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Comparing Long-Term Care in Germany and the United States: What Can We Learn from Each Other?

by

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A Note on Currencies

Throughout this report, monetary values are reported in the most appropriate denomination (euros for Germany, dollars for the United States). With some key comparisons, we report the value in both currencies. In this report, the exchange rate used for conversion is 1.4295 dollars to the euro, as reported in the Friday, October 19, 2007 edition of the Wall Street Journal.

Executive Summary

Background

With its much "older" population, Germany's experience in sustaining its long-term care $(LTC)^1$ system over the last 12 years reveals important lessons for the current policy debate in the United States. In the early 1990s, Germany and the United States faced similar issues related to their LTC systems:

- growing demand for supportive services related to the aging of the population and projected increases for the coming decades;
- increasing costs that individuals largely paid out-of-pocket;
- a welfare-based public safety net that paid for LTC services only after individuals had exhausted their own resources;
- a federal system that placed much of the responsibility for funding and regulating LTC with state governments; and
- reports of quality problems.

Since the mid-1990s, public policies related to LTC financing in the United States and Germany have diverged. In 1995, Germany began implementing a federal social insurance program that provides long-term care coverage for nearly all of its population. During the same period, much of the policy focus in the United States centered on promoting the purchase of private long-term care insurance. Both countries have encouraged more consumer choice in services and more home and community-based service options – through incremental changes in the U.S. social assistance program for low income persons and as a feature of Germany's universal program for LTC. Both countries are also concerned about the need to improve quality in all LTC settings.

In September 2007, the government coalition parties in Germany introduced legislation to implement major reforms to the program. These reforms would improve benefits, especially for home and community-based services, and take new steps to encourage rehabilitation and prevention. Another key objective is to help ensure the financial sustainability of the system, for example, through a small increase in contributions (0.25 percent of income).

Purpose

The primary purpose of this report is to examine developments in the LTC systems in Germany and the United States to understand their impact on:

- financing and coverage,
- consumer options and choice,

- family caregivers,
- the LTC workforce, and
- the quality of services.

It also provides a brief overview of LTC reform proposals in both Germany and the United States.

Methods

Information for this report was collected from multiple sources, including published and unpublished literature from journals, government documents, and websites. The German Ministry of Health facilitated the authors' access to current documents on proposed German LTC reforms, assisted with translation, and provided comments on the report. Long-term care experts in the United States also provided peer review for the report.

To help ensure comparability, data in the report are from international sources whenever possible. International data sources included data from the European Union, the Organisation for Economic Co-operation and Development (OECD), and the United Nations. Other data analyzed for the report came from official country sources, including LTC time series data from the German Ministry of Health.

Principal Findings

Financing

Germany spends roughly the same share of its GDP on LTC (1.44 percent in 2005) as the United States does (1.37 percent), according to OECD data. However, its system provides a mix of public and private financing that does not require individuals to become impoverished to receive LTC services, and has not led to exorbitant costs to taxpayers. Moreover, Germany spends less of its gross domestic product (GDP) on institutional care (0.80 percent of GDP versus 0.98 of GDP percent in the United States) and more on home care (0.64 percent versus 0.39 percent in the United States).

Public spending on LTC is somewhat higher in Germany than it is in the United States (1.09 percent of GDP in 2005 versus 0.90 percent in the United States), but the most dramatic difference is in the type of public spending. In the United States, Medicaid, a means-tested social assistance program, is the primary source of public funding. In Germany, a universal insurance program for persons of all ages provides LTC benefits based on need for assistance with essential activities of daily living (ADLs), not income.

Publicly funded LTC benefits in Germany are basic, not comprehensive, leaving a role for individual contributions (such as for "room and board" costs of nursing home care) and for private LTC insurance. The government has contained LTC spending since the program was implemented, due in part to caps on benefits, which cannot exceed fixed amounts.

Germany's (welfare) program remains in place as an important "safety net" for low-income individuals. However, expenditures by the social assistance program for nursing home care have been reduced by roughly two-thirds since introduction of the social insurance program.

In the United States, Medicaid LTC beneficiaries can be vulnerable to budget reductions as federal and state governments respond to economic conditions and pressures to reduce public spending. In recent years, some states have targeted cost-cutting measures on Medicaid LTC spending, which represented 31.5 percent of Medicaid's total spending in 2005.

Consumer Options and Choice

Eligibility and benefits for LTC services in Germany can be explained relatively simply to consumers, while the U.S. LTC system's complexity and fragmentation can frustrate even the most knowledgeable professionals. Germany's system for determining eligibility is simpler both because it is not means-tested and because it has clear, nationally uniform criteria for each level of care. The fact that all assessments for services are conducted in individuals' homes is another plus.

In contrast to the United States, everyone in Germany who meets the relatively strict functional eligibility criteria has a choice of benefits in the settings they believe will best meet their needs, in their homes or in institutions. They also have a choice of home care benefits as a cash allowance, formal services, or a combination of cash and formal services. However, in both countries, eligibility criteria for services often do not adequately capture the needs of persons with cognitive and mental impairments.

The trend in the United States is toward increasing home and community-based services and assisted living, with declining use of nursing homes. In Germany, the use of institutional care has been growing modestly. Assisted living has been one of the most rapidly growing forms of LTC in the United States, but Germany has no directly comparable licensing category and no reimbursements to encourage such arrangements. More flexibility in integrating services into housing is an important issue in both countries.

Family Caregiving

In both countries, families are the primary caregivers for older persons with disabilities. However, German family caregivers can enlist more formal support from services ranging from training to respite. Such professional support has been shown to reduce "burnout" among family caregivers and may be critical to maintaining high levels of family support in the future.

Encouraging family support was one of the key objectives of Germany's social LTC insurance program. Today, 90 percent of persons in need of care receive informal support, a slight increase since introduction of the program. Caregiver supports are more generous than those currently available the United States, for example, up to four weeks of respite per year and pension (social security) credits to assist eligible caregivers with their future retirement security. In both countries, only relatively small numbers of caregivers use the available supportive services, making improvements in outreach and more "user-friendly" information and referral services imperative.

Substantial proportions of family caregivers of working age are in the labor force in both countries, and the proportion of women in the labor force in their mid-40s through their 50s is quite similar. It is predominantly women in these age groups who simultaneously provide family care and try to advance their careers, or at least hold onto their jobs, in the face of competing priorities. In both Germany and the United States, expert opinions vary concerning the extent to which patterns of family caregiving may change in the future.

Workforce

Both Germany and the United States are facing major labor force shortages in meeting future demand for LTC services. While the current supply of workers is seen as adequate in Germany, the long-term outlook may be more challenging there because of the decline in the working-age population.

In both countries, women provide the overwhelming majority of caregiving, both professional and informal. As other career opportunities open for women, recruiting LTC workers may be increasingly challenging.

Both countries have seen growth in recent years in the number of foreign-born workers providing LTC services, with some working in the gray economy where they do not pay taxes or receive benefits. The incentives to hire such workers may be fewer in Germany, where agency-provided home care is an option for LTC beneficiaries. European integration is also regularizing the flow of workers from the new member states that provide many of Germany's foreign workers.

Germany has created a special credential of "elder care" for nurses in the LTC sector, while nursing degrees in the United States are not specific to LTC. The German approach provides much more specialized training in caring for older persons than is done in the United States, but this degree does not allow mobility into higher-wage jobs in the acute health care sector.

LTC work in both the United States and Germany is characterized by lower pay and lower prestige than work in other health care sectors. In the United States especially, these characteristics have contributed to very high turnover rates and poor morale among professional caregivers.

Quality

The federal systems of Germany and the United States divide responsibility for regulating and enforcing quality between federal and state governments. Both countries have moved toward more national uniformity in standards, although Germany still has divided responsibilities between the Länder and the LTC insurance funds with respect to nursing homes. The United States has federal regulations for nursing homes but state regulations for assisted living and other supportive housing.

Some say regulations in both countries are too focused on structural and process aspects of LTC and evidence too little concern with quality outcomes. The United States has funded research and demonstrations related to measuring and reporting quality outcomes.

Neither country generally makes adjustments in payments to reward high quality or to reduce payments for low quality. The United States is experimenting with demonstrations for value-based purchasing or pay-for-performance.

Both countries have some regulatory barriers to quality and price competition. A larger private-pay sector in the United States, especially in assisted living, may promote innovation in services, but these services remain out of reach for many low-income older people. Germany has taken steps recently to promote more competition among profit-motivated providers.

The "culture change" movement is a private sector response to consumer demand that is beginning to develop different models of service in the United States.

Conclusions: Implications for the United States and Other Countries

The German social insurance approach to LTC financing has successfully addressed a number of problems by:

- Providing universal access to services based on level of disability, not level of income;
- Promoting consumer choice in types of services and settings;
- Providing more support to family caregivers who are the backbone of caregiving for older people with disabilities;
- Relieving fiscal pressures on state (Land) governments, while maintaining overall spending on LTC at levels comparable to the U.S. and other OECD countries; and
- Developing more uniform standards of quality throughout the country.

Both Germany and the U.S. have labor forces that are aging. Keeping both informal caregivers and other older workers in the labor force longer will likely be essential to the health of the economies in both nations. Better support for family caregivers may well hold the key to sustainable health and LTC services. "Mixed care" arrangements, combining both informal and formal LTC services, may also serve as an important model for the future in both countries.

The increasing diversity of LTC services, LTC settings, LTC clients, and LTC workers all increase the challenges of assuring high quality in both Germany and the U.S.

In addition, neither country will be able to meet the future demand for services without recruiting and retaining more professional and paraprofessional workers. Low wages, low prestige, and dangerous working conditions will have to improve to expand the pool of workers willing to do the difficult tasks associated with long-term care. Both countries are likely to rely increasingly on foreign-born workers to provide care.

Germany's social LTCI program was implemented with surprisingly few difficulties, and continues to maintain broad popular and political support more than a decade since implementation. To date, only relatively minor changes in contributions and benefits have been implemented. However, ongoing discussion among German political parties and periodic adjustments, including the upcoming major reforms, reflect a pragmatic approach. These reforms are intended to address many of problems that have been identified, including the financial sustainability of the system and the decreasing purchasing power of LTCI benefits to consumers due to the lack of indexation of the benefits.

In the U.S., the debate about LTC reform still remains at the periphery of public policy discussions at the federal level. However, as in Germany over a decade ago, concerns are growing in the U.S. that the Medicaid safety net will be under increasing pressure with demographic changes and increasing demands on state budgets. Even today, many Americans with disabilities experience unmet needs for assistance with the most essential of daily activities.

In the U.S., the basic foundation of universal health and LTC benefits is still to be built. Americans of all ages and of all incomes are still faced with the risk of catastrophic out-ofpocket expenditures for both health and LTC. Over 47 million Americans have no health insurance, and the vast majority have no insurance at all for LTC. Moreover, those who do have access to benefits are vulnerable to the loss of job-related health benefits. Even safety net services through Medicaid for health and LTC are vulnerable to cuts when the federal government and states respond to fiscal pressures. This lack of security in the U.S. is perhaps the most striking difference between the two countries.

Introduction and Purpose

In the early 1990s, Germany and the United States faced similar issues related to their long-term care (LTC) systems:

- growing demand for supportive services related to the aging of the population and projected increases for the coming decades;
- increasing costs that individuals largely paid out-of-pocket;
- a welfare-based public safety net that paid for LTC services only after individuals had exhausted their own resources;
- a federal system that placed much of the responsibility for funding and regulating LTC with state governments; and
- reports of quality problems and pressure from consumer advocates for both expanded public coverage of LTC costs and increased consumer choice and control over the types of services received.

Since the mid-1990s, public policies related to LTC financing in the United States and Germany have diverged. In 1995, Germany began implementing a federal social insurance program that provides long-term care coverage for nearly all of its population. During the same period, much of the policy focus in the United States centered on promoting the purchase of private long-term care insurance. Both countries have encouraged more consumer choice in services and more home and community-based service options – through incremental changes in the U.S. social assistance program for low income persons and as a feature of Germany's universal program for LTC. Both countries are also concerned about the need to improve quality in all LTC settings.

The purpose of this report is to examine developments in the long-term care systems in Germany and the United States to understand their impact on:

- financing and coverage,
- consumer options and choice,
- family caregivers,
- the LTC workforce, and
- the quality of services.

Background

The aging of the populations in both Germany and the United States has increased the importance of LTC as a public policy issue. In part due to the United States' unique position as the only developed country lacking a universal health care system, health policy rather than LTC policy usually dominates social policy discussions. Hence, LTC policy in the United States has been characterized as "always the bridesmaid, never the bride" (Health Care Financing and Organization [HCFO], 2003). Nonetheless, the increased attention to health care reform in recent years is also opening the door for more serious discussions of LTC reform proposals at both federal and state levels. Many public opinion leaders, including members of Congress, state legislatures, and the media, have experienced personal LTC crises and are looking for better solutions.

With one of the oldest populations in Europe, Germany has had a much higher proportion of persons age 80 older for some time than has the United States, and its policy discussions are dominated by concerns with meeting the demands of an aging population. After almost 12 years of experience with this program, Germany is expected to make substantial changes to its social long-term care insurance (LTCI) program largely in response to demographic trends For the last several years, the federal government, the Länder (states), the major political parties, and LTC experts have been examining a host of potential changes to improve benefits for beneficiaries and to ensure the system's long-term sustainability. We discuss these potential reforms in more depth later in this paper.

Historical and Comparative Context

Germany and the United States share a number of important similarities relevant to the development of LTC policy:

Federal/state systems of government: States play key roles in regulating and financing LTC services in both countries. Among the key drivers of reform in Germany were the states (Länder), which were faced with rising LTC costs in their social assistance programs. States also drive much of the discussion in the United States, where state-based Medicaid programs are the primary source of LTC financing.

A contributory approach to financing social insurance: The "Bismarckian model," the basis for Germany's social insurance approach, served as the model for the U.S. Social Security system. This contributory approach seems more consonant with U.S. history and experience than those of a number of other European countries, such as in Scandinavia, which rely on general taxation to provide universal social protection.

A social market economy: Germany's system combines elements of a market economy with regulations, along with social insurance to protect against risks that are considered too much for individuals and families to assume alone. Germany has been characterized as one of the more "conservative" social welfare states in its efforts to balance a comprehensive system of social protections with the need to encourage personal responsibility. The tension between these two goals also underlies much of the debate in the United States about both health and LTC reform.

A private sector-based delivery system: In both countries, almost all long-term care services are provided privately rather than by government agencies. In addition, Germany and the United States both have strong traditions of charitable, nonprofit service provision. For-profit service provision is more common among nursing homes and assisted living in the United States, although this sector has been growing in recent years in Germany.

Share of GDP spent on LTC: Both countries spend about the same proportion of their GDP on long-term care—1.44 percent in Germany compared to 1.37 percent in the United States in 2005.

Despite these similarities, many differences—demographic, historical, cultural, political, and socioeconomic—also exist between the two countries, and it is not possible to simply transplant any nation's structure onto another's. In particular, Germany has a universal health care system, upon which its LTC system was built. This fundamental difference has implications for almost all aspects of LTC, particularly for financing and quality of care.

After more than 20 years of debate, Germany enacted its current social insurance LTC system in 1994 to complement its existing health insurance, pension, unemployed, and accident insurance systems (Harrington, Geraedts, and Heller, 2002). As in the current U.S. debate, a number of different models of LTCI reform were under discussion before Germany implemented its current system, including: (1) improving means-tested services under the Federal Social Assistance Act; (2) financing LTC through general taxation; (3) establishing a private LTCI system, either mandatory or voluntary; and (4) financing LTCI though social insurance, either by integrating it into existing social insurance branches, such as health insurance, or by establishing a new independent branch for social LTCI (Schulte, 2002).

The following sections present more in-depth comparisons of the two countries' LTC systems in hopes of stimulating evidence-based debate and discussion about potential ways to improve the LTC systems in both countries.

1. Demand for Long-Term Care Services

The demographic dynamics of the German and U.S. populations are markedly different, with critical implications for their LTC systems. The U.S. population is much "younger" and will remain so for the foreseeable future, because of its higher rates of fertility and immigration.

Germany

Demographic Trends

Germany has one of the oldest populations in Europe. In 2005, an estimated 18.3 percent of the German population was age 65 and older, and this is projected to increase to 21.7 percent of the population by 2020 (Organisation for Economic Cooperation and Development [OECD], 2005).

While the overall German population is projected to decline in the coming decades (Arntz et al., 2006), the older population – those most likely to need care – will continue to rise. The share of persons 80 and older is projected to triple from 3.9 percent in 2001 to 12.1 percent in 2050, which will likely mean substantial increases in the number of frail older persons in need of care. At the same time, the United Nations Population Division projects that working-age population (age 15–64) will decline by 25 percent between 2005 and 2050. As a result, the "old age dependency ratio" (the number of persons age 65 and older for every 100 persons age 15–64) is projected to increase from 28 in 2005 to 54 in 2050 (United Nations Population Division, 2007). In other words, there will be less than two people of working age for every person age 65 and older in Germany in 2050.

The older population in Germany is becoming more ethnically and culturally diverse, which will affect services to its aging population. Aging guest workers who immigrated in the 1960s and 1970s from Turkey, the former Yugoslavia, and other Mediterranean countries combine with large numbers of ethnic Germans who emigrated from Central and Eastern European countries as well as the former Soviet Union to create a more culturally diverse older population (Werner, 2001). As a result, in 2005, nearly 20 percent of the German population was either immigrants or had parents who were foreign-born (OECD, 2007).

Projections of Future Demand for LTC services

Current projections (see Federal Ministry of Health, 2006) indicate that the number of persons needing care will rise from approximately 2.0 million in 2006 to approximately 3.1 million by 2030, an increase of 55 percent, assuming no changes in health status, disability rates, or other factors that influence the need for care.

Some experts in Germany anticipate a further shift to formal care, due to such factors as (1) a declining ratio of potential informal caregivers to older persons in need of care; (2) the increasing labor force participation of women; and (3) the increasing share of older persons living alone (Rothgang and Igl, 2007).

United States

Demographic Trends

Because of the relatively low birth rates in the United States between 1929 and 1945, the increase in the number of individuals age 80 and older during the next two decades will be relatively modest. More rapid growth will start after 2026, when the oldest baby boomers turn 80, and will peak in the 2030s and 2040s, when all of the boomers reach late old age. Between now and 2026, most of the growth among the older population will be among those age 65–80, who are at a relatively lower risk of needing LTC. But the proportion of the population age 80 and older will roughly double between 2005 and 2050, from 3.6 percent to 7.0 percent. The working-age population will continue to rise by 27.2 percent during that period; therefore, the old age dependency ratio will increase from 18 to 32—or a little more than Germany's current old age dependency ratio of 28.

Not only is the U.S population aging, but the older population is increasingly racially and ethnically diverse, with 18 percent of persons age 65 or older reporting they were non-White or Hispanic in 2004. That proportion is projected to increase to 39 percent by 2050. During the same period, the proportion of older Asians will increase from 3 to 8 percent; older Blacks, from 8 to 12 percent; and older Hispanics, from 6 to 18 percent (Federal Interagency Forum on Aging Related Statistics, 2006). These trends have important implications for all aspects of LTC, particularly the need for culturally appropriate services.

Projections of Future Demand for LTC services

Projections of future demand for LTC services vary considerably. A recent analysis in the United States projected that the number of persons receiving paid home care will more than double between 2000 and 2040, increasing from 2.2 million to 5.3 million. This analysis considered demographic trends, varying assumptions about health and disability status, longevity, and the availability of informal care by family members and others. Even under the most optimistic scenarios of steadily decreasing rates of disability, this analysis projected that the number of older adults using paid home care will increase by three-fourths between 2000 and 2040 (Johnson, Toohey, and Wiener, 2007).

This analysis also projected that the number of older nursing home residents will more than double between 2000 and 2040, from 1.2 million to 2.7 million—an increase that will still be two-thirds even under more optimistic assumptions. However, using recent trend data from the National Nursing Home Survey, the Lewin Group (Alecxih, 2006) lowered its projected increase in the older nursing home population between 2004 and 2030 from 830,000 (or a 62 percent increase over the 2004 level of 1.317 million) to 320,000 (a relatively modest 24 percent increase).

Discussion

- (1) Germany and the United States both have aging societies where LTC needs are likely to increase substantially in the coming decades. Societal aging will be more pronounced in Germany where birthrates and immigration rates are lower.
- (2) The aging populations in both countries will become more ethnically diverse, though this trend will be more pronounced in the United States. Providing culturally appropriate care will be an increasing challenge in both countries.
- (3) Demographic and social changes will also affect the number of professional and family caregivers available. The declining numbers of working-age women will affect Germany in particular, although the United States will also see relatively slow growth in the workforce compared to the growing numbers of older people.
- (4) The older population will not grow at a constant rate. The United States has particularly large baby boom cohorts that will likely result in substantial increases in demand for LTC services in the 2020s and 2030s after relatively slow increases before that time. The German age structure in 2050 will resemble an inverted pyramid, with relatively few workers supporting a very large older population.
- (5) Projections of future demand are very sensitive to a number of factors, including economic well-being and rates of disability, childlessness, divorce, and widowhood. Future cohorts of older people in both countries are likely to be better off financially than past cohorts and may have lower rates of disability. But future cohorts in both countries are also more likely to be divorced or single and to have fewer adult children to serve as caregivers.

2. Coverage and Financing

Germany

<u>Coverage</u>

Germany's universal social LTCI program, enacted in 1994, provides nursing home and inhome benefits to eligible persons of all ages. The Ministry of Health administers the program. Approximately 90 percent of the population is covered through a public social insurance approach, and 10 percent is covered under private LTC insurance.

Public LTC insurance is built on Germany's health insurance system. Self-employed persons, civil servants, and high-income employees² have several options. They can choose to: (1) stay in the public health and LTC insurance programs, or (2) "opt out" of the public program but obtain mandatory private health and LTC insurance. In addition, supplementary private health and LTC plans are available on a voluntary basis.

The program is designed to cover many but not all LTC services and supports that may be needed. Those services and other supports the program does not cover generally are paid out-

of-pocket or by the means-tested social assistance program. For example, nursing homes residents are required to pay the costs of "room and board." As in many other countries, medically related home nursing care is covered under the health insurance program.

The LTCI program provides capped benefits to eligible individuals according to their level of functional needs. These benefits, in order of budgetary significance, are: (1) nursing home care; (2) home care, with a choice of a cash benefit, a service benefit, or both; (3) contributions to pension funds for family caregivers; (4) day care, night care, or short-term nursing home care; (5) respite care; (6) medical equipment, assistive devices, and home modifications; and (7) training for family caregivers (Rothgang, 2002). (See section 4 below for more details about benefits and eligibility criteria.)

<u>Financing</u>

Germany has a mixed public-private system of financing. The public LTCI program is financed through a nationally uniform payroll tax of 1.7 percent of wages shared equally by employer and employees (0.85 percent each),³ subject to a wage ceiling of 3,562.50 (\$5,093) per month in 2007.⁴ Dependents (spouse and children) with incomes below a

certain threshold are covered without any additional worker contributions. Beginning in 2006, retirees have been paying the full contribution rate of 1.7 percent, which had been split equally between retirees and Germany's pension funds.

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Since 2000, individuals must have been insured for at least five years throughout the 10 years preceding application for benefits. As of January 2005, childless employees age 23 or older began paying an additional 0.25 percent of gross income, raising their contribution rate to 1.1 percent, and also subject to a wage cap. The rationale was that child rearing is "one of the pillars of the viability of social insurance system, which is being financed as a pay-as-you-go system" (Federal Ministry of Health, 2006).

Benefits are not indexed for inflation, which has led to erosion of their value to consumers. Some researchers fear that rising costs to consumers may lead to a greater need for Länderfunded social assistance, especially for those in institutional care (Meyer, 2007). Also, there are no regional adjustments, such as higher payments in urban areas than in rural ones, resulting in regional variations in the benefit's purchasing power (Cuellar, 2003).

The financing system is a capped entitlement in the sense that average payments for LTC services per beneficiary in institutional care, except for special cases, cannot exceed €15,339 a year on average. In practice, this regulation has never been important because the aggregate amount paid out by the LTCI funds has always been below this threshold (Federal Ministry of Health, 2007 b).

Most Germans receive coverage through LTC insurance funds that collect contributions, negotiate fee schedules, and reimburse providers. They are closely linked to the 250 health insurance funds, although they are legally independent entities under public law. About 50 private LTC insurers implement the mandatory private LTCI program for those individuals who choose to "opt out" of the public LTCI program (Federal Ministry of Health, 2006).

Private mandatory LTCI in Germany is quite different from private LTCI in the United States. In Germany, mandatory private LTCI, which covers approximately nine million persons, must offer at least the same level of benefits as the public LTCI program does for about 70 million persons. Premiums may not exceed the contribution levels for the public program. In addition, employers must pay a premium subsidy that corresponds to the employer's 50 percent share of the contribution for public mandatory LTCI. There is no underwriting for private LTCI (Federal Ministry of Health, 2007b). Premiums are established primarily on the basis of the age at which the individual becomes insured⁵ and are the same for men and women.

In 2006, approximately 977,000 persons (about 1 percent of the population) had private supplementary LTCI, which is more similar to private U.S. LTCI. Eligibility and premiums for supplementary benefits and premiums are subject to underwriting on the basis of risk. Hence, some persons may not be eligible for coverage, and others may pay higher premiums for certain risk factors. Three primary types of private supplementary LTCI policies are available, with policies that offer a daily allowance by far the most common⁶ (Federal Ministry of Health, 2007b).

Consumer Responsibility for Cost Sharing

Individuals do not pay coinsurance for home care services covered under the home care benefit. For institutional care, they are required to pay the "room and board" charges, in addition to at least 25 percent of the cost of care. While these "hotel" charges vary substantially, they averaged about €578 in 2005 (Federal Ministry of Health, 2007 b). In part because the benefit has not kept up with inflation, individuals are paying higher out-of-pocket expenses, with several analyses suggesting they are paying close to 50 percent of the total cost of care (Harrington et al. 2002; Rothgang and Igl, 2007).

Many residents also pay for a share of the investment costs of building or modernizing care facilities. While these capital investments are considered to be the responsibility of the Länder, regulations about the amount of the subsidies for such costs vary greatly among the Länder. In practice, these costs have often been passed on to residents, at an estimated average monthly amount of about €376 (Rothgang and Igl, 2007).

Germany's Social Assistance Safety Net

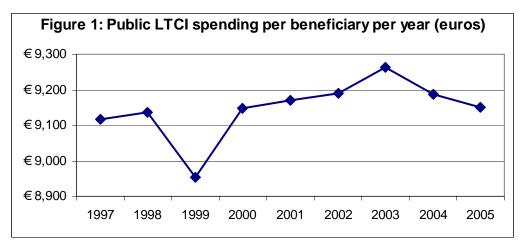
Germany's social assistance program continues to provide crucial protection to low-income persons in need of LTC. Today, it covers (1) the very small share of persons who are not insured under LTCI and (2) insured persons who cannot afford to pay out-of-pocket for benefits that fall outside of the scope of the LTCI program, such as those with severe disabilities who need intensive home care and nursing home residents who cannot afford the

costs of room and board. Benefits are means-tested based on uniform, national income standards and assets (MISSOC, 2006), and local authorities may try to recover at least a part of the assets of persons who receive social assistance benefits.⁷

Trends in LTC Financing

Consistent with one of the major goals of the public LTCI program, spending for the social assistance program has been reduced substantially. For example, social assistance spending on nursing homes is now less than one-third of the 1995 level (Rothgang and Igl, 2007). In addition, in 2003, less than 5 percent of persons receiving home care benefits, and less than 25 percent of persons receiving institutional benefits received additional assistance under the Federal Social Assistance Act (Federal Ministry of Health, 2006).

The program built up a sound financial reserve fund in the first years of its implementation that has not yet been jeopardized by the deficits of recent years. Expenditures exceeded revenues by about 2 percent in 2002, 4 percent in 2003, and 2 percent in 2005 (Federal Ministry of Health, 2006). The reason for this imbalance is largely on the revenue side rather than the spending side. As shown in Figure 1, total LTC spending per person served has been relatively stable.



Source: AARP Public Policy Institute analysis based on data from the Federal Ministry of Health, 2007a

Annual increases in revenues under the fixed contribution rate in most years have been even lower than the growth in spending, which has been modest—less than 2 percent per year in almost all years. A gradual shift toward greater use of both institutional and formal home care benefits, compared with the cash allowance, is likely contributing to this modest spending growth (Federal Ministry of Health, 2006).

In addition to the lack of premium increases since introduction of the LTCI program more than a decade ago, other factors influencing low revenue growth include structural unemployment, low increases in wages and pensions, and reductions in the number of jobs subject to social insurance contributions (Rothgang and Igl, 2007). For example, workers in "mini-jobs" with low earnings (no more than €400 monthly) are exempted from contributions, and this informal economy has been growing. Reductions in government contributions for those who are unemployed have also been reported.

Over the longer term, the primary cost driver in Germany will be demographic trends, especially the increasing number of persons age 80 and older, leading Germany to plan for a "demography reserve." Because the maximum benefits are capped by law, prices and cost of services have relatively little direct effect on the financial situation of LTCI. They do, however, affect the value of the benefit to beneficiaries.

United States

<u>Coverage</u>

In the United States, persons who need LTC are generally expected to meet the costs themselves, and many have few options for coverage. With no national system for insuring individuals against the risk of having major LTC expenses, individuals needing LTC have been termed "the invisible uninsured" because they are rarely the focus of public policy discussion about options for expanding coverage.

Medicare is a federal social insurance program that provides health insurance to persons age 65 and older and younger persons with disabilities. It provides only modest funding for LTC through limited "post-acute" coverage of short stays for rehabilitative care in nursing homes and some home health care services.

The primary public financing source for LTC is the welfare-based **Medicaid** program. Federal and state governments share funding responsibility for Medicaid, which provides both health and LTC services for low-income children, pregnant women, parents of dependent children, the elderly, and people with disabilities. While serving as a critically important "safety net" for lower-income persons with disabilities, Medicaid has stringent financial eligibility criteria and requires people to exhaust most of their assets and income to qualify for coverage. Applicants must meet strict income and assets rules, which vary widely from state to state, within broad federal guidelines, as do the LTC services covered. Medicaid is a welfare-based program, not an insurance program.

The only insurance coverage for LTC available in the United States is through **private**, **voluntary**, **LTCI plans**. Private policies' benefits have become much more comprehensive over time, and the purchase of such coverage has been growing. However, only 3 percent of the adult population has such policies. Younger persons are much less likely to purchase coverage than are older persons; approximately 8 percent of persons age 50 and older have LTCI, as do about 10 percent of persons age 65 or older (Feder, Komisar, and Friedland, 2007).

Brokers in the individual market sell most private LTCI policies (more than 80 percent). The group market, comprised primarily of employers, is growing but still small (Manard, 2006). In 2000, Congress established a voluntary LTCI program for federal employees, retirees, and family members as an example for other employers. About 6 percent of those who are eligible have enrolled, roughly similar to enrollment in the general group market (Manard, 2006).

Private LTCI is too costly for many Americans. In 2005, the average national premium was \$1,973 (Kassner, 2007). Those who purchase private LTC generally have higher incomes and more assets than do nonpurchasers. In 2005, 49 percent of purchasers had incomes over \$75,000 per year, and 76 percent had assets of more than \$100,000. In addition, private LTCI is unavailable to many individuals with health conditions or disabilities because of medical underwriting. Purchasing such policies can be complex for professionals as well as consumers because multiple companies offer a bewildering array of policies that have differing daily benefits, inflation protection, and other features (Burns, 2006).

Tax advantages to purchase private LTCI are available in a number of states and at the federal level. Nearly all policies sold today meet federal standards for favorable tax treatment, which include no taxation of benefits paid through qualified policies (Kassner, 2007). Taxpayers who itemize can deduct LTC premiums up to a maximum limit that increases with age if their medical costs exceed 7.5 percent of their "adjusted gross income." In addition, since 2003, taxpayers have been allowed to make deductible contributions to health savings accounts and use them tax free to pay for LTCI (Stone, 2007).

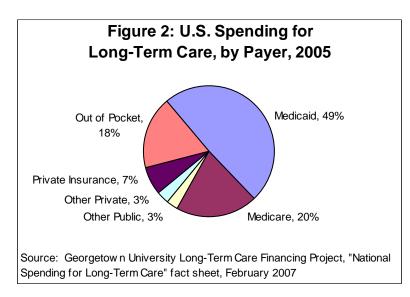
In summary, the vast majority of the U.S. population does not have insurance coverage for LTC. Their primary source of protection is through the Medicaid program for low-income individuals, similar to the situation in Germany before 1995. Persons with disabilities with incomes "in the middle"—too high to be eligible for Medicaid and too low to be able to afford private LTC insurance—fall through the cracks. Those persons who do not have family caregivers or whose caregivers are unable to provide all of the assistance needed are particularly vulnerable. Approximately three in 10 (29 percent) persons age 50 or older with disabilities do not receive all of the assistance they need with essential daily activities, such as bathing, dressing, and cooking; financial barriers are the most important predictor of these unmet needs (Gibson and Verma, 2006). Unmet needs for personal assistance can result in more severe disability and unnecessary acute care hospitalization or institutionalization.

Financing

As shown in Figure 2 below, the primary source of long-term care spending in the United States in 2005 was Medicaid (49 percent), followed by Medicare, out-of-pocket spending by individuals, private insurance, and other public or private sources (Komisar and Thompson, 2007)

These data underestimate the financial burden on individuals and families for several reasons. First, they do not include privately paid costs of assisted living, which typically must be paid out-of-pocket (Manard, 2006). Second, they do not reflect any of the contributions of family and other informal caregivers, who provide the vast majority of the care received by persons living in the community. These unpaid contributions were recently estimated at about \$350 billion per year, an amount that far exceeds total public and private spending for both nursing home and home care in the United States (Gibson and Houser, 2007). Third, the risk of having out-of-pocket expenditures is not distributed evenly. While relatively few people need nursing home care or extended home care, those who do are at risk for catastrophic expenses. For example, because the average private-pay cost for a semi-private

room in nursing home care was \$66,795 in 2006 (Metlife, 2006), most people who had an extended stay had to rely on Medicaid for at least a portion of the cost.



The traditional fee-for-service Medicare program is financed by a combination of beneficiary contributions, payroll taxes, and general revenues. Part A, Hospital Insurance, is funded by payroll taxes and a portion of the taxation of Social Security taxes. Part B, Supplementary Medical Insurance, is funded jointly by beneficiary premiums and general revenues. In 2007, the standard Part B premium beneficiaries paid was \$93.50 per month.⁸

Medicaid is financed jointly by the federal government and the states under a formula designed so that the federal government pays a larger portion of Medicaid costs in states with lower per capita income relative to the national average (and vice versa for states with higher per capita incomes).

Total Medicaid spending, as well as LTC spending, varies considerably from state to state. For example, in 2005, LTC spending represented 56 percent of total Medicaid spending in North Dakota, compared with 21 percent in Tennessee. In addition, some states devote far higher shares of spending to nursing home care than to home and community-based services (HCBS). Oregon devoted the highest share of its total LTC spending to HCBS (70 percent) in 2005, and Mississippi (13 percent) devoted the lowest (Burwell, Sredl, and Eiken, 2006).

Consumer Responsibility for Cost Sharing

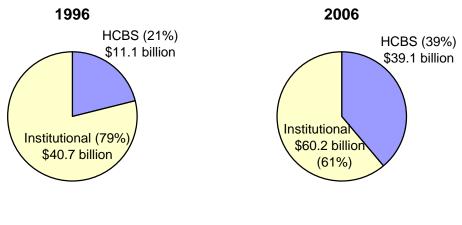
Americans pay out-of-pocket for all LTC services not covered by private LTCI or by Medicaid or Medicare. Few Americans have private LTCI. For Medicaid services, nursing home residents without a spouse in the community⁹ must contribute all of their income, except a small "personal needs allowance"—about \$30–\$40 a month in most states, to cover basic expenses such as personal hygiene supplies and phone calls. Nursing home residents covered by Medicare for short stays pay no coinsurance for days 1–20; \$124 per day in 2007 for days 21–100; and the benefit ends after 100 days. Cost sharing for home care under Medicaid varies by state, but it is nominal. Medically oriented home health is covered under Medicare with no coinsurance.

Trends in LTC Financing

Aggregate growth in total LTC spending has not been as pronounced as the growth in other national health expenditures. The public and private cost for LTC was about \$158 billion in 2004, or roughly 8.4 percent of total U.S. health care spending for that year. From 1994 to 2004, expenditures for nursing home and home care increased by 69 percent. However, during this same period, spending for all national health expenditures grew by 94 percent and prescription drug spending increased by 247 percent (Tritz, 2006).

The most consistent trend in LTC financing in recent years has been the growth in home and community-based services (HCBS) and the decline in institutional spending as a share of total spending. This trend occurred in both total national expenditures for LTC (Tritz, 2006) and within the Medicaid program, the primary funding source for LTC services. The shift in Medicaid spending for HCBS is shown in Figure 3.





Total Spending = \$51.8 billion

Total Spending = \$99.3 billion

Source: Burwell, Sredl, and Eiken, "Medicaid Long Term Care Expenditures FY 2006," Thomson Healthcare, 2007; prepared by AARP Public Policy Institute, 2007

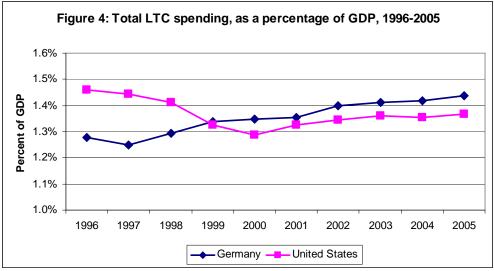
Although the LTC share of the Medicaid budget has not grown as fast as other parts of the Medicaid budget in recent years, it has nonetheless presented a major challenge to state governments confronting difficult budget trade-offs. In 2002–2004, states faced one of the most severe fiscal challenges in half a century, according to the National Governors' Association (NGA and NASBO, 2005). State Medicaid budgets for LTC and proposals for reform became a central focus of attention, with some states using traditional cost-containment measures such as cutting Medicaid services or payment rates, and some exploring innovative ideas for LTC system reform (Reinhard, 2005). Examples of the latter include "rebalancing" LTC spending to focus less on nursing home care and more on HCBS.

One major point of controversy between states and the federal government involves spending for low-income persons, known as "dual eligibles," who are eligible for both Medicaid and Medicare. Most of these individuals are older persons who are in fair or poor health, and many need LTC services, which are funded under Medicaid (Reinhard, 2005). The states have long held that the federal government should assume all expenses for persons in this costly category, including both health and LTC costs. While some costs for prescription drugs were transferred to the federal government in the Medicare Modernization Act, controversy continues over state versus federal roles in financing LTC.

Increased longevity and increasing numbers of older people have not been factors in increasing Medicaid costs. According to the Congressional Budget Office (CBO), growth in the number of older beneficiaries contributed only 0.6 percent to the increase in Medicaid expenditures between 1975 and 2002. The total number of Medicaid beneficiaries increased by 127 percent during that time, but the number of older beneficiaries increased by only 8 percent—despite the fact that the population age 65+ had grown by 57 percent. Costs per older beneficiary increased Medicaid expenditures by 22.7 percent; but these cost increases reflect increasing costs of care, not increasing numbers of beneficiaries.

LTC Spending in Germany and the United States as a Share of GDP

Accurate estimates of national LTC spending are difficult to achieve, and these difficulties are multiplied in cross-national comparisons. Hence, comparative estimates of LTC spending are subject to many caveats, and international organizations such as the OECD and the European Union are attempting to improve the comparability of cross-national LTC data.¹⁰ The data presented below are from OECD Health Data 2007, based on national health accounts.¹¹ (See endnotes for details).

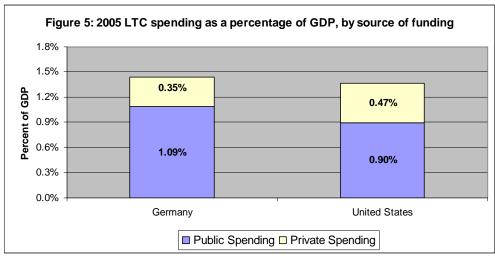


Source: AARP Public Policy Institute analysis of OECD Health Data 2007

As illustrated in Figure 4, based on OECD data¹², Germany spends roughly the same share of its gross domestic product (GDP) on LTC (1.44 percent in 2005) as does the United States

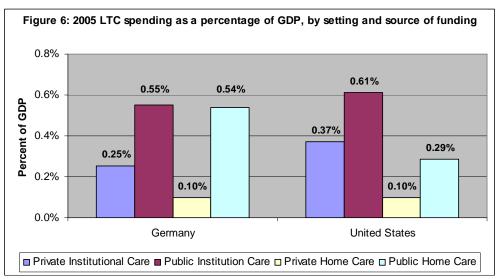
(1.37 percent). However, Germany's system provides a mix of public and private financing that no longer requires individuals to become impoverished to receive LTC benefits.

As shown in Figure 5, Germany's public spending¹³ on LTC is somewhat higher than such spending in the United States (1.09 percent of GDP in 2005 versus 0.90 percent in the United States), but the most dramatic difference is in the type of public spending. In the United States, Medicaid, a means-tested social assistance program, is the primary source of public funding. In Germany, a universal insurance program for persons of all ages provides LTC benefits based on needs for assistance with essential activities of daily living, not income.



Source: AARP Public Policy Institute analysis of OECD Health Data 2007

Germany also spends less of its GDP on institutional care (0.80 percent versus 0.98 percent in the United States – see Figure 6) and substantially more on home care (0.64 percent versus 0.39 percent in the United States). Public spending on institutional care is higher in Germany than it is in the United States, and private spending is lower.



Source: AARP Public Policy Institute analysis of OECD Health Data 2007

Discussion

- (1) One of the major social policy goals of the German LTC program was to reduce Germany's high costs for social assistance, a means-tested program financed by local authorities and the Länder (states). That goal was met successfully (Federal Ministry of Health, 2006); spending on Germany's LTC social assistance (welfare) program has been reduced by roughly two-thirds since introduction of the social insurance program. However, social assistance remains in place as an important "safety net" for low-income individuals. In the United States, means-tested Medicaid programs can be vulnerable to reductions in state budgets as states respond to fiscal pressures associated with economic conditions and pressures to reduce public spending. In recent years, Medicaid LTC spending, which represented 31.5 percent of Medicaid's total spending in 2005, has been the target of some states' cost-cutting measures.
- (2) Germany spends about the same share of its GDP on LTC as does the United States, but the former allocates its funding differently, with a higher share of public rather than private spending and a higher share devoted to home care rather than institutional care.
- (3) In both countries, individual payments for LTC services are underestimated due to data limitations. For example, spending for services in assisted living settings, which is paid privately almost exclusively, is often not captured in public data sets. In addition, families in both countries provide substantial hours of unpaid care.
- (4) The costs of public LTC spending in Germany have been contained, largely through the lack of indexation of benefits and the capped nature of the entitlement, along with tighter eligibility determinations. (See section below on eligibility trends.) Germans make quite substantial out-of-pocket payments for institutional care. While they do not pay coinsurance for covered home care services, they do pay out-of-pocket for any home services not covered under the LTCI benefits.
- (5) As in the United States, cost shifting among health and LTC funds occurs, with health insurance funds having financial incentives to shift some costs to the LTCI funds and vice versa. Health insurance funds, for example, reportedly underfund rehabilitation services, for which they are responsible (Arntz et al., 2006). In the United States, many experts believe that cost shifting between Medicare and Medicaid programs is pervasive (Doty, 2000). However, the lack of unified data sets and the complexity of such analyses have been major deterrents to quantifying the magnitude of such shifts. In Germany as well, barriers exist to data sharing between the health and LTCI programs (Cuellar, 2007).

3. Consumer Options and Choice

Germany

<u>Eligibility</u>

Persons eligible for the LTC program are those who, "owing to a physical, psychological, or mental disease or handicap," are expected to need a substantial amount of help to carry out the routine activities of everyday life for approximately six months or more. While the program covers persons of all ages, in 2005, 79 percent of beneficiaries were age 65 and older; 51 percent, age 80 and older; and 31 percent, age 85 and older (Federal Ministry of Health, 2007a).

Individuals are assessed for limitations in activities of daily living (ADLs), such as bathing and dressing, and in "instrumental activities of daily living" (IADLs), such as shopping and cooking, as well as hours of care needed per day. These assessments have focused largely on physical needs for personal care, nutrition, and mobility rather than on needs for supervision or cueing, which persons with dementia or learning disabilities often need.

Individuals in need of LTC are classified by three levels of disability, based on the type and the hours of care needed per day, as shown in Table 1. Persons with the least severe level of disability (Level I) generally have more difficulty with personal hygiene than with mobility, and their basic needs can be met by assistance once a day. At the middle level (Level II), persons typically need help with personal hygiene, feeding, or mobility several times a day. At the most severe level (Level III), care is generally needed at various times around the clock (Cuellar, 2003).

	Level I	Level II	Level III	
Need help with Basic	At least once a day at	At least three times	Help must be	
ADLS (bADL)	different times	a day at different	necessary around	
		times	the clock	
Need help with	More than once a	More than once a	More than once a	
Instrumental ADLs	week	week	week	
Total time required	At least 1.5 hours a	At least 3 hours a	At least 5 hours a	
	day, with at least .75	day, with at least 2	day, with at least 4	
	hours for bADLs	hours for bADLs	hours for bADLs	

 Table 1: Eligibility for LTC Services in Germany

Source: Rothgang and Igl (2007), based on German code 15 SGB XI

Fifteen Medical Boards nationwide conduct in-home assessments for the LTCI funds. These assessments are done primarily by geriatric-trained nurses and physicians, who observe both the home and social environment of the person in need of care and assess their health and functional status on the basis of national standards. In accordance with the principle that rehabilitation services should be available before LTC services, the assessment encompasses options for rehabilitation, including the need for medical equipment and technical aides. Moreover, the "stresses in caring and the stress-bearing capacity" of informal caregivers—mostly family members—are assessed and, if possible, help is offered to them as well, such

as measures to improve the home environment (Federal Ministry of Labor and Social Affairs, 2006).

Consumer-Directed Benefits

The German system is structured to give beneficiaries a wide range of choices among services, providers, and settings, in both the home and institutions. However, the program is designed to encourage home care and family caregiving rather than institutional care. It is based on the following guiding principle:

Prevention and rehabilitation before LTC and home care before institutional care

Individuals are entitled to a choice among institutional care, formal home care services, a cash allowance for home care, or a combination of cash and formal home care services, up to a ceiling at each care level¹⁴ (see Table 2). Persons selecting a cash allowance for home care receive benefits that are about one-half of the amount of formal home care services. For example, home care benefits for persons with very severe disabilities (Level III) are €665 (\$951) per month for the cash allowance compared with €1,432 (\$2,047) for formal services.

Table 2. Wonting Benefits for Home Care and Institutional Care in Germany (Euros)					
Type of Service	<i>. .</i>		II–Severe	III–Very Severe	Special Cases ¹⁵
Home care cash benefit / service benefit		€205 / €384	€410/€921	€665 / €1,432	*/€1,918
Partial day or partial night institutional care service benefit		€384	⊕ 21	€1,432	
Respite care (up to 4 weeks per year) by near relatives/ others or in institutions		€205 / €1,432	€410/€1,432	€665 / €1,432	
Supplemental benefit for persons with dementia, mental illness (annual amt)		€ 460	€460	€460	
Full-time institutional care benefit		€1,023	€1,279	€1,432	€1688

 Table 2: Monthly Benefits for Home Care and Institutional Care in Germany (Euros)

Source: German Ministry of Health, http://www.bmgesundheit.de

In addition to the benefits in Table 2, beneficiaries can receive benefits for (1) durable medical equipment and other technical aids, such as beds or wheelchairs (90 percent of cost, with a maximum copayment of C5 per item); (2) consumable products (up to C1 per month); and (3) home modifications (up to C2557 per modification, with a "reasonable" copayment).

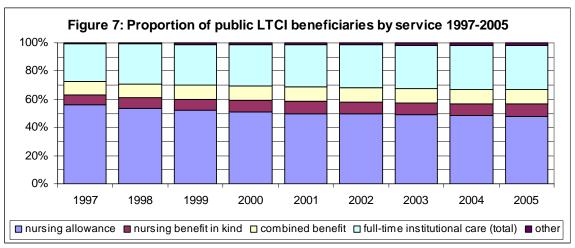
The LTCI pays for personal care associated with ADL needs, mobility, and some domestic help, such as cooking, with no cost sharing; however, it does not cover psychosocial care, cleaning, and most housework. A new act supplementing home care services, implemented in 2002, strengthened benefits for in-home care of persons with high levels of needs for

supervision and care, such as those with dementia, by adding a small additional benefit (\notin 460 per year), which is often used for respite purposes. The new law also committed \notin 20 million to developing new programs where volunteers, under the supervision of trained workers, assist persons with dementia in group or home settings (Cuellar, 2003).

Given a choice between home and institutional care, roughly two-thirds of beneficiaries chose home care in 2005. Within the home care program, beneficiaries are given a choice of spending a fixed amount on formal services, receiving a lower fixed amount as an unrestricted cash allowance (roughly 50 percent lower, depending on level of disability), or a mix of cash and services. The cash allowance is often used to pay relatives to provide care. In 2005, 72 percent of beneficiaries electing home care chose to receive a cash allowance; 15 percent, a combination of cash and services; and 13 percent, formal services only.

Trends in Use of Services

Far more beneficiaries continue to choose the cash allowance rather than formal home care services, despite its lower value. When the program was introduced, the Ministry of Social Affairs had predicted that 50 percent, rather than 80 percent, of those receiving home care benefits would choose cash (Naegele and Reichert, 2002).



Source: AARP Public Policy Institute analysis based on data from the Federal Ministry of Health, 2007a

A modest, gradual shift toward formal services (Figure 7) is thought to be contributing to rising expenditures. From 1997 to 2005, the proportion of beneficiaries in nursing homes increased from 27.1 percent to 32.5 percent, while the share of those who chose home care benefits decreased from about 73 percent to 67.5 percent.

It is surprising that, given the aging of the German population, the proportion of beneficiaries in the lowest (moderate) Level I care category has been increasing, while the proportion in both Level II and III has been decreasing (see Table 3).

Home Care				Institutional Care				
		Care Level			Care Level			
		Ι	II	III		Ι	II	III
19	997	47.5%	40.6%	11.9%	1997	34.5%	41.0%	24.5%
20	001	55.3%	34.6%	10.1%	2001	37.9%	42.0%	20.1%
20	005	58.0%	32.5%	9.5%	2005	39.2%	40.9%	20.0%

Table 3: Proportion	of Beneficiaries	by Care Level for	Home and Institutional Care
I uble of I topol fion	of Dementional les	by Cure Deverior	Home and institutional care

Source: Federal Ministry of Health, 2007a

Reasons for this trend are the subject of debate, with some experts arguing that it is likely the effect of tighter assessments by the medical assessment unit and rules for Level III based on court jurisdiction (Rothgang and Igl, 2007).

Emerging housing and service models (Rothgang and Igl, 2007) that provide services lying between home and institutional care include:

- Sheltered Housing—akin to assisted living in the United States, sheltered housing provides a range of services that differ from facility to facility.
- Self-organized Collective Projects—These mutual help groups often build on what are referred to as naturally occurring retirement communities (NORCs) in the United States.
- Village for Older People (Altendorf)—Similar to continuing care retirement communities (CCRCs) in the United States, housing and service arrangements are located on one campus so a resident does not have to leave the village to receive care.
- House Communities—Somewhat similar to intensive assisted living or cottage-style nursing homes in the United States, these communities attempt to offer a genuine housing alternative to nursing home care.

While these housing and service models are growing in Germany, they are often small in scale and available only in limited areas. They are not generally licensed or regulated, and the LTCI reimbursement system has not recognized these quasi-institutional arrangements (Rothgang and Igl, 2007).

Consumer Protections and Consumer Information

Applying to the LTC insurance fund for LTCI benefits is a formal administrative process that results in a written administrative action, including justification for the decision to deny benefits or assign applicants to a particular level of care and available legal remedies, including court if needed. Beneficiaries can reapply to the medical unit for reassessment of their disability level if their functional status changes. In the case of home care services, beneficiaries are also entitled to a written care agreement from the home care agency outlining which services will be provided and how much they will cost (Federal Ministry of Labor and Social Affairs, 2006),

As is also the case in a number of U.S. states, some German Länder are experimenting with innovative ways to provide information and coordination services for consumers. For example, in the Rhineland-Palatinate, the "Menschen pflegen" initiative has established centers that serve as the intersection between family caregiving and professional care services. The centers provide counseling and support as well as care coordination services. In the future, they will place additional emphasis on recruiting and supporting volunteers to help provide support for family caregivers and to counteract isolation among persons living alone (Dreyer, 2007).

Supply of LTC Services

According to the German Ministry of Health, the introduction of public LTCI not only has led to a substantial expansion in home care and institutional care services, but also to improvements in the inadequate infrastructure of caregiving providers. Today, the number of providers is considered to be sufficient to ensure beneficiary access. Since inception of the program, both the number of home and community-based providers and institutional care facilities has more than doubled, from about 4,000 to 10,600 home care agencies and from 4,300 to 9,700 nursing homes. In addition, there were 1,500 day care institutions at the end of 2003 (Federal Ministry of Labor and Social Affairs, 2006).

Due to this expansion, no significant waiting times for institutional care have been reported (OECD, 2005). Roughly half of all beds in nursing homes were in private rooms in 2001, slightly more than in the UK but considerably fewer than in Norway and Sweden (OECD, 2005). Some policy experts have recommended that Germany make a commitment to private rooms as the Scandinavian countries have (Kuratorium Deutsche Altershilfe, 2005).

Most nursing homes in Germany (55 percent) are private, nonprofit; 38 percent are private, for-profit; and 7 percent, public. In contrast, most home care agencies (58 percent) are private, for-profit, 41 percent are private nonprofit, and 2 percent are public (Federal Ministry of Health, 2006b). Home care providers in Germany, especially for-profit providers, tend to be small organizations (Cuellar, 2003), although some consolidation has been occurring. After the initial boom in new providers, the number of nursing homes continued to increase between 1999 and 2005, and overall home care capacity also has grown moderately (Rothgang and Igl, 2007).

Provider and Insurer Competition

For the first time in Germany's social legislation history, market mechanisms were introduced in the 1994 LTCI legislation to increase competition among LTC providers (Knuver and Merfert, 2002). Before 1995, LTC services were provided predominantly by publicly financed nonprofit social welfare organizations. The LTCI reform specifically sought to put private sector providers on a "level playing field" with public providers, and enactment of the LTC program spurred the entry of private companies into the market.

To help ensure an adequate supply of providers and competition, every provider that meets licensing requirements has a legal right to be licensed, regardless of whether another provider is needed. Some Länder, however, restricted the subsidies they are supposed to provide for

the investment costs for new nursing homes to those they considered necessary, thereby limiting competition in some areas.

The degree of *provider* competition that actually occurs continues to be debated. According to official documents, such competition has increased substantially. Each care facility is supposed to negotiate its per diem rates for care individually with the LTC funds, and each facility has its own individual benefit and pricing structure (Federal Ministry of Health, 2006). However, since the LTC funds operate collectively, this raises potentially anticompetitive buying power issues. In addition, some economists have argued that price competition in the German LTC program is limited by such factors as fixed prices for care packages and the lack of consumer representation in the negotiation process between insurance funds and care providers (Arntz et al., 2006).

Little if any competition occurs among the LTC *insurer* funds, in contrast to the German health insurance funds. The LTC funds all have identical benefits, contribution rates, and contracts with providers, so some observers have characterized these funds as "branches" of one LTCI fund.

For home care, provider associations have developed about 20 service "bundles" (e.g., brief morning and evening visits to help with dressing and personal hygiene) that are assigned weights and form the basis for payment for most providers, although the negotiation process differs for charitable versus independent, private home care providers (Cuellar, 2003). The three levels of payment for nursing home care in Germany stand in distinct contrast to U.S. payment rates, which distinguish among 44 resident level-of-care classifications (called "resource utilization groups," or RUGs). RUGs are used for nursing home payments by Medicare, and about half of the states' Medicaid nursing home payment systems are based on RUGs. According to the Federal Statistical Office, at the end of 2005, €2,706 was paid on average each month to nursing homes at the highest level of LTC (III) for full in-patient nursing care and accommodation. At level II, the average monthly rate was €2,280, and at level I it was €1,854.

United States

Eligibility/Assessment

Generally, older persons and younger persons with disabilities are eligible for Medicaid LTC services if they have low incomes and/or are "medically needy," which means they have incurred catastrophic medical or LTC expenses. Individuals must exhaust their assets by paying privately for care before becoming eligible for Medicaid. In most states, aged or disabled adults who are eligible for cash assistance under the Supplemental Security Income (SSI) program¹⁶ are eligible for Medicaid. In 2006, the federal SSI limits for individuals were \$603 (€422) per month in countable income and no more than \$2,000 (€1,399) in countable assets.

States may elect to cover "medically needy" individuals who qualify for Medicaid by deducting the cost of their medical care from their income when determining eligibility.¹⁷ This concept of "spending down" to Medicaid eligibility is often used for elderly individuals

who are in nursing facilities, assisted living, or other community-based settings and who have high medical or prescription drug expenses. Thirty-nine states provide eligibility to "medically needy" individuals (Ryan, 2007). States may also use a special income rule to qualify individuals whose income does not exceed 300 percent of the federal SSI benefit.

Medicaid applicants must meet health and functional criteria as well as financial eligibility criteria. Then they are assessed for the type and amount of services they need. Criteria vary among states and among LTC programs within states. Most states refer to health and functional criteria for Medicaid as "level of care" criteria because individuals often must need a specific level of nursing home care to receive services. In many states, the criteria for determining eligibility for nursing home care or HCBS waiver services have a medical bias. More weight is given to medical and nursing needs than to functional impairments, particularly those caused by cognitive and other mental impairment or mental illness.

Medicare benefits are available to persons age 65 and older and persons with disabilities under age 65. To be eligible for home health benefits, one must be homebound and need skilled care, such as nursing care or therapy ordered by a doctor. To be eligible for skilled nursing facility care, one must be discharged from a hospital and need skilled care.

<u>Services</u>

Medicare home health services include skilled nursing care, various therapies such as rehabilitation, and home health aide visits. Medicare also covers post-hospital, skilled nursing facility care for a limited time.

Medicaid covers LTC services that Medicare coverage excludes, and states have some flexibility in determining which long-term care services to offer. States must provide *long-term nursing home care* to all qualified persons, and they must cover medically oriented home health services for persons who would quality for nursing home coverage.

States have several options for providing personal care services and other HCBS, such as care management, adult day care, and respite care. The Medicaid state plan also may provide HCBS through optional benefits for case management or personal care services. To receive services under the *personal care* option, beneficiaries must meet the standard financial criteria for Medicaid, which generally require that a recipient's income be at or below the SSI level, which is lower than the poverty guideline.

Although all states provide some level of HCBS services to some eligible individuals, each state's program is different. A *waiver option* gives states substantial flexibility to provide a comprehensive range of services and supports. Roughly 1 million participants were receiving such services in February 2007 through more than 225 waivers in the 48 states and Washington, D.C. (Stone, 2007, citing Centers for Medicare and Medicaid Services estimate). Most funding for Medicaid HCBS now comes through the HCBS waiver program, with the majority of that spending (about 75 percent) devoted to individuals with mental retardation and developmental disabilities and about 23 percent to older persons and persons with physical disabilities (Stone, 2007). While such waiver services have expanded

substantially in recent years, funding is still limited, enrollment may be capped, and many states have long waiting lists for services.

Other home and community-based services are funded under the federal Older Americans Act, including home-delivered meals and transportation services. Total funding for these Title III services was approximately \$1.3 billion in fiscal year (FY) 2007. Priority is given to older persons with the greatest social or economic need. A "National Family Caregiver Support Program," administered by the Administration on Aging, provides modest funds to each state for a range of services, including respite care. (See also family caregiving section below.)

Private LTCI policies generally cover both home care and institutional services. Eligibility for benefits is defined under almost all policies as either severe cognitive impairment or the need for help in performing at least two activities of daily living, such as bathing and dressing.

Consumer-Directed Services

Consumer-directed services—also called "self-direction"—empower persons with disabilities to decide what services and supports they want and how they want to receive them. Depending on the program, consumers may be able to select when they wish to receive services, hire and manage the workers of their choice, including family members, and manage their own budgets.

Medicaid and some state-only funded programs cover a wide range of age groups and specific conditions, with programs in almost every state. For example, California's In-Home and Supportive Services program is the largest in the nation, serving more than 350,000 low-income people of all ages with disabilities each month in 2006.

"Cash-and-counseling" programs are one type of consumer-directed HCBS program. Cashand-counseling provides Medicaid beneficiaries who are eligible for personal care services with a monthly budget to choose, purchase, and manage their own care or to pay a care manager. The programs also offer counseling to assist consumers who want help managing their services. The Robert Wood Johnson Foundation, in partnership with the U.S. Department of Health and Human Services, originally funded cash-and-counseling demonstration programs in three states (Arkansas, Florida, and New Jersey). Following the success of the original demonstration, there are now federally funded case and counseling demonstrations in 15 states that allow consumers to manage their own budgets for care with counseling and help with managing payroll and paperwork. Studies of cash-and-counseling programs have documented their positive outcomes, including reductions in unmet needs, better health outcomes, and improved quality of life.

Another program that promotes consumer direction is the Independence Plus initiative. Created by the federal government in 2002, Independence Plus helps states apply for and receive approval for consumer-directed services to promote self-direction, control, and choice in the Medicaid program. As of 2007, there are 11 approved Independence Plus Medicaid waivers in 10 states, and several states are preparing to submit proposals.¹⁸ The federal government also has awarded "Money Follows the Person" grants to help states move people from institutions into the setting of their choice. In addition, the Deficit Reduction Act of 2005 provides states with expanded options for funding consumer-directed services.

Trends in Use of LTC Services

• <u>Nursing Homes</u>

Long-term care use has changed dramatically over the past several decades in the United States. The nursing home resident population age 65+ was essentially the same in 2004 (1,317,200) as it was in 1985 (1,318,300), despite the fact that the 65+ population grew by 24 percent during that time, and the 75+ population most at risk grew by 55 percent. If 1985 utilization rates had remained unchanged, the older nursing home population would have been 2.1 million in 2004, 56 percent higher than the actual number. As Table 4 shows, nursing home use has declined steadily among all age groups 65 and older over the past two decades.

Age Group	1973–74	1985	1995	1999	2004	Percent Change 1973–2004
65–74	12.3	12.5	10.2	10.8	9.4	-23.6%
75–84	57.7	57.7	46.1	43.0	36.1	-37.4%
85+	257.3	220.3	200.8	182.5	138.5	-46.2%
Total 65+, Crude	44.7	46.2	42.4	42.9	36.2	-19.0%
65+, Age- Adjusted*	58.5	54.0	45.9	43.3	34.5	-41.0%

 Table 4: Nursing Home Utilization Rates per Thousand Population, 1973–2004

*The National Center for Health Statistics age-adjusted numbers to the 2000 population (except for 2004, which was adjusted to the 2000 population by AARP's Public Policy Institute).

In absolute numbers, the nursing home population peaked in the mid- to late 1990s and has declined sharply in recent years. The older population in nursing homes declined by 10 percent between 1999 and 2004, according to the National Nursing Home Survey (NNHS). Moreover, the characteristics of residents have changed as nursing homes increasingly move from providing long-term services to providing relatively short-term, post-hospital care. According to the NNHS, most discharges are now for short stays, most of which are financed by Medicare and private-pay sources. Indeed, the proportion of nursing home costs paid by Medicare (primarily for post-hospital care) rose from 1.3 percent in 1985 to 15.7 percent in 2005 (AARP PPI analysis of National Health Expenditure data). On the other hand, the number of older nursing home residents with longer stays (over 90 days) declined by 12 percent between 1999 and 2004, from 1.21 million to 1.06 million, and 68 percent of these residents were on Medicaid at the time of the survey. About half of these (35 percent of all nursing home residents) were on Medicaid at the time of admission, and the rest spent down to eligibility (Kasper and O'Malley, 2007).

The shift away from nursing homes reflects consumer preferences regarding LTC. Surveys indicate that most people who need LTC strongly prefer to remain in their homes, receiving

assistance from family or friends or from paid home-care providers, especially if less than 24-hour help is needed (Gibson et. al., 2003). When they need or want to move to receive services, people strongly prefer to live in an assisted living residence or other residential setting, rather than in a nursing home.

Despite these changes, many people still equate LTC only with older-style nursing home care and are unaware of publicly and privately funded home and community-based services, as well as opportunities to manage their own services and supports. Moreover, access to LTC, especially services that consumers want and control, is severely restricted for millions of Americans because of their high costs coupled with limited public funding.

<u>Assisted Living</u>

Assisted living and related forms of residential care have been among the fastest-growing forms of LTC in the United States, although there is no directly comparable licensing category in Germany and no specific reimbursement for care in such settings. Assisted living provides housing and services to individuals who need assistance with activities of daily living (ADLs) but who do not need the more complex medical services available in skilled nursing facilities. Because these services are licensed and regulated by states, assisted living facilities range widely in the types of housing and services they provide. According to a 2006 industry survey (American Association of Homes and Services for the Aging [AAHSA], American Seniors Housing Association, Assisted Living Federation of America, National Center for Assisted Living, and National Investment Center, 2006), the typical resident is female (76 percent), 86 years old (median), and widowed (71 percent). Assisted living residents have median annual incomes of \$15,688.

The supply of assisted living has grown rapidly since its origins in the mid-1980s. The number of licensed assisted living and related residential care units increased by 53 percent between 1998 and 2004, from 612,000 to 938,000 (Mollica, 2006). According to the 2006 industry survey (AAHSA et al., 2006), only 11 percent of assisted living units housed more than one resident. More than two-thirds (69 percent) of the units were in assisted living facilities owned by for-profit providers, with 27 percent in nonprofit facilities, and 1 percent in government-sponsored facilities. In sharp contrast to nursing homes, the vast majority of assisted living residents pay for their services out-of-pocket (52 percent), with the help of family (34 percent), or with private insurance (3 percent). Only 11 percent rely on public sources of payment—Medicaid (8 percent), SSI (2 percent), or veterans' benefits (1 percent).

The rapid growth and relatively light regulation of assisted living has given rise to concerns about the quality of care in some facilities, especially since the disability level of assisted living residents has increased in recent years. Assisted living residents have an average of 2.0 ADL needs for assistance, and a third of residents (33 percent) have dementia or a related cognitive impairment. In addition, the average assisted living resident takes 8.7 medications (AAHSA et al., 2006).

Degree of Provider Competition

Several factors have tended to limit competition with respect to LTC services in the United States. Similar to measures by the German states to limit the number of nursing homes by need, most states have "certificate of need" laws that limit the licensure of new nursing homes. Some states also have imposed license moratoria to stop new construction of nursing homes. The states have generally promulgated these restrictions in an effort to control their Medicaid costs, although there is scant evidence that this strategy is effective (Grabowski, Morrisey, and Ohsfeldt, 2003). For the majority of nursing home residents who rely on Medicaid, competition is also limited by the fact that rates are set by state governments, at levels that providers contend are often below the cost of providing quality care (American Health Care Association [AHCA], 2006).

In contrast, only a few states have imposed restrictions on the supply of assisted living or other types of LTC services, primarily because assisted living has largely been a private-pay market. The resulting growth in assisted living as well as home care has created more competition in LTC in recent years, especially for consumers who can pay privately for care. The competition is also beginning to affect nursing homes as well, as they seek to change the culture of care by offering private apartments as in assisted living, more consumer choice in services, and improved working conditions for direct care staff.

Discussion

- (1) One of the most obvious differences between the German and the U.S. long-term care systems is that eligibility and benefits for LTC services in Germany can be explained relatively simply to consumers. The U.S. LTC system's complexity and fragmentation can frustrate even the most knowledgeable health and LTC professionals. Germany's system for determining eligibility is simpler because it is not means-tested and because it has clear, nationally uniform criteria for each level of care. The fact that all assessments for services are conducted in individuals' homes is another big plus.
- (2) In contrast to the U.S. Medicaid program, everyone in Germany who meets the relatively strict functional eligibility criteria has a choice of benefits in the settings they believe will best meet their needs, their homes or institutions.
- (3) In both countries, eligibility criteria for services often do not adequately capture the needs of persons with cognitive and mental impairments.
- (4) The U.S. trend is toward increasing use of home and community-based services and assisted living, with declining use of nursing homes. In Germany, use of institutional care has been growing modestly.
- (5) Assisted living has been one of the most rapidly growing forms of LTC in the United States, but Germany has no directly comparable licensing category and no reimbursements to encourage such arrangements.

- (6) The supply of providers is said to be adequate in Germany. Occupancy rates in U.S. nursing homes average 85 percent and have declined somewhat over time, indicating that the supply is adequate. However, the average U.S. nursing home is more than 30 years old, so much of the supply may be antiquated and not responsive to what residents want or need.
- (7) In both Germany and the United States, the vast majority of institutional and home care providers are private (at least 90 percent) rather than public. However, Germany has a higher share of for-profit home care providers (58 percent) than does the United States (34 percent). Conversely, the majority of U.S. nursing homes are for-profit (61 percent), compared with 38 percent of institutions in Germany, which has a much larger nonprofit sector (55 percent) (NCHS, 2007); Federal Ministry of Labor and Social Affairs, 2006).
- (8) More flexibility in integrating services into housing is an important issue in both countries.

4. Family Caregiving

Note: In this section, the term, "family caregiver," encompasses both relatives and other informal caregivers, such as friends and neighbors.

Germany

Patterns of Family Caregiving

As in other countries, family members provide most LTC in Germany. One of the explicit goals of German LTC reform was to encourage family caregiving, and enactment of public LTCI brought economic relief for many families. Family caregivers and older persons receiving care generally express a high level of satisfaction with the LTCI program (Meyer, 2007).

In fact, since introduction of the LTC program, there has been a slight increase in the number of informal caregivers involved in support and care at home. More than 90 percent of persons in need of care receive informal support: 36 percent receive care from one primary caregiver; 29 percent from two persons; and 27 percent from three or more persons. On average, two persons, including the primary family caregiver, are involved in domestic care arrangements and providing regular care and support (Döhner et al., 2007).

Profile of Family Caregivers

Women provide the great majority (73 percent) of informal caregiving assistance (Infratest Sozialforschung, 2003). Most caregivers (54 percent) are ages 40–64, with about one-third age 65 or older and about 10 percent younger than age 39. Co-residence is common; in 2003, 70 percent of family caregivers and care recipients were living in the same household or very nearby, and another 14 percent were living no more than 10 minutes apart. As a rule, family

caregiving is a full-time job; family caregivers are actively engaged in caregiving and support tasks an average of 36.6 hours a week (Döhner et al., 2007).

Caregiving Burden

Social isolation, along with physical and mental stress, especially among those who provide intensive levels of care, are among the factors associated with burden in the family caregiving literature in Germany. One nationally representative survey found that only 7 percent of caregivers said they had no physical or mental burdens (Döhner et al., 2007). Caregivers for persons with dementia were at particular risk for serious stress. As in many other countries, dementia is a key factor in nursing home admission in Germany, with aggression, sleep disorders, and incontinence among the most important precipitating factors.

Labor Force Participation and Caregiving

Substantial proportions of working-age family caregivers are in the labor force in both Germany and the United States. As illustrated in Table 5, the proportion of women in the labor force in their mid-40s and through their 50s is quite similar in both countries, although these patterns diverge markedly at age 60. It is predominantly women in these age groups who are simultaneously providing family care and trying to advance their careers, or at least hold onto their jobs in the face of competing priorities.

Age	U.S.	Germany
45–49	79.5%	85.8%
50–54	76.6%	78.6%
55–59	66.8%	69.8%
60–64	47.5%	27.6%
65+	10.7%	1.8%

 Table 5: Percent of Women in the Labor Force, by Age, 2007

Source: ILO, Labor Statistics Database, 1998–2007

Among working-age caregivers (16–64) in Germany, about one-third in the former West Germany are in paid employment, as are about 44 percent of those in the former East Germany (Meyer, 2007). Roughly 16 percent of female caregivers and 8 percent of male caregivers gave up their jobs once they became caregivers, although this share was considerably higher (34 percent) among caregivers who provided daily or constant care.

LTCI Programs to Support Family Caregivers

In addition to a respite benefit of up to four weeks of vacation per year for family caregivers, LTCI beneficiaries may receive day and night care services. Public pension (Social Security) credits are available to persons providing care at least 14 hours a week and who are not otherwise employed more than 30 hours a week; those receiving the credit are overwhelmingly women (Keefe, 2004). The contributions can total up to €382 per month, placing caregiving almost on a par with other jobs subject to social insurance contributions (Federal Ministry of Health, 2006). Family caregivers are also covered under the social insurance program for work-related accidents and injuries.

Free, voluntary courses to provide information and training for relatives and other informal caregivers have been available since the inception of the LTCI program. Only about 10 percent of all informal caregivers participated initially, but the situation is said to be improving (OECD, 2005). Because of the relatively low take-up rate, these courses are now also available in the home of the person needing care, and it is expected that they will be held in the home environment more often in the future.

Care "consultancy" home visits by trained providers, predominantly nurses, must be made at regular intervals to beneficiaries who receive the cash allowance in order to monitor the quality of their care. Visits are also intended to detect health burdens on family caregivers and offer the family advice about services and benefits (Federal Ministry of Health, 2007 b).

Information and training courses are offered outside the auspices of the LTCI program. For example, in Wiesbaden, the Department of Social Work runs a course for older volunteers who wish to support family caregivers who need a few hours of free time; courses for migrant family caregivers in Wiesbaden are also offered to Turkish migrants in both Turkish and German (Mestheneos and Triantafillou, 2007).

Other Services/Supports Needed

In addition to the LTCI services summarized above, various forms of counseling, self-help groups, and hotlines may be available under various auspices. In a recent cross-national analysis of such service use among caregivers in Europe, only about 20 percent of family caregivers in Germany reported using at least one of these supportive services. Caregiving husbands were more likely to use formal services and caregiving wives to use self-help groups. Fewer caregivers reported using available services and supports in Germany than in some other European countries, a situation that researchers attribute in part to Germans' reticence to use formal services, especially those that involve personal activities requiring "strangers to meddle" in the household (Döhner et al., 2007).

One of the biggest service gaps was emotional/psychological support, with more than 40 percent of caregivers in Germany asking for additional support in this area (Döhner et al., 2007). In addition, working female caregivers who expressed the greatest level of burden had the biggest gap in getting support.

Services involving short home visits seemed to bring the greatest relief to family caregivers by permitting them to escape the everyday routine of caring, for example, by pursuing special activities, either alone or with the care recipient (Döhner et al., 2007). More "light" care services to help give caregivers a break, such as someone to accompany an older person to the doctor or to shop, are also needed (Mestheneos and Triantafillou, 2007).

United States

Patterns of Family Caregiving

The unpaid care family caregivers provide has been the predominant source of LTC for older persons with disabilities in the United States for many years. In 2004, an estimated 44.4

million caregivers age 18 and older (21 percent of the adult population) provided unpaid care to an adult family member or friend (National Alliance on Caregiving (NAC) and AARP, 2004). More than 90 percent of persons age 65 and older with disabilities living in the community care receive informal care, either alone or in combination with formal care (Spillman and Black, 2005).

Debate continues over how family caregiving patterns may be changing over time. The use of any formal, paid care declined significantly among persons 65 and older living in the community between 1994 and 1999, while sole reliance on family caregivers increased. The reasons for this decline are not clear, but they may in part reflect new restrictions on Medicare home health benefits over that same period (Spillman and Black, 2005).

Profile of Family Caregivers

According to a nationally representative survey, the "typical" family caregiver is a 46-yearold woman who has some college education and provides more than 20 hours of care each week. More caregivers are women (61 percent), as are more care recipients (65 percent), many of whom are widowed. The average age of care recipients is 66 (NAC and AARP, 2004). About one-quarter (24 percent) of caregivers live in the same household as the care recipient, and about 42 percent live no more than 20 minutes away.

Caregiving Burden

Factors associated with higher levels of burden among caregivers include fair or poor health, lower income, and living with the care recipient. Caregiving appears to create more emotional stress (reported by 35 percent of caregivers) than physical stress. The two greatest predictors of emotional stress are the intensity of the care provided and whether caregivers felt they had a choice in assuming the caregiving role (NAC and AARP, 2004).

Health problems among caregivers are beginning to be recognized as an emerging public health concern (Talley and Crews, 2007). Caregivers report having one or more chronic conditions at nearly twice the rate of non-caregivers (45 percent vs. 24 percent) (Ho et al., 2005). Spousal caregivers (age 66–96) who have a history of chronic illness and who experience mental or emotional stress have a 63 percent higher mortality rate than non-caregivers (Schultz and Beach, 1999).

Labor Force Participation and Caregiving

Most caregivers work either part time or full time (59 percent) while providing care (NAC/AARP, 2004). Changes in work patterns resulting from caregiving responsibilities in midlife can have particularly serious consequences for income, job security, and retirement savings. Caregiving has been found to reduce paid work hours for middle-aged women by about 41 percent (Johnson and Lo Sasso, 2006). Caregivers may also receive reduced Social Security benefits due to lower earnings, more limited access and contributions to employer-sponsored pensions and 401(k) plans due to working part time, and more limited personal savings due to less time in the workforce (Young and Newman, 2003).

While some caregivers in the workforce report making no or few adjustments in their work life, the vast majority (92 percent) of those with the most intense level of caregiving responsibility report one or more major changes in their working pattern. These changes included including having to take a leave of absence, going from full time to part time, and giving up work entirely (NAC and AARP, 2004).

Programs to Support Family Caregivers

Existing federal and state programs offer some assistance to family caregivers. For example, modest financial assistance may be available through the tax system to some caregivers:

- Federal law allows a caregiver to classify an older person receiving care as a dependent and claim a personal exemption, if the caregiver and care recipient live in the same house and meet other strict criteria. Relatively few caregivers can claim this dependent care tax credit.
- Taxpayers who itemize their income tax deductions may deduct qualified LTC expenses (including for a dependent) if their combined medical and LTC expenses exceed 7.5 percent of the taxpayer's adjusted gross income.
- Some employers provide flexible spending accounts for dependent care as a benefit to employees who are caring for a dependent child or an adult who is incapable of caring for him or herself. These accounts allow employees to reduce their taxable salary by the amount of money they elect to contribute, up to a maximum of \$5,000 per year.

One of the most important federal programs assisting family caregivers is the National Family Caregiver Support Program (NFCSP), enacted in 2000 as part of the Older Americans Act. NFCSP funds enable states to provide services for persons caring for (1) individuals age 60 and older; (2) persons with dementia; and (3) grandparents or relative caregivers age 55 and older caring for children 18 and under or a child of any age with a disability. The program provides five basic services:

- information about available services;
- assistance in gaining access to supportive services;
- individual counseling, support groups, and caregiver training;
- respite care; and
- supplemental services, on a limited basis

The NFCSP, along with HCBS waivers and state-funded respite care and family caregiver support programs, provides the bulk of public financing to support family caregiving (Feinberg, Newman, and Fox-Grage, 2005). For Medicaid HCBS waiver programs, total national respite expenditures in fiscal year 2002—the most recent year for which these data are available—were about \$101 million. Total funding for the NFCSP was about \$156

million in FY 2007, which represents only a minute fraction of the estimated value of unpaid family caregivers' contributions (Gibson and Houser, 2007).

Assistance for family caregivers is also provided through the federal Family and Medical Leave Act, which allows workers in companies with 50 or more employees to take up to 12 weeks of leave to care for an ill parent. Employers are not required to provide paid leave. However, in 2004, California implemented the California Paid Family Leave Law, the nation's most comprehensive paid family and medical leave program, which provides most workers with up to six weeks of pay equal to 55 percent of their weekly earnings, to a maximum of \$882 per week in 2007 (Sherriff, 2007). A limited number of other states have enacted some kinds of leave with partial pay for some employees.

The availability of caregiver support services varies considerably across states. Some states, such as California, Florida, New Jersey, and Pennsylvania, commit significant state general funds to provide respite and other direct caregiver support services. Local access to information about programs and services also differs within and between states. For example, programs may make services available in one part of the state but not in others, or they may use differing eligibility criteria and service limits.

Use of Services and Service Gaps

Almost half of all caregivers (48 percent) use one or more supportive services, with persons caring for someone with dementia more likely to use services than others (NAC and AARP, 2004). The most commonly used services are information about financial help (25 percent); training (18 percent); and transportation services (18 percent). Only about 5 percent of caregivers enrolled the care recipient in adult day care or used a respite service.

The most frequently mentioned unmet needs for help or information are finding time for oneself, keeping the care recipient safe at home, balancing work and family responsibilities, and managing emotional and physical stress (NAC and AARP, 2004).

Discussion

- (1) Encouraging family support was one of the key objectives of Germany's public LTCI program, and benefits under the program are more generous than those currently available to caregivers in the United States. For example, Germany provides up to four weeks of respite per year and pension (social security) credits to assist eligible caregivers with their future retirement security.
- (2) While the data presented above are not directly comparable, some cross-cutting themes emerge. Only relatively small proportions of caregivers use the supportive services that are available in both countries, making improvements in outreach and more "user-friendly" information and referral services imperative. Finding effective ways to encourage family caregivers to participate in training opportunities, which are free of charge in Germany, is also difficult. And in both countries, the emotional stress of caregiving is at least as, or even more onerous than, the physical burden, yet counseling and self-help programs are often limited. Similarly, caregivers for persons

with dementia are usually at highest risk for very serious stress, which is often an important factor in nursing home admissions.

- (3) Substantial proportions of working-age family caregivers are in the labor force in both Germany and the United States. At the same time, both countries have labor forces that are aging, so finding ways to keep informal caregivers and other older workers in the labor force longer will be essential to the economic health of both nations.
- (4) In both Germany and the United States, expert opinions vary concerning the extent to which family caregiving patterns may change in the future. For example, in Germany, some have argued that LTCI benefits permit caregivers to continue in their role, particularly when unemployment rates are high (Mnich and Döhner). Others believe changing social roles and norms will mean that formal sources of care will become much more important (Rothgang, 2003).

5. Workforce Issues

Germany

In 2005, more than two-thirds (68 percent) of long-term care beneficiaries received assistance at home, and one-third (32 percent) received care in an institution. The workforce profile in these two settings differs considerably. Most of those living at home receive care exclusively from family or friends (46 percent), although 22 percent receive some professional support. Only 29 percent of workers providing care in the home work full time; 46 percent work part time, and 21 percent have "mini jobs" where they work very few hours. In contrast, 42 percent of nursing home workers have full-time jobs, 41 percent are part time, and 10 percent are "mini jobbers." The vast majority of professional caregivers, 85 percent, are women (Rothgang and Igl, 2007).

Strong growth in the supply of home care providers, which by law must be private (either nonprofit or for-profit), was sparked by introduction of the social insurance plan. The Ministry of Health and Social Security sees the supply of home care providers today as sufficient (OECD, 2005). In terms of the overall LTC workforce, over 250,000 new jobs have been created since the introduction of LTCI (Federal Ministry of Health, 2006b). Looking to the future, Rothgang and Igl (2007) project that the demand for LTC workers will increase by 70–130 percent between 2000 and 2040, with increased demand primarily in nursing homes. During the same period, they project that the number of full-time LTC workers will decrease by 28 percent—100,000 workers—if current rates of entering the caring professions remain constant.

The fact that the German system allows for agency-provided services in the home at a higher reimbursement rate than for cash benefits means Germans do not have a large incentive to hire home care workers from the gray economy of "irregular" workers from other countries as is common in Italy and other European countries. Nonetheless, the last few years have seen an increase in domestic care workers from eastern Europe, particularly Poland, the

Czech Republic, and Slovenia. These workers are often employed to do household tasks but are also required to provide care, sometimes remaining on duty 24 hours a day.

The "irregular" status of these privately paid household workers was legalized recently through adoption of new migration and work laws. Foreign domestic care workers can now receive a work permit for up to three years of full-time employment to help in private homes with persons in need of care in compliance with the long-term care insurance law. Generally, work by individuals from the new states of the EU in the LTC sector (as in other sectors of the economy) can only be temporary and occasional. More permanent work permits are still subject to tight restrictions, although more labor market liberalization in the EU is scheduled to begin in 2009.

"Elder care" in Germany is a separate occupational category, differing from "nursing care" with respect to education and licensure. A new law enacted in 2000 requires three years of nationally uniform training for "elder care," which more closely resembles training for nurses, with stipends provided for training. This law seeks to improve the training of care providers and increase the attractiveness of the profession. Nonetheless, some have argued that specific credentials for "elder care" traps professional workers in low-wage, low-prestige jobs when they could have access to higher-paying jobs in health care by seeking a nursing degree (Rothgang and Igl, 2007). For home care aides, training must be for one year; the Länder have greater flexibility in setting curriculum for aides than they do for skilled "elder care" workers (Cuellar, 2003).

The contributions of nurses, including nurse practitioners, are seen in Germany as central to achieving "integrated home care," which helps beneficiaries to manage daily activities and achieve as much independence as feasible. The great majority of LTCI beneficiaries receive care exclusively from family caregivers, but many need professional help in the form of information and support. Hence, the role of home care nursing in Germany is seen as encompassing advisory and coordinating responsibilities in partnership with informal caregivers and other professionals, such as nutritionists and social workers (Kesselheim, 2001).

United States

In discussing projections for demand of long-term care workers in the U.S., Friedland (2004) observes:

[A]fter 2015 the number of people likely to need long-term care will increase substantially faster than the number of people available either as family or as paid caregivers. Families will need more support to supplement their efforts and more paid caregivers will be necessary to provide this support. (p. 1)

For example, the U.S. Department of Health and Human Services (2003) projects that between 2000 and 2010, the number of workers providing LTC services (including nurses, aides, and personal care workers in institutional and home-based settings) will grow from 1.9 million to 2.7 million, a 45 percent increase. Looking further into the future, the demand for LTC workers may increase to between 3.8 million and 4.6 million by 2050—a 100–140 percent increase over 2000 levels. However, the U.S. population age 15–64 is only projected to increase by 27.2 percent between 2005 and 2050. The Health Resources and Services Administration (2004, p. 6) notes that the shortfall may be especially critical for aides and other paraprofessional workers since "[t]he pool...from which such workers have traditionally been drawn—largely women between 25 and 50 without post-secondary education—continues to shrink."

Recruiting and retaining sufficient workers to provide quality services have become increasingly difficult because of low wages and inadequate benefits, lack of respect or appreciation, lack of advancement opportunities, and inadequate training. Too often, direct service workers carry workloads well beyond the safe limits recommended in professional standards. To address the shortage of workers, the United States has increasingly turned to employing foreign-born and -trained workers (Redfoot and Houser, 2005). The number of foreign-born nurse aides in LTC settings increased fourfold between 1980 and 2003, more than doubling the proportion of foreign-born aides in such settings from 6 percent to 16 percent. Growth was even more dramatic among foreign-born nurses, as their numbers grew more than sixfold, and the proportion of foreign-born nurses in long-term settings also increased from 6 percent to 16 percent (see Table 6).

Table 6: Foreign-Born Nurses and Nurse Aides in the United States in LTC Settings,1980–2003

	1980	1990	2000	2003 ACS
Foreign-born nurses, % of total	6%	7%	13%	16%
Number of foreign-born nurses	9,900	17,700	51,000	64,000
Foreign-born aides, % of total	6%	9%	14%	16%
Number of foreign-born aides	34,000	71,000	115,000	145,000

Source: AARP Public Policy analysis of data from 1980–2000 U.S. Decennial Census and 2003 American Community Survey, 2005.

Discussion

- (1) Both Germany and the United States are facing major labor force shortages in meeting future demand for LTC services. While the current supply of workers is seen as adequate in Germany, the long-term outlook may be more challenging there because of the decline in the working-age population.
- (2) In both countries, families are the primary caregivers for older persons with disabilities. However, German family caregivers can enlist more formal support from services ranging from training to respite. Such professional support has been shown to reduce "burnout" among family caregivers and may be critical to maintaining high levels of family support in the future.
- (3) In both countries, women provide the overwhelming majority of professional and informal caregiving. As labor force participation rates increase among women, more family caregivers are dealing with the combined stresses of family and work responsibilities.

- (4) Both countries have seen growth in recent years in the number of foreign-born workers providing LTC services, some working in the gray economy where they do not pay taxes or receive benefits. The incentives to hire such workers may be less in Germany, where agency-provided home care is an option for LTC beneficiaries. European integration is also regularizing the flow of workers from new member states who account for many of Germany's foreign workers.
- (5) Germany has created a special credential of "elder care" for nurses in the LTC sector, while nursing degrees in the United States are not specific to LTC. The German approach provides much more training on issues of specific relevance to caring for older persons than does training in the United States, but this degree does not allow mobility into higher-wage jobs in the acute health care sector.
- (6) LTC work in both the United States and Germany is characterized by lower pay and lower prestige than work in other health care sectors. In the United States especially, these characteristics have contributed to very high turnover rates and poor morale among professional caregivers.

6. Quality and Consumer Satisfaction

Discussions about quality in LTC often distinguish among three ways of addressing care issues: structural indicators (such as life safety codes or staffing ratios), process indicators (such as the use of restraints or medication management errors), and outcomes indicators (such as changes in functional status or consumer satisfaction). While all three types of indicators have always received attention in some fashion in both countries, tracking the focus of policy discussions in both countries can illuminate similarities and differences in the German and American systems of promoting quality LTC services.

Germany

The transition from a program based on means-tested social assistance to social insurance raised the "status" of LTC and increased attention to quality assurance as well. Rothgang and Igl (2007) suggest that "[q]uality in the field of LTC was not really an important issue before the enactment of the LTC-Act in 1994." The responsibility for licensing facilities and monitoring quality was with the Länder, and the primary focus was on structural aspects of quality such as building code requirements, staffing qualifications, and requirements for equipment. Little attention was paid to process, let alone outcomes factors.

As new monies flowed into both home care and nursing home care, the focus on quality also increased (Cuellar, 2003). The LTC insurance funds are required to oversee quality in nursing homes and home care as part of their responsibilities, but local and state authorities continue to play their traditional roles in quality monitoring for nursing homes. The LTC insurance funds oversee the quality of LTC through their contracts with home care agencies and nursing homes, while the Länder use their authority to license and certify nursing homes as the basis for quality monitoring. Providers have complained about the double oversight that has resulted, and LTC insurance funds and local regulators have worked increasingly to carry out joint inspections. Similarly, Länder sometimes have blocked new quality measures

out of concerns about costs (Wiener, Tilly, Cuellar, Howe, Doyle, Campbell, and Ikegami, 2006).

While data about quality issues are scarce, a 2003 federal report on the quality of LTC provides some insights about quality issues. Results from scheduled and complaint-generated reviews of home care and nursing home providers showed that nursing homes, particularly large ones, generally fared well when structural aspects of care were measured, but they often fell below standards on process issues related to resident care. For example, 83 percent of nursing homes had a defined model of care, a description of care processes, internal communication channels, and a quality assurance system. But only 54 percent of facilities conducted their own audits of care, and 51 percent documented the capabilities of each resident. Consumer satisfaction rates were high, exceeding 90 percent across a number of categories, even though care was considered to be below minimum standards in 17 percent of client cases reviewed.

Only 68 percent of home care agencies had adequate quality assurance mechanisms, and only 52 percent conducted their own audits of the care provided by their staff. Staffing levels for direct care personnel and management were considered adequate for most agencies, but 60 percent of agencies had deficiencies in documentation of care. Home care agency reviews showed that more than 90 percent of consumers and families interviewed were satisfied with their home care services, but care reviews showed that in 9 percent of client cases, care was considered to be below minimum standards. In only 39 percent of cases did home care agencies note individuals' capabilities and deficits (Wiener et al., 2006).

To address these problems and bring greater uniformity of standards throughout the country, the Health Insurers' Medical Service, which oversees the medical offices of the LTC insurance funds, established quality inspection guidelines that have been in force since January 2006 (Federal Ministry of Labor and Social Affairs, 2006). These standards have focused primarily on process issues, such as assessments of beneficiary needs. New expert standards are also being developed, including those for prevention of decubiti (bedsores), discharge management, pain management, fall prevention, and incontinence management.

Neither the LTC insurance funds nor the Länder are responsible for overseeing the quality of services for the majority of beneficiaries who receive cash benefits. These beneficiaries are required to have counseling by a formal home care provider, the frequency of which ranges from every three to six months, depending on the level of care the beneficiaries can use (Rothgang and Igl, 2007). But since there are no restrictions on what beneficiaries can use the cash benefits for, and caregivers are almost always family members, this system of oversight rarely results in any official actions (Wiener et al., 2006).

United States

One can broadly characterize the history of public policy discussions about LTC quality in the United States as an evolution from a focus on structural issues in the early years to more focus on process issues in middle years to a recent focus on measuring, reporting, and rewarding quality outcomes (Capitman, Leutz, Bishop, and Casler, 2005). As in the German system, licensing and regulation of nursing homes was historically the states' responsibility.

There were no national standards for regulations, and monitoring and enforcement systems were very uneven from state to state.

Based on a 1986 report from the Institute of Medicine, Congress enacted the Nursing Home Reform Act as part of the Omnibus Budget Reconciliation Act (OBRA) of 1987 (IOM, 2001). OBRA established national standards and provided the means for federal payments to state agencies to monitor and enforce standards. Home health agencies also come under federal regulation through certification in the Medicare and Medicaid programs. But other forms of LTC, most notably assisted living and related forms of residential care, are almost exclusively regulated and monitored by the states with no federal standards or oversight.

The United States undoubtedly has the most adversarial approach to quality assurance for nursing homes among developed countries (Wiener et al., 2006). In other words, the emphasis of the quality assurance system is enforcement of regulations through penalties for noncompliance. While the Institute of Medicine's 2001 review of the quality of LTC concluded that nursing home care had improved in some areas, most notably in reducing chemical and physical restraints, it also noted persistent problems in many areas of the quality of care. The Government Accountability Office (GAO, 2007) has found that nearly one in five nursing homes was cited for serious deficiencies that caused actual harm to residents or placed them in immediate jeopardy of harm. As in Germany, providers complain about too much regulation, and consumers complain that too little attention is paid to consumer choice and quality of life (Institute of Medicine, 2001).

While much of the regulation that resulted from OBRA '87 focused on structural and process issues, the statute also emphasized promoting better measures of functional and clinical outcomes and stressed the need to improve the quality of life and the quality of care. Development of measures of outcomes has been slow, but steps by the federal Centers for Medicare and Medicaid Services (CMS) have emphasized comparative measures of outcomes that consumers can access to make more informed decisions about which nursing homes to use. Though it has received some criticism (GAO, 2002), a "nursing home compare" website has been established by CMS with outcomes measures in key quality domains that allow consumers to make comparisons. CMS is also funding some demonstrations to test "value-based" or "pay-for-performance" reimbursement mechanisms to improve quality by rewarding high-quality outcomes (CMS, 2007).

One of the most significant developments in promoting a new approach to quality has not come from government regulation or policy, but from a "culture change" movement among long-term care providers, consumer advocates, regulators, and other stakeholders (see www.pioneernetwork.org). While culture change has no official definition or standards, it has focused on three major elements of LTC: 1) changing the service delivery model to give consumers more choice and control over the services they receive; 2) changing the physical settings of care to provide more private rooms and apartments and a more residential atmosphere; and 3) changing the staffing model to give more control, more training, and better compensation to the paraprofessional direct care staff (Weiner and Ronch, 2003). One specific approach to culture change, the "Green House" approach, recently received a \$10 million award from the Robert Wood Johnson Foundation to replicate the model in all 50 states. While it is too early to evaluate the impact of the culture change movement, early

research on the Green House model (Kane et al., 2007) has found significant improvement in the quality of life and some functional measures among residents when compared to residents in more traditional nursing homes. Staff turnover rates were also sharply reduced in the Green Houses.

Discussion

- (1) The federal systems of Germany and the United States divide responsibility for regulating and enforcing quality between federal and state governments. Both countries have moved toward more national uniformity in standards, although Germany still has divided responsibilities between the Länder and the LTC insurance funds with respect to nursing homes. The United States has federal regulations for nursing homes but state regulations for assisted living and other supportive housing.
- (2) The regulations in both countries have been accused of being too focused on structural and process aspects of LTC and too little concerned with quality outcomes. The United States has funded research and demonstrations related to measuring and reporting quality outcomes, and some of these measures have become the model for efforts to develop international measures of quality in a variety of LTC services and settings (interRAI, 2007).
- (3) Neither country generally makes any adjustment in payments to reward high quality or to reduce payments for low quality. However, the United States is experimenting with some demonstrations for value-based purchasing or pay-for-performance.
- (4) Both countries have some regulatory barriers to quality and price competition. A larger private-pay sector in the United States, especially in assisted living, may promote innovation in services, but these services remain out of reach for many lowincome older people. Germany has taken steps recently to promote more service provision from profit-motivated providers.
- (5) The "culture change" movement is a private sector response to consumer demand that is beginning to develop different models of service in the United States.

7. The Long-Term Care Reform Debate

Germany

The maturing of the German LTCI system has been accompanied by increasing debate among policy makers, policy analysts, and other stakeholders about ways to improve and sustain it. In addition, a number of commissions, including the "Parliamentary Enquete Commission on Demographic Change (2000), the Ruerup Commission (2003), and the Council of Economic Advisors (2004/05), have held expert group meetings to evaluate LTCI. In June 2007, the coalition parties of the Social-Democratic Party of Germany (SPD) and the Christian Democratic Union (CDU/CSU) agreed to resolutions to reform LTCI, which served as the foundation of the bill introduced into the German legislative process in September (SPD and CDU/CSU, 2007). Reforms are intended to permanently stabilize LTCI as a core security system. The benefit levels, which have not been increased since the program was introduced, will be increased gradually between 2008 and 2012, and subsequently indexed to inflation every three years, beginning in 2015. In addition, emphasis on home care over institutional care will be reinforced, and new steps will be taken to encourage rehabilitation and prevention. Another key objective is to ensure both financial sustainability of the system and fair distribution of the financing burden. Hence, the general premium rate will be increased by 0.25 percent as of July 1, 2008 (from the current 1.7 percent to 1.95 percent) to meet the modest shortfall in revenues and to finance the benefit improvements.

More specific reforms included in the legislation that is currently being debated are:

Encouraging Home and Community-Based Care Based on Individual Needs

- Funding will be provided for "integrated local care and support stations" to provide a type of "one-stop center" for information and counseling about health, LTC, and social service benefits for older persons and persons with disabilities.
- Beneficiaries will receive the legal right to assistance and advice, and public LTC insurers will be required to offer care management to meet individual needs. Care managers will be integrated into the local support centers, with a guideline of 100 beneficiaries per one care manager. Care managers will develop coordinated care plans for all beneficiaries who request assistance; however, beneficiaries will not be required to have a care manager.
- More funds will be made available to strengthen volunteer programs, such as support groups for family caregivers of persons with dementia, "helper circles," and other voluntary initiatives.
- Public LTC insurers, which now can only contract with entities such as home care agencies or nursing homes, will have more flexibility to enter into contracts with qualified individual providers.

Increasing Benefit Levels

- Benefits levels will be increased gradually between 2008 and 2012 for the cash allowance, formal home care services, and institutional care (see Table 7).
- Formal home care and institutional care benefits will be put on a more level playing field, by increasing benefits for both the cash allowance and agency-provided home care and not increasing benefits for persons in institutional care who do not have very severe disabilities (levels 1 and 2)
- The supplementary amount for persons who need considerable general care, particularly those with dementia who require considerable supervision and services, will be increased from the current €460 (\$658) to €2,400 (€3,431) per year.

Disability Level	Cash benefit		Home service benefit		Full-time institutional care benefit	
I–Substantial	Current	€205	Current	€384	Current	€1,023
	2008	€215	2008	€420	2008	no change
	2010	€225	2010	€ 440	2010	no change
	2012	€235	2012	€450	2012	no change
II–Severe	Current	€410	Current	€921	Current	€1,279
	2008	€420	2008	£ 980	2008	no change
	2010	€430	2010	€1,040	2010	no change
	2012	€440	2012	€1,100	2012	no change
III-Very Severe	Current	€665	Current	€1,432	Current	€1,432
	2008	€675	2008	€1,470	2008	€1,470
	2010	€685	2010	€1,510	2010	€1,510
	2012	€700	2012	€1,550	2012	€1,550
Special cases			Current	€1,918	Current	€1,688
			2008	no change	2008	€1,750
			2010	no change	2010	€1,825
			2012	no change	2012	€1,918

 Table 7: Proposed Increases in Monthly Benefits for Home Care and Institutional Care

 in Germany (in Euros), 2008–2012

Source: (SPD and CDU/CSU, 2007).

Encouraging Prevention and Rehabilitation Services for LTCI Beneficiaries

- Financial incentives will encourage both local "support stations" and nursing homes to provide preventive and rehabilitative services. For example, nursing homes will receive a one-time payment, around €1,536, for each resident who is able to move to a lower level of care.
- Health insurance funds will be obliged to provide rehabilitative services recommended when individuals are assessed for LTC eligibility in a timely manner, or they will have to pay a penalty to the LTCI fund.

Supporting Family Caregivers

• A new family leave policy for caregivers will entitle employees to (1) leave for up to 10 days to care for relatives and (2) unpaid leave for up to six months while retaining their right to return to their job. Employers with fewer than 10 employees are exempt. Continuous public pension (social security) coverage is ensured, with premium subsidies from the public LTCI fund in some circumstances.

Encouraging New Combinations of Housing with Services

• More flexible use of LTCI benefits in new forms of shared housing will be permitted. For example, retirees who are sharing homes or small groups living in sheltered housing will be able to pool their formal service entitlements.

Expanding Quality Assurance

• The measures for quality assurance will be expanded, for example, by (1) requiring that internal quality improvement initiative be taken into account during quality inspections by the LTCI insurance funds and (2) requiring publication, in consumer-friendly language, of the results of inspections of nursing homes and home care agencies.

Encouraging Options for Supplementary Coverage

• Individuals' options for supplementary private coverage will be expanded. Social health and LTCI insurers will be treated more like private insurers, for example, they will be permitted to offer new optional private insurance plans.

The 2007 draft resolutions of the government coalition partners, the SPD and the CDU/CSU (2007), reflect the culmination of internal discussion of diverse proposals that are summarized briefly below to inform debate in the United States and other countries. These proposals have ranged from modest coverage expansions to benefit improvements within the existing system to more radical structural overhaul.

Structural Reform Proposals

Financing reform proposals, in particular, have reflected the ideological spectrum, from conservative to progressive. They have ranged from proposals for a fully private system—in which the current LTCI social insurance program would be converted to mandatory private insurance—to a fully public, tax-funded system that would apply to everyone, including higher-income individuals and civil servants, and would entirely eliminate private insurance. Another area of fundamental disagreement is whether the current "pay as you go" system based on payroll taxes should be converted into a fixed-premium, fully funded system, with each generation building its own capital stock from lifetime paid contributions; this option was also debated at length before enactment of the current social insurance program (Cuellar, 2007b).

Reforms within Existing System

While more radical proposals often seem to receive the most attention, general agreement in Germany about reforming the existing system seems to have been building for some time. Listed below are some of the reforms that reportedly have been widely supported by expert opinion and/or the general public.

Improve Benefits and Coverage

- Adjust benefits according to some measure of inflation.
- Put benefits for formal home care services and nursing home care on a more level playing field, especially for beneficiaries with moderately severe limitations, where the gap is largest.
- Make benefit options more flexible, so care arrangements are not classified as either home care or institutional care, which has disadvantaged persons living in small-group residences and other alternative housing settings (Rothgang, 2002, p. 69).
- Provide better coverage and benefits for persons with dementia and others. The current benefit of only €460 a year, taken as a first step in 2002, is widely considered to be inadequate. Almost as soon as the LTCI program was introduced, debate began over the definition of "dependency," which is considered too narrow and too oriented toward physical limitations (Naegele and Reichert, 2002). Persons with dementia and younger persons with developmental disabilities and mental illnesses, for example, may need supervision or some support, but they are not covered.

Expand Revenues

- Raise the contribution rate, at least modestly.
- Provide some tax-financed subsidies or contributions, which both the public pension system and health insurance system now receive.

One potential reform that is still being examined is introducing individual budgets similar to those in the Netherlands and in some U.S. states that permit consumer-directed home care. A "personal care budget" evaluation and demonstration program, initiated in 2005, will conclude in 2008. A total of up to 900 persons in seven regions in the Federal Republic of Germany will receive a budget equal to the amount for formal home services, which they may use for care by informal caregivers, individual "freelance" providers, or licensed service providers. The providers are not required to have a contract with an LTC insurance fund, but they must have legal status. Care managers will play an important role in the pilot program by helping recipients and putting pressure on service providers to work more flexibly (Federal Ministry of Labor and Social Affairs, 2006).

United States

During the late 1980s into the mid-1990s, serious efforts were made to put LTC reform "on the public policy map." The Long-Term Care Campaign, a coalition of organizations that included AARP, the Alzheimer's Association, and the Villers Foundation, was successful in getting LTC issues on the 1988 Presidential election agenda. During this same period, several legislative proposals would have resulted in significant expansion of publicly supported LTC services, that is, those from the 1989 Pepper Commission on Long-Term Care (1989) and a proposal for creation of a large home care program for people of all ages and incomes as part

of the Clinton administration's 1993–1994 Health Security Act (Wiener et al., 2001). With the demise of the major health care reform and the Health Security Act in 1994, discussion of universal, publicly funded LTC also fell off the federal policy agenda.

Since the mid-1990s, much of the policy debate has focused on reducing Medicaid costs, rebalancing Medicaid LTC spending toward more home and community-based care, and encouraging the purchase of private LTC insurance through tax incentives. For example, Medicaid eligibility standards and cost-recovery requirements were tightened in the Deficit Reduction Act (DRA) of 2005. That legislation also included features to "rebalance" the Medicaid program toward more HCBS and to promote independent living options for people with disabilities. The Olmstead Supreme Court decision in 1999, in which the Court ruled that the Americans with Disabilities Act requires states to provide care for people with disabilities in community settings when appropriate, provided important legal support and incentives to the states in their efforts to rebalance their LTC systems toward HCBS.

Arguably, the most significant LTC reforms in the last several decades have occurred at the state level. For example, long before most other states, both Washington and Oregon began efforts to expand HCBS for persons with disabilities and limit institutionalization in the 1980s, and they have continued to be leaders in promoting consumer choice in LTC. Other examples include New Jersey's nursing home transition program and a bold initiative in Vermont that would replace most of the state's existing Medicaid LTC program.

Only recently have more comprehensive proposals for LTC reform begun to reemerge at the federal level. The National Council on Disability (2005) published a detailed review of options for financing and system reforms for long-term services and supports for Americans of all ages with disabilities. More specific proposals are now beginning to emerge, including: (1) the CLASS Act, a pre-funded program that would provide cash benefits to working-age persons with disabilities; and (2) a discussion paper by the American Association of Homes and Services for the Aging (AAHSA), which represents non-profit providers of aging services, with some key features similar to those of Germany's LTCI system.

Many of the major LTC reform options at the federal level, recently categorized and analyzed by the Georgetown University LTC Financing Project (Feder, Komisar, and Friedland, 2007), fall into four major groups:

- Promote private LTC insurance by making it more affordable, for example, through tax incentives, or improve its benefits and overall value.
- Expand the Medicaid safety net for persons with low incomes.
- Establish public "catastrophic" insurance with private insurance to "fill the gap."
- Establish universal public LTCI.

None of the proposals in this category would meet all costs and needs, but would provide a core benefit that private insurance could supplement, leaving roles for both complementary private insurance and a social assistance "safety net." Proposals vary in such features as the

scope of benefits provided; degree of beneficiary cost sharing; whether cash benefits or both service and cash benefits are provided; and financing mechanisms, for example, general revenues, increases in payroll tax, income tax, or possibly a new value-added tax (VAT).

Discussion

Reform proposals in the United States today generally fall into the same broad categories as those discussed in Germany before enactment in 1994 of social LTCI. Some experts have argued that the much greater constitutional power of the Länder, compared with American states, was a determining factor in the different paths the two countries have taken to reform (Campbell and Morgan, 2005). In addition, the burdens of reunification in the early 1990s led to major deficits in the Land and local governments, leading to calls for fiscal relief. Unlike in the United States, Germany's strong fiscal equalizing tools, with a common pool of tax dollars, make the fiscal health of the Länder far more interdependent than in the United States, where states have incentives to maximize their share of federal resources vis-à-vis other states. Hence, the Land governments were able to act from a more powerful and united position in pressing for LTC reform to help alleviate the budget crises. Ironically, say Campbell and Morgan (2005), the solution to fiscal crisis in Germany was to expand rather than scale back social protections through the new contributory LTCI program that freed up general revenues.

8. Conclusions and Implications

As both countries look to provide LTC coverage to their citizens, improve quality, and increase consumer choice, the ways in which financing, benefit options, and quality assurance are structured can have unintended consequences that these countries can better anticipate by comparing experiences.

Financing

The German experience suggests that providing universal coverage for LTC is fiscally feasible. The two countries currently spend about the same proportion of GDP on LTC, but distribute those costs very differently. The key issue is: who bears the risk?

- (1) individuals through private savings and use of housing equity;
- (2) private insurance, possibly with support from the public sector, for example, tax incentives;
- (3) general revenues, through a means-tested social welfare approach that provides a safety net for lower-income individuals;
- (4) universal public insurance funded through general revenues; or
- (5) social insurance through dedicated contributions.

The options above, of course, are not mutually exclusive. Indeed, the social insurance benefits in Germany are basic, not comprehensive, leaving roles for private insurance and individual personal contributions in cost sharing. Germany's safety net also remains in place as a critical protection for low-income individuals.

As in Germany over a decade ago, concern is growing in the United States that the Medicaid safety net will be under increasing pressure as a result of demographic changes and increasing demands on state budgets. Today, many Americans with disabilities experience unmet needs for assistance with the most essential daily activities. And the financing options available today leave the middle class without much recourse.

One of the thorniest issues in expanding coverage in the United States is to how treat older persons who already need LTC services or who are at risk of needing such services in the near future. They are not eligible for private LTCI due to underwriting, yet covering these individuals under a "pay as you go" plan is often seen as prohibitively expensive and unfair to other generations because they would reap "windfall" benefits while making only minimal contributions. Because of the expense, proposals to fully "pre-fund" future benefits also do not tend to encompass those who need LTC today, whose more limited incomes also are rarely adequate to bear all of the costs of "buying into" such programs without any subsidies. In addition, younger individuals have widely varying abilities to pre-fund their LTC costs because of long-term disabilities or low wages. Germany's experience here is instructive. In implementing its "pay as you go" financing system, Germany also built up a substantial reserve as the program was phased in. It subsequently doubled the contributions paid by pensioners (from 0.85 percent to 1.7 percent of their pensions) when deficits arose. While that was not an ideal situation, it was far better than the alternative of leaving these individuals without any coverage except the existing "safety net."

Germany's LTCI program was implemented with surprisingly few difficulties, and it continues to maintain broad popular and political support more than a decade later (Cuellar, 2003). To date, only relatively minor changes in contributions and changes have been implemented.¹⁹ However, evaluation and discussion are ongoing among German political parties about the future of the LTC insurance program and periodic adjustments, including the upcoming reforms. These reforms, the most far reaching since the program was enacted, are intended to address many of the problems that have been identified, including financial sustainability of the system and the decreasing purchasing power of LTCI benefits to consumers due to the lack of indexation of the benefits. In the United States, debate about reform options still needs to move from outside the periphery of public policy discussions.

Consumer Options and Choice

More consumer control and more options for care are increasingly characterizing the LTC systems in both Germany and the United States. The German LTCI program builds in considerable consumer choice among service or cash options. Consumer-directed care approaches with cash benefits have been used more commonly to support younger persons with disabilities in the United States, although CMS has supported expansion of earlier "cash and counseling" demonstrations for older people with disabilities. Both countries have recently been experimenting with consumer-directed individual budgets, which allow for

consumer control over service options but without some of the management responsibilities associated with cash benefits.

In both countries, new forms of housing with services are proliferating, ranging from assisted living and adult foster care in the United States to sheltered housing and house communities in Germany. Both nations face difficult issues in designing payment and quality assurance structures with sufficient flexibility to encompass these new forms while also providing protections for consumers. These options may also be having an effect on institutional care, with the culture change movement in the United States and the greater availability of private rooms in Germany.

Family Caregiving

Germany purposely designed its LTC system to sustain family caregiving, and evidence suggests that it has been largely successful in doing so. Central to this design was inclusion of a cash allowance option, which is used predominantly to pay family caregivers. That allowance continues to be beneficiaries' top choice among different options, even though it represents only about half of the amount of the home care service benefit.

The fact that family caregiving has not declined since the introduction of the program may provide some solace to policy makers and others in the United States who fear that making home care services more widely affordable and available will undermine caregivers' willingness to "stay on the job." At the same time, use of respite benefits and other caregiver supports has grown very gradually since the German program was introduced. Although spending on respite, for example, has more than tripled since 1997, it still represents only a very small part of the overall LTCI budget—less than 1 percent in 2007.

Increasing attention in both countries is being devoted to the importance of "mixed care" arrangements, combining informal and formal services, as an important model for the future. Such arrangements could also promote more active partnerships between professional caregivers and family caregivers, whose skills and knowledge are often complementary. Thus far, relatively few data in either country indicate that such arrangements have been increasing. In the United States, older persons living in the community were found to be less likely to receive care from both informal and formal sources, and more likely to receive informal care only. In Germany, the proportion of beneficiaries who choose both the cash allowance and formal services has remained relatively stable since the program was introduced. However, the past does not predict the future. Such factors as trends in women's labor force participation, changing patterns in living arrangements, and the role of public policy in encouraging or discouraging the availability of formal home care services will also be important.

Support for family caregivers holds a major if not *the* key to sustainable health and LTC services. Because both countries are also encouraging greater labor force participation, especially among midlife and older workers, finding better ways to help family caregivers combine their caregiving roles with their roles in the labor force will be crucial.

Workforce

Workforce shortages are among the most pressing problems facing the LTC systems in both Germany and the United States. Neither country will be able to meet the future demand for services without recruiting and retaining more professional and paraprofessional workers. Low wages, low prestige, and dangerous working conditions will have to improve to expand the pool of workers willing to undertake the difficult tasks associated with LTC. Opportunities for training and professional advancement will also have to improve to retain workers. Both countries are likely to rely increasingly on foreign-born workers to provide care. Assuring adequate training for and integrating these workers into the workplace and the larger society will be important challenges.

Quality

The increasing diversity of LTC services, LTC settings, LTC clients, and LTC workers increases the challenges of assuring high quality in both Germany and the United States. Moving regulatory and reimbursement systems from a narrow focus structure, and process issues to a greater focus on outcomes, especially consumer quality of life outcomes, presents many challenges. Methods for measuring outcomes and adjusting for the level of disability are in nascent stages. Reporting data on quality outcomes to consumers and their families in ways they can use in making care decisions is in the early stages in the United States, but does not exist in Germany. Reimbursement systems that reward high quality through "value-based purchasing" or "pay-for-performance" are in the experimental stages, and these approaches are likely to drive policy discussions on LTC quality as consumers demand more choices and higher quality.

Germany, which implemented universally available, basic benefits for LTC well over a decade ago, is now taking steps to coordinate and integrate health and LTC services. For older persons in particular, who are more likely to experience multiple chronic illnesses that lead to limitations in functioning, such coordination is imperative. In addition, Germany is placing substantial emphasis on both prevention and rehabilitation services *for persons who need LTC* and on expanding benefits for HCBS.

In the United States, the basic foundation of universal health and LTC benefits is still to be built. Americans of all ages and all incomes still face the risk of catastrophic out-of-pocket expenditures for both health and LTC. More than 47 million Americans have no health insurance, and the vast majority of Americans have no insurance at all for LTC. Moreover, those who do have access to benefits are vulnerable to the loss of job-related health benefits. Even safety-net services through Medicaid for health and LTC are vulnerable to cuts when states respond to fiscal crises or the federal government cuts benefits. This lack of security in the United States is perhaps the most striking difference between the two countries.

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Endnotes

¹ A note on terminology: In the United States, many persons with disabilities prefer the term "longterm 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 the 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 report, *Beyond* 50.03, A Report to the Nation on Independent Living and Disability.

http://www.aarp.org/research/housing-mobility/homecare/Articles/aresearch-import-752-D17817.html

² "High income" is defined in 2007 as employees with annual earnings exceeding \pounds 47,700; also, persons with incomes of \pounds 42,750 who were privately insured at the end of 2002 are not required to be in the public program. MISSOC 2007.

³ When the program was first introduced, employers were compensated for their share of the payroll tax by abolishing one legal public holiday in all of the Länder, except for the Free State of Saxony, which increased the contribution rate for employees (Federal Ministry of Health, 2006).

⁴ The contribution rate is fixed by law at 1.7 percent, with a maximum monthly contribution of €0.56 in 2007, shared equally by employers and employees.

⁵ The private LTCI rate for married couples where only one spouse works, or where both work but one spouse's income is low enough to qualify as marginal employment, may not be more than 150 percent of the maximum rate for statutory LTCI. The married couple rate does not apply for those who took out private health insurance after the introduction of compulsory private LTCI on January 1, 1995. Children receive free coverage; see http://www.bmg.bund.de/nn_617004/EN/Long-term-care-insurance/info-long-term.htm.

⁶ According to the German Association of Private Health Insurance, 805,400 persons had LTC policies with a daily allowance, and 184,800 had LTC cost insurance in 2006. In addition, about 25,000 LTC pension policies were in force, according to the Confederation of German Insurers; such policies are offered by life insurance companies.

⁷ While no one may be forced to sell a house, a beneficiary may be asked to take a loan to cover part of the LTC expenses (personal communication with Gabriele Langerhans, Federal Ministry of Health, October 2007).

⁸ Beneficiaries with incomes above \$80,000 pay higher premiums; beneficiaries with incomes below 135 percent of the federal poverty level and limited resources are eligible for assistance with their Part B premiums.

⁹ Special Medicaid income eligibility rules apply to nursing home residents in the community to prevent the spouse from being impoverished as well.

¹⁰ See, for example, OECD 2005, and Huber, 2007.

¹¹ Long-term care expenditure data for Germany and the United States are taken from OECD Health Data 2007. Because of different data collection and reporting systems in the two countries, it can be difficult to obtain comparable data. The LTC expenses cited in this report were chosen to maximize

comparability between Germany and the United States and may differ slightly from other sources that focus only on a single country or other combinations of countries.

In this paper, total LTC spending is given by HC.3 (long-term care, including institutional and home care) + HC.1.4 + HC.2.4 (curative and rehabilitative home care). In the United States, this is equal to the total spending reported for home health care and nursing home care in CMS National Health Expenditure data. The United States OECD data do not contain any HC.3.4 expenditures (at home provision of LTC), as all home care expenditures are reported in HC.1.4 and HC.2.4.

OECD data for Germany, however, separate home care into HC.3.4 (at-home provision of LTC) and HC.1.4/HC.2.4 (curative and rehabilitative home care), with a sizeable majority—about three-fourths—of the expenses in HC.3.4. In this report, for comparability with the United States, expenditures in categories HC.1.4 and HC.2.4 are included as part of Germany's total LTC expenditures and result in a slightly higher total than is reported by the Federal Statistical Office. Partially offsetting this increase, expenditures in HC.8.6.1 (social services in kind) are not included in the LTC total for Germany, as no comparable data are available for the United States.

¹² "Institutional Care" consists of expenditures reported in OECD data as in-patient, long-term nursing care (HC.3.1). "Home Care" consists of expenditures reported as services of curative home care (HC.1.4), services of rehabilitative home care (HC.2.4), day cases of long-term nursing care (HC.3.2), or long-term nursing care: home care (HC.3.3).

¹³ In Germany, private spending includes individual out-of-pocket expenses and private supplementary LTC insurance, while public funding includes social LTC insurance, private mandatory LTC insurance, and social assistance. In the United States, private spending includes out-of-pocket spending and private insurance, and public funding includes Medicare and Medicaid LTC spending.

¹⁴ For example, at the highest level of care (3), individuals may receive a monthly benefit of 1,432 for agency-provided home care or for institutional care, or 665 as a cash allowance.

¹⁵ A "special case" might be the need for several caregivers at the same time, including nights, to meet basic needs, or if help with personal care, nutrition, or mobility requires at least seven hours a day, at least two of which are at night.

¹⁶ Supplemental Security Income (SSI) is a poverty program that provides monthly cash benefits to persons who have very low incomes and who are aged, blind, or disabled. Eligibility for SSI can allow older persons to receive other means-tested benefits, such as food stamps.

¹⁷ Under the medically needy option, the individual's incurred medical costs are deducted from income over a period of one to six months, depending on the state. If after deducting medical costs, the individual's income is below the state-established income limit, the individual qualifies for Medicaid coverage for the remainder of the period (e.g., either one or six months).

¹⁸ The 10 states with Independence Plus waivers are California, Connecticut, Delaware, Florida, Louisiana, Maryland, New Hampshire, New Jersey, North Carolina, and South Carolina.

¹⁹ Benefits changes include the introduction of a small supplement for persons with dementia in 2002. Changes in contributions include requiring pensioners to pay the full contribution rate of 1.7 percent of income (2006), and childless individuals to pay an additional .25 percent, raising their share to 1.1 percent (2005).