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Report of the Long-Term Care Study Panel

Developing a Better Long-Term Care Policy:

A Vision and Strategy for America's Future

November 2005

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The Robert Wood Johnson Foundation provided the primary financial support for this project. Other funders include the TIAA-CREF Institute, the Service Employees International Union, GE Financial Assurance, and the John D. and Catherine T. MacArthur Foundation.

Suggested Citation:
Burke, Sheila P., Judith Feder, and Paul N. Van de Water (eds.) 2005. *Developing a Better Long-Term Care Policy: A Vision and Strategy for America's Future.* Washington: National Academy of Social Insurance.

ISBN: 1-884902-44-8

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National Academy of Social Insurance
Study Panel on Long-Term Care

Sheila P. Burke, *Co-Chair*
Smithsonian Institution

Judith Feder, *Co-Chair*
Georgetown University

Dwight K. Bartlett III
Bartlett Consulting Services

Christine E. Bishop
Brandeis University

Henry Claypool
Social Security Administration

Penny H. Feldman
Visiting Nurse Service of New York

Len Fishman
Hebrew Rehabilitation Center for the Aged

Iris C. Freeman
Advocacy Strategy

Lee Goldberg
Service Employees International Union

Kimberly J. Morgan
The George Washington University

Marta Sotomayor
National Hispanic Council on Aging

Shelly White-Means
University of Tennessee Health Science Center

Project Staff

Paul N. Van de Water
Study Director and Vice President for Health Policy (from June 2005)

Kathleen M. King
Study Director and Vice President for Health Policy (through March 2005)

Cyanne Demchak
Research Assistant

June Eichner
Senior Research Associate

Mark Merlis
Consultant

Reginald D. Williams II
Research Assistant

Acknowledgments

The National Academy of Social Insurance and the Study Panel on Long-Term Care gratefully acknowledge the assistance of a number of individuals for their help on this report. Researchers from the Georgetown University Long-Term Care Financing Project, including Robert Friedland, Harriet Komisar, Ellen O'Brien, and William Scanlon, provided valuable advice, information, and data. Diane Braunstein, Marilyn Moon, Janet Shikles, and Deborah Stone reviewed the draft report or issue briefs. David Colby, our project officer at the Robert Wood Johnson Foundation, offered support and encouragement.

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Executive Summary

In 2003, the National Academy of Social Insurance convened a study panel to examine the future of the long-term care system. Members of the panel are recognized experts in long-term care and related issues. This report reflects their views, not those of the Academy, which does not take positions on policy issues. The panel focused on two issues: developing a vision of a better, more responsive long-term care system and the policies to promote it; and developing a strategy to put long-term care on the national policy agenda. Achieving a long-term care system that meets individual needs and distributes costs equitably, the panel concluded, will require greater federal involvement and financing.

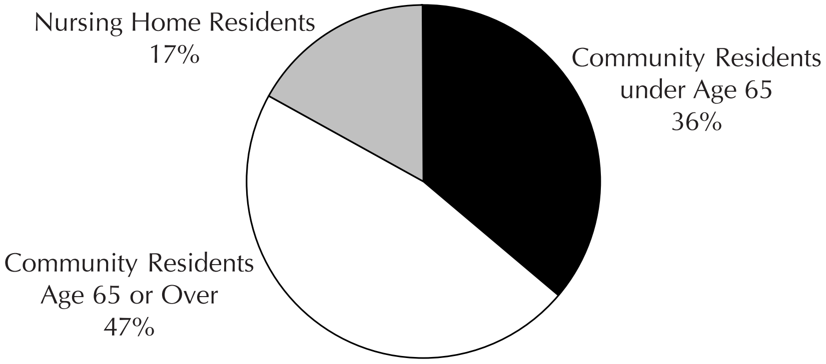
The study panel believes that a better long-term care system is essential to enable all Americans, regardless of age or disability, to participate fully in our society. Three tenets should guide the long-term care system of the future:

- *Meeting Individual Needs*. The needs of individuals should determine the kinds of services available.
- *Preserving Autonomy*. Service delivery should preserve the autonomy of the people receiving services.
- *Promoting Equity*. The costs of services should be shared equitably among individuals, families, and the society in which we live, and services should be similarly available and affordable regardless of the state in which a person lives.

Nearly 10 million Americans need help with basic tasks of living, such as bathing, eating, dressing, or walking, or help with other activities that maintain their independence, such as shopping, cooking, or cleaning. More than 80 percent of those who need care live in their communities, not in nursing homes, and nearly 40 percent of them are under age 65 (see Figure A).

Figure A

Who Needs Long-Term Care? 10 Million Americans

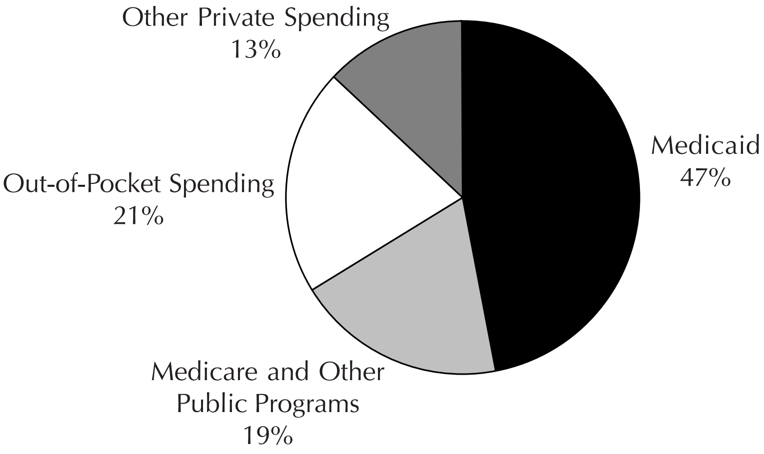


Source: Georgetown University 2003b.

National spending on formal long-term care is approaching $200 billion a year, of which about two-thirds is for institutional care. Informal care—unpaid care given voluntarily to ill or disabled persons by their families and friends—is the predominant form of care for people living in the community. Public programs pay for two-thirds of formal long-term care and services, and Medicaid alone pays for almost half (see Figure B).

Figure B

Who Pays for Long-Term Care?



Source: Georgetown University 2004.

Shortcomings of the Current Long-Term Care System

The current long-term care system falls far short of meeting reasonable expectations in several ways:

- *Unmet Needs*. Many people receive inadequate care. Nationally, 20 percent of people living in the community and needing services get less help than they need. As a result they are more likely to fall, soil themselves, or be unable to bathe or eat.
- *Burden on Caregivers*. Unpaid caregivers play a critical role in the system but often pay an economic, physical, and emotional toll. Workers in the formal long-term care system labor under difficult conditions and low wages, frequently without fringe benefits.
- *Financial Jeopardy*. The cost of long-term care can impose financial hardship or even spell financial catastrophe for many families. Few people have any type of insurance against the expense of long-term care, which can reach $26,000 a year at home and more than twice that amount in an institution.
- *Limitations in Medicaid*. The federal-state Medicaid program finances long-term care only for those who are or have become impoverished. Its benefits vary widely from state to state, and it requires some people who need help to move to institutions, when they would much rather live in their communities.
- *Quality Problems*. Serious quality problems persist in some nursing homes, partly as a result of inadequate staffing. Quality in non-institutional settings is also a concern.
- *Demographic Challenges*. The long-term care system is unprepared to meet the demands that the large baby boom generation will impose upon it. The coming demographic shift will also exacerbate staffing shortages.

Although the current long-term care system has very serious flaws, some seeds of a better system are beginning to take root. A few pioneers are making institutional care more home-like and less regimented. States are providing much more home and community-based care. Congress has established some modest grant programs to support caregivers and community care systems. The U.S. Supreme Court has altered the landscape by finding (in *Olmstead v. L.C.*) that unnecessary institutionalization of persons with disabilities violates the Americans with Disabilities Act. President Bush's New Freedom Initiative encompasses a variety of steps to ensure effective implementation of the *Olmstead* decision. These efforts move in the right direction, but they are not enough.

Two Promising Approaches

Transforming long-term care ultimately requires fundamental reform of its financing and a substantial commitment of federal resources. Because the need for long-term care is a risk, not a certainty, it should be handled like other unpredictable and potentially catastrophic events—that is, through insurance. Private long-term care insurance, while growing, is affordable for only 10 percent to 20 percent of the elderly. To assure access to long-term care without making families face impoverishment, federal involvement is therefore essential. Expanded federal financing could take one of two forms:

- *Universal Approach*. One option, modeled on Social Security, would provide everyone access to a basic, limited long-term care benefit, supplemented by private insurance for the better-off and enhanced public protection for the low-income population.

- *Means-Tested Approach*. Another option would establish a national floor of income and asset protection that would reform or replace Medicaid's coverage of long-term care. People could purchase private long-term care insurance to protect a larger amount of assets.

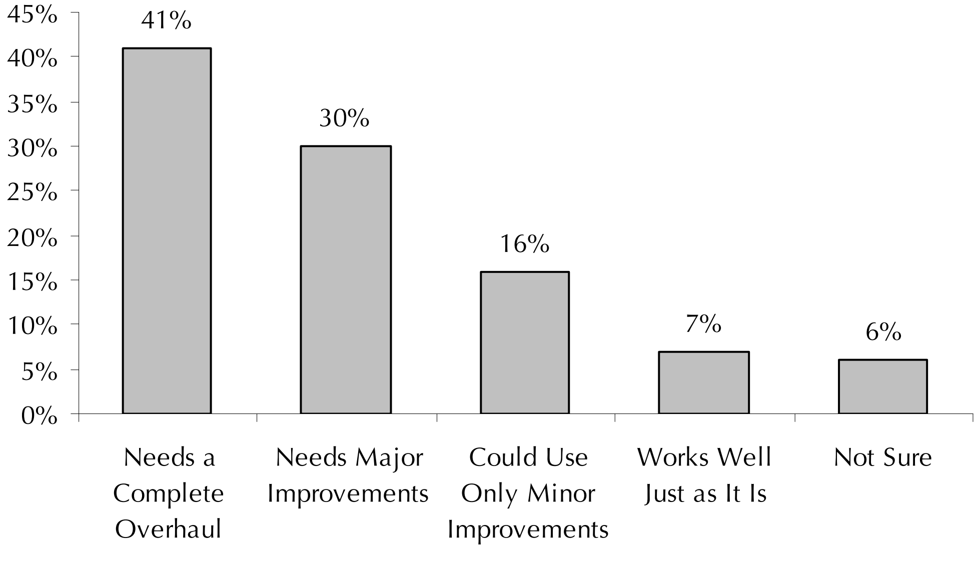
Other countries have demonstrated that either approach—or a hybrid of the two—can target benefits to those in greatest need, retain personal responsibility through cost-sharing, and control costs. (See National Academy of Social Insurance Health and Income Security Brief No. 9, *Long-Term Care: Lessons from Abroad*.)

Reaching the Top of the Agenda

The American public understands that the financing of long-term care is a serious policy problem and seems receptive to change. Nearly three-quarters of baby boomers and seniors are concerned either a great deal or a fair amount about paying for long-term care, according to a poll commissioned by the study panel. Seven in ten believe that government should do more to help people meet the costs of long-term care. Even those less concerned about the problem are troubled that the current system impoverishes people before it helps them. After hearing that Medicaid covers care only after people have exhausted virtually all their own resources, 41 percent of respondents concluded that the system of paying for long-term care "is broken and needs a complete overhaul," and another 30 percent thought that it needs major improvements (see Figure C). (For more information about the poll, see National Academy of Social Insurance Health and Income Security Brief No. 8, *Long-Term Care: The Public's View*.)

Figure C

What Does the Public Think About the Current System of Paying for Long-Term Care?



Source: Peter D. Hart Research Associates 2004.

Although long-term care is seen as a public policy problem, the issue has not yet reached the top of the national policy agenda. As the recent experience with the Medicare drug benefit illustrates, favorable public opinion alone is not enough to galvanize action. To achieve a better long-term care system, several additional steps are required. Researchers must continue to demonstrate the extent of unmet needs for long-term care, the financial costs of care, and the burden placed on caregivers. Advocates must frame the problem of long-term care financing in terms that resonate with the public. Policy analysts must refine and disseminate specific proposals that will provide for a more equitable sharing of responsibility between individuals and government. Finally, leaders must emerge who will take up the cause of long-term care, build coalitions for change, and take advantage of opportunities for action.

The study panel recognizes the fiscal pressures facing federal and state governments. Medicaid is straining state budgets to the point that the nation's governors have declared that it cannot continue to be the nation's primary funding mechanism for long-term care. The impending retirement of the baby-boom generation will add to already large demands on the major federal entitlement programs. As policymakers grapple with these budgetary issues, meeting the needs of the elderly and the disabled for long-term care should have an important place on the agenda, and our society should not shrink from providing the resources that will be required.

Introduction

In 2003, the National Academy of Social Insurance convened a study panel on the future of the long-term care system. Members of the panel were selected for their recognized expertise in long-term care or related issues. Their views do not represent the official position of the Academy, which does not take positions on policy issues.

The study panel's work focused on two issues: developing a vision of a better, more responsive long-term care system and policies to promote it; and developing a strategy to put long-term care on the national policy agenda. As part of its work, the study panel commissioned a research paper on financing and delivery options and a national survey to assess public opinion about long-term care. This is the panel's final report.

The Robert Wood Johnson Foundation provided the primary financial support for this project. Other funders include the TIAA-CREF Institute, the Service Employees International Union, GE Financial Assurance, and the John D. and Catherine T. MacArthur Foundation.

A Long-Term Care System for the Future

The long-term care system has evolved and improved over the last twenty years, but long-term care remains inadequate and unaffordable for many people. The study panel believes that a better long-term care system is not only achievable but also essential to enable all Americans, regardless of age or disability, to participate fully in our society. Action is necessary not only for the future elderly population, but also for those currently in need, both under and over age 65. Millions of Americans now lack the kind of help they need or face destitution and unwanted institutionalization to get that help.

Three tenets should guide the long-term care system of the future:

- The needs of individuals should determine the kinds of services available.
- Service delivery should preserve the autonomy of the people receiving services.

- The costs of services should be shared equitably among individuals, families, and the society in which we live, and services should be similarly available and affordable regardless of the state in which a person lives.

Meeting Individual Needs

Long-term care supports and services should help people improve, maintain, or slow the deterioration in the quality of their lives by aiding them in living as productively, meaningfully, independently, and normally as possible. The system should be structured to provide the services and supports needed by those who use the system rather than skewed toward one set of services—institutional care—as is typically the case. Acute and long-term care services should be coordinated to assure seamless transitions across all settings and providers, thereby improving the quality of care. Information about the type, availability, and quality of services should be readily available and understandable to individuals who need services and to their caregivers, regardless of the language they speak and consistent with their culture. Fundamental to such a system should be respect for the dignity, humanity, culture, and preferences of individuals.

Most people have a strong preference for receiving assistance at home. In one survey of adults age 50 and over with disabilities, 87 percent of respondents said they wanted to be cared for at home, either by family and friends or an agency. People also seek greater control over their care. In another recent survey, only 15 percent preferred that a home care agency control the money and management of care; 53 percent would like to control the money and management themselves, and another 25 percent would prefer to manage the workers and the services and have the agency pay the workers (AARP 2003).

Younger people who need long-term supports and services are even more passionate about their preference for receiving assistance in their communities. They emphasize living as productively, meaningfully, and normally as possible, and to a large extent they reject institutional living and even standard home health care. They prefer personal care attendants who accompany them everywhere they go and enable them to participate in the labor force and in their communities.

Autonomy

The long-term care system should preserve and protect, to the greatest extent possible, not just the lives, but also the liberty of those it serves. Individuals receiving long-term care supports and services should have as much autonomy as possible. Individuals have a right to be informed about their health, functional status, and plan of care and to make decisions about their care to the extent they are able to do so. For individuals not capable of acting in their own behalf, family members or others acting for them should make decisions based on the expressed wishes of the person receiving services. Individuals should direct their caregivers and exercise as much choice as possible in their daily routines, such as deciding when to eat and bathe.

Because most people strongly prefer to remain in their own homes and continue to participate in their communities, services should be provided, to the maximum extent possible, in an individual's own home or a community-based setting. Housing should be adapted to help people remain in their own homes, and independence-enhancing technologies should be more widely used. Home and community-based services, such as personal care, adult day care, home-delivered meals, and respite services, should be more widely available to assist both those who need services and their caregivers.

Because family and other informal caregivers are the vital link that allows many individuals who need assistance to remain in their communities, their roles should be supported and strengthened. Caregivers should have access to more services to relieve them of some of the burdens associated with providing assistance over the long term. These services could include information about services available for those with long-term care needs, help in obtaining supportive services, financial assistance for those services, individual counseling and organization of caregiver support groups, and training to help become better caregivers.

Equity

We believe that the current long-term care system is not fair. Instead of costs falling overwhelmingly on individuals who need care or their families, the burden of providing and paying for services should be shared more equitably among individuals, families, and the society in which we live. Obtaining access to care should not require individuals to endure extreme financial hardship or to impoverish themselves. People with similar needs should have access to a similar range of services, regardless of where they live. Racial and ethnic disparities in care should be eliminated. The workers who provide formal care should receive adequate wages and benefits and should be viewed as equal partners in the long-term care system. And informal caregivers should receive the support they need to perform their crucial role.

The Current System

As part of our work, we evaluated the current long-term care system to see how close it comes to fulfilling our vision. We found many serious flaws.

Nearly 10 million people currently need long-term care services. This means that they need another person's assistance with fundamental tasks (called activities of daily living or ADLs) including bathing, eating, dressing, using the toilet, getting in and out of a bed or chair, and getting around inside their home; or help with other activities to be independent, such as meal preparation, managing money, managing medications, using the telephone, doing light housework, and shopping for groceries or other necessities (called instrumental activities of daily living, or IADLs); or therapies designed to help restore functional abilities.

The majority of people with long-term care needs are women, but many men also require care. Of those living in the community, 60 percent of those age 18-64 needing long-term care services are women, as are 69 percent of those sixty five and older. Seventy-two percent of all nursing home residents are women.

Although people frequently associate long-term care services with nursing homes, that perception both understates the amount and mischaracterizes the scope of services being provided. Services are provided in a wide range of settings, including private homes, other community settings such as adult day care centers, and residential settings including assisted living facilities, board and care homes, and nursing homes. More than 80 percent of those who need long-term care live in their communities, not in institutions (see Table 1). Seventy-eight percent of people receiving long-term care services in their communities get care provided exclusively by unpaid family members or volunteers. Eight percent receive care exclusively from paid staff, including home health aides, certified nursing assistants, and personal care assistants, often under the direction of nurses, and 14 percent receive both paid and unpaid care (Georgetown University 2003b).

Table 1

People with Long-Term Care Needs, 2002 (in millions)

	Age			
Place of Residence	**Under 65**	**65 or Over**	**Total**	
Community Residents	3.4	4.5	7.9	(83%)
Nursing Home Residents	0.2	1.5	1.6	(17%)
Total	3.5	6.0	9.5	(100%)
	(37%)	(63%)	(100%)	

Source: Georgetown University 2003b.

Long-term supportive service is probably a more appropriate term to use than long-term care for two reasons: The word "supportive" more accurately describes the help being provided, and it does not imply dependence or connote paternalism (AARP 2003). Although we use both terms interchangeably, we are mindful that the purpose of the services we describe in this report is to help support and maintain the independence and the dignity of those who receive them.

Just as there are misperceptions about what constitutes long-term care services and the settings in which they are provided, is there also a lack of understanding about those who receive these services. The typical view is that long-term care services are provided to very old people who are physically or cognitively impaired. In fact, nearly 40 percent of people needing long-term care are under age 65, although it is true that the need for services increases with age, with half of those over age 85 needing services. The need for supportive services arises from many causes, including diseases, disabling chronic conditions, injury, severe mental illness and developmental disabilities.

National spending on formal long-term care is nearly $200 billion a year, of which about two-thirds is for institutional care. Informal care—unpaid care given voluntarily to ill or disabled persons by their families and friends—is the predominant form of care for people living in the community. If this unpaid care had to be replaced by paid home care, the additional cost would approach $100 billion (DHHS/ASPE 1998). Including the value of unpaid care, recipients and their families bear roughly half of all long-term care costs.

Public programs pay for two-thirds of formal long-term care services, and Medicaid alone pays for almost half (see Table 2). Medicaid is funded by the federal and state governments and is administered by the states. It pays for nursing home care and medically necessary home health care for people with very low income and assets. States may also provide home and community-based services generally or for specific populations under a waiver of federal requirements. Two-thirds of Medicaid-financed home care is covered by waivers, which allow states to limit participation and spending.

Medicare is a social insurance program that provides health coverage to almost everyone over age 65 and to people who have been receiving Social Security Disability Insurance for at least two years. It covers long-term care only under limited circumstances—in a skilled nursing facility for up to 100 days after a hospitalization or at home for those requiring part-time skilled nursing or therapy services. Still, Medicare pays for 17 percent of long-term care expenditures.

Private parties pay for one-third of long-term care. Recipients and their families pay for over 20 percent out of their own pockets, and private insurance pays 10 percent. Most of the insurance share is attributable to health insurance, even though health insurance pays for long-term care in only a few situations. Private long-term care insurance provides more comprehensive benefits but is not widespread (Georgetown University 2004).

Table 2

National Spending for Long-Term Care, by Payer, 2002

Payer	Billions of Dollars	Percent of Total
Public		
Medicaid	84.7	47
Medicare	30.7	17
Other	4.2	2
Subtotal	119.6	66
Private		
Out-of-pocket	37.2	21
Private insurance	18.2	10
Other(a)	4.6	3
Subtotal	60.0	34
Total	179.6	100

(a) Includes philanthropy, investment income, and non-patient-care revenues.

Source: Georgetown University 2004.

Why Change is Needed

The current long-term care system is in urgent need of change because it falls so far short of meeting reasonable expectations for its performance. It does not meet the needs of a substantial number of people who require help coping with their limitations; it does too little to support the unpaid caregivers who form the backbone of the system; it imposes substantial financial hardship on many of those who need services or requires them to put themselves in real financial jeopardy; it suffers from wide variations in benefits depending on the state in which a person resides; it requires some people who need help to move to institutions, when they would much rather live in their communities; it suffers from persisting quality problems across the spectrum of services; and it is unprepared to meet the increased demands that the baby boom generation will impose on it.

Many Needs Not Met

The long-term care system helps large numbers of people who need it, but it provides many with insufficient support and does not come close to helping everyone who requires assistance. One national survey of adults with disabilities living in the community in the mid-1990s found 20 percent who needed help getting less care than they needed and were consequently more likely to fall, soil themselves, or be unable to bathe or eat (Georgetown University 2003b).

A 1999 survey of elderly Medicare-Medicaid dual eligibles living in the community also found widespread shortfalls in people's ability to get needed care.[1] Fifty-eight percent of dual eligibles needing help with activities of daily living reported unmet needs, and 56 percent of those suffered at least one of five serious consequences because they did not receive assistance. Thirty-three percent were unable to bathe as often as they wanted, 14 percent were unable to dress themselves, 28 percent fell out of bed or a chair, 15 percent wet or soiled themselves, and 3 percent went hungry (Komisar, Feder, and Kasper 2005).

Younger adults with disabilities had similar problems. A recent Kaiser Family Foundation survey of non-elderly adults with disabilities found that, despite various sources of help, 42 percent reported falling while getting out of bed or a chair because no one was available to help. More than two-thirds of those surveyed said they often feel depressed. They also worry about how they will manage as they and their families grow older, with 45 percent reporting concern that they will become too much of a burden on their families, and 23 percent worry that they will have to go into a nursing home (Kaiser Family Foundation 2003).

The Crucial Role of Informal Caregivers

Millions of Americans provide informal, unpaid long-term supports and services to individuals who need assistance in their daily lives. Caregivers provide a wide range of services, including making meals, managing bills and insurance forms, shopping, housework, and transportation, and they often help with personal needs such as bathing, dressing, toileting, and walking. Most caregivers are helping their parents, grandparents, or spouses, but nearly 20 percent are caring for someone who is not a relative (Kaiser Family Foundation 2002). Without informal caregivers, spending for long-term care services would be much higher than it is now.

Although informal caregivers are not paid for their services, and most caregivers find their roles rewarding, care giving takes an economic, physical, and emotional toll on those who provide services, such as health risks, emotional strain, mental health problems, job issues, and financial problems. Sixty-two percent of caregivers say that they must make adjustments to their work life, such as taking time off, leaving work early, or taking a leave of absence to fulfill their caregiving responsibilities. Lost productivity due to caregiving has been estimated to cost employers $29 billion a year (National Governors Association 2003).

Caregivers report some negative effects on their physical and mental health, with one-fifth of caregivers in one survey reporting that their physical health has suffered as a result of caregiving. Depression is much more common among caregivers than among non-caregivers, with surveys finding between 30 percent and 59 percent reporting depressive disorders or symptoms (Thompson 2004). More than half of all caregivers (55 percent) report being isolated, and half report that the burden of caregiving is frequently or sometimes too much to handle (Robert Wood Johnson Foundation 2001).

Caregivers also report that their needs for assistance are frequently not met. Nearly 20 percent of informal caregivers in a Kaiser Family Foundation survey said they needed help caring for the person that they did not receive. When asked why they did not receive help, 31 percent cited financial or insurance barriers, 15 percent said the service was not available, 11 percent said that family would not help, and 7 percent said that the doctor or hospital refused (Kaiser Family Foundation 2002).

Caregivers must frequently make decisions about what kinds of care are needed, or help those who need services determine what kinds of services are most appropriate, what kind of insurance is available, where to obtain services, and how to assess their quality. In many cases they must overcome resistance to accepting help by the person they care for. A considerable part of the difficulty in choosing long-term care services stems from a lack of understanding of the way long-term care services are financed—not surprising in light of the complicated, even overlapping roles of Medicaid and Medicare. In a survey of adults aged 40 and over conducted for the study panel, 20 percent of respondents admitted to being uncertain about these matters. However, two-thirds did not know that Medicaid covers long-term care costs for low-income people with little or no savings.

Acquiring an adequate understanding of the way long-term care services are financed and navigating the system to get the best possible results present a real challenge for most informal caregivers and can be extremely trying for many others. Making these choices is difficult under the best of circumstances. Frequently, the need for long-term care services arises from a health crisis, such as a stroke, a fall, a traumatic accident, an unexpected hospitalization, or an untoward event that makes caregivers realize that an individual's health or cognitive state has deteriorated to the point that they are no longer capable of taking care of themselves. Making important decisions about long-term care services under this kind of duress causes even further stress to caregivers.

Financial Jeopardy

The need for substantial amounts of assistive supports and services can impose financial hardships or even spell financial catastrophe for many people. Long-term supportive services are very expensive. In 2004, the average annual cost of nursing home care was $61,685 for a semi-private room. Care at home is costly, too. The average hourly rate for home health aide care was $18. If four hours of care were needed each day, the annual cost would be $26,000, which would constitute a real financial hardship for most families (MetLife 2004).

Recent research from the Urban Institute confirms that the onset of a need for long-term care causes substantial erosion in the financial well-being of older Americans. The analysis shows that acquiring a severe disability or cognitive impairment or entering a nursing home is associated with striking reductions in wealth. The authors conclude that more attention should be paid to improving the financing of long-term care services (Johnson, Mermin, and Uccello 2005).

Few people have any type of insurance against the possible expense of long-term care. Medicare covers long-term care only tangentially through its limited skilled nursing facility and home health benefits. The private health insurance policies that cover most working-age Americans for acute health care services also provide little protection for long-term care supports and services. As a result, almost half of formal long-term care is financed by Medicaid, which becomes available only when a person is impoverished.

The market for private long-term care insurance began to develop in the 1970s and is growing, but it is still quite small. Current policies cover not only nursing homes but also home care, adult day care, and assisted living. By the end of 2002, a total of 9.2 million long-term care insurance policies had been sold, with about 70 percent, or 6-1/2 million, still in effect. In 2002, the latest year for which data are available, private long-term care insurance paid $1.4 billion in claims, a small fraction of the spending for long-term care (America's Health Insurance Plans 2004).

In addition to stand-alone long-term care policies, many life insurance policies now offer accelerated death benefit or long-term care riders that provide benefits if long-term care is needed. Although no data are available about the volume of such riders, their inclusion would supplement the figures for stand-alone policies in the financing of long-term care by private insurance.

Average annual premiums of $2,862 for 65 year-olds make long-term care policies affordable only to those with relatively high income or assets.[2] Some studies suggest that it is affordable for only 10 percent to 20 percent of the elderly (GAO 2001). In addition, long-term care insurance does not offer any protection to those who already need assistive supports and services because all policies currently being sold exclude those with pre-existing conditions. Thus, these policies are not an option for those born with a disability such as cerebral palsy, or for young adults who suffer a traumatic spinal cord or brain injury, except in the unlikely event that they had already purchased a long-term care policy prior to being injured.

Continuing-care retirement communities provide another means by which an individual can protect against the risk of needing expensive long-term care. These communities typically combine independent living, assisted living, and nursing home care in a single setting. By paying an up-front entry fee, residents can assure that their monthly costs will not increase if they eventually need a higher level of care (Barney and Bond 2002). Although an attractive option for those who can afford it, the cost of a continuing-care retirement community is out of reach for many. In 2004, entrance fees ranged from $38,000 to $400,000 and monthly payments from $650 to $3,500 (DHHS/CMS 2005b).

Three-quarters of elderly households have some home equity that could be tapped to help pay for long-term care or long-term care insurance (Merlis 2005). If their equity is sufficient, some older homeowners may sell their homes and use the proceeds to pay the up-front fee of a continuing care retirement community. Another way of accessing home equity is through a home equity conversion loan, or reverse mortgage, in which a lender advances money to an older homeowner in return for a future claim on the home.

Although reverse mortgages could help finance long-term care for many households, they are at best a partial solution to the problem of long-term care financing. Borrowers who paid directly for care would exhaust their loans if they needed services intensively or for a long time. And borrowers who used the proceeds of the loan to purchase long-term care insurance would incur substantial transaction costs (Merlis 2005). Most important, reverse mortgages do not help spread the risk of needing long-term care.

Limitations in the Medicaid Safety Net

Medicaid finances care only for people with very limited income and resources or those who have exhausted their resources paying for care, and it requires that they contribute virtually all their income and assets toward the costs of care. Medicaid beneficiaries are not required to liquidate the house in which they or their spouses live to pay for health care. In addition, spousal impoverishment provisions allow community-dwelling spouses of Medicaid beneficiaries residing in long-term care facilities to keep a certain amount of income and resources so that they can provide for themselves. States may recover some of the cost of long-term care and other Medicaid services from the estate of a beneficiary or that of the beneficiary's surviving spouse. Transferring assets may make a person ineligible for Medicaid for a period of time.

States have wide latitude in designing Medicaid long-term care systems. Only nursing facility and home health services are mandatory, and states have discretion in setting eligibility criteria and can establish limits on the amount, duration, and scope of all covered services. States may offer a wide range of optional services, including home and community-based services, personal care and case management, and adult day care. Under federal demonstration authority, states may also provide a broad package of services that Medicaid does not routinely cover. Under these waiver programs, states can exert even more fiscal controls than they can in their regular Medicaid programs. Most states provide home and community-based services, but they are likely to provide them through waivers that allow them to establish waiting lists and cap funding. The volume of home and community-based services has expanded, but many states have waiting lists for these services (O'Brien and Elias 2004).

As a result of the flexibility given to states, there is little uniformity in the scope of Medicaid benefits. Medicaid expenditures for long-term care vary widely. The average annual expenditure per U.S. resident was $264 in 2001, but ranged from a low of $147 per resident in California to a high of $709 in New York (Wiener and Tilly 2003). Studies comparing access for individuals with similar needs in different communities show that people served in one community get little or no service in another (Summer 2003; GAO 2003).

These differences in states' policies can have real consequences. One study comparing the use of paid services in six states finds that, the greater the use of paid home care in a state, the lower the likelihood of unmet needs. In the state with the lowest proportion of people receiving paid care, 65 percent of dual eligibles had unmet needs. In the state with the most paid care, the incidence of unment needs was only 47 percent (Komisar, Feder, and Kasper 2005).

Despite Medicaid's limitations, rapid increases in spending have come to place a large share of the costs of long-term care on state governments. Between 1987 and 2001, Medicaid spending increased from 8 percent to almost 15 percent of state general fund expenditures (Milligan and Forbes 2002). States are ill equipped to absorb increases at that rate, especially during economic downturns and recessions. To keep their commitments within their resources, states have curtailed not only Medicaid benefits but also other services, such as education and transportation. The projected growth in the demand for long-term care services will further exacerbate this already difficult situation.

Two proposals are currently attracting attention as possible ways of limiting Medicaid spending for long-term care. One proposal is to expand the Long-Term Care Partnership Program, a demonstration project begun in the early 1990s with the support of the Robert Wood Johnson Foundation and currently limited to four states. The partnership allows people who buy private long-term care insurance and exhaust its coverage to access Medicaid and protect assets at least equal to the value of the insurance. Although permitting all states to create such partnerships has bipartisan support from governors and members of Congress and is proposed in the President's 2006 budget, the efficacy of the program remains unclear. Proponents contend that Medicaid will save money because private insurance will become the primary payer in more cases, but it is equally or more likely that Medicaid will lose money by paying additional benefits to people who would not otherwise have been eligible (Ahlstrom et al. 2004; CBO 2004; CBO 2005). Even the governors acknowledge that "long-term care partnerships do not promise a silver bullet for Medicaid's long-term care crisis" (NGA 2005).

Another proposal included in the President's budget and endorsed by the governors would further limit eligibility for nursing-home benefits for people who have recently transferred or given away assets. Those who shelter or divest assets are ineligible for Medicaid for a period of time. Under current law, the period of ineligibility begins on the date of the transfer and may have expired by the time the person applies for Medicaid. Under the Administration's proposal, the period of ineligibility would not begin until the person applies for Medicaid or enters a nursing home, if later. This proposal arises out of concern that many individuals are deliberately sheltering assets from Medicaid by transferring them through joint bank accounts or other means to close relatives (NGA 2005).

Studies find little evidence, however, that asset transfers are widespread or costly to Medicaid (O'Brien 2005). The Congressional Budget Office estimates that over the 2006-2010 period the Administration's proposal to clamp down on asset transfers would save $1.4 billion—0.1 percent of total federal Medicaid costs (CBO 2005). Extending the penalty period would adversely affect seniors who transferred assets in good faith to help a child, grandchild, church, or charity and unexpectedly became sick and needed long-term care. Some low-income frail elderly people could also be denied needed care because they had kept insufficient financial records.

Persisting Quality Problems

Concerns about the quality of long-term care are longstanding. A 1986 Institute of Medicine committee report on nursing home regulations laid the groundwork for a major reform of nursing home regulations enacted by Congress in 1987 (IOM 1986). Since that time, the quality of nursing home care has improved, although nursing homes are now serving a more seriously ill population. Still, serious quality problems, including pressure sores, pain, and malnutrition, persist in some nursing homes (IOM 2001; Pear 2004). In 2003, the General Accounting Office (GAO, now the Government Accountability Office) reported that 20 percent of nursing homes had serious deficiencies that caused actual harm to residents or placed their lives in immediate jeopardy (GAO 2003). Recently, the federal government has taken steps to make the quality of nursing home care more transparent. Since 2003, Medicare has published online information about staffing levels and deficiencies. U.S. attorneys in some states have charged nursing homes under the False Claims Act for failing to provide quality care, and a few have posted information about settlements on their Web sites (Gaul 2005).

Quality in non-institutional settings is also a concern. Federal standards govern Medicare home health agencies, but inspections and enforcement are a low priority for both federal and state governments (GAO 2002). No federal quality standards apply to assisted living facilities, personal care, or adult day care services (Wiener and Tilly 2003). State regulation of these services varies, and quality issues have been identified in these settings. In one study, GAO found that 22 percent of the assisted living facilities in their survey had five or more verified quality problems, including inadequate care, staffing, and medication problems (GAO 1999).

The backbone of the long-term care system is its workers, who are primarily paraprofessionals—nursing assistants, home health and home care aides, personal care workers, and personal care attendants. These workers earn among the lowest wages in the service industry, little more than the minimum wage. They work in difficult conditions that frequently require heavy lifting, making them prone to workplace injuries. Although they provide frontline physical and emotional support that improves the quality of the lives of those they help, they seldom receive public recognition for their contributions. Difficult working conditions and low wages, frequently without benefits, combine to produce a chronic workforce shortage and very high annual turnover rates, ranging from 45 to 100 percent annually in nursing homes (Stone and Wiener 2001).

Improving staffing is critical to improving the quality of long-term care. Research conducted for the Health Care Financing Administration (HCFA, now the Centers for Medicare and Medicaid Services) finds that, on average, quality of care in nursing homes is seriously impaired when staffing falls below certain minimum levels. Nationwide, more than half of the nursing homes surveyed for HCFA were below the preferred minimum staffing level for total licensed staff. Two-thirds were below the preferred minimum level for registered nurses (DHHS/HCFA 2000). High turnover rates contribute to understaffing, add to the cost of care, and may also translate into lower quality or unsafe care (Seavey 2004; Stone and Wiener 2001).

Demographic Challenges

The aging of the baby boom generation will place more demands on an already strained system. About 10 million people now need long-term care services, and current projections indicate that the number needing services will more than double by 2050 (Spillman and Lubitz 2002; DHHS/ASPE 2003). Complicating the situation is another demographic trend, falling fertility rates. As a result of declining birth rates, there will be fewer working-age people to bear the costs of providing services to the baby boom generation. In 2001, there were 5.3 people of working age for each person over age 65. By 2025, the ratio will be only 3.1 to 1, although growth in the elderly population is projected to vary widely by state (Merlis 2004b).[3] Differential patterns of fertility and immigration will also alter the racial and ethnic composition of the population. These demographic trends will place increasing fiscal pressure on both Medicare and Medicaid, particularly in states with the fastest growing elderly populations.

The coming demographic shift will also exacerbate staffing shortages. In the next few decades, the demand for long-term care workers will grow substantially, while the number of workers who have traditionally filled these jobs is projected to increase only slightly (DHHS/ASPE 2003). Several efforts are currently underway to identify and implement ways to reduce high vacancy and turnover rates in the long-term care workforce, to find new sources of workers, and to evaluate which staffing measures are most closely correlated with quality outcomes (National Commission on Nursing Workforce for Long-Term Care 2005; Kauff, Kirby, and Pavetti 2005; Lipson 2005). As the population ages and the demand for long-term care workers grows, such measures will become even more critical.

Paths to the Future

Some seeds of a better long-term care system are already beginning to germinate. A few pioneers are rethinking the way institutional care is provided. For example, the Eden Alternative has established about 240 alternative institutional settings that give residents a more home-like, decentralized environment, maximum possible decision-making authority, and opportunities to give as well as receive care (Eden Alternative 2005).

States have also made significant changes in their approach to long-term care. All states now have federal waivers that allow them to shift long-term care out of institutions and into home and community-based settings, particularly for mentally retarded and developmentally disabled individuals. Spending trends in Medicaid clearly reflect this shift. In 1991, institutional spending accounted for 86 percent of long-term care spending. By 2003, that figure had fallen to 67 percent, while spending for home and community-based waivers increased from 5 percent to 22 percent during the same time period, as shown in Table 3. Nearly 75 percent of home and community-based waiver spending was for individuals with mental retardation or developmental disability, with the remaining 25 percent spent on aged or disabled individuals, as shown in Figure 1. While the shift was greatest for mentally retarded or disabled individuals, aged individuals and those with other types of disabilities also received more services in the community than they had previously (Stone-Axelrad 2004; O'Shaughnessy 2003).

Table 3

Distribution of Medicaid Long-Term Care Spending, by Fiscal Year (in percents)

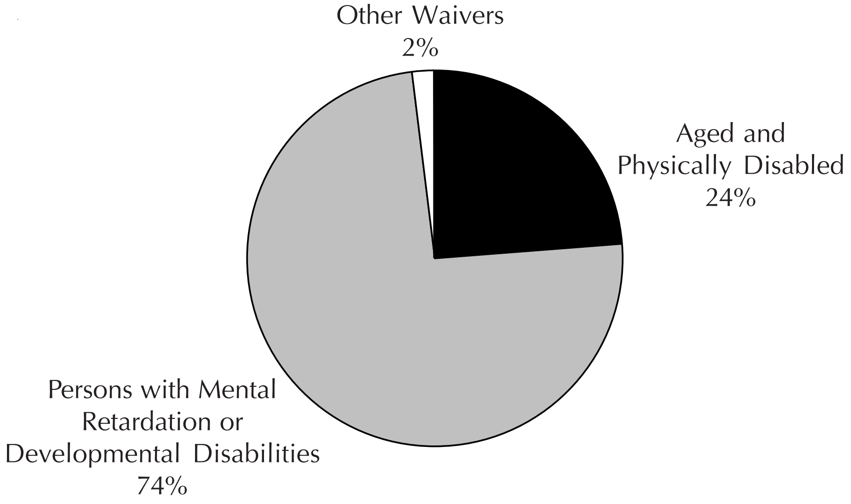
Type of Spending	1991	2001	2003
Nursing Home	62	56	53
ICF/MR	24	14	14
Subtotal, institutional	86	70	67
HCBS Waivers	5	20	22
Other HCBS	9	10	11
Subtotal, HCBS	14	30	33
Total	100	100	100
Memorandum:			
Long-Term Care as Percent of Medicaid Spending	38	35	32

IFC/MR = Intermediate care facilities for the mentally retarded
HCBS = Home and community-based services

Source: Burwell, Sredl, and Eiken 2004.

Figure 1

Medicaid Home and Community-Based Waiver Spending by Target Population, 2001



Source: O'Shaughnessy 2003.

While states have paid the most attention to Medicaid, because it accounts for the bulk of long-term care expenditures, they have also improved other programs providing long-term care services. The National Governors Association undertook an initiative in 2003 to bring increased attention to the long-term care system and to highlight best practices for improving home and community-based care, including strengthening supports for families and caregivers and promoting independence for older adults. The initiative also included efforts to encourage personal planning for long-term care (NGA 2004a; NGA 2004b).

Congress took modest steps to support community-based care by establishing the National Family Caregiver Program as part of the Older Americans Amendments of 2000. The act provides grants to states for programs that provide support to help families maintain their caregiver roles through services such as information and assistance, counseling, support groups and training, and respite services (Wiener and Tilly 2003). Its 2005 appropriation was $156 million (DHHS/AoA 2005).

The U.S. Supreme Court has also altered the landscape regarding community-based alternatives for individuals with disabilities. In 1999, in a significant decision *(Olmstead v. L.C)* whose full effects are not yet known, the court held that the unnecessary institutionalization of individuals with disabilities who desire to live in community settings violates the Americans with Disabilities Act (ADA). The ability of individuals with disabilities to seek redress through the courts has the potential to reshape long-term care policy. To comply with *Olmstead*, states must remedy involuntary institutionalization by making reasonable modifications to avoid discrimination based on disability and to provide services in the "most integrated setting appropriate to the needs of qualified individuals with disabilities." The court did not define "reasonable modifications" but stipulated that they did not require actions that would "fundamentally alter the nature of the service, program, or activity." A state will meet the requirement if it has a "comprehensive, effectively working plan" to place individuals in a less restrictive environment and the waiting list moves "at a reasonable pace" (GAO 2001; Rosenbaum and Teitelbaum 2004).

Congress, the executive branch, and state governments have taken various paths toward complying with the *Olmstead* decision. In 2000, Congress created a program of Real Choice Systems Change Grants to create "effective and enduring improvements in community long-term support systems." In 2005 Congress appropriated $39 million for these grants (DHHS/CMS 2005a). In 2000 and 2001, the Centers for Medicare and Medicaid Services and the HHS Office of Civil Rights issued guidance to state Medicaid directors on complying with the *Olmstead* decision, requiring states to develop "effective working plans" for moving institutionalized individuals into their communities. As of 2004, 29 states have issued *Olmstead*-related plans or reports, focusing on Medicaid options that make it possible for individuals with disabilities to live in their communities (Rosenbaum and Teitelbaum 2004).

In February 2001, President Bush announced the New Freedom Initiative. Key components of the initiative include increasing access to assistive and universally designed technologies, expanding educational opportunities through the Individuals with Disabilities Education Act, promoting home ownership for individuals with disabilities, integrating Americans with disabilities into the workforce, and promoting community integration to ensure that all individuals with disabilities can participate fully in the lives of their communities. As part of the initiative, the President issued Executive Order 13217, which calls upon federal agencies to undertake a range of activities to ensure swift implementation of the *Olmstead* decision. The activities fall broadly into three categories: coordinated technical assistance to states; identification of specific barriers to full integration in federal law, regulation, policy and practice; and enforcement activities, including investigating and resolving ADA complaints (White House 2001).

Although these efforts are steps in the right direction, they fall far short of the transformation we believe is necessary. Incremental changes are helpful, but the real key lies in fundamental reform of the long-term care financing system.

Spreading the Risk

Often, long-term care is viewed as an inevitable expense of old age. In reality, the need for long-term care is unpredictable. People currently turning age 65 will need either formal or informal long-term care for three years on average, but this average masks enormous variation. While some 30 percent of 65-year-olds will not need any long-term care before they die, 20 percent will need care for more than five years (Kemper, Komisar, and Alecxih 2005).

Because the need for long-term care is a risk, not a certainty, it is logical to treat it like other unpredictable and potentially catastrophic events—that is, to rely on insurance. Reliance on savings alone will be inefficient and ineffective. People will tend to save either too much or too little to cover expenses. However, few people now have adequate private or public long-term care insurance.

The expansion of private long-term care insurance is evidence that long-term care can be treated as an insurable event. Yet private insurers as well as policymakers recognize the limited capacity of the private market on its own to assure adequate protection, both today and in the future. To assure access to affordable long-term care without the risk of impoverishment, greater public involvement is essential.

Federal Initiative Needed

Creating an effective long-term care system requires a substantial new commitment of public resources, and—if benefits are to be adequate in all states—they must be federal resources. Expanded federal financing for long-term care could take a variety of forms and need not eliminate personal responsibility—through family care, direct purchase of care, cost-sharing, or the purchase of private insurance.

One approach, modeled on Social Security, would provide everyone access to a basic, limited long-term care benefit, supplemented by private insurance for the better-off and enhanced public protection for the low-income population. The Social Security system was designed to provide beneficiaries with a base of income, which they can supplement with pensions and savings. Social insurance for long-term care could provide the same kind of basic protection through Medicare, Social Security Disability Insurance, or a new public program. Individuals with sufficient income and assets could purchase private insurance to supplement the public insurance program, while a safety net program could help low-income people unable to afford private supplemental insurance (Ball 1989).

Another approach would establish a national floor of income and asset protection that would reform or replace Medicaid. Such a national program would assure everyone access to affordable quality long-term care—at home as well as in a nursing home—without having to give up their life savings, as Medicaid requires today. The floor could be set to allow people who worked hard all their lives to keep their homes and a modest amount of other assets, while those who are sufficiently well off could purchase private long-term care insurance to protect a larger amount of assets.

Either approach could not only better protect people in need; it could also provide substantial fiscal relief to states that would allow them to focus on other pressing needs. In a recent report on Medicaid reform, the National Governors Association reaches the same conclusion:

> The easiest solution may be to incorporate long-term care services into Medicare, but an alternative approach could be to link long-term care funding to Social Security, or broader pension reforms or other changes to solidify the link between personal responsibility and end-of-life care. What is clear is that Medicaid can no longer be the financing mechanism for the nation's long-term care costs and other costs for the dual eligibles (National Governors Association 2005).

Some countries have adopted a universal approach to providing public long-term care insurance, while others use means testing. Their experiences illustrate different ways to balance public financing that spreads risk with personal responsibility through cost-sharing, as well as different ways of controlling costs. A comparative study prepared for the study panel reveals a wide range of possibilities (Merlis 2004a). The study is summarized in National Academy of Social Insurance Health and Income Security Brief No. 9, *Long-Term Care: Lessons from Abroad.*

Germany, for example, covers long-term care through a social insurance system. Benefits are not open-ended but are limited to a specified amount per person based on the level of disability. Someone who requires more costly services will have to pay for them out of his or her own pocket or receive supplementary means-tested assistance. Germany also provides incentives to high-income people to purchase private insurance by allowing the top 10 percent of the population to opt out of the social insurance system if they can show equivalent private coverage.

France's new autonomy pension is also universal, but benefits vary significantly based on income. Depending on their level of disability, people aged 60 and above are eligible for one of four payment amounts. Beneficiaries must pay coinsurance of up to 90 percent, however, according to a sliding scale based on income. The French program, which took effect in 2003, had significant cost overruns because of a much higher than anticipated participation rate, to which the government responded to by tightening eligibility criteria and lengthening the waiting period before benefits begin.

Israel employs a means-tested approach to providing home care, but the income standards are relatively generous. An aged person who meets the disability tests and whose income does not exceed the average wage (1.5 times the average wage for a couple) will receive a full benefit. No benefit is paid to single people whose income is more than 1.5 times the average wage or to couples whose income is more than 2.25 times the average.

Analysis by the Organization for Economic Cooperation and Development (OECD) of long-term care policy in 19 countries finds a growing number with universal public plans for financing long-term care (OECD 2005). Many OECD nations have substantially larger proportions of elderly than the U.S. does today, and their experience can be instructive to us as we adjust to an aging society. Public protection, the OECD reports, does not imply the absence of private obligations, such as cost sharing and out-of-pocket spending, nor does it imply unlimited service or exploding costs. Rather, it aims to strike a fairer balance between public and private financing—relating personal contributions to ability to pay and targeting benefits to the population in greatest need. For the U.S. to move in that direction will require major political action.

Getting Long-Term Care on the Political Agenda

Over the years, a spate of policy initiatives has been proposed to address inadequacies in our nation's long-term care financing. The 1990s began with proposals from Senate health policy leaders and the Bipartisan Commission on Health and Long-Term Care Reform (the Pepper Commission) to initiate limited social insurance for long-term care financing. In 1993, the Clinton Administration's health proposal included a substantial new commitment to financing home and community-based care for people of all ages and incomes with significant impairments. Yet only modest and less costly action has been taken—clarifying that long-term care insurance premiums would receive most of the same tax preferences as health insurance premiums and making long-term care insurance available to federal employees at their own expense. In the current debates about the future of Medicare and Social Security, long-term care has received little notice.

The contrast between the attention we believe long-term care needs and the attention it receives provided the impetus for our committee's work. Specifically, alongside our effort to describe the flaws in current financing arrangements and identify goals for the future, we asked ourselves what it would take—politically—to move policy.

Our guide in our deliberations was John Kingdon, a political scientist who has systematically examined why public officials and other participants in the political process pay attention to and act on some issues and not others—in short, what makes an issue "an idea whose time has come" (Kingdon 1995). In relying as heavily as we do on Kingdon, however, we by no means present the full scope of his work, and we use it selectively to guide our own thinking. Kingdon identifies three requirements for putting an issue such as long-term care on the policy and political map:

- Perception in the political community that inadequate long-term care financing is not simply an unfortunate "condition" but instead a "policy problem" requiring political action.
- Generation of proposals for policy action regarded as sufficiently debated and tested for feasibility and effectiveness to "soften up" political actors and pave the way for policy action.
- Emergence of leaders—in Kingdon's words, "policy entrepreneurs"—willing and able to find "windows of opportunity" to capture the public mood, overcome ideological controversies regarding public expenditures and the role of government, and resolve stakeholders' conflicting interests to achieve reform.

Moving from a Problematic Condition to a Policy Problem

Data, analysis, real-world experience, and the language we use can each have powerful effects in putting policy problems on the political agenda. Recently, for example, advocates have combined analysis and rhetoric to frame Medicare's lack of prescription drug coverage as morally (and therefore politically) unacceptable. The way a condition is framed—the constellation of values and issues to which it is connected—affects not only policymakers' views but also their perception of the public's readiness for action.

Has long-term care been successfully framed as a policy problem? To some extent, yes. Exposure of nursing home tragedies and abused or mistreated patients in long-term care facilities provided a powerful impetus for nursing home reforms in 1987. Claims of harm likely to befall elderly and disabled beneficiaries have more than once impeded federal budget cuts in Medicaid. The Supreme Court's pronouncement that limited access to home and community-based care can constitute a violation of civil rights is proving a powerful impetus to expansion of services for people with disabilities.

Why have these powerful examples not given greater impetus to reforming the financing of long-term care? To learn more, we commissioned a poll of baby boomers and seniors. Pollsters Peter D. Hart Research Associates and American Viewpoint summarize their results in a National Academy of Social Insurance Health and Income Security Brief, *Long-Term Care: The Public's View*.

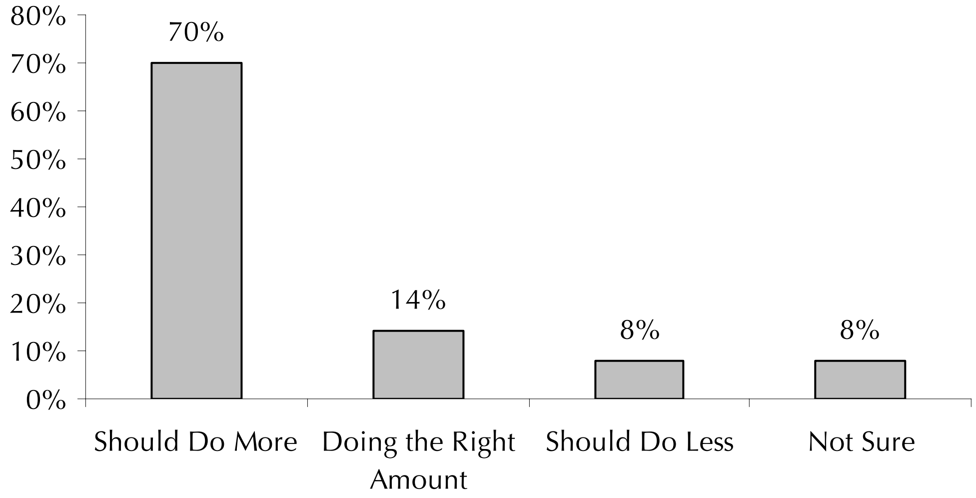
The findings were surprising. Our initial view that people did not perceive a policy problem or a basis for government action regarding long-term care proved incorrect. Instead, among adults aged 40 and over:

- The vast majority (90 percent) recognize that affording the costs of long-term care is a difficult proposition, including 62 percent who say that it is very difficult. Affording long-term care is considered far more difficult than problems that sometimes receive more attention, such as finding high-quality care or information about government financial help.
- Nearly three-quarters are concerned either a great deal (54 percent) or a fair amount (18 percent) about paying for long-term care—a proportion nearly identical to proportions expressing concern with paying for a major illness or a comfortable retirement.
- Seven in ten believe that government should do more to help people meet the costs of long-term care (see Figure 2).

Contrary to our expectations, then, there is a strong public perception that long-term care financing is not just a condition but also, in Kingdon's sense, a policy problem worthy of government attention.

Figure 2

What Should the Federal Government Do to Help People Meet the Costs of Long-Term Care?



Source: Peter D. Hart Research Associates 2004.

The poll also provides some guidance on attitudes that might promote policy change. The survey showed that baby boomers (aged 40 to 60) and seniors (aged 60 or over) have similar attitudes toward financing as a policy problem, and that direct personal experience with long-term care was not necessary for concern about the issue. Further, about half the respondents found several facts very convincing as reasons for policy action to improve long term care financing—including the aging of the population, high and rising long-term care costs and expenditures, heavy dependence on family members as caregivers, and limited Medicare coverage or private insurance for long-term care.

Particularly noteworthy was a strong negative reaction to the description of current Medicaid policy, which requires individuals to virtually exhaust their assets before becoming eligible. Respondents found this one of the most convincing reasons to do more about long-term care. As the pollsters observe, "The image conjured by informing people about the Medicaid spend down requirement is obviously troubling even for people who generally are not inclined to support more action on long-term care affordability—half of . . . those who say that long-term care costs are a moderate or low priority for the nation (51 percent) find this message very convincing." After hearing that Medicaid covers care only after individuals have exhausted virtually all their own resources, 41 percent of respondents concluded that the system of paying for long-term care "is broken and needs a complete overhaul," and another 30 percent thought that it needs major improvements.

The results of the survey clearly demonstrate, according to the pollsters, that Americans age 40 and over are deeply concerned about long-term care and believe that more must be done to help people meet its expense. Almost half believe that addressing the costs of long-term care should be a high priority for the nation, and a third believe that it should be a very high priority. But public opinion—far more supportive of long-term care financing as worthy of political attention than we expected—is by itself insufficient to put an issue on the map.

Generating Policy Proposals

Political action requires a policy proposal—formulation of the specific steps the government should take. Policy proposals, Kingdon tells us, emerge from "policy communities" of interest groups, congressional staff, researchers, and advocates, who continually create ideas, seek champions and coalitions, and watch for windows of opportunity to move them forward. Just as there is a process through which conditions become policy problems, there is a process through which myriad ideas coalesce into a recognizable set of policy options or alternatives.

The policy ideas that last, Kingdon says, meet several criteria: technical feasibility, concordance with the values of the policy community, tolerable costs, and receptivity by policymakers and the public. Believing that a proposal makes sense both from a values perspective and a practical perspective is tremendously important to elected officials. When Medicare was enacted, for example, the decision to have private health insurance companies administer the program reflected both values and practical concerns. Reliance on private insurers deflected potential criticism about a government-run health care system and drew on proven expertise in administering health insurance programs, which could help ensure a smooth implementation of a complicated new program. Use of Pharmacy Benefit Managers in the Medicare prescription drug program serves a similar purpose.

The policy community has been working on long-term care issues since the enactment of Medicare and Medicaid, but the focus has generally been on small improvements rather than comprehensive reform. Policymakers have grappled with a wide range of operational issues: what kinds of institutions could qualify as nursing homes, how they would they be certified, and how—and how much—they would be paid. They have expanded the definition of nursing homes from extended care or skilled care to intermediate care facilities, experimented with the provision of non-institutional care in Medicaid, and varied the definition of home health care in Medicare. Medicaid policies have supported substantial growth in long-term care spending, and an increasing portion has been devoted to home and community-based care.

Further expansion of the federal role in long-term care financing, however, faces formidable obstacles. Today as in the past, conflict rages over the scope of government, the roles of public support and private responsibility, and levels of spending and taxation. Enactment of Medicare and Medicaid forty years ago, Medicaid expansions in the 1980s, and Medicare prescription drug coverage in 2003 had to overcome similar obstacles. Although the policy community has increasingly, if not totally successfully, softened up the public and policymakers on using an insurance model to finance long-term care, policymakers remain resistant to greater public spending for long-term care, particularly in the form of an entitlement. Proposals in recent years have focused on modest tax credits, either to support the purchase of private long-term care insurance or to enhance income for people who need long-term care and their family caregivers. So ingrained is the opposition to public financing that a recent Congressional Budget Office report on long-term care financing focused only on cutting federal costs and ignored proposals to expand public financing (CBO 2004).

The public seems more receptive toward mixed public/private financing mechanisms than to fully public solutions. In our poll, the 70 percent of respondents wanting government to do more for long-term care financing were asked to indicate which of two statements came closer to their view of that action—one, a shared responsibility between individuals and government, relying on tax incentives for savings or the purchase of long-term care insurance plus government financing for low-income people; the other, long-term care coverage through Medicare, financed through premiums and taxes. Respondents favored the first option by a margin of two-to-one. When asked to rate their own views on personal versus governmental responsibility on a scale from one to seven, most people chose a number toward the middle of the scale. Although the pollsters note that respondents were not provided information that might reduce support for more government responsibility—the future costs of Medicare, Medicaid, and Social Security, as a prime example—their findings nevertheless suggest that proposals for sharing responsibility are consistent with the public's values.

Georgetown University's Long-Term Care Financing Project, with funding from the Robert Wood Johnson Foundation, is currently assessing a range of policy proposals that share responsibility for long-term care financing in different ways. The project is focusing on eleven proposals, developed by a range of experts, that move from the current public/private partnership—in which individuals must contribute virtually all they have before receiving public support—towards partnerships that involve an insurance model. The proposals fall into four categories that span a continuum from modest to substantial government involvement (see Table 4).

These eleven proposals differ considerably in the income and age groups they benefit, the scope of protection they provide, and the sharing of costs among taxpayers and affected individuals. Many of the proposals do not satisfy the study panel's criteria for a good long-term care system, and many fail to provide the additional public dollars that the panel believes are required. Nonetheless, they illustrate and illuminate the variations that are possible and will provide a basis for the policy debate that still needs to occur.

Table 4

Long-Term Care Financing Options

Promote Purchase of Private Long-Term Care Insurance

1. Market private long-term care insurance with Medicare "seal of approval" and with marketing support from Medicare
2. Provide tax deduction for purchase of private long-term care insurance, and allow premiums to be paid from cafeteria plans or flexible spending accounts
3. Introduce regulatory changes and tax credits to facilitate employer plans that integrate long-term care insurance with life annuities [a]

Provide Public Coverage of Catastrophic Costs

4. Enhance asset protections under Medicaid for purchasers of private long-term care insurance (expand Long-Term Care Partnerships)
5. Provide catastrophic long-term care insurance through Medicare to beneficiaries who forego Part B home health benefits and purchase qualified private insurance

Mandate Financial Contributions to Pre-Fund Long-Term Care

6. Replace a portion of Social Security retirement benefits with a limited long-term care benefit to be supplemented by private insurance
7. Mandate payroll deductions for workers to create accounts for purchase of long-term care insurance or long-term care services after age 65

Provide More Comprehensive Public Coverage

8. Raise the income and asset limits for Medicaid home and community-based care, and subsidize a buy-in for people with additional resources
9. Enhance and standardize Medicaid coverage across states, and create a public catastrophic long-term care benefit with a three-year waiting period
10. Expand Medicare to cover comprehensive long-term care services, financed through a surcharge on the income tax
11. Establish a new, comprehensive social insurance program modeled on the German system

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[a] This product aims to address private insurers' concerns about adverse selection and thereby reduce the underwriting restrictions that limit access to long-term care products. Sellers of long-term care insurance face the financial risk that too many purchasers will be sick and need long-term care; sellers of lifetime annuities face the financial risk that too many purchasers will be healthy and collect payments for a long time. By combining the two products, the risks can offset each other, reducing the need to screen out the sick and the healthy, respectively.

Winning the Politics

Whether a policy proposal reaches the top of the political agenda depends not only on public opinion, however, or on the results of an election, but also on how events unfold and advocates latch onto it. Skillful policy entrepreneurs do not simply "push, push, and push for their proposals or for their conception of problems," Kingdon says. "They also lie in wait—for a window to open." And when political leaders, especially the President, make an issue theirs, the political process moves into high gear.

Thomas Oliver, Phillip Lee and Helene Lipton describe how the processes of framing a problem, achieving policy acceptability, and gaining political momentum came together to achieve the unexpected and dramatic passage of Medicare prescription drug legislation in 2003 (Oliver, Lee, and Lipton 2004). As these authors describe, Medicare's lack of prescription drug coverage had long been a problematic condition for beneficiaries and had emerged on the agenda as a policy problem intermittently over several decades. It was pushed onto the agenda in the late 1990s by unusually large increases in prices of prescription drugs, which resulted in reductions of employer-provided retiree drug benefits and drug benefits in Medicare managed care plans. These factors highlighted growing inequities in access to the pharmaceutical miracles continually appearing on the market.

Attention to these developments was highlighted by the deliberations of the National Bipartisan Commission on the Future of Medicare—a body that President Clinton and the Republican Congressional leadership agreed to establish to study and make recommendations regarding Medicare's solvency. The Commission picked up where the Republican's unsuccessful 1995 effort at Medicare reform had left off. Its charge, with no mention of prescription drugs, was to explore restructuring Medicare to fend off the impending exhaustion of the program's trust fund. Once in motion, however, Democrats on the commission defined "reform" quite differently—focusing less on Medicare's financing than on the inadequacy of its benefits. In essence, they sought to reframe the policy problem, focusing on prescription drugs.

By this time, Oliver and his colleagues observe, policy proposals to add prescription drug coverage had been in the policy arena for more than a decade. Indeed, Medicare prescription drug coverage had actually been enacted as part of the Medicare Catastrophic Coverage Act of 1988, only to be repealed a year later because of hostility from beneficiaries. Although that experience proved a powerful deterrent to future legislative action, it also provided lessons for how different coverage and financing policies would be perceived by Medicare beneficiaries. Development and testing of options for prescription drug coverage continued in the Clinton health reform plan, a Medicare drug proposal in the second Clinton Administration, and—after the issue heated up in the 2000 Presidential campaign and the subsequent Congress—a variety of proposals from the Bush administration and members of Congress. Belief in the feasibility of action was strengthened by the experience of private insurers in providing prescription drugs and, for a few years after 1998, by the emergence of a budget surplus.

Still, Oliver and colleagues make clear, Medicare prescription drug legislation faced enormous hurdles. Its appeal to Republicans, ordinarily opposed to government expansions, was mainly as a "sweetener" to make palatable a fundamental shift toward a more market-oriented Medicare program. The cost of a benefit was both enormous and unpredictable, and the budget surplus that had appeared in 1998 quickly evaporated. Fiscally conservative Members of Congress were loath to add hundreds of billions to the deficit, but controlling costs by providing limited rather than comprehensive benefits—the strategy that emerged—risked creating a backlash from the very beneficiaries whose approval many politicians were seeking.

The political window finally opened in 2003 when the Republicans took control of both houses of Congress and when President Bush decided to invest heavily in reaching a prescription drug program in order to take that issue away from Democrats in his 2004 reelection campaign. The president and the Republican leadership in Congress intensely lobbied legislators and the pharmaceutical industry to accept their agenda on Medicare in order to strengthen their broader political position. Key members of Congress came to believe that they had more to lose than to gain in the 2004 election from failure to pass legislation. Policy proposals were shaped and reshaped to appease opposition and balance competing interests. The expiration of Congressional budget rules, which for a decade had required that new spending be offset by spending reductions, eliminated a significant procedural obstacle to an initiative with such sizable costs.

Not until its dramatic conclusion (with prolonged and visible arm-twisting in the House of Representatives) was it clear that the Medicare drug benefit's time had actually come. The features that made its passage politically feasible—costly but limited benefits and reliance on private insurance—remain controversial. Fiscal conservatives object to its boost to already substantial Medicare spending; social insurance advocates object to its departure from Medicare's traditional protections. When the new benefit is implemented in 2006, beneficiaries will have to navigate a complicated system of plans, premiums, and subsidies. All these factors will keep the issue on the political agenda for some time to come.

This brief review of what it took to enact a Medicare prescription drug benefit illustrates the unpredictability and the significance of political forces in achieving major policy reform. Evidence that existing policy fell short of providing adequate protection mattered, as it would in a debate on improvements in long-term care financing. But it was electoral politics—both for the Congress and the Presidency—that created the windows of opportunity and the rewards to political entrepreneurs that turned an unfortunate condition into a policy problem demanding action. Policy professionals developed and massaged proposals to achieve political acceptability, and partisan competition and presidential priorities overcame powerful ideological and budgetary obstacles. None of it was simple or straightforward—and action was by no means a foregone conclusion.

Accomplishing similar results for long-term care will be at least as complicated and uncertain—perhaps even more so because of the costs and controversies that enactment of prescription drug coverage itself created.

Making the Time Come for Long-Term Care

Our review of the gap between what is and what ought to be our nation's long-term care system provides the evidence—or policy case—for action to improve long-term care financing. What ought to be is a system that meets the needs of individuals, preserves the autonomy of those who need care, and promotes equity in distributing costs and assuring access to services. What exists is a financing system that leaves millions of people inadequately served, places untenable demands on family caregivers, makes the purchase of care unaffordable or financially catastrophic for many of those who need it, requires impoverishment as a condition for public financial support, and targets the bulk of that support to care in institutions even though people prefer care at home.

To move from what exists to what ought to be requires a substantial change in public policy. The need for extensive long-term care is an unpredictable, catastrophic event, best dealt with through insurance. Public protection through Medicaid falls short of insurance; it finances care for people only once they are or have become impoverished, and states are increasingly pressed to guarantee even that. Despite improvement and expansion of private long-term care insurance, its capacity to meet people's needs is significantly limited. Public insurance is clearly required to assure all Americans adequate protection. As demonstrated by experience in other nations, that insurance can take a variety of forms and can complement rather than replace personal and family responsibility. Nevertheless, to provide effective protection regardless of the state in which people live will require a substantial new commitment of federal resources.

Making the case for improving long-term care financing, however, is just the beginning of a move toward policy action. Action requires that policymakers and the public not only perceive a problem but also expect government to address it; that the policy community develop, refine, and come to accept specific government action; and that political leadership and opportunities exist to overcome ideological obstacles, resolve conflicting interests, and garner the fiscal resources necessary for meaningful reform.

Our analysis gives us reason to believe that the public does indeed perceive government action as not only appropriate but necessary to address long-term care financing concerns. In our poll of adults aged 40 and over, overwhelming majorities expressed concern about being able to afford long-term care, were troubled by impoverishment as a condition for public financial support, and supportive of a "complete overhaul" or "major improvements" in financing policy. Generalized support, however, does not necessarily translate into support of a specific policy proposal. Despite decades of discussion on long-term care, debate has never been sufficiently intense to generate acceptance of even a narrow range of options on how public support might be improved. Among the 70 percent of our respondents wanting government to do more for long-term care financing, the majority favored "shared responsibility" between individuals and government, rather than full government responsibility—suggesting a direction for future policy development. Our analysis of international experience shows that other nations, with far larger proportions of elderly citizens than we have in the U.S. today, have adopted a variety of policies that more fairly balance personal or family responsibility and public support.

Adopting similar policies is a challenge not to our abilities but to our political will. The long, tortuous and still contentious experience with Medicare prescription drug coverage demonstrates how mustering political will can depend on partisan competition, presidential and congressional politics, and conflicts of ideology as well as interest. We cannot predict when windows of opportunity for long-term care action may emerge. However, as advocates for improving the financing of long-term care, we cannot simply sit back and wait.

- As researchers, we must continue to demonstrate the extent of unmet needs for long-term care, the financial costs of care, and the burdens of caring on caregivers.

- As advocates, we must frame the problem of long-term care financing in terms that resonate with the public, building on the increasing sensitivity to retirement security and equal treatment for people with disabilities.
- As analysts, we must refine and disseminate specific policy proposals, assess their costs and benefits, encourage debate among stakeholders, and build confidence that policy action is not only desirable but feasible.
- As activists, we must muster the evidence on problem, policy, and politics to convince political leaders that long-term care is the cause they ought to champion and to identify the political arenas where their cause can take hold.

The study panel recognizes that obtaining political and fiscal support for a humane, equitable, and effective long-term care system will be daunting. But inaction means deterioration in already inadequate financing and care. The nations' governors have declared that states cannot continue to be the nation's primary funder for long-term care. The aging of the baby boom generation will only intensify the already substantial pressure states face. As policymakers grapple with the budgetary concerns, the long-term care needs of the nation's elderly and disabled citizens must be recognized, and our society must not shrink from providing the resources that will be required.

Notes

[1] Dual eligibles are entitled to Medicare on the basis of age or disability and also entitled to Medicaid because they have limited income and resources or have exhausted them to meet their health care needs. The survey was conducted in six states: Georgia, Iowa, Massachusetts, New Jersey, Washington, and Wisconsin.

[2] Premium data are for 2002 based data submitted to AHIP by 11 of the 13 sellers identified as having sold 80 percent of all individual and group association long-term care insurance plans. Premiums are based on a $150-a-day benefit, four years of coverage, and a 90- day elimination period. The policy includes a 5 percent inflation protection and a nonforfeiture provision, which means that policyholders can retain a reduced level of coverage if they do not continue to pay premiums (AHIP 2004).

[3] For example, the ratio of elderly people to workers is projected to grow by 32 percent in the District of Columbia and by 136 percent in Colorado, the state with the fastest growing elderly population.

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1776 Massachusetts Avenue, NW
Suite 615
Washington, DC 20036

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