



ALLIANCE FOR
HEALTH REFORM

Long-Term Care:

Options in an Era of Health Reform

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RTI International



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INTRODUCTION

As President Barack Obama and Congress debate health care reform, it is important that long-term care be included.¹ While not central to providing basic health insurance to all Americans, long-term care should be part of efforts to improve health care for all Americans. Contrary to widespread belief that long-term care affects only a small minority of the population, 69 percent of people turning age 65 will need long-term care before they die and a third of the population will spend some time in a nursing home (Kemper, Komisar and Alecxih, 2005/2006). In thinking about the place of long-term care in the health reform debate, four factors are important:

First, with the aging of the population, the number of older people with disabilities is sure to grow substantially. According to one estimate, the number of older people with disabilities will approximately double between 2000 and 2030 (Johnson, Toomey, and Wiener, 2007). As a result, the relative financial and other burdens of long-term care will be greater in the future than they are now. Comprehensive reform will need to take into account both the number of people needing long-term care in the future and their characteristics, which may be very different than today.

Second, the federal and state governments spend substantial amounts of money on long-term care. In 2006, the public sector spent \$231 billion on long-term care for people of all ages (Tumlinson and Aguiar, 2008). With the aging of the baby boom generation, it is highly likely that public spending for long-term care will increase significantly over the next 30–40 years. In addition, no other part of the health care system is as dependent on public financing as long-term care. In 2008, for example, 77 percent of nursing home residents had their care covered by either Medicare or Medicaid (American Health Care Association, 2008a). As a result, government policy is especially important for long-term care providers and consumers.

Third, not only do older people and younger persons with disabilities use expensive long-term care services, they have high acute care expenses related to their underlying chronic diseases. An analysis of the Medicare Current Beneficiary Survey by Avalere Health suggests that, in 2005, older people with problems performing at least one activity of daily living had average Medicare costs of \$14,775 compared with \$4,289 for beneficiaries with no problems with the activities of daily living (Tumlinson and Aguiar, 2008). One study estimated that disability-associated health and long-term care expenditures were \$398 billion in 2006 (Anderson, Wiener, & O’Keeffe, 2006).

Fourth, the current long-term care financing and delivery system is broken. The United States does not have, either in the public or private sectors, satisfactory mechanisms for helping people anticipate and pay for their long-term care. As a result of the lack of insurance coverage, long-term care expenses are the leading cause of catastrophic health care costs among older people. The disabled elderly and their families find, often to their surprise, that neither Medicare nor their private insurance covers the costs of nursing home care or home and community-based services. Instead, people needing long-term care must rely on their own resources, or when those have been exhausted, must turn to welfare in the form of Medicaid. Despite the strong preference of people with disabilities for home and community-based services, the available financing is highly skewed toward institutional care. Moreover, the home and community-based services that are available do not necessarily meet the preferences of people with disabilities. Quality of care is often deficient and the workforce needed for high-quality care is lacking.

¹ This paper primarily addresses long-term care for older people and younger persons with physical disabilities. The important topic of long-term care for people with intellectual disabilities or mental illness is not the main focus of the paper..

The goal of this paper is to frame the main issues of long-term care reform and to lay out the principal reform options available to policymakers. While long-term care is unlikely to be at the center of the upcoming debate on health care reform, much can and should be done to improve the system in the near term. The paper begins with a brief background section that sets the stage for a discussion of financing, service delivery, and quality assurance. In most cases, the options presented are not mutually exclusive in principle, but limited resources will require choices among them.

BACKGROUND

The following features of the long-term care system are critical to evaluating options for reform.

The Nature of Long-Term Care: How Long-Term Care Is Different From Acute Care

- Long-term care is the help needed to cope when physical and mental impairments reduce individuals' ability to perform the activities of everyday life, such as eating, bathing, and dressing; going shopping; managing money; and using the telephone. While these disabilities are often the consequence of diseases, such as osteoporosis, heart disease, multiple sclerosis, and Alzheimer's disease, long-term care focuses primarily on compensating for functional limitations rather than managing disease processes. At the same time, many people with long-term care needs also require ongoing health and health-related services, such as medication management and skilled and unskilled nursing care. However, the majority of long-term care does not involve highly technical medical services furnished by physicians or registered nurses; personal care provided by modestly trained staff provide the large majority of paid care.
- Long-term care is about how we live our lives. Because long-term care includes such fundamental and intimate tasks as bathing, dressing, and going to the toilet, provided over an extended period, it is an intensely personal service. Historically, the goals of long-term care were limited to keeping people with disabilities safe, clean, and well fed. More recently, this narrow vision has been rejected in favor of goals that maximize independence and self-sufficiency. Increasingly, the goals of the service system are defined as maintaining health and functioning and providing access to the same freedoms and life enjoyed by nondisabled persons. This goal means integrating individuals who need long-term care into community life, providing consumer choice and control, and tailoring services to the needs and preferences of individuals.

Population Projections and Characteristics

- A substantial number of people have disabilities, many of whom have long-term care service needs. Rogers and Komisar (2003), for example, estimated that there were 9.5 million people of all ages with disabilities in 2000, the vast majority of whom lived in the community rather than in nursing homes. Importantly, more than a third of people with disabilities are under age 65, many of whom need long-term care for many decades, not just a short period at the end of life.
- Older people with disabilities are much less well off financially than older people without disabilities. Older people with disabilities are disproportionately poor and have less in the way of financial assets and home equity. In 2001, 36 percent of older community-based people with severe disabilities had incomes below 125 percent of the federal poverty level, while only 11 percent of older people with no disabilities had income at that level (Johnson and Wiener, 2006). In 2002, total median household

assets (including home equity) for older people with severe disabilities were \$47,913 compared with \$205,869 for older people with no disabilities.

Financing

- With very little public or private insurance coverage against the high costs of long-term care, users of services often incur very high out-of-pocket costs. The average private pay cost for a year in a private room in a nursing home was more than \$76,000 in 2008 (Genworth Financial, 2008). Among persons turning age 65 in 2005 who will have long-term care out-of-pocket costs during their lifetime, 36 percent will have expenditures that exceed \$25,000 and 10 percent will have expenditures that exceed \$100,000 (Kemper, Komisar, and Alexih, 2005/2006).
- Related to but separate from the issue of catastrophic out-of-pocket costs is the heavy dependence on Medicaid to finance long-term care. Almost two thirds of all nursing home residents depend on Medicaid to pay for their nursing home care (American Health Care Association, 2008a). A substantial portion of residents were not eligible for Medicaid when they lived in the community, but spent down to Medicaid eligibility levels because of the high cost of nursing home care (Wiener, Sullivan, and Skaggs, 1996). Long-term care for people of all ages and disabilities accounts for about a third of Medicaid spending.

Service Delivery

- Among the 35 percent of older people who will spend some time in a nursing home before they die, about half will stay for a year or longer (Kemper, Komisar, and Alexih, 2005/2006).
- For older people with disabilities, about 68 percent of total expenditures for long-term care were for nursing homes rather than home and community-based services in 2004 (U.S. Congressional Budget Office, 2004).
- Only about 17 percent of people with disabilities live in nursing homes; the vast majority live in the community (Rogers and Komisar, 2003). Most people with severe disabilities living in the community rely on informal caregivers rather than paid care. In 2002, only 37 percent of older persons who needed assistance with the activities of daily living received any paid home care; the percentage is much lower among people with less severe impairments (Johnson and Wiener, 2006).
- Among the older population with severe disabilities, 81 percent received informal care from family and friends. The economic value of informal care provided to older people with disabilities was estimated at \$354 billion in 2006 (Gibson and Houser, 2007). Informal caregiving is a substantial financial, psychological, and physical burden to many who provide care to their relatives.

Long-Term Care Workforce

- In 2007, there were more than 3 million direct care workers in long-term care (U.S. Department of Labor, 2008).
- Nationally, the turnover rate for certified nurse assistants in nursing homes was approximately 67 percent per year in 2007 (American Health Care Association, 2008c).

Quality of Care

- In 2006, nearly one fifth of all nursing homes were cited for serious deficiencies that caused harm or immediate jeopardy to residents (Harrington, Carillo, and Blank, 2007).
- Very little systematic information is available on the quality of home and community-based services (Wiener, Freiman, and Brown, 2007).
- Most long-term care is provided by direct care workers, such as certified nurse assistants and personal care workers, who receive low wages, few fringe benefits, and relatively little training (Institute of Medicine, 2008).

FINANCING

The debate over long-term care financing is primarily an argument over the relative merits of private versus public sector approaches. Some people believe that the primary responsibility for care of older people and younger persons with disabilities belongs with individuals and families and that government should act only as a payer of last resort for those unable to provide for themselves. Policymakers who hold this view generally advocate private sector initiatives, such as private long-term care insurance and using reverse mortgages to pay for long-term care services and insurance, and may advocate tightening eligibility for public programs to prod people to plan for their own long-term care needs. The long-term care financing systems of the United Kingdom, New Zealand, and the United States largely reflect this view (Organization for Economic Co-operation and Development, 2006).

The opposite view is that the government should take the lead in ensuring that all people with disabilities, regardless of financial status, are eligible for the long-term care services they need. The long-term care financing systems of Germany, Japan, the Netherlands, and Sweden reflects this view. U.S. policymakers who hold this view generally favor expansions of Medicaid, Medicare, the Older Americans Act, and other public programs and advocate a social insurance program for long-term care. Between these polar positions, many variations are possible.

Cutting across political ideology is the question of whether the current system of long-term care financing will be affordable in the future because of increased demand associated with the aging of the baby boom generation. Surprisingly, recent projections to assess this issue are lacking, but Wiener, Illston, and Hanley (1994) projected that total long-term care for older people would increase from about 1.4 percent of the gross domestic product (GDP) in 2008 to about 2.1 percent of GDP in 2048; public spending would account for about half those amounts. In the view of the author, new projections might put the total spending percentage at about 3.0 percent for 2048, roughly doubling the percent of GDP for long-term care. Projections of this type depend on a number of factors, including assumptions about the growth of the economy. Under a “slow” growth scenario, total long-term care expenditures for older people were projected to be 3.7 percent of GDP in the earlier projections (Wiener, Illston, and Hanley, 1994).

Moreover, long-term care for persons of all ages accounted for about a third of total Medicaid expenditures. As a result, Medicaid long-term care for persons of all ages accounted for 4.6 percent of state-revenue expenditures in 2004, and might, therefore, account for roughly 10 percent of state revenue expenditures in 2048 (author’s calculation based on Scott, 2005). States, in particular, are worried about the long-range impact of an aging population on their budgets.

Countries such as Germany, the Netherlands, and the United Kingdom that have populations older than the United States spent between 1.35 and 1.44 percent of GDP for long-term care for older people in 2000; Sweden, where 17 percent of the population was elderly, was the outlier, spending a little over 3.0 percent of GDP for long-term care for older people (Organization for Economic Co-operation and Development, 2006).

How policymakers view these projections heavily determines what type of financing reform they propose. Advocates for private sector initiatives view these increases and their implications for public spending to be unacceptably high and worry that they will crowd out other worthwhile public spending, especially for younger people. In addition, they note that long-term care expenditure increases would be on top of huge projected increases for Social Security and Medicare spending, programs that serve the same population. Because of these fiscal burdens, they argue that it is imperative to shift as much long-term care cost to the private sector as possible.

On the other hand, the implicit assumption of advocates for a greater role for the public sector is that these costs are affordable. From their perspective, long-term care is a small portion of the total health care system and even if its proportion doubled, it would remain a small portion of the health care system. Indeed, overall national health expenditures increased by more than 2 full percentage points of the GDP between 2000 and 2006 (Catlin et al., 2008) with relatively little notice and modest economic consequences. Moreover, from a macroeconomic perspective, it may matter little in terms of the burden to the economy whether services are financed by the public or private sector (Wiener, Illston, and Hanley, 1994).

The choice of emphasis between public and private programs also depends on who would benefit and whether they meet specified policy goals. For example, if a large majority of citizens were to purchase private long-term care insurance, then many people would see less need for expanding government programs. Conversely, if private insurance were to prove widely unaffordable or otherwise encounter barriers that prevent people from voluntarily purchasing policies, then the case for an expanded public role would be stronger.

Private Sector Initiatives

Private sector approaches are appealing because they reflect the American tradition of individuals taking responsibility for their own lives and those of their families. Moreover, problems of the economy, the huge budget deficit, resistance to new taxes, and the aging of the baby boom generation make large-scale expansions of public programs difficult. In the case of long-term care, advocates contend that private sector initiatives might hold down public spending by preventing the middle class from spending down to Medicaid, although most previous research suggests that this is unlikely (Rivlin and Wiener, 1988; Wiener, Illston, and Hanley, 1994). Over the last decade, most national policy debate on financing reform has focused on private initiatives.

Private sector initiatives fall into two broad categories—individual asset accumulation and use and various forms of private risk pooling, principally long-term care insurance. These options are summarized in *Exhibit 1*, along with their strengths and weaknesses.

Exhibit 1: Principal Private Long-Term Care Financing Options

Option	Pros	Cons
Reverse mortgages	<ul style="list-style-type: none"> Older people have substantial home equity, although older people with disabilities have much less 	<ul style="list-style-type: none"> Various restrictions, fees, and interest payments reduce the amount of money available for long-term care Older people may resist using home equity for long-term care costs Recent drop in home prices may reduce demand by older people and lenders
Employer-sponsored long-term care insurance policies	<ul style="list-style-type: none"> Reduces premium costs and medical underwriting Encourages private responsibility 	<ul style="list-style-type: none"> Employer and employee market take-up has been low Policies still relatively expensive Selling to younger people means predicting what will happen far into the future More employers may offer policies, but few help pay for them
Tax incentives for private long-term care insurance	<ul style="list-style-type: none"> Reduces net cost of policies, making them more affordable Encourages individual responsibility 	<ul style="list-style-type: none"> Results in loss of federal revenue May be inefficient, providing benefits mostly to people who would have purchased policies without the incentive Tax deductions are regressive, providing greater benefits to upper-income persons Most people would receive relatively small tax benefits, not solving affordability problem
Public-private partnership, whereby people who purchase state-approved long-term care policies can become eligible for Medicaid while retaining much higher level of financial assets	<ul style="list-style-type: none"> Brings together public and private sectors Makes policies more affordable to middle class 	<ul style="list-style-type: none"> Previous partnerships have had limited market penetration Asset protection and easier access to Medicaid may not motivate many purchasers Inflation protection provided in the Deficit Reduction Act is weak
Hybrids of long-term care insurance with other types of insurance (e.g., disability insurance)	<ul style="list-style-type: none"> Allow people to buy one policy to protect against two or more risks 	<ul style="list-style-type: none"> Products are complicated and difficult to understand Offer only small premium savings by combining products

Individual Asset Use: Reverse Mortgages

Motivated by the historically large amount of home equity among older people and, up to recently, the substantial increases in housing prices, there has been interest in finding ways to use reverse mortgages to finance long-term care (Merlis, 2005). Typically, reverse mortgages are home equity loans that do not have to be paid off until the borrower dies or moves from the house. These loans can be used for long-term care or anything else. They can either provide a regular stream of income or a line of credit. In 2007, there were approximately 100,000 older people with reverse mortgages (National Council on the Aging, 2009).

Reverse mortgages raise a number of issues: First, home prices are falling rapidly. Thus, like everyone else, older people are likely to have much less home equity than just a few years ago and mortgage lenders may be more reluctant to offer reverse mortgages, which are riskier than conventional mortgages. Second, even before the housing crash, home equity by older people with disabilities was not as high as it is for people without disabilities. In 2002, median home equity among older persons with disabilities (including those with no home equity) was only \$56,956, and \$35,640 for persons with severe disabilities (Johnson and Wiener, 2006). Third, restrictions on the amount of home equity that can be obtained, closing costs, and interest costs substantially erode the amount of money available to pay for long-term care directly (Merlis, 2005). Finally, the home has a near mythic quality in the United States, and it is uncertain how many older people would be willing to deplete their major asset, especially if home values are not rising.²

Risk Pooling: Private Long-Term Care Insurance

A viable private long-term care insurance market, primarily sold on an individual basis, has existed since the mid-1980s. In 2005, approximately 7 million policies were in force, covering about 3 percent of the total American population aged 20 and older; about 10 percent of older people, but only 0.2 percent of people aged 20–49, have private long-term care insurance (Feder, Komisar, and Friedland, 2007). Most policies have substantial limitations in terms of length of covered benefits, inflation adjustments, and benefits in case of lapse.

Among the reasons that relatively few people have private long-term care insurance are that people think that Medicare covers long-term care services, failure to recognize the potential risk, medical underwriting of policies which excludes many applicants, and the existence of a public safety net in Medicaid. Especially in the current economic environment, questions about the financial stability of insurance companies may deter people from buying policies. Perhaps the greatest obstacle to purchase, however, is that private long-term care insurance is expensive, especially for older people on relatively

² Some analysts have suggested using home equity conversions to purchase private long-term care insurance, which provides more coverage than may be available through direct use of home equity to purchase long-term care services. While the use of home equity would marginally increase the proportion of older people who can afford private long-term care insurance, it seems unreasonable to expect that people will partly deplete their major asset to purchase a product, one of whose major purposes is to protect their major asset. Moreover, individually sold private long-term care insurance has high overhead, because of substantial marketing, commission, and profit costs. Most private long-term care insurance policies have long-term loss ratios of 60 percent, which roughly means that 60 percent of the premiums are used for benefits (U.S. Government Accountability Office, 2006). Thus, the use of home equity (with a “loss ratio” of 66 percent) to purchase a private long-term care insurance policy (with a “loss ratio” of 60 percent) would result in only about one in three home equity dollars providing long-term care benefits (Merlis, 2005).

fixed incomes (Feder, Komisar, and Friedland, 2007; Wiener, Illston, and Hanley, 1994). The average premium for private long-term care insurance policies providing \$150 daily benefit amount, 4 years of coverage, a 90-day elimination period, 5 percent compound inflation protection, and a nonforfeiture benefit was \$2,862 per year if purchased at age 65 in 2002, meaning that married couples would face premiums exceeding \$5,000 a year (Coronel, 2004). However, the median income for households headed by persons aged 65–74 was \$34,243 in 2004, and declines sharply with increasing age (U.S. Census Bureau, 2006). Thus, even with generous assumptions about the willingness of people to pay, private long-term care insurance is expensive for most older people. It is also expensive for many working-age adults, who may lack health, life, and disability insurance.

The limitations of the unsubsidized, individual private long-term care insurance market has led to a number of proposals and initiatives to “jump start” the private long-term care insurance market, primarily by finding ways to make policies more affordable. These initiatives or proposals include encouraging employer-sponsored policies so that people will buy policies when they are younger when policies are less expensive, federal and state tax deductions or credits for the purchase of private long-term care insurance so that the net cost to the purchaser would be lower, public-private partnerships that apply less stringent Medicaid financial eligibility requirements to persons who purchase a state-approved private long-term care policy, and combining long-term care insurance with other types of insurance (such as life insurance) to provide value to people with other types of financial products.

Public Sector Initiatives

Private sector initiatives can play a bigger role than they do today, but none of the options described above is likely to result in private long-term care insurance or similar initiatives replacing public financing of long-term care without very substantial federal subsidies. An alternative approach would rely more heavily on the public sector. For advocates of a greater role for public sector programs, four factors are important:

First, long-term care services are already heavily financed by the public sector. In 2004, 56 percent of long-term care spending for older people was by Medicare, Medicaid, the Older Americans Act, state home care programs, and the Department of Veterans Affairs (U.S. Congressional Budget Office, 2004). In addition, a large portion of out-of-pocket payments are, in fact, contributions toward the cost of care required of Medicaid beneficiaries in nursing homes and not purchases of services by private payers. A substantial but unknown proportion of the out-of-pocket payments for long-term care is paid for with Social Security payments to individuals. A heavy role by the public sector in financing long-term care is typical of virtually all developed countries (Organization for Economic Co-operation and Development, 2006).

Second, the public sector originated or played an important role in many innovations in long-term care, including consumer-directed home care, cash and counseling, money follows the person, case management, capitated approaches to integrating acute and long-term care, and third-party funding for residential care facilities such as assisted living.

Third, the public sector is more likely to be able to address the needs of younger people with disabilities, who accounted for 36 percent of people with long-term care needs in 2000 (Komisar and Rogers, 2003). Medical underwriting for private long-term care insurance products excludes people with existing disabilities and working-age adults are less likely to purchase private long-term care insurance because the risk seems small and far away.

Fourth, because they require substantial discretionary income to be affordable, private sector initiatives are likely to be regressive or at least not to target working class and lower-middle class families. On the other hand, Medicaid targets a relatively low-income population and Medicare covers virtually all older people regardless of financial status. The relatively low incomes and assets of people with substantial disabilities (Johnson and Wiener, 2006) means that most additional spending, even under most social insurance programs, would be spent primarily on lower- and moderate-income people with disabilities (Wiener, Illston, and Hanley, 1994).

At least three broad strategies exist for expanding the role of the public sector—increasing funding for the Older Americans Act or similar appropriated programs, expanding Medicaid eligibility and covered services, and establishing a social insurance program. These options are summarized in *Exhibit 2*. While increasing funding for the Older Americans Act or similar programs and expanding Medicaid are incremental approaches that could have relatively modest costs, establishing a new social insurance program would be a major departure for the existing financing system and would require large additional investment of federal funds, now and in the future.

Exhibit 2: Principal Public Sector Long-Term Care Financing Options

Option	Pros	Cons
Increase funding for Older Americans Act and similar programs	<ul style="list-style-type: none"> • Provides funding for people not eligible for Medicaid, but not high income • Focuses on home and community-based services • Could provide funding to build infrastructure through Aging Network 	<ul style="list-style-type: none"> • Might increase fragmentation of financing system • Funding for appropriated programs less likely to increase over time than entitlement programs • Would require additional government spending
Expand the Medicaid program	<ul style="list-style-type: none"> • Easy to implement because it builds on existing system, which dominates long-term care financing • Targets people in greatest financial need 	<ul style="list-style-type: none"> • Does not prevent people from incurring catastrophic out-of-pocket costs • Higher Medicaid spending may squeeze other priorities at state level • States will resist additional mandates • Increases number of people dependent on public means-tested system • Would require additional government funding
Expand Medicare nursing home and home health benefits	<ul style="list-style-type: none"> • Builds on already existing program • Administrative structures already in place • Provides near universal coverage for older people and some younger persons with disabilities 	<ul style="list-style-type: none"> • Would require substantially greater government funding • Medical model would likely dominate • Program could be rigid and bureaucratic • Limited range of services • Does not make use of state expertise
Social insurance for long-term care	<ul style="list-style-type: none"> • Treats needs of people with disabilities the same as acute care • Provides universal coverage • Recognizes that vast majority of people cannot afford long-term care • Spreads risk over largest possible group 	<ul style="list-style-type: none"> • Would require substantially greater government funding • Some funding would support services to upper-income and wealthy individuals • Program could be rigid and bureaucratic

Increase Funding for the Older Americans Act or Similar Programs

Apart from Medicare and Medicaid, the federal government funds long-term care through a number of appropriated programs, including the Older Americans Act, the Social Services Block Grant, and the Department of Veterans Affairs. Compared with Medicare and Medicaid, these programs are very small and have been relatively flatly funded in recent years. As a result, their role in the direct funding of long-term care services has declined over time (Rabiner et al., 2007).

Through programs funded by the Older Americans Act, the U.S. Administration on Aging funds three types of activities. First, the Older Americans Act funds a nationwide system of 655 Area Agencies on Aging and 56 State Units on Aging, which provide information and referral, advocacy, and services to the older population. Many State Units on Aging and Area Agencies on Aging are involved in administering Medicaid home and community-based services waivers. Second, the Administration on Aging funds a variety of home and community-based services to people aged 60 and over, including supportive services, senior centers, congregate- and home-delivered meals, disease prevention and health promotion services, and caregiver support services. Third, the Administration on Aging funds long-term care infrastructure development grants to states and Area Agencies on Aging on improving Alzheimer's disease services, establishing health promotion and disease prevention services, implementing nursing home diversion programs, and creating Aging and Disability Resource Centers, which are "one-stop shops" for information and referral on long-term care.

Expand the Medicaid Program

Medicaid, a means-tested welfare program, has strict requirements on income and assets and home care coverage that vary greatly by state. For example, the \$2,000 limit on financial assets that single Medicaid beneficiaries may retain has not increased since 1984. The Deficit Reduction Act of 2005 restricted Medicaid eligibility for long-term care by reducing the amount of home equity that beneficiaries may retain and by tightening the rules against transfer of assets. Most states allow nursing home residents to retain only \$40 per month or less in income as a personal needs allowance, only about \$1 a day (Bruen, Wiener, and Thomas, 2003). In 2007, while almost all states provided home and community-based services through Medicaid waiver programs, only 34 states and the District of Columbia covered personal care services as part of their regular Medicaid program (Burwell, Sredl, and Eiken, 2008).

An incremental approach to long-term care reform would be to expand the Medicaid program. This approach targets public expenditures to people in greatest financial need. Possible changes could be establishing more lenient financial eligibility standards—raising the level of protected assets and increasing the amount of income that nursing home and community-based beneficiaries can retain for personal needs—and expanding home care coverage either by providing financial incentives to states or by mandating coverage. Another example would be to repeal the requirement that states recover the cost of home and community-based services from the estates of Medicaid beneficiaries, a requirement widely believed to deter some people from receiving needed services. Without the federal government providing all or almost all of the funds for any expansion, states are likely to resist any new requirements as unfunded mandates.

It should be noted that some observers contend that the existence of Medicaid as a safety net for long-term care and the possibility of transfer of assets to qualify for Medicaid lead middle class people to forego private insurance (Moses, 2005). The provisions in the Deficit Reduction Act of 2005 that tightened transfer of assets restrictions and lowered the level of protected home equity were heavily influenced by the argument that it is too easy for middle-class persons to obtain Medicaid long-term care

services. However, given the widespread misunderstanding of Medicare coverage, the denial of the risk of needing long-term care, and the lack of knowledge about Medicaid eligibility rules, it is unlikely that Medicaid eligibility rules are a major reason why people in their 50s and early 60s do not buy long-term care insurance. Moreover, despite the conventional wisdom that transfer of assets to obtain Medicaid eligibility is widespread, there is a large, rigorous research literature that finds that transfer of assets is relatively infrequent and usually involves quite small amounts of funds when it occurs (Bassett, 2004; Lee, Kim, and Tanenbaum, 2006; O'Brien, 2005; Waidmann and Liu, 2006). The maximum amount of asset transfer is probably no more than about 1 percent of Medicaid nursing home expenditures (Bassett, 2004; Waidmann and Liu, 2006).

Augment the Post-Acute Care Benefits Under Medicare

The Medicare program already provides some coverage for skilled nursing facility care and home health on a non-means-tested basis. However, this coverage is oriented toward short-term, medically oriented services; Medicare does not cover nursing home or home health care over an extended period and does not cover services such as assisted living. For beneficiaries with at least a 3-day hospital stay, Medicare covers up to 100 days of care in a skilled nursing facility for beneficiaries requiring skilled nursing or rehabilitation services on a daily basis. The average length of a Medicare covered stay is only about 26 days (U.S. Centers for Medicare & Medicaid Services [CMS], 2008c). In addition, Medicare covers home health care, but it is limited to people who need part-time or intermittent skilled nursing care or physical, speech-language, or occupational therapy. Although no hospital stay is required, beneficiaries must be homebound. During the 1990s, the Medicare home health benefit was used by many beneficiaries with largely long-term care needs, but this practice ended abruptly with passage of the Balanced Budget Act of 1997. Thus, one option would be to expand Medicare coverage, perhaps by eliminating the 3-day hospitalization requirement for skilled nursing facility care or by removing the homebound requirement for home health.

New Social Insurance Program for Long-Term Care

A much more ambitious approach to reform would be to establish a new social insurance program for long-term care. This strategy offers coverage to all persons who need it, regardless of their financial need. While not much discussed in the United States in recent years, a number of other countries, including Japan, Germany, the Netherlands, and some parts of Canada and Scandinavia, have financing systems that are based on a universal coverage approach (Organization for Economic Co-operation and Development, 2006). One example of a social insurance proposal is the Community Living Assistance Services and Supports (CLASS) Act, introduced by Senator Edward Kennedy. The CLASS Act would create a nationwide voluntary long-term care insurance program financed through voluntary payroll deductions of \$30 per month, with an option to opt out for those who choose not to participate. This legislation would provide a \$50–\$100 per day cash benefit to those individuals who need long-term care for a limited period of time.

SERVICE DELIVERY

Long-term care is provided by many different providers, including nursing homes, home health agencies, home care agencies, homemaker agencies, personal assistants, adult day health programs, assisted living facilities, and many more. In addition, as noted above, people with disabilities are, on average, heavy users of acute care services, such as physicians and hospitals. The five main critiques of

the long-term care delivery system are that the system is biased toward institutional care, service delivery is fragmented, home and community-based services are often too rigid, the needs of informal caregivers are ignored, and acute and long-term care are fragmented into separate financing and delivery systems that do not meet the needs of people with disabilities.

Balancing the Long-Term Care System

Probably the most common critique of the long-term care delivery system is its institutional bias. Despite the fact that the overwhelming majority of people with disabilities are at home and want to stay there (AARP, 2003), spending for long-term care for older people is overwhelmingly for nursing home rather than home care.

In addition to meeting the preferences of people with disabilities to remain in the community if at all possible, consumer advocates and state and some federal officials support home and community-based services because they believe that they are less expensive than nursing home care and that expanding services will result in less costly systems of care. The primary argument for the cost savings potential of home care is that average annual Medicaid expenditures for home care for older people and adults with physical disabilities (\$8,355 in 2004) are dramatically less than average annual expenditures (\$27,650 in 2004) per person for nursing home care (Kitchener et al., 2007; CMS, 2008b).

Although virtually all of the studies on this topic are very old (done more than 20 years ago) and do not incorporate more recent state experiences with Medicaid home and community-based services waivers, most research evaluating demonstration projects finds that expanding home care increases rather than decreases total costs (Grabowski, 2006). This finding of increased costs results primarily from inadequate targeting; in these demonstration projects, most persons receiving home care would not have entered a nursing home without the services. In other words, while home care provided a desirable service to people with real needs, in these demonstrations, it was primarily a supplemental service and did not substitute for nursing home care in most instances. The high percentage of persons with substantial disabilities not receiving services makes targeting people who would be institutionalized without it difficult (Johnson and Wiener, 2006). Thus, in these studies, the costs of large increases in home care use more than offset modest reductions in nursing home use. Although not directly addressing the issue of cost-effectiveness, a recent study of Medicaid long-term care spending patterns found that expenditure growth was greater for states offering limited noninstitutional services than for states with large, well-established home and community-based services programs (Kaye, LaPlante, and Harrington, 2009).

Over the last 10 years, states, in part encouraged by the federal government, have expanded home and community-based services. To support this trend, the federal government has provided approximately \$270 million since FY2001 for more than 330 Real Choice Systems Change Grants to help states develop more balanced long-term care delivery systems (CMS, 2008a). In addition, the U.S. Administration on Aging offers grants to states to develop Aging and Disability Resource Centers (in conjunction with CMS), nursing home diversion programs, and improved home and community-based services for persons with Alzheimer's disease. The Deficit Reduction Act of 2005 included several provisions designed to encourage states to expand home and community-based services, including encouraging flexible use of services through models that allow participants to direct their own services, establishing new Medicaid options that enable states to offer more home and community-based services without requiring a waiver, and authorizing a large demonstration program to transition people from nursing homes to the community (Crowley, 2006).

Despite these efforts, long-term care financing remains heavily tilted toward institutional services, especially nursing home care, although it is becoming less so. The U.S. Congressional Budget Office (2004) estimated that 32 percent of total (public and private) long-term care spending for older people was for home and community-based services in 2004. Although Medicaid home and community-based services for older people and younger persons with physical disabilities have been increasing, only 31 percent of Medicaid long-term care expenditures for this population were for noninstitutional services in 2007 (Burwell, Sredl, and Eiken, 2008). To achieve their goal of increasing home and community-based services, states have relied largely on Medicaid home and community-based services waivers, which give states much greater fiscal control and allow coverage of a much broader range of services than is possible under the standard Medicaid program, but require targeting a relatively severely disabled population.

Rural and other underserved communities face special problems in providing long-term care services, including home and community-based care (Freiman, Mitchell, and Wiener, 2008; Wiener and Mitchell, 2007). For rural communities, most of the problems are a consequence of low population density, including a level of need and demand for long-term care services that may not be of sufficient magnitude to be economically viable for service providers; high travel costs, both in terms of the cost of transportation and of the service provider's time; and a limited supply of service providers and organizational staff. Culturally competent providers who speak the language are often lacking in ethnic communities.

Consumer Empowerment

Over the last 10 years, states have used the flexibility of home and community-based services waivers to experiment with a variety of new services. A new paradigm of home and community-based services has taken hold, especially in the research and policy communities, drawing heavily on the long-term care systems in Oregon, Washington, and Wisconsin, among others. This new paradigm emphasizes consumer choice and empowerment and is embodied in federal and state initiatives to give program participants greater choice of and control over their services, including cash and counseling programs; nursing facility transition/money-follows-the-person initiatives; and providing services in residential care facilities, including assisted living facilities.

Traditional public home care programs rely on public or private agencies to hire and manage home care workers, schedule and direct services, monitor quality of care, discipline and dismiss workers if necessary, and pay workers and applicable payroll taxes. In the agency-directed model, clients can express preferences for services or workers, but have no formal control over them. This approach to care is based on the assumption that professional expertise and accountability are critical to the provision of good quality care at reasonable cost. At its extreme, a "medical model" is imposed and individuals with disabilities are considered to be "sick," as opposed to needing compensatory services, such as help with bathing.

Programs that allow participants to direct their services represent the opposite end of the management continuum from agency-directed services. These programs give participants control over who provides services, when they are provided, and how these services are delivered. Typically, participant-directed programs allow the consumer to hire, train, supervise, and dismiss the home care worker. In some programs, participants have individual budgets with which they purchase the goods and services they need.

A growing number of states are incorporating participant direction into their home care programs, including California, Michigan, Oregon, Washington, and Wisconsin. The National Association of State

Units on Aging reported that 40 states and territories operated a total of 62 participant-directed programs that served older people in 2004 (Infield, 2005). CMS promoted consumer-directed services through the Real Choice Systems Change Grants and the Independence Plus Initiative (O’Keeffe, Wiener, and Greene, 2005; O’Keeffe et al., 2007). In addition, the Office of the Assistant Secretary for Planning and Evaluation, CMS, and the Robert Wood Johnson Foundation sponsored Cash and Counseling demonstrations in Arkansas, Florida, and New Jersey where Medicaid beneficiaries of all ages are being given the opportunity to receive a flexible budget rather than service benefits (Doty, Mahoney, and Simon-Rusinowitz, 2007). The same funders sponsored a replication of the Cash & Counseling service model in 12 additional states in 2004.

New approaches have also developed around entrance to the long-term care system and exit from nursing homes. One strategy has been to establish single point of entry programs, which provide information about the range of services, perform functional assessments and preadmission screening for nursing homes, and sometimes develop plans of care. Building on Wisconsin’s Family Care demonstration (Alecxi et al., 2003), the U.S. Administration on Aging and CMS are funding 43 states to develop Aging and Disability Resource Centers to implement this concept (U.S. Administration on Aging, 2008d). While many grants are not statewide, they commit the state to the concept of an integrated entry point to the long-term care system. The premise of Aging and Disability Resource Centers is that more information about alternatives to nursing home care and help gaining access to the home care financing and delivery system will divert people from nursing home placement.

Other approaches aimed at establishing mechanisms to return to the community from institutional settings are nursing facility transition programs and the money-follows-the-person initiatives (Anderson, Wiener, and O’Keeffe, 2006). Nursing facility transition and money follows the person programs identify people in nursing homes who wish to return to the community and help them to do so. In money follows the person programs, Medicaid funds budgeted for institutional services are spent on home and community services when individuals move to the community from nursing homes. To further explore this concept, the Deficit Reduction Act of 2005 allocated \$1.75 billion over 5 years for a demonstration of this concept, with the funds earmarked for enhanced federal Medicaid match for people transitioning out of nursing homes and other institutions as an enticement for states to participate in the demonstration. This will be the largest federal long-term care demonstration ever implemented.

Transitioning individuals with intellectual disabilities from institutions to the community has been a central component of long-term care policy for that population for more than three decades. On the other hand, identifying people in nursing homes who want to live in the community and actively working to transition them out of the institution is a radical change in approach for older people and younger persons with physical disabilities. For the past 25 years, the overwhelming focus has been on preventing admissions to nursing homes, not discharging residents from them. This new strategy takes as its premise that there are people living in nursing facilities who want to return to the community and can do so at a reasonable cost, and that some people admitted to nursing facilities improve rather than decline in functional status and may desire to return to the community. Nursing facility transition programs also reflect an increasingly widespread view that people of all ages with severe disabilities can successfully live in the community with the proper supports, thus challenging the notion of a continuum, in which each service is reserved for persons of a particular disability level.

Residential care facilities, such as assisted living facilities and smaller board and care or personal care homes, are an important and growing component of long-term care services. State interest in funding residential care through Medicaid, largely through home and community-based services waivers, is fueled by a desire to offer a full array of home and community services, reduce nursing home utilization, and

achieve the economies of scale of nursing home care without the undesirable institutional characteristics. A recent study of state-licensed residential care facilities reported that there were 38,373 residential care facilities nationally with 974,585 units/beds in 2007 (Mollica, Sims-Kastelein, and O’Keeffe, 2007). By contrast, in June 2008 there were an estimated 15,739 nursing homes with 1,670,419 beds (American Health Care Association, 2008b).

Informal Caregivers

Although informal caregivers provide the overwhelming majority of long-term care to people with disabilities, they receive little financial or program support. Public programs focus on services to the eligible participant, and generally do not address the needs of family caregivers. The Administration on Aging’s National Family Caregiver Support Program is a relatively rare exception, but is funded at only \$153 million annually (U.S. Administration on Aging, 2008a). In addition, the Alzheimer’s Disease Support Services Program (previously known as the Alzheimer’s Disease Demonstration Grants to States program) focuses on demonstrating innovative programs for caregivers of people with dementia; it is funded at \$11 million per year. Limited federal and state tax deductions are available for informal caregivers, but they are very restricted in terms of who can qualify and how much money is available.

Coordinated Care for People with Long-Term Care Needs

People with disabilities currently receive care in a fragmented and uncoordinated financing and service delivery system, both within and between the health and long-term care systems. Financing for acute care is largely the responsibility of Medicare and the federal government, while long-term care is dominated by Medicaid and state governments. Other sources of limited funding for long-term care include a variety of sources, including Medicare, the Older Americans Act, the Department of Veterans Affairs, and state-funded home care programs.

Federal initiatives to better coordinate care provided in the health and long-term care systems by integrating financing for health and long-term care date to the 1980s and early 1990s, although some states have more recent projects. Almost all of these initiatives depend on managed care taking responsibility for both acute and long-term care services. Under these models, capitated organizations have financial incentives to avoid both the functional decline that can result from unmet needs and the unnecessary costs associated with providing services in needlessly expensive settings. The hypothesis is that this coordinated approach will produce savings in acute care because lower cost long-term care services will substitute for more costly hospital and physician services and that home care will substitute for more expensive nursing home care. The best known and most extensively researched of these projects are the Social Health Maintenance Organizations (HMOs), the Program of All-inclusive Care of the Elderly (PACE), and the Arizona Long-Term Care System (ALTCs), but other examples include Texas’ STAR+PLUS program, the Minnesota Senior Health Options (MSHO), New York’s Medicaid Long-Term Care Capitation Program, and Wisconsin’s Family Care program.

Although no longer an active demonstration project, Social HMOs extended the traditional concept of HMOs by adding a modest amount of long-term care to the benefits covered by Medicare (Leutz and Capitman, 2005). A coordinated case management system authorized long-term care benefits for those who met the established eligibility criteria. Social HMOs were intended to serve a cross section of the older population, including people both with and without long-term care impairments. While all enrollees were eligible for Medicare, relatively few Medicaid beneficiaries are enrolled.

Also starting as a demonstration project, PACE provides a comprehensive set of acute and long-term care services in an integrated financing and service setting (Eng et al., 1997). Although PACE became a part of the regular Medicare and Medicaid programs with the passage of the Balanced Budget Act of 1997, there were only about 60 programs in 2008 (National PACE Association, 2008). While Social HMOs targeted a broad range of people with and without disabilities to pool risk, enrollment in PACE is limited to people who are disabled enough to meet Medicaid nursing home admission criteria. Because expenditures per person are so high, very few people can afford to pay an actuarially fair premium. As a result, almost all enrollees are dually eligible for Medicare and Medicaid. PACE sites operate as geriatric-oriented, staff model HMOs, with primary care physicians as employees of the organization. A hallmark of the program is heavy use of adult day health programs, which are integrated with primary care.

The Arizona Health Care Cost Containment System (AHCCCS) is a statewide demonstration project that finances medical services for the Medicaid population through prepaid contracts with providers (McCall, 1996). Beginning in 1989, the ALTCS program incorporated Medicaid long-term care services into the AHCCCS program (Weissert et al., 1997). Arizona is the only state to provide for capitated acute and long-term care services on a statewide basis. Participation is limited to individuals who are certified to be at risk of institutionalization. ALTCS covers Medicaid acute care services, nursing facilities, intermediate care facilities for the mentally retarded, and home and community-based services.

While Social HMOs, PACE, and ALTCS seek to integrate acute and long-term care services and financing, Wisconsin's Family Care Demonstration focuses solely on integrating long-term care, including both a wide range of home and community-based services and institutional care (Alexih et al., 2003). Family Care has two major components—aging and disability resource centers and care management organizations, both of which are run by the counties. The resource centers offer a wide range of information and counseling on long-term care services and providers, conduct functional assessments for Family Care and, if appropriate and chosen by the client, assist with enrollment into a care management organization. The goal is for the resource centers to be a “single point of entry” into the entire long-term care system for persons of all income levels.

Care management organizations serve as capitated, managed care organizations for institutional and home and community-based long-term care services. The state consolidates funding for long-term care from Medicaid state plan services, the Medicaid home and community-based services waivers, and state and county-funded programs into a single monthly capitated payment. The goal is one “pot” of money that can be used to create a seamless system in which individuals' needs dictate service provision, rather than state financing “silos” for specific programs or settings. To consumer advocates, a major advantage of Family Care is that it provides an entitlement to an array of flexible home and community-based services to everyone who meets certain criteria.

Surprisingly, despite the fact that the vast majority of people with functional impairments have chronic illnesses and much higher health care costs than people with only chronic illnesses (Anderson and Knickman, 2001), virtually all recent chronic care initiatives have ignored long-term care and people with disabilities (Institute of Medicine, 2008). A preliminary analysis of the Medical Expenditure Panel Survey by RTI International suggests that acute care expenditures for people with chronic illnesses who have disabilities are generally twice those of people with chronic illnesses without disabilities. This lack of inclusion of long-term care in chronic care initiatives illustrates the divide that exists between Medicare and Medicaid financing.

In a separate set of initiatives, Medicare has been funding efforts to increase integrated, accessible information on beneficiaries' service needs, treatments, and options across acute and post-acute care settings (e.g., short stays in nursing homes, rehabilitation hospitals, and short-term receipt of home health services after a hospitalization). To support coordination in post-acute care, Medicare is testing the Continuity Assessment and Record Evaluation (CARE) tool, which is designed to collect longitudinal patient-level information across the continuum of care and is not specific to any one individual type of provider. This tool will standardize the types of information collected across the Medicare program, while an electronic record system will permit key information transfers across different providers. For example, when fully implemented, the CARE system would provide home health providers with access in "real time" to hospital and nursing home data on medical, functional, and cognitive status and on social support before patients are admitted to home health care. The tool is currently being tested to capture information from home health and institutional providers but potentially can be used in physician and outpatient offices as well.

While the CARE tool will be able to provide useful information to improve coordination among Medicare-covered service providers, nursing homes and home care agencies also provide services to many populations with less skilled care needs. The type of information collected in the CARE tool, and the system developed for its use, hold the potential for expansion into the broader service system that furnishes care in the aging and disability communities. The CARE initiative is designed to be expanded to allow communication across provider and insurance networks as the federal government moves toward developing interoperable data standards.

Reform Options

Options to reform the long-term care delivery system fall into five categories—strengthening state long-term care infrastructure, modifying legislative and regulatory requirements for Medicaid home and community-based services, increasing funding for noninstitutional services, providing more financial support for family caregiver programs, and funding innovative demonstration projects that integrate services—the pros and cons of which are summarized in *Exhibit 3*.

Strengthen State Long-Term Care Infrastructure

Many states lack the administrative infrastructure to manage a comprehensive system of home and community-based services. Developing this infrastructure is time consuming and labor intensive, requiring additional staff that states cannot or do not want to hire, especially in the current economic environment. Moreover, sometimes these initiatives require expensive changes to computer systems. To aid states in reforming their long-term care systems, CMS and the Administration on Aging have provided grants to develop Aging and Disability Resource Centers, consumer-directed home and community-based services, quality assurance systems for home and community-based services, nursing home diversion programs, Alzheimer's disease capable service systems, and supports for informal caregivers (Shirk, 2007; U.S. Administration on Aging, 2008c). Thus, one strategy is to increase funding for these grant programs with the expectation that the new infrastructure will enable the state to expand and improve home and community-based services.

Exhibit 3: Options to Reform the Long-Term Care Delivery System

Strategy	Pros	Cons
<p>Increase funding for grants to strengthen state long-term care infrastructure</p>	<ul style="list-style-type: none"> • Helps states develop innovative programs • Low cost • Voluntary to the states 	<ul style="list-style-type: none"> • Existing infrastructure grants have had difficulty going to statewide implementation • Sustainability of projects after funding stops a problem • With exceptions, existing infrastructure grants have been small, limiting impact • In current fiscal environment, grants requiring state matching funds may have limited take-up
<p>Modify regulations or legislative requirements that impede state provision of Medicaid home and community-based services</p>	<ul style="list-style-type: none"> • Modifies existing programs that are already in place • Regulatory change could be implemented relatively quickly • Removes barriers to HCBS • Depending on changes, could be low cost 	<ul style="list-style-type: none"> • States already have great flexibility in HCBS, so further changes may not affect state policy • Some regulations require legislative changes • Some regulations that states find objectionable are designed to prevent maximization of federal Medicaid funds or to protect beneficiaries
<p>Provide more federal financial support for home and community-based services through Medicaid, Older Americans Act, and veterans benefits</p>	<ul style="list-style-type: none"> • Directly provides funds for home and community-based services or financial incentive for states to expand services 	<ul style="list-style-type: none"> • States will resist any additional mandates • Depending on how designed, funds to increase Medicaid match for home care could mostly increase federal costs for existing services rather encourage new services
<p>Provide more federal financial support for informal caregivers, through additional training, direct service programs, or tax benefits</p>	<ul style="list-style-type: none"> • Supports neglected families, who are cornerstone of long-term care system • Helps to meet need for caregiver training • Tax benefits provide recognition of sacrifice caregivers are making 	<ul style="list-style-type: none"> • Tax options relatively expensive because many people qualify • Tax credits for informal caregivers unlikely to change behavior or lead to the provision of more care

Continued

Exhibit 3: Options to Reform the Long-Term Care Delivery System (Continued)

Strategy	Pros	Cons
Fund demonstration projects of innovative chronic care models that integrate acute and long-term care	<ul style="list-style-type: none"> • Addresses fragmentation of the financing and delivery systems • Recognizes the multiple needs of people with disabilities • Offers possibilities for efficiencies 	<ul style="list-style-type: none"> • Past efforts to integrate Medicaid and Medicare have encountered great difficulties • Could result in overmedicalization of long-term care because of dominance of hospitals and physicians • Evaluations of past demonstrations integrating acute and long-term care have found only very modest gains

Modify Regulations or Legislative Requirements that Impede State Provision of Medicaid Home and Community-Based Services

States often argue that federal Medicaid rules are barriers to the expansion of home and community-based services. For example, in 2008, CMS issued a regulation that limits the extent to which states can use targeted case management to transition nursing home residents to the community. Similarly, Medicaid spend-down rules are very strict and deter many people from applying for needed services. Many consumer advocates criticize the Medicaid statute for mandating nursing home care coverage, but making home and community-based services optional. The ability of states to impose provider taxes on nursing homes, but not home and community-based services, establishes a bias toward institutional care because states that rely on the provider tax may be reluctant to lose the revenue when nursing home use declines.

Provide More Federal Financial Support for Home and Community-Based Services

While the options above focus on infrastructure development and providing more options to the states, this strategy expands home and community-based services by providing more federal financial resources. Several existing federal programs finance home and community-based services, including Medicaid, the Older Americans Act, and the Department of Veterans Affairs. For example, the entire budget for the Administration on Aging was \$1.4 billion in FY2008; thus, tripling the agency’s budget would cost an incremental \$2.8 billion (U.S. Administration on Aging, 2008a). Alternatively, a higher federal Medicaid match for home and community-based services would provide a powerful financial incentive for states to expand these services rather than nursing home care, but most new expenditures would simply refinance existing spending unless limited to new spending. The federal government could also make personal care a mandatory service under the Medicaid program, forcing the 16 states that do not cover the service to do so, a requirement which most affected states would resist.

Provide More Federal Financial Support for Caregivers, Through Additional Training, Direct Service Programs, or Tax Benefits

The vast majority of federal funds for long-term care are focused directly on the person with a disability, rather than the informal caregiver. One strategy that recognizes the role of the family and the

financial burdens and sacrifices that they make in caring for relatives would be to increase funding for programs to support informal caregivers. These programs include the Administration on Aging's National Family Caregiver Support Program and the Alzheimer's Disease Support Services program. A more expansive and costly approach would provide tax credits for informal caregivers, such as was proposed as part of the CARE Act proposed by Senator Bob Menendez in the 110th Congress. Social Security credits could also be provided for workers who leave the labor force to become informal caregivers, as done in several European countries.

Fund Demonstration Projects of Innovative Chronic Care Models That Integrate Acute and Long-Term Care

A recent Institute of Medicine (2008) committee recommended that Congress and foundations significantly increase support for research and demonstration programs that promote the development of new models of care, especially in the areas of prevention, long-term care, and palliative care. The report noted that the Medicare Modernization Act mandated several chronic care demonstrations, but the demonstrations have neglected long-term care and have not focused on people with disabilities.

LONG-TERM CARE WORKFORCE

Long-term care is a service provided by people, not machines. While there are workforce issues related to licensed professionals, such as physicians and nurses, most public policy discussions about the long-term care workforce focus on the "direct care workforce," such as certified nurse assistants, home health aides, personal care attendants, and personal assistants. These workers are the backbone of the formal long-term care delivery system (Stone and Wiener, 2001). These "frontline" workers help people by assisting with activities of daily living, such as eating, bathing dressing, and toileting, and with instrumental activities of daily living, such as taking their medication and meal preparation. The central role of these workers in providing "hands-on" services makes them the key factor determining the quality of paid long-term care. As a consequence, the discussion in this section is closely related to, and in some cases overlaps with, the following section on quality of care. In the current economic environment, some advocates argue that investment in expanding and improving long-term care services would create new jobs and stimulate economic growth (PHI, 2008b).

Problems of the Long-Term Care Workforce

There are at least three broad problems facing the long-term care direct care workforce. First, it is difficult to recruit and retain long-term care workers because of low wages, limited fringe benefits, the physically demanding nature of the work, and the work environment. In 2005, three quarters of responding states reported that vacancies in the direct care workforce were a "serious" or "very serious" issue (Harmuth and Dyson, 2005). Moreover, many individuals trained to provide long-term care do not stay in long-term care. As a result of high turnover and vacancy rates, providers incur substantial recruitment and training costs. Typically, recruitment and retention is more difficult in good economic times and less urgent when unemployment is high and there are fewer job alternatives.

The shortage of workers is likely to be exacerbated in the long run by the increased demand for long-term services as a result of the aging of the population, even if the current economic downturn lessens the problem in the near term. Over the long run, there is a major demographic imbalance between the number of people likely to need long-term care services and the number of people likely to be available to provide it. The ratio of persons aged 18–64 (the working-age population) to the number of

persons aged 85 and older (the population most likely to need long-term care services) is projected to decline from 34 to 1 in 2010 to 13 to 1 in 2050 (author's calculations of U.S. Census Bureau data, 2008). While these data are often used to illustrate the potential economic burden of Medicare, Medicaid, and Social Security, they also have profound implications for the availability of personnel to provide long-term care services. It will be far more difficult to recruit and retain workers in the future, and probably more costly.

Second, the quality of long-term care services is compromised by the vacancies, high turnover, and low levels of training of long-term care workers. The vacancies mean that long-term care providers are short staffed, and even at full staffing have inadequate numbers of personnel. A CMS report to Congress found "strong and compelling" statistical evidence that nursing homes with a low ratio of nursing personnel to patients were more likely to provide substandard care (CMS, 2002). Several studies have found that inadequate staffing levels, an inevitable byproduct of worker shortages, are associated with poorer nutrition and preventable hospitalizations among nursing home residents (Institute of Medicine, 2001). High turnover also means that continuity of care is reduced, with staff not having time to get to know the needs and preferences of individual consumers. Workers who are providing care in understaffed settings may experience high levels of stress and frustration and low levels of job satisfaction, which can further increase already high turnover and poor quality of care.

The low levels of education and training of direct care workers may also adversely affect quality of care. Approximately three quarters of certified nursing assistants in nursing homes had only a high school education or less in 2004 (Squillace et al., 2007). Federal law requires only 75 hours of initial training for nursing assistants and home health aides. This lack of training may lead to poor job performance, which may result in low levels of job satisfaction and high turnover rates. These direct care occupations are often considered dead-end jobs because of the lack of additional training and opportunity for advancement. While this minimal training makes entry into the job market for frontline long-term care workers fairly easy, the training requirements are greater than for many other low-wage jobs, which may deter some entrants.

Third, the current labor force situation has negative implications for the quality of life of workers themselves and contributes to recruitment and retention problems. Paraprofessional long-term care workers receive low wages. In 2007, the median hourly wage for all direct-care workers was \$10.48 (U.S. Department of Labor, 2008). Inflation-adjusted wages for the direct-care workforce show that, between 2000 and 2008, while nursing aides, orderlies, and attendants experienced a modest increase in their real wages to just over \$9.00 (measured in 1999 dollars), real wages for home health aides and personal and home care aides have declined and are under \$8.00 an hour (measured in 1999 dollars) (PHI, 2008a). In addition, because of the times during the day when care is most needed, many home care aides only work part-time, further reducing their earnings. Not surprisingly, these workers have high uninsurance rates for health coverage.

Reform Options

A large number of policy, provider, worker, and consumer initiatives have been proposed and implemented to address long-term care workforce problems. These strategies can be grouped into four broad categories—recruitment efforts, training programs and career ladders, extrinsic rewards, and organizational culture. The pros and cons of these options are summarized in *Exhibit 4*.

Exhibit 4: Options to Improve the Long-Term Care Workforce

Strategy	Pros	Cons
Recruitment initiatives, such as worker registries, marketing campaigns, establishment of backup systems, and recruitment of nontraditional workers	<ul style="list-style-type: none"> • May expand target population for recruitment • Meets immediate needs of consumers and providers • May reduce provider recruitment costs • Relatively low cost • Economic recession may make it easier to recruit workers in near term 	<ul style="list-style-type: none"> • Does not address fundamental issues of why recruitment is difficult (e.g., wages, benefits, and organizational culture) • Effectiveness of initiatives is uncertain • Nontraditional workers may not be good “fit” for long-term care jobs
Increase training programs and career ladders	<ul style="list-style-type: none"> • Helps make direct care work more of a career • Improves ability of workers to provide high-quality care to consumers • Higher levels of competency may promote greater self-worth among workers and increased job satisfaction 	<ul style="list-style-type: none"> • Increased training without higher wages may not retain workers • High exit rates from long-term care means that trained personnel may not stay in the field • Little research establishing what training is effective • Depending on what is required, cost could be significant
Increase wages and fringe benefits by mandating minimum wages or wage-pass-throughs in Medicare and Medicaid payment rates	<ul style="list-style-type: none"> • Economic theory predicts that higher wages and fringe benefits will attract more workers • Higher wages and fringe benefits likely to reduce turnover • Increases financial well-being of low-wage workers 	<ul style="list-style-type: none"> • Higher wages and fringe benefits will increase costs to providers and Medicare and Medicaid • Research on the effect of higher wages and fringe benefits on turnover and quality of care is limited • Wage pass-throughs may not result in higher wages for workers • In short term, providers may be able to recruit workers without higher wages and benefits because of the recession
Change the organizational culture of long-term care providers by providing grants to states or providers to develop these initiatives	<ul style="list-style-type: none"> • Systematically alters culture of care to focus on meeting consumer needs and empowering workers • Addresses many critiques of nursing homes 	<ul style="list-style-type: none"> • Limited research on impact on quality and workers • Replicability unclear • May result in higher costs • Limited federal and state policy levers to promote behavioral change in providers

Recruitment Initiatives

One strategy to address the long-term care workforce shortage is to increase the number of qualified applicants for available positions. One option would be to provide grants to the states to establish programs to recruit staff to long-term care. States have experimented with at least four

recruitment strategies (Anderson et al., 2004.) The first is to conduct broad educational and marketing initiatives to reach populations from whom workers are traditionally drawn. A second strategy is to develop worker registries to provide consumers with a centralized list of qualified and screened workers. A third strategy is to develop systems of backup workers to meet the needs of consumers whose regular workers are not available to provide services when needed. A fourth strategy targets recruitment efforts in certain nontraditional groups of potential workers, such as older workers, family members, students, and welfare beneficiaries.

Training Programs and Career Ladders

Direct service workers receive relatively little training. Potential workers lack both funds and time to participate in training. Once a worker is hired, funding is needed for tuition or wages while workers receive training. Funding often must also be found for substitute staff while workers are being trained. Ultimately, the cost of training must be borne by provider agencies or sponsoring government agencies, because workers usually cannot afford training costs. Increased federal and state funding is an alternative way to pay for training.

Improved training may be important to help workers develop competencies and functional skills that will improve their confidence and job satisfaction, and ultimately worker retention. Improved training may also indirectly affect recruitment of workers if better-trained and more satisfied workers improve public opinion of these jobs, making these jobs more attractive to potential recruits. Career ladder development for workers is important if states want to reduce the turnover rate and develop a cadre of quality workers. Several states are exploring the new career options for direct service workers by developing new job categories, expanding the scope of duties under existing categories, and developing career ladders.

Extrinsic Rewards

Proposals to improve extrinsic benefits of the job, such as wages and fringe benefits, make a straightforward economic case. Workers are more likely to stay on the job when they are well paid, especially relative to other employment opportunities. The argument is also that better worker compensation packages could help draw marginal workers into the labor force. Moreover, increases in the compensation of long-term care staff relative to other low-wage positions could reallocate the available low-wage workforce to long-term care (Holzer, 2001). In a rare study of the effects of wage increases, a near doubling of wages of home care workers in San Francisco County, California, increased the retention rate over a 52-month period from 39 percent to 74 percent (Howes, 2005). An analysis of the 2004 National Nursing Home Survey and the National Nursing Assistant Survey found that higher wages were associated with longer job tenure by certified nursing assistants (Wiener et al., forthcoming).

To implement higher wages, just over half the states funded wage pass-throughs for direct care workers in recent years and over 40 percent of wage pass-throughs have been for workers in nursing facilities (Seavey and Salter, 2006). In these initiatives, Medicaid or other public payment rate increases are earmarked for higher wages for long-term care staff. Although consistent with economic theory, there is little evidence as to whether wage pass-throughs affect recruitment and retention of workers; the wage increases are often small and enforcement and accountability mechanisms for the pass-throughs are often lacking. And because long-term care providers are so dependent on Medicare, Medicaid, and other public programs, wage increases and more fringe benefits for direct care workers require higher reimbursement levels from public programs, which will be difficult in the current economic climate.

Organizational Culture

Initiatives to improve the organizational culture of nursing homes focus on the values that determine organizations' behavior, the relationships between internal and external stakeholders, traditions, what is rewarded and punished in the organization, and behavioral norms. While extrinsic rewards may draw individuals into an organization to work, the satisfaction that they receive while on the job may contribute to longer job tenure. Productive relationships with supervisors and coworkers, opportunities for teamwork, and respect are potentially important intrinsic factors that could improve job tenure.

A number of nursing homes are attempting to change their organizational culture by empowering and involving workers in care decisions and by providing more feedback, autonomy, and respect (Institute of Medicine, 2008). Many of these initiatives (such as the Eden Alternative, the Wellspring Model, the Pioneer Network, and Green House homes) focus mainly on improving quality of care, but these approaches have important spillover effects that affect workforce issues (Kane et al., 2007). Although these models represent primarily a provider initiative, some states have provided financial incentives for nursing homes to replicate them (Stone and Wiener, 2001).

QUALITY ASSURANCE

Concern about poor quality of care by nursing homes and other long-term care providers is long standing (New York State Moreland Act Commission, 1975; Wiener, 1981). Unease about quality is not limited to the United States, but exists in a number of countries (Wiener et al., 2007). Despite improvements in nursing home quality following the enactment of the Omnibus Budget Reconciliation Act of 1987, poor-quality nursing home care and questions about the effectiveness of government oversight continue to be problems (Institute of Medicine, 2001; Wiener, Freiman, and Brown, 2007).

The U.S. Government Accountability Office (GAO, 2005) found that there was a significant decrease in the proportion of nursing homes with serious quality problems during the first half of this decade, declining from about 29 percent of facilities in 1999 to about 16 percent of facilities in January 2005. However, the same report concluded that this trend masked two important concerns: inconsistency among state surveyors in conducting surveys and understatement by state surveyors of serious deficiencies. In addition, GAO (2007a,b) found that many poor-quality facilities continued to cycle in and out of compliance on subsequent surveys. The Administration on Aging's national ombudsman reporting system received nearly 200,000 complaints in 2006 concerning nursing facility residents' quality of care, quality of life, and rights (U.S. Administration on Aging, 2008b).

One of the policy rationales for expanding home and community-based services is that the quality of care of these services is better than in nursing homes. However, much less is known about the quality of home and community-based services, in part because there is less government oversight, especially by the federal government. Although people who use home care typically report high levels of satisfaction, measuring quality of care in the home and community setting is at a fairly early stage of development compared with nursing home care (Khatutsky, Anderson, & Wiener, 2006). Although states have increased regulation of residential care facilities, including assisted living facilities, there is no systematic information about the quality of care provided.

To fully meet the needs of individuals who need long-term care, quality assurance systems need to address both quality of care and quality of life domains. The vast majority of existing regulations and quality measures focus on quality of care, generally measured by indicators of health and safety, including

potential markers of poor quality such as dehydration, urinary tract infections, malnutrition, bedsores, excessive use of hypnotics and antipsychotic medications, undertreatment of depression, weight loss, and uncontrolled pain. For example, quality of care assessments include whether nursing homes carefully help residents with eating, whether there is adequate staffing to assist residents at mealtime, and whether residents maintain an appropriate weight.

In contrast, quality of life refers to much more intangible factors, such as autonomy, dignity, individuality, comfort, meaningful activity and relationships, a sense of security, and spiritual well-being (Kane et al., 2003; National Citizens' Coalition for Nursing Home Reform, 1985). These factors are, by definition, subjective, but they are critical to living a good and meaningful life. To continue with the feeding example, quality of life refers to the ability to choose preferred foods, the tastiness and the temperature of the food, the ability to choose meals that fit with personal preferences and ethnic heritage, the friendliness and patience of the staff helping with feeding, and the willingness of the staff to let residents feed themselves to the extent possible, even if it takes additional time.

An important hypothesis articulated by some advocates of assisted living and consumer-directed services is that there may be a tradeoff between quality of care and quality of life. As Rosalie Kane of the University of Minnesota puts it:

One little-tested assumption is that safety—defined vaguely or not at all—is the be-all and end-all of long-term care. Embedded in most of our rules and regulations is the idea that long-term care should aspire to the best quality of life *as is consistent with health and safety*. But ordinary people may prefer the best health and safety outcomes possible *that are consistent with a meaningful quality of life* (Kane, 2001).

The use of negotiated risk agreements in some assisted living facilities, where informed consumers or their agents explicitly identify and accept risks and the possibility of adverse outcomes to achieve quality of life goals, are an effort to address these tradeoffs.

Reform Options

To achieve the goals of high-quality long-term care, a large number of strategies have been proposed and implemented (Wiener, Freiman, and Brown, 2007). These approaches can be broadly grouped into three categories—increase external mandatory requirements, increase voluntary external incentives, and promote voluntary approaches by providers to directly change their internal operations (*Exhibit 5*).

Increase External Mandatory Requirements

The federal government dominates the quality assurance system for nursing homes, although states actually perform the inspections. States, on the other hand, are responsible for most regulation of home and community-based services, although CMS has recently increased quality of care oversight in Medicaid home and community-based services waivers. One group of strategies to improve quality of care increases mandatory federal or state provider requirements by strengthening the regulatory process with tougher enforcement of existing nursing home standards and more extensive monitoring of home and community-based services (GAO, 2007a,b; Institute of Medicine, 2001). This strategy would also raise regulatory standards, for example, by requiring higher staffing ratios in nursing homes (Institute of Medicine, 2001, 2008) and more extensive training (Institute of Medicine, 2008). Increasing staffing

levels and training will require higher Medicare and Medicaid reimbursement rates, which will increase government expenditures.

Exhibit 5: Strategies to Improve Quality of Care and Quality of Life in Long-Term Care

Strategy	Pros	Cons
Mandatory Approaches that are External to Providers		
Strengthen the regulatory process	<ul style="list-style-type: none"> • Builds on large existing system of quality assurance for nursing facilities and home health agencies • Great deal of data available • Main approach used in many other countries • Addresses weak enforcement for nursing facilities • Addresses limited monitoring of home and community-based services 	<ul style="list-style-type: none"> • Many regulations address paperwork and structural requirements rather than outcomes • Nursing home regulations inconsistently interpreted and applied across geographic areas <ul style="list-style-type: none"> ▪ May stifle innovation ▪ Little knowledge base on which to establish regulations for home and community-based services
Increase staffing levels and training requirements in nursing homes	<ul style="list-style-type: none"> • Current staffing in nursing facilities below recommended levels • Training requirements for direct care workforce minimal or absent 	<ul style="list-style-type: none"> • Organization and management of services may be as important as staffing levels • Increased staffing expensive to implement, requiring high Medicare and Medicaid payments • Little research on effects of training on quality of care
Voluntary Approaches that are External to Providers		
Provide consumers with more information	<ul style="list-style-type: none"> • Builds on existing CMS websites, which already provide a great deal of information on nursing home and home health quality • Makes market work better by encouraging competition on quality • Provides motivation for provider improvement • Low-cost initiative 	<ul style="list-style-type: none"> • Little research evidence on the effectiveness of this approach • Structural aspects of market may reduce possibility of competition on quality • Consumers may not use information to make choices because it is too complicated or choices are made during “crises” • Current data are focused on quality of care rather than quality of life

Continued

**Exhibit 5: Strategies to Improve Quality of Care and Quality of Life in Long-Term Care
(Continued)**

Strategy	Pros	Cons
Voluntary Approaches that are External to Providers (Continued)		
Strengthen consumer advocacy	<ul style="list-style-type: none"> • Provides a counterbalance to nursing home industry • Gives voice to views of consumers • Ombudsman program provides resolution to individual complaints 	<ul style="list-style-type: none"> • No research on effectiveness • Volunteers often lack technical expertise • Fear of retaliation by providers against consumers may limit complaints
Reform the payment systems for Medicare and Medicaid	<ul style="list-style-type: none"> • Could prevent states from underpaying nursing homes and other providers for Medicaid beneficiaries • Government controls amount and method of most payment systems • Providers depend heavily on government financing, making them sensitive to government reimbursement system 	<ul style="list-style-type: none"> • Higher rates increase government costs • Research shows modest relationship between cost and quality • Little research evidence on the effectiveness of pay-for-performance in long-term care
Voluntary Strategies that are Internal to Providers		
Develop and implement practice guidelines	<ul style="list-style-type: none"> • Low-tech aspects of long-term care make guidelines potentially very useful • Many guidelines already exist 	<ul style="list-style-type: none"> • Some guidelines raise costs • Accurate reporting on use of guidelines may expose providers to surveyor sanctions • Limited federal and state government policy levers
Change the organizational culture of long-term care providers	<ul style="list-style-type: none"> • Systematically changes culture of care to focus on consumer needs and empowering workers • Addresses many critiques of nursing homes 	<ul style="list-style-type: none"> • Limited research on impact on quality • Replicability unclear • May result in higher costs • Limited federal and state policy levers

Increase Voluntary External Incentives

Another group of strategies depend on federal or state government actions or other organizations to structure the market so that providers have to compete for customers based on the quality of care they provide. These initiatives include providing consumers with information on the quality of care of individual providers, changing Medicare and Medicaid reimbursement methods, and increasing support for consumer advocacy, such as the Administration on Aging’s ombudsman program. To help consumers

choose among providers, CMS has added a large number of quality measures to the Nursing Home and Home Health Compare websites. While this initiative has broad support, there is little evidence that it changes consumer behavior (Shugarman & Brown, 2006; Stevenson, 2006). CMS is operating a Medicare pay-for-performance demonstration to provide financial incentives to nursing home and home health agencies to improve the quality of care. Although funding is limited, the U.S. Administration on Aging operates the long-term care ombudsman program, which advocates for residents of nursing homes, board and care homes, assisted living facilities, and similar adult care facilities.

Promote Voluntary Approaches by Providers to Change Their Internal Operations

A final group of strategies includes a range of voluntary initiatives by providers to directly change their internal operations to improve quality. These strategies include implementing practice guidelines and changing the organizational culture of individual providers. A substantial number of practice guidelines, including those for the treatment of incontinence, the use of restraints, prevention and treatment of pressure ulcers, and the treatment of pain and depression, already exist, but are not widely used (Institute of Medicine, 2001).

As noted above in the section on the long-term care workforce, policymakers and providers have promoted culture change as a means of improving quality of care. These initiatives involve direct care workers, such as certified nurse assistants and personal care attendants, in care decisions, empowering workers, and providing more feedback, autonomy, and respect. Some of the better known of these experiments include the Eden Alternative, the Wellspring Model, and Green House homes. While the federal and state government can facilitate these changes by altering or waiving regulations that may impede implementation and by offering modest startup funding, responsibility for the implementation of these initiatives belongs primarily to providers themselves.

MOVING FORWARD: FIRST STEPS

The long-term care financing and delivery systems in the United States are broken and need a dramatic overhaul. Although long-term care affects people of all ages, the increase in the elderly population over the next 40 years, and with it the growth in the number of older people with long-term care needs, inevitably will force long-term care onto the policy agenda. Some observers worry about whether the current Medicaid-dominated system can be sustained, although it seems likely that America can muddle through, albeit in a less than optimal fashion. While the costs and other demands of long-term care are almost certain to be greater in the future than they are today, long-term care in the future does not have to look like the long-term care of today. We have the opportunity and the responsibility to build a better system than the one we have today.

Common Understanding of the Problems

While there are strong disagreements among long-term care stakeholders on many issues, most observers would agree with the following observations:

Financing

- Because each state has its own coverage and eligibility rules, the heavy emphasis on Medicaid financing results in great variation across the country in what services older and younger persons needing long-term care have available to them.

- States are not fiscally structured to address the large long-run increase in demand for long-term care.
- Addressing the problem of long-term care financing is likely to require a combination of public and private initiatives and will need to address both older people and younger persons with disabilities.
- While private sector financing is likely to increase, it will not become a major source of financing without much greater financial incentives, which would be costly to federal and state governments.

Service Delivery

- Although substantial progress has been made over the last 10 years, the long-term care delivery system continues to be tilted toward institutional care rather than to home and community-based services.
- States have experimented with service delivery options that increase program participants' control over their services, but many of these new approaches have not been widely implemented.
- The split between acute and long-term care results in suboptimal care for older and younger people with long-term care needs.

Long-Term Care Workforce

- The current long-term care financing and delivery system depends heavily on minimally trained, low-wage workers with high turnover rates.
- Staffing shortages in nursing homes and home and community-based services are common.
- Although the recession may ameliorate worker shortages in the short term, over the long run the demographic imbalance between consumer demand and worker supply is likely to result in substantial shortages, which may have a major impact on the cost and availability of services.

Quality of Care

- Poor quality of care in long-term care is a longstanding problem, one that receives regular, if episodic, attention by the media and high-level public officials.
- While a detailed regulatory system is in place for nursing homes, a widely agreed upon and implemented quality assurance framework for home and community-based services is lacking.

Agreements and Disagreements on Policy Directions

Long-term care stakeholders agree on some policy directions and disagree about others. In terms of financing, policymakers face a fundamental choice on whether they wish to devote the resources necessary to substantially change the existing system. Significant changes from the status quo—be it a large expansion of private long-term care insurance, modifying Medicaid, expanding Older Americans Act programs, or enacting a new public insurance program or expanding Medicare—will require substantial additional government spending either as direct government expenditures or as tax losses through deductions or credits for private long-term care insurance or other private financing mechanisms. As with the stimulus package and health care for the uninsured, sharp disagreements exist among policymakers over whether expansion of public or private programs is desirable or possible.

In contrast to the disagreements about long-term care financing, there is broad policy consensus to expand and reform home and community-based services. Most, but not all, stakeholders would strongly prefer that this expansion be accompanied by a decline in the use of nursing homes. The Medicaid funds to attain this goal are lacking in most states, but the direction is clear. Moreover, a number of initiatives are underway to expand participant-directed care, the use of residential care facilities, nursing facility transition programs and money-follows-the-person initiatives, and single points of entry to the long-term care system. This policy direction enjoys remarkable consensus across the political spectrum—liberals view these initiatives as a way of empowering a disadvantaged underclass and conservatives view these initiatives as a way of promoting market solutions.

The importance of the long-term care workforce has only recently been broadly recognized. In the past, attention to workforce issues has waxed and waned with the overall economy, which has affected the ease with which providers could recruit workers. While there is broad agreement that increased training, higher wages and more fringe benefits, and organizational change would be desirable, providers and federal and state officials resist incurring the additional costs required by these initiatives. Some observers also question whether the benefits will be worth the costs.

Closely related to workforce issue are concerns about quality of care. While there is broad support for organizational change, providing more information to consumers, developing care guidelines, and voluntary initiatives to improve quality (such as Advancing Excellence in America’s Nursing Homes), provider groups oppose stronger and increased regulation of nursing homes, arguing that the industry is already too heavily regulated. Moreover, some stakeholders, especially those advocating participant-directed care, worry that more regulation of home and community-based services will introduce the rigidities that plague nursing homes, undermining the independence and autonomy that these services seek to promote. As noted above, while consumer groups advocate increased staffing levels in nursing homes and assisted living facilities and higher wages and fringe benefits, nursing home groups oppose these initiatives, at least as requirements imposed by the government.

Starting the Conversation

The health reform debate of the next few years will not focus on long-term care. However, it would be a missed opportunity if long-term care was not part of the debate. While major reform would be costly, there are many initiatives that are fairly widely agreed upon that could be implemented at relatively low cost, especially in the context of significant health care reform. Presented below is a list of initiatives that in the opinion of the author represent the “low-hanging fruit” of long-term care reform. Under the proper circumstances, much more ambitious initiatives could be adopted. As such, these initiatives set the stage for a future debate about more fundamental reforms. These initiatives, which are summarized on *Exhibit 6*, include the following:

Educating the American People

Although an increasing number of people have experience with long-term care either directly or through relatives, most Americans know little about long-term care. For example, despite the fact that Medicare covers only short-term skilled nursing facility and home health care, most Americans continue to believe that Medicare covers long-term care (GfK NOP Roper Public Affairs & Media, 2006). Building on the existing *Own Your Future Campaign*, the federal government could mount a major campaign to educate Americans on the long-term care financing and delivery system, with a major focus

Exhibit 6: The Beginning Elements of a Reform Agenda

Proposal	Description
Educate the American people on long-term care	<ul style="list-style-type: none"> Public education campaign to increase public understanding of the long-term care financing and delivery system
National Commission on Long-Term Care	<ul style="list-style-type: none"> High-level, bipartisan commission, including appointees by the President, the House and Senate, to recommend a strategy for long-term care reform
Increase federal funding for state long-term care infrastructure initiatives	<ul style="list-style-type: none"> Substantially increase funding for existing or new grants to states to help states establish infrastructure, such as Aging and Disability Resource Centers, Alzheimer’s disease programs, participant-directed home care programs, quality assurance systems for home and community-based services, and nursing facility transition programs
Ease Medicaid spend-down requirements for beneficiaries receiving home and community-based services	<ul style="list-style-type: none"> Allow states to establish higher Medicaid income and asset spend down limits for people receiving home and community-based services
Increase funding for Administration on Aging and other appropriated long-term care programs	<ul style="list-style-type: none"> Increase funding for infrastructure development and for home and community-based services
Increase support for a variety of relatively low-cost initiatives related to quality of care	<ul style="list-style-type: none"> Increase funding for the Administration on Aging Ombudsman program Increase research funding on quality of care of home and community-based services Amend Medicaid to more clearly require states to establish standards for and monitor the quality of Medicaid home and community-based services Establish Medicaid pay-for-performance demonstrations for nursing homes Continue financial support for integrated data systems that cut across provider settings, such as the CARE tool
Establish grant program to states, providers, and consumers to improve direct care workforce	<ul style="list-style-type: none"> Establish grant program to promote training programs, organizational change, worker registries, and other workforce initiatives
Research and development	<ul style="list-style-type: none"> Increase funding for long-term care research and policy analysis. Conduct demonstrations of innovative approaches to long-term care, including ways to coordinate and integrate with acute care.

on eligibility and coverage of government programs and options within the public sector.³ The campaign should also educate the public about the range of long-term care services.

A National Commission on Long-Term Care

A national commission on long-term care, modeled on the Pepper Commission of the late 1980s, could be a useful way to create a consensus on long-term care reform. Mandated by the Medicare Catastrophic Coverage Act of 1987, the Pepper Commission was a bipartisan group composed primarily of members of Congress, charged with addressing health care for the uninsured and long-term care. Despite lopsided majorities on the Commission for major long-term care initiatives, they were not enacted. However, the Commission did educate Congress and the public on the problems of long-term care and its potential solutions, and was a touchstone for the long-term care debate over the next several years. While establishing a commission is likely to have significant support, some observers might object to this proposal because they see it as a way for politicians to avoid dealing with the issue, or as the British say, “kicking the ball into the long grass.”

Federal Funding for State Long-Term Care Infrastructure Initiatives

As noted above, the federal government currently operates a number of small programs that provide grants to the states to improve the long-term care infrastructure. For example, these grants have funded state initiatives to develop single points of entry to the long-term care system, improved quality management systems, develop nursing home transition and participant-direction programs, establish workforce initiatives, and improve services for people with Alzheimer’s disease. However, the size of many of these grants has been only a few hundred thousand dollars, limiting their impact; many projects have had difficulty going statewide or becoming permanently integrated into ongoing programs. In this proposal, funding for existing infrastructure programs would be increased or a new program that would consolidate and increase funding for these grants would be established. These infrastructure grants would address entry to the long-term care system, expansion and reform of home and community-based services, and workforce and quality of care initiatives.

Ease Medicaid Spend-Down Requirements

Medicaid beneficiaries eligible for home and community-based services waivers may have incomes up to 300 percent of the federal Supplemental Security level (over 200 percent of the federal poverty level), but beneficiaries receiving other home and community-based services (such as personal care under the regular Medicaid state plan) must meet normal Medicaid eligibility rules. Many states use the “medically needy” option to provide Medicaid eligibility to people who incur substantial medical expenses. However, people who “spend down” to the medically needy income level must incur expenses, which, when subtracted from their income, leave them little income on which to live. Under federal law, the maximum level of protected income is only 133 percent of each state’s old Aid to Families with

³ The Own Your Future Campaign is a project, started in January 2005, to increase consumer awareness about, and planning ahead for, long-term care. The project’s core activities are state-based direct mail campaigns supported by each participating state’s Governor, and targeted to households with members between the ages of 45 and 70. Campaign materials include a Long-Term Care Planning Kit and state-specific information and resources. The Own Your Future Campaign is a collaboration of CMS, the Office of the Assistant Secretary for Planning & Evaluation, and the U.S. Administration on Aging, and has support from the National Governors Association.

Dependent Children level (the Aid to Families with Dependent Children program was replaced a decade ago by the Temporary Assistance to Needy Families program). These income levels are extremely low, well below the federal poverty level and the Supplemental Security Income payment level. In this proposal, states would have the option to set higher levels of protected income and assets for persons receiving Medicaid home and community-based services outside of waivers.

Funding for Administration on Aging and Other Appropriated Programs

Federal funding for Administration on Aging and other appropriated programs providing home and community-based services could be increased without committing the federal government to large and possibly unknown increases in Medicaid and Medicare. For example, the entire budget for the Administration on Aging was only \$1.4 billion in FY2008 (U.S. Administration on Aging, 2008a), so significant percentage increases could be obtained at relatively low cost. Funding could be increased for Administration on Aging service programs, such as the supportive services program, the National Family Caregiver Support Program, and the Ombudsman program and for the administrative costs of State Units on Aging and the Area Agencies on Aging.

Workforce Grant Program

Options to improve the direct care workforce that involve increasing wages and fringe benefits will require significant investment of funds, which may or may not be available. Health insurance coverage for these workers is likely to be addressed as part of other health care reform initiatives. Progress on a number of other initiatives could be promoted by establishing a grant program to states, providers, and consumers to implement training programs, promote organizational change, develop worker registries, and a variety of other workforce initiatives.

Quality of Care Initiatives

While many proposals to improve quality of care, such as raising staffing levels in nursing homes, carry high price tags, other initiatives are less expensive. These initiatives include (1) increasing funding for the Administration on Aging Ombudsman program; (2) funding research on quality of care of home and community-based services; (3) amending Medicaid to more clearly require states to establish standards for and monitor the quality of Medicaid home and community-based services (Institute of Medicine, 2008); (4) establishing Medicaid pay-for-performance demonstrations for nursing homes; and (5) increasing support for integrated data systems that cut across provider settings, such as the CARE tool.

Research and Development

Despite the aging of the population, federal funding for research and development in long-term care has been very modest at best. Moreover, in recent years, several private foundations have reduced or narrowed their funding of long-term care research and policy analysis. Ironically, as the need for long-term care has increased, research funding has declined. Broad health services research funding earmarked for long-term care could be increased in the Office of the Secretary, CMS, the National Institute on Aging, the Administration on Aging, and the Agency for Healthcare Research & Quality. Beyond health services research, increased biomedical research on Alzheimer's disease would target one of the main causes of disability and use of long-term care services and increase the likelihood that interventions that prevent or treat this disease would be discovered, thus potentially reducing the need for long-term care services.

Closely allied to increasing the research base would be sponsoring new demonstrations of innovative long-term care programs, including those that better coordinate acute and long-term care services, including those that integrate these two systems. In addition, recognizing the high health care costs of people with long-term care needs, including long-term care and older and younger persons with disabilities in future Medicare chronic disease demonstrations is critical to meeting the needs of this population and finding ways to reduce costs. These demonstrations should include rigorous evaluation of their impacts.

Conclusion

Despite the fact that long-term care is the third main pillar of retirement security along with health care and income support, it has not received the policy attention it deserves. There is no doubt that when the baby boom generation is age 80 or 85, long-term care will be at the center of public policy debates, but those days are still quite far away (although not as far as they used to be). However, we are now at a time when the parents of the baby boom generation are now elderly; some of these parents are quite old and in need of long-term care. It may be the combination of the baby boomers and their parents that put long-term care on the national political agenda sooner rather than later. The health reform debate that is about to begin is a vehicle to begin to achieve the needed reforms.

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