

Freedom of choice and dignity for the elderly

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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

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). 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).

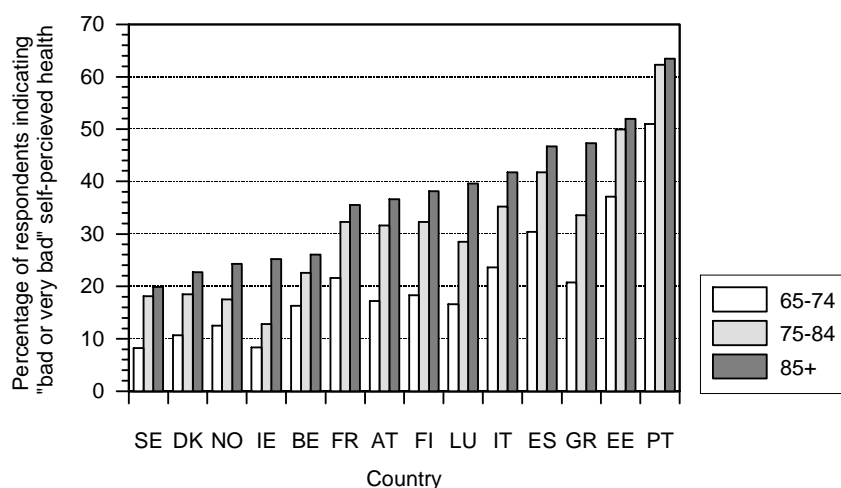


Figure 1: Self-perceived health by age group. Percentage of respondents answering “bad or very bad” self-perceived health. Source: EU-SILC 2006 (European Commission, 2006a)

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.

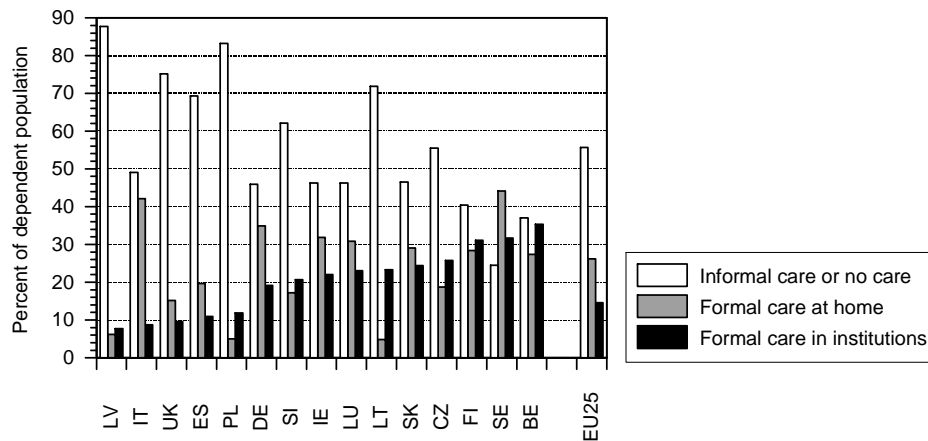


Figure 2: Dependent population in EU member states with informal or no care, formal care at home or formal care in institutions in 2004. Source: DG Economic and Financial Affairs (Tsolova & Mortensen, 2006, p. 4)

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.

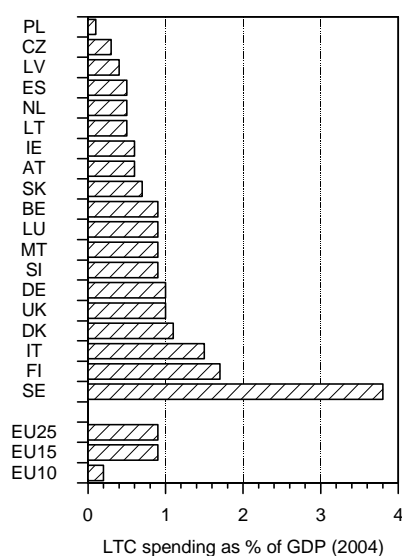


Figure 3: Long-term care spending as percent of gross domestic product (GDP) in 2004. Source: Ageing Working Group (AWG) of the Economic Policy Committee (EPC), (European Commission, 2006a)

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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