THE CROSS-ATLANTIC EXCHANGE TO ADVANCE LONG-TERM CARE

SPECIAL CEPS REPORT

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BACKGROUND PAPER PREPARED FOR THE
EUROPEAN COMMISSION AND AARP JOINT CONFERENCE ON LONG-TERM CARE

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Contents

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I. Introduction

Providing high-quality, affordable long-term care (LTC) for older people is a policy challenge for many nations. Growing numbers of older people and extended longevity in the European Union (EU) and the United States (US) are increasing the demand for LTC. As major payers for LTC services and regulators for quality of care, governments are grappling with how to fund and deliver these services so that people can age with independence, dignity, and quality of life. See definitions of these key concepts in Box 1.

In the EU, Member States and the European Union have committed, in the context of their work with LTC and health care through the Open Method of Coordination on Social Protection, to ensure universal access to quality LTC in a financially sustainable manner, recognizing that policy responsibility is with the EU Member States.[1]

Box 1. Definition of long-term care and dependency

Long-Term Care (LTC) brings together a range of supports and services for persons who need help with basic activities of daily living over an extended period of time. Such activities include bathing, dressing, eating, getting in and out of bed or a chair, moving around and using the bathroom, often in combination with rehabilitation and basic medical services.[2] LTC services are needed by individuals with long-standing physical or mental disability, who rely on assistance with basic activities of daily living, many of whom are in the highest age groups of the population.

The concepts of 'dependency' and 'disability' are here used as generic terms but in reality may not be defined rigorously in the same way in all countries. The very notion of 'dependency' is not commonly utilized in the United States, where the focus is on different degrees of disability and promoting independence. Dependency refers to having functional impairments requiring some assistance, though countries differ in what they include under that term.

In certain countries and contexts, LTC is increasingly considered as one aspect of a broader 'integrated' approach, including active ageing, preventive measures, promotion of autonomy, social assistance, health care and end-of-life care.

The European Commission and the AARP Global Aging Program are hosting a joint conference to help policy-makers, researchers, providers, and advocates meet the challenge of planning and preparing for the needs of an ageing population. Delegates to this international conference include high-level representatives, senior officials from the EU and US and researchers. The conference and this background paper are intended to highlight common challenges and opportunities with the aim of developing a platform for exchange and dialogue on important policy issues facing ageing societies.

[1] European Commission (2005), Working Together, Working Better: A New Framework for the Open Coordination of Social Protection and Inclusion Policies in the European Union (http://ec.europa.eu/employment_social/social_inclusion/objectives_en.htm).

[2] OECD (2005), *LTC for Older People*, The OECD Health Project. Paris, pp. 10-17 (http://www.oecd.org/document/50/0,2340,en_2649_37407_35195570_1_1_1_37407,00.html).

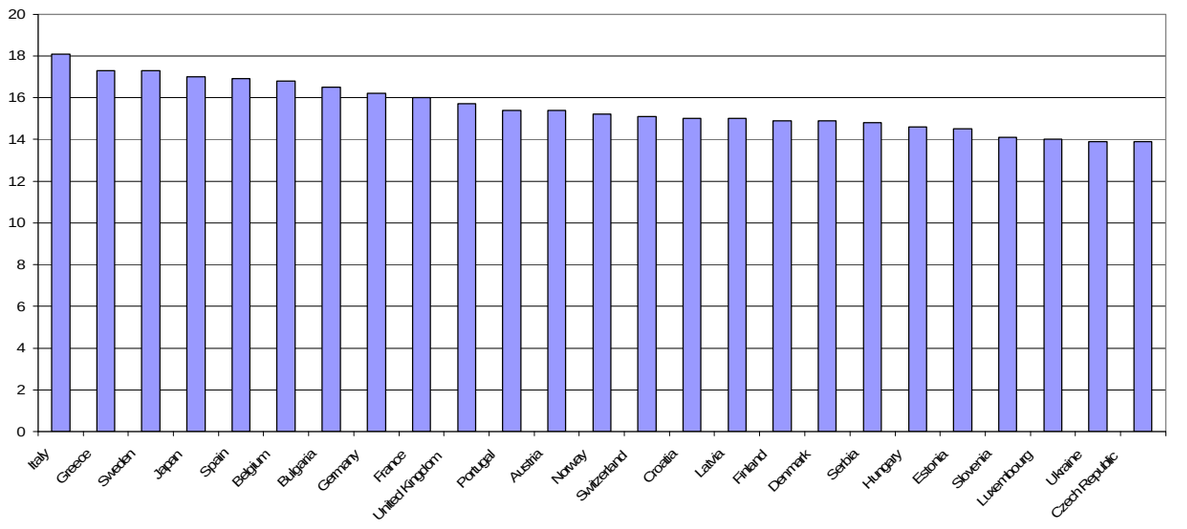
This background paper begins with a discussion of the overall goal of promoting healthy and active ageing, followed by three sections that provide a brief overview of the topics to be discussed in the three sessions of the conference with background information of developments in the EU and US:

1) Enhancing independence by receiving care at home and in the community as much as possible;
2) Identifying sources of quality LTC services, including supporting family caregivers, promoting consumer-directed approaches to services, and developing the capacity of the LTC workforce; and
3) Ensuring sustainable financing of LTC systems.

II. Long-Term Care in Developed Nations

The population in developed countries is ageing rapidly. With the exception of Japan, the world's 25 oldest countries are all in Europe (see Figure 1). Although policy decision-makers have expressed concern about ageing in the US, the US is comparatively young with a proportion of older people of less than 13 percent in 2000 that will increase only slightly during the next decade.[3] Nonetheless, the oldest old—those aged 85 and older who are most likely to need LTC—are the fastest growing portion of the American population.

Figure 1. The world's 25 countries with the highest share of older people: 2000 (population aged 65+, percentage of total population)



Source: US Census Bureau.

[3] K. Kinsella and V. Velkoff (2001), *An Aging World: 2001*, U.S. Census Bureau, Series P95/01-1, U.S. Government Printing Office, Washington, D.C. (http://www.census.gov/prod/2001pubs/p95-01-1.pdf).

Age is not the only indicator and may not be the best gauge of need for LTC services. Other elements include the number of people with limitations in self-care or mobility and the number of seniors living alone. Low income is an important indicator of the need for publicly-funded LTC services. In the US, roughly 10 percent of people age 65 and older live in poverty. Even more live just above the poverty line and would not be able to afford LTC services if needed. Roughly one-fifth of Americans age 65 and older have self-care or mobility limitations.

As shown in Table 1, in the United States about 6 million persons, or 17 percent of the population aged 65+, are in need of LTC services. Only about one-quarter of those persons are nursing home residents, with the remaining three-quarters receiving care at home or in the community.

Table 1. Long-Term Care in the US

In need of care	**Million**	**% of US population**	**% of 65+**
Aged 65+	6.0	2.2	17.1
Community residents	4.5	1.6	12.9
Nursing home residents	1.5	0.5	4.3
Under age 65	3.6	1.3	
Community residents	3.4	1.2	
Nursing home residents	0.2	0.1	
Total	9.5	3.4	

Source: Kaiser Commission (2005), Medicaid fact sheet, March

The overall proportion of older people in need of LTC is approximately the same in the US and the EU. In fact, as shown in Table 2, the number of dependent persons aged 65+ in the EU25 (excluding some countries, see note) was estimated to have been 12.6 million persons in 2004, which is 17 percent of the total population aged 65+, as in the US. According to these estimates, the degree of dependency, however, shows a considerable disparity, ranging from only 15 percent of those aged 65+ in Austria to more than 30 percent in the United Kingdom.

Disability rates are higher for older women than for older men in both the US and the EU. According to the 1999 National Long-Term Care Survey,[4] 14.5 percent of older men reported any disability, compared to 23.4 percent of women. Among those aged 85 and older, 43.6 percent of men and 60.4 percent of women reported any disability. The situation in the EU is similar; 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.[5] A 65-year-old woman in the US faces an estimated 72

[4] The National Long Term Care Survey (NLTCS) is funded through a Cooperative Agreement (2 U01 AG0007198) between the National Institute on Aging (NIA) and Duke University's Center for Demographic Studies. The project is a longitudinal survey designed to study changes in the health and functional status of older Americans (aged 65+). It also tracks health expenditures, Medicare service use, and the availability of personal, family, and community resources for care giving. The survey began in 1982, and follow-up surveys were conducted in 1984, 1989, 1994, 1999, and 2004 The Center for Demographic Studies, CDS, is one of the centers on the Demography of Aging established by the National Institute on Aging (NIA) to provide policy-relevant research on issues that affect the elderly population of the United States.

[5] Economic Policy Commission (2001 and 2006) and the European Commission (2006c).

percent chance of developing a high level of disability likely to require LTC services over her lifetime, compared to 44 percent for a 65-year-old man.[6]

Although full data comparability may not be assured, despite considerable efforts, for the EU as a whole, only four out of ten dependent older persons receive formal LTC at home or in specialized institutions, with the remaining six out of ten persons receiving informal home care or no care.[7]

Table 2. Dependent population in EU Member States

Dependent population, 2004, absolute and percent of total population 65+					
	Number of persons	**Percent of population aged 65+**	**Per cent of dependent population**		
	(000's)		**Formal care in institutions**	**Formal care at home**	**Informal or no care**
BE	416	23.1	35.3	27.4	37.0
DK	139	17.4	9.4	126.6	0.0
DE	2790	18.7	19.2	34.9	45.9
ES	1449	20.4	10.9	19.7	69.3
IE	91	22.8	22.0	31.9	46.2
IT	2214	19.9	8.7	42.1	49.1
LU	13	13.0	23.1	30.8	46.2
NL	362	15.7	21.8	n/a	n/a
AT	197	15.2	n/a	n/a	n/a
FI	183	22.9	31.1	28.4	40.4
SE	322	21.5	31.7	44.1	24.5
UK	2899	30.5	9.6	15.2	75.2
CZ	299	21.4	25.8	18.7	55.5
LT	103	20.6	23.3	4.9	71.8
LV	65	16.3	7.7	6.2	87.7
MT	19	19.0	68.4	26.3	5.3
PL	885	17.7	11.9	5.0	83.3
SK	127	21.2	24.4	29.1	46.5
SI	58	19.3	20.7	17.2	62.1
EU25	12631	16.8	14.6	26.2	55.7
EU15	11075	17.0	14.3	28.5	53.4
EU10	1556	15.4	17.0	10.3	72.6

Note: Data not available for Greece, France, Portugal, Cyprus, Estonia and Hungary.
Source: Directorate-General for Economic and Financial Affairs (AWG projections).

[6] Cohen et al. (2005), *Becoming Disabled After 65: The Expected Lifetime Costs of Independent Living*, AARP Public Policy Institute Report #2005-08 (http://www.aarp.org/research/health/disabilities/2005_08_costs.html).

[7] The data in the table do not fully add as details are not available for the Netherlands and Austria, and the breakdown on categories for Denmark add up to a higher figure than the total.

III. Key Objectives of Long-Term Care Policy

The following sections discuss common goals for LTC in the EU and the US, including:

1. Promoting 'active ageing'; that is, allowing people to realize their potential for physical, social and mental well-being throughout the course of their lives, notably in older ages.
2. Increasing provision of home and community-based services to reflect the preferences of people with care needs and to enhance their independence.
3. Improving the quality of LTC, including supporting family caregivers, promoting consumer-directed approaches to services, and developing the capacity of the LTC workforce.
4. Ensuring sustainable financing of LTC systems.

1. Healthy and Active Ageing

Active ageing aims to minimize the need for LTC by expanding healthy life expectancy and supporting the quality of life for all people as they age, including those who are frail, have disability and are in need of care.[8] The word 'active' refers to continuing participation in social, economic, cultural, spiritual and civic affairs, and not just the ability to be physically active or to participate in the labor force. The aim is to support the participation of dependent persons in society according to their needs, desires and capacities with adequate protection, security and care when required. Measures to promote active ageing are therefore considered as a necessary complement to policies that specifically address issues related to disability and LTC. For example, US government and private foundation grants are developing private/public partnerships to increase seniors' access to disease prevention programs to focus on intervention in disease self-management, falls prevention, nutrition, physical activity and medication management.

The EU approach to ageing aims at mobilizing the full potential of people of all ages. The basic assumption is that adequate responses to ageing must go beyond paying attention to those who are currently old. Adjusting well to population ageing is an issue for people of all ages, and a life-time approach can help the development of adequate policy responses taking account of the related age and gender-specific issues. Consequently, the EU Council of Ministers in October 2004 endorsed the Social Protection Committee's (SPC) proposal to apply the rules of the Open Method of Coordination (OMC) to health and LTC, implying the submission and common assessment of national reports on the approach to the challenges resulting from the demographic ageing.[9] As the result of this action, the EU will explore in an integrated framework how Member States can promote healthy and active life styles (notably 'healthy ageing', but also the prevention of obesity, smoking, and alcohol and drug abuse throughout the life cycle), health and safety at work and more preventive care (e.g., screening). The EU will also examine to what extent this approach can contribute to improved health status and lower expenditures on health

[8] WHO (2002), *Active Ageing: A Policy Framework* (http://www.euro.who.int/document/hea/eactagepolframe.pdf).

[9] European Commission (2005), *Review of Preliminary National Policy Statements*; Memorandum of the Social Protection Committee on Health Care and LTC, Employment, Social Affairs and Equal Opportunities Directorate General.

and LTC. The preliminary national policy statements submitted to the SPC to date, however, mainly concern health and LTC as traditionally defined.

2. Shifting Policy from Institutional to Home and Community-Based Services

A majority of older persons receive the bulk of support in daily living activities (together with lower-level care) in their own homes from informal (unpaid) caregivers, either family or friends. As far as formal care is concerned, the general trend in both Europe[10] and the US has, in recent years, been to shift from institutional care to home care.

Formal (paid) LTC services are provided in a variety of settings. Formal care services can be provided at home and in the community by professional home care service agencies, including paid personal assistants. Alternatively, they can be delivered in care institutions, such as nursing homes and assisted living facilities.

Increasingly, individuals prefer to live independently in their own homes for as long as possible. Nursing homes often are the last choice for receiving LTC when other options are not available.[11] When AARP surveyed people over the age of 50 with a disability, 87 percent said they preferred services in their own homes – either from family and friends (61 percent) or from agencies (26 percent). Only eight percent preferred assisted living and one percent would prefer to receive services in a nursing home.[12] Even when family caregivers are not or no longer available, people clearly prefer formal care delivered in their homes to institutional care.[13]

Among EU countries, the percentages of persons receiving formal LTC at home or in an institution range widely. At one extreme, 90 percent of dependent older persons in Denmark and 75 percent in Sweden receive regular formal care while in Spain, the UK, Lithuania, Latvia and Poland less than 30 percent of the dependent population receives formal care.

Among those receiving formal care, on average about two out of five persons are found in institutions while three out of five receive formalised care at home. Once again, the disparities in this respect are huge. In Denmark, only 10 percent of the dependent population is located in institutions: formal home care is the dominant form of care. In Malta and Belgium, on the contrary, the provision of LTC in institutions is much more common, with 48 and 35 percent respectively of the dependent population (see Figure 2).

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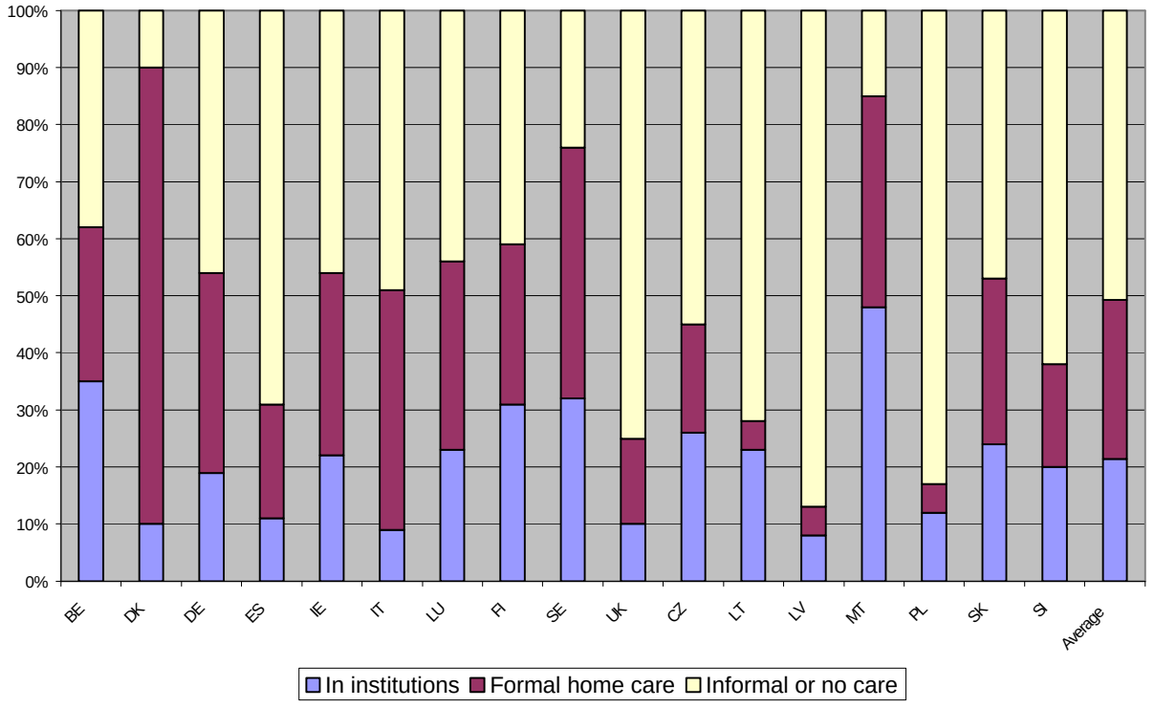
[10] In Denmark, the number of people in nursing homes has fallen dramatically, from 50,000 in 1987 to 36,500 in 1996. This was accompanied by a large increase in the number of home nurses and home-help assistants employed by municipalities. In the UK between 1960 and 1980, around 100,000 people in need of LTC have been discharged into the community. Another trend could be observed in Belgium, where there are plans to increase the places in combined rest and nursing homes, which provide a high level of nursing care.

[11] E. Schulz (2004), *Use of Health and Nursing Care by the Elderly*; ENEPRI Research Report No. 2, July 2004 (http://shop.ceps.be/BookDetail.php?item_id=1139).

[12] AARP (2003), *Beyond 50.03: A Report to the Nation on Independent Living and Disability* (http://www.aarp.org/research/housing-mobility/homecare/aresearch-import-752-D17817.html), p. 146.

[13] M. Cantor (1979), "Neighbors and Friends: An Overlooked Resource in the Informal Support System", *Research on Ageing*, 1, pp. 434–436.

Figure 2. Dependent population by category of care



Note: Data not available for Greece, France, Portugal, Cyprus, Estonia and Hungary.

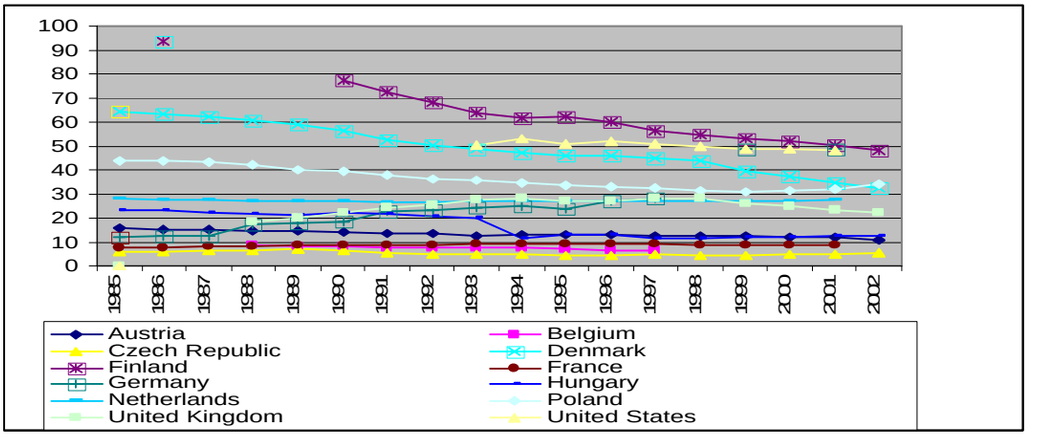
Source: Directorate-General for Economic and Financial Affairs (AWG projections), European Commission.

Until the age of 60, LTC is seldom required, and for people aged 60 to 79 the prevalence rate is low. After age 80, the probability of receiving LTC in institutions rises dramatically. In the oldest age group (90+), the prevalence rates are between 20 percent for France to more than 50 percent in the Netherlands. Furthermore, the institutionalization rate is higher for women than for men due to higher life expectancies, higher disability rates and higher rates of widowhood. Most care giving at home is also provided to the oldest old, but, on average, the people receiving formal care at home are younger than institutionalized people. Around three percent of people in Finland and Germany and around 1.3 percent in Belgium aged 60 to 79 receive formal home care, but no more than 0.15 percent were institutionalized.

In the US, the number of nursing facility beds has generally been much higher than in most European countries. In the mid-1990s, the US had an average of 49 LTC beds per 1,000 persons in the age 65+ as compared to 35 in Denmark or 23.5 in the UK, but there is now a clear tendency both in the EU and in the US toward decreasing the number of beds for institutional care (see Figure 3). For example, the US rate of nursing home use among those aged 65 and over declined in relative terms by 36 percent in age-adjusted terms between 1985 and 2004.[14] Recent declines in this ratio have also occurred in Australia, Austria, and Norway.[15]

[14] National Nursing Home Survey data from the National Center for Health Statistics at: www.cdc.gov/nchs. Rates for 65+ category are age-adjusted using the 2000 standard population. In the graph below, the 1997 population figures are adjusted for net under-enumeration using the 1990 National Population Adjustment Matrix from the US

Figure 3. LTC beds per 1000 population aged 65+



Source: OECD Health Data 2004.

3. Identifying Sources of Quality Long-Term Care Services

Quality of care can be addressed in many ways, ranging from provider licensure and regulatory standards to measuring consumer satisfaction. As the US and EU countries have moved from institutional care toward more home and community-based services, the challenge of monitoring the care delivered in millions of private homes has gained attention. Traditional methods for assessing quality such as licensure and training, alone, are inadequate. In addition the concept of 'quality' is increasingly considered as encompassing important factors such as:

a) Supporting family caregivers;

b) Giving consumers choices through consumer-directed care;

c) Ensuring the capacity of the LTC workforce; and

d) Assistive technologies.

a) Family Caregivers

In Europe as well as the US, the majority of care is provided by unpaid family members, neighbors and friends – especially daughters, daughters-in-law and spouses. The term 'caregiver' refers to people involved in the everyday delivery of services to the users, regardless of professional or educational qualifications.[16] In the EU, around four percent of persons in households look after older or disabled persons. On average, around 68 percent of caregivers in EU countries are women, and about 60 percent of those are aged 30 to 59.

Census Bureau. Reference population: These data refer to the resident population. Persons residing in personal care or domiciliary care homes are excluded.

[15] OECD (2005), *Long-Term Care for Older People*, The OECD Health Project. Paris (http://www.oecd.org/document/50/0,2340,en_2649_37407_35195570_1_1_1_37407,00.html).

[16] E. Neményi et al. (2006), *Employment in Social Care in Europe, European Foundation for the Improvement of Living and Working Conditions*, Dublin (http://www.eurofound.eu.int/pubdocs/2005/125/en/1/ef05125en.pdf).

Since many women providing care are middle-aged, formal employment holds implications for informal care giving. Combining care giving with paid employment can be an arduous task, and the labor force participation of women often conflicts with providing care.[17] The increasing labor force participation of women (one of the EU policy objectives in the field of employment and social affairs) is likely to affect the future supply of informal care, resulting in increased demand for professional care – either at home or in an institution. Changes in family structure and household composition (e.g., fewer children, higher divorce rates and increasing mobility)[18] also affect the informal care potential and the need for professional home care or institutional care.[19]

Data concerning care giving by relatives, friends or neighbors in Germany show that one-third of informal caregivers are spouses, 13 percent are parents, 38 percent are children or children-in-law, 10 percent are other kin and 7 percent are neighbors or friends.[20] In the US, 21 percent of the adult population (an estimated 44 million Americans) provide unpaid support to people in need of care.[21] While estimates of the economic value of informal care-giving vary, it is generally recognized that the market value of the unpaid labor of family care is greater than the cost of paid home care assistance in all countries.

b) Consumer-Directed Care[22]

Given demographic ageing and the growing number of older people requiring care, the need for and importance of social care services—that is, non-medical supportive services—is on the increase. Almost every household will eventually make use of social care services. Home care, day care and residential care are costly and labor-intensive, with staff costs accounting for the majority of overall costs. The labor supply in the social care sector is rapidly becoming an important issue.[23]

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[17] K. Spiess and U. Schneider (2002), *Midlife Caregiving and Employment: An Analysis of Adjustments in Work Hours and Informal Care for Female Employees in Europe*, ENEPRI Working Paper No. 9, CEPS, Brussels, February (paper also presented at the ENEPRI workshop in Berlin, 2001) (as quoted by Schultz).

[18] In all EU countries, family structures are changing: the proportion of elderly persons living with their children has fallen. In the northern European countries, only one person out of 10 lives with their children and in Norway, the Netherlands and Denmark only one person out of 25 does.

[19] S. Jacobzone (1999), *Ageing and Care for Frail Elderly Persons: An Overview of International Perspectives*, Labour Market and Social Policy Occasional Paper No. 38, OECD, Paris (as quoted in E. Schultz, 2004).

[20] Schneekloth, U. and Müller U. (2000), Wirkungen der Pflegeversicherung. (Impact of LTC insurance), Schriftenreihe des Bundesministeriums für Gesundheit, Band 127, Baden-Baden. (as quoted by Schultz).

[21] S. Pandya (2005), *Caregiving in the U.S.*, AARP Public Policy Institute April, FS111, Washington, D.C. (http://www.aarp.org/research/housing-mobility/caregiving/fs111_caregiving.html).

[22] The US National Institute on Consumer-Directed LTC defines consumer direction as "a philosophy and orientation to the delivery of home and community-based services whereby informed consumers make choices about the services they receive".

[23] G. Coomans (2002), "Labour Supply in a European Context: Demographic Determinants and Competence Issues", paper presented at conference on Care Workers: Matching Supply and Demand – Employment Issues in the Care of Children and Older People Living at Home, Sheffield Hallam University, 20–21 June, as quoted by E. Neményi et al. (2006), *Employment in Social Care in Europe, European Foundation for the Improvement of Living and Working Conditions*, Dublin (http://www.eurofound.eu.int/pubdocs/2005/125/en/1/ef05125en.pdf).

The current trend towards self-management and consumer choice will also have an effect on the structure and provision of care services and, hence, labor supply issues.

Consumer-directed programs are extremely varied in the number and range of issues for which the consumer may assume responsibility. There are three models:

- Direct pay: the consumer is the employer and has full hiring, firing, tax and payroll responsibilities;
- Fiscal intermediary: a designated agency handles payroll and taxes and the consumer selects and manages the employee;
- Supportive intermediary: a public agency provides supportive services such as recruitment assistance, criminal background checks and training.[24]

The concept and practice of consumer-directed home care challenges the paternalistic nature of traditional home and community services for older people. Among EU countries, the Netherlands and Germany are successfully moving ahead in this direction, providing people with more control over the care and support services they require.[25] Consumer choice and direction are also increasingly being embraced in the US. Research demonstrates that more than three-fourths of Americans age 50 and older would prefer to have control over the management of their support themselves.[26] Consumer-directed services are well established for younger people in need of care and support; however, they are less common for older people.

c) The Capacity of the Long-Term Care Workforce

Approximately 10 to 13 percent of the overall workforce in the EU is employed in the health and social care sector, with three to five percent employed in the LTC sector.[27] Between 1995 and 2001, more than two million jobs were created in the health and social care sector in the EU – 18 percent of all new jobs created. Despite this increase, the provision of high quality care is becoming a challenge, due to insufficient staffing levels to meet the increasing need for care, mainly for older people. Staff shortages, staff qualifications and high staff turnover are a policy concern in many countries.[28] An initial analysis of the European care sector suggests a number of shortfalls, such as relatively few young labor-market entrants and increasing levels of staff turnover (often due to the lack of career prospects, poor working conditions, low salaries and low

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[24] National Council on Aging (http://www.ncoa.org/) and AARP (http://assets.aarp.org/rgcenter/consume/ib36_ltc.pdf).

[25] AARP Public Policy Institute (2003), *Consumer-Directed Home Care in the Netherlands, England, and Germany*; (http://assets.aarp.org/rgcenter/health/inb77_eu_cd.pdf).

[26] B. Coleman (2003), *Consumer-Directed Personal Care Services for Older People in the U.S.*, AARP Public Policy Institute Research Report IB64, October (http://www.aarp.org/research/housing-mobility/homecare/aresearch-import-11-IB64.html).

[27] P. Driest. (2006), "LTC in Europe: An Introduction", chapter 8 in J. Hassink and M. van Dijk (eds), *Farming for Health*, Springer (http://library.wur.nl/frontis/farming_for_health/08_driest.pdf).

[28] OECD (2005), *LTC for Older People*, The OECD Health Project, Paris (http://www.oecd.org/document/50/0,2340,en_2649_37407_35195570_1_1_1_37407,00.html).

status).[29] The ageing of care workers themselves is an additional complication. In the EU, 40 to 50 percent of the nurses are over 40 years old.

Despite strong performance in terms of job creation, care provision has remained an almost hidden feature of European, national and regional labor markets. Weak labor supply in the care sector is occurring at a time of increasing demand for quality care provision, arising from demographic and societal change. In most cases, demand for social care services exceeds the supply of resources available, particularly in terms of labor and the financial supports afforded to the sector in different countries.

The scarcity of paid caregivers is likely to become more pronounced in the near future. In the US, the Bureau of Labor has declared that the required growth in employment for care workers for the period 2000-10 will be more than twice the projected growth in overall employment (15.2 percent) during this same period. Between 2000 and 2010, the number of care workers in the US is projected to increase by 36.3 percent.[30] This increase is needed well before the oldest baby boomers reach 85 years of age in 2031. Increasingly, the supply of social care workers (e.g., by means of working with employers to allow for better wages and working conditions) will need to be a priority across EU Member States and the US.[31]

Table 3. Number of direct care workers, US (000's of jobs)

	2000	**Projected 2010**	**Increase (%)**
Nurse aids, orderlies and attendants	1,373	1,697	23.5
Home health aides	615	907	47.3
Personal & home care givers	414	672	62.5
Total	2,402	3,276	36.3
Net change over decade		874	

Source: US Bureau of Labor Statistics, Employment by occupation, 2000 and 2010.

Another issue is that, at least in the US, a disproportionate share of direct-care workers live in poverty and without benefits. For example, the median monthly income of direct-care workers is roughly US $1,000, and four out of ten persons do not have health insurance. Overall, approximately 18 percent of direct care workers have an estimated family income at or below the federal poverty level compared to 11 percent of the workforce nationally.[32] Poor working conditions and low wages and benefits risk further constraints on the supply of qualified human resources for LTC in the future.

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[29] E. Neményi et al. (2006), *Employment in Social Care in Europe*, European Foundation for the Improvement of Living and Working Conditions (http://www.eurofound.eu.int/pubdocs/2005/125/en/1/ef05125en.pdf).

[30] In fact, Personal and Home Care Aides rank 8th in terms of the fastest-growing occupations between 2000 and 2010.

[31] E. Neményi et al. (2006), *Employment in Social Care in Europe*, European Foundation for the Improvement of Living and Working Conditions, Dublin (http://www.eurofound.eu.int/pubdocs/2005/125/en/1/ef05125en.pdf), p. 61.

[32] S. Harmuth (2002), "The Direct Care Workforce Crisis in LTC", *North Carolina Medical Journal*, March/April 2002, Volume 63 Number 2 (http://www.ncmedicaljournal.com/mar-apr-02/ar030205.pdf).

d) Assistive Technologies

Assistive technologies have growing potential to improve the lives of persons with disabilities by enabling them to live more easily in community-based settings. Assistive technologies also have the potential to:

- relieve the effects of shortages of allied health and social services personnel;
- decrease burdens on family caregivers; and
- provide people with a greater sense of independence and privacy.

However, the potential of assistive technologies is not being fully realized. For example, a recent survey of persons age 50 and older with disabilities in the United States found that, among those who do not use any special equipment or assistive technologies to help with daily activities, 22 percent believe that some type of special equipment or technology could help improve their quality of life.[33]

Recent reports, one commissioned by the European Commission (EC) and the other published by AARP, indicate that there are several common issues faced by the United States and European countries. One of the conclusions of the report commissioned by the EC[34] is that assistive technology decisions should reflect the objective needs of the person with the disability, not be a reflection of the health-care and social-service systems that create obstacles to meeting individual needs. The report states that a "one-stop shop" for assistive technologies for persons with disabilities would constitute tremendous progress in most countries.

An AARP report[35] similarly finds that government funding of the range of assistive technologies in the United States is a patchwork, the overall effect of which is incomplete and irregular. In particular, Medicare and Medicaid are health care programs that have very limited coverage of assistive technologies because these programs generally require substantiation of medical necessity to cover an assistive technology, as opposed to improvement in functioning (a broader concept). Assistive technologies place a substantial burden on individuals' finances – over half the cost of assistive technologies in the United States is paid for out-of-pocket.

4. Ensuring Sustainable Financing of Long-Term Care Systems

LTC today in most countries absorbs a relatively modest part of public expenditures. But there is a widely shared perception that growth of LTC expenditures will accelerate over the next 20 to 30 years, mainly as a result of larger numbers of older persons, and a steep increase in the numbers of the oldest old. The most common challenges for the financing of LTC highlighted by the EU member states are related to ageing, notably the prospective increase in number of the oldest old, and to labor shortages in a sector that is extremely labor-intensive.

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[33] AARP (2003), *Beyond 50.03: A Report to the Nation on Independent Living and Disability*, Washington, D.C., p. 149.

[34] Deloitte & Touche (2003), *Access to Assistive Technology in the European Union*, study prepared for the European Commission, Directorate-General for Employment and Social Affairs, Unit E. 4 (http://ec.europa.eu/employment_social/publications/2004/cev503003_en.pdf).

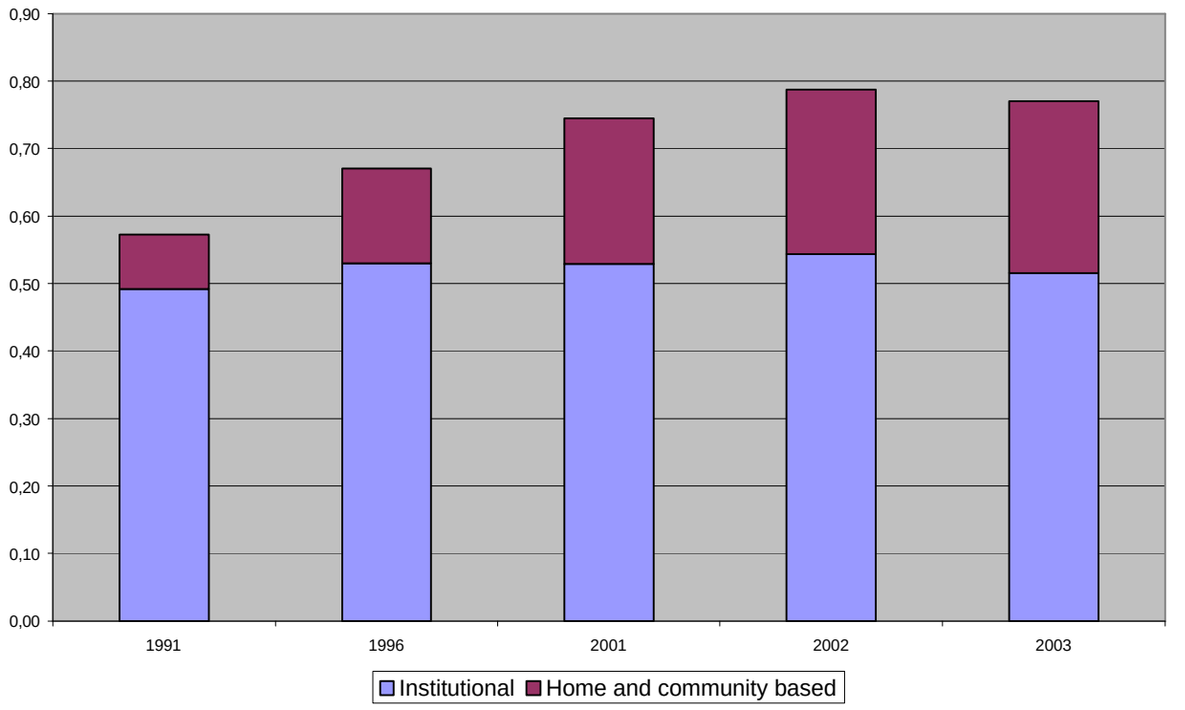
[35] M. Freiman (2006), *Public Funding and Support of Assistive Technologies for Persons with Disabilities*; AARP Public Policy Institute Report - 2006-04, January.

In most developed countries, public expenditures on LTC range from 0.5 percent to 1.6 percent of GDP, with only Denmark, Norway, Sweden and the Netherlands having expenditure ratios well above that level. Quite different ways of organizing and funding LTC have led to similar expenditure outcomes, in terms of overall spending levels. For example, Australia, Canada, Germany, the United Kingdom, and the US have spending ratios that lie within a narrow range of 1.2 to 1.4 percent of GDP.[36]

In the United States, total spending on LTC in 2003 amounted to 1.4 percent of GDP. Public spending, mainly Medicare and Medicaid, constituted about 60 percent of this total, corresponding to some 0.85 percent of GDP, with private funds covering an additional 0.06 percent and private out-of-pocket financing 0.35 percent (see Table 4).

From 1991 to 2002, public LTC spending in the US rose from 0.57 to close to 0.8 percent of GDP, with public funding of home and community-based LTC expanding more rapidly than institutional care. A modest decline was recorded on 2003, reflecting some contraction of funding for institutionalized LTC (Figure 4).

Figure 4. Public long-term care spending in the US (percent of GDP)



Source: Kaiser Commission, Medicaid Fact Sheet, March 2005.

[36] OECD (2005), *LTC for Older People*, The OECD Health Project., Paris, p. 26 (http://www.oecd.org/document/50/0,2340,en_2649_37407_35195570_1_1_1_37407,00.html).

Financing of LTC services is drawn from different sources. Programs[37] in many countries consist of in-kind services for both home care and institutions. However, a growing number of programs offer cash allowances or consumer-directed budgets. In most cases, LTC programs serve all age groups.

Public funding is the most important source of financing for LTC services in all countries where data on the public-private mix of funding are available (with the exceptions of Spain and Switzerland). Nonetheless, public spending on LTC is still relatively low as a proportion of GDP, when compared with other ageing-related expenditures such as pensions or acute health care. Spending on institutionalized care accounts for over half of public spending on LTC in all OECD countries. Public home care programs have received increasing attention as the preferred option; as a result, home care now accounts for more than 30 percent of public resources for LTC in the OECD countries for which data are available.

Table 4. Long-term care financing in the US, 2003

	Total	**$ billon**	**Nursing homes**	**$ billion**	**Total**	**Nursing homes**
					(% of GDP)	**(% of GDP)**
Medicaid	40%	60.3	46%	50.9	0.55	0.47
Medicare	18%	27.1	12%	13.3	0.25	0.12
Other public	3%	4.5	2%	2.2	0.04	0.02
Other private	4%	6.0	4%	4.4	0.06	0.04
Private insurance	10%	15.0	8%	8.9	0.14	0.08
Out of pocket	25%	37.7	28%	31.0	0.35	0.28
	100%	150.8	100%	110.8	1.38	1.02

Source: Kaiser Foundation, Medicaid Fact Sheet, March 2005.

A few countries (Germany, Japan, the Netherlands and Luxembourg) have set up universal social insurance schemes to cover LTC. However, taxation constitutes the main source of public financing of LTC in many countries. For example, Norway and Sweden both offer universal coverage of LTC services funded from general taxation, but differ in the cost-sharing required for services provided in nursing homes. Austria also has a universal system funded from general taxation. In other countries, the main health insurance program finances a limited amount of care in hospitals in the absence of other programs, but the total amount involved is quite small (e.g., Hungary and Poland).[38]

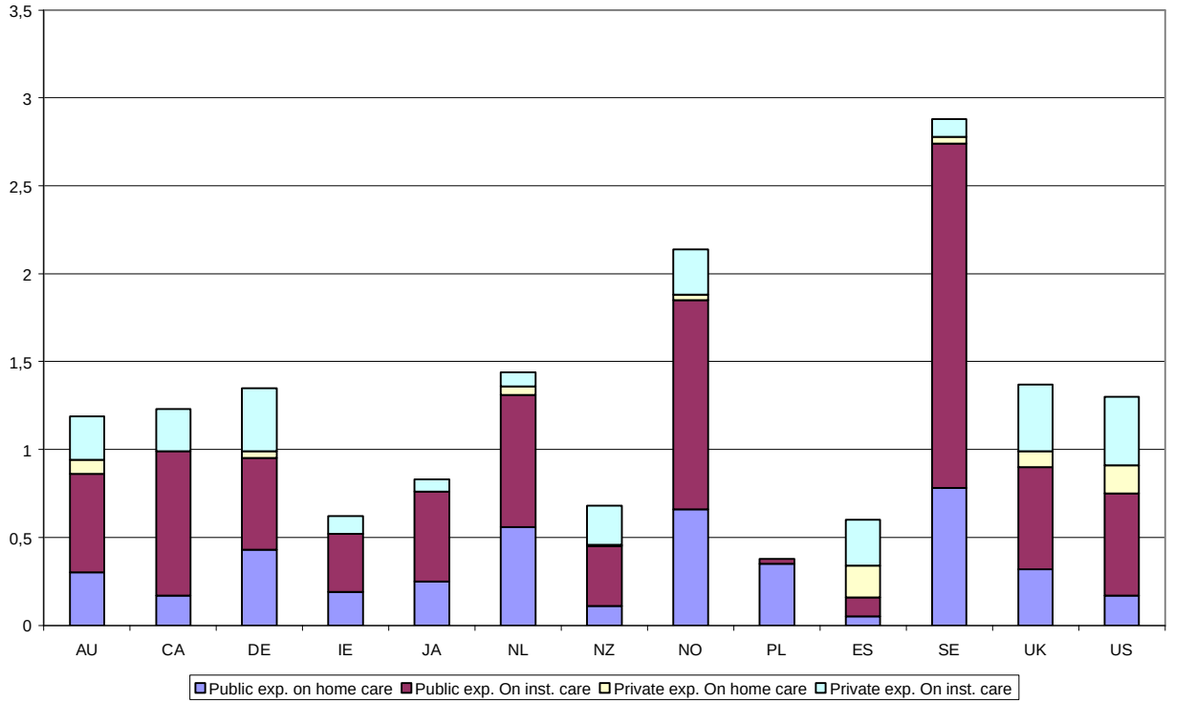
Nevertheless, in several countries private resources constitute an important source of funding for care in institutions, contributing 30 percent or more of total spending in Germany, United Kingdom and the United States for example. The share of private funding for institutional care ranges from more than 70 percent in Spain to less than 10 percent in Sweden (see Figure 5)..

[37] Detailed outline of LTC programs in OECD countries by type of program, source of financing, eligibility criteria and the use of private cost-sharing is presented on pp. 22-24 in the OECD report.

[38] OECD (2005), *LTC for Older People*, The OECD Health Project, Paris, p. 26 (http://www.oecd.org/document/50/0,2340,en_2649_37407_35195570_1_1_1_37407,00.html).

The financing picture is not complete without taking account of the important role of informal home care. The imputed value of donated care has been estimated to amount to more than one-third of the total value of LTC in the US.[39] Home care provided by external service providers but financed entirely by the household without public support is also an important aspect of LTC and this part of the provision of LTC is rising in a number of countries, often delivered by immigrant workers in the "grey economy."[40]

Figure 5. Public and private spending on long-term care (percent of GDP, 2003)



Source: OECD (2005), *LTC for Older People.*

In 2005, the EU Economic Policy Committee and the European Commission updated their projections for age-related expenditures in the future, including projections of the future cost of LTC for elderly. This work includes projections for the number of elderly people, the number of dependent elderly, some possible developments of various care solutions, and public expenditures for LTC from 2004, through 2025 until 2050. The resulting report, from February 2006,[41] provides an overview of the projected numbers of elderly in the EU Member States in the future.

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[39] Congressional Budget Office (2004), *Financing LTC for the Elderly*, Washington, D.C. (http://www.cbo.gov/showdoc.cfm?index=5400&sequence=0).

[40] D. Redfoot and A. Houser (2005), *We Shall Travel On: Quality of Care, Economic Development, and the International Migration of LTC Workers*, AARP Public Policy Institute Report #2005-14 (http://www.aarp.org/research/longtermcare/quality/inb104_intl_ltc.html).

[41] European Commission (2006c), *The Impact of Ageing on Public Expenditure: Projections for the EU25 Member States on Pensions, Health Care, LTC, Education and Unemployment Transfers (2004-2050),* Special Report No.

As shown in Table 5, the total number of elderly (65+) is projected to increase for EU25 from 75.3 million in 2004 to 133.3 million in 2050, an increase of 77 percent over these 46 years. Growth will be especially strong among the population aged 80 and over who are at highest risk of needing LTC services. That oldest old population is projected to grow by 174 percent between 2004 and 2050. The number of older people is also projected to increase more rapidly in the New Member States as longevity is expected to increase faster than in the old Member States. The total number of older people is projected to reach about 29 percent of the total population both in EU15 and in EU10.

In the US, the total number of older people is projected to increase much faster than in the EU, from 36 million in year 2004 to 82 million in 2050 or by 125 percent. However, as a consequence of the much higher fertility and expected immigration, the US population is projected to increase by about 40 percent between year 2000 and 2050, while the total population of the EU is projected to decline by one percent. The share of older people in the US is therefore projected to increase only to 19.7 percent of the total population. While the population of the oldest old in the US is projected to grow at roughly the same rate as the EU, as a percentage of the total population the oldest old are projected to rise to 7 percent in the US compared to 11 percent in the EU.

Table 5. Changes in the older populations of the EU and the US, 2004-50

	Age 65+			**Age 80+**		
	2004	**2050**	**% change**	**2004**	**2050**	**% change**
Population in millions						
EU25	75.3	133.3	77.0	18.2	49.9	174
EU15	65.2	114.2	75.2	16.3	44.2	172
EU10	10.1	19.1	89.1	1.9	5.7	193
US	36.3	81.5	124.5	10.4	28.7	176
Percent of total population						
EU25	16.5	29.4		4.0	11.0	
EU15	17.0	29.4		4.3	11.4	
EU10	13.6	29.2		2.6	8.7	
US	12.4	19.7		3.5	7.0	

Source: EU data from the Directorate-General for Economic and Financial Affairs, European Commission (AWG projections); US data from the US Census estimates for 2004 and UN Population Division projections for the US, constant fertility rate assumptions.

At stake is, however, the evolution of the rate of dependency for the different age groups. In view of the fact that demographic projections assume a considerable increase in life expectancy, it would not seem inappropriate to assume a certain increase in the 'disability-free life expectancy' (DFLE); that is, the part of life during which a person is not in need of assistance with daily

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1/2006; Directorate-General for Economic and Financial Affairs (http://ec.europa.eu/economy_finance/epc/documents/2006/ageingreport_en.pdf).

living activities. In fact, certain comparative studies suggest that disability rates in older age are declining, and consequently suggest slower growth in projected costs of LTC in the future.[42] An optimistic hypothesis would be that DFLE would rise in line with the rise in total life expectancy, implying that the whole of the gain in the latter would be translated into additional disability-free years of life. A more pessimistic hypothesis would, on the contrary, assume that the gain in life expectancy would essentially be obtained by "keeping sick people alive for longer," resulting in no increase in DFLE.

In order to explore the consequences for the financial sustainability of LTC systems, the Ageing Working Group (AWG) of the EU Economic Policy Committee has prepared two projections of the dependent population. As can be seen in Table 6, the 'pure ageing scenario' (with no change in the age-specific dependency ratios) would result in a doubling of the number of dependent persons, from 12.6 million in 2004 to some 26 million in 2050. The 'constant disability scenario,' assuming that the disability-free life expectancy increases with the rise in longevity, would result in an increase of only 31 percent over the level of 2004.

Table 6. Projections of dependent population in the EU: two alternatives

	2004	**2050**			
		Pure ageing scenario		**Constant disability scenario**	
	€ million	**€ million**	**Percent change, 2004-50**	**€ million**	**Percent change, 2004-50**
EU25	12.6	26.1	106	16.5	31
EU15	11.1	22.7	105	14.4	30
EU10	1.6	3.4	118	2.1	34

Note: Excluding Greece, France, Portugal, Cyprus, Estonia and Hungary for which no data were available.
Source: Directorate-General for Economic and Financial Affairs, European Commission.

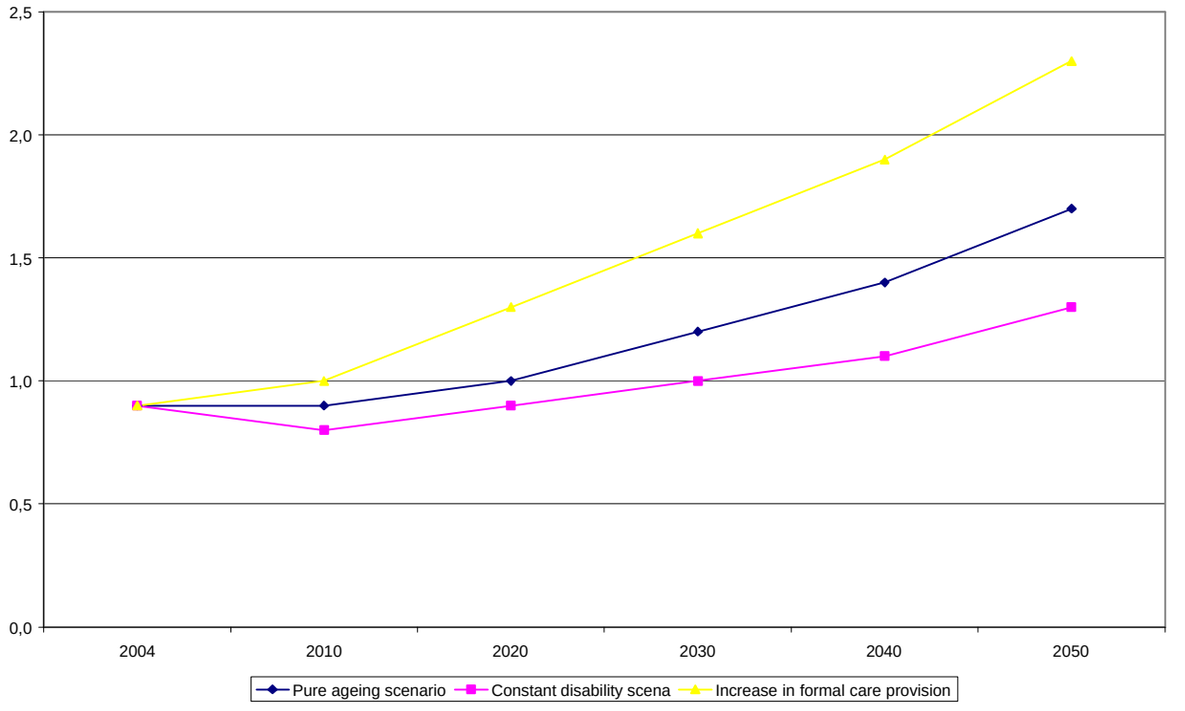
However, the demand for LTC will be influenced not only by the evolution of DFLE but also by possible changes in the structure of care giving. First, as already indicated above, in a number of EU Member States the need for formal care could become stronger in response to the projected increase in the female labor force participation. Second, the perceived preferences for formal care at home rather than in institutions may in some countries lead to a change from institutional to

[42] For Sweden, see M. Lagergren and I. Batljan (2000), "Will There Be a Helping Hand?", Annex 8 to The Long-Term Survey 1999/2000, Swedish Ministry of Health and Social Affairs, Stockholm; for the US, see K. Manton, K. and X. Gu. (2001), "Changes in the Prevalence of Chronic Disability in the United States Black and Non-black Population Above Age 65 from 1982 to 1999", Center for Demographic Studies, Duke University, Durham, NC (http://www.pnas.org/cgi/content/abstract/98/11/6354) and J. Knickman and E. Snell (2002), "The 2030 problem: Caring for the Aging Baby Boomers", Health Services Research, 37(4), 849-884; and for the EU, see Comas-Herrera, A, R. Wittenberg (eds) (2003), European Study of Long-Term Care Expenditure, Report to the European Commission, Employment and Social Affairs DG. PSSRU Discussion Paper 1840, Brussels.

home care. Consequently, there would seem to be a distinct possibility of a substantial increase in formal home care. Furthermore, this change would seem likely to be stimulated by technological developments in support of autonomy of older people.

Figure 6 plots three scenarios developed by the AWG for public spending on LTC in 2050, based on assumptions of i) pure aging, ii) constant disability and iii) an increase in formal care provisions. The projected public expenditures range from a low of 1.3 percent of GDP for the optimistic constant disability scenario to a high of 2.3 percent. The latter figure is derived by combining the pure ageing scenario with an assumption of a certain increase in formal LTC, resulting from a switch from informal or no care to formal care in institutions or to formal care at home.[43]

Figure 6. Three scenarios for public spending on LTC, EU25 (percent of GDP)



Source: Directorate-General for Economic and Financial Affairs, European Commission.

Again it should be stressed that these projections are based on a no-policy-change assumption with only limited increase in formal LTC in the Member States where the level of public spending in this field is low.

According to the National LTC Survey, the prevalence of functional impairment (the US definition of "dependency") among US seniors appears to have declined significantly since 1982, although some types of impairment, such as those requiring the use of a cane, have been increasing. However, impairment among people under age 65 seems to be increasing, which could eventually lead to higher future rates of impairment among seniors. One recent study

[43] Details of these scenarios by country and category of care can be found in the Economic Policy Committee (2005).

projects that the currently declining trend in the prevalence of impairment among seniors will reverse, leading to greater rates of institutionalization than exist today.[44]

Projections of LTC spending in the US prepared by the Congressional Budget Office (CBO) envisage an increase of total spending, including an estimated value of donated care, from about 2 percent of GDP in 2000 to 2.3 percent in 2040. This projection was based on an assumption of a decline in the (age-specific) prevalence of impairment of about 1.1 percent per year and may thus be broadly comparable to the 'constant disability scenario' for the EU discussed above, with the proviso that the latter does not include an estimated value of donated care. However, if these declines in impairment do not occur, as under the "pure ageing scenario," CBO projects that LTC costs will increase to 3.3 percent of GDP in 2040. Even if the prevalence of impairment should increase more than assumed in the US baseline scenario and the EU "constant disability scenario," the sustainability of the US LTC system would, as a consequence of the faster prospective growth in output and employment, appear much less of a problem for public finance than in the EU.

Public health and medical developments may also have important effects on the need for LTC. Medical innovations over the coming decades may lead to break-through treatments of some of the most debilitating neurodegenerative diseases, such as Parkinson's or Alzheimer's diseases. On the other hand, the increase in obesity in developed countries enhances the risk of diabetes and cardio-vascular diseases with likely negative consequences for the state of health of older people.

IV. Some Issues for Discussion

Taking into account uncertainties with respect to medical breakthroughs and the risk of a further increase in 'life style-determined diseases' serves to stress that the further we look into the future, the wider the margins of uncertainty and, consequently, the greater the possibility that outcomes may be different from the 'charted course'. Demographic changes, ongoing and still to come, may lead to unexpected social conflicts regarding the demand for and supply of health and LTC. An important policy priority should, therefore, be to provide a degree of flexibility and adaptability of systems and institutions sufficient to face up, not just to the challenges of 'baseline projections', but also to unanticipated developments. The greatest dangers may, in fact, result from events that the systems are unprepared to deal with.

The future of LTC is one of the most complex health and fiscal issues confronting the EU and US. To face this challenge, it is important for representatives and officials from these countries to share ideas and promising practices and, most importantly, to learn from each other. Against this background, delegates to the conference may wish to consider the following questions:

(1) How can people with care needs obtain access to affordable, quality LTC, and what is the role of authorities and other stakeholders in providing this access? How can the commitment to sustainable access to quality LTC for all be realized in the EU and the US?

[44] Congressional Budget Office (2005), testimony by Douglas Holtz-Eakin before the Subcommittee on Health, Committee on Energy and Commerce, U.S. House of Representatives, 27 April.

(2) How can EU Member States and the US best promote active and healthy ageing, e.g. through promoting prevention, better nutrition and physical activity for seniors and active participation in society?

(3) Given that some EU Member States and some states within the US have more well-developed home and community-based services than others, how can governments ensure the proper infrastructure and funding to provide care in the community? What policies should be in place to allow people to grow old where they choose?

(4) How can quality be assured for the millions of people who are cared for in their homes across the EU and US? How can quality be assured for those who need residential care in nursing homes or assisted living facilities?

(5) How will the trend toward consumer-directed care impact the provision of formal care and family caregivers?

(6) What should governments do to support family caregivers, so they can continue to provide care support?

(7) How can government, social partners—i.e., trade unions and employer's associations, and care providers—facilitate recruitment and retention of LTC workers? What broader strategies, including training and improving remuneration and working conditions, would be most effective in assuring an adequate workforce?

(8) What can be the contribution of voluntary or statutory insurance schemes or specially targeted funding schemes in ensuring sustainability of LTC provision?

(9) What additional financing options may be useful to help make LTC more accessible and affordable?

(10) How can systems of LTC be designed so as to allow smooth adjustment in case of unanticipated demographic, bio-medical or social developments?

List of Abbreviations

AWG	Ageing Working Group
CBO	Congressional Budget Office
DFLE	Disability Free Life Expectancy
EC	European Commission
EU	European Union
EU25	Current set of 25 EU Member States (Austria, Belgium, Cyprus, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Ireland, Italy, Latvia, Lithuania, Luxembourg, Malta, the Netherlands, Poland, Portugal, Slovak Republic, Slovenia, Spain, Sweden and the United Kingdom
EU15	15 Member States comprising the European Union prior to May 2004 (Austria, Belgium, Denmark, Finland, France, Germany, Greece, Ireland, Italy, Luxembourg, the Netherlands, Portugal, Spain, Sweden and the United Kingdom)
EU10	10 new Member States joining the European Union in May 2004 (Cyprus, Czech Republic, Estonia, Hungary, Latvia, Lithuania, Malta, Poland, Slovak Republic and Slovenia)
GDP	Gross Domestic Product
LTC	Long-term care
OECD	Organization for Economic Cooperation and Development
OMC	Open Method of Coordination
SPC	Social Protection Committee
US	United States

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