Long-Term Care in Developed Nations: A Brief Overview

By:

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The AARP Public Policy Institute, formed in 1985, is part of the Policy and Strategy Group at AARP. One of the missions of the Institute is to foster research and analysis on public policy issues of importance to mid-life and older Americans. This publication represents part of that effort.

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Executive Summary

Background

The aging of the population in all developed countries, and in many developing countries as well, is accelerating the search for ways to enhance the long-term independence of persons of all ages with disabilities. All industrialized nations are grappling with issues of access, cost, and quality in long-term care services, leading to new opportunities to share experiences and knowledge cross-nationally. While there are many examples of innovative long-term care services in the United States, this overview concentrates on examples from other countries, mostly European, that have much “older” populations. With the exception of Japan, the world’s 25 oldest countries are all in Europe; the United States ranks 29th.

Purpose

The purpose of this report is to provide a brief overview of many of the key long-term care policy trends that cross national boundaries in developed nations. The first section addresses trends in delivering and organizing formal and informal long-term care services. The second section, on financing long-term care, discusses the movement toward universal (not means-tested) public programs for long-term care. It also presents comparative data on long-term care spending for both home care and institutional care, and by the public and private sectors. The final section briefly addresses a few of the issues in improving the quality of long-term care and its coordination with medical care for chronic conditions.

Methods

The information included here was derived from an extensive search of cross-national literature on long-term care in developed nations from international organizations, primarily the Organisation for Economic Cooperation and Development (OECD), the European Union (EU), and the World Health Organization (WHO), as well as from government and nongovernmental sources. The search included both print and electronic sources. In addition, we searched for the most current empirical data available on key long-term care indicators, such as the share of persons age 65 and older receiving institutional versus home care, and the share of Gross Domestic Product (GDP) devoted to long-term care spending. We also attempted to synthesize a wide range of recent data and information in the form of charts that permit cross-national comparisons.

Principal Findings

Many developed nations are encouraging long-term independence among persons with disabilities of all ages by:

Providing “consumer-directed” home care programs to enhance choice and independence. Finding the right balance between providing cash so individuals can select and manage their own services versus having agencies provide home care services directly is an increasingly important
issue in many developed nations. European nations with public programs permitting cash benefits for home care include Austria, France, Germany, the Netherlands, and England.

**Encouraging home and community-based services rather than institutional care.** Rates of institutionalization have been dropping in most OECD member nations since the 1980s. Denmark is an example of a country that has used savings in nursing home care to expand home and community-based services to nearly a quarter of all older persons, with substantial savings in its total public long-term care spending.

**Encouraging family support of persons with disabilities.** Support for family and other informal caregivers can include respite services to give caregivers a break, payments to informal caregivers, and tax benefits. For example, Japan provides up to one week respite stay per month for care recipients at the highest level of disability; Australia provides a network of adult day centers and in-home respite services. Germany permits up to four weeks of holiday leave per year for caregivers and gives public pension (social security credits) to caregivers who provide a substantial amount of informal care.

**Providing universal coverage for long-term care services.** Whether publicly-funded long-term care services should be available only to the poor, or to the non-poor as well, is a fundamental question. Many developed nations, including Austria, Germany, Japan, the Netherlands, and many Scandinavian nations, have established universal long-term care programs that base eligibility for personal care and other benefits on the need for such services, rather than on an individual’s income and/or assets. In contrast, many English-speaking countries, including the United States and England, “means-test” personal care services. However, most developed nations, including most English-speaking nations, provide universal medically-related nursing care in the home.

**Insuring individuals against the high costs of long-term care through a mix of public and private financing.** Those countries with universal long-term care programs use a mix of financing sources, although public sector spending predominates. Total spending on long-term care remains less than 2 percent of GDP in most developed nations, compared to spending on health care (a median of 8 percent of GDP in 2000 in most OECD nations). As with health care, the United States relies more heavily on private sources of long-term care financing, through out-of-pocket spending by individuals or private insurance, than do most other developed nations.

**Improving coordination between chronic medical care and long-term care services.** “Home visitation” programs for older persons to delay or prevent functional decline and subsequent nursing home admissions are part of national policy in several nations, such as the U.K., Denmark, and Austria.

**Conclusions**

In summary, many developed countries share similar goals with respect to the delivery and financing of long-term care. With respect to delivery of services, these goals include encouraging (1) choice and independence, such as through “consumer-directed” home care programs; (2) greater access to services in the home and community; and (3) support for family
and other informal caregivers. In the financing arena, a growing number of countries seek to provide universal coverage for long-term care services, and to insure individuals against the high costs of long-term care through a mix of public and private financing sources. As populations age, both policy makers and the general public may increasingly view long-term care as a normal risk of life, with financing to be shared by the working-age and older populations². Improving the quality of long-term care is a high priority goal as well, with many countries now trying to identify and implement practices that improve both quality of care and quality of life.

While there are common goals, there are also common tensions. For example, most developed countries cover home nursing care under universal systems, but many, especially in English-speaking countries, means test personal care services. This division is one that often surprises and confuses individuals who need long-term care, and can create incentives to providers to shift costs between health and long-term care budgets. Such a division can also exacerbate tendencies to “overmedicalize” services.

Other boundaries that divide health and social care are beginning to blur. In Scandinavian countries and the Netherlands, in particular, the boundaries between nursing homes/residential homes and community services, such as day hospitals and adult day services, are disappearing. And trends toward cash payments for persons with disabilities of all ages, typically used to help compensate family caregivers, are blurring the lines between paid versus unpaid work and informal versus formal services.

The toughest issue, especially in the current climate of global economic uncertainty, is how to pay for an appropriate range of long-term care services in the face of other competing priorities, and how to sustain availability of services in the face of growing demand. The key themes from a brief look at financing issues are:

(1) Current long-term care spending is a relatively small share of GDP in most developed nations, but it is growing.

(2) While a high degree of uncertainty surrounds all long-range projections about the need for long-term care, a high degree of consensus exists about the need to promote the cost-effectiveness of such care. Such steps include promoting healthy aging and delaying disability for as many years as possible, increasing support for family caregivers, and increasing services in homes and communities.

Demography is not destiny, but demographic trends indicate that the time to prepare for the long-term care needs of the cohorts of post-WWII boomers, a cross-national phenomenon, is now. The “oldest” nations, such as Japan, Italy, and many other European countries, which have already experienced very rapid aging, will face new challenges as an increasing share of their population is age 80 or older, the age when long-term care is most likely to be needed. For countries with younger populations, such as Canada, the United States, and Australia, the next two decades, before boomers begin turning 75, offer a window of opportunity to build stronger long-term care systems. In some nations, including the United States, part of that preparation may involve public debate about universal versus means-tested systems for long-term care. This debate may be driven by the rising expectations of future cohorts of boomers, who will want...
better options to live independently and with dignity but often have difficulty paying for them, as well as growing consumer activism in many nations. Such activism includes younger persons with disabilities and associations for caregivers as well as advocates for the aging.
Long-Term Care in Developed Nations: A Brief Overview

The aging of the population in all developed countries, and in many developing countries as well, is accelerating the search for ways to enhance the long-term independence of persons of all ages with disabilities. All industrialized nations are grappling with issues of access, cost, and quality in long-term care services, leading to new opportunities to share experiences and knowledge cross-nationally.

While there are many examples of innovative long-term care services in the United States, this overview concentrates on examples from other countries, mostly European, that have much “older” populations. The United States, with 12.6 percent of its population age 65 and older in 2000, does not rank as one the world’s 25 “oldest” countries. Italy, Greece, Sweden, and Japan—each with 17 percent or more of its population age 65 and older—topped the list in 2000. (See Figure 1) While that figure will likely reach 20 percent or more in the United States by 2030, that proportion will still be lower than in most countries in Europe and Japan, which also have post-WWII baby boom cohorts.

Figure 1. The World’s 30 Oldest Countries, 2000 (% of persons 65 years and over)

The purpose of this report is to provide a brief overview of many of the key long-term care policy trends that cross national boundaries in developed nations. The information included here was derived from an extensive search of cross-national literature on long-term care in developed nations from international organizations, primarily the Organisation for Economic Cooperation and Development (OECD), the European Union (EU), and the World Health Organization (WHO), as well as from government and nongovernmental sources. The search included both print and electronic sources. In addition, we searched for the most current empirical data available on key long-term care indicators, such as the share of persons age 65 and older receiving institutional versus home care, and the share of Gross Domestic Product (GDP) devoted to long-term care spending. We also attempted to synthesize a wide range of recent data and information in the form of charts that permit cross-national comparisons.

The report is divided into three sections: (1) delivering and organizing long-term care services; (2) financing long-term care services; and (3) improving the quality and coordination of long-term care services. The first section addresses trends in formal and informal long-term care services. It examines the growth of home and community-based care, support for family caregivers, consumer-directed programs and direct payments for long-term care, and integration of housing and services. The second section, on financing, discusses the movement toward universal (not means-tested) public programs for long-term care. It then presents new data on total long-term care spending as well as spending on home care versus institutional care and by public versus private sectors. The final section briefly addresses a few of the issues in improving the quality of long-term care and improving chronic medical care and its coordination with long-term care. The serious shortage of direct service workers, such as home care and nursing home aides, which is occurring in many nations, could not be addressed in this brief overview, but it does have implications for almost all of the other issues examined. The workforce issue will be addressed in a forthcoming AARP Public Policy Institute paper. Among the other issues of importance to persons of all ages with disabilities which fall beyond the scope of this brief paper are access to assistive technologies and reliable, accessible transportation.

The report highlights examples from one or more countries in each section. Inevitably, the selection of country-specific examples is somewhat subjective and depends heavily on the availability of sufficient information on which to base analysis. In general, European nations and Japan, with their rapidly aging populations, are the focus. However, some examples from several Commonwealth nations, such as the United Kingdom, Canada, and Australia, are included as well to show the diversity of national long-term care policies. Interested readers should refer to the detailed endnotes for additional examples and resources.

A note on terminology: In the United States, many persons with disabilities prefer the term “long-term services and supports” rather than “long-term care” because the latter can convey paternalism and dependence. Here, we use the term “long-term care” because of its familiarity to persons in other countries and the reliance in this paper on data from international organizations and other sources using that term. Regardless of the terms used, the ability to be independent and “in charge” helps to define quality of life for persons of all ages with disabilities. For further discussion of the independent living philosophy in the United States, as well as the influence of environmental factors and “livable” communities in encouraging long-
term independence, see AARP’s recent study, Beyond Fifty.03: A Report to the Nation on Independent Living and Disability.5

Delivering and Organizing Long-Term Care Services

Encouraging home and community-based services rather than institutional care. In most developed countries, the share of the population age 65 and older in institutional care varies between 5 percent and 7 percent.6 (Although definitions of institutional care may vary from country to country, researchers conducting cross-national studies reconcile them to the extent possible.) As Table 1 indicates, variation in the provision of home care services seems to be even greater than variation in rates of institutionalization, that is, between 5 percent and 25 percent. How much of this variation is due to differences in definitions of home care or other methodological issues, rather than to the actual use of such services, is not clear. While the data presented below should be used cautiously, they do present a sense of the order of magnitude of cross-national differences.

<table>
<thead>
<tr>
<th>Country</th>
<th>Source Year</th>
<th>Share of population aged 65 and over in institutions (% of total) ¹</th>
<th>Share of population aged 65 and over receiving formal help at home (% of total) ²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australia</td>
<td>2003</td>
<td>5.7</td>
<td>21.0</td>
</tr>
<tr>
<td>Austria</td>
<td>1998</td>
<td>4.9</td>
<td>24.0</td>
</tr>
<tr>
<td>Belgium</td>
<td>1998</td>
<td>6.4</td>
<td>4.5</td>
</tr>
<tr>
<td>Canada</td>
<td>1993</td>
<td>6.2</td>
<td>17.0</td>
</tr>
<tr>
<td>Denmark</td>
<td>2001</td>
<td>9.1</td>
<td>25.0</td>
</tr>
<tr>
<td>Finland</td>
<td>1997</td>
<td>5.3</td>
<td>14.0</td>
</tr>
<tr>
<td>France</td>
<td>1997</td>
<td>6.5</td>
<td>6.1</td>
</tr>
<tr>
<td>Germany</td>
<td>2000</td>
<td>3.5</td>
<td>7.0</td>
</tr>
<tr>
<td>Israel</td>
<td>2000</td>
<td>4.5</td>
<td>12.0</td>
</tr>
<tr>
<td>Japan</td>
<td>2003</td>
<td>2.9/6.0</td>
<td>8.0</td>
</tr>
<tr>
<td>Netherlands</td>
<td>2003</td>
<td>8.8</td>
<td>12.5-13.0</td>
</tr>
<tr>
<td>Norway</td>
<td>2001</td>
<td>11.8</td>
<td>15.6</td>
</tr>
<tr>
<td>Sweden</td>
<td>2001</td>
<td>8.2</td>
<td>7.9</td>
</tr>
<tr>
<td>United Kingdom</td>
<td>1996</td>
<td>5.1</td>
<td>5.5</td>
</tr>
<tr>
<td>United States</td>
<td>2000</td>
<td>4.2</td>
<td>8.7</td>
</tr>
</tbody>
</table>

Sources: Adapted from S. Jacobzone, “Ageing and Care for Frail Elderly Persons: An Overview of International Perspectives” Paris: Organization for Economic Cooperation and Development, 1999. United States institutional data are from CMS OSCAR 2000 data, and home care data are from the 2000 MEPS. Data from Germany are from T. Fukawa, 2002. Data for Japan are from John C. Campbell, Dr. Naoki Ikegami, and the Embassy of Japan. Data for Israel are from WHO, Brodsky et al., 2000. Data for Denmark, Norway, and Sweden are from NOSOSCO, Social Protection in the Nordic Countries 2001. Data for Australia are from the Australian Department of Health and Ageing. Data for the Netherlands are from the Ministry of Health, Welfare, and Sports. ¹ Estimates may vary according to the definition of institutions. For example, 2.9% of Japanese 65+ are in nursing homes; if individuals in long-stay hospitals are also included, the share rises to around 6%. The United States data do not include individuals in assisted living facilities, while those from the Nordic countries and the Netherlands include those in “service housing.” For Denmark, “older persons” refers mostly to over age 67. ² Proportion of older persons receiving formal help at home, including district nursing and help with Activities of Daily Living. For Australia, data include those receiving services under both CACP and HACC.
Most developed nations have placed a high priority on encouraging more home and community-based care, and rates of institutionalization have been dropping in most member nations of the OECD since the 1980s. Denmark, which relied heavily on institutional care in the early 1980s, is a good example. Over a roughly 20-year period, Denmark moved to extensive reliance on home and community-based care by freezing nursing home construction and expanding community services. The share of persons age 80 and older who lived in nursing homes decreased from 20 percent to 12 percent between 1982 and 1996. The savings in nursing home care were used to expand home and community services to nearly a quarter of all older persons, while public long-term care funding as a share of gross domestic product (GDP) dropped from 2.6 percent in 1982 to 2.3 percent in 1994. The Danish experience, which suggests that expanding home and community-based services can be cost-effective, offers lessons in how an efficient system might be structured, and how the transition process from institutional to community-based care can be managed successfully.

Like Denmark, Sweden has also made use of home and community-based care a priority. The basic principle in Sweden is that older persons who wish to remain in their homes or in the community can do so notwithstanding illness or disability. Substantial efforts have been made to improve support for and services to older persons in their homes, including “round-the-clock” care and in-home nursing services provided by specialized nurses. However, family members are increasingly shouldering the majority of care, and rates of coverage for home help services have decreased in recent years following cutbacks in funding for these services.

There has also been a major shift from institutional care toward less intensive residential care and community care in Australia. Key players in this shift are the teams of care professionals who provide expert assessment and advice about long-term care options. The teams may include geriatricians, physicians, social workers, and nurses. Individuals must be assessed by these teams to be eligible for (1) publicly funded residential care (at high “nursing home” or low “hostel” levels); or 2) equivalent community services to help them stay in their own homes. Community Aged Care Packages (CACPs) provide tailored, case-managed packages for older persons who qualify for the hostel level of residential care. Services include assistance with personal care, household tasks, meal preparation, transportation and social activities. A relatively new program, Extended Aged Care at Home (EACH), serves as an alternative to the “high” skilled nursing home level of care. This program is small but growing.

While most nations have made progress in expanding home and community-based services in recent years, numerous barriers remain, including underfunding of home and community-based services. For example, some nations, including the United States, rely heavily on “targeting” of services in the home only to those with more severe disabilities; such targeting means that services are only available to a narrow segment of the population with disabilities. Waiting lists for formal home care services in a number of industrialized countries, including the United States and the Netherlands, are also common.

**Encouraging family support of persons with disabilities.** Informal long-term care continues to far outweigh care provided through the formal sector in all developed and developing nations. In an OECD study, Jacobzone and colleagues observe that “most international data show that informal care could account for up to 80 percent of total care.”
Most family caregivers are women, although men may be informal caregivers as well. Labor force participation among women 30-54 increased between 1980 and 1998 in most European countries, the United States, Australia, and Japan.\textsuperscript{16} This trend means that more women are facing conflicting pressures on their time due to responsibilities in the labor force and as caregivers for frail older relatives. In some cases, they are also caring for young or adolescent children as well. Moreover, because of high unemployment among young adults in many countries, traditional “empty nests” are often no longer empty.

While family support remains strong in developed and developing nations alike, it can take different forms. For example, in Greece, a daughter may be “the sole provider of substantial personal and domestic help for a very dependent parent towards whom she feels a duty to care, reinforced by a legal duty, social attitudes, and lack of alternative options.”\textsuperscript{17} In contrast, a daughter in Denmark is “likely to be caring in quite a different way: visiting, chatting, and occasionally shopping or doing the laundry.”\textsuperscript{18} She expects that her parents’ needs for personal care and domestic help will be met through the public sector.

In general, as women’s labor market participation increases, the level of social care provision\textsuperscript{19} increases as well. According to a researcher in the United Kingdom, the “provision of social care services for frail older persons is less strongly related to GDP than to women’s economic activity” in the six European countries studied, i.e., Norway, Denmark, the United Kingdom, Ireland, Italy, and Greece.\textsuperscript{20} This finding probably also reflects differing attitudes toward the respective role of families (especially women) and the state in providing long-term care.

As Table 2 suggests, both legal provisions and societal expectations affect the types of services and supports available. Some European countries, such as France, Italy, and Greece, have filial responsibility rules obligating families to support aging parents.\textsuperscript{21} In England, Norway, and Denmark, older persons have a legal right to assessment of their needs by a professional, although health and social workers have discretion in determining what services will be provided.\textsuperscript{22}

While home and community care can be more cost-effective than institutional care, heavy reliance on informal care carries its own costs. Opportunity costs to family caregivers include the costs of foregone earnings and leisure; additional expenditures within the household, and the health effects and impact on marriages.\textsuperscript{23}

Several decades of research on family caregiving in many countries have demonstrated that the caregivers themselves need more support. Such support can take a variety of forms, including providing information and training, respite services to give caregivers a break, tax benefits, and payments to informal caregivers. To help compensate caregivers, some countries, such as Germany, provide public pension (social security) credits to caregivers who provide a substantial amount of informal care. Pension contributions are provided for people providing informal care for more than 14 hours per week and working less than 30 hours per week. In Austria as well, informal caregivers who have ever been in the workforce can receive some credits in the social insurance pension system.\textsuperscript{24}
Table 2. Examples of Social Care Offered to Two Individuals in Five Nations*

| Mrs. A: 75, with severe osteoarthritis, discharged from hospital after heart attack following sudden death of her husband. Lives in low income housing with son who often works away. Sister lives nearby and helps with housework. | Assessment at home by community nurse. Free home help for housework once a fortnight and bathing once a week (not shopping). Free loan of walking frame and alarm. Weekly nurse visits if necessary. Son expected to offer some practical help. | Assessment at home by community nurse. Home help for housework once a fortnight (small charge). Bathing assistance only if very frail. Safely alarm (small charge). Free bereavement counseling. Weekly nurse visits for 4-6 weeks. Son and sister encouraged to continue their help. | Assessment by hospital social worker. If informal support judged adequate, only offered alarm and telephone. If not adequate, she could be offered 2 hours a week home care and possibly day care once a week. Occupational therapist would assess needs for technical aids. Help from a voluntary bereavement counselor may be available. | Initial assessment by doctors and nurses in hospital. Referral to district social worker who would decide whether needs are health or social, why she cannot afford private help, and why her daughter and son cannot help. If poor, she will be offered a little home help, but it depends on social worker’s discretion and financial circumstances of son and daughter. May be offered some free rehabilitation. | Assessment as part of hospital discharge planning. Home health and personal care services covered for a limited time by Medicare if skilled nursing care or therapy is needed and she is homebound. If income & assets are sufficiently low, she may also qualify for Medicaid if meets state’s nursing home eligibility criteria. Medicaid coverage of personal and other home care varies by state, and there may be waiting lists. Otherwise, payment is generally out of pocket. |

| Mrs. B: 83 years old, chronically and terminally ill. Low income. Recently discharged following hospital care for heart problem. Wants to remain at home, where she lives with husband who can offer little practical help. Son and daughter live 30 minutes drive away. | Hospital assessment by nurse before discharge would identify 3 options: (a) free 24 hour nursing home care (accommodation and food must be paid for); (b) free transport to nursing home for night stays plus meals (to be paid for) and day time home care; (c) free 24 hour home care plus daily district nurse visits and daily meals on wheels (to be paid for). Free loan of technical aids and alarm. Some municipalities would encourage (a) as cheapest option. | Assessed by a nurse. Terminal illness diagnosis would result in immediate offer of nursing home placement. Local authority home care would not be regarded as satisfactory without family or voluntary help (husband would be identified as at risk from burden of care). Mrs. B could insist on remaining at home. Would then be offered technical aids and regular home nurse visits day and night. | Assessed by social worker. Home care likely to be offered 21/2 hours a day, 7 days a week (means-tested). Free district nurse visits 4-5 times a week plus night nurse. Meals on wheels 7 days a week (means tested). Alarm and telephone (means tested). Possible hospice placement if one available. If domiciliary package exceeds cost of nursing home care, additional cost expected to be met by family. | Assessed by the district interdisciplinary Geriatric Evaluation Unit. Social worker would manage the case. Nurse visits at least 3 times a week (free). Home help visits 2 hours every day for personal care and housework – her children would be expected to pay for part or all of this, depending on their income. | For beneficiaries who are terminally ill, Medicare pays for nearly all the costs of in-home hospice care, including nursing care, homemaker services, therapy, drugs for symptom control and pain, respite care, and counseling. |

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Respite services to provide a break from caregiving duties is one of the forms of support most requested by caregivers. As shown in Table 3, countries such as Australia, Germany, Japan, and the United Kingdom provide respite relief, although specific provisions vary widely.

Table 3. Respite Services for Caregivers

<table>
<thead>
<tr>
<th>Benefit</th>
<th>Legal Limits on Use and Availability</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>AUSTRALIA</strong>&lt;sup&gt;1&lt;/sup&gt;</td>
<td><strong>RESIDENTIAL RESPITE</strong>&lt;br&gt;Residential respite provides short-term care in aged care homes for people who need residential care temporarily. Annual subsidies are provided for about one million bed days for respite stays in aged care homes. Residential respite may be used on a planned or emergency basis to help with carer stress, illness, holidays, or the unavailability of the carer for any reason.&lt;br&gt;&lt;br&gt;<strong>COMMUNITY-BASED RESPITE CARE SERVICES</strong>&lt;br&gt;These include a network of day centres and ‘in home’ respite services. There is at least one Commonwealth Carer Respite Centre in each HACC region across Australia, helping carers arrange a break for a few hours, days or weeks. These centers have pools of funds, called brokerages, to be used to purchase short-term or emergency respite care. Centers encourage services to develop more flexible approaches to respite care and to link carers to appropriate respite care services including residential respite.</td>
</tr>
<tr>
<td><strong>CANADA</strong>&lt;sup&gt;2&lt;/sup&gt;</td>
<td><strong>QUEBEC RESPITE CARE ALLOWANCE</strong>&lt;br&gt;$600 (US $452; 400 Euros) per year</td>
</tr>
<tr>
<td><strong>GERMANY</strong>&lt;sup&gt;3&lt;/sup&gt;</td>
<td><strong>RESPITE CARE PROVIDED under LONG TERM CARE INSURANCE</strong> (per year)&lt;br&gt;Delivered by: Close relative Other than close relative, such as agency personnel&lt;br&gt;Care level I: US$222/up to 4 weeks $1,548 up for 4 weeks&lt;br&gt;Care level II: $443/up to 4 weeks $1,548 up to 4 weeks&lt;br&gt;Care level III: $719/up to 4 weeks $1,548 up to 4 weeks</td>
</tr>
<tr>
<td><strong>UNITED KINGDOM</strong>&lt;sup&gt;4&lt;/sup&gt;</td>
<td><strong>CARERS AND DISABLED CHILDREN’S ACT 2000</strong> (England and Wales)&lt;br&gt;Local authorities have discretion to issue short-break vouchers for services. They may be expressed in terms or money or as a period of time for delivery of services.</td>
</tr>
<tr>
<td><strong>JAPAN</strong>&lt;sup&gt;5&lt;/sup&gt;</td>
<td><strong>RESPITE CARE PROVIDED UNDER LONG TERM CARE INSURANCE</strong></td>
</tr>
</tbody>
</table>

---

A few nations provide allowances directly to caregivers to help compensate them for the lost opportunity costs of caregiving. For example, Australia has a long tradition of paying family caregivers. (See Table 4 below for details on Australia.) Canada provides some support for caregivers through its tax system. A federal tax credit of up to Canadian $595 is available to caregivers who live with and provide care to a child with a disability or a relative age 65 or older whose income falls below a threshold.\(^{25}\)

<table>
<thead>
<tr>
<th>Table 4. Care Payments That Go Directly to Informal Caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Name of Benefit</strong></td>
</tr>
<tr>
<td>AUSTRALIA</td>
</tr>
<tr>
<td>CARER PAYMENT (formerly Carer Pension)</td>
</tr>
<tr>
<td>Carers Allowance (replaced Domiciliary Nursing Care Benefit and Child Disability Allowance)</td>
</tr>
<tr>
<td>Carer Payment</td>
</tr>
<tr>
<td>AUSTRALIA</td>
</tr>
<tr>
<td>CARER PAYMENT (formerly Carer Pension)</td>
</tr>
<tr>
<td>Carers Allowance (replaced Domiciliary Nursing Care Benefit and Child Disability Allowance)</td>
</tr>
<tr>
<td>Carer Payment</td>
</tr>
</tbody>
</table>


More common than allowances for caregivers are cash payments paid directly to persons with disabilities. Table 5 on the following page provides information on several of the largest such programs, which are discussed in more detail in the following section. Because care recipients frequently hire family members, such payments are also seen as a form of family support. Hence their impact needs to be assessed from the standpoint of caregivers as well as care recipients. In a recent study of care allowances for the frail elderly and their impact on female caregivers in seven OECD nations, Jensen and Jacobzone found that their effects on women’s participation in the labor force depend largely on the level of the payment. In some cases, the benefit levels are so small as to be symbolic only.\(^{26}\) In other cases, such as in Germany, they are sufficient to help compensate for some of the opportunity costs of caregiving, and may foster part-time employment. However, the modest level of most benefits means they have little effect on the amount of care that is provided because of need, and likely would have been provided in the absence of the care allowances. The researchers concluded that greater emphasis should be placed on longer-term compensation, such as public pension rights and more flexibility in work schedules and leave policies for caregivers. With respect to more flexibility from employers, they observe that “few countries have moved very far in this direction.”\(^{27}\) In addition, few countries seem to guarantee any training and assistance to caregivers returning to the labor force.

For policy makers, the challenge is to provide assistance to overburdened caregivers through policies designed to strengthen family care in the face of social and economic forces that may undermine such care. Among the thorny issues related to providing such assistance are: (1) the extent to which caring for persons with disabilities is an individual and family responsibility or the responsibility of society as a whole; (2) how public policy should address the conflicts between work and caregiving; and (3) whether support to families should be in the form of services, such as respite care, or cash payments to caregivers.\(^{28}\)
<table>
<thead>
<tr>
<th>Name of Benefit</th>
<th>Means Testing and Interaction with other Age Benefits</th>
<th>Legal Limits on Use and Availability</th>
</tr>
</thead>
<tbody>
<tr>
<td>AUSTRIA* ATTENDANCE ALLOWANCE</td>
<td>Non-income, non-asset tested. Rate adjusted to care needs (7 levels of payment). Available to care recipients. Cash only, no in-kind benefits.</td>
<td>No limits except need. Available to all permanent residents in need of care, according to level of dependency (7 levels). Not meant to cover all care needs. Benefit estimated to cover about 16% of needs at the lowest level of disability, and about 44% at the highest.**</td>
</tr>
<tr>
<td>GERMANY* LONG-TERM CARE INSURANCE</td>
<td>Non-income-tested. Based on assessment of needs for care. May be paid to a person living at home, in sheltered housing, in a service flat. Cash or in-kind benefits, or combination.</td>
<td>No limits on use for cash payment. Recipient may also choose whether to spend or save the payment. Beneficiaries may choose among a cash payment, in-kind home care services, or institutional care. Not meant to cover all care needs. For in-kind home care services, covered about 37% of needs at lowest level of disability and 42% at the highest in 1995.**</td>
</tr>
</tbody>
</table>

*Adapted from J. Jenson and S. Jacobzone, Labour Market and Social Policy—Occasional Papers No. 41: Care Allowances For the Frail Elderly and Their Impact on Women Care-Givers, OECD, 2000(2).  
Note: All US Dollar amounts are based on exchange rates during October 2003.

### Providing consumer-directed home care programs and direct payments for long-term care.
Consumer-directed programs, a concept pioneered by disability rights advocates, are increasingly common in Europe and in some states in the United States. The premise of consumer direction programs is that consumers with disabilities know their own needs best and should be able to control the services they receive. In the words of Judith E. Heumann, co-founder of the World Institute on Disability, “Independent living is not doing things by yourself, it is being in control of how things are done.”

Until recently, most of these programs were directed toward younger persons with disabilities, but they are increasingly being used by older persons as well. Moreover, a sizable majority of Europeans support empowering older people and/or their families and friends to make decisions rather than having professional service providers do so (see Figure 2 on the following page).

Many countries are now grappling with finding the right balance between direct long-term care services (services provided by agencies) and support in cash. Public programs involving consumer-directed home care benefits for long-term care have been implemented in a number of
European countries, including Austria, France, Germany, Italy, the Netherlands, and the United Kingdom, as well as in some states in the United States.

These programs differ in design and in how they fit into their nations’ overall long-term care systems. For example, according to one comparative study of programs in Austria, Italy, the Netherlands, and the United Kingdom, “choice” is maximized in Austria and Italy, where there are no restrictions on how the money is used. Other factors influencing the degree of real choice include the amount of the care payments as well as the level of development of services in the formal sector. The programs are also generally seen as direct or indirect financial support (incentive) for informal caregiving.

The largest program, in Germany, introduced a social insurance program for long-term care that includes a cash benefit option. This option provides beneficiaries with a cash payment to purchase services or support informal caregivers. In Germany, most cash benefits go to informal caregivers or are given to the household rather than used to buy formal services. On the other hand, in the Netherlands, beneficiaries receive a budget that must be used to buy covered services, primarily for assistance with activities of daily living. France gives beneficiaries a cash allowance, most of which must be used to pay workers. Austria and Germany place no significant restrictions on how the cash benefit can be used, nor do their national governments monitor how beneficiaries are using their money. In most United States consumer-directed programs, beneficiaries are allowed to hire and fire workers but almost always must rely upon
third-party fiscal agents to handle such administrative tasks as paying workers. All four European countries allow beneficiaries to hire or pay family members, as do most United States programs.  

A recent in-depth examination of programs in the Netherlands, England, and Germany found that, contrary to the expectations of some observers, consumer-directed home care is used by older as well as younger persons with disabilities. (This is less the case in England.) In all three countries, some cognitively impaired persons participate, relying upon surrogates to assist with decision-making. While the adequacy of quality oversight in consumer-directed programs has been a controversial issue in the United States, the three countries in this study seem to take a “minimalist” approach to monitoring quality, with Germany and the Netherlands apparently relying on the strength of family ties to prevent poor quality care.

Providing cash payments seems to be less common in countries without a competitive social services sector, such as Denmark, where local authorities have traditionally been the sole providers of most kinds of social service, including an extensive system of home help. However, since 1998, there has been some movement toward direct payments as a form of empowerment in Denmark. For example, such payments are provided as an option to a relatively small number of persons, e.g., persons under 67 with very severe disabilities who need personal care for more than 20 hours a week.

Providing cash payments for family caregivers was the most controversial issue in Japan’s debate over the design of its mandatory, public long-term care system, which was implemented in 2000. Advocates for women’s rights were the strongest critics of cash payments, which they argued would reinforce traditional family caregiving roles, in which daughters-in-law typically provide the care, and discourage the development of formal home and community-based services. They also argued that caregiving by formally trained providers is better than that provided by many families. In addition, it was feared that offering cash benefits might induce more individuals to apply in the first few years of the program, undermining hopes for a gradual phase-in of benefits. While the critics prevailed, the issue is still being debated. Some observers believe a cash alternative may be introduced when the system is reviewed in 2005.

**Integrating housing and services.** The Netherlands and Scandinavian countries are leaders in coordinating housing and health/social care. One non-governmental example from the Netherlands is the Humanitas Foundation, a nonprofit provider of housing, nursing home, home care, and other supportive services based in Rotterdam. Started in 1959, it was one of the earliest foundations to adopt a “client-centered” approach that stresses independence and self-care in an environment integrated with the local community. In a typical “block” of apartments, about one-third of residents are persons age 55 and over with no functional limitations requiring services; one-third need supportive services, and one-third need nursing care. Humanitas dwellings are “apartments for life,” in that extensive nursing care is provided in the clients’ own homes, “with no need to separate from life partners.” Even persons with severe disabilities remain in their homes, e.g., a typical apartment block has 20 people with Alzheimer’s disease out of 250 residents. Residents pay for their own housing expenses, e.g., rent and housing maintenance.

The Netherlands government, advocating a policy of deinstitutionalization since the 1970s, has expanded the supply of home and community-based services, as well as “sheltered housing”
arrangements. Sheltered housing is an intermediate form of purpose-built housing (newly built rather than adapted housing) for older people who need some on-site help and support. These apartments are very accessible. Most services in sheltered housing are covered under the nation’s public long-term care insurance program.

In Denmark, nursing homes and other more institutional types of housing are being phased out and replaced with various forms of service-enriched housing which are designed to promote “aging in place.” The goal is to create supportive living arrangements for older people in non-institutionalized environments. Such arrangements are typically associated with and located near existing nursing homes, sheltered accommodations, day homes, day or community centers.

To encourage such innovation in Denmark, the national government provided demonstration grants to municipalities. One example of a successful demonstration project took place in Skaevinge, a rural municipality with 5,000 residents and one 54-bed nursing home. This municipality had one of the highest levels of expenditure per capita for long-term care in the country. The nursing home in Skaevinge was converted into a “health center,” complete with private residences available for rent. Both residents and staff were trained in areas of personal responsibility, joint decision making between residents and staff, and optimization of self-care and independence.

Germany also provides service-enriched arrangements which combine some features of independent housing and some features of nursing home facilities. Such housing includes purpose-built flats adapted to the needs of older people, usually with low incomes and with physical or mental disabilities. Older people receive a direct financial subsidy under the national government’s system of housing benefits and/or a combination of housing and social help from the states to finance the costs of such arrangements.

Both Denmark and Germany “co-locate services,” whereby multiple agencies serving older people are placed under one roof. This arrangement maximizes the efficient use of personnel and facilities, provides easy access by consumers to different forms of help, and enhances interagency communication, cooperation, and teamwork. In Denmark, the “community health center” is the base for home help and, occasionally, home nursing services, and caters to a mix of frail older persons and those living independently in the community. For example, it reaches out to those in the community by offering health promotion and exercise activities. In Germany, there are “social stations,” staffed by nurses and social workers who coordinate a wide range of long-term care services, including home help, transportation, meals, and day care, among others. As in Denmark, these social stations may also arrange for home nursing services.

Financing Long-Term Care Services

Moving toward universal public programs (not means-tested) for long-term care. Whether publicly-funded long-term care services should be available only to the poor, or also to the non-poor, is fundamental in the design of long-term care systems. A related issue is whether families can – or should – be expected to provide most long-term care services themselves. Public attitudes toward public versus individual/family responsibility often underlie national choices between means-tested and universal approaches to providing long-term care.
How, then, are different developed nations approaching this often divisive issue? The United Kingdom is an example of a nation where the choice between a means-tested rather than universal program has generated considerable scrutiny and public debate. A 1999 Report by the Royal Commission on Long-Term Care made far reaching recommendations to change the current system, including eliminating means-tested programs for personal care services. While the United Kingdom has begun offering nursing services both at home and in institutional settings on a non-means-tested basis, personal care is still means-tested in England. (Under means-tested programs, the only eligible persons are those with incomes and/or assets below a certain level.) However, as of July 2002, Scotland began providing free personal home care to eligible individuals 65 and over regardless of income, capital assets, or marital status.

Austria, Japan, Germany, and the Netherlands are among the developed nations that have established universal long-term care programs that provide benefits to which all eligible individuals, regardless of their income, are entitled. Thumbnail sketches of Austria, Germany, the Netherlands, and Japan, are below:

**Austria:** Since 1993, long-term care cash benefits have been available to Austrians of any age with disabilities regardless of income or assets. The system provides for cash benefits at seven levels of need for care and these benefits may be used for in-home, institutional care, or any other purpose. Austria is unique in providing a “full cash” strategy, i.e., providing an allowance that may be used to purchase formal home care services, pay informal caregivers, or for any other purpose. There is no “in-kind” home care benefit.

**Germany:** Germany’s universal long-term care program, enacted in 1994, provides nursing home and in-home benefits to people of all ages with severe disabilities. Within the home care program, beneficiaries are given a choice of spending a fixed amount on formal services, receiving a lower, fixed amount as a cash allowance, or receiving a mix of cash and services. In 1998, Germany devoted almost half of the expenditures under its long-term care insurance program to services in noninstitutional settings. The program was implemented with surprisingly few difficulties, and continues to maintain broad popular and political support eight years after implementation.

**Japan:** In April 2000, Japan instituted a social insurance program for long-term care that covers nursing home and home and community-based services, including home helpers, adult day centers, assistive devices, and minor home remodeling. Everyone age 65 and older, as well as anyone age 40-64 with an aging-related disability (such as stroke or Alzheimer’s disease), is eligible. While there is some concern that spending on the program will be higher than officially estimated, and that benefits will need to be reduced or premiums will need to be raised, the program operated within its budget the first three years after implementation and is “broadly accepted as an appropriate and effective social program.”

**The Netherlands:** Since the 1960s, the Netherlands has provided coverage for long-term care primarily through non-means-tested social insurance programs financed by premiums. The program covers a broad range of institutional and non-institutional services. Until recently, there have been substantial waiting lists for services due to strict budgeting. However, since
2001, the program has begun operating as an open-ended individual entitlement due to a court ruling that waiting lists and budgeting are inconsistent with insurance principles. Despite the court ruling, there are still waiting lists due to supply constraints.\textsuperscript{56}

The nations above with universal programs have all increased the resources devoted to long-term care, allocating funding at the national level so that access is less determined by local resources and priorities. Their strategies for increasing the availability of services have included encouraging for-profit agencies to enter the long-term care market. However, competition has been restricted to quality rather than price (which is mostly fixed). According to a WHO-sponsored review, this policy is intended to help prevent the emergence of separate services for the rich and poor, and to control costs.\textsuperscript{57}

The universal long-term care programs all share many of the characteristics identified by the WHO as typifying social insurance health programs, e.g., (1) the funding structure requires taxpayers to make regular, mostly income-related contributions that are not tied to individual benefit use, and (2) equal benefits are provided to everyone who is eligible through a set of cross-subsidies from the healthy to the sick, the well-off to less well-off, and the young to the old.\textsuperscript{58} In almost all countries, beneficiaries make payments toward the cost of services.

Table 6 illustrates how long-term care coverage, eligibility age, and cost-sharing by beneficiaries vary among developed nations for home and institutional care. Because the term “home care” can include medical and non-medical services that are often funded and administered in different programs, they are shown separately. Note that the term “universal” is used here synonymously with “non-means-tested” – to convey that the program is open to all, regardless of income or assets. Where possible, beneficiary cost-sharing (defined as deductibles and coinsurance, but not premiums) is also specified. Beneficiaries also typically contribute to the financing by paying premiums, which are often income-related.

As Table 6 indicates, almost all developed countries provide universal medically related home care without beneficiary cost-sharing. Many countries in Western Europe, as well as Japan, also provide non-medical home care, such as personal care, as well as institutional care, on a universal basis. Means-testing for eligibility for non-medical home care and institutional care occurs primarily in English-speaking countries, as well as in some Southern European nations.\textsuperscript{59} With respect to cost-sharing, almost all countries with universal programs require beneficiary cost-sharing, especially for institutional care.

According to a WHO-sponsored study, as well as to other observers,\textsuperscript{60} support for providing services to the broader population, rather than just to the poor, has several rationales, including the desire to provide protection through social insurance, viewing long-term care as a “normal life” risk. This rationale is reinforced by difficulties in developing private long-term care insurance, as well as the risk that broad segments of the population may become impoverished by paying for long-term care services, and hence burden public programs. Another rationale is the desire to substitute long-term care services for more costly acute care (particularly hospitalization), as was the case in Japan. Finally, movement toward universal programs may also reflect a desire to reduce stress on families, with a related interest in preserving family care by providing assistance to help sustain caregiving.\textsuperscript{61}
<table>
<thead>
<tr>
<th>Country</th>
<th>Medical Home Care (Home Nursing Care)</th>
<th>Non-Medical Home Care (Personal Care/Home Help)</th>
<th>Institutional Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australia</td>
<td>Universal</td>
<td>Universal. Eligibility age: No age limit(^8)</td>
<td>Universal. Eligibility age: No age limit(^8)</td>
</tr>
<tr>
<td></td>
<td>Cost-sharing: There may be</td>
<td>Cost-sharing: For CACPs, fees are capped. There</td>
<td>Cost-sharing: Income- and asset-related daily living fees and charges for housing costs vary by state.(^5)</td>
</tr>
<tr>
<td></td>
<td>income-related payments that vary by state(^2)</td>
<td>may be income-related payments that vary by state for HACC. (^2)</td>
<td></td>
</tr>
<tr>
<td>Austria</td>
<td>Universal Cost-sharing: none</td>
<td>Universal. Eligibility age: No age limit(^9)</td>
<td>Universal. Eligibility age: No age limit(^9)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Cost-sharing: None</td>
<td>Cost-sharing: Yes</td>
</tr>
<tr>
<td>Canada</td>
<td>Universal. Cost-sharing: none</td>
<td>Not means-tested, but availability varies by</td>
<td>Residents with incomes below certain limits pay nothing in most provinces; those above limits pay income-related charges subject to a ceiling. Spending down assets not required. Eligibility age: No age limit(^8)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>province. Eligibility age: No age limit(^8)</td>
<td>Medical component through NHI(^4)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Cost-sharing: Income-related in seven provinces</td>
<td></td>
</tr>
<tr>
<td>Denmark</td>
<td>Universal Cost-sharing: none</td>
<td>Universal. Eligibility age: No age limit(^9)</td>
<td>Universal. Eligibility age: No age limit(^9)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Cost-sharing: none for permanent home help;</td>
<td>Cost-sharing: Residents pay for housing costs(^5), fees are income related. About 10% of total LTC spending is out-of-pocket.(^6)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>temporary help is income-related.(^6)</td>
<td></td>
</tr>
<tr>
<td>France</td>
<td>Universal(^7) Cost-sharing: None(^5)</td>
<td>Means-tested(^1),(^4) Eligibility age: Varies, depending on the allowance(^9)</td>
<td>Means-tested assistance for low income(^4)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Cost-sharing: Residents pay for housing and basic care(^5)</td>
</tr>
<tr>
<td>Germany</td>
<td>Universal Cost-sharing: None(^5)</td>
<td>Universal. Eligibility age: No age limit(^9)</td>
<td>Universal. Eligibility age: No age limit(^9)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Cost-sharing: None</td>
<td>Cost-sharing: at least 25% of cost of institutional care</td>
</tr>
<tr>
<td>Israel</td>
<td>Universal Cost-sharing: None</td>
<td>Means-tested. Eligibility age: Women at age 60;</td>
<td>Means-tested. Eligibility age: Women at age 60; men at age 65(^10)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>men at age 65(^10) Mean-test, but set at a high</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>level relative to income status of the elderly, i.e., income no higher than average wage for single person, and 1.5 for couple for full benefit.(^3)</td>
<td></td>
</tr>
<tr>
<td>Japan</td>
<td>Home nursing covered under long-term care system Cost-sharing: None</td>
<td>Universal Eligibility age: Persons 65+, and those 40–64 with age-related illnesses Cost-sharing: 10% coinsurance; lower for low-income.</td>
<td>Universal Eligibility age: Persons 65+, and those 40–64 with age-related conditions, such as dementia. Cost-sharing: 10% coinsurance; Residents must pay for meals in institutions.</td>
</tr>
<tr>
<td>Netherlands</td>
<td>Universal Cost-sharing: Income-related copayments, usually nominal</td>
<td>Universal Eligibility age: No age limit(^9) Cost-sharing: Income-related copayments, usually nominal; maximum is 124 Euros (US $144) per week.(^7)</td>
<td>Universal Eligibility age: No age limit(^9) Cost-sharing: residents make income-related payments for food &amp; housing</td>
</tr>
<tr>
<td>New Zealand</td>
<td>Universal Cost-sharing: none</td>
<td>Universal. Cost-sharing: None for personal care. Homemaker services are income-tested.(^4)</td>
<td>Means tested (income &amp; assets)(^3) Cost-sharing: Income-related copayments.</td>
</tr>
<tr>
<td>Medical Home Care (Home Nursing Care)</td>
<td>Non-Medical Home Care (Personal Care/Home Help)</td>
<td>Institutional Care</td>
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</tr>
<tr>
<td>--------------------------------------</td>
<td>-----------------------------------------------</td>
<td>-------------------</td>
<td></td>
</tr>
<tr>
<td><strong>Sweden</strong></td>
<td>Universal</td>
<td>Universal</td>
<td></td>
</tr>
<tr>
<td>Cost-sharing: Municipalities allowed to charge fees that vary in amount &amp; design.</td>
<td>Universal Eligibility age: No age limit Cost-sharing: Municipalities allowed to charge fees that vary in amount &amp; design. Only a small share of total LTC spending (about 8%) is financed out-of-pocket</td>
<td>Universal Eligibility age: No age limit Cost-sharing: Municipalities allowed to charge fees, which vary in design &amp; amount. Only a small share of total LTC spending (about 8%) is financed out-of-pocket.</td>
<td></td>
</tr>
<tr>
<td><strong>United Kingdom</strong></td>
<td>Universal</td>
<td>Personal care in nursing homes is subject to means-testing in England. The asset limit was $28,100 in 2001, including home equity. Home equity is disregarded for first 3 months of nursing home care.</td>
<td></td>
</tr>
<tr>
<td>Cost-sharing: None</td>
<td>Personal care is subject to means-testing in England, but not in Scotland. Eligibility age: Varies, depending on allowances Cost-sharing: Varies by local authority; personal care is free in Scotland</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>United States</strong></td>
<td>Universal. Covered under Medicare for homebound persons 65+ and disabled persons under 65. Cost-sharing: None.</td>
<td>Universal for short-term nursing home care. Covered under Medicare for persons 65+ or disabled who are discharged from a hospital and need skilled care. Cost-sharing: none for days 1-20, $105 per day in 2003 for days 21-100. Benefit ends after 3 months. Long-term nursing home care is means-tested (both income and assets) under Medicaid. Cost-sharing: Residents without a spouse in the community must contribute all of their income except a small “personal needs allowance”, about $30 - $40 per month.</td>
<td></td>
</tr>
<tr>
<td>Means tested under Medicaid. Eligibility age: No age limit Cost-sharing: Varies by state, usually nominal</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

3. Australian Department of Health and Ageing, personal communication.

**Total spending on long-term care.** Accurate estimates of national long-term care spending are not easy to obtain, and these difficulties are multiplied when attempting to compare long-term care spending cross-nationally. A primary reason for this difficulty is that long-term care is often
divided between health and social service systems and budgets, with unclear boundaries. In
addition, long-term “social” services are often provided at local or state levels, making it difficult
to monitor national trends. While comparative estimates of long-term care spending are subject
to multiple caveats, international organizations and researchers do their best to reconcile
definitional and other differences in cross-national data.

According to OECD data presented in Table 7 below, total spending on long-term care in 2000
ranged from 0.35 percent of GDP in France to 2.88 percent of GDP in the Netherlands. (For
absolute spending in million US$, see appendix Table 7a.) Because the OECD data include only
health-related long-term care spending, and not social care spending, they underestimate actual
long-term care spending.

<table>
<thead>
<tr>
<th>Table 7. Total Long-Term Care, Institutional, and Home Care Expenditures, 1995 &amp; 2000 (as % GDP)</th>
</tr>
</thead>
<tbody>
<tr>
<td>% GDP US$, PPP**</td>
</tr>
<tr>
<td>-----------------</td>
</tr>
<tr>
<td>Australia</td>
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<tr>
<td>Canada</td>
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<tr>
<td>Denmark</td>
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<td>France</td>
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<tr>
<td>Germany</td>
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<tr>
<td>Japan</td>
</tr>
<tr>
<td>Netherlands</td>
</tr>
<tr>
<td>United States</td>
</tr>
</tbody>
</table>

Notes: Institutional care expenditures represent the OECD classification for In-Patient Nursing Care (HC3.1) for Australia, Canada, France, Japan, and the United States. For Denmark, Germany, and the Netherlands, institutional care expenditures are reported from the OECD provider classification for Nursing and Residential Care Facilities (HP.2). Except for the United States, home care expenditures represent the OECD classification for LT Nursing Care at Home (HC3.3). Japan’s home care figures also include Curative Home Care (HC1.4) and Rehabilitative Home Care (HC2.4); the United States reports home care expenditures exclusively in these two classifications. Australian data for 2000 are from the Australian Department Health and Ageing. Japanese data are derived from OECD and T. Fukawa, December 2002. Danish expenditures cannot be divided between institutional care and home care because individuals in institutions, which include assisted living and other “service housing” as well as nursing homes, also receive home help services.**

* PPP = Purchasing Power Parity
** Johannes Nielsen of the Nordic Social Statistics Committee.

Source: OECD Health Data 2003; Analysis by AARP Public Policy Institute.

The data in Table 7 indicate that total spending on LTC remains less than 2 percent of GDP in
most countries, while spending on total health care is a median of 8 percent of GDP in 2000 in
OECD nations.62 These data also indicate that total long-term care spending as a share of GDP
increased only modestly, or even fell in some countries, such as the United States, between 1995
and 2000. (An exception is Japan, which implemented its new long-term care insurance program
in 2000.) However, the rapid growth in GDP between 1995 and 2000 in all of the countries
listed, except Japan, was a moderating factor. For example, if United States GDP had grown at a
more typical 3 percent a year, instead of 5.8 percent between 1995 and 2000, long-term care
spending would have been 1.47 percent of GDP rather than 1.29 percent.63 Figure 3, which
shows per capita spending on long-term care, takes GDP out of the equation. In the United States example, total per capita spending increased modestly over this period. In fact, except for the Netherlands and Denmark, the U.S. spent more per capita on long-term care than the other countries examined.

While recent trends suggest relatively low growth, the proportion of GDP devoted to long-term care is projected to rise in the future. On average, public long-term care expenditures as a proportion of GDP are projected to increase 70 percent between 2000 and 2050 among Member States of the European Commission, compared with 30 percent to 40 percent for health care.64 Another recent European Union (EU)-funded cross-national study of four European countries revealed that the share of GDP devoted to long-term care is projected to more than double between 2000 and 2050, with the highest increase in Germany, followed by Spain, Italy, and the United Kingdom.65

While such data may seem alarming at first, these projections were based solely on demographic factors, and do not reflect assumptions about other critical factors that could affect expenditures, such as potential improvements in the health and disability status of older persons. Projected increases are significant, but they are not unaffordable or unsustainable, according to the authors of the EU study. In addition, the authors of both studies underscore the high degree of uncertainty about future demand for long-term care.
From a policy perspective, it is important to understand the reasons for the high degree of uncertainty surrounding such long-term projections. Population aging per se is unlikely to be the major factor driving demand for long-term care in the future. In fact, no link exists between the level of health spending at the aggregate level and the relative demographic situation of countries. With respect to long-term care, changes in any of the following factors could lead to major future changes in long-term care spending:

- rates of morbidity and disability by age;
- rates of institutionalization;
- supply of informal care, driven by such factors as changes in labor force participation by women or the share of older persons living alone; and
- unit costs of care, e.g., for formal home care services.

**Spending on institutional versus home care.** The relative balance between spending on institutional care and home care is an important indicator of a nation’s long-term care system. Older persons overwhelmingly prefer services in their own homes to institutional care. As shown in Figure 4, most spending on long-term services is for institutional care rather than home care. Of the seven countries examined, Germany allocated the highest share of its total long-term care spending in 2000 to home care (38 percent), followed by Japan (33 percent), the United States (25 percent) and the Netherlands (21 percent).

Another way to look at the balance between spending on home care and on institutional care is by spending per capita, rather than as a share of GDP. This is a measure of spending allocation
focuses on people rather than on goods and services, and it paints a somewhat different picture of cross-national differences. As Figure 5 indicates, the nation with the highest per capita spending on home care is the Netherlands, followed by Germany and the United States.

As with rates of use of home care and institutional care, caution should be exercised in interpreting the data in Figures 4 and 5 due to varying definitions. For example, institutional care may include “assisted living” facilities as well as nursing homes in some countries but not in others. Obtaining comparable data for home and community-based spending is especially difficult because these services are more likely to be funded by local governments, making them harder to capture, or they may be captured under “social service” spending, which is not included in these data.

![Figure 5. Institutional Care and Home Care Per Capita Spending, 2000](image)

Public versus private sector spending. The balance between public and private spending on long-term care is another important indicator. In practice, most developed countries rely on both the public and private sectors to finance long-term care. For example, most nations provide at least a publicly financed safety net for the poorest group of older people needing long-term care, and wealthier persons are often expected to rely upon their own savings or purchase private insurance. However, the balance between the two sectors varies considerably. Five broad approaches to funding long-term care, whose differences lie in the balance between private and public funding and in the extent of risk pooling, have been identified. The key question posed is, who carries the risk?
Approaches to Long-Term Care Financing: Who Carries the Risk?69

(1) Private savings, such as through special savings accounts or the use of housing equity (individuals and their families carry the full risk)
(2) Private insurance, on a voluntary basis, including long-term care insurance or insurance linked with pensions, disability policies, or life insurance (groups of individuals, enrollees in the insurance plans, carry the risk)
(3) Private insurance with support from the public sector, such as subsidies, tax incentives, or partnership arrangements (same as with private insurance, but part of the risk may be transferred to the public sector)
(4) Public sector tax-based support, funded from general tax revenue, with services or cash based on need and possibly on income and assets as well (taxpayers carry the risk)
(5) Social insurance, funded through dedicated contributions, with services or cash provided based on needs and contributions (those who make the contributions, such as all workers if contributions are based on a payroll tax, bear the risk.)

Most European health care systems are funded from a mix of public and private sources. However, taxation and social health insurance dominate in nearly all of these systems, and private insurance still plays a minor role.70 Taxation and social health insurance are more progressive and promote more equity in access than do private health insurance or out-of-pocket payments, according to a WHO-sponsored study on funding options for health and long-term care systems.71 Such arguments would seem to apply to long-term care as well.

Table 8 provides details on the financing sources for the four universal long-term care programs described above.

<table>
<thead>
<tr>
<th>Source of Financing</th>
<th>Austria</th>
<th>Germany</th>
<th>Netherlands</th>
<th>Japan</th>
</tr>
</thead>
<tbody>
<tr>
<td>Premium or special payment</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>General (income) taxation</td>
<td>Yes (100%)</td>
<td>Yes</td>
<td>No</td>
<td>Yes (50%)</td>
</tr>
<tr>
<td>Cost-sharing</td>
<td>Yes, for institutional care</td>
<td>Yes, for Institutional care</td>
<td>Yes, for all Services</td>
<td>Yes, for all services</td>
</tr>
<tr>
<td>Premium amount (payroll tax)</td>
<td>Not relevant</td>
<td>1.7% of wages, shared equally by employees and employers, subject to a wage ceiling of $4,117 per month; retirees share cost with pension fund</td>
<td>10.25% of taxable income up to a wage threshold; with no employer contribution.</td>
<td>0.9% of wages, shared equally between workers ages 40-64 and employers. Income-related premium for persons 65+, averages $30 per month; deducted from pension</td>
</tr>
</tbody>
</table>


Most direct expenditures on long-term care in developed nations are public rather than private, as indicated in Table 9. In 2000, public spending on long-term care as a proportion of GDP ranged
from much less than 1 percent (.62 percent in Australia) to more than 1 percent (1.03 percent in Canada).72 (For absolute spending in million US$, see appendix Table 9a.) While comparable data were not available on public versus private spending in Denmark, Germany, and the Netherlands from the sources used for Table 9, total long-term care spending in Denmark and the Netherlands exceeds 2 percent of GDP, and a high share of that spending is public. In Sweden, not included in Table 9, where the share of spending on institutional care increased during the 1990s, 3.2 percent of GDP was spent on publicly financed long-term care in 1999.73

Table 9. Public and Private Long-Term Care Spending, 1995 & 2000
(as % GDP)

<table>
<thead>
<tr>
<th>País</th>
<th>Total Long-Term Care Expenditures</th>
<th>Public Long-Term Care Expenditures</th>
<th>Private Long-Term Care Expenditures</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australia</td>
<td>0.63%</td>
<td>0.80%</td>
<td>0.49%</td>
</tr>
<tr>
<td>Canada</td>
<td>1.04%</td>
<td>1.29%</td>
<td>0.78%</td>
</tr>
<tr>
<td>Denmark</td>
<td>2.02%</td>
<td>2.12%</td>
<td>NA</td>
</tr>
<tr>
<td>France</td>
<td>0.31%</td>
<td>0.35%</td>
<td>0.31%</td>
</tr>
<tr>
<td>Germany</td>
<td>1.09%</td>
<td>1.23%</td>
<td>NA</td>
</tr>
<tr>
<td>Japan</td>
<td>0.26%</td>
<td>0.69%</td>
<td>0.22%</td>
</tr>
<tr>
<td>Netherlands</td>
<td>2.88%</td>
<td>2.94%</td>
<td>NA</td>
</tr>
<tr>
<td>United States</td>
<td>1.43%</td>
<td>1.29%</td>
<td>0.87%</td>
</tr>
</tbody>
</table>

NA = Not available; data for these countries are derived from the OECD provider classification for Nursing and Residential Care Facilities (HP.2). Public and private spending are not reported in this classification; however, long-term care in these countries is funded primarily by public sources. Australian data for 2000 are from the Australian Department Health and Ageing.

* PPP = Purchasing Power Parity
Source: OECD Health Data 2003; Analysis by AARP Public Policy Institute

Cross-national estimates of long-term care spending indicate that the United States continues to rely more heavily on private sources of financing than do many other developed nations.74 As indicated in Figure 6 on the following page, the share of private spending in the United States (42 percent) in 2000 was more than double that in Canada and Japan, and almost double that in Australia. Among eight countries examined in an earlier study, the United States and New Zealand were found to have the highest proportion of private spending.75 These private expenditures are usually made out-of-pocket, since private long-term care insurance is a relatively small source of funding in either country. Another OECD analysis also concluded that the share of public spending is relatively lower in the United States than in the Nordic countries, Australia, and the United Kingdom.76

The disparities are even more pronounced when comparing public and private spending per capita. As shown in Figure 7, private spending on long-term care in the United States is more than four times that in Australia, 2.5 times that in Canada, and nine times that in Japan.

Whether through social insurance plans, as in Germany, or by other means,77 developed countries are trying to find ways to distribute the costs of long-term care more broadly.78 Funding long-term care “inevitably involves redistributing costs across the life cycle,” as well as to those with greater needs and fewer resources.79
Figure 6. Public and Private Spending on Long-Term Care as a Share of Total Long-Term Care Spending, 2000

Figure 7. Public and Private Per Capita Spending on Long-Term Care, 2000

Sources: OECD Health Data 2003; Australia data are from the Australian Department of Health and Ageing; Prepared by AARP Public Policy Institute

PPP = Purchasing Power Parity
Key Questions for Health and Long-Term Care Funding Systems

According to the authors of a WHO publication, both equity and efficiency are critical policy objectives in funding systems for health and long-term care. Some questions they suggest which can help frame public policy discussions about both objectives are included in the box below.

Questions related to the equity of a funding system
- Is it progressive (affluent people pay proportionately more)?
- Is it horizontally equitable (people with the same income and wealth pay the same)?
- Does it result in redistribution?
- How does it affect coverage and access to health and long-term care?

Questions related to the efficiency of a funding system
- How does it affect cost containment?
- How does it affect the wider economy?
- How does it affect allocation efficiency (e.g., between different sectors, such as preventive care, acute care, chronic care, home help) and technical efficiency (achieving the most bang for the buck)?

Health and long-term care funding systems also reflect nations’ differing social values and institutional frameworks, as historians and other observers remind us. Long-term care systems tend to evolve in accordance with the social security traditions in different countries, e.g., “Bismarckian” social insurance approaches in Germany and Austria; universal, tax-funded approaches in Sweden; and heavy reliance upon individuals and the private sector in the United States. That countries can break sharply with history and tradition, however, is illustrated by Japan, which has given the public sector a much more extensive role in financing long-term care than this sector plays in other areas of the economy.

Containing the costs of long-term care. Containing the costs of health care has been the subject of much more policy discussion in developed nations than has containing the costs of long-term care, which represents a far smaller share of their economies. Nonetheless, policymakers have many tools available to contain long-term care costs, ranging from relatively blunt and immediate ones to those that require a longer time frame to achieve greater efficiency.

Examples of blunt instruments include budget appropriations that limit eligibility for services or increase waiting lists, as has occurred in the United Kingdom. When initiating universal programs, most countries have sought to contain costs by setting minimum levels of disability for eligibility and benefit maximums, requiring beneficiary cost-sharing, and, in some cases, not indexing benefit levels for inflation, as is the case in Germany.

Other methods rely upon changing the organization and delivery of services to allocate resources more appropriately and efficiently. For example, in some countries, cash payments for home
care are seen as being less costly than traditional agency-provided home care, as well as introducing greater consumer choice and competitive market forces. Care coordination models that combine health and long-term care services and spending for frail older persons have been used in some countries, including the United States, to contain costs and improve outcomes. However, such models remain the exception rather than the rule. As one United States expert has pointed out, the fragmentation of financing for long-term care in the United States makes differentiating "cost effectiveness" from "cost-shifting" between health and social care budgets, as well as between formal and informal care, almost impossible.

There is cause for optimism about containing the costs of long-term care in the future. For example, the types of "technologies" used in long-term care, such as most assistive devices, tend to be less expensive than the high-technology equipment that helps to drive health care costs. Some evidence indicates that assistive technologies are substituting for human help for persons with lower levels of disability. As discussed above, the potential for preventing or delaying health and functional declines is a major wildcard in long-term care cost projections. Further, the sustainability of long-term care financing depends heavily on assumptions about the level of economic growth—strong economic growth means long-term care will be in less competition for scarce resources.

With respect to expanding home and community services while containing costs, the experiences of both Germany and Japan are encouraging. In Germany, a key goal was to spend more on long-term care overall while also spending less on means-tested social assistance. From 1991-1998, spending on social assistance declined steeply (by 45% for home and community care and by 51% for institutional care). The long-term care insurance program built up surpluses for several years. In 2002, there was a very small deficit (less than 1 percent). The program has reserves equal to 25% of program expenditures. Despite Germany’s prolonged economic recession, the long-term care program has not been a particular focus of cutbacks, although benefit expansions are considered unlikely.

Costs also have not exploded in Japan. The use of community-based services was relatively low in the first year. However, as individuals have learned about the program, the use of services, including day care and respite care, as well as home help, has been growing steadily, both in numbers of persons served and in how many services individuals use. This expected expansion meant that premiums were raised for the second three-year fiscal period starting in 2003, and that they will be raised again in 2006. The expansion in utilization is consonant with the original goals of the program -- to provide assistance to frail older persons and to relieve family caregivers.

Improving the Quality and Coordination of Long-Term Care Services

Improving quality. Quality assessment is a crucial component in a country’s long-term care system. In 2000, WHO reviewed long-term care laws of selected health care systems and analyzed the alternatives available in each country and the choices these countries have made in terms of long-term care. This review, which also included policy makers’ concerns in each of the selected countries, concluded that quality of long-term care is a “weak-link” in all of the
countries examined. Many of these countries have stressed the need to develop clearer criteria for quality assurance and to augment regulation. According to a recent EU report, most member states have set structural standards, such as building standards and staff qualifications, for institutional care, but relatively little attention has been devoted to home care quality.

To achieve optimal quality of care, it may be necessary for countries to take a closer look at their entire long-term care systems, including their accessibility, and how they deliver services, in addition to their methods of quality assurance and improvement. Assuring that consumers are receiving quality care may include myriad factors, among them the training and supervision of formal caregivers, information system development, standard setting, development of guidelines, and legislation. The growth of direct payment programs for long-term care, in which consumers themselves pay relatives or other providers, raises complex issues of what constitutes quality in home care and how it can best be monitored.

WHO recommends the following to help countries to move toward greater quality:

- Any health system should define the scope and extent of its long-term care coverage.
- All primary care services also need to address the long-term care needs of people with chronic conditions and disabilities, along with adequately responding to their needs for preventive and curative care.
- Long-term care coverage should be based on an assessment of needs of the person requiring long-term care. However, because the majority of long-term care is provided by informal caregivers and is dependent upon their health and well-being, caregiver needs must be assessed as well to plan resource allocation.
- Regulatory systems should establish and enforce minimum standards for long-term care facilities, including such aspects as the level and qualifications of staff, minimum staffing levels and skill-mix, procedural standards, and infrastructure specifications.
- Standards to Protocols should be established where sufficient evidence is available, and research encouraged to expand the knowledge base necessary for quality long-term care.
- Some measure of outcomes assessment may need to be implemented to assess the extent of outcomes achievement and thus to improve care accordingly. In addition, agreement over outcomes definitions should be established.
- Responsiveness to the legitimate expectations of persons with chronic conditions and disabilities, and responsiveness to the legitimate expectations of their “informal caregivers,” must be translated into continued improvement of services.
- Evaluation of the extent of effective coverage across disability groups, and across social determinants that may hinder access to long-term care (such as age or gender, social and economic status, race, ethnic or religious groups, geographical residence, or other criteria) should be performed.

The United Kingdom has recently undertaken several broad quality initiatives, including setting national standards for quality in residential and nursing home care. Such standards are “under consultation” in relation to home care. In addition, a newly established Commission for Social Care is charged with registering providers, inspecting and reviewing, and publishing an annual report for Parliament. A “Social Care Institute of Excellence” was established in April 2001 to identify and disseminate information on evidence-based best practice in social care.
Another country that has taken important steps to improve long-term care quality is Australia. As part of its 1997 reform package aimed at overhauling the aged care system, the Australian government introduced major reforms in quality, particularly in nursing homes. Among the reforms were new privacy and space requirements for existing and new residential care buildings calling for a maximum number of residents per room. Before reform, there was a great disparity between the number of residents per room in nursing homes, which tend to care for people with high degrees of frailty and the number in hostels, which provide accommodation and personal care, and occasionally, some highly skilled nursing care. Typically, the number of residents per room in a nursing home was 3 or more; in a hostel, most residents lived in single rooms. To date, the Department of Health and Aged Care reports that the majority of nursing homes that have been built or renovated since 1993 are meeting or exceeding these requirements.

In Germany as well, most quality initiatives to date have concentrated on nursing home care. However, a law passed in 2001 focused on home care quality. This law has generated substantial recent controversy, with some of the implementing regulations being blocked by the Laender because they were seen as being too bureaucratic and burdensome to providers. The new law gave a wide range of enforcement actions to the sickness funds when quality problems are identified. It also proposed requiring all home care providers to collect data for quality measurement and accreditation by newly formed third party accrediting bodies every two years, a more frequent interval than occurs under the current audit system for inspecting home care providers. Quality standards that rely on outcomes, rather than structure or processes, in either institutional care or formal home care, however, are still lacking.

**Improving chronic medical care and its coordination with long-term services.** Providing better chronic care and crossing boundaries between health and long-term supportive services remains a major problem in most developed countries. Problems in coordinating health and long-term care services are exacerbated in the United States, which stands alone among developed nations in not providing health insurance to its entire population, including persons of all ages with disabilities. The United States is not alone, however, in trying to overcome boundary problems between health and long-term care services.

Some examples of bridging the gap between chronic medical care and long-term care follow:

- Preventive “home visitation” programs for older person are an approach that sits at the intersection of health and long-term care. Intended to delay or prevent functional limitations and subsequent nursing home admissions, these programs are part of national policy in several countries, such as the United Kingdom, Denmark, and Austria. Such programs involve primary prevention (immunizations); secondary prevention (detection of untreated problems); and tertiary prevention (improvements in medication use.) A recent in-depth analysis of the international literature on these programs found they can be successful in reducing functional decline and nursing home admission, and in increasing survival.

- To coordinate medically-related long-term care services, such as home nursing, with non-medical home care, Department of Health officials in England, who oversee the nation’s
home and community services program, have begun encouraging local health authorities and social services departments to pool budgets, and in some case, to commission or provide services jointly.99

- Another example of an innovation aimed at bridging this divide is Transmural Care in the Netherlands. Here, nurses are responsible for overseeing clinics and patient care. Nurse-led clinics are available in some other European countries as well and country-specific data have shown that these clinics produced better outcomes than physician-led clinics in many areas including reduced mortality and admissions with heart failure in Sweden; improved detection of diabetic nephropathy, and better management of anticoagulation and chronic obstructive pulmonary disease in the United Kingdom.100

Conclusions

In summary, many developed countries share similar goals with respect to long-term care, including:

- enhancing consumer choice and independence, e.g., through consumer-directed home care programs;
- encouraging access to services in the home and community;
- supporting family and other informal caregivers;
- providing universal coverage for long-term care services;
- insuring individuals against the high costs of long-term care through a mix of public and private financing;
- treating the need for long-term care as a normal risk of life, with financing shared by the working-age and older populations;101
- containing the costs of long-term care;
- improving the quality of long-term care; and
- overcoming “boundary problems” between medical and long-term care, a long-standing challenge, and one that has grown more urgent as health care increasingly involves management of long-term chronic conditions.

While there are common goals, there are also common tensions. For example, most developed countries cover home nursing care under universal systems, but many, especially in English-speaking countries, means-test personal care services. This division often surprises and confuses individuals who need long-term care, and it can create incentives to providers to shift costs
between health and long-term care budgets. Such a division can also exacerbate tendencies to “overmedicalize” service.

Other boundaries that divide health and social care are beginning to blur. In the Scandinavian countries and the Netherlands, in particular, the boundaries between nursing homes/residential homes and community services, such as day hospitals and adult day services, are disappearing. And trends toward cash payments for persons with disabilities of all ages, typically used to help compensate family caregivers, are blurring the lines between paid versus unpaid work and informal versus formal services. Finally, in countries where both cash and in-kind service options are available, such as Germany, a growing number of consumers are choosing to “mix and match” both forms of support to meet their individual needs and circumstances.

The toughest issue, especially in the current climate of global economic uncertainty, is how to pay for an appropriate range of long-term care services in the face of other competing priorities, and how to sustain availability of services in the face of growing demand. The key themes from a brief look at financing issues are:

(1) Current long-term care spending is a relatively small share of GDP in most developed nations, but it is growing.

(2) While a high degree of uncertainty surrounds all long-range projections about the need for long-term care, a high degree of consensus exists about the need to promote the cost-effectiveness of such care. Such steps include promoting healthy aging and delaying disability for as many years as possible, increasing support for family caregivers, and increasing services in homes and communities.

Demography is not destiny, but demographic trends indicate that the time to prepare for the long-term care needs of the cohorts of post-WWII boomers, a cross-national phenomenon, is now. The “oldest” nations, such as Japan, Italy, and many other European countries, which have already experienced very rapid aging, will face new challenges as an increasing share of their population is age 80 or older, the age when long-term care is most likely to be needed. For countries with younger populations, such as Canada, the United States and Australia, the next two decades, before boomers begin turning 75, offer a window of opportunity to build stronger long-term care systems. In some nations, such as in the United States, part of that preparation may involve public debate about universal versus means-tested systems for long-term care. This debate may be driven by the rising expectations of future cohorts of boomers, who will want better options to live independently and with dignity but often have difficulty paying for them, as well as by growing consumer activism in many nations. Such activism includes younger persons with disabilities and associations for caregivers, as well as advocates for the aging.
## Appendix

### Table 7a. Total Long-Term Care, Institutional, and Home Care Expenditures, 1995 & 2000 (in Million US$)

<table>
<thead>
<tr>
<th>Country</th>
<th>Total Institutional Expenditures</th>
<th>Total Home Care Expenditures</th>
<th>Total Long-Term Care Expenditures</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australia</td>
<td>$2,290</td>
<td>$3,393</td>
<td>$155</td>
</tr>
<tr>
<td>Canada</td>
<td>$6,043</td>
<td>$9,521</td>
<td>$1,025</td>
</tr>
<tr>
<td>Denmark</td>
<td>$2,426</td>
<td></td>
<td></td>
</tr>
<tr>
<td>France</td>
<td>$3,352</td>
<td>$4,654</td>
<td>$421</td>
</tr>
<tr>
<td>Germany</td>
<td>$12,370</td>
<td>$16,445</td>
<td>$6,624</td>
</tr>
<tr>
<td>Japan</td>
<td>$7,390</td>
<td>$15,218</td>
<td>$124</td>
</tr>
<tr>
<td>Netherlands</td>
<td>$9,873</td>
<td></td>
<td></td>
</tr>
<tr>
<td>United States</td>
<td>$74,574</td>
<td>$93,784</td>
<td>$30,529</td>
</tr>
</tbody>
</table>

Notes: Institutional care expenditures represent the OECD classification for In-Patient Nursing Care (HC3.1) for Australia, Canada, France, Japan, and the United States. For Denmark, Germany, and the Netherlands, institutional care expenditures are reported from the OECD provider classification for Nursing and Residential Care Facilities (HP.2). Except for the United States, home care expenditures represent the OECD classification for LT Nursing at Home (HC3.3). Japan's home care figures also include Curative Home Care (HC1.4) and Rehabilitative Home Care (HC2.4); the United States reports home care expenditures exclusively in these two classifications. Japanese data are derived from OECD and T. Fukawa, December 2002. Danish expenditures cannot be divided between institutional care and home care because individuals in institutions, which include assisted living and other “service housing” as well as nursing homes, receive home care services.**

* PPP = Purchasing Power Parity
** Johannes Nielsen of the Nordic Social Statistics Committee.

Source: OECD Health Data 2003; Analysis by AARP Public Policy Institute.

### Table 9a. Public and Private Long-Term Care Spending, 1995 & 2000 (in Million US$)

<table>
<thead>
<tr>
<th>Country</th>
<th>Total Long-Term Care Expenditures</th>
<th>Public Long-Term Care Expenditures</th>
<th>Private Long-Term Care Expenditures</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australia</td>
<td>$2,445</td>
<td>$4,051</td>
<td>$1,917</td>
</tr>
<tr>
<td>Canada</td>
<td>$7,068</td>
<td>$11,176</td>
<td>$5,277</td>
</tr>
<tr>
<td>Denmark</td>
<td>$2,426</td>
<td>$3,257</td>
<td>NA</td>
</tr>
<tr>
<td>France</td>
<td>$3,773</td>
<td>$5,226</td>
<td>$3,773</td>
</tr>
<tr>
<td>Germany</td>
<td>$18,994</td>
<td>$26,640</td>
<td>NA</td>
</tr>
<tr>
<td>Japan</td>
<td>$7,514</td>
<td>$22,816</td>
<td>$6,532</td>
</tr>
<tr>
<td>Netherlands</td>
<td>$12,481</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>United States</td>
<td>$105,103</td>
<td>$125,512</td>
<td>$63,993</td>
</tr>
</tbody>
</table>

NA = Not available; data for these countries are derived from the OECD provider classification for Nursing and Residential Care Facilities (HP.2). Public and private spending are not reported in this classification; however, long-term care in these countries is funded primarily by public sources. Australian data for 2000 are from the Australian Department Health and Ageing.

* PPP = Purchasing Power Parity

Source: OECD Health Data 2003; Analysis by AARP Public Policy Institute
Endnotes

1 Programs in the United States that have been cited as examples of “best practices” include the On Lok Senior Health Services Program, part of the PACE program; the Wisconsin partnership programs, and the Minnesota Senior Health Options program; see Minford, M.,” “The Boundaries Between Health and Social Care for Older People in Developed Countries,” HM Treasury & Department of Health, June 2000.


3 See footnote 1


9 Stuart, M., and Weinrich, M. “Home and Community-Based Long-Term Care: lessons from Denmark,” The Gerontologist, Vol. 41 (2001): 474-480. For example, during the transition from nursing home to community care, the community of Odense formed a partnership in which private developers built and operated new assisted living units, with the municipality providing health and social support services. The assisted living facility became a hub for community services, including day care, rehabilitation, and 24 hour home care.


13 Ibid.


22 Ibid.


26 Jenson, J. and Jacobzone, S., 2000, op. cit., p. 34.

27 Jenson, J. and Jacobzone, S., 2000, op. cit., p. 36.


30 Ibid., p. 23.
33 Ibid.
35 Ibid.
36 Campbell, J.C. and Ikegami, N. “Japan’s Radical Reform of Long-Term Care,” in Social Policy & Administration ISSN 0144-5596. Vol. 37, No. 1, February 2003, p. 27.
38 Ibid.
39 Minford, June 2000.
40 Kodner, Dennis L. Long Term Care Integration in Four European Countries: A Review, in Key Policy Issues in Long-Term Care, World Health Organization Collection on Long-Term Care, 2003, pp. 91-128.
41 Brodsky, 2000, p. 59.
43 Ibid.
45 Ibid.
47 O'Shaughnessy, C.V. Trends in Long-Term Care Financing in Selected Countries, testimony before the Senate Special Committee on Aging, Congressional Research Service, June 20, 2002, p. 6.
48 Age Concern Scotland Briefing, History of the We Care Campaign, April 2002.
50 Ibid.
53 Ibid.
54 Campbell, J. C. and Ikegami, N. “Japan’s Radical Reform of Long-Term Care,” in Social Policy & Administration ISSN 0144-5596. Vol. 37, No. 1, February 2003, pp. 21-34.
56 Ibid., p. 29.
58 Saltman, R, Busse, R., and Figueras, J., “Social Heath Insurance Countries in Western Europe: Outline of a Subregional Comparative Study, Study Proposal to the European Observatory on Health Care Systems,” WHO Regional Office for Europe, 2003: “A country has social health insurance if a majority of or the whole population is legally required to obtain health insurance with a designated (statutory) third-party payer through non-risk-related contributions that are kept separate from taxes or other legally mandated payments.” The four broad concepts that characterize social insurance programs are: solidarity, pluralism, participation, and choice. Solidarity refers to providing equal benefits to all who are eligible through a set of cross-subsidies from the healthy to the sick, well-off to less well-off, young to old, and individuals to families. Other necessary characteristics of such programs are pluralism (a mix of various public and private actors), self-regulation, and choice among contracted providers.
59 Sufficient information on long-term care programs in Spain, Portugal, Greece, and Italy was not available to the authors at the time this report was written to include these nations in Table 6.
62 Anderson, G. et al. “It’s the Prices, Stupid: Why the United States Is So Different from Other Countries,” Health Affairs (May/June 2003), p. 91. In the OECD data to which this note refers, long-term care costs are included in the median figure of 8% of GDP spent on total health care in OECD nations. An estimate of public spending on health and long-term care by the EU indicates that 5.3% of GDP in 2000 was spent on health care compared with 1.3% on long-term care (weighted averages for EU countries.) See Council of the European Union, Joint Report by the Commission and the Council on supporting national strategies for the future of health care and care for the elderly; Brussels, 20 February 2003, p. 24.
63 Mark Merlis, personal communication with the authors, September 2003.
69 Ibid.
71 Ibid.
72 Jacobzone, S., Camblis, E., and Robine, J.M., 2000, op. cit., p. 170; data refer to a “baseline year” in the mid-1990s. Total long-term care expenditure data were not available for France, Germany, or Japan. See also O’Shaughnessy, 2002, op. cit.
74 Mark Merlis, personal communication with the authors, observes that the large disparities between private long-term care spending in the United States and in other countries may partially be an artifact of reporting differences. In some other countries, institutional care residents lose most or all of their public pension, and their care is publicly funded, so the money shows up in the public column. In the United States, residents continue receiving their Social Security check and use it to pay for nursing home care, so the money winds up in the private column, September 2003.
75 Anderson, G., and Hussey, P., “Population Aging: A Comparison Among Industrialized Countries,” Health Affairs (May/June 2000), pp. 196-197; the eight countries studied were Australia, Canada, France, Germany, Japan, New Zealand, the United Kingdom, and the United States. Total long-term care expenditure data were not available for France, Germany, or Japan.
76 Jacobzone, S., Camblis, E., and Robine, J.M., 2000, op. cit., p. 170. Data refer to a “baseline year” in the mid-1990s. Total long-term care expenditure data were not available for France, Germany, or Japan.
79 Wittenberg, p. 237
80 Mossialos and Dixon, p. 272
81 Karlssan, p. 51
83 The Program of All Inclusive Care for the Elderly (PACE), an integrated model of care, is an established part of the Medicare program that is expanding slowly. Center for Medicare Education, The PACE Model, Issue Brief Vol. 2, No. 10, 2001.
85 Beyond Fifty.03, op. cit., p. 95.
87 Ibid.
89 John C. Campbell, personal communication with author.
93 Larizgoitia, I. Approaches to Evaluating LTC Systems. Chapter 7 in Key Policy Issues in Long-Term Care, World Health Organization Collection on Long-Term Care, 2003, pp. 238-239
97 Ibid.