by a care manager. Citizens who have been granted assistance can choose between a number of private and municipal providers. About 12 percent of estimated hours of assistance reported by the municipalities in October 2006 were delivered by private sector care providers (Swedish Ministry of Health and Social Affairs, 2007c, p. 4). The instrument for remuneration is the municipal cheque. The cheque states the number of hours of support which the resident is entitled to receive per month. No actual cheque is handed over when purchasing services (the care provider fills in a timesheet, which the customer signs as confirmation that the service has been carried out). The citizen pays a fee (in the year 2002, this fee was SEK 50 or EUR 5.40 per hour, with a maximum of SEK 1,516 or EUR 165 per month). The slightly different procedures of assessment for people receiving home care and people living in special housing are resting on the same principles. The municipality of Nacka has designed a measurement instrument for needs assessment which takes into account four factors: physical status, change in mental age, psychological status and need for medical input. No information, however, about the quality of this measurement instrument is given. There are eight groups of "need of care" with different entitlements (in 2002 the amounts paid by the municipality varied between SEK 686 and SEK 1,442 per day). There is also a fee which has to be paid by care recipients (SEK 1,516 per month in 2002). If there is a waiting list, those who have the greatest need will be offered the first available place.

### *B.4.2 Ensuring quality*

In general, in Swedish municipalities that apply the client choice model providers all receive the same payment in the client choice system, with the exception of supplementary services where the providers themselves set the price. As the price is given, the providers have to market themselves on the basis of their service quality instead. As many users receive information about the various providers from their neighbours, friends and acquaintances, the provider's reputation is important for the choice made by the user. Also in the municipality of Nacka, the work of care providers is initially assessed and approved by the customer. As the municipality has the ultimate responsibility for care services, the municipality's assistance officer follows up the services carried out. Anyone is free to establish a care operation in Nacka, although authorisation from the municipality is required. The requirement for private care providers is in compliance with applicable legislation and approval by the County Administrative Board. A company must have necessary knowledge and experience within long-term care for the elderly. Nacka's Elderly Services Committee is responsible for financing and following up quality within home care and care in special housing. In general, Sweden's health care services are supervised by the National Board of Health and Welfare and social services by the County Administrative Boards (Johansson, 2004, p. 29).

It is difficult, however, to establish the actual quality of home care and residential care in the community of Nacka as there is no information on quality indicators. This is not untypical for the Swedish situation: Decentralization of responsibility for social care has meant that national data are frequently lacking. There will soon be an improvement here because the National Board of Health and Welfare and the Swedish Association of Local Authorities and Regions have agreed to establish a model for comparing and evaluating achieved goals and results (Swedish Ministry of Health and Social Affairs, 2007d). The aim of this initiative is to provide the general population with more easily accessible information and possibilities to compare between different providers.

#### *B.4.3 Striving for financial sustainability*

In the year 2005, about one third of Nacka's tax revenue is spent for care and assistance of the elderly and disabled (Nacka Kommun, 2006). In 2005, there were about 1,350 persons receiving home care under the Social Services Act and about 550 people were living in special forms of housing. Although the financial situation of the municipality of Nacka seems sound at the time being, it is unclear if this can be said about Swedish municipalities in general.

### **B.5 Any intended future adoptions to the policy**

The development of health care and social care for older people is one of the Government's highest priority areas in welfare policy. The list of intended goals is long: "The Government wants to increase security and dignity by clarifying the content of elderly care, increase accessibility in health care and social care, especially for persons with extensive needs, support the development of forms of housing for the elderly, develop support for family members, work for better information about the quality of elderly care to both citizens and decision-makers, support diversity among providers and freedom of choice for the elderly, stimulate systematic reviews of medication prescribed for older people, support the development of dementia care, stimulate health promotion and preventive action, reinforce developments by providing support for research on older people and ageing, stimulate the development of new assistive devices wanted by older people and their family members" (Swedish Ministry of Health and Social Affairs, 2007a). Although no priorities are given in this list, not all of these areas will be funded by the national government. Substantial amounts of money are provided for incentive grants to increase quality of health and social care for old people (SEK 1.35 billion, about EUR 145 million), investment grants for elderly housing (SEK 500 million per year, about EUR 54 million), support for family carers (115 million in 2007, about EUR 12 million), and development of technology for older people (SEK 22 million per year in the period 2007-2009, about EUR 2,4 million).

Several of these initiatives point to quality improvement of long-term care services. The government states, that security, accessibility and a perspective on the needs of the individual have priority. It should



be pointed out that the Swedish government will support clarifying the content of (good) elderly care. National guidelines for the care of persons with dementia are in the process of being prepared. In addition, an inquiry chair has been appointed which will present proposals for a dignity guarantee for health and social care for older women and men. Such a dignity guarantee is intended to make clear to everyone what elderly care has to offer and what older persons and their relatives can expect when they need elderly care. This initiative is very similar to the above mentioned "Charter of Rights of Persons in Need of Care and Assistance". In addition, the Swedish government acknowledges, that it is necessary to measure the quality of home care and care in special housing delivered by care providers. Information about the quality of long-term care services in Sweden is urgently needed. In this respect, the government strives to arrange for open comparisons of care services. Later this year, these comparisons will be implemented in order to give citizens, staff, and decision makers access to relevant information about quality, cost, and efficiency of care services.

## **Part C: The results of the Swedish policy on long-term care and its European Implications**

In this section, the empirical data on the Swedish situation will be presented. In the main part of this section, the quantitative results of the Swedish policy on long-term care will be described. National Swedish data will be used and, whenever appropriate, European comparative data. In the end of the section, an evaluation of the delivery system of the policy and other achievements of the policy will be discussed. Finally, an assessment of obstacles and success factors and aspects of transferability of the Swedish policy on long-term care for other European member states will be presented.

### **C.1 The quantitative results of the Swedish policy on long-term care**

#### *C.1.1 Ageing and health*

In the year 2005, over 17 percent of the Swedish population, or about 1.6 million people, were 65 years old or older (see table 3). Population projections show that in the next 40 years, this proportion will increase to about 23.6 percent. The very oldest part of the population has increased since the mid-20th century and the number of people aged over 80 is projected to almost double between now and 2050 (Swedish Ministry of Health and Social Affairs, 2007c). As the percentage of older men will increase in the next years, more women and men could grow old together.

Table 3: Number and percentage of people aged 65 years and older in the Swedish population

<i>Year</i>	<i>Number aged 65+</i>	<i>Percentage aged 65+</i>	<i>Of whom women, percent</i>
2005	1,565,000	17.3	57
2020	2,056,000	21.2	54
2030	2,303,000	22.9	53
2040	2,464,000	23.9	53
2050	2,478,000	23.6	53

Source: Statistics Sweden 2006 (Swedish Ministry of Health and Social Affairs, 2007c)

In a comparative European perspective, figure 1 shows the percentage of old and very old people indicating poor self-perceived health. Although cross-country differences should be interpreted with caution (culturally based reference frames could lead to different response behaviour), there is no doubt, that there are large differences between countries in the proportion of older people which might eventually need support and care. Sweden has the lowest proportion of people with poor self-perceived health and there are small differences in the proportion of strongly limited persons between the three age groups (65-74, 75-84, 85 years and older).

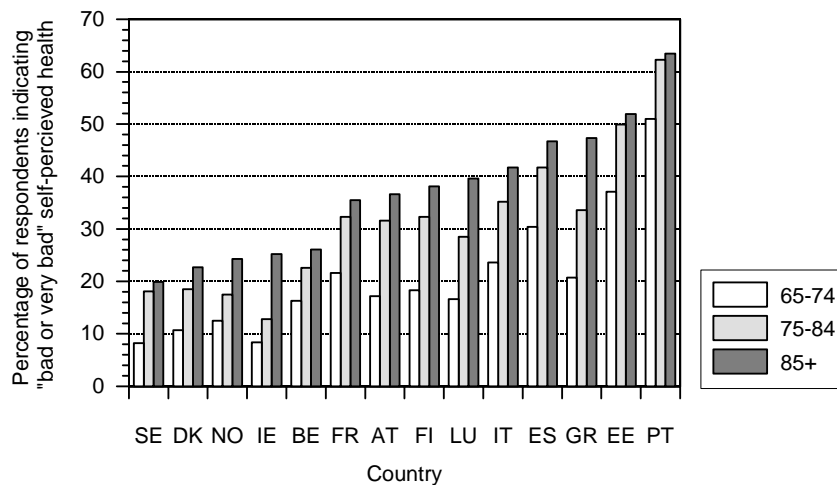


Figure 1: Self-perceived health by age group. Percentage of respondents answering "bad or very bad" self-perceived health. Source: EU-SILC 2006 (European Commission, 2006a)

The increase in the proportion of persons aged 80 years and older could mean that there will be more frail persons in the future. However, if the health of future generations of old and very people will be better this trend might be moderated (see the discussion about "compression of morbidity" in section A3).

The empirical data for Sweden show mixed results in this respect. On the one hand, there are studies showing an improvement in functional health over time. Analyses of the survey "Hemma På Äldre Da'r" ("Ageing at Home") showed an improvement of functional health in the age group of persons 75 years of age and older between 1994 and 2000 (Davey, Savla, Sundström, Zarit, & Malmberg, 2007) and analyses using surveys of Statistics Sweden from 1988/9 and 2002/3 showed improvements in different ADL's for both women and men aged 65 years and older (Larsson, 2006). However, when considering complex health problems like multimorbidity (which takes another perspective on health in old age) a different picture emerges. Using data from two waves of the Swedish Panel Study of Living Conditions of the Oldest Old (SWEOLD, 1992 and 2002), a decrease in the proportion of persons 77 years and older without severe health problems decreased between 1992 and 2002 and the proportion of persons and several domains (and among those people with poor cognitive abilities) increased. Hence, at the time being the future need for elder care in Sweden should not be underestimated.

### C.1.2 Accessibility of care

In Sweden (October 2006) almost 239,000 people aged 65 and above were living permanently in special housing or had been granted home care in ordinary housing (about 15 percent of this age group). About 140,300 people (about 8.6 percent) received home care services and around 98,600 people (about 6.4 percent) lived in special housing. In a European comparative perspective, there are large country differences in the proportion of people with informal or no care, formal care at home or formal care in special housing (see figure 2). In Sweden the majority of dependent people receive formal care at home (44 percent) or in special housing (32 percent). Compared to other countries, Sweden has the highest rate of formal care provision. For instance, in Spain there is a high percentage of dependent people who receive informal (or no) care. Accordingly, the percentages of people receiving formal care at home or in special housing in Spain is small.

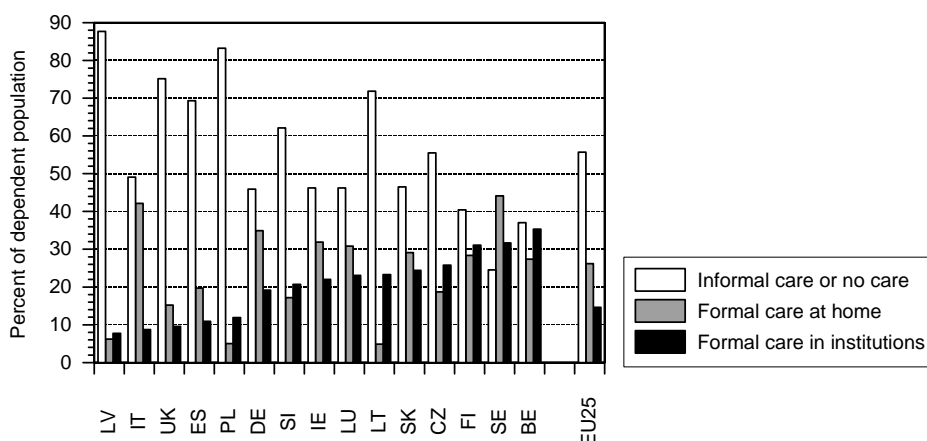


Figure 2: Dependent population in EU member states with informal or no care, formal care at home or formal care in institutions in 2004. Source: DG Economic and Financial Affairs (Tsolova & Mortensen, 2006, p. 4)

As the need for assistance rises with increasing age, persons aged 80 or above accounted for the bulk of help recipients. However, does this mean that all those who need care have access to home or residential care? Individuals can claim services but they have no automatic right or entitlement to services as there is a needs assessment. If the individual requesting services is dissatisfied with the care manager's decision on formal care provision, the case can be appealed in the administrative court. As the number of appeals are residual (Johansson, 2004, p. 6) one can assume that the acceptance of the needs assessment and the subsequent decision is quite high. However, three aspects need discussion in this respect: Historic changes in the provision of care, targeting of services according to need, and regional differences in accessibility of care.

(a) Historic changes: In 1975, 30 percent of persons aged 80 years or older were institutionalized, and 38 percent used home help. Because of economic reasons, coverage rates declined, especially during the 1990s. In 2000, 21 percent of persons aged 80 years or older were institutionalized, and 19 percent received home help. In the social policy debate, the relationship between state and the family often has been discussed in dichotomous terms: where one gets stronger, the other gets weaker ("crowding out"). However, more often "crowding in" effects (the encouragement of family help through formal service provision) or mixed responsibilities have been found empirically (Motel-Klingebiel, Tesch-Römer, & Kondratowitz, 2005). The Swedish case has shown that families step in when the state reduces provisions in social care (Sundström, Johansson, & Hassing, 2002). Carers from the private network, especially the family have become more important in the last years. Informal carers very often are women, but among spouses there are as many caring men as women. Sweden's municipalities support for informal carers for example consists of respite care, counselling, and information and training programmes for informal carers (Johansson, 2004, p. 22). However, studies also showed that improved functional health accompanied the reduction in formal care which means that the need for care services decreased in the last years (Davey, Savla, Sundström, Zarit, & Malmberg, 2007; Larsson, 2006).

(b) Targeting of services according to need: In the context of the changing provision of home care it has also been analysed if an under-provision of services has been occurred during the period of restructuring social care services. Apparently, need factors like restrictions in ADL/IADL, dementia and depression, are the most important factors which influence the use of elder care in Sweden and not other characteristics like age, gender, education (Larsson, Thorslund, & Karebolt, 2006).

(c) Regional differences in accessibility of care: The Swedish system of social care services lies in the hand of municipalities which differ in a geographical extended country like Sweden. Hence, there are large regional differences (at least in the year 1985): In the 282 municipalities in 1985, home help coverage rates for individuals aged 80 years and more ranged from 17 to 80 percent with an average of 43 percent (Davey, Savla, Sundström, Zarit, & Malmberg, 2007). According to the Swedish Ministry of Health and Social Affairs, data from 2005 shows that the coverage rates for people 80 years and older varies between 20 to 27 percent for men and 40 to 49 percent for women.

Most of the studies cited here are considering changes which took place between the 1990's and the early 2000's. Official statistics show that the total number of granted home care hours have increased by

21 percent between 2000 and 2006. In contrast, the number of residents in special housing has been decreased by 17 percent in the same time (Swedish Ministry of Health and Social Affairs, 2007c). Hence, taking together all evidence, one can conclude that accessibility of services is rather high in Sweden.

### *C.1.3 Quality of care*

Despite the excellent situation concerning empirical facts in respect to accessibility of services, the data on quality of long-term care in Sweden is rather scarce (cf. also Davey, Savla, Sundström, Zarit, & Malmberg, 2007). The Swedish situation is characterized by a high degree of decentralization. Although the Swedish government sets the general framework of long-term care, municipalities are free to shape services to the local situation. From the perspective of the Swedish government, quality of home and residential services can be improved, apparently. "Over the next ten-year period, the Swedish Government intends to raise the level of aspiration and quality in medical care and social services for the elderly" (Swedish Ministry of Health and Social Affairs, 2006, p. 49). For instance, as has been stated above already, the definition of what constitutes good care is being discussed at the initiative of the Swedish government. The National Board of Health and Welfare has been given the task to develop quality indicators and promote the development of quality registers. Although quality of care has been discussed for an extended period of time in the nursing sciences (especially aspects of structural and procedural quality), a shift towards focussing on outcome quality from the perspective of the user has come relatively lately. In order to judge effectiveness and efficiency of long-term care services, information on outcome quality is indispensable. However, in other European and OECD countries the situation on the availability of quality indicators of long-term is similar (OECD, 2005).

Nevertheless, there is some information on the quality of care services. The housing standard in long-term care facilities is high. For instance, between 2003 and 2005 there has been a reduction in the number of multi-bed rooms and the number of people sharing a room with someone other than their spouse, partner or other family member. Only about 1,800 residents (out of 98,600 residents in total, or about 2 percent) shared a dwelling with someone other than their spouse or partner or another person close family member. About 56 percent of the residents live in one to one-and-a-half rooms with cooking facilities, a WC and a shower or bath, about 19 percent live in single rooms without cooking facilities but with a WC and bath/shower, and about 16 percent live in two rooms with cooking facilities and a WC and bath/shower. Around 5 percent, or some 4 600 persons, lived in single rooms without cooking facilities, a WC or a bath/shower (Swedish Ministry of Health and Social Affairs, 2007c).

Swedish local authorities conduct user surveys which show high satisfaction on the side of home care users and care receivers in special housing. In addition, between 1998 and 2005 five quality surveys have been carried out by the Swedish National Board of Health and Welfare. The majority of users and their families gave positive assessments of community medical and social care (Swedish Association of Local Authorities and Regions [SALAR], 2007, p. 6). However, in respect to long-term care it is not enough to measure satisfaction with services, only. This shows the first report on the quality of home and residential care of the German Medical Services of the Sickness Funds which was published in 2004

(MDS [Medizinischer Dienst der Spitzenverbände der Krankenkassen], 2004), the second report is to be published in September 2007). Between 1995/1996 (the introduction of the long-term care insurance in Germany) and 2004, about 52 percent of the about 12,000 home care services and 63 percent of the about 8,000 residential care institutions had been examined at least once. When asked, users indicated high satisfaction with home and residential care: More than 90 percent of the users were satisfied with either home or residential care. This optimistic picture could not be confirmed, however, when looking at quality of care from the perspective of professional nursing. "Acceptable quality of care" had been found in 91 percent of home care users and 83 percent of residents of long-term care facilities, only. These results are by no means satisfactory. Severe shortcomings like pressure sores or malnutrition existed for up to 9 percent of the home care users and for up to 17 percent of residents living in long-term care facilities (as many of the examinations followed complaints, these figures could overestimate the prevalence of problems). The second report concerning the quality of German long-term care facilities has been published recently (MDS [Medizinischer Dienst der Spitzenverbände der Krankenkassen], 2007). Between 2004 and 2007, an improvement in the quality of German long-term care facilities could be observed: Acceptable quality of care had been found in 94 percent of home care users (plus 3 percent) and 90 percent of residents of long-term care facilities (plus 7 percent). Although this situation still can not be accepted, one can assume that close monitoring of quality (and public discussion of the care situation in Germany) has helped to improve the situation. Although it is unclear, if similar situations exist to the same extent in other European countries, one may state that the merits of an open, public discourse about the quality (and deficiencies) of care consist in establishing the basis for improving the quality of long-term care.

#### *C.1.4 Financial sustainability of care*

The total costs for care of the elderly in 2005 amounted to about SEK 80 billion (about EUR 8.6 billion). Although there is an increase in gross amounts, when taken into account wage trends and inflation, there was actually a slight decrease of 1.7 percent in costs between 2004 and 2005 (Swedish Association of Local Authorities and Regions [SALAR], 2007, pp. 69-72). Most of the funds come from taxes. Fees financed only 4 percent of the costs. Although the fees are not intended to have a controlling effect, they can reduce demand somewhat, which helps to keep costs down. About 64 percent of the funds went to medical and social services in special housing, 34 percent to medical and social services in regular housing, and 2 percent to preventive activities.

Table 4: Cost per care recipient in regular and special housing between 2000 and 2005

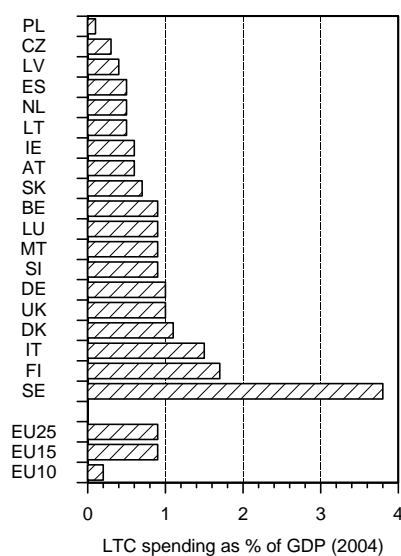
<i>Year</i>	<i>Regular housing</i>	<i>Special housing</i>
2000	169,100	335,100
2001	183,700	363,500
2002	198,900	389,800
2003	208,500	421,400
2004	214,800	439,600
2005	218,000	454,300

Source: (Swedish Association of Local Authorities and Regions [SALAR], 2007)

In 2005, the annual cost per home care user was SEK 218,000 (about EUR 23,400) and SEK 454,300 (about EUR 48,700) for residents of special housing (see table 4). Between 2004 and 2005 there was a small increase in costs (1.5 percent respectively 3.3 percent). There are large regional differences in care costs. For instance, in respect to home care, ten percent of the local authorities had costs that were SEK 149,500 or less and 10 percent had costs of SEK 295,500 or more.

In a comparative European perspective, public spending on long-term services varies strongly between countries, with Sweden the country with the highest share in LTC spending (see figure 3). European societies acknowledge that long-term care expenditure will increase in the near and distant future. For example, the 2006 EPC/EC projections predict an increase in public long-term care expenditure of 0.6 percentage points of GDP (with Finland and Sweden showing a 1.8 and 1.7 percentage points increase) due to population ageing.

Figure 3: Long-term care spending as percent of gross domestic product (GDP) in 2004. Source: Ageing Working Group (AWG) of the Economic Policy Committee (EPC), (European Commission, 2006a)



## **C.2 An evaluation of the delivery system of the policy**

The Swedish policy on health and medical care is shaped by actors on three levels. On the national level, government and parliament set the general standards for health and social care. The county councils are responsible for the health care. The municipalities are responsible for the social services in ordinary homes as well as in special housing and in daycare. The municipalities are also responsible for the health care in special housing and in daycare including nurses. The physicians are employed by the county councils. The municipalities are not allowed to employ physicians. Half of Sweden's municipalities are also responsible for the health care to people living in ordinary homes. This distribution of responsibilities allows to implement general standards on the national level and specific solutions that apply to the local situation in different municipalities. As always in decentralised systems, this allows differences between municipalities. In general, however, high autonomy on the local level is very much welcomed by the citizens concerned.

## **C.3 Other results and achievements of the policy**

One of the most remarkable results of the Swedish long-term care policy is high degree of social inclusion of care users with different backgrounds. Social inequality, e.g. because of gender, education, and income, does not play a major role in receiving adequate care. In order to meet the requirements to receive social care, the potential user has to go through a needs assessment (measuring the need for long-term care), but no means testing (scrutinizing the income situation) is necessary. This procedure is in accordance with the universality of Sweden's social policy in general. Hence, care recipients feel as citizens whose rights are fulfilled, not as petitioners who are granted alms. The good accessibility of services at a low cost certainly have an effect on the low risk of poverty, as well. Finally, the support for carers like respite care, counselling, and information and training programmes for informal carers can be listed here.

## **C.4 An assessment of obstacles and success factors**

Obstacles and constraints of the Swedish policy may be seen in two aspects: First, some difficulties arise because of regional differences. Secondly, the Swedish welfare state is based on high proportions of taxation. This means that citizens have to agree to both high taxes and high responsibility of the state. At the moment, this seems to be the case although there is a social policy debate on taxation in Sweden as well. Factors determining success of Swedish long-term care policy is the high consensus in Sweden about the relevance of long-term care – and the role of the state in this respect. In general, the data for monitoring the state of long-term is very good in Sweden, and Swedish scientist critically and productively accompany the government in shaping care policy of the future. From the outside, it is quite remarkable that the Swedish government uses different benchmarking instruments in order to improve the quality of the system.



### **C.5 An assessment of the transferability of the Swedish policy on long-term care and its learning value for other member states**

Several aspects of the Swedish policy on long-term care are of high interest to the European debate and to the debate in member states. Especially the good accessibility of home care services can be a model for other European states. However, some aspects of the Swedish situation might not be easily transferable, e.g. the normative consensus in the Swedish population that responsibility for care services rests with the state. The Swedish experience highlights many of the current underpinnings of the European debate on long-term care including:

- Healthy ageing
- Access to care services
- Consumer direction and choice
- Qualified staff
- Financial sustainability of care

In addition, the Swedish strategy identifies some specific issues that are emerging as key issues or where there is still insufficient evidence or debate. These include

- Quality of care
- Continuum of care
- Family and the state
- Technology

## **Part D: The policy debate – Good practice and open questions**

Among the European welfare states, Sweden has always been an outstanding reference point when discussing access, quality, and financial sustainability of long-term care. However, as Sweden belongs to the “Nordic” type of welfare states the particular organization of its social policy, and also the system of long-term care, has to be seen in the context of the history and the culture of the country. Hence, the exceptional combination of trust in the state on the one hand and self-confidence of the civic society and its citizens on the other hand are certainly a particular characteristic of Sweden. As these elements are the basis also for Sweden’s system of long-term care, issues of transferability have to be discussed with caution. However, there are many aspects of the Swedish social policy on long-term care and its implementation which could be transferred to European member states (see section D.1). Successful as Sweden’s social policy on long-term care has been in the past, there are open questions and areas of debate on the policy. At the time being, these topics are being discussed in Sweden already. However, as these questions might be of general interest in the European debate they will also be presented in detail below (see section D.2).

## D.1 Issues of transferability

### *D.1.1 Healthy ageing: Avoiding (and accepting) dependency*

Sweden has one of the oldest populations worldwide. However, the health of old Swedish people is very good as compared to other European states. In the Swedish policy there is an emphasis on prevention starting early in life, promotion of a healthy lifestyle up to old age, and good access to health care for all. Avoiding dependency is a basic goal of Sweden's policy on health and long-term care. However, and this is remarkable, measures which enhance prevention and health promotion are combined with a very good infrastructure for long-term care. Hence, when frailty and dependency in old age happen, this is accepted as part of the life-span, as well. Quality of life, freedom of choice and dignity when care is necessary is a characteristic of Sweden's policy – a good example for other European states.

### *D.1.2 Access to care services: Reducing inequalities*

In Sweden, the accessibility to care services for all is high and the individual costs for using services are low. Sweden is among the European countries with the highest support of formal care, both in home care and care in special housing. Use of long-term care is a universal right to all Swedish citizens and is based on needs assessment, but no means testing. Persons in need of care will get support when they need it after assessment of care needs. Consequently, in Sweden the access to care is not related to social class or other aspects of social inequality. As municipalities are responsible for maintaining the necessary infrastructure (or at least financing the infrastructure), specific local needs can be taken into account by those committees which are responsible within municipalities. In addition, there are short ways between the users of care services and the municipality. However, the high autonomy on the local level may lead to differences (and maybe also to inequalities) between municipalities.

### *D.1.3 Consumer direction: Supporting freedom of choice*

Sweden strives to increase the freedom of choice of people in need of care. Hence, in a variety of municipalities care users may choose between different providers of care services contracted by the municipalities. There is an emphasis on home care in Sweden, for two reasons. First, older people wish to grow old at home and want to be supported in the privacy of their own place. Secondly, home care services are less costly than care in special housing even for persons with complex care needs. The number of persons living in special housing have decreased in the last years. However, the private network, and especially the family, accomplishes indispensable tasks in home care. Hence, Sweden supports informal carers with a variety of support schemes. However, in certain situations home care might be not the best solution neither for the old person nor for their informal carers. Hence, care in special housing should be available, too. This is the case in Sweden (and the percentage of old people living in special housing belongs to the highest in Europe).

#### *D.1.4 Qualified staff: Strengthening the backbone of good care*

Competent and motivated professionals are key prerequisites for high quality in care services. Sweden's policy on qualifications acknowledges the relevance of human resources with several qualification programmes. To improve the qualification and the working conditions of professional (and non-professionals) working in the long-term care sector which also includes adequate career models might be a good example for other European countries.

#### *D.1.5 Financial sustainability: Mediating between different claims*

Funding for social care is exceptionally high in Sweden: No other country in the world funds the care for the older generation with a larger share of the gross domestic product. Nevertheless, the debate on generational equity and the related weighing of claims of different age groups is not very pronounced in this country. Apparently, Sweden has been very successful in distributing money in a reasonable way which is supported by the public. For instance, during the recession in the 1990's Sweden successfully directed the shrinking budgets to those people in need. Although the general level of home care decreased in this decade (and the proportion of older people grew), all those in need of care received services (because not only functional health improved during this period, but also because informal care increased during this period). However, systems of social policies gain legitimacy when members of all age groups and generations profit. Hence, the current endeavour to combine an increase of efficiency with more preventive and health promoting measures are a model to follow, as well.

## **D.2 Questions for discussion**

#### *D.2.1 Quality of care: Defining, measuring, and allowing public access to quality indicators*

As has been stated above, quality is an indispensable characteristic of health and social care services. However, the public debate on "good care" has only begun. While there is general agreement on the dimensions of care (structure, process, outcome), quite often structural and procedural aspects are emphasized in analysing quality of care systems. Of course, adequate structures and processes like size and equipment of buildings, qualification of staff, and good organisation and documentation of work are highly important. From the perspective of the user, however, quality of structure and process are mainly necessary, not sufficient conditions for good care. Hence, outcome quality should be shifted in the focus of the quality debate. Of course, several aspects of outcome quality are undisputable and have been confirmed in scientific and professional arena for quite some time already. Examples are avoiding pressure sores, maintaining good nutrition, abstention from physical or pharmaceutical fixation. Using the perspective of universal human and social rights might broaden the perspective on quality of care. Moreover, in an European perspective definitions of care quality should allow comparisons between countries. Of course, defining quality of care is not enough: Measurement instruments have to be

developed and (independent) agencies have to be given the task to measure quality of care regularly. Finally, information on quality indicators should be made available to the public.

#### *D.2.2 Continuum of care: Making health and social care services cooperate*

Dependency in old age quite often stems from chronic illness and multi-morbidity. Hence, although social care services might be responsible to the main part of support in old age, a close cooperation to medical services are highly relevant. The combined efforts of the county and municipality level in Sweden have lead to integrated care in terms of combining medical and social care for residents of special housing. However, even in Sweden health and social services are not always cooperating very well. Hence, improving this coordination and assuring a continuum of adequate care services from the perspective of the user is a burning problem in many European member states.

#### *D.2.3 Family and the state: Crowding out or crowding in?*

The social policy discourse often discusses the question if long-term care is the responsibility of the state or the family (sometimes under the perspective that public support is "crowding out" family support). In many cases, however, long-term care is a shared responsibility by both formal care services (as provided by the state) and informal carers (as provided by the private network and mostly the family). Hence, it can be argued that extensive formal service support enables families not only to continue or increase informal support ("crowding in"), but to provide support that suites families: emotional support, advice, and joint activities. Hence, the most desirable situation might be "mixing responsibilities", striving to complement formal and informal support systems and let families and services do what they can do best. The Swedish social policy includes allowance to care for a family member and for disabled and handicapped children. Finally, it should be noted, that informal carers very often are spouses or belong to the children's generation (daughters and daughters in law) – and many of them are women. In Sweden, however, among the caring spouses there are as many men caring for a wife as women caring for a husband. Hence, not only the right balance of responsibilities taken over by the state and the private network, but also the balance of responsibilities taken over by women and men need to be debated.

#### *D.2.4 The role of technology: Using intelligent tools in an intelligent manner*

Finally, one should point to the role of technology in social care. While the progress in medical and health care is closely linked to the use of new technologies, the sector of social care is reluctant to use high technology. Of course, many routines in social care are based on (or at least involve) interaction and communication between persons, the person cared for and the carer, and should not be replaced by technology. Technology can help to support professional and informal carers in the caring process, though. For instance, technology can simplify the process of documentation, support communication, and increase security. However, at the moment the acceptance and use of technology seems rather low. It would be a task for social policy to change this in order to improve the quality of care services.

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# Synthesis Report

## Freedom of choice and dignity for the elderly

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### Summary

This paper discusses European policy approaches which aim to support freedom of choice and dignity for older people with needs for long-term care. In the context of the Open Method of Coordination the Swedish national social protection policy had been discussed during a Peer Review Meeting which took place on 13-14 September 2007 in Stockholm. The present paper contains the results of this Peer Review Meeting. First, the policy debate on long-term care on the European and international level is treated (Part A). Secondly, the Swedish policy on long-term care will be described: its goals, resources, implementation strategies, and results (Part B). Thirdly, the situation of long-term care in five European Member States – Austria, Czech Republic, Ireland, the Netherlands, Portugal – is described briefly (Part C). Fourthly, the issues which were discussed during the Peer meeting will be presented (Part D). Finally, the attempt is made to describe the lessons learned during the Peer Review meeting (Part E).

**Readers who are interested especially in the results of this Peer Review might read parts D and E of this synthesis report (pp 16-20).**

Readers who are interested in the *complete discussion process* might read not only the current synthesis report, but also consult the host country report, the discussion paper, the comments of the peer countries and the comments of the stakeholders (these papers can be found at this website: <http://www.peer-review-social-inclusion.net/peer-reviews/2007/freedom-of-choice-and-dignity-for-the-elderly>).

### Part A: The policy debate on long-term care at European level

Life expectancy has increased in the past and will be increasing in the future. Especially European societies are witnessing the presence of an ever-rising number of very old persons, many of them in need of support and long-term care. The population in developed countries is ageing rapidly<sup>1</sup>. As a result of increasing life expectancy and

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<sup>1</sup> European Commission, 2005

the ageing of the baby boom generation the age group over 65 years of age (2005: 79 million) will grow to 107 million in 2025 and to 133 million in 2050. Within this age group the largest growth is to be expected for people over 80 years of age (2005: 19 million, 2050: 51 million<sup>2</sup>). Although age does not cause dependency and may not even be the best indicator of need for long-term care services, the probability of dependency is raising with advancing age. When discussing long-term care (LTC) policies these demographic developments have to be kept in mind. Also the differences in welfare state systems<sup>3</sup>, demand of care and cultural differences such as the reliance on family or state for LTC in the Member States play a role. In this section of the report the policy debate on LTC at European level and the overarching aims will be discussed.

## A.1 Long-term care policy principles at European level

Following the Lisbon and Gothenburg European Council meetings, the European Commission identified three principles that serve as a basis for the development of health and long-term care systems which could meet the challenges of demographic ageing. These principles refer to accessibility, quality, and financial sustainability of medical and social care. Early in 2007, the European Commission published a supporting document to the "Joint Report on Social Protection and Social Inclusion" which is based on national reports of the European Member States and discusses the current state of long-term care in Europe thoroughly<sup>4</sup>.

### *A.1.1 Accessibility of care*

Accessibility of care for all means taking into account the needs and difficulties of the most disadvantaged groups and individuals, as well as those requiring costly, long-term care, based on fairness and solidarity. One issue effectively acting as a barrier to access to long-term care are high private costs, particularly for low-income groups. The lack of public long-term care services can also result in substantial waiting times for care services, particularly residential care. Uneven geographical provision (across regions, urban versus rural, within cities) can also be observed as social services are typically the responsibility of local authorities or regions. In general, many Member States want to expand long-term care services.

In the European discourse, other aspects of accessibility are discussed as well. Even if long-term care services are available, they may not be known to potential users. Long-term care policies must therefore develop care systems which are sufficient and well adapted to the needs of the population – and which are easy to identify and to find. "Single entry" solutions seem to support the accessibility of services. Finally, a general problem in European societies seems to be the lack of well-trained and competent staff, which might stem from the low salary and prestige of positions in the long-term care sector. Hence, it seems important to improve the education and career opportunities for personnel working in the LTC sector.

### *A.1.2 Quality of care*

High-quality care for the population means to keep up with medical advances and the emerging needs associated with ageing and are based on an assessment of their health benefits. It also includes defining, monitoring

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<sup>2</sup> Münz, 2007, p.5

<sup>3</sup> e.g. Esping-Andersen, 1999; Lamura et al., 2007; Titmuss, 1987

<sup>4</sup> European Commission, 2007b, pp. 100-110

improving quality of services, to respect consumer direction and choice, establishing a continuum of care and the use of new technologies.

**Defining, monitoring, and improving quality of services:** Although quality of care belongs to the central objectives in the European debate, there is a lack of definition. Clearly, there is no gold standard of good care. Quite often, quality of long-term care is defined on three levels: quality of structure, process, and outcomes. As will further outlined below, it might be useful to consider fundamental human rights as a basis for defining and measuring quality long-term care<sup>5</sup>.

**Consumer direction and choice:** Highly important for the concept of quality of services is the degree to which the provision of services meets the demand for patients and their private network. There is a clear trend in the European discussion that, where available, home or community care is preferred to institutional care as older people prefer to live at home. However, institutional care provision will continue to be important for patients with severe disability. Arrangements which increase consumer choices should lead to improved empowerment, autonomy, and independent living.

**Establishing continuum of care:** Care needs of older people tend to be complex and call for co-ordinated approaches to provide a continuum of care. In many instances, acute health care, rehabilitative services, long-term care, support with household chores and advisory services may be fragmented, not only because of different institutional organisations, but also because of different funding schemes. This can result in negative outcomes for users and in inefficient use of resources.

**Using technology:** Information and communication technology (e-health solutions such as tele-monitoring, telemedicine and independent living systems) can help to ensure independent living and more user-oriented services.

### *A.1.3 Financial sustainability of care*

For the future, it is highly important to ensure the long-term financial sustainability of care and aiming to make the system as efficient as possible. Hence, offering accessible, high-quality care without taking funds away from other sectors or political priorities is a major challenge. In Europe, a large proportion of spending for health and social care comes from public funds. However, there are large disparities in the proportion of GDP spent for health and social care, and also in respect to increasing or decreasing spending in this area over the last decade. Although there is a discussion about the adequate mix between public and private sources of finance, there is no global European solution to this open question. In general, appropriate measures should be taken to ensure sound management of public funding for health care and long-term care, concentrating on the need to improve the quality and effectiveness of public expenditure. In detail, this could mean to develop prevention and guidance policies to reduce the need for expensive treatments, but also to offer cost-effective care and improve the effectiveness and efficiency of the care system.

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<sup>5</sup> Townsend, 2006

## A.2 Measuring the results of long-term care policy

In order to comparatively evaluate the impacts of policies on long-term care, it is necessary to define adequate indicators which measure the commonly agreed objectives – accessibility, quality, and financial sustainability of long-term care. The European Commission has published a portfolio of overarching indicators on social inclusions, pension, and health<sup>6</sup>.

However, the indicators listed in the portfolio of overarching indicators in the health domain are mainly covering the area of medical services. The only indicator referring to long-term care and social services refers to financial sustainability (HC-C8: projection of public expenditure on long-term care as percent of GDP). Clearly, the areas of accessibility and quality of care services are not covered with the existing scheme of indicators. Hence, it could be useful to add indicators which would allow a better assessment of policy impact in the area of long-term care and social services. Table 1 shows some suggestions for indicators which would allow to measure results of policies on long-term care in a European comparative perspective.

Lately, it has been suggested to focus on human rights in order to evaluate the adequacy and efficiency of services to older people: "Human rights instruments offer the hope ... of using resources more appropriately and generously, according to the severity of need"<sup>7</sup>. Hence, human rights might be used to develop indicators of good care. Two European documents may demonstrate this claim. In the Charter of Fundamental Rights of the European Union<sup>8</sup> the right for adequate medical and social services is mentioned several times. A counterpart of this document is the European Social Charter, which includes rights to provision for health care, social security, welfare services and care for old and disabled persons (cf. article 23 "The Right of Elderly Persons to Social Protection"). The European Charter describes political goals which are to be reached in cooperation between public and private organisations. These European charters are important in setting important goals for securing adequate long-term care. However, because of their broad scopes, these charters are highly abstract, and it is not easy to spell out what freedom of choice and dignity for the elderly in the context of dependency and long term care means. For instance, the general right of older people "to remain full members of society for as long as possible" (European Social Charter) has to be explained in more detail. An example for the attempt to define the rights of older people in need of care in simple and concrete terms is the "Charter of Rights for People in Need of Long-Term Care and Assistance" which has been published by the German Government<sup>9</sup>.

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<sup>6</sup> European Commission, 2006a

<sup>7</sup> Townsend, 2006, p. 177

<sup>8</sup> European Union, 2000

<sup>9</sup> German Federal Ministry of Family Affairs Senior Citizens Women and Youth & German Federal Ministry of Health, 2007; the text of the charter can be obtained at [http://www.dza.de/allgemein/Charta\\_English\\_Final\\_Draft.pdf](http://www.dza.de/allgemein/Charta_English_Final_Draft.pdf)

Table 1: Indicators which allow to measure results of policies on long-term care in a European comparative perspective

	<i>Access</i>	<i>Quality</i>	<i>Sustainability</i>
<i>Primary Indicators</i>	Self-reported unmet need for social care services	Outcome indicators based on dignity, free choice, privacy, and physical integrity	Projection of public expenditure on long-term care as percent of GDP
<i>Contextual Indicators</i>	Number of home care services or number of beds in residential care on 100.000 inhabitants	Structural indicators, e.g. proportion of single rooms in residential care facilities or proportion of qualified staff	Willingness of population to adapt public spending on long-term care to the needs of the ageing population

## Part B: Policy and situation in the host country – Sweden<sup>10</sup>

### B.1 Background

The Swedish welfare state model can be described by several characteristics: wide-ranging social sector, active employment policies, universal rights for benefits or services, citizenship as basic criterion for support, taxation as the main source of financing, and a combination of income related and flat rate benefits. Equality between women and men is a highly important goal: This entails efforts to reach equal employment opportunities, equal pay, and the provision of day care services for children. In Europe, Sweden has the highest gross expenditure on overall social protection in relation to GDP (32.9 percent in 2004).

Overall responsibility for care of the elderly in Sweden rests with the state. There are three tiers of the state in Sweden: The national level (Parliament and Government), the regional level of 21 counties with county councils, and the municipality level with 290 municipalities. The three levels have different roles and responsibilities in respect to health and social care. On the national level, legislation governs the general framework for health and social care in Sweden, like for instance over the Health and Medical Service Act or the Social Services Act. The county councils operate the hospitals and out-patient clinics, while the responsibilities of municipalities include health care in special forms of housing, e.g. nursing homes and home health care in ordinary homes in half of Sweden's municipalities. Finally, the responsibility for social care rests with the municipality. Within the broader

<sup>10</sup> The following description of the Swedish policy on long-term care has been based on several official papers from the Swedish Government, the Swedish Association of Local Authorities and Regions, and the European Commission (European Commission, 2007a; Swedish Association of Local Authorities and Regions [SALAR], 2007; Swedish Ministry of Health and Social Affairs, 2006, 2007a, 2007b, 2007c, 2007d). Hence, this brief discussion by no means claims to be comprehensive.

framework of national legislation, county councils and municipalities are autonomous, i.e. local politicians are elected at general elections, and both municipalities and county councils levy taxes<sup>11</sup>.

## B.2 The Swedish policy on long-term care and its reform

One of the most important principles of Swedish policy for the elderly is that society's initiatives are to be framed in such a way that older persons can continue living in their own homes for as long as possible, even when in need of extensive care and social services. The following description of Swedish policy will be explained along the main objectives of the European debate, namely accessibility, quality, financial sustainability of long-term care and the principle mentioned above.

### *B.2.1 Accessibility*

Health and social services in Sweden are open to all those in need of care. The following services are part of Sweden's LTC policy: home care services, adult day care, personal safety alarms, short stay housing, home health care, assistive devices, home adaptations, transportation services, special housing, support for family carers, and dental care<sup>12</sup>. Although the Swedish welfare policy has a universal perspective, special attention is given to particularly vulnerable groups. For instance, the special needs of old persons with dementia or of persons with certain functional impairments are taken into account on the level of the municipalities<sup>13</sup>. Also the situation of elderly who migrated to Sweden during their life course is considered in respect to access and use of social services, e.g. in form of housing allowance when the pension is below a certain threshold.

In Sweden (October 2006) almost 239,000 people aged 65 and above were living permanently in special housing or had been granted home care in ordinary housing (about 15 percent of this age group). About 140,300 people (about 8.6 percent) received home care services and around 98,600 people (about 6.4 percent) lived in special housing.

Individuals can claim services but they have no automatic right or entitlement to services as there is a needs assessment. If the individual requesting services is dissatisfied with the care manager's decision on formal care provision, the case can be appealed in the administrative court. As the number of appeals is residual<sup>14</sup> one can assume that the acceptance of the needs assessment and the subsequent decision is quite high. However, three aspects need discussion in this respect: Historic changes in the provision of care and regional differences in accessibility of care: In 1975, 30 percent of persons aged 80 years or older were institutionalized, and 38 percent used home help. In 2000, 21 percent of persons aged 80 years or older were institutionalized, and 19 percent received home help. There are several reasons to this development. One example is older peoples health. During the 1990s older peoples health has improved and lifetime-expectancy is higher than in 1975. Other examples are the housing standard that has increased and home help services that have developed. In 1975 there were only home help services during the daytime. Today there is home help services all around the clock. The development of assistive and medical devices has influenced the possibility to stay on in the ordinary home. All together this means that old people are able to stay in their own homes longer than before. During the 1990 coverage rates

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<sup>11</sup> Swedish Ministry of Health and Social Affairs, 2007b

<sup>12</sup> *Ibidem*

<sup>13</sup> Swedish Association of Local Authorities and Regions [SALAR], 2007

<sup>14</sup> Johansson, 2004, p. 6

declined also for economic reasons. Carers from the private network, especially the family have become more important in the last years. Informal carers very often are women, but among spouses there are as many caring men as women. The Swedish system of social care services lies in the hand of municipalities which differ in a geographical extended country like Sweden. Hence, there are large regional differences (at least in the year 1985): In the 282 municipalities in 1985, home help coverage rates for individuals aged 80 years and more ranged from 17 to 80 percent with an average of 43 percent<sup>15</sup>. According to the Swedish Ministry of Health and Social Affairs, data from 2005 shows that the coverage rates for people 80 years and older varies between 20 to 27 percent for men and 40 to 49 percent for women. Taking together all evidence, one can conclude that accessibility of services is rather high in Sweden.

### *B.2.2 Quality in LTC*

The quality of health and social care is of central importance in Swedish social policy law. Unfortunately, the data on quality of long-term care in Sweden has been rather scarce so far<sup>16</sup>. The Swedish situation is characterised by a high degree of decentralization. Although the Swedish government sets the general framework of long-term care, municipalities are free to shape services to the local situation. From the perspective of the Swedish government, quality of home and residential services can be improved. For instance, the definition of what constitutes good care is being discussed at the initiative of the Swedish government. The National Board of Health and Welfare has been given the task to develop quality indicators and promote the development of quality registers.

Nevertheless, there is some information on the quality of care services. The housing standard in long-term care facilities is high. For instance, between 2003 and 2005 there has been a reduction in the number of multi-bed rooms and the number of people sharing a room with someone other than their spouse, partner or other family member. Swedish local authorities conduct user surveys which show high satisfaction on the side of home care users and care receivers in special housing. In addition, between 1998 and 2005 five quality surveys have been carried out by the Swedish National Board of Health and Welfare. The majority of users and their families gave positive assessments of community medical and social care<sup>17</sup>. However, in respect to long-term care it is not enough to measure satisfaction with services, only.

Another initiative to improve health and social care is the programme "Steps for Skills" set up by the Swedish government. The purpose is to improve the internal quality of health and social care through training and education of the staff working with older people. In the period 2005-2007 a total of more than one billion SEK (about EUR 107 million) will be awarded to municipalities that want to enhance skills of their staff<sup>18</sup>.

### *B.2.3 Sustainability*

The Swedish economy is growing at the time being. Growth is expected to be 3.0 percent in 2007. The public finances are also developing well. However, financial sustainability of long-term care requires long-term

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<sup>15</sup> Davey, Savla, Sundström, Zarit, & Malmberg, 2007

<sup>16</sup> ibidem

<sup>17</sup> Swedish Association of Local Authorities and Regions (SALAR), 2007, p. 6

<sup>18</sup> Swedish Ministry of Health and Social Affairs, 2007d

strategies. Parliament has taken several initiatives to support municipalities and county councils in their efforts to combine both better quality and improved efficiency in delivering long-term care services. Good quality and good efficiency are essential if legitimacy is to be secured for long-term care services among the public. However, it is difficult to predict the future development of the demand for long-term care services as a variety of factors have to be considered, like demographics, trends in health, income, technologies, changes in expectations and values and the relationship between the efforts of the public institutions and those of family members<sup>19</sup>.

The total costs for care of the elderly in 2005 amounted to about SEK 80 billion (about EUR 8.6 billion). Although there is an increase in gross amounts, when taking into account wage trends and inflation there was actually a slight decrease of 1.7 percent in costs between 2004 and 2005<sup>20</sup>. Most of the funds come from taxes. Fees financed only 4 percent of the costs. Although the fees are not intended to have a controlling effect, they can reduce demand somewhat, which helps to keep costs down. About 64 percent of the funds went to medical and social services in special housing, 34 percent to medical and social services in regular housing, and 2 percent to preventive activities.

In 2005, the annual cost per home care user was SEK 218,000 (about EUR 23,400) and SEK 454,300 (about EUR 48,700) for residents of special housing. Between 2004 and 2005 there was a small increase in costs (1.5 percent respectively 3.3 percent). There are large regional differences in care costs. For instance, in respect to home care, ten percent of the local authorities had costs that were SEK 149,500 or less and 10 percent had costs of SEK 295,500 or more.

### **B.3 Future improvements to the policy of long-term care**

The development of health care and social care for older people is one of the Government's highest priority areas in welfare policy. The list of intended goals is long: "The Government wants to increase security and dignity by clarifying the content of elderly care, increase accessibility in health care and social care, especially for persons with extensive needs, support the development of forms of housing for the elderly, develop support for family members, work for better information about the quality of elderly care to both citizens and decision-makers, support diversity among providers and freedom of choice for the elderly, stimulate systematic reviews of medication prescribed for older people, support the development of dementia care, stimulate health promotion and preventive action, reinforce developments by providing support for research on older people and ageing, stimulate the development of new assistive devices wanted by older people and their family members"<sup>21</sup>.

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<sup>19</sup> Swedish Ministry of Health and Social Affairs, 2006

<sup>20</sup> Swedish Association of Local Authorities and Regions [SALAR], 2007, pp. 69-72

<sup>21</sup> Swedish Ministry of Health and Social Affairs, 2007a



## B.4 Study visit to the Nacka municipality

A study visit to the Nacka municipality<sup>22</sup> was included in the Peer Review meeting. The Nacka municipality provides home help and care for elderly, as well as special housing (residential care) for elderly, with a customer choice system<sup>23</sup>. This played an important role in the continued discussions.

## Part C: Policy and situation in the peer countries Austria, Czech Republic, Ireland, the Netherlands, Portugal<sup>24</sup>

European Member States have different welfare state systems, due to cultural, political and social reasons. Some Member State show similarities, while others are very different. Along the three European main objectives (access, quality and sustainability) the policies on LTC of the European Member States which took part as peer countries in the review process on the topic freedom of choice and dignity for the elderly – Austria, Czech Republic, Ireland, the Netherlands, Portugal - will be introduced. However, the particular policies can not be described in-depth in the current context. The comment papers submitted by the peer countries describe the national policies and the issues evolving around them more extensively.

### C.1 Austria

#### *C.1.1 Background*

Austria can be described as a standard-care mix country, which means medium to high demand for long-term care, medium to low provision of informal care and medium provision of formal care<sup>25</sup>. Two main components make up the policy system of LTC. (a) There is a universal cash allowance accessible to all of those in need of long-term care, which is entirely funded by taxes, and (b) the provinces (Länder) are responsible for the provision of social care for long-term care. All users of services contribute co-payments, which vary strongly between the provinces. About 90% of the long-term care allowance recipients are mainly attended to by a family member, nearly all are women. About 25% are supported by a mobile care service, 15% are in residential and nursing care, while 5% receive care provided by migrant care workers. Institutional care is predominantly provided by provinces and municipalities, or by religious and other non-profit organisations. Home care services are provided by non-profit organisations.

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<sup>22</sup> <http://www.nacka.se/default/PlatsID.8/vis.1>

<sup>23</sup> [http://infobanken.nacka.se/www/english/customer\\_choice.htm](http://infobanken.nacka.se/www/english/customer_choice.htm)

<sup>24</sup> The following description of the participating peer counties and their policies on LTC is based on the comment papers the peer countries submitted for the Peer Review meeting and a publication of the European Commission on that topic (Carolan, 2007, European Commission, 2007a, Lorman & Wija, 2007, Nies, 2007, Paül, 2007, Schenk, 2007).

<sup>25</sup> Lamura et al., 2007

### *C.1.2 Access*

The long-term care allowance was introduced in 1993 as a tax-financed benefit. It is based on a need assessment and is not means tested. Seven different levels of care are differentiated. To be eligible, the minimum time is more than 50 hours of care per month. The benefit amounts to between EUR 148.30 for level one and EUR 1 562.10 for level seven. However, income and assets, as well as care allowance, are taken into account in calculating the users' co-payments to social services. In the Austrian welfare state system co-payments are the highest in the LTC sector. Some actors in the Austrian long-term care sector believe that long-term care is still seen as a private risk and not a life risk that is covered by the security system of shared risks. Even so lower income groups profit the most from the care allowance, about 23.000 of the long-term care allowance users in private households are still at risk of poverty, according to the EU-SILC household survey, and another 56.000 social benefit recipients living in homes for the elderly or nursing homes are not able to pay for the care they need. In the moment more than 39.000 people receive the care allowance. Regional differences of service provision and its prices are also pronounced in Austria; in extreme cases citizens of a certain region will pay up to 42% more for the same service in another region.

### *C.1.3 Quality*

Austria is working on uniform and binding national standards for home and residential care. So far the federal government and the provinces agreed on uniform standards for social care training and work. In 1993 minimum standards for institutional care, including e.g. priority for small care facilities integrated in the local community and free choice of doctor, were defined. Further more, all provinces have now adopted rules for supervising old-age and nursing homes, including provisions that ensure the legal protection of residents. A key tool to monitor the quality of home care is home visits by certified care workers. These care workers check, inform and counsel all those involved in a home care situation. Austria has a long history of divided budgets for health and social care, which is by some seen as an obstacle to integrated and continuous care. Providing support to caring family members is considered a top priority within long-term care, as the work of informal carers is very valuable to society as a whole but frequently associated with great physical and psychological stress.

### *C.1.4 Financial Sustainability*

In 2005 the federal government spent € 1 566 million on long-term care benefits and the municipalities spent € 292 million on long-term care benefits in 2005. Expenses on benefits in kind for social services totalled € 1 423 million in 2004, mainly financed by the provinces budgets (social assistance) and partly by municipalities. According to the 2006 EPC/EC projections public long-term care expenditure is projected to increase by 0.9 percentage points of GDP by 2050 (this includes only the expenditure on the long-term care allowance) due to population ageing (from 0.6% of GDP in 2004), these projections only include the LTC allowance financed mainly by the federal state. The Austrian welfare benefits system was created for emergency situations rather than structural nursing care. Especially the expected demographic developments will be a major challenge for the financial sustainability of the long-term care system<sup>26</sup>. An increase in the numbers of people aged 85 and older and a drop in care capacity within the family will lead to a higher demand of social services and professional care staff<sup>27</sup>. One immediate challenge, and an important point in the drafting of the new government's agenda,

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<sup>26</sup> European Commission, 2006b: 38

<sup>27</sup> European Commission, 2006b: 27

concerns the current availability of professional nursing and care staff, including the recruitment of migrant workers.

### *C.1.5 Future adjustments to the policy*

Future adjustments to the Austrian policy on long-term care may take into account the demand for professional, affordable support for care and nursing in private homes, such as the expansion of the mobile services, part-time care provided by municipal care workers and care assistance services, night care, emergency night care call centres, short-term care at home, coordinated community support, assisted housing, part-time service units such as day care centres and community centres.

## **C.2 Czech Republic**

### *C.2.1 Background*

The Czech Republic and its long-term care policies can be described as a transitional country, which means low demand for care, high provision of informal care and medium to low provision of formal care<sup>28</sup>. This year the Social Services Act came into force, which included a “care allowance” based on a needs assessment. This law is also concerned with the provision of social care and quality assurance. A main goal of the Czech policy on LTC is to increase the provision of home care services and shift from institutional to home care. The long-term care of citizens is not ensured by a single system, but it is partially included in the health care system, which is the responsibility of the Ministry of Health, and in the social services system, which is run by the Ministry of Labour and Social Affairs of the Czech Republic. Apart from the state guaranteed systems, long-term care and support is also provided by family members and other close persons and volunteers, mainly students. Municipalities primarily fund residential and community services for older persons. In addition to residential and home care services, a further range of social services is ensured by non-governmental organisations, which have the form of a civic society, special-purpose church facility or beneficiary association.

### *C.2.2 Access*

The current supply of residential care in the Czech Republic was felt to be insufficient, waiting times for placement in public long-term care facilities (e.g. pensioners’ homes) varies from several months up to several years. Regional inequalities (e.g. availability, waiting times, financial costs) are high. Moreover, co-payment obligations work as a financial barrier to access of services. There is low availability of short stay accommodation or short-term health (respite) care in special housing facilities and especially residential homes for people with special needs. The strategies to tackle these issues differ from region to region depending on local government performance. Some municipalities are introducing new care paths to replace institution-based care with home-care, while others are extending nursing care or modernising facilities.

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<sup>28</sup> Lamura et al., 2007

### *C.2.3 Quality*

The overarching goal of the Minister of Labour and Social Affairs' strategy is to increase quality of life in old age and to improve freedom of choice and dignity for the elderly. The new Social Services Act (mentioned above) defines the conditions for the registration of social service providers and is expected to improve the current fragmented framework and the quality of care. Social services quality standards set basic levels for personnel training and procedural and operational aspects regarding the provision of social services. They seem to work well and help to set benchmarks for what is needed and expected in care provision. The existing division between health and social budgets poses a serious obstacle to the integration of services and increases the risk of poorly coordinated care for the elderly. Nevertheless, strong commitment and partnership between the central government and local authorities and the creation of a single point of entry to the care system may help to solve this problem.

### *C.2.4 Financial Sustainability*

According to the 2006 EPC projections, expenditure is projected to increase by 5.6 percentage points of GDP by 2050 due to population ageing. That shows that financial sustainability is an important issue. The shift to home care and improvements towards integrated care are steps into that direction. One measure to integrate care is the model project "institute of the social-health-care bed". Within this new system, health care facilities will be able to integrate nursing care units with medical facilities or transform acute care beds into aftercare beds. Another aspect to reach financial sustainability is the use of new technologies.

### *C.2.5 Future adjustments to the policy*

Future plans to improve long-term care policy in the Czech Republic as mentioned several times above are to enhance coordination between health and social care and between different stakeholders and to improve access to long-term care services. Furthermore, independent bodies have to be established to monitor quality standards and check for signs of abuse and neglect. And the care for users with dementia has to be further developed.

## **C.3 Ireland**

### *C.3.1 Background*

Ireland can be defined as a family based country, which means high demand for care, medium provision of informal care and low provision of formal care<sup>29</sup>. Services available include home nursing, home help and care attendants, day centres, grants to adapt homes, meals-on-wheels, nutrition advice, therapy and rehabilitation, day hospitals, public residential care and private nursing homes. Long-term residential care is provided through the public and private sectors as well as a small not for profit sector. A large amount of informal care continues to be provided. There is some financial support for carers such as the carer's allowance for low income carers and the respite care grant. Care in the community is considered the preferred option by authorities both for the individual and on economic grounds. The goal is to maintain people in dignity and independence at home in accordance with their wishes; to support family, neighbours and voluntary bodies; and to provide hospital and residential care when needed.

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<sup>29</sup> Lamura et al., 2007

### *C.3.2 Access*

Health care is free for all over the age of 70 years of age. Most community based services are also provided free of charge based on assessed need regardless of age or means. This would include home care packages designed to support an older person to remain at home for as long as possible. At present, care users face greatly different costs depending on whether they are in public or private nursing homes (68% of long-stay beds are in the private sector). A new nursing home support scheme is being introduced in January 2008, "A Fair Deal" which will eliminate this differences. It will be means tested and include co-payments. The new scheme is blind as to whether care is received in a public or private facility in terms of the support it offers. The scheme will be based on three components: assessment of need, assessment of means, and choice of long term care facility.

### *C.3.3 Quality*

The quality of health and social care is an important issue in Ireland. The Health Information and Quality Authority (HIQA) was established in May 2007. This is an independent authority which has been set up as part of the government's health reform programme, to help drive continuous improvement in Ireland's health and social care services. HIQA's first assignment has been to develop standards for residential care for older people which have just been published in draft form. On the basis of these standards, HIQA will take over the function of the inspection of private nursing homes in 2008. This will raise a number of challenges for all service providers such as the need to develop measurement instruments to ensure appropriate staffing levels. The same is planned for the home care service. Integration of care is not such an important issue in Ireland, because health and many aspects of social services are the responsibility of the same government department (Department of Health and Children) and delivery agency (The Health Service Executive).

### *C.3.4 Financial Sustainability*

The 2006 EPC/EC age-related projections show an increase in public expenditure of 0.6 percentage points of GDP by 2050. Even so, Ireland has the lowest proportion of its population aged 65 or over among EU countries at about 11% (2006 census). This compares with the EU average of about 17%. Still the population is ageing as well and several reports have been looking at ways of financing long-term care. Combined systems of taxation, co-payments and social insurance or pre-funding mechanisms are the different options discussed. Public expectations of what the State will provide in terms of health and social care is very high and growing, due to the unprecedented period of sustained economic growth in Ireland in the recent years. Supporting the policy of continuing to increase home care and the challenge of supporting people with increased dependencies at home has implications financially and make a contribution to the financial sustainability of LTC in Ireland.

### *C.3.5 Future adjustments to the policy*

An important adjustment to the LTC policy will be the introduction of "A Fair Deal" as mentioned above. Furthermore, quality standards for home care by the Health Information and Quality Authority (HIQA) and a national assessment instrument have to be developed. It also has to be ensured that older people are cared for by suitably trained staff. And there is a need for more measures in Ireland to enhance prevention of dependency and health promotion as people age.

## C.4 The Netherlands

### *C.4.1 Background*

The Netherlands can be described as a Public-Nordic country, which means medium demand for care, low provision of informal care and high provision of formal care<sup>30</sup>. For people in need of LTC at least four sources of funding are relevant: health insurance for acute care, Exceptional Medical Expenses Act (AWBZ) for long-term care, social support (WMO i.e. welfare, domestic care, assistive devices, transport) and housing income support. In 2007, the Social Support Act came into force, giving a greater say to municipalities – amongst others – to improve cohesion at social support at the local level. This means the role of the national government is slowly decreasing and its task is to formulate policy objectives and frameworks, to allocate macro-budgets and to guarantee access to care for all citizens and quality of care. A paradigm shift has occurred in the Netherlands: All relevant actors in the long-term care sector (service providers, professionals, service users, health care insurers, the health care inspectorate and national government) agreed that quality of care should not be the final aim, but quality of life.

### *C.4.2 Access*

To enter the LTC system and to receive care under the AWBZ a valid statement of need from the Care Needs Assessment Centre is needed. From there the care administration offices take over to direct the process of long-term care at regional level. Income policy is closely connected to service provision, in the sense that co-payments for care, service provision, social support and special housing are income dependent. Housing (in residential and nursing homes) is part of the insurance. As a consequence, quality levels of care and housing are quite similar across the country. From the point of equal access, this may be an advantage, but in order to meet individual and local or regional needs, this can be a shortcoming.

### *C.4.3 Quality*

There has been criticism about the quality of care in Dutch nursing homes. A number of measures have been taken to eliminate this problem, such as large scale improvement programmes, a clear inspection policy and the formulation of outcome indicators. For the last point a roadmap to monitor and commission care, based on outcome indicators was issued. Service providers, professionals and service users developed a new set of indicators which were then adopted by the health care insurers, the health care inspectorate and national government. Quality of life was broken down into a number of indicators covering four main fields: physical well-being and health, housing and living conditions, participation and mental well-being. Now these sets of indicators are tested and will be implemented in 2008. The outcomes will be published in order to have more transparency for service users. The outcomes will also be the basis for funding, next to cost-effectiveness. To empower service users, the Netherlands introduced personal budgets, which have been quite successful.

### *C.4.4 Financial Sustainability*

In the discussion of financial sustainability three topics are discussed especially: reduction of bureaucracy, cost-effectiveness and sufficient staffing levels. Bureaucracy leads to systematic inefficiency; it is seen as a severe burden and a waste in the system. The new Dutch government has formulated an objective to reduce bureaucracy by 25%. Another important issue is cost-effectiveness in order to achieve a sustainable system of long-term care. There appear to be significant differences between service providers in terms of cost-

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<sup>30</sup> Lamura et al., 2007

effectiveness. Large scale multi-dimensional benchmarking has taken place among home care and residential care organisations, but the differences between cost-effective service providers are to be further explored. Large shortages of staff are expected in the Netherlands. The current percentage of 11 % of people working in the care sector should almost double in the next two decades in order to meet increasing demand, especially because of the ageing of the population<sup>31</sup>. Measures such as campaigning for a better image of work in the care sector, re-entering the labour force at later age, reducing bureaucracy and stimulating innovations in work and technology are the main mechanisms to reduce shortages on the labour market.

#### *C.4.5 Future adjustments to the policy*

The Dutch government plans to work on the following aims: to strengthen and increase consumer's choice, user-direction, transparency and quality based purchasing, new initiatives in the field of housing and care (accessible housing, small scale housing, 'life span proof' neighbourhoods), the implementation of ICT and smart housing, integrated care for older people, the connection of geriatrics and (para-)medical nursing home care with general practitioners, patient safety, the labour force and a reduction of bureaucracy.

## **C.5 Portugal**

### *C.5.1 Background*

Portugal can be described as a family based country<sup>32</sup>, which means a high demand for care, medium provision of informal care and low provision of formal care. In Portugal 21% of the population live below the threshold of poverty risk in 2004. The elderly are particularly vulnerable to poverty and 29% are poor (30% women and 29% men). To remedy that situation the Portuguese government introduced several measures to reduce the risk of poverty in old age and make services available for people in need of LTC. These services include a solidarity supplement for old people (CSI), a pilot project to restore old people's own houses, long-term care networks to increase places for short and long-term care, and the creation of a National Voluntary Service Network to support older people. Non-profit and profit-oriented organisations operate facilities for rehabilitation, long-term care and residential care. Day care centres provide activities, meals, laundry services, bathing, assistance with medication and attendance at health centres. There are a number of private nursing and residential homes. The non-profit organisations, mainly financed by the state, provide only basic care. The alternative consist of profit-oriented organisations, who are very expensive and can only be afforded by upper class clients.

### *C.5.2 Access*

In Portugal demographic ageing, the demand and provision of care differs greatly between regions and between rural and suburban areas. Cities and costal areas have a younger population and a better provision of LTC services. In the rural areas the distribution is the opposite. High private expenditure (out-of-pocket payments were 29% of total health expenditure in 2004), high reliance on indirect taxes and the various social insurance systems lead to regressive financing and a pro-rich use of care.

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<sup>31</sup> RVZ, 2006

<sup>32</sup> Lamura et al., 2007

### *C.5.3 Quality*

Residential care in Portugal has been reported to be quite often of poor quality. Resources which are necessary for good care are lacking, e.g. most of the facilities only offer double rooms and do not guarantee privacy. The right to self-determination and choice, access to information and counselling and quality care that goes beyond subsistence (supply of basic needs like shelter, food and hygiene) are not guaranteed. Care for people with dementia can hardly be found. A National Network of Integrated Continuous Care was established with the aim to monitor, both health care and organisational quality. The Network units and teams are subject to regular (self and external) evaluation by the regional coordination team.

### *C.5.4 Financial Sustainability*

At the time being, there is a large demand for more services. As many people cannot afford good quality care, there is a political guarantee for specific funding; centralised control of management and financial allocation; payment models to providers, adapted to the nature of the services; and permanent economic and financial evaluation. Another problem that has to be tackled in the near future is lack of qualified staff.

### *C.5.5 Future adjustments to the policy*

It was felt that the following points should be addressed by the Portuguese government to guarantee access and quality of care in a financially stable manner: Reforming the pension system, tackling regressive financing in health care, reducing the financial costs of care for disadvantaged groups, reducing geographical disparities of supply and enhancing the provision of long-term care. To improve efficiency (notably through reinforcing primary care, adjusting hospital capacity and controlling pharmaceutical expenditure) and implement comprehensive all-ages promotion policies to improve health status and reduce health inequalities.

## **C.6 Comparison between countries**

Table 2 gives an overview about the situation of long-term care in the six European countries which took part in the Peer Review on the topic "Freedom of Choice and Dignity for the Elderly" (Austria, Czech Republic, Ireland, the Netherlands, Portugal, and Sweden). The table presents very briefly the specific situation of the countries in respect to access, quality, and sustainability of long-term care. Please note, that this overview does not take into consideration the complexities of the national situation<sup>33</sup>.

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<sup>33</sup> for more information please refer to European Commission, 2007a; 2007b



Table 2: Overview about six European countries (Austria, Czech Republic, Ireland, the Netherlands, Portugal, and Sweden) in respect to access, quality, and sustainability of long-term care.

	Access to Long-Term Care	Quality of Long-Term Care	Sustainability of Long-Term Care
<b>Austria</b>	Improved since introduction of LTC provision, but regional variability. Needs tested care allowance; high private co-payments.	Regional differences in quality standards. Divided budgets for health and social care, which is seen as an obstacle to integrated care by some.	Financial sustainability for demographic change needs joint effort. Expected lack of care staff.
<b>Czech Republic</b>	Since 2007, new Social Service Act with single entry and needs-tested care allowance. Waiting lists for residential care.	New Social Services Act introduced quality assurance system. Quality standards for social care. No conception of LTC. Divided budgets for health and social care, obstacle to integrated care.	Shift to home care in the communities. Use of new technologies in LTC.
<b>Ireland</b>	Free health care over the age of 70. No universal right to LTC, new policy to eradicate price differences private and state homes.	Health Information and Quality Authority (2007) developed standards for residential care. Good integrated care.	Discussion about new options of financial funding. Growing public expectations of what the State will provide in terms of LTC.
<b>Netherlands</b>	High provision of professional care, single entry. Co-payments are income dependent.	Quality of life as aim in long-term care. Quality indicators are being developed. Large scale quality improvement programmes.	Attempts to increase efficiency of the system and reduce bureaucracy. Expected shortage of staff.
<b>Portugal</b>	Large differences between public and private providers and regions; social inequality.	Quality has to be improved. A National Network of Integrated Continuous Care was established.	Financial sustainability for demographic change not guaranteed. Expected shortage of staff.
<b>Sweden</b>	Very good accessibility to services. Regional differences in provision of care.	National quality standards will be developed. "Steps for Skills".	Generous financing of long-term care, public consensus is high.

## Part D: Issues Discussed

European social policy aims to support freedom of choice and dignity for older people with needs for long-term care. In the context of the Open Method of Coordination the Swedish national social protection policy has been chosen as one point of departure for mutual learning. In the Peer Review process on "Freedom of Choice and Dignity for the Elderly" a variety of topics has been discussed. Open questions will be described in the present section (Part D: Issues Discussed). Topics which were discussed in consensus, will be presented in the following section (Part E: Lessons Learned).

### *D.1 Using European variety productively?*

In the discussion it was acknowledged that there are large differences between European countries, e.g. in the structure of social policy, in societal wealth, in cultural beliefs, in demographic composition. Although the idea of benchmarking processes means to learn from good examples, this should not imply that all European countries will converge. Rather it was felt that cultural differences in Europe should be recognized as strength and should be used productively. In respect to long-term care, countries with high provisions of formal care might be models for countries with a higher share of informal care, but countries with a strong family tradition of care might also offer solutions to learn from. The well-being of persons in need of care and their carers are the main criteria for evaluating solutions.

### *D.2 Maintaining solidarity by introducing differentiation?*

Solidarity is a central characteristic of European welfare states. It was felt that maintaining solidarity within long-term care systems is of central importance. The following problem was posed (but not solved) in the discussion: Legitimacy of social policy requires to convince all members of society, that they gain from this policy. Hence, societal solidarity makes it necessary to keep those members of the society in the solidarity systems which are able to contribute most (and, hence, quite often do not need societal solidarity). Hence, it was suggested that it could be possible to increase choice especially for affluent, upper-middle class citizens in order to maintain their interest in societal systems of solidarity.

### *D.3 Family and the state: Crowding-in or crowding out?*

Sometimes it is assumed that public support is "crowding out" family support. However, formal services may enable families to continue or increase informal support (in the scientific discourse this encouraging consequence of formal services has been labelled as "crowding in" effect). The most desirable situation might be "mixing responsibilities". However, not only the right balance of responsibilities taken over by the state and the private network, but also the balance of responsibilities taken over by women and men need to be debated.

### *D.4 Developing European quality indicators?*

At the European level, there are only few indicators on long-term care. Especially, indicators on the quality of long-term care are needed in order to compare the situation in European Member States. In a European perspective definitions of care quality should allow comparisons between countries. Of course, defining quality of care is not enough: Measurement instruments have to be developed and (independent) agencies have to be given the task to measure quality of care regularly. Although there was no final agreement on quality indicators it was acknowledged that these indicators should embrace structures, processes and outcomes of long-term care.

### *D.5 Abolishing bureaucracy and losing rationality?*

Accountability and documentation of services are central principles in long-term care as they enforce rational action. However, accountability may also lead to an excess of bureaucracy which means that work capacity is not used for central tasks of long-term care. The problem of diminishing bureaucracy without losing accountability was acknowledged.

## **Part E: Lessons Learned**

European social policy aims to support freedom of choice and dignity for older people with needs for long-term care. In the context of the Open Method of Coordination the Swedish national social protection policy has been chosen as one point of departure for mutual learning. In the Peer Review process on "Freedom of Choice and Dignity for the Elderly" a variety of topics has been discussed. In this section, topics which emerged as "lessons learned" from the discussion will be presented.

### **E.1 General issues**

#### *E.1.1 Healthy ageing: Avoiding (and accepting) dependency*

National health policy should emphasise prevention starting early in life, promote a healthy lifestyle up to old age, and ensure good access to health care for all. However, when frailty and dependency in old age happen, this should be accepted as part of the life-span, as well. Quality of life, freedom of choice and dignity when care is necessary is a characteristic of Sweden's policy – a good example for other European states.

#### *E.1.2 Balancing central direction and local autonomy*

The right balance between central direction and local autonomy in care provision needs to be struck. Laws on the national level can reduce regional inequality. Local autonomy may increase the adequacy of services which should be tailored to the needs of the particular municipality. It was felt that countries could usefully examine this question together.

#### *E.1.3 Combining formal and informal care*

Informal care provides a substantial part of the coverage in many European countries. But often there is simply no alternative. This is a challenge for the future, because family structures are weakening and people often live far away from their elderly relatives. Informal care must be supported in such a way that it corresponds to people's choices and is a realistic option. Informal care should be a positive choice to care, not an obligation to care. The gender difference should be recognized and maybe even slowly eradicated. Some countries have a strong history of formal care, and some of informal care. Mutual learning could take place at some point between those two models. However, it may be that the balance will need to be different in different cultures.

### *E.1.4 Responsibility of employers*

Employers should be more aware of their responsibilities to support employees who care for relatives. Support can be given in a variety of ways (e.g. flexible working hours).

## **E.2 Access to long-term care services**

### *E.2.1 Providing information*

A precondition for real choice by consumers is full information about what is available. But complete information about care for the elderly is also very complex. "One-stop shops" could draw the information together and help users and their families to arrive at a choice.

### *E.2.2 Needs assessment*

Needs assessment should involve standardised instruments. Using standardized instruments may contribute to equal access. If needs assessment are based on international models (e.g. International Classification of Function or other widely used instruments) this may improve the comparison between European Member States.

### *E.2.3 Paying attention to preferences*

Staying at home is many elderly people's preference, but for others "home" may have negative connotations – due to bad social or housing conditions, for example. In these cases, they may prefer residential accommodation, because it provides more safety and security. The participants praised the way in which Sweden strikes the balance between care at home and residential care.

### *E.2.4 Ensuring adequate services*

While it is important to have some practical form of needs assessment, this must be related to the care that is provided afterwards. It was noted that universal access to services is a major Swedish achievement. If people are assessed and are found to be eligible for services, then the service providers must be required to accept them.

### *E.2.5 Improving dementia care*

Demographic change leads to an increasing number of very old people. At the time being, advanced age is related to the risk of dementia. However, adequate care for persons with dementia is far from being available in all European Member States. Hence, there should be a joint effort to improve the care for persons with dementia.

### *E.2.6 Supporting freedom of choice*

Freedom of choice implies, that there are alternatives to choose from. Hence, it is not enough to provide infrastructure of long-term care services, but to provide real choice between alternatives. Two examples might illustrate this point. Care users may choose between different providers of care services contracted by the municipalities (as it is the case in some Swedish municipalities). Alternatively, municipalities may accredit care providers which then offer their services on the market (some Swedish municipalities report that this second option may actually increase consumer choice). Finally, the special needs of vulnerable groups such as people with dementia or illiterate people have to be taken into account, too, when it comes to freedom of choice.

### *E.2.7 Private providers*

The Swedish use of private providers was of great interest to many of the participants, as in most other countries, there is undersupply of private care providers. It was felt, that all types of care providers have to fulfil the same requirements (e.g. in terms of the personnel's knowledge, quality of services).

### *E.2.8 Personal budgets*

Personal budgets could be an interesting complementary instrument between formal and informal care. Personal budgets allow individuals to use an (virtual) account to buy care, employ care assistants or pay for personal services suited to person's needs.

### *E.2.9 Technology*

The use of technology in care services is being studied in a number of the peer countries, and indeed in EU-supported projects (e.g. "Ambient Assisted Living", "Ageing Well in the Information Society"), and this information could be shared. Technology can help to support professional and informal carers in the caring process. For instance, technology can simplify the process of documentation, support communication, and increase security. However, at the moment the acceptance and use of technology seems rather low. It would be a task for social policy to change this in order to improve the quality of care services

## **E.3 Quality of long-term care services**

### *E.3.1 Highlighting dignity*

Dignity is a very important issue in care for the elderly and it was suggested to rely on human rights and charters for persons in need of care to define this concept. There was a general agreement on the need to examine this issue in more detail.

### *E.3.2 Measuring quality of services*

Quality should be measured (by independent agencies) if the goal is to improve quality delivered by services. There have to be quality indicators, and it was suggested that these might be set at the European level. It was suggested to rely on dignity and human rights in defining good quality of care. While there is general agreement on the dimensions of care (structure, process, outcome), quite often structural and procedural aspects are emphasized in analysing quality of care systems. From the perspective of the user, however, quality of structure and process are mainly necessary, not sufficient conditions for good care. Hence, outcome quality should be shifted in the focus of the quality debate. Finally, information on quality indicators should be made available to the public. From the perspective of service providers, benchmarking is a tool to improve quality of care and efficiency of services.

### *E.3.3 Linking health and social care services*

Dependency in old age quite often stems from chronic illness and multi-morbidity. Hence, although social care services might be responsible to the main part of support in old age, a close cooperation to medical services are highly relevant. The usefulness of linking health services with social services was recommended to Sweden for consideration. Furthermore, the provision of health services and social services should not be split between county and municipal level.

## **E.4 Sustainability of long-term care services**

### *E.4.1 Maintaining qualified staff*

Competent and motivated professionals are key prerequisites for high quality in care services. A sufficient supply of well-qualified staff is essential. However, working in long-term care often has a negative, low-status image which must be upgraded. Good pay is an important part of this, but so is good training. Improving the qualification and the working conditions of professionals (and non-professionals) in the long-term care sector should be central goals. In some countries, the employment of immigrants in care leads not only to questions of adequate salary and social protection of migrant workers, but also to ensuring communication between carers and persons cared for. Sweden's programme "Steps for skills" to improve educational and training levels of personnel was broadly discussed and was seen as a good example for other European countries.

### *E.4.2 Migration and care*

In some European countries there are large groups of legal, but also non-legal care workers. The problem of migration in long-term care needs to be highlighted as an EU issue. Although migration may play a role in solving the problem of labour force sustainability in the host countries, it may pose a threat to the care systems of the countries of origin of migrants.

### *E.4.2 Financial sustainability: Mediating between different claims*

The financial sustainability of care services, and the implications for the future of the welfare state, has been well studied in Sweden, and participants have been able to draw valuable information from those analyses. Social policies gain legitimacy when members of all age groups and generations profit. Hence, combining efficiency with more preventive and health promoting measures is a good model to follow.

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