AARP EUROPEAN LEADERSHIP STUDY:

European Experiences with Long-Term Care

France, the Netherlands, Norway, and the United Kingdom

October 2006
European perspectives on LTC are a largely untapped resource for examining ways to improve the financing and delivery of LTC in the U.S.

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With health care costs rising at unsustainable rates and the Baby Boom Generation nearing retirement, the United States faces essential and imminent debates on the reform of our health care and long-term care systems. As the leading organization in America for positive social change, AARP is poised to lead the discussion on how to achieve better and more affordable health care in the United States and provide long-term care for older Americans. To further inform the discussion, AARP’s Board of Directors and senior management traveled to Europe in June 2006 on a fact-finding mission to examine the experiences, trends, and best practices in global aging.

The European Leadership Study (The Study) concentrated on AARP’s priority issues of health care and long-term care and examined how certain European countries are addressing challenges similar to those faced in the United States. In particular, The Study provided a deeper understanding of the European experience on pharmaceutical pricing, health information technology, financing and delivery of long-term care services and health care cost containment.

During The Study, the AARP delegation visited France, Norway, the United Kingdom and the Netherlands. The Study provided an opportunity for direct conversations with government officials, representatives from key nongovernmental organizations, consumers, and business leaders. The Study participants held discussions with national health ministers, health care consumers and practitioners, including sessions with the Chief Executive of the United Kingdom’s National
Institute for Clinical Excellence (NICE), representatives from Sanofi-Aventis, France’s leading pharmaceutical company, and political party officials in the Norwegian Parliament from the Standing Committee on Health and Care Services. The Study also included site visits to hospitals and long-term care facilities that provided invaluable first-hand observation of care as it is practiced abroad.

With the publication of four Issue Papers prepared by the AARP Public Policy Institute, AARP is presenting the background materials prepared in advance of The Study and the lessons learned that were compiled afterwards. The four Issue Papers address: long-term care; health information technology; pharmaceutical pricing; and health care cost containment. The Issue Papers rely on published materials, readily available data sources (such as reports and studies from the Organization for Economic Cooperation and Development and the European Commission, among others) and include, when possible, knowledge from first-hand, in-country experiences.

Due to the nature of available information sources, it was difficult to systematically draw direct comparisons among the four countries visited. Nevertheless, the papers offer important lessons for the United States and teach us that, while we are progressing in some areas of health and long-term care, there is much we can learn from European countries as we address these critical issues.

ERIK OLSEN  
President

BILL NOVELLI  
CEO
Introduction to Long-Term Care Issues

The United States does not have a comprehensive long-term care (LTC) system. Arguably, it has no system at all. Medicare does not cover long-term care services. Private long-term care insurance remains expensive and not available to everyone. Americans rely primarily upon the unpaid contributions of family members and friends, who provide the vast majority of LTC services received by people of all ages who need help with basic daily activities. Medicaid, a safety net program and payer of last resort designed for people with low incomes and few assets, is the primary public financing system for LTC, with benefits varying from state to state.

European perspectives on LTC are a largely untapped resource for examining ways to improve the financing and delivery of LTC in the U.S. Virtually all European countries have had far higher proportions of people age 80 and older than the U.S. has had for some time. Some of these countries have implemented LTC programs that hold important lessons for the U.S. and can serve as “natural laboratories” for tracking the impact of LTC policy changes over time.

This paper concentrates on describing the LTC systems in the Netherlands, Norway and, to a lesser extent, the UK and France. Dutch and Norwegian policies offer the most relevance for LTC reform in the United States as LTC in England (although not Scotland) involves stringent means-testing for personal care and other non-medical services, and in France requires steep income-related copayments.
A. LTC FINANCING

Issues concerning the public financing of LTC services involve the thorniest policy questions of all. European countries offer examples of differing mixes of public and private responsibility, such as in the balance between public financing that spreads risk broadly across the entire population and private responsibility through individual cost-sharing and family caregiving support. Private LTC insurance is relatively rare in other countries.¹

The last several decades have seen movement toward contributory social insurance approaches for LTC in a number of European countries:² Germany (1995-1996); Luxembourg (1999); and the Netherlands (1968 for nursing home care and 1989 for home care). Japan also added a LTC social insurance benefit in 2000, and Korea did so in 2006. These programs are based on employer/individual insurance contributions and have a dedicated financing source. They are “universal” programs in that they cover most or all of the population and provide benefits on the basis of assessed needs due to disability, without an income or means-test. As social insurance programs, they have a dedicated financing source. These programs “entitle” individuals to services in the sense that individuals have a statutory right to benefits based on level of disability, and individuals’ cost-sharing levels are specified in national legislation.

The Scandinavian countries, including Norway, provide coverage through a social democratic model, funded through general revenues, in which everyone is entitled to LTC services through municipal programs based primarily on local and regional tax revenues. Costs are covered through general taxation. Although coverage is universal, benefits or required cost-sharing often vary substantially by locale. Municipalities can adjust criteria for eligibility to fit available finances. Their systems have been characterized as “budgeted systems,” which can ration care informally.³

In addition to the U.S., England, Australia, and New Zealand are examples of countries that rely primarily on means-tested programs, which cover only people with income and assets below a certain level. These programs are financed from general tax revenues.
Public LTC insurance programs must have criteria to determine eligibility, and they vary not only in their stringency but also in how explicit the criteria are. Explicit criteria are more common in entitlement systems, while budgeted programs give more discretion to decision makers, who can vary eligibility requirements according to funding targets.4

In examining both financing and delivery systems for LTC, it is important to distinguish between medically oriented LTC services, such as skilled nursing care at home or in an institution, and non-medically oriented LTC, including personal care services such as assistance with bathing and eating, and other home care services such as help with cooking and managing medications. Almost all European countries cover skilled nursing services under universal health legislation, usually without cost-sharing. This coverage pattern is similar to the Medicare program in the U.S., which covers skilled home care and some skilled nursing facility services for people age 65 and older and people with disabilities. This paper will focus on non-medical supportive services, or social care services, in European parlance. Some basic distinctions are described below and shown in Table 1.

| TABLE 1: Type of Coverage for Long-Term Care and Primary Public Funding Sources |
|-------------------------------------------------|-----------------|-----------------|-----------------|-----------------|-----------------|
| Norway                                         | Netherlands     | U.K.*           | France          | U.S.            |
| Eligibility                                    | Universal coverage | Universal coverage | Means-tested    | Hybrid**        | Means-tested    |
| Funding source                                 | General revenue  | Social Insurance contribution | General revenue | General revenue | General revenue |
| Role for private LTC insurance                 | Almost none      | None currently; but may begin after recent LTC reforms | Very limited    | Information not available | Larger than others*** |

Definitions: The table refers to non-medical services, excluding home nursing care, which is covered separately under health legislation in most countries. "Universal coverage" refers to eligibility based on need for services with no income or asset test in order to receive services. "Means-tested" refers to a test of user’s income and/or assets in order to receive services. Source: OECD 2005, pg. 24

"Social insurance" refers to programs based on employer/individual insurance contributions and which have a dedicated financing source. "General revenue" refers to programs based on general taxation.

* As of 2001-2002, all parts of the UK introduced non-means-tested, fixed rate contributions toward the cost of nursing care in nursing homes, based on varying levels of need, not income. In Scotland only, non-means tested payments are made by the government for personal care in both residential care and home care. Sources: D. Hirsch5 S. Johnstone6

** France’s system is not means-tested, but it has steep income-related coinsurance.

*** According to CBO, private LTC insurance in the U.S. covered 3-4% of total LTC costs in 2004. National Health Expenditure data for 2003 indicate that private insurance accounted for 7.6% of nursing home spending.
As the figure below indicates, Norway has noticeably higher total LTC expenditures than the other countries being examined. Other Scandinavian countries also have relatively higher expenditures, which is likely due to a greater provision for LTC services and a higher proportion of people 80 or older in their populations. The UK and the U.S. are at about the same level of total expenditures as a percentage of GDP, with the Netherlands somewhat higher. The mix of public and private financing differs considerably, as does the nature of coverage (universal versus means-tested).

All European countries are searching for ways to control rising expenditures for LTC. Instruments for controlling costs include budget cutting to limit eligibility; increasing waiting lists; targeting only those with the most severe disabilities; increasing personal cost-sharing; and not indexing benefits for inflation. In addition to paying taxes or making insurance contributions, beneficiaries also contribute to the financing of LTC services through cost-sharing, which varies substantially by type of service. Many European countries require nursing home residents to pay for “room and board.” Nursing services, both in institutions and at home, generally do not require any cost-sharing. Cost sharing for personal care services and for home help, such as shopping, however, varies widely and can be substantial (see Table 2).
B. ENCOURAGING HOME- AND COMMUNITY-BASED SERVICES.

Rates of institutional care use and home care use vary considerably, as shown in Table 3 below. Much of this variation is likely due to differences in cross-national definitions of institutional care and home care, although researchers at the OECD, EU, and elsewhere try to reconcile differences to the extent possible. Data for home care in particular should be viewed with considerable caution because they may include formal in-kind services only or both formal services and cash benefits. Further, the cash benefits may be substantial or quite small, such as the attendance allowance in the UK. Hence the range in the home care data reported by different sources is very wide.8

Rates of nursing home use have been dropping in many OECD countries in recent years, including Australia and Austria, as they have in the U.S. Countries also vary in the mix of public and private sector providers of both institutional care and home care. Public sector providers predominate in Scandinavian countries. Private sector entities, largely non-profit, predominate in England, France, Germany, and the Netherlands. The U.S. has much larger for-profit involvement in providing LTC services (see Table 3 below).

### TABLE 2: Cost-Sharing for Publicly Funded LTC Services in Five Countries

<table>
<thead>
<tr>
<th></th>
<th>Norway</th>
<th>Netherlands</th>
<th>U.K.</th>
<th>France</th>
<th>U.S.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nursing home care</td>
<td>Residents pay 75%–80% of their public pension</td>
<td>Residents make income-related payments for food and housing</td>
<td>Personal care is means-tested in England (asset test includes home equity)</td>
<td>Residents pay for housing and basic care; means-tested assistance available for low income</td>
<td>See footnote below*</td>
</tr>
<tr>
<td>Home nursing</td>
<td>None</td>
<td>Income-related copayment usually nominal</td>
<td>None</td>
<td>None</td>
<td>See footnote below*</td>
</tr>
<tr>
<td>Personal care/home help, such as shopping</td>
<td>Personal care: none Home help: varies by municipality; usually income-related</td>
<td>Income-related copayment; maximum is about $150 per week</td>
<td>Varies by local authority in England; personal care is free in Scotland</td>
<td>Income-related copayment: 80% at highest income level (about $3,900 per month)</td>
<td>See footnote below*</td>
</tr>
</tbody>
</table>

Sources: OECD; national reports for EUROFAMCARE; Gibson, Gregory, and Pandya; Szebehely

*U.S. Data for Comparison: No cost sharing for days 1-20 in Medicare-covered skilled nursing facility care; $119 per day in 2006 for days 21-100; benefits end after 3 months. Long-term nursing home care and home care are only covered under Medicaid, which is means-tested. Nursing home residents without a spouse in the community must contribute all of their income except a small personal needs allowance.
C. CONSUMER-DIRECTED HOME CARE AND DIRECT PAYMENTS FOR LTC

Consumer-directed programs are increasingly common in Europe and in many states in the U.S. The premise of these programs is that consumers with disabilities know their own needs best and should be able to choose and direct the non-medical services they receive. These programs vary both in the degree of consumer direction or autonomy and in the type of benefits provided (cash, formal services, or a combination). (See Table 4.)

The Scandinavian countries, including Norway, offer examples of provider-based programs in which providers, in this case public, select and approve care plans. At the other end of the extreme, France provides only a cash option called the autonomy pension, which can be used for literally anything, from paying for LTC to using the autonomy pension as income.9

D. ENCOURAGING FAMILY SUPPORT

Informal LTC provided by family and friends continues to far outweigh care provided through the formal sector in European nations as well as in the U.S. Several decades of research in many countries have demonstrated that informal caregivers themselves often need support, both in order to deter adverse health and financial effects from caregiving and to help prevent or delay institutionalization of the care receivers. Such support can take a variety of forms, including information and training; assessment of the needs of caregivers themselves; respite services to give caregivers a break; tax benefits; and direct payments to caregivers (see Table 5). Labor policies that support employed caregivers are also important.
### TABLE 4: Options for Consumer-Directed Home Care in Five Countries

<table>
<thead>
<tr>
<th></th>
<th>Norway</th>
<th>Netherlands</th>
<th>U.K.</th>
<th>France</th>
<th>U.S.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Type of benefits available</strong></td>
<td>Formal services</td>
<td>Cash, formal services, or both</td>
<td>Formal services or cash allowance</td>
<td>Cash</td>
<td>Formal services; cash, in some states under Medicaid and some state programs</td>
</tr>
<tr>
<td><strong>% of home care users of all ages using consumer-directed care</strong></td>
<td>Not available</td>
<td>10% (2002)</td>
<td>2% (2002)</td>
<td>Not available</td>
<td>Not available</td>
</tr>
<tr>
<td><strong>Possible to hire relative</strong></td>
<td>Not available</td>
<td>Yes, including spouses and parents</td>
<td>Generally no if lives in same household</td>
<td>Yes, but not spouses</td>
<td>Yes, but most states prohibit hiring spouses</td>
</tr>
</tbody>
</table>

Sources: Wiener; Tilly, and Cuellar, 2003.

### TABLE 5: Supports for Family Caregivers in Five Countries

<table>
<thead>
<tr>
<th></th>
<th>Norway</th>
<th>Netherlands</th>
<th>U.K.</th>
<th>France</th>
<th>U.S.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Direct financial support</strong></td>
<td>Care wage</td>
<td>Tax deduction*</td>
<td>Carers’ allowance</td>
<td>Tax deduction</td>
<td>Some states provide cash payments under NFCSP**; some state programs; child and dependent care tax credit.</td>
</tr>
<tr>
<td><strong>Public pension credit</strong></td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td><strong>Paid leave</strong></td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No, except CA</td>
</tr>
<tr>
<td><strong>Caregiver assessment</strong></td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>A few states have demos</td>
</tr>
<tr>
<td><strong>Respite care</strong></td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Not available</td>
<td>Varies by state** NFCSP</td>
</tr>
</tbody>
</table>

Note: Specific provisions for these benefits vary widely. Additional details are available upon request. Cash payments to people with disabilities who are receiving care, which can also be used to support family caregivers, are included in Table 3 on page 10.

* Tax deductions are for direct expenses paid out-of-pocket by caregivers that exceed minimum thresholds

** NFCSP is the National Family Caregiver Support Program in the U.S. Additional information on state programs in the U.S. is available upon request.
Differing societal expectations concerning women’s role in the labor force and in the family, as well as legal “filial” responsibility laws, also affect the types of services and supports available. Some European researchers have argued that as women’s labor market participation increases, the level of publicly funded LTC or “social” care increases. An OECD report examined the relationship between women’s labor force participation and the provision of cash payments and other financial support to caregivers. It concluded that countries with extensive provision of formal home care but limited financial support for informal care (such as the Scandinavian countries) generally have higher employment rates for women ages 50-59 than countries with “average provision of formal care but extensive financial support for informal care . . .” such as the UK, Germany, and Austria. However, this finding does not imply a causal relationship. The lower employment rates of women in Austria, Germany, and the Netherlands may be associated with such cultural factors as preferences for single-earner couples.

A key policy issue concerning family support is whether formal services “substitute for” or “supplement and complement” family care. This issue is not just a matter of semantics. Policymakers in many countries fear that the provision of formal services will undermine family caregiving support. So far, most of the evidence suggests that there has been no breakdown in family support, even in countries with the highest provision of formal sector, publicly funded care, such as the Scandinavian nations. However, the type of family support changes as more formal services are available, with families providing fewer direct personal care services, such as help with eating or bathing, and more help with instrumental activities of daily living, such as shopping and transportation, as well as negotiating and coordinating with formal service providers. Even in Sweden and Norway, family care continues to predominate for “light” care.
NORWAY

Overview of Long-Term Care: Norway is a constitutional monarchy, with a long tradition of state responsibility for the welfare of older people. Indeed, "Most Norwegians hold the view that the welfare state should be the primary source of care, with the family in a supporting role." More than 80 percent in a 1998 survey felt that care of older people should be a public responsibility. Most of the cost of long-term care services is covered by taxation.

The provision of LTC services is largely decentralized and integrated at the level of the municipality, the lowest tier of government. There are 431 municipalities in Norway, about half of which have fewer than 5,000 residents. In addition to differences in population density, municipalities vary widely in such areas as per capita income, age composition, geographic conditions, and revenue generated from local taxes. Municipalities finance and manage primary health care, including rehabilitation services, and long-term care ("social care"). Most service providers are public sector: 90 percent of institutional care is public, while 10 percent is nonprofit or for-profit. Local public providers are also the largest supplier of home care services. The national government finances hospital care and specialized medical services, delivered at the regional level. A universal old age pension is provided under a national social insurance plan, with normal retirement age at 67 and early retirement at age 62.
A major national strategic initiative from 1998-2001, called the “Action Plan for the Elderly,” focused on strengthening home-based care, expanding sheltered housing (similar to assisted living in the U.S.), and modernizing nursing homes. Some recent commentators say these goals have largely been met. The Action Plan was estimated to cost 30 billion Norwegian kroner (NOK) (about $4.8 billion) over the four-year period, laid out concrete action steps, and made earmarked funds available to local authorities to implement the plan.

Now, the Ministry of Health and Care Services has announced another new National Plan of Action that will focus intensely on quality of care and quality of life, such as encouraging social engagement and activities. Action steps will include substantially expanding the number of care workers, particularly full-time workers; better education and training for health and LTC workers; a major focus on dementia services; and social and cultural activities for older people.

**Financing:** Most of the cost of LTC in Norway is covered by municipalities. With the exception of Sweden, Norway spends a higher share of its GDP on LTC than do other OECD nations for which data are available. (See Table 1 on page 7.) In 2000, total expenditure for LTC in Norway was 2.15 percent of GDP, with 1.45 percent going to institutions and 0.69 percent to home care. Public expenditures were 1.85 percent of GDP, and private were 0.29 percent, with almost all of the latter devoted to private expenditures in institutions rather than home care. One possible reason for higher expenditures, according to the OECD, is that both Norway and Sweden offer more single rooms in nursing homes and have comparatively new and better equipped facilities for older people than do other countries. Quality of care measures, such as staff ratios, may also explain some of the variation.

With respect to cost-sharing, the highest fees are paid by people using long-term institutional care. Residents in nursing homes pay a charge of approximately 75 percent to 80 percent of their public pension, and 85 percent of any other forms of income, after taxes. These fees exclude savings and property. On average, residents pay about one-third of the total cost of nursing home care, with low income residents paying less. Residential care is partly funded by public local authorities and partly paid by residents. Out-of-pocket spending across all in-home services is much lower, covering only about 5 percent of the total cost of home care services. Home nursing, both day and night, is free of charge to consumers. Daily home care for hygiene and other personal care is also free of charge, as is respite care. Home help for cleaning and other in-home services is subject to income-related user fees, which the municipality can choose to drop for lower income users; about 60 percent of home health is free to users. Out-of-pocket payment for medical care is limited to NOK 1,550 (about $250) per year.

**Home- and Community-Based Services:** Enabling older people to live independent lives in their homes and communities as long as they wish is a national goal, and in-home services are a core component of Norway’s long-term care system. According to the Norwegian Ministry of Health, 15 percent of people 65 or older
receive home nursing or home help, a proportion that almost doubles (to 29 percent) for people age 80 or older.24 Both medically oriented home nursing and “social care” services are managed and delivered under the same authority (the municipality), and are often integrated into a common organization even though they are regulated under different legislation. Social care services include home care, respite care, help with heavy cleaning, and meals-on-wheels.

Home nursing has undergone considerable expansion in Norway since the early 1990s, and services are increasingly available around the clock. By 1998, over 80 percent of municipalities could provide 24-hour home nursing services. For example, in the city of Trondheim, more people whose needs match a “nursing home level of care” receive the support needed to live in their own homes rather than reside in nursing homes.25 Although both home nursing and home care services are widely available, there are reports that home help services have been cut back in the last few years. The Ministry of Health and Care notes that increasing home help services is currently a goal.

Consumer direction programs are slowly growing in some municipalities.26 Giving cash to families has been a controversial ideological issue, with some arguing that it would lead to greater inequality in payment for services because the wealthy could pay more for services. However, the possibility of implementing a “personal assistance allowance” for people with disabilities along the lines of the Swedish program is being explored.27

Norway has been able to closely integrate primary health and social care because budgets are combined at the level of the municipality. The usefulness of such flexibility and integration is illustrated by a story reported by State Secretary Rigmor Aasrud of the Royal Ministry of Health and Care Services. A municipality in Norway observed a high incidence of hospitalization for falls among older women, with peak occurrence around Christmas. Investigations revealed that many older widows were falling in the process of climbing on chairs to put stars on top of their Christmas trees. In response, the municipality began sending helpers to assist older women living alone in decorating their trees in December. Subsequently, the incidence of falls declined.

Norwegians have a legal right to an assessment of their needs for long-term care by competent authorities every six months. However, “substantive rights to municipal services are limited, as eligibility criteria, service content, and public sector obligation are not clearly specified in law,” according to one Norwegian researcher.28 Municipalities can adjust eligibility criteria, and services vary widely across municipalities.

Informal caregiving: Research has not supported the common view that informal care is declining as a consequence of state provision of formal personal care services.29 Instead, the division of labor has been changing, due to women’s equality in the labor force, with families providing help with laundry, shopping, and trans-
portation, and negotiating with formal service providers. Increasingly, family members are viewed as “care administrators” for older people, giving information and support in arranging for services, and being both partners and “watch dogs” in their relationship with the formal service sector. Services are allocated on the basis of need, not the availability or willingness of families to provide care. However, older adults with frailties who live alone may be evaluated as more “at risk” and receive more formal support.

Financial support for caregivers includes a “care wage,” which was received by about 6,700 caregivers caring for people of all ages with a severe disability in 2002. The wage is not income-tested or taxable; the amount depends on needs, with an average of NOK 4,600 (about $740) per month. Utilization of this benefit is said to be low because caregivers must meet criteria for “extraordinary burdensome care obligations.” As is also the case in the U.S., direct caregiver payments are more heavily used in sparsely populated areas, where formal home care services are less available.

Pension credits are provided automatically to people receiving the care wage; other caregivers must apply every year and provide at least 22 hours of care a week. The value of the credit corresponds to a “below average wage.” Pensions are also provided for former family caregivers who are unmarried and who lost their source of livelihood upon the death or institutionalization of the care receiver. These caregivers had to be out of the workforce for at least five years due to extensive care obligations. Employed caregivers who are nursing a “permanently ill or terminally ill” family member can receive a full wage for a period of up to 20 days leave. Non-financial support for family caregivers can be at least as important as financial support. Non-financial support to caregivers in Norway includes counseling, support groups, and respite care.

**Nursing Home/Residential Care:** Both nursing home and residential care are also the responsibility of municipalities. Residential care is similar in some respects to “assisted living” residences in the U.S., and differs from nursing home care in that no nursing staff are available on the premises. A large number of these special “sheltered” or “supported” housing residences have been built in recent years. They can be rented or owned; most are close to an emergency alarm service and café, and residents can receive publicly funded home help or home nursing services as needed, as if in their own homes.

At the national level, the proportion of people age 67 or older in nursing homes (6.6%) has remained fairly stable in recent years, while the proportion of those in sheltered housing has increased; that is, from 3.3 percent in 1994 to 5.2 percent in 2000. Many surveys have shown that the great majority of nursing home residents would prefer to have private rooms. Roughly 95 percent of residents in nursing homes had private rooms in 2005, a substantial increase since 2000 (78%). Many Norwegian nursing homes also function as short-term accommodation for rehabilitation or respite care, and may also function as day care centers.
Under the National Action Plan for the Elderly (1998-2001), the government allocated substantial funding to build new nursing homes, financing 40-50 percent of the costs. In some communities, all nursing home beds are now either in newly built “health and welfare centers” or in older institutions that have been completely updated. The community of Trondheim offers a good example of a “health and welfare centre” for older people. It includes a small nursing home in which groups of 6-8 patients have their own room and bathroom and share a living room, dining room, and kitchen; independent living flats where older people can “age in place;” and integrated community services, such as home care, day care center, and café. Such centers also serve as resources to older people living in the surrounding neighborhoods, serving as a community center for cultural activities.

Another innovative example is a freestanding home for people with dementia in the community of Eidsvoll. Although no specific staffing ratios are required in Norway, the ratio in Eiswold is 20 full-time equivalent staff for 24 residents. The home, which has waiting lists, is characterized by its homelike atmosphere, large private apartments, and the respectful and caring attitudes of its staff, who encourage residents to engage in as much self-care, including doing everyday household tasks, as possible. The home is affordable to any Norwegian with a minimum pension; people with higher incomes pay about $1,250 per month for rent and food; the “care” component is funded by the municipality.

**Housing Policy:** Consonant with the goals of the earlier National Action Plan, around 25,000 adapted dwellings for older people have been built in recent years, at considerable cost. The Norwegian Housing Bank, the primary implementing agency for government housing policy, also has substantial experience in promoting “lifespan dwellings” in the regular housing market. A new “government plan for universal design” was recently adopted, which will encompass the building sector, outdoor areas, and transportation.

**Quality and Workforce:** Municipalities set quality standards for both primary health care and social care, including LTC. Part of the overall goal of the National Action Plan was to improve the quality of local social and health care services for older people and to help ensure that they had the capacity to keep up with growth in the older population. Existing quality of care as measured by institutional and housing standards and the number of qualified personnel was considered unsatisfactory. The new action plan will now focus on improving both the quality of care and quality of life.

Norway recently implemented a new system of prospective payment for hospital care and, as in the U.S. after the implementation of hospital payment reform some years ago, problems related to the “quicker and sicker” release of patients were reported. The continuity of care between hospital and post-acute settings, such as nursing homes, is also a problem. Part of the new action plan refers to strengthening geriatric care and the relationships among family caregivers and health care per-
sonnel, including hospital staff. Telemedicine is also being used to educate patients with rare and chronic disorders in rural areas, as well as their formal and informal caregivers.

Norway’s LTC workforce receives relatively high wages compared with many other countries, and professional training technically is required for care workers. As with most other developed nations, Norway has a general shortage of certified care workers and has many untrained part-time workers. Nurses and assistant nurses need to be certified, but one report says that untrained personnel are often hired due to shortages.41 Furthermore, staff turnover is higher in urban areas.

Applications for general health care personnel in Norway have been decreasing, and shortages are far greater for people trained in geriatric care. While providers in Oslo reported no shortages of RNs in hospitals, shortages are anticipated in the near future by the Health Ministry. Shortages currently exist for home care aides in both nursing homes and home care. Many health and LTC personnel in Norway work part-time, and the Ministry of Health hopes to dramatically expand the number of full-time positions available. Poor working environments (especially in nursing homes), lack of career paths, and low status complicate the picture. Recruiting more men is one way they are attempting to raise the social status of the position. While no data were available on the extent of staff turnover in nursing homes and home care, providers and others report that the lack of continuity in patient care (with up to 20 different aides coming to a home within a short period) was problematic.42

Immigration rates are low—about 7 percent of the population is foreign-born—but recent legislation has liberalized immigration restrictions.43 The number of legal workers with a non-Norwegian ethnic background in formal care for elderly is increasing, especially in urban areas and among unskilled workers.44 However, according to informal reports, language barriers have prevented many workers from being employed in nursing homes, either as RNs or aides.

The Norwegian Health Ministry mentioned the internationalization of the health care workforce and noted the trend toward “health care without borders.” 30,000 Norwegians live in Spain, for example, and advocate for better access to health and LTC care services in that country.

Issues and Debates:45 The considerable variation among services available in municipalities, especially in the balance between home care and institutional services and political choices in how to allocate funding, is the subject of debate. In addition, as home care services have taken on more responsibilities in the community by serving people with higher levels of disability, concern exists that people with lower levels of need have become ineligible or are receiving inadequate services. According to the OECD, growth in home care has declined recently relative to the number of older people, but there has been growth in provision of 24-hour nursing care and home alarm systems since 1990.
The Norwegian system of budgeting means that funds flow directly to municipalities from the central government, essentially as a block grant. While this permits important flexibility, the downside is that services for older adults can vary substantially from municipality to municipality. In addition, cost shifting occurs between hospital budgets that are financed through national health insurance and municipal budgets for primary health care and social care. This situation appears to be somewhat analogous to the cost-shifting that occurs between Medicare and Medicaid in the U.S. For example, the municipalities are apparently bearing some of the cost of the reductions in the length of stays in hospitals as patients are released more quickly to the community.

Emphasis on cost containment also appears to vary considerably from municipality to municipality. For example, some health care providers (primarily members of the Norwegian Nursing Association) in Oslo indicated that the “right wing” government in Oslo has placed strong emphasis on exposing public services to competition. The goal is for both public and private home care agencies to compete on the basis of price and quality, with the price competition occurring around the delivery of extra home care services paid out-of-pocket. Problems that have reportedly occurred include a shortage of private agencies that wish to enter the market.

Observers have called for more study of the consequences for family caregivers of the increasing proportion of care delivered at home, which has resulted from both the “Action Plan for the Elderly” and the reform of the hospital payment system. Another issue for some family caregivers is inadequate transportation, especially in remote areas.

Organizations such as The Norwegian Pensioner’s Association and The Dementia Federation of the Norwegian Health Association advocate for more support for family caregivers. Recent demonstration projects and innovations are in dementia care (e.g., special units for dementia in sheltered housing, and special respite arrangements for people with dementia). Finally, as in many countries, mental health services for older people appear to be in relatively short supply.

NETHERLANDS

Overview of Long-Term Care: Compared with other European countries, the Netherlands is a relatively “young” country, at the beginning of the rapid aging of its population. Nonetheless, it is preparing for the future by adopting a new national policy for older people. This policy includes: (1) urging healthy lifestyles across the life course, including exercise; (2) making working until age 65 more attractive; (3) providing more opportunities for retirees to contribute actively in their communities; (4) decreasing the number of beds in institutional and residential facilities, with more care provided at home; (5) greatly expanding the number of “no step” homes; (6) making residential districts “aging-proof,” with better public transportation and more accessible public buildings; and (7) ensuring provision of sufficient
and good quality medical care. Recent reforms in the Dutch health insurance program are intended to ensure the affordability of medical care in the future. Other reforms, discussed below, also are occurring in the Dutch LTC insurance program.

The Netherlands, with almost 40 years of experience in providing social LTC insurance benefits, is unique in the scope of the benefits provided, which have been characterized as closer to publicly funded arrangements in Scandinavian countries than those in social insurance programs in other European countries. The Netherlands also is unique in its division of spending between health and LTC, or at least in the way such costs have been grouped. Unlike most other countries, spending under the long-term care program, called the “Exceptional Medical Expenses Act” (AWBZ), comprised a greater share of total health spending (41%) in 2002 than spending in the health insurance program (38%). Private spending, including both private insurance payments and out-of-pocket spending, accounted for the remaining 21 percent.47

As these figures attest, insurance in the Netherlands is divided into “cure” and “care” (health/medical care and long-term care). The “care” component includes “exceptional” or “catastrophic” costs that were considered to be uninsurable in the private sector. These costs include spending not only for what is traditionally considered LTC but also high cost medical care beyond one year; medical care provided in institutional LTC settings, by nursing home doctors, rehabilitation doctors, and some other acute care for chronic conditions.48

LTC, as well as the former health insurance program (ZFW), is provided without a means-test, but premiums and coinsurance are income-related. The social LTC insurance program, initiated in 1967, is mandatory, covering the entire population. In contrast, ZFW, phased out in January 2006, was mandatory only for people below a certain wage threshold, with about 63 percent of the population covered in 2002.50

Residents are universally entitled to LTC regardless of age, nationality, and income. Coverage includes a wide range of institutional, residential, and home care services, such as home nursing, personal care, homemaking, day care, respite care, assistive devices, and night care. Income-related payments are made by nursing home residents for the costs of “room and board”; personal care and home help services are also income-related, up to a maximum of 124 euros per week. Nursing homes and providers of institutional care, as well as home care providers, are predominantly private nonprofit organizations.

A new Health Insurance Act, which came into effect on January 1, 2006, ended the difference between compulsory national health insurance for lower income people and voluntary private health insurance for others. Now, every person in the Netherlands must be insured at roughly the same cost for roughly the same standard package of medical coverage defined by law. Insurers compete with each other based on a package of benefits, deductibles, premiums and provider networks, but
premiums cannot vary for age or health status for the same insurance policy. Insurance companies are not permitted to refuse anyone who applies for the standard package, regardless of age or health condition. While this legal obligation does not apply to supplementary insurance, in practice, virtually all health care insurers have accepted anyone applying for supplementary insurance, regardless of their health condition. According to Mrs. Clémence Ross-van Dorp, State Secretary for Health, Welfare and Sport, this change has benefited people with chronic illnesses and older people because some of them previously could not have obtained supplementary insurance.\textsuperscript{51}

Reforms are also occurring in the long-term care program (AWBZ), which had expanded so much it was in danger of becoming unaffordable. Reforms beginning in 2003 have moved the program toward more consumer-directed care, including the choice of a cash option for LTC services in lieu of formal services. In addition, more responsibility has been shifted to local governments. A new act, the Social Support Act of 2006, will encompass those portions of the AWBZ program related to domestic help and supportive counseling with independent living.\textsuperscript{52} This transfer will come into force in January 2007, if passed by the Upper House of Parliament at the end of June 2006. Services under this act will now be provided by municipalities.\textsuperscript{53}

**Financing:** The LTC program (AWBZ) is financed primarily by a payroll tax (13.45\% in 2005) up to a wage threshold, with no employer contribution; those who are not in paid employment and are liable for income tax receive tax assessments for their contributions.\textsuperscript{54} While this amount seems very high by international standards, it is important to remember that it includes a substantial proportion of spending for medical care.

Although it is an insurance program, for many years the AWBZ was not an open-ended entitlement. There were substantial waiting lists for services until a court decision ruled that waiting lists are inconsistent with insurance principles and ordered the AWBZ to operate as an open-ended entitlement since 2001.\textsuperscript{55} With the most recent reforms in 2006, the national government will continue to provide intensive long-term care, including care for people with dementia, which continues to be considered an uninsurable risk, under the AWBZ. However, responsibility for providing domestic help and some other forms of social welfare assistance will be transferred to the municipalities, where such services will not be an entitlement.\textsuperscript{56}

**Home- and Community-Based Services:** A wide range of home- and community-based services are available, including day centers and night care. Professional, interdisciplinary assessment teams determine eligibility for both home care and services in nursing homes and residential care through a single point-of-entry system. These teams have considerable discretion, and the availability of informal care is taken into account.\textsuperscript{57} The assessment process, formerly conducted by about 70 assessment boards, was to be centralized into about 16 regional offices in 2005.\textsuperscript{58} If informal caregivers are present, home care services are generally restricted to washing,
bathing, and dressing the care receiver and performing heavy household tasks. Other domestic tasks, such as running errands, preparing meals, and doing laundry are generally left to informal caregivers. Help with domestic tasks is available to those without informal caregivers, or if there is a serious risk of institutionalization due to caregiver burden.59

**Consumer Direction:** For home care, individuals currently can choose between receiving services from an agency or consumer-directed care, called “personal budgets,” with an allocated amount of money; they can also choose a combination of cash and services. Formerly, these budgets were confined to purchasing AWBZ-covered services, expenditures were monitored closely, and they represented only a small share of total home care expenditures, about 10 percent in 2002.60 Following reform in 2003, all home care users are now offered the option of services from agencies, directly employing a care assistant, or using cash to pay a relative, including spouses and parents, to provide care.61

The use of personal budgets has been growing rapidly, with over 90,000 recipients in 2006, and growth of between 10,000 and 20,000 people a year.62 Budgets are reduced by about 25 percent from agency prices, an “efficiency discount” because of lack of overhead.63 Although most individuals receive far less, personal budgets for home and nursing care have a ceiling that roughly represents the upper limit of the cost of nursing home care. On average, the budgets are about £12,000 (about $15,350) annually, but amounts vary widely, and can reach roughly £100,000 (about $128,000) in very rare instances when recipients need intensive support.64 People age 55 or older represent about 35 percent of budget holders; those ages 20-55 about 55 percent, and youth about 20 percent. Roughly 40 percent of budget holders hire family members and neighbors; the other 60 percent hire formal providers. Reportedly, not many new home care providers are entering the market. To date, the expansion in consumer-directed services has been driven largely by consumer demand. However, waiting lists for agency home care services are now appearing, so about 10 percent of providers are urging people to get a budget in lieu of services.65

**Informal Caregiving (other than direct payments):** Several provisions in Dutch labor policy are designed to enable employees to provide caregiving assistance without significant financial hardship. Employed caregivers (child, partner, or parent) can receive emergency leave, such as for sudden family illness; and 10 days care leave per year at 70 percent of their pay with the government reimbursing employers. In addition, caregivers can also take unpaid leave (usually between 2-6 months), if the employer agrees; this leave can only be paid (up to a maximum amount) if the caregiver is replaced with someone who is unemployed.66 Respite care is available for “weekend breaks.” Other forms of respite are available in institutional settings, at home, or at day centers.67
Nursing Home/Residential Care: About 2.4 percent of Dutch older adults are in skilled nursing homes, according to OECD statistics, and about 5 percent in residential homes. The proportion of nursing home residents with private rooms (22%) is far lower than in Norway, and roughly one-third of residents are in rooms with four beds.

Humanitas, a nonprofit foundation, has had a long tradition of providing housing with supportive services in innovative environments. Today, it serves roughly 4,000 older clients, primarily in what are termed “apartments for life.” These large three-room apartments incorporate accessible features designed to promote independent living by residents and are no more costly than nursing home care. According to Dr. H.M. Becker, CEO of Humanitas, the primary goal is the happiness of residents. He suggested that substantial savings in medical care are possible if residents are happy and actively engaged since they may then experience lower pain thresholds.

The Humanitas philosophy is to mix healthy residents with those who would otherwise be in nursing homes, and the rich with the poor. Its central goal is to promote independent living, with as much as possible being done by residents rather than staff, and self-determination, with residents determining their own schedules and activities. At the original Humanitas building in Rotterdam, the common areas are filled with light and pleasing aromas and are bustling with activity; they include a vibrant café, Internet area, music and singing, pet therapy, and “attic” with rooms of antiques in which residents can reminisce and share their earlier experiences with friends and family. The medical, nursing rehabilitation offices are intentionally “hidden” behind the supermarket and beauty parlor.

Housing Policy: Initiatives to build new universally designed and accessible housing, as well as to adapt existing housing, are underway. “Clustered” housing, in which dwellings are clustered around courtyards, is a long tradition in the Netherlands and is often preferred by older people because it facilitates social interaction. Clustered housing has also been created for older people in some ethnic minorities, such as the Chinese community in Rotterdam and the Surinamese Hindus in The Hague. If residents do not want to arrange for their own home care or need a higher level of service, they often move to sheltered housing. “Sheltered housing zones,” with specially adapted independent homes integrated into neighborhoods but still fairly close to each other, have also been piloted. The Ministries of Health, Welfare, and Sport and of Housing Spatial Planning and the Environment have also been examining new ways of combining housing and LTC services.

Quality and Workforce: According to some observers, the quality of home care is not perceived to be a major problem, and home care agencies must meet regulatory requirements. No training is required for “independent providers” hired by consumers who hold personal budgets, except for those providing skilled care.
The Netherlands has a relatively low female labor force participation rate compared to many other countries in Europe. Immigrants have not been a major part of the LTC workforce, although some immigrants from former colonies (Suriname and Indonesia) play a role, especially in the bigger cities. Independent providers are legally entitled to a number of fringe benefits beyond what is typical in the U.S., including health and disability insurance.\textsuperscript{73} Although care workers are overwhelmingly part-time, their earnings are reportedly comparable to the national average and they are in a relatively strong economic position. Many Dutch care workers, for both home care and institutional care, are unionized. Unions representing care workers play a strong economic role on behalf of the entire sector, not just their members; collective bargaining agreements are applied to all care workers, whether or not they are union members.\textsuperscript{74}

General shortages of long-term care workers, especially for agency home care workers, persist. These shortages have meant there are waiting lists for both institutional care and home care service, leading more people to opt for the personal budgets, which have functioned as a type of “escape valve.”

**Issues and Debates:** The decentralization of responsibility of authority for social care services from the national government to local government under the new Social Support Act of 2006 is controversial. According to one report, compared to the former AWBZ, the changes resulted in: weakening the entitlement to services; differential access to services because of greater autonomy for local governments in the use of funds; higher copayments for consumers; and less regulation of the quality of care.\textsuperscript{75}

Now, much stricter control and assessment for social care services are being conducted by new assessment entities, which are trying to decrease rates of institutional care. Experts in informal caregiving report that reform of LTC insurance may lead to higher beneficiary payments, and more difficulties getting domestic help and perhaps respite care, although the impact is not yet clear.\textsuperscript{76} Similarly, concerns have been expressed by Per Saldo, the organization representing “budget holders,” that the new Social Support Act will have a negative impact on access to, and possibly the amount of, personal care budgets.

Some advocacy organizations and family caregivers have raised concerns that, in practice, assessments for formal services take for granted that family caregivers will make significant contributions to caregiving. According to a survey of informal caregivers whose care is supplemented by formal help, about 43 percent of caregivers think the formal help provided is insufficient.\textsuperscript{77} Consumer groups and providers have also pushed to raise the amount of personal budgets by eliminating the “efficiency discount” in the budgets.
UNITED KINGDOM

Overview of LTC: In all parts of the UK, the National Health Service covers nursing care in the community and in nursing homes at no cost to beneficiaries and on a non-means-tested basis. However, non-medical LTC, called “social care” is furnished by localities on a means-tested basis, with substantial variation among local authorities. The exception is Scotland, where “free” personal care is provided in the homes of those who are assessed as needing it. Local governments are responsible for coordinating LTC care and providing assessment and care management. Services are provided by the public sector or by the private sector under contract to local governments. Funding is primarily from general taxation, partly through the central government and partly from local taxation. Recent legislation has required local governments to offer cash alternatives to services, called “Direct Payments,” in order to increase consumer choice and control. Another recent policy change is the development of more short-stay, post-acute care homes with rehabilitative services for older people occupying acute hospital care beds who could be treated in alternative facilities. 78

The UK has adopted national legislation that formally acknowledges the need to support family caregivers. Legislation in England and Wales also gives caregivers the right to an assessment of their own needs; local councils have discretion in authorizing services for caregivers. Caregivers providing intensive family care with limited income can receive a cash benefit known as the Carers’ Allowance.

With rising demand for well-trained workers and a falling supply, LTC workforce issues are becoming a focus of policy attention. As in other countries, most LTC workers are women, and a substantial share of workers (around 50%) work part-time. 79 Reliance on immigration to address workforce needs is high. The UK is one of the largest importers of professional health care workers in the world, with a large proportion working in the LTC system, especially as nurses. 80 Both recruitment and retention are especially difficult in LTC, because of such factors as low wages, lack of career pathways and training, and competition from the health care and education sectors. 81

Issues and Debates: Considerable policy debate about reforming the UK’s system of providing LTC has been occurring in recent years. A Royal Commission report in 1999 recommended that both nursing care and personal care, for both institutional and home-based services, be covered by general taxation, as is done in the National Health System. 82 Recently, the prestigious Joseph Rowntree Foundation issued a paper arguing that the present LTC funding system is simply not working, and called for national reform based on six core principles. 83 According to these principles, the system should: (1) be fair and be seen to be fair in the way the money is raised and allocated; (2) support preventive measures, encouraging early intervention; (3) recognize the diversity of needs and allow care recipients to retain
their dignity; (4) promote personal and family responsibility; (5) be sustainable; and (6) encourage an efficient supply response, through adequate resources for the range of care needed.84

A major report by the King’s Fund on funding for social care has also just been issued.85 This review, led by Sir Derek Wanless, seeks to determine how much should be spent on social care for older people in England over the next 20 years and how that care should be funded in order to support high-quality outcomes. The analysis is based on a financing model that yielded cost projections of specific approaches for different “benchmark” packages of social care services.

FRANCE

Overview of LTC: France’s system for financing LTC is a “hybrid.” Institutional care is provided through its health insurance program; people with low income receive home care benefits through retirement programs.86 An independence allowance, or “autonomy pension,” provides cash payments to be used for LTC services for people age 60 and older. This benefit covers everyone. However, benefits are based on a steep sliding scale, with the highest income beneficiaries, defined as those with income of ?2,483 (about $3,180) per month receiving only 10 percent of the maximum benefit for their disability level.87 Minimum eligibility criteria are strict (i.e., the need for assistance with three or more activities of daily living). A maximum benefit is set for each of four disability levels. This allowance is jointly funded by the central government and regional governments, resulting in regional variations in the amounts available.

The hours of care provided by family members are taken into account in assessing needs for the independence allowance, with more assistance allocated to those who do not live with family members.88 Under French civil law, children are obliged to take care of their parents, and children must report their income to the “Aide social” when a parent applies for social assistance.89 Home care services are provided by private, nonprofit associations and by municipalities. Access to home care services, either for personal care or home help, is not a legal right, although access to the “autonomy pension” is.

Issues and Debates: Sporadic political debate on setting up a LTC system analogous to Germany’s has occurred for some years. However, steadily growing deficits in the national health insurance system, which have led to calls for its reform, along with increasing unemployment, make improved coverage for LTC unlikely in the near term.90 Following the deaths of 15,000 older people during the heat wave of August 2003, the government has been focusing attention on preventive measures. For example, a government inspection called for major renovations of residential care institutions. All homes for older adults were required to have a room with air-conditioning by June 2004, although potential funding sources for this improvement reportedly were not identified.91
The opportunity to interact directly with Norwegian and Dutch residents, from highly placed political leaders to research experts to taxi drivers, helps to place data and analysis in cross-cultural context. Hence this section includes qualitative—and inevitably subjective—observations.

The concept of “solidarity” emerged repeatedly during the Leadership study. While lacking a precise definition in the U.S. context, it comprises beliefs in community values and social cohesion, intergenerational reciprocity, and a sense of responsibility for one’s fellow citizens and those who are less fortunate. This concept, which underpins both social health insurance and social welfare systems in Western Europe, is of central importance in describing the commitment of politicians as well as the general public to core policy values at the national level as well as at the European Union. In the area of health care, solidarity has been characterized as putting “flesh on the belief” that all individuals should be treated equally, reflecting normative values from the dominant Christian religions (both Catholic and Protestant.)

Solidarity does not necessarily mean uniformity or lack of individual choice. Instead, solidarity has been described as a community of individuals who obtain their freedom through the social group, making mutual relationships a precondition for individual freedom. Indeed, site visits suggested that LTC policy in both
Norway and the Netherlands strongly encourages individual choice and autonomy, as well as individuals' quality of life (more concretely expressed in the Netherlands as “happiness”).

The “sustainability” of European health and LTC policies in the face of aging populations was also the subject of much discussion. What was most striking is that we did not hear frequent comments about the “age crisis” or the “aging problem” as we do in the U.S., despite the much older age structure of most European countries. Instead, in both the Netherlands and Norway, politicians from diverse political persuasions have engaged in systematic long-range planning for LTC needs, as well as for other needs for aging populations, by adopting and implementing national action plans for the aging. As Dutch policy makers emphasize, it takes a “yes” culture to plan well.

While the commitment to substantial public financing of both health and LTC remains strong, a number of nations are encouraging greater competition and private sector involvement in the delivery of care. For example, efforts to “level the playing field” for private (both nonprofit and for-profit) and publicly owned entities in the delivery of care is reportedly a cross-national trend. In addition, since social spending cannot be easily increased in the future, many countries will be devoting much greater attention to the careful targeting of expenditures (e.g., toward priority services such as respite services for family caregivers).

**MORE SPECIFIC LESSONS FOR LTC POLICY:**

This brief review of the LTC policies of several European countries illustrates different paths to potential LTC reform in the U.S. In the financing arena, a growing number of countries are providing universal coverage for LTC in an effort to insure people of all income levels and their families against the risk of catastrophic LTC expenses. A social insurance approach to LTC financing, such as that in the Netherlands, seems more consonant with the history of U.S. social policy than one through general taxation, as is found in the Scandinavian countries.

The difficulties in drawing sharp boundaries between health care and LTC or “social care” were apparent in policy and practice during the study visits. The lack of universal health care in the U.S. further complicates efforts to coordinate these services, particularly for people under age 65 with chronic conditions. Personal care services, which include hands-on assistance with such intimate daily activities as bathing and dressing, sit at the center of the great divide between health and LTC. Coverage for these services can fall within health insurance programs in some European countries, and can facilitate the closer integration and delivery of coordinated chronic health care and long-term services. (Domestic help and assistance with other daily activities, including shopping and transportation, are more commonly covered under separate LTC legislation and disability policy.) Hence one important issue for potential health care reform in the U.S. is how to incorporate coverage for those services most closely related to home nursing care. A larger les-
son is that efforts to reform our nation's health care system should use a broad definition of health and health services that includes long-term supportive services that can help to prevent the need for costly medical care (e.g., through the prevention of falls and unnecessary hospitalizations). In addition, unless both health and LTC reforms are discussed simultaneously, the pervasive cost-shifting that characterizes current Medicare and Medicaid policy will persist.

When viewed through the traditional health policy lens of “access, affordability, and quality,” several general impressions emerge. The principal difference between the U.S. and many European countries seems to be in access to basic LTC services in both institutional and home settings by everyone who needs them, regardless of income. In contrast, high levels of unmet need among people with disabilities for essential personal assistance services have been well documented in the U.S. In the European countries visited, the uncertainty and confusion about both health and LTC coverage that one hears in everyday conversations in the U.S. was not apparent. Instead, confidence among the general population that basic health and long-term care services would be available to themselves or their relatives, if needed, seemed high.

On the less positive side, both Norway and the Netherlands seem to be struggling with an imbalance between institutional care and home care and are trying to reduce the number of nursing home beds. Concerns about the quality of care were also mentioned, such as rocky transitions between hospitals and long-term care settings and the lack of physician involvement in nursing homes. Shortages of geriatric personnel, including both physicians and nurses, are a major cross-national problem, as is the inadequate supply of an appropriately trained direct care LTC workforce, including nursing home and home care aides. Both countries are relying more on workers from other countries.

The “open health borders” of the EU are encouraging increased migration of workers, some of whom work in LTC settings. In addition, large numbers of both Norwegian and Dutch retirees are resettling in Spain, and demanding better health and LTC services—a harbinger of the globalization of retirement and health-related policies.

Another major issue pertinent to the U.S. debate is the decentralization of some responsibility for LTC from the central government to the municipal level, which is occurring in both Norway and the Netherlands. This decentralization is intended to empower local citizens and decision makers to allocate funding toward services and other forms of support that best meet their needs. However, as in the U.S., such flexibility is also criticized as resulting in unwarranted variations in access to services, as well as disputes between higher and lower cost areas with respect to funding formulas.
Consumer-directed home care is slowly becoming an international policy trend. For example, consumer-directed payments in the Netherlands have offered beneficiaries more flexibility in selecting services that fit their own individual needs, a choice many have been willing to make even though the monetary value of the benefits is substantially discounted in comparison with formal services. Many beneficiaries reportedly use the cash to pay family members’ caregivers. Consistent with research on cash benefits in Europe, recent results from the U.S. Cash and Counseling program have demonstrated that people with disabilities and their families are more satisfied with the services provided.96 Offering options for cash payments, however, has not obviated the need for expanding formal services options, especially those in the home and those that complement and support the involvement of family caregivers.

The Norwegian experience in particular provides a window through which to examine attitudes that underlie important LTC policy decisions—but which are often not openly discussed in the U.S. policy debate. These attitudes involve expectations about what family responsibilities for LTC “should” be, both today and in the future. This issue involves attitudes toward the role of women in the labor force, since women continue to provide the bulk of family care. Even in Scandinavian countries, family support of older people remains strong, although the nature of the care provided is changing, with families providing less heavy personal care and more assistance in other areas, such as shopping, transportation, and service coordination. According to a major EU-funded study on care for older people, “carers” hold a major if not the key to sustainable health and LTC services.97 In addition to the need to provide practical, financial and emotional help to caregivers, measures to help individuals combine caring responsibilities with paid employment must be expanded if efforts to support a longer working life are to be successful. Norway may provide a model for encouraging workforce participation by women while supporting family carers.

Both Norway and the Netherlands have long been leaders in innovative housing design and the integration of housing with supportive services. For example, small homelike living environments for people with dementia, integrated into communities in both Norway and the Netherlands, hold implications for U.S. policy. While examples of such residences exist in the U.S. as well, and are expanding through the Greenhouse and assisted living movements, these European residences both encourage residents’ dignity and autonomy and are affordable to people at all income levels.
Many critical questions will need to be answered if the U.S. is to build a more rational long-term care system during its demographic “window of opportunity,” roughly the next two decades before the boomers begin reaching age 80 and older. These include:

- Who should pay for long-term care—informal caregivers who work for free, the people receiving the care, or the entire population through insurance or taxation? The easy answer is all three; the hard answer is the specific division of responsibility among the three.

- How will care be financed—private savings or insurance, social insurance contributions, general taxation, or in what combination?

- Who will provide care in the face of workforce shortages and increasing demands on family caregivers?

- What is the right balance between institutional care and home care?

The U.S., of course, is not likely to “import” any other nation’s system of health or LTC care. Issues uniquely affecting policy in this country include: our nation’s federal-state jurisdictional responsibilities; its cultural diversity; and its labor market and provider structures. However, examining the experiences of other countries is a major and underused policy tool for testing ideas and approaches that might be adapted to the American context.
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