
Wisconsin Family Impact Seminars Briefing Report

Long-Term Care: State Policy Perspectives



University of Wisconsin-Extension
Center for Excellence in Family Studies
School of Human Ecology
University of Wisconsin-Madison

Long-Term Care: State Policy Perspectives

First Edition

**Wisconsin Family Impact Seminars
Briefing Report**

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Purpose, Presenters, and Publications

Family Impact Seminars have been well received in Washington, D.C., by federal policymakers, and Wisconsin is one of the first states to sponsor the seminars for state policymakers. Family Impact Seminars provide state-of-the-art research on current family issues for state legislators and their aides, Governor's Office staff, state agency representatives, educators, and service providers. Based on a growing realization that one of the best ways to help individuals is by strengthening their families, Family Impact Seminars analyze the consequences an issue, policy, or program may have for families.

The seminars provide objective nonpartisan information on current issues and do not lobby for particular policies. Seminar participants discuss policy options and identify common ground where it exists.

"Long-Term Care: State Policy Perspectives" is the 12th seminar in a series designed to bring a family focus to policymaking. This seminar featured the following speakers:

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Each seminar is accompanied by an in-depth briefing report that summarizes the latest research on a topic and identifies policy options from across the political spectrum. Copies are available at Extension Publications, Room 245, 30 North Murray Street, Madison, WI 53715, (608) 262-3346.

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Executive Summary

Many Wisconsin residents rely on long-term care services because of frailty or a disability. Although most long-term care is provided informally by family members, formal services also are provided in nursing homes, intermediate care facilities, and community-based settings. In 1996, Wisconsin spent approximately 1.2 billion Medicaid dollars to pay for long-term care services for those who could not afford them. This report provides an overview of long-term care for elderly and nonelderly individuals, discusses the role of the family in providing care, and proposes strategies for reducing the rate of increase in long-term care spending.

Robyn Stone is the executive director and CEO of the International Longevity Center and is the former U.S. Acting Assistant Secretary for Aging. According to Dr. Stone, long-term care includes a broad range of services needed by people with chronic illness or disabling conditions over a long period of time. In 1995, approximately 13 million Americans of all ages needed long-term care. Current estimates indicate that the older U.S. population will more than double between now and the year 2040. Because 57% of all users of long-term care are over age 65, this trend will substantially increase the future demand for long-term care services.

In 1995, approximately 80% of disabled older adults living in the community received informal care from family members. Currently, the competing demands of child care, employment, and elder care place a significant strain on family caregivers. A recent study indicates that the larger the number of problems family caregivers report, the greater the chance that their care recipients will be institutionalized. As such, several initiatives have attempted to help relieve family stress, including the Family and Medical Leave Act, “family friendly” work policies, respite care programs, and caregiver support groups. In addition, some states have begun to pay family members rather than hiring strangers to provide care.

For those individuals who need them, formal services are available in nursing homes and community-based settings. Funding for such services comes from a patchwork of public and private dollars. The most significant funding source is Medicaid, which spent approximately \$50 billion on long-term care in 1995. Other funding mechanisms include the Medicare program, which primarily covers acute care and home health service costs; private insurance, which finances a small proportion of nursing home and home care costs; and private dollars. In recent years, some states have moved toward a managed care approach to providing long-term care services, and some have sought to integrate acute and long-term care services. In addition, many policymakers and consumers have called for an increase in assisted living services, as well as a larger emphasis on consumer direction.

In the second chapter of this report, Joshua Wiener, principal research associate at the Health Policy Center of the Urban Institute, describes the under-65 population who uses long-term care services. Advocates for younger people with disabilities have suggested that long-term care providers must move beyond the goals of keeping people safe, clean, and well fed to maximizing independence and self-sufficiency.

Although the use of institutions by younger people with disabilities is declining, this type of care is still common, particularly for individuals with developmental disabilities. Advocates for younger people believe that institutional care should be replaced with home and community-based alternatives. Although this would result in lower costs per person, costs might increase if a larger number of people opt to use home and community-based options.

Services for younger people with disabilities are financed through many sources, including state and federal programs, out-of-pocket payments, and private insurance. In 1993, nearly 40% of Medicaid spending on long-term care went to services for nonelderly people. Because Medicaid applicants must meet eligibility requirements based on an inability to work, the current system of care tends to encourage dependence rather than independence.

In the third chapter of this report, Joshua Wiener discusses three general strategies that states have used to control the rate of increase in long-term care spending. The first involves offsetting state spending for long-term care. Specifically, some states have encouraged individuals to purchase private long-term care insurance. Recent studies indicate that if employers offer group rates for insurance, Medicaid expenditures could decline as much as 31% and the number of nursing home residents could fall by as much as 17% by the year 2018. So far, however, less than one tenth of 1% of middle-aged people have long-term care insurance. Other states have attempted to offset state spending by reducing Medicaid estate planning, whereby individuals transfer, shelter, and underreport assets to appear poor enough to qualify for Medicaid-financed nursing home care. States also have sought to recover the cost of Medicaid long-term care from the estates of beneficiaries who have died. Between 1991 and 1996, estate recovery in Wisconsin increased from \$471,000 to more than \$9.7 million. Finally, some states have sought to shift long-term care costs from the state to the federal government by maximizing Medicare financing of long-term care services.

A second general strategy for saving money is reorganizing health care delivery in ways that make care more cost effective and efficient. One way is to integrate acute and long-term care services through managed care. This practice has several benefits, including the potential of improving quality of care. However, many long-term care advocates are concerned that managed care providers have little experience with older adults, that financial pressure may shortchange long-term care, and that care would become less consumer directed. A second reform strategy is to expand home and community-based services. Policymakers will need to consider, however, if an increased number of people would consider using long-term care if more attractive options become available.

A third general strategy for reducing costs involves the use of traditional cost-saving methods, such as controlling the supply of providers and lowering reimbursement rates, which was recently made possible through the repeal of the Boren Amendment. Although both of these methods have the potential to save money in the short term, each has potential drawbacks. For example, decreasing the supply of providers does not decrease the demand for services. In addition, cutting reimbursement rates too much has the potential to negatively impact the quality of long-term care services.

A Checklist for Assessing the Impact of Policies on Families

The first step in developing family-friendly policies is to ask the right questions:

- What can government and community institutions do to enhance the family's capacity to help itself and others?
- What effect does (or will) this program (or proposed policy) have for families? Will it help or hurt, strengthen or weaken family life?

These questions sound simple, but they can be difficult to answer.

The Family Criteria (Ad Hoc) Task Force¹ developed a checklist to assess the intended and unintended consequences of policies and programs on family stability, family relationships, and family responsibilities. The checklist includes six basic principles about families that serve as the measure of how sensitive to and supportive of families policies and programs are. Each principle is accompanied by a series of family impact questions.

The criteria and questions are not rank ordered (Ooms & Preister, 1988). Sometimes these criteria conflict with each other, requiring trade-offs. Cost effectiveness also must be considered. Some questions are value-neutral. Others incorporate specific values. People may not always agree on these values, so sometimes the questions will require rephrasing. However, this tool reflects a broad, nonpartisan consensus, and it can be useful to people across the political spectrum.

Checklist: A Tool for Analysis

Check all that apply. Record the impact on family well-being.

1. **Family support and responsibilities.** Policies and programs should aim to support and supplement family functioning and provide substitute services only as a last resort.
 - ' How does the proposal (or existing program) support and supplement parents' and other family members' ability to carry out their responsibilities?
 - ' Does it provide incentives for other persons to take over family functioning when doing so may not be necessary?
 - ' What effects does it have on adult children's ties to their elderly parents?

¹Adapted from T. Ooms & S. Preister (Eds.) (1988). In *A strategy for strengthening families: Using family criteria in policymaking and program evaluation*. Washington, DC: Family Impact Seminar.

- ' To what extent does the policy or program enforce absent parents' obligations to provide financial support for their children?
 - ' Does the policy or program build on informal social support networks (such as community/neighborhood organizations, churches) that are so essential to families' daily lives?
- 2. Family membership and stability.** Whenever possible, policies and programs should encourage and reinforce marital, parental, and family commitment and stability, especially when children are involved. Intervention in family membership and living arrangements is usually justified only to protect family members from serious harm or at the request of the family itself.
- ' What incentives or disincentives does the policy or program provide to marry, separate, or divorce?
 - ' What incentives or disincentives are provided to give birth to, foster, or adopt children?
 - ' What effects does it have on marital commitment or parental obligations?
 - ' How does the policy or program enhance or diminish parental competence?
 - ' What criteria are used to justify removal of a child or adult from the family?
 - ' What resources are allocated to help keep the family together when this is the appropriate goal?
 - ' How does the policy or program recognize that major changes in family relations such as divorce or adoption are processes that extend over time and require continuing support and attention?
- 3. Family involvement and interdependence.** Policies and programs must recognize the interdependence of family relationships, the strength and persistence of family ties and obligations, and the wealth of resources that families can mobilize to help their members.
- ' To what extent does the policy or program recognize the influence of the family and family members upon individual needs or problems?
 - ' To what extent does it involve immediate and extended family members in working toward a solution?
 - ' To what extent does it acknowledge the power and persistence of family ties, especially when they are problematic or destructive?
 - ' How does it assess and balance the competing needs, rights, and interests of various members of a family? In these situations, what principles guide decisions (i.e., the best interests of the child)?

4. **Family partnership and empowerment.** Policies and programs must encourage individuals and their close family members to collaborate as partners with program professionals in delivery of services to an individual. In addition, parent and family representatives are an essential resource in policy development, program planning, and evaluation.
 - ' In what specific ways does the proposed or existing program provide full information and a range of choices to families?
 - ' In what ways do program professionals work in collaboration with the families of their clients, patients, or students?
 - ' In what ways does the policy or program involve parents and family representatives in policy and program development, implementation, and evaluation?
 - ' In what ways is the policy or program sensitive to the family's need to coordinate the multiple services they may require?
5. **Family diversity.** Families come in many forms and configurations, and policies and programs must take into account their different effects on different types of families. Policies and programs must acknowledge and value the diversity of family life and not discriminate against or penalize families solely for reasons of structure, roles, cultural values, or life stage.
 - ' How does the proposal or program affect various types of families?
 - ' If the proposed or existing program targets only certain families, for example, only employed parents or single parents, what is the justification? Does it discriminate against or penalize other types of families for insufficient reason?
 - ' How does it identify and respect the different values, attitudes, and behavior of families from various racial, ethnic, religious, cultural, and geographic backgrounds that are relevant to program effectiveness?
6. **Targeting vulnerable families.** Families in greatest economic and social need, as well as those determined to be most vulnerable to breakdown, should have first priority in government policies and programs.
 - ' Does the proposed or existing program identify and target publicly supported services for families in the most extreme economic or social need?
 - ' Does it give priority to families who are most vulnerable to breakdown and have the fewest supports?
 - ' Are efforts and resources targeted on preventing family problems before they become serious crises or chronic situations?

Long-Term Care: Coming of Age in the 21st Century

Robyn Stone

Long-term health care for older adults has emerged as a significant issue, both in terms of quality and financing, during the past 30 years. This article provides an overview of long-term care in this country, highlighting why it is an issue, who uses care, what types of settings are available, and how family members play a role as caregivers. It concludes with a discussion of policy trends for the future financing and delivery of long-term care.

Long-term care public policy issues have been a major concern in the United States for 30 years and will continue to pose challenges in the next century. In 1995, 13 million Americans of all ages needed long-term care. A much larger number of relatives, friends, and others faced decisions about long-term care. For example, 80% of disabled older adults living in the community receive unpaid assistance from family and others; three out of five rely only on unpaid help, usually from wives and daughters. Many relatives provide indirect help, including making care arrangements and providing unpaid help to older adults living in nursing homes.

The demand for long-term care is expected to skyrocket as the baby boomers age. Between now and the year 2040, the U.S. older adult population will more than double. For the first time in history, one in five Americans—77 million people—will be age 65 or over. The number of people age 85 and older will triple by the year 2040, to 14 million. Even if estimated declines in disability rates among older adults are accurate, the sheer volume of very old adults probably will increase long-term care demands. Survey data applied to U.S. Census Bureau projections estimate that those 65 and over with activity limitations will rise from 12 million in 1994 to 22 million 2020, and to 28 million in 2030. At the same time, the pool of available family caregivers—especially adult daughters—will shrink. As more women work outside the home, have children later in life, and find adult children returning to the nest, the competing demands of child care, employment, and elder care could put a great strain on the backbone of the current long-term care system.

Given our changing society, major issues include how to design and implement a system of long-term care that best meets the needs of future older adults and their families, and how to pay for this system. Although these issues are not new, the aging baby boomer generation raises the stakes. This paper offers a brief history and an overview of the current status of long-term care in the United States, highlighting the implications of demographic and policy trends for the financing and delivery of future long-term care.

Between now and the year 2040, the U.S. older adult population will more than double.

What Is Long-Term Care?

Long-term care includes a broad range of services needed by people with chronic illness or disabling conditions over a long period of time. Long-term care needs are highly correlated with medical conditions such as arthritis, paraplegia, dementia, traumatic brain injury, or chronic mental illness. These services focus on providing assistance with daily activities to minimize, rehabilitate, or compensate for loss of independence. The services include assistance with (a) daily living activities such as bathing, dressing and eating; and/or (b) instrumental activities of daily living such as household chores, meal preparation, cleaning, shopping, money management, and transportation.

In 1995, more than 80% of older adults who needed support with daily living skills lived in the community.

Most long-term care is low-tech, but it may include high-tech medical interventions such as intravenous drug therapy, ventilator assistance, and wound care. Long-term care may be provided by unpaid family members or friends (informal caregivers) or by specially trained paid professionals and paraprofessionals (formal caregivers.) Services include human assistance and the use of assistive devices and technology. Long-term care occurs in a range of settings, depending on the person's needs, the availability of informal support, and the source of reimbursement. The most restrictive end of the continuum is nursing home or facility care. Home and community-based care is a catchall for a wide variety of noninstitutional options. Residential care, such as assisted living facilities and adult foster homes, falls in this category, although the boundaries between institutional and noninstitutional settings are gray. In general, residential care, which combines room and board with some level of care, is an option for people who do not require nursing homes but are no longer able to live independently. Other home and community-based settings include adult day care and care in one's own home. In the home, care is further differentiated between home health care, which includes some level of skilled nursing and custodial care, and home care, which includes personal care services and homemaking chores.

Who Needs and Uses Long-Term Care?

People using long-term care are diverse in age and level of need. Of the 12.8 million Americans with long-term care needs in 1995, 57% were over age 65. Another 40% were working-age adults; 3% were children. The need for care generally increases with age. Among Americans under age 65, one tenth of 1% relied on institutional care and 2% lived in the community with some care. In contrast, among the 34 million older adults, 5% lived in nursing homes and 12% received community-based care. Among those age 85 or older, 21% lived in nursing homes, and nearly half received community-based care. More than 80% of older adults who needed support with daily living skills lived in the community, and they tended to be much less disabled than those in nursing homes.

Who Pays the Bill?

The proportion of older adults likely to use nursing homes ranges from 39% to 49%. Nationwide, the average lifetime nursing home use is one year, and the average home care use is just over 200 visits. Whereas many users receive care for just short periods of time, a small proportion uses much more long-term care. The vast majority of long-term care is provided free by unpaid, informal caregivers, usually family and friends. In fact, less than 1 in 10 disabled older adults living in the community receives only formal, paid care. The availability of informal caregivers is often the decisive factor in whether a person's care needs can be met outside an institution. As an example, half of all older adults with long-term care needs and no family network are in nursing homes, compared with only 7% of those with needs who have family caregivers.

The financing of long-term care services is a patchwork of public (federal, state, and local) funds and private dollars. An estimated \$106 billion were spent on long-term care in the United States in 1995, and long-term care costs have increased from 4% in 1960 to more than 11% of all personal health care expenses in 1993. Public resources accounted for 57% of long-term care costs, with Medicaid being the largest payer (21% of federal and 17% of state dollars), followed by Medicare (18%) and other federal and state funds, such as Veterans Affairs, Older Americans Act, and Social Services Block Grant. Private insurance made up only 6% of costs, with 1 in 3 dollars spent on out-of-pocket costs.

Medicaid

Medicaid, the federal/state health insurance program for low-income people, is the major public program covering long-term care for older adults and people with disabilities. Despite public interest in and demand for home care, Medicaid continues to show a strong institutional bias, with more than 80% of the \$50 billion spent on long-term care in 1995 going to nursing homes and institutions for people with cognitive disabilities. Although the institutional bias prevails in most states, movement has occurred toward home and community-based options. Several states have explicitly recognized nursing home placement as the setting of last resort and have intentionally reduced the number of nursing home beds. With an aggressive home and community-based care policy, Oregon has placed many seriously disabled adults in alternative assisted living facilities and adult foster homes, while providing a strong case management program that allows disabled people to stay in their own homes.

The vast majority of long-term care is provided free by unpaid, informal caregivers.

Medicare

Medicare has not been considered a major payer for long-term care in the past, primarily covering acute care costs. Skilled nursing and home health benefits have been covered only short term to meet post-acute-care needs after a hospital stay. However, Medicare now supports more long-term, nonskilled personal care as a result of administrative changes since 1989, and Medicare spending for

home health services increased tenfold from 1987 to 1995. Most of this growth has been attributed to an increase in the number of home visits, particularly for personal care. The other Medicare area of growth is in the fuzzy area of sub-acute care, which is described by proponents as a set of intensive and coordinated treatments and services for post-acute-care patients to minimize or bypass expensive hospital stays.

Private Long-Term Care Insurance

Private insurance finances only a tiny proportion of long-term care—less than 6% of nursing home and home care costs in 1995. However, the market for private insurance policies has grown. Controversy surrounds the issue of private long-term care insurance, with the private sector arguing that public programs will never meet the demand, while consumers and regulators voice concerns about affordability and fraudulent marketing practices surrounding private long-term care policies. A recent *Consumer Reports* article suggests that only 10% to 20% of older adults can afford long-term care insurance.

Emerging Trends in Long-Term Care

Policymakers, practitioners, and consumers see the need to address long-term care costs while maintaining and improving quality. These two objectives have led to several trends in financing and delivering long-term care with important implications for the future, when aging baby boomers will increase the demand for a broad array of long-term care services.

Managed Care

Managed care has become a buzzword of the 1990s, both as a panacea for exploding costs and as the nemesis of quality care. The major definitions of managed care include (a) per-person payment to a plan or system of providers, (b) assumption of full or partial risk by the plan or provider, and (c) a gatekeeping mechanism to assure delivery of the most efficient and appropriate type and level of care. Managed care has been sold as a way to save money, but the growth of plans with profits and shareholder obligations as the bottom line has raised concerns about trading quality care for cost savings. Medicare managed care now covers 14% of beneficiaries. However, there is evidence that plans have been “cherry-picking” healthy older adults, resulting in questions about whether the plans have really saved the government any money. Given the healthier population served, most managed care plans have not covered long-term care. Most plans and provider networks also do not have the trained workforce to provide long-term care.

Only 10% to 20% of older adults can afford long-term care insurance.

Integration of Acute and Long-Term Care Services

Although no exact definition exists, these elements are part of integration:

- Broad, flexible benefits, including primary, acute and long-term care;
- far-reaching delivery systems that can go beyond traditional HMOs to community-based long-term care, case management, and specialty providers;
- adoption of mechanisms for integrating care, such as case management and care planning protocols, interdisciplinary care teams, and centralized member records;
- overarching quality systems with a single point of accountability; and
- integrated financing with flexible funding and the incentives to align payers and eliminate cost shifting.

Although people talk about integration, little experimentation has occurred. Fragmented funding sources are one barrier. Another is concern about financial risk and fear of trying to address the special challenges of acute and long-term care for high-risk, high-cost people. Perhaps the most overlooked barrier is lack of knowledge, information, and training to offer a coordinated, well-managed array of services. Most of the research on integrating acute and long-term care has been conducted through federal demonstration projects, which have not been very successful at demonstrating true savings. However, the idea behind integration seems to make intuitive sense, and the models have helped shed light on better ways to coordinate care across a broad range of services and systems. Despite a lack of proof of cost savings, several states have begun implementing integrated systems, especially for their “dual eligible” population—those who qualify for both Medicare and Medicaid. However, these projects are in the very early stages, and results of these studies will not be available for some time.

An estimated 15% to 70% of nursing home residents could live in residential care.

Assisted Living

Another trend receiving attention from policymakers and consumers is assisted living. However, the term is not consistent across providers, regulators, and policymakers. Some states have tried to use residential care to save money on institutions. One recent study (Spector, Reschovsky, & Cohen, 1996) estimates that 15% to 70% of nursing home residents could live in residential care. Some hospital discharge planners refer disabled older adults to nursing homes rather than other arrangements, although Kane (1997) has found that in reality, little nursing care is provided in nursing homes. Research, however, has not been clear on whether substituting residential care for nursing home care is suitable or saves money.

The major difference between assisted living and nursing home care seems to be philosophy and emphasis on care and housing arrangements (Kane, 1997). Some suggest residential care is for people who can afford to pay, whereas nursing care is for people who rely on federal and state money to cover costs. A few states use the terms “assisted living” and “residential care” interchangeably. For other states, differences between assisted living and residential care are that assisted living offers

- a focus on privacy, autonomy and independence;
- an emphasis on apartment settings shared by a choice of residents; and
- the direct provision or arrangement of personal care and some nursing, focusing on various levels of disability and need.

Although assisted living is a trend to consider, barriers do exist. Assisted living is now mostly for well-off older adults, with little available to moderate or low-income consumers because of inadequate public financing to subsidize costs. State policymakers and potential private providers also have concerns about balancing consumer choice and privacy with health, safety, and fear of liability. The extent of care actually provided in these facilities also is questionable. As providers look for new markets, there is concern that skilled nursing facilities will lay down carpet, install doors with locks, and call themselves assisted living.

Consumer Direction

The 1990s seem to be the coming of age of the health and long-term care consumer, starting with younger physically disabled people voicing strong opposition to facilities and desiring a range of home and community-based options with consumers in control. That movement is now taking hold among older adults, who want privacy, autonomy, and the right to “manage one’s own risk.” Consumer direction in long-term care is a way of leveling the playing field between institutions and home and community-based care. It also may be a potential way to save money. Consumers now have involvement ranging from care planning and decision making, to purchasing their own services.

Much of the consumer direction at the state level has been through Medicaid home and community-based waiver and state-funded personal assistance services programs. At least 35 states have programs providing some form of financial payment to relatives and other informal caregivers for chores and personal services (Linsk, Keigher, & Simon-Rusinowitz, 1992). Some compensate for work done or out-of-pocket expenses incurred by caregivers. Medicaid does not allow direct cash payments to care recipients. However, four states will soon apply for a Medicaid waiver to experiment with providing cash to recipients of home and community-based care.

Historically, U.S. policymakers have been comfortable providing cash benefits to certain groups, like veterans, while being less willing to provide cash payments to individuals perceived to be less deserving, such as Supplemental Security Income

At least 35 states provide financial payment to informal caregivers for chores and personal services.

(SSI) beneficiaries. Depending on the perspective, consumer-directed programs can be seen as a safe and low-cost way to satisfy consumer needs and allow payment of informal caregivers, or as a vehicle for depressing wages, exploiting workers, and jeopardizing the health and well-being of vulnerable consumers who cannot supervise their own care (Feldman, 1997).

The Future of Long-Term Care Demand

Many factors will shape the scope and nature of the future, including changing demographics, the health of older adults, the availability of family and informal caregivers, the financial status of future generations, their degree of planning for long-term care needs, and the availability and cost of institutional and community-based alternatives.

Studies indicate medicine has increased life expectancy without changing the onset of illness.

The Impact of Population Aging

The 21st century will see unprecedented growth in the elderly population as baby boomers age. Although most older adults are not disabled, the likelihood of long-term care increases with age. The number of very old—over 85—is estimated to increase from 4 million in 1998 to 8.5 million in 2030 to 14 million in 2040.

Life Expectancy and Disability

Part of the projected increase in number and proportion of older adults in the future is due to an increase in life expectancy at age 65. At age 65, men can expect to live another 18 years in 2020 and 19 years in 2030, up from 16 years in 1995. Women can be expected to live 21 more years in 2020 and 22 years in 2030, compared with 19 years in 1994. But the extent to which people can live those years without disability is debatable. Some studies indicate medicine has increased life expectancy without changing the onset of illness. Declining death rates could actually increase long-term care needs.

Geographic Diversity

The number of elderly and its impact on long-term care demand varies greatly among states. As baby boomers begin to reach retirement in 2011, the size of the 65 and older population will increase in every state, with California and Florida ranking first and second. But by 2025, Texas will rank third, passing New York and Pennsylvania. Currently, only five states have at least 15% of the population age 65 or older. But by 2025, 48 states will reach or exceed that proportion.

The Future of Informal Caregiving

Several factors will affect the future supply of informal caregivers. The most important predictor of a strong informal network is being married because spouses and children are most often providers of care. Researchers estimate that 1.2 million people 65 or older will live alone and have no living children or siblings in 2020—up from 682,000 in 1990. These are the people most likely to use formal services and have no informal care. Another basic measure of the availability of

informal caregivers is the ratio of population in the average caregiving range, which is 50 to 64, to the population age 85 and older. In 1990, the ratio was 11 to 1; by 2050, the ratio will be only 4 to 1.

Researchers have found that informal caregivers typically adjust their level of care when meeting other family needs, such as the needs of their own children. As women delay having children, they are more likely to juggle childrearing and elder care, resulting in fewer care hours for a disabled parent. The more children a disabled parent has, the greater the volume of help. Another consideration is women's work outside the home. The proportion of women age 45 to 54 in the labor force is expected to increase from just over 75% in 1996 to nearly 80% in 2006.

A large unknown in this area is related to how new family structures will affect the pool of informal caregivers. Increases in divorce and remarriage mean many older adults have step-in-laws and step-grandchildren. Researchers do not know if this will affect caregiving.

Economic Status of the Future Elderly

Another factor affecting the future of long-term care is the extent to which older adults will be able to afford services. One measure of elderly economic status and their potential use of formal services is educational level because more highly educated people are more likely to be wealthy and to purchase care. Older adults will clearly be more educated in the next century. In 1997, 40% of those aged 75 and older had less than a high school education, and only 13% had a college degree. In contrast, only 13% of people ages 45 to 54 have less than a high school education, and 28% have a college degree. Only one in eight older adults is below the poverty level, although many elderly remain poor. Nearly 80% of older adults ages 55 to 64 were homeowners in 1997.

Assuming reasonable economic growth, baby boomers should have higher real incomes during retirement than today's retirees. Married couples will be better off than singles; with single men better off than single women. However, boomers have few financial assets. The typical boomer has assets of only \$1,000, and the lowest one quarter have liabilities that exceed their assets. A recent survey found almost half of boomers had done little or no long-term care planning.

The Future Supply of Long-Term Care Services

Another factor affecting the future of long-term care is whether nursing homes will remain the dominant setting for services. Much depends on public and private incentives to develop more community-based alternatives, including assisted living. Currently, little substitution between nursing homes and assisted living exists. Most institutional care is supported by Medicaid, and people must be low income or become poor to qualify. In contrast, assisted living is used primarily by the wealthy with few attempts to reach a modest or low-income market. The

As women delay having children, they are more likely to juggle childrearing and elder care.

assisted living market is estimated at \$13 to \$15 billion, with an expected increase to \$20 billion in 2020. However, it is unclear whether the industry will expand its consumer base.

Sinking or Swimming Into the Future

The rapidly changing health and long-term care environments make it hard to predict what kind of financing and delivery system will emerge in the future. Some factors, however, are known. First, a major demographic shift is overtaking the world. The number and proportion of elderly, including the very old, will increase dramatically, expanding the need for long-term care.

Another trend is the role of family and friends in providing long-term care. Policy discussions continue to focus on how to support informal caregiving, with one objective being to avoid formal, paid care when family care is possible. The nature and character of these informal networks may change. There will be more adult children available as potential caregivers. However, by the year 2025, the potential pool of caregivers will decrease. More women in the labor force and a trend toward delayed childbearing will increase the “sandwich generation,” comprised of individuals who must juggle multiple caregiving and work demands.

Researchers have noted that family caregivers tend to experience stress. Whether the stress comes from anxiety and grief associated with having a sick family member, or whether it is the physical and mental toll of caregiving tasks is less well known. One study found the greater the number of problems caregivers reported, the greater the chance that their care recipients would eventually be institutionalized (McFall & Miller, 1992).

The most prominent workplace initiative aimed at supporting informal caregivers is the Family and Medical Leave Act of 1993, which requires employers with more than 50 workers to permit employees to take up to 12 weeks of unpaid leave to care for a newborn, adopted child, or ailing family member. Some employers and unions also have established “family-friendly” programs to reduce conflict between work and family caregiving, including flexible scheduling; part-time work options with benefits; information and referral services; and caregiver support groups. Financial benefits like dependent care assistance programs and reimbursement accounts are less often available.

Respite care frequently is requested to help relieve family stress. Many services, including home care aides, companion care, adult day care, and short-term residential placement are considered respite if the focus is on giving caregivers time off while meeting the disabled person’s needs. Yet, evaluations of programs that provide free or subsidized respite care found as many as 30% to 50% of participating families did not use available services. Overall, respite seems to have a modest positive impact on preventing residential placement.

The more problems reported by caregivers, the greater the chance of their care recipients being institutionalized.

Caregiver support groups and training in coping skills can alleviate some stress. Support groups and other counseling and educational programs draw on professional expertise, but are often sponsored by voluntary associations of caregivers. These programs are particularly successful for caregivers of people with Alzheimer's disease and other conditions causing cognitive impairment.

Some states are increasingly paying family members instead of hiring strangers for care. Formal helpers who supplement informal caregivers also are on the rise. President Clinton recently proposed a \$1,000 tax credit that compensates for the formal or informal costs to Americans of all ages with long-term care needs or the family caregivers who support them. The proposed initiative also includes a new National Family Caregiver Support Program (\$625 million over 5 years) administered through state units and local area agencies on aging, and a \$10 million nationwide campaign to educate Medicare beneficiaries about long-term care options. Although an extremely modest proposal, the President has put long-term care on the national agenda with this initiative.

***In an ideal world,
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rather than the
provider.***

What role long-term care insurance will play remains unclear. As mentioned before, limits on the market do not bode well for this option. However, future elders will be more highly educated and wealthier, and may be able to buy this insurance. One long-term care product—the disability option—needs serious attention. Currently offered by a few insurers, it provides claimants with a set dollar amount tied to level of disability, rather than access to certain services. This model might appeal to people who want to know what they will be buying 30 years into the future and who want maximum flexibility.

Recognizing the need for a group long-term care market, the President's recent long-term care initiative also calls on Congress to pass a new proposal that allows the federal government's Office of Personnel Management to use its market leverage and set a national example by offering nonsubsidized quality private insurance to all federal employees, retirees, and their families at group rates.

Although no clear answer exists for balancing public and private financing of long-term care, several elements are important for the future. First, the system must address the long-term care needs of all age groups, recognizing services must be tailored to meet each person's needs. Second, the system should be sensitive to family needs as well. Although formal care cannot and should not replace family and friends, the array of services should include family needs, preferences, and supports. The future system also should recognize the options possible to meet residential and care needs. It should be flexible enough to address fluctuating needs that may be acute, chronic, or nonmedical (e.g., transportation, housekeeping). People who want to make their own choices should have that option, although it is important that they know the tradeoffs involved in managing their own risk.

In an ideal world, the money would follow the person, rather than the provider. People and their families would be able to make choices that include preferences

and values, with financial constraints set by public programs and their private resources. This type of system requires major changes in our current public programs so funding streams become seamless.

Long-term care will be one of the major challenges of the next century. We can wait for a crisis, or be proactive in developing a financing and delivery system that learns from past successes and failures, that balances public and private resources, and that puts long-term care clients and their families in the driver's seat.

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Long-Term Care for the Younger Population: A Policy Synthesis

Joshua Wiener and Catherine M. Sullivan

Although long-term care financing issues for older adults has been a public policy issue for 3 decades, long-term care for younger people has been virtually ignored until recently. This paper looks at the size of the younger population, what younger people want from the long-term care system, how service delivery should be organized, and what options are needed to finance services for younger people with disabilities.

Although attention to the problems in the long-term care system for older adults has increased, similar problems facing younger people with disabilities have been ignored by policymakers until recently. Between one third and two thirds of all disabled people are not elderly, but little is known about how younger people finance and use long-term care.

Interest in younger people with disabilities has grown for two reasons. First, younger people with disabilities have demanded recognition. After the 1990 enactment of the Americans With Disabilities Act, younger people made long-term care reform a priority and pushed themselves into the political process. Second, advocacy groups for older Americans have promoted long-term care as a problem affecting all ages to counter arguments that public long-term care spending takes money away from younger people.

Between one third and two thirds of all disabled people are not elderly.

Disabled People Under Age 65

The size of the population of younger people with disabilities is fundamental to policymaking, but has conflicting implications. If the number is large, more public attention is needed. But the bigger the population, the larger the expense and the less willing public officials may be to commit resources.

Estimates Vary Substantially

In 1995, the estimated number of young people with disabilities living in the community varied from 20 million to 33 million, with between 1 million and 14 million having substantial disabilities. Depending on estimates, younger people with disabilities account for one third to three quarters of those with disabilities living in the community. Also, recent statistics indicate that about 1 million people under age 65 with disabilities are homeless, in jail, or in institutions such as nursing homes or long-term care facilities.

Philosophy Behind the Disability Movement

One major impact from the disability movement has been a rethinking of the goals for long-term care, which in the past had been limited to keeping older people safe, clean, and well fed. Advocates for younger people reject these goals, arguing that they are far too limited. This group believes that the aims of long-term care should be to maximize independence and self-sufficiency (DeJong, 1979), implying a radical change in how the services should be organized and financed (Simon-Rusinowitz & Hofland, 1993). This philosophy has five basic tenets:

- Younger persons with disabilities reject the notion that a disability makes them less of a person. They argue that people with disabilities are handicapped by society's attitudes and barriers in the environment, not by their impairment (DeJong, 1993). According to this view, the service system's goals should be to provide access to the same freedoms associated with full community integration, including working at paying jobs, marrying and having a family, and realizing their potential as human beings.
- Disabled people are capable of making decisions about their lives. For people with mental retardation and mental illness, the scope of decision making is usually expanded to family and friends, although not always. Advocates of this philosophy oppose medical models that include professional case management and institutionalized care.
- Because each person is unique, the philosophy suggests that services should be tailored to the individual needs and desires of each person with a disability. Advocates of this idea reject traditional goals of long-term care for older adults that offer a continuum of personal care, home health, and nursing home care, which individuals progress through as their disability increases. Instead, they believe services should follow individuals and should be provided regardless of where individuals live.
- Services should be a right, not the result of charity, because each individual is capable of a normal life in the community. In contrast with older adults, unpaid and informal care from family and friends is considered undesirable because it leaves people with disabilities vulnerable to the whims of their caregivers.
- To replace the existing system, advocates propose a more unified financing system that would provide a broader range of ways for people to finance their personal needs. According to this view, the system should emphasize individuals' needs for personal assistance, not their finances.

Younger persons with disabilities argue that they are handicapped by society's attitudes and barriers in the environment, not by their impairment.

Delivery System Organization

Although the use of institutions by younger people with disabilities is declining, this type of care still plays a role in the delivery of long-term care, especially for those with developmental disabilities. For people living at home, the existing system relies heavily on informal care. In 1986, family members provided care to 87% of nonelderly individuals who were living in the community and needed help with personal care, getting around the house, preparing meals, or managing their money (Harpine, McNeil, & Lamas, 1990). Recent statistics indicate that paid services account for a small but significant share of home care. Of the nearly 6 million users of formal home care in 1987, about half were under age 65 (Altman & Walden, 1993).

Replacing Institutional Care

A strong dividing line between younger and older persons with disabilities involves the role of institutions in long-term care. Advocates for younger people see institutions as the antithesis of everything the system should be—little personal autonomy and independence, community segregation, professional domination, and standardized instead of individualized services (Shapiro, 1990, 1991). In contrast, although older adults seek to avoid nursing home placement, there is more acceptance of the major role of institutions for older people, especially those without family support (Rivlin & Wiener, 1988).

A key question of policymakers is whether advocates' goals of radically reducing institutions and replacing them with home and community-based care is practical and affordable (Smith & Gettings, 1994). Almost everyone could be served in the community if enough resources were available. However, questions remain regarding how much it costs to do so for people with very involved disabilities, particularly those with cognitive impairment. Some have argued that providing home and community services to severely disabled older adults could exceed the cost of nursing home care, especially if people do not have strong informal supports. However, intermediate care facilities for the mentally retarded are so costly that community-based services are often less expensive per person. The cost of intermediate care facilities averaged \$62,180 a year in 1993, whereas the cost per person under the Medicaid home and community-based waiver program was \$25,176 (Mangan et al., 1994).

An issue complicating per-person costs is the “woodwork effect.” Specifically, an increased number of people might come out of the woodwork to use a broad range of community-based services if they become available. Studies show that in demonstration projects offering expanded home care to older adults, total costs rose rather than declined (Wiener & Hanley, 1992).

An increased number of people might “come out of the woodwork” to use a broad range of community-based services if they become available.

Flexibility and Scope of Services

A significant issue related to the consumer movement among people with disabilities relates to the responsibility taxpayers have to disabled people. Is the public's responsibility only to help people meet certain basic, minimal needs, or is it to truly help people with disabilities realize their potential and live full lives?

A major issue for younger people with disabilities is the extent to which the long-term care system can be adapted to encourage greater workforce participation.

A major issue for younger people with disabilities is the extent to which the existing long-term care system can be adapted to encourage greater workforce participation. Although less than a quarter of younger adults with disabilities are employed, most unemployed disabled adults say they would like to work (Harris & Associates, 1994). Advocates point to real jobs, rather than sheltered workshops that pay minimal wages, as the key to financial independence for disabled adults.

Managed Care

As with older adults, there is increasing interest in integrating acute and long-term care services for young people, mainly through the use of HMOs and other managed care (Wiener & Skaggs, 1995). A concern among advocates, however, is that long-term care would become overmedicalized and less consumer-directed in integrated settings.

Personal Assistance Services

Advocates of consumer-directed services argue that people who use services should be in direct control of service delivery, including the hiring, training, supervision, direction, and firing of attendants. By definition, the worker would do what the client wants. This raises several issues, including whether disabled people are capable of performing these functions; whether everyone with disabilities wants to manage their own services; what the quality assurance of care would be; and whether the market would provide enough qualified workers, especially because studies have found most independent personal care workers are employed at just above the federal minimum wage.

Long-Term Care Financing

Long-term care services for younger people with disabilities are financed through many sources, including a large number of public programs at the state and federal level, out-of-pocket payments, and private insurance. Overall, spending has been viewed as inadequate by advocates and is mostly limited to institutions and a narrow set of home and community services. The reliance on Medicaid excludes many people who are not poor but who cannot afford to pay for out-of-pocket services. Strong work disincentives are tied to Medicaid in efforts to limit eligibility to people who cannot work. Furthermore, private long-term care insurance, which holds some promise for older adults, seems unlikely to work for younger people.

Public Financing Sources

Medicaid spent \$44 billion on long-term care in 1993, not including mental health services. Of that amount, 38% was for nonelderly services. Medicaid accounts for a significantly larger proportion of long-term care financing for younger people than for older adults with disabilities. Medicaid is an especially important

funding source for institutional long-term care, although it also plays an important role in noninstitutional long-term care services for younger people with disabilities. Total Medicaid expenses for noninstitutional long-term care in 1993 were \$7.4 billion, of which nearly half went to younger people (Office of Assistant Secretary for Planning and Evaluation, 1994).

People with disabilities who receive Social Security Disability Insurance (SSDI) for 24 months are eligible for Medicare. Medicare plays a modest role in long-term care financing. In 1993, it paid approximately 20% of nursing home and home care expenses for older adults, and only 3% of the expenses for younger disabled people (Wiener, Illston, & Hanley, 1994).

State funding accounts for much more long-term care spending for younger people, compared with the elderly. Not including Medicaid matching payments, the states contributed 20% of the total long-term care expenditures for the nonelderly in 1993, compared with just 1% for older adults.

Policy Issues

The existing long-term care financing system for younger individuals raises at least five major issues. First, financing and services for younger people with disabilities is mostly available for institutional, rather than community-based, services. Second, conflict exists between open-ended entitlement programs, such as Medicaid, and government spending on a very broad range of services with capped funding and no entitlement. Third, eligibility rules for Medicaid and Medicare encourage dependence, not independence. To qualify for Medicaid or Medicare with a disability, applicants must meet eligibility requirements based on inability to work. This presents disabled people with a difficult dilemma. They can work and lose income, health care, and long-term care coverage, or they can remain unemployed and receive benefits, but give up the opportunity for financial and personal independence.

Fourth, important sources of long-term care financing are means tested, which often results in lower political support, stigma among beneficiaries, and inferior access to services that are sometimes of lesser quality (Wiener et al., 1994). Finally, resistance to the expansion of public programs means there is increasing interest in private long-term care insurance as a means of financing services for older adults. Unfortunately, its role in financing long-term care is limited by problems of affordability and marketability. In addition, private policies do not seem to be of interest to younger people with disabilities. More importantly, because all individually sold policies are medically underwritten, members of the younger disabled population tend to be excluded from purchasing such policies in the first place.

State funding accounts for much more long-term care spending for younger people, compared with the elderly.

Concluding Remarks

This synthesis of research and policy issues and research indicates that to adequately meet the needs of younger individuals with disabilities, policymakers will need to reconsider the goals of long-term care, address issues related to service delivery, and develop creative mechanisms for financing services. Recent research indicates that younger disabled individuals comprise an increasingly important force in the policy arena. As such, any future policy initiatives in long-term care will almost certainly need to consider the younger as well as the older disabled population.

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State Policy on Long-Term Care for the Elderly

Joshua M. Wiener and David G. Stevenson

In 13 states included in the *Assessing the New Federalism* project, strategies to control the rate of increase in long-term care spending are extremely varied. States use three broad strategies: offsetting state spending with increased private and federal contributions; making the delivery system more efficient; and using traditional cost-control mechanisms, such as controlling nursing home bed supply and cutting Medicaid reimbursement rates.

Long-term health care for older adults is a critical component of Wisconsin's health care system and plays a major role in its Medicaid program. The increasing number of older adults in the United States and the continuing higher costs of health care have caused Wisconsin and all states to look seriously at ways to curb spending on long-term care services for the elderly (see Table 1). Neither private insurance nor Medicare has been likely to cover long-term care, and few older adults carry private long-term care insurance. As a result, in 1995, nursing home and home health care accounted for 12% of all personal health costs and 14% of all state and local health care spending nationwide (Levit, Lazenby, Braden, Cowan, & McDonnell, 1996). Wisconsin has higher percentages both of older adults and Medicaid beneficiaries than the national average, and spent a much higher proportion of Medicaid expenses on long-term elderly care than most other states—31% of all non-disproportionate share hospital (DSH) Medicaid expenses in 1995, or a total of \$750 million (Wiener & Stevenson, 1998).

Most older adults who are disabled must rely on their own resources until they are depleted. Then, even middle-income people who have exhausted their savings turn to Medicaid or state-funded programs to pay for long-term care, at an average cost of \$46,000 for a single year of nursing home care. In 1997, more than two thirds of nursing home residents depended on Medicaid to pay for at least some of their care (American Health Care Association, 1997). Medicaid long-term care expenses for older adults, when adjusted for inflation, are projected to more than double nationwide between 1993 and 2018. Wisconsin is a national leader in innovative home and community-based services. Still, in 1995, 96% of Medicaid funds went to institutional care, whereas only 4% went for home and community-based services. Because Wisconsin counties control a large portion of long-term care funds, local officials have a large influence over policy and resource allocation. This means there is great variation in services from county to county.

This study is part of the Urban Institute's *Assessing the New Federalism* (ANF) project, which has analyzed state health, income support, and social service pro-

Wisconsin spent a much higher proportion of Medicaid expenses on long-term elderly care than most other states.

grams for low-income residents in 13 states. Together, these states account for more than half of all Medicaid spending in the United States for long-term elderly care.

Table 1. Medicaid Long-Term Care Expenditures for Elderly Beneficiaries in Thirteen States, by State and Type of Service, 1995

| | Total long-term care spending (thousands) | Long-term care as percent of total Medicaid | Long-term care spending | | Proportion of long-term care spending | | | |
|---------------|---|---|-------------------------|----------------------|---------------------------------------|---------------------|---------------|-----------|
| | | | Per elderly beneficiary | Per elderly resident | Nursing facility | ICF-MR ^a | Mental health | Home care |
| United States | \$30,413,715 | 19.5% | \$ 7,821 | \$ 967 | 84.1% | 2.0% | 3.6% | 10.3% |
| Alabama | 371,497 | 19.0 | 5,210 | 632 | 92.0 | 0.4 | 3.1 | 4.5 |
| California | 2,100,690 | 11.1 | 4,319 | 620 | 79.8 | 3.4 | 8.4 | 8.4 |
| Colorado | 266,248 | 17.5 | 7,290 | 862 | 89.9 | 0.1 | 0.8 | 9.1 |
| Florida | 1,117,491 | 18.2 | 5,293 | 475 | 94.2 | 0.6 | 1.2 | 4.0 |
| Massachusetts | 1,302,359 | 23.3 | 12,872 | 1,763 | 92.7 | 2.3 | 1.1 | 4.0 |
| Michigan | 934,999 | 18.3 | 10,859 | 793 | 89.9 | 1.4 | 4.7 | 4.0 |
| Minnesota | 871,810 | 31.7 | 15,403 | 1,817 | 93.2 | 1.4 | 1.8 | 3.6 |
| Mississippi | 239,414 | 15.7 | 3,593 | 752 | 98.6 | 1.2 | 0.0 | 0.2 |
| New Jersey | 1,011,315 | 18.8 | 11,184 | 1,008 | 83.7 | 3.5 | 2.3 | 10.5 |
| New York | 5,702,398 | 24.2 | 15,354 | 2,444 | 66.4 | 3.2 | 7.4 | 23.1 |
| Texas | 1,400,461 | 16.1 | 4,547 | 785 | 76.3 | 2.5 | 0.0 | 21.2 |
| Washington | 483,899 | 17.1 | 9,111 | 876 | 92.7 | 1.4 | 0.2 | 5.7 |
| Wisconsin | 747,715 | 31.0 | 11,676 | 1,418 | 92.4 | 2.5 | 0.7 | 4.4 |

Note. The data do not include disproportionate-share hospital (DSH) payments, administrative costs, accounting adjustments, or spending in the U.S. Territories. The totals may not add because of rounding. "Nursing facility" refers to skilled nursing facilities and intermediate care facilities. The table was compiled from Urban Institute calculations based on Health Care Financing Administration (HCFA) Form 64 data, which were prepared for the Kaiser Commission on the Future of Medicaid.

^aIntermediate care facility for the mentally retarded.

Strategies to Control Long-Term Care Spending

The 13 states in the study use three very different strategies to control long-term care spending: (a) offsetting state spending for long-term care with increased private and Medicare contributions; (b) reforming the delivery system for more efficient care delivery; and (c) using traditional cost-control mechanisms, such as controlling nursing home bed supply and cutting Medicaid reimbursement rates. Each state in the study varies in how much they use each strategy and in how far they have gone in creating substantial reform.

Increased Private and Federal Resources

States use several strategies to add private and federal resources to the long-term care financing system.

Encourage private long-term care insurance. Private long-term care insurance could prevent both impoverishment and state Medicaid spending for many middle-class nursing home residents. However, only 6% of older adults have this type of insurance because of its high cost. One option with potential for making private insurance more affordable is to offer long-term care policies through employers to large numbers of younger persons. This would allow families, in effect, to purchase group insurance. Group rates are always lower than individual rates and may make this type of insurance more affordable for some families. If employers sponsor but do not help pay for private insurance, Medicaid expenditures could decline as much as 31% and the number of nursing home residents could fall by as much as 17% by the year 2018. For this method to work, however, the employer-sponsored market must dramatically increase because less than one tenth of 1% of middle-aged people currently have long-term care insurance. In addition, most middle-aged workers have more pressing expenses, such as mortgages, children's educations, and child care.

California and New York have established public-private partnerships to promote the purchase of private long-term care insurance. These states allow people who buy state-approved policies to keep more assets than normally allowed to qualify for Medicaid. California consumers can buy a level of private coverage equal to the assets they wish to protect. New York residents can protect an unlimited amount of assets by purchasing 3 years of long-term care coverage. So far, however, these incentives have failed. The California and New York efforts have spurred a total of fewer than 17,000 policy purchases. Yet, both states are committed to expanded efforts.

Whereas Wisconsin says it supports the idea of private long-term insurance, it has done relatively little to promote it. A never-enacted proposal in the 1980s would have provided public-private partnerships to encourage purchase of insurance. Currently, private long-term insurance is offered to state employees.

Reduce Medicaid estate planning. Policymakers and the media have focused attention on middle-class and wealthy people who transfer, shelter, and underreport assets, so-called "Medicaid estate planning," to appear poor enough to qualify for Medicaid-financed nursing home care. Congress has attempted to decrease this practice through legislation, but some argue these laws are easy to get around.

Three states in the study—Massachusetts, New Jersey, and New York—identified this problem as a major public policy issue. In New York, state officials believe that reducing asset transfer is critical to motivating people to purchase long-

Offering long-term care policies through employers would allow families to purchase group insurance.

term care insurance policies and ultimately viewing long-term care as a private, rather than public, responsibility.

Wisconsin's estate recovery program recoups Medicaid expenses for long-term care from the estates of deceased Medicaid beneficiaries. Estate recovery increased from \$471,000 in 1991–92 to more than \$9.7 million in 1995–96, making Wisconsin's program one of the country's most effective.

Maximize Medicare financing. States have long tried to shift Medicaid long-term care expenses to Medicare, which essentially shifts costs from the state to the federal government. These efforts, however, have been stopped by the narrow range of Medicare coverage for nursing home and home health care. This situation has changed since the late 1980s, when Medicare coverage rules were changed, making benefits more oriented toward long-term care. Some states have responded by initiating “Medicare maximization” efforts to ensure that Medicare pays for home health and nursing facility care whenever possible. These efforts center around educating providers and consumers about Medicare benefits, improving the data system to identify inappropriate billing, finding people eligible for both Medicare and Medicaid, and billing Medicare whenever there is a chance of reimbursement.

Wisconsin's estate recovery program recoups Medicaid expenses for long-term care from the estates of deceased Medicaid beneficiaries.

Despite the perceived benefits associated with shifting expenses, these strategies can pose problems. In Wisconsin, which actively pursues Medicare maximization, agencies struggle with extensive audits of home health agency payments and directives for billing Medicare first. Home health agencies say this mandate subjects them to Medicare penalties if too many claims are submitted and then rejected. Retrospective audits also sometimes come after the Medicare window for billing has closed.

Incentives for Medicare maximization also depend on how similar the payment rates are for Medicaid and Medicare. For example, some states say Medicaid rates are so low that economic incentives, not policy, drive providers to seek Medicare payments when possible.

System Reform

A second general strategy for saving money is reorganizing health care delivery in ways that make care more effective and efficient. Two ways to accomplish this are by extending managed care to include long-term care and by expanding home care and non-medical, residential long-term care services.

Integrate acute and long-term care services through managed care. Older adults who need long-term care currently encounter fragmented financing and delivery. Financing acute care, mainly physician and hospital care, is primarily the responsibility of Medicare and the federal government, whereas long-term care is dominated by Medicaid and state government. Because of the separation, there is a strong incentive for each level of government to try to shift costs to the other. A

lack of coordination in delivery is another problem that can result in higher costs. For example, some nursing home residents are unnecessarily discharged to a hospital because adequate physician services are not available in the facility.

State policymakers hope that integrating acute and long-term care through managed care can result in better-quality care and lower costs by substituting home-based care for inpatient care. They also hope to save money by shifting costs to Medicare for people who are eligible for both programs. Some states, including Wisconsin, are deliberately reducing the number of providers so officials can focus on setting contract standards and monitoring performance. A final goal of expanding managed care is to make state spending more predictable by setting per-person rates that shift much of the financial risk from the government to providers.

Although integrating acute and long-term care could improve quality of care, long-term care advocates have some major concerns. One is that HMOs and other managed care providers have little experience with older adults and none with older adults who are disabled. Another concern is that financial pressures will end up shortchanging long-term care. Finally, there is a fear that long-term care will become more focused on medical care and less consumer-directed because the balance of power would shift from individuals and their chosen provider to HMOs, insurance companies, and administrators.

Expand home and community-based services. Policymakers in all 13 states support expanding home care and creating more balanced delivery systems. However, nationwide only 10% of Medicaid long-term elderly care expenses went for home care in 1995. Medicaid home and community-based service spending has increased significantly in recent years, but most of the growth has been for younger persons with disabilities. Some states that have implemented home and community care expansion have chosen to use Medicaid waivers, which give states greater control over use and eligibility. Wisconsin is among several states that have sizeable state-funded home and community-based care programs. As mentioned earlier, however, the amount of Medicaid money spent on long-term care still overwhelmingly goes to institutional care.

In almost every state, home and community-based services are promoted primarily on the ability to save money, although meeting unmet needs and responding to consumer preferences also are important. Most research, however, predicts a rise in total long-term health costs as large increases in the use of home care more than offset small reductions in nursing home use. The “woodwork effect” is that although many older people would forego paid long-term care if the only option is nursing home care, many of these same people would come out of the woodwork to use home care services if given the choice. However, a 1996 study of Washington, Oregon, and Colorado found that home and community-based services were cost-effective alternatives to institutional care in those states (Alexih, Lutzky, & Corea, 1996). As the commitment to community care in-

In 1995 only 10% of Medicaid long-term elderly care expenses went for home care.

creases, some in the nursing home industry have questioned the cost effectiveness of these services. Wisconsin proponents of community care say the statewide decline in stays at Medicaid nursing homes is a sign of success. Others caution against reading too much into the declines because of other possible influences.

All states in the study are exploring the possibility of residential alternatives to nursing home care. Some states finance the “care” part of residential facilities through their Medicaid home and community-based waivers, or through a combination of state and Supplemental Security Income (SSI) funds. The states hope to provide services that are more homelike, provide greater personal independence, and cost less than nursing homes. The nursing home industry argues that its residents are too disabled to be served adequately in these alternative settings, although in Wisconsin and other states, the nursing home industry is expanding into nonmedical residential facilities.

Most assisted-living facilities are geared to upper-income people.

Difficult issues come with these alternatives. States struggle over how to combine the new concepts of consumer-oriented, homelike care with a large existing stock of nonmedical residential facilities that do not necessarily share this ideology. Another major issue is how to regulate these facilities so people can “age in place,” without making these facilities into substandard nursing homes. Federal state regulatory structures work on the concept of a continuum of care, where people must move from level to level as they become more disabled. However, the notion

of letting people age in place means bringing services to them in the place they live. Wisconsin has adopted detailed regulations for community-based residential facilities, which are limited to people without severe disabilities. Yet, the state has adopted very little regulation for assisted-living facilities, even though it allows these facilities to serve disabled people needing up to 28 hours of care a week.

Finally, states want to know how to make new residential options available to moderate- and lower-income older adults. Except for those in Oregon, most assisted-living facilities are geared to upper-income people. Wisconsin is among the states where critics say middle-class people exhaust their private resources paying for care in residential facilities, then apply to nursing homes as Medicaid recipients.

Traditional cost-control strategies

If states are not successful in reducing costs of long-term care through increasing outside resources or delivery system reform, federal law still allows quite a bit of flexibility in conventional cost-saving methods, such as controlling the supply of providers and lowering reimbursement rates.

Control the supply of providers. Many states have responded to rising Medicaid long-term care spending by limiting the number of providers, particularly at nursing homes, where a majority of beds are likely to be filled with Medicaid recipients. A strategy used by many states, including Wisconsin, is to place a moratorium on more beds for Medicaid participation. However, Wisconsin still has more nursing home beds per 1,000 older adults than most states, and no moratorium for

residential long-term care facilities. Although limiting nursing home supply can control spending in the short term, the care needs of older adults do not disappear just because the supply is limited. Some observers argue that access to nursing home care can be difficult, especially in rural areas.

Lower reimbursement rates. Medicaid payment rates for nursing home care are a logical target for states trying to reduce their rate of long-term care spending because cutting rates results in predictable, immediate, and potentially large savings. Reimbursement rates were targeted for savings in almost all states studied. Savings proposals include reducing ceilings on payment levels; curbing administrative costs; and changing from facility-specific, cost-based reimbursement to case-mix-adjusted, flat-rate systems. A Minnesota demonstration project had 120 nursing facilities agree to freeze rates in exchange for waiver of certain state regulations.

From 1980 to 1997, states set Medicaid payment rates at whatever level they chose for home and community-based care. However, they met a minimum standard for nursing home and hospital reimbursement under the Boren Amendment, which required that Medicaid nursing home rates be “reasonable and adequate to meet the costs which must be incurred by efficiently and economically operated facilities in order to provide care and services in conformity with applicable State and Federal laws, regulations and quality and safety standards” (Section 1902(a)(13) of the Social Security Act). Although the law was supposed to relax previous standards, many states said they had difficulty meeting the standard. State Medicaid officials opposed the Boren Amendment, saying they spent too much on nursing homes and courts forced them to go beyond the minimal language of the law. In Wisconsin, advocacy groups also supported repeal of the Boren Amendment, seeing it as an opportunity to shift money from nursing home care to home care.

With the repeal of the Boren Amendment in 1997, states have almost complete freedom in setting nursing home payment rates. The problem with repealing the standard is that Medicaid nursing home payment rates already are low, and access to nursing home care could be a problem for Medicaid recipients as the payment differential between private-pay and Medicaid patients widens. Because few nursing homes could survive completely independent of Medicaid recipients, the extent to which facilities can restrict access is somewhat limited. In addition, although there is not a simple relationship between cost and quality, there is probably some level of reimbursement below which it is impossible to provide quality care. Although care in nursing homes has improved nationwide over the past 20 years, advocates for nursing home residents remain concerned about quality issues.

Although limiting nursing home supply can control short-term spending, the care needs of older adults do not disappear just because the supply is limited.

Resource Allocation and Politics

State politics play a major role in long-term care reform efforts. Players in the political landscape include the nursing home industry, home health care groups, and consumer groups focused on the rights of the elderly and younger

people with disabilities. The for-profit nursing home industry is the strongest health lobby on Medicaid issues in all states studied, largely because nursing homes are far more focused on Medicaid and state policy than other provider groups and are much more dependent on Medicaid revenue than are hospitals or physicians. Because nursing homes are so focused on state policy, they meet frequently with state officials and develop strong personal ties. The nursing home industry also is well financed to afford lobbyists, make contributions to political campaigns, and commission studies that support its positions. However, states are still not always willing or able to fund higher rates for nursing homes. Quality concerns and reports of fraud and abuse also have damaged the industry's image.

In addition, there are other players on the long-term care stage, including home care associations and advocacy groups for people with disabling conditions. In Wisconsin, elderly advocacy groups are relatively well organized and financed.

Conclusions

States vary greatly in their policies regarding long-term care for older adults. Private, long-term care insurance has been heralded as a potential fix for rising Medicaid long-term care spending. However, only 2 of the 13 states studied seem seriously committed to this strategy. Although most states believe Medicaid estate planning is a major problem, only a few states have tried to address it through public policy. Wisconsin's estate recovery program has been one of the country's most effective. Some states are increasing federal contributions through effective Medicare maximization, but this strategy simply shifts costs from state to federal government.

A more ambitious approach being discussed in almost every state studied is using managed care to integrate acute and long-term care services. Progress has been slow, in part because Medicaid and Medicare waivers often are needed for implementation.

All states in the study have committed to expanding home and community-based care for older adults. However, most Medicaid home care growth seen recently has focused on younger people with disabilities. In fact, most states, including Wisconsin, spend a significant proportion of Medicaid long-term dollars on institutional care for older adults. To save money, states must keep per-person costs down and limit the woodwork effect. Several states continue to look at what role the sizable number of nonmedical residential care facilities should play in cost-saving efforts.

In the short term, states tend to rely on traditional cost-saving strategies. However, this approach does not address the increasing number of aging adults in this country. With the repeal of the Boren Amendment in 1997, states have had much greater legal freedom to impose rate cuts on nursing homes. Yet, cutting rates may still be difficult because the for-profit nursing home industry is powerful at

To save money, states must keep per-person costs down and limit the woodwork effect.

the state level. Also, advocacy groups working with older adults oppose rate cuts, believing that they will have a negative effect on quality of care. Although all states complain about the high costs of long-term care for older adults, the hard reality is that the current method of Medicaid long-term care financing is actually quite economical. Payment rates are usually much lower than Medicare and the private sector. People receive government help only after going through their own assets. Finally, the focus on institutional care assures that people with the most severe disabilities who do not have family supports are most likely to use the care. In this current system, it is difficult to find further ways to cut spending.

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