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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). A study visit to the Nacka municipality was included in the Peer Review meeting. 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.

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[1]. 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[2]). 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[3], 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[4].

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

[1] European Commission, 2005
[2] Münz, 2007, p.5
[3] e.g. Esping-Andersen, 1999; Lamura et al., 2007; Titmuss, 1987
[4] European Commission, 2007b, pp. 100-110

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 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[5].

C*onsumer 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

[5] Townsend, 2006

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.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[6].

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"[7]. 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[8] 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[9].

6 European Commission, 2006a
7 Townsend, 2006, p. 177
8 European Union, 2000
9 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

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

	Access	*Quality*	*Sustainability*
Primary Indicators	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
Contextual Indicators	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[10]

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 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[11].

[10] 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.

[11] Swedish Ministry of Health and Social Affairs, 2007b

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[12]. 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[13]. 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[14] 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 devises 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 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

[12] ibidem

[13] Swedish Association of Local Authorities and Regions [SALAR], 2007

[14] Johansson, 2004, p. 6

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[15]. 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[16]. 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[17]. 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[18].

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 strategies. Parliament has taken several initiatives to support

[15] Davey, Savla, Sundström, Zarit, & Malmberg, 2007
[16] ibidem
[17] Swedish Association of Local Authorities and Regions [SALAR), 2007, p. 6
[18] Swedish Ministry of Health and Social Affairs, 2007d

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[19].

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[20]. 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"[21].

[19] Swedish Ministry of Health and Social Affairs, 2006
[20] Swedish Association of Local Authorities and Regions [SALAR], 2007, pp. 69-72
[21] Swedish Ministry of Health and Social Affairs, 2007a

B.4 Study visit to the Nacka municipality

A study visit to the Nacka municipality[22] 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[23]. 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[24]

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[25]. 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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22 http://www.nacka.se/default/PlatsID.8/vis.1

23 http://infobanken.nacka.se/www/english/customer_choice.htm

24 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, Paúl, 2007, Schenk, 2007).

25 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 then 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 then 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[26]. 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[27]. One immediate challenge, and an important point in the drafting of the new government's agenda, 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[28]. 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.

[26] European Commission, 2006b: 38
[27] European Commission, 2006b: 27
[28] Lamura et al., 2007

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.

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[29]. 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.

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. HIQAs 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

[29] Lamura et al., 2007

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[30]. 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

[30] Lamura et al., 2007

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-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[31]. 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[32], 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

[31] RVZ, 2006
[32] Lamura et al., 2007

in 2004), high reliance on indirect taxes and the various social insurance systems lead to regressive financing and a pro-rich use of care.

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[33].

[33] 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
Austria	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.
Czech Republic	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.
Ireland	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.
Netherlands	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.
Portugal	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.
Sweden	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 there 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 loosing 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 loosing 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 (such as Nacka[34]) only approve or authorise the care providers, who then offer their services on the market. (This second option may 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 use of private providers in the Nacka municipality 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.

[34] See section B.4.

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 war 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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