What Happened to Long-Term Care in the Health Reform Debate of 1993–1994? Lessons for the Future

JOSHUA M. WIENER, CARROLL L. ESTES,
SUSAN M. GOLDENSON, and
SHERYL C. GOLDBERG

*Urban Institute; University of California, San Francisco;
William M. Mercer, Inc.*

During 1993 and 1994, the United States debated but did not enact major health care reform. Although the main focus of reform proposals was on providing health coverage for the uninsured and controlling acute-care costs, many proposals included substantial long-term care initiatives. While a lot has been written on what happened to health reform involving acute care during this period, the long-term care component of the debate has been almost entirely ignored (Johnson and Broder 1996; Skocpol 1997; Aaron 1996). The aims of this study are to fill that gap by providing an intellectual and political history of long-term care within the context of the health reform debate in 1993–1994 and to derive implications for future reform efforts. The analysis focuses on the development and fate of the long-term care component of the Clinton health plan, and within it, on the new home-care program. Even more than the acute-care proposal, the Clinton plan dominated the long-term care debate. In addition, in designing the long-term care component, the Clinton administration struggled with many of the basic policy choices that must be decided in all reform efforts, including whether

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initiatives should be limited to older people or apply to people of all ages, how to balance institutional with noninsitutional care, whether to rely on government programs or the private sector, and how to control costs.

President Clinton's Health Security Act proposed creation of a large state-run home-care program for the severely disabled of all ages and all income groups, slight liberalization of the financial eligibility rules for the Medicaid nursing home benefit, favorable tax clarification and tougher regulation of private long-term care insurance, and tax credits for the long-term care expenses of the nonelderly disabled workers. By stressing non-means-tested public programs, the President's plan was a major departure from the current Medicaid-dominated financing system for long-term care. The appendix describes the Clinton long-term care plan in detail.

Information for this paper was collected primarily from interviews with 38 federal executive-branch officials, health reform task force staff and members, representatives of nursing home, home care, elderly and disability organizations, state officials, legislators, congressional staff, and researchers. A list of people interviewed is available on request from the authors. To encourage candor in their answers, respondents were assured that they would not be quoted by name or otherwise identified. The exceptions to this were congressional testimony and other public information sources. Supplementary information was obtained from newspaper and other media accounts of health reform and public government documents. In addition, one of the authors, Joshua M. Wiener, was a member of the long-term care workgroup of the White House's Task Force on National Health Reform, and provided his recollections of the process.

This article is divided into five sections. The first section describes how long-term care got on the health reform agenda in 1993–1994. The second section analyzes the policy choices that the administration faced in designing the long-term care component of its health plan. The third section relates the position of major stakeholders—including states, elderly and disability advocacy groups, and providers—on the plan as it developed. The fourth section traces the fate of long-term care as Congress debated major health reform. The last section draws implications of the 1993–1994 initiatives for the future.

Getting Long-Term Care on the Health Reform Agenda

That long-term care was part of the health reform agenda in 1993–1994 was not a foregone conclusion, nor was it an accident. Long-term care was on the policy agenda as a result of the deliberate effort of consumer advocates, the Clinton administration's political calculation of what it took to enact acute-care reform, and the extremely comprehensive nature of the Clinton reform initiative.

Setting the Stage: 1987 to 1992

In the five years prior to 1993, there had been a concerted effort by reform advocates to raise the salience of long-term care as a national political issue. The Long-Term Care Campaign, a coalition of more than 100 health and social service groups cofounded by the Villers Foundation (later renamed Families USA) and the American Association of Retired Persons (AARP), was formed in 1987 with the avowed goal of promoting a social insurance solution to long-term care. During the 1988 presidential campaign, the Long-Term Care Campaign videotaped answers to questions about long-term care from each of the presidential candidates, which were then distributed.

Between 1988 and 1992, several prominent members of Congress introduced bills that would have greatly expanded public funding of long-term care on a social insurance basis (Wiener, Illston, and Hanley 1994). Representative Claude Pepper (D-Fla.) tried and failed to add a major new home-care benefit to the Medicare Catastrophic Coverage Act of 1988. And in 1990, the U.S. Bipartisan Commission on Comprehensive Health Care (the Pepper Commission) recommended a major new public long-term care program (U.S. Bipartisan Commission on Comprehensive Health Care 1990).

As the 1992 presidential election approached, the Long-Term Care Campaign made a major effort to make long-term care part of the candidates' platforms. The cornerstone of their activities was their "New Hampshire Asks" initiative, in which activists "bird-dogged" candidates at events, asking questions related to the affordability of acute and long-term care.

As the campaign progressed, candidate Bill Clinton made comprehensive health reform a major component of his platform. In his campaign manifesto, *Putting People First*, Clinton promised to "expand Medicare . . . to include long-term care; place special emphasis on home and community-based care; and make funding flexible so that those who need care can decide what serves them best" (Clinton and Gore 1992, p. 110). Clinton also promised younger people with disabilities that he would establish a personal assistance program.

Once elected, President Clinton established a health group as one element of his transition planning. As part of the health effort, a long-term care workgroup developed a list of incremental initiatives, reflecting what it believed to be politically possible.

Including Long-Term Care on the Task Force Agenda

By January 1993, the newly installed Clinton administration was planning a major effort to develop its health reform proposal, raising the question of whether long-term care should be included. There were plenty of reasons not to include long-term care. First, as one task force staff person put it, "long-term care was not intellectually central to health reform, defined as providing health care to the uninsured and controlling acute-care costs." Moreover, while some staffers within the White House believed that "expansion of home-care services would provide savings for acute as well as long-term care," long-term care did not fit within the managed competition framework of private insurance that had been endorsed by the president. Unlike acute care, few people had private insurance covering long-term care, and the prefunding aspect of the product made the switching of enrollment based on quality and price, which was central to the managed competition model, difficult.

Second, in January 1993 as well as later, there was concern that the administration might be overreaching in its desire to completely revamp the country's health care system. Clinton's economic team—including the Council of Economic Advisors, the Office of Management and Budget, and the Department of the Treasury—was concerned that the costs associated with universal health insurance, prescription drugs, and long-term care would be too high and could explode in the future.

From the beginning, Ira Magaziner, who directed the health reform effort, believed that long-term care should be included and argued that "a comprehensive health reform package without some provisions for addressing long-term care problems may be flawed economically, socially and politically" (Magaziner 1993, p. 11). There were also plenty of other substantive reasons to make changes in the existing system, including the delivery and financing system's bias toward institutional care, the heavy reliance on welfare funding (Medicaid), and the routine impoverishment of people to pay for long-term care.

Moreover, many actors in the process believed that "the 1992 election was a contest between incremental and comprehensive reform, and comprehensive reform had won." The administration's commitment to truly "comprehensive" health reform meant that virtually every issue in health care was on the table. There was also a strong sense of 1993 being a "historic moment" for health reform. According to one participant, "The Clinton health plan was the train that was going to leave the station and would set the agenda for health care for the next 30 years. You had to be on that train or you would be left in the dust." Some members of the administration believed that managed care would drastically reduce the rate of increase in health care costs, and "that would provide a one-time opportunity to reinvest the savings in health care for the uninsured and other initiatives without a tax increase."

Including long-term care seemed to make sense politically as well. Public opinion polls found much greater enthusiasm for health reform if it guaranteed a broad set of benefits, including long-term care (Gallup Organization 1993; ICR Survey Research Group 1993a; 1993b). Some officials believed that an extremely comprehensive proposal gave the administration "bargaining chips" that could be traded away later on in the process.

Probably most important, however, in ensuring that long-term care (and prescription drugs for Medicare beneficiaries) were included in the health reform proposal was the political calculation that doing so was the price of obtaining political support for health reform from elderly advocacy groups, who might otherwise sit out the debate. Virtually all older people had Medicare and would not directly benefit from initiatives to provide health insurance to younger people. In addition, the political debacle of the passage and then abrupt repeal of the Medicare Catastrophic Coverage Act of 1988 had left some elderly advocacy groups, especially AARP, very cautious. As one high-level government official put it, "Long-term care and prescription drugs for the elderly were there to energize the elderly for health reform." More crudely, some respondents said that long-term care was there to “buy votes” for the acute-care proposal. In particular, the Administration was eager to obtain the backing of AARP because of its potential ability to mobilize millions of older people in support of health reform.

Designing the Long-Term Care Component of the Clinton Plan

Designing the long-term care component of the Clinton health plan took place within, but largely separate from, the general process of the task force that designed the acute-care reforms. The Administration began with less of a policy prescription in long-term care than it did in acute care. Thus, it faced fundamental policy choices that it did not have to make on the acute-care side. Once the basic structure was decided, however, there were still many design decisions to be made.

General Process

The basic process of designing the Clinton health plan was assigned to the National Task Force on Health Care Reform and its numerous workgroups, which were charged with generating options, fleshing out the details of the alternatives, developing pros and cons of proposals, and working out the operational details of the chosen options. Approximately 500 people took part in the health reform workgroups at various times between February and May 1993, which was also the life span of the long-term care workgroup. After that time, a much smaller group took charge, completing the design, helping to draft legislation, and estimating the cost of the plan. For most components of the Clinton health plan (but not long-term care), this post-task-force process ended up significantly changing the design of the plan.

The workgroup on long-term care was led by Robyn Stone, a researcher at Project Hope who had worked for the Pepper Commission. Although not yet through the clearance process, Stone was to become the Deputy Assistant Secretary for Planning and Evaluation for Disability, Aging, and Long-Term Care at the Department of Health and Human Services, and she carried the long-term care policy development responsibility from that position once the task force went home. Membership in the long-term care workgroup included as many as 35 to 40 people, but the core work was done by about 10 to 15 people, depending on the issue. The key participants inside the government were Mary Harahan, Pamela Doty, Ruth Katz, and John Drabeck from the Office of the Assistant Secretary for Planning and Evaluation (Department of Health and Human Services); Peter Kemper from the Agency for Health Care Policy and Research; Deborah Lucas from the Council of Economic Advisors; Steven Clauser from the Health Care Financing Administration; and Susan Daniels from the Administration on Developmental Disabilities. Participants from outside the government included Simi Litvak of the World Institute on Disability, a public policy analyst specializing in younger people with disabilities, and Joshua Wiener of the Brookings Institution, a researcher who had written extensively on long-term care financing. Staff from the offices of Senators John D. "Jay" Rockefeller (D-W.Va.), Harris Wofford (D-Pa.), and Edward Kennedy (D-Mass.) were active in the process. Other participants represented the Veterans Administration, the Office of Management and Budget, and the Administration on Aging. No providers were on the task force and no state officials contributed actively to the workgroup. In addition, David Kennell and Lisa Alecxih, of Lewin-ICF, Inc., and Brian Burwell, of MEDSTAT, played critical technical assistance roles. Thus, although consultations with state officials were common, workgroup participants were exclusively researchers and policy analysts rather than program administrators or providers.

A great deal has been written on the general process of the plan's development, especially about secrecy of its deliberations, the cumbersomeness of working with 500 people, and the "tollgate process" by which options were developed (Johnson and Broder 1996; Skocpol 1997; and Aaron 1996). Several points are important in illustrating how the general structure of the overall plan development process affected long-term care.

First, the use of nonpermanent, temporary governmental staff allowed the full-time participation of some experts from outside government—notably Litvak and Wiener—who would not have been able or willing to join a more open-ended process that would have required leaving their jobs. According to one high-ranking official, "The administration believed that it needed original thinkers and experts from around the country to be involved in the process."

Second, the long-term care workgroup, largely independent from the acute-care workgroups, received little guidance from administration officials concerning policy or budget constraints until late in the process. There was not even a “bumper-sticker slogan” that could guide the deliberations. As a result, the workgroup considered an extraordinarily broad set of options. Table 1 outlines the main “packages” of options that were considered.

Members of the long-term care workgroup met with the President in April 1993 to discuss four options for possible inclusion in the Health Security Act: making incremental changes to public programs, providing incentives to promote private long-term care insurance, developing a new social insurance program for long-term care, and establishing a mandatory private long-term care insurance system that would apply principles of managed competition. At the meeting, the president expressed interest in home- and community-based services, suggesting that they would save money. The only specific decision he made was to reject the mandatory private insurance option as not solving the problem for the current elderly population and as imposing a double burden on the nonelderly population, who would have to finance care for the current population as well as prefunding their own long-term care needs. After the formal meeting, the president remarked to one workgroup member that he did not “have a good sense of what the customer wanted in long-term care.”

Third, probably the most controversial aspect of the overall task force process was its secrecy and the perceived closed nature of the policy development process. The long-term care workgroup believed its process was more open. According to one task force member, “We met with tons of disability groups and every aging group. We also had conference calls with lots of states. These outside groups were really influential in designing the program. It wasn’t just show and tell.” Nonetheless, interest groups complained bitterly about the time wasted in just trying to find out who was on the workgroup.

Fourth, given the overall cost of health reform and the marginality of long-term care to acute-care reform, there was continual uncertainty about whether long-term care would remain in the president’s proposal and at what level of funding. In March 1993, members of the president’s economic team raised strong objections to the costs of the prescription drug benefit for seniors and the new long-term care program. Within the administration, the first lady and Magaziner insisted that long-term care should be in the plan and the president ultimately sided with them.

Fifth, once the basic structure of the main long-term care proposal—a large, non-means-tested home-care program—was more or less set, the workgroup had enormous freedom to design the program. Despite the large sums of money involved, "there was shockingly little direct intervention from the White House in terms of what we were doing. . . . We had free rein to play out our biases and expertise," recalled one task force participant.

Sixth, the goal of obtaining political support for health reform from senior citizens was undercut by the Clinton proposal's planned Medicare cuts. The administration proposed five-year Medicare cuts of $125 billion against the current services baseline, almost entirely through provider reimbursement rate cuts (although a copayment for Medicare home health benefits was proposed). The amount of the cuts was less than the cost of the combination of the prescription drugs and long-term care, but most senior groups were very nervous about them. In response, the Committee to Preserve Medicare and Social Security prepared a massive mailing to oppose the Clinton health plan as a whole. According to one high-level official, "We managed to stop the mailing, but support from seniors plummeted. We had counted on AARP and the unions to finance advertisements in favor of reform. With this Medicare problem, AARP got cold feet."

Basic Policy Choices in Long-Term Care

As the long-term care workgroup began to consider options for long-term care reform, it identified five major issues that had to be addressed, including whether the initiative should include people of all ages, whether it should be integrated with acute care, whether it should cover institutional or noninstitutional services, whether it should rely on public or private initiatives, and whether it should be means-tested.

Elderly People Only or Disabled People of All Ages? Although the Pepper Commission's recommendations had included younger people with disabilities, most previous policy debates about long-term care reform had focused almost entirely on older people. One of the first decisions was that the initiative would cover people of all ages and that there should be a single program for the target population. As is discussed later, this decision to include younger people with disabilities had a far-reaching impact on the design of the proposal.

TABLE 1
"Packages" of Options Developed by Long-Term Care Workgroup

	#1 Incremental	#2 New means-tested program and voluntary insurance	#3 Social insurance for home care	#4 Social insurance for nursing home and home care
Home care	Slight modification of Medicaid; home- and community-based waiver; other incremental reforms	New means-tested program for people of all ages below 100% of FPL with severe disabilities (state option to 300% FPL); state-administered, high federal match rate; new federal/state program for MR/DD, including funds for ICF/MRs	New large, non-means-tested program for people of all ages with severe disabilities; high federal match rate; state-designed and administered	(Same as package #3)
Institutional care	Increase level of protected assets under Medicaid to $12,000; raise personal-needs allowance to $100 per month; mandatory medically needy program	(Same as package #1)	(Same as package #1)	Provides unlimited nursing home care on non-means-tested basis; level of protected assets raised to $30,000 for persons unable to pay coninsurance; personal needs allowance raised to $100 per month

Long-term care insurance	Favorable tax clarification and increased regulation; public/private partnerships	New, limited, unsubsidized public insurance program package; same as package #1 for private long-term care insurance	(Same as package #1)	No provisions
Working disabled	No provision	Tax credit for expenses of personal assistance services	(Same as package #2)	No provisions
Net federal and state costs in 2020 (in 1994$)	$20.7 billion	$24.5 billion	$50 billion	$112 billion

FPL = federal poverty level; MR/DD = mentally retarded/developmentally disabled; ICF/MRs = intermediate care facilities for the mentally retarded.

The arguments for keeping the proposals limited to the elderly were that costs would be lower, that less data were available to make credible cost estimates for younger people with disabilities, and that a single program would raise a number of difficult issues in terms of defining eligibility and determining the scope of services. On moral and ethical grounds, however, it was difficult to rationalize covering older people but not younger people with the same disabilities. Moreover, the administration wanted younger people with disabilities to be represented in the policy discussions. Health reform was also the vehicle to redeem Clinton's campaign promise to establish a personal assistance services program, which would have provided help with activities such as eating, bathing, and dressing.

Integration with Acute Care or a Separate Program? From the beginning of the process, long-term care was perceived as independent from acute care, although the workgroup knew that there were both substantive and political arguments in favor of integrating services and financing for the two. The substantive problem was that people with disabilities received care in a fragmented financing and delivery system that was less than optimal (Wiener 1996). From the political perspective, integration with acute-care would help insure long-term care's survival in the process. As one task force member put it, "If long-term care was part of the overall benefit package, then it would be guaranteed because it would be an entitlement."

Overwhelming these concerns was the fear that turning long-term care over to the acute-care-dominated insurers and managed care organizations might be disastrous for long-term care. Managed care organizations knew hardly anything about long-term care. There was real anxiety, as one workgroup member put it, "that long-term care might become overmedicalized if it were included with acute care and that acute care might gobble up the money for long-term care, once again leaving our services underfunded."

At the end, the workgroup proposed only demonstration projects on the integration of acute and long-term care. Thus, there was to be little integration of the two.

Institutional or Noninstitutional Services? Assuming that funds were limited, a choice had to be made between improving institutional care and expanding home- and community-based services. The final proposal concentrated almost all new spending on home- and community-based services, with only minor expansions of Medicaid nursing home financial eligibility standards.

There was a very strong sentiment within the long-term care workgroup for investing in home- and community-based services rather than institutional care. Administration officials, including the president, believed that the United States had a very imbalanced delivery system, with too small a portion of the dollars being spent on home care. In 1993, only about 30 percent of total long-term care expenditures were for noninstitutional services (U.S. Department of Health and Human Services 1994a). Moreover, the president and a few high-level members of the administration believed that expanded home care would reduce both acute-care and nursing home costs, although members of the workgroup pointed out that the research literature did not support this position (Wiener and Hanley 1992; Kane and Kane 1987; Kemper, Applebaum, and Harrigan 1987; Weissert, Cready, and Pawelak 1988). Ending means-testing for nursing-home care also would be about twice as expensive as a home-care-only plan (Wiener, Illston, and Hanley 1994). In addition, workgroup members who represented younger people with disabilities strongly opposed spending any new money on institutional care and argued that current funding should be redirected to home care.

The case for allocating new resources to nursing homes rested on the fact that they, rather than home care, were a primary cause of catastrophic out-of-pocket health care expenses for the disabled elderly (Wiener, Sullivan, and Alecxih 1995). Politically, providing some additional coverage for nursing-home care was very important to elderly advocacy groups. To try to accommodate these concerns, the workgroup examined social insurance options that included nursing-home care and a voluntary public insurance program that would have been fully funded by premiums. Ira Magaziner temporarily promised this voluntary program to aging groups, but ultimately it was not included in the president's proposal partly because of the potential for adverse selection.

Public Programs or Private Insurance? Although the debate over long-term care financing reform had many facets, it was primarily an argument over the merits of public programs as opposed to private insurance. While Clinton's acute-care reforms depended wholly on private insurance, the Administration chose a different path for long-term care. Although the plan included tax clarification and stronger regulation of private long-term care insurance, the heart of the proposal was a new public program.

A much-watered-down version of these private insurance initiatives ultimately became part of the Health Insurance Portability and Accountability Act of 1996.

Most advocates of private long-term care insurance argued that the primary responsibility for care of people with disabilities belonged with individuals rather than the government. Although none of the workgroup's members thought that private insurance could be a complete solution, some believed that it could play a much larger role and that a substantial minority might be able to afford insurance (Cohen, Tell, Greenberg, et al. 1987; Cohen, Wallack, and Kumar 1992). In addition, one member of the workgroup proposed a novel approach: applying the acute-care model of managed competition to long-term care, achieving universal coverage through a system of mandatory private long-term care insurance (Lucas 1996).

Most participants in the process believed that private long-term care insurance was not a realistic option for more than a small portion of the population. Only about 4 to 5 percent of the elderly and a negligible percentage of nonelderly people had any kind of private long-term care insurance, largely because such insurance was very expensive (Rivlin and Wiener 1988; Friedland 1990; Zedlewski and McBride 1992; Crown, Capitman, and Leutz 1992; Wiener, Illston and Hanley 1994; Estes and Bodenheimer 1994). As one high-level official put it, "There was no great confidence in private long-term care insurance. It required a lot of subsidies, and the long-term care insurance market was especially flawed at that time. A private system was unrealistic."

Means-tested or Universal Coverage Programs? A major ideological divide within the workgroup existed over whether publicly funded long-term care should be provided on a means-tested or universal basis. The plan eventually provided for non-means-tested home-care benefits, but institutional care remained means-tested, as did home- and community-based services for people with less severe disabilities. Although non-means-tested, the proposed home- and community-based services program had a fairly steep income-related cost-sharing schedule.

Indeed, the administration was schizophrenic on the issue of means-testing in long-term care. The Omnibus Budget Reconciliation Act of 1993—which strengthened prohibitions against individuals transferring their assets to qualify for Medicaid nursing-home care and mandated that states recover the Medicaid costs of long-term care from the estates of deceased beneficiaries—tightened Medicaid means-testing. There was little coordination between deficit reduction and health reform.

Some members of the workgroup believed that the government only should be a payer of last resort for those unable to provide for themselves. According to one participant, "These workgroup members felt that it was unfair to tax lower- and moderate-income people to pay for benefits for upper-income elderly and did not believe that the income distribution issue could be solved through the way premiums or taxes were paid." They also contended that it was unfair to create yet another program (in addition to Social Security and Medicare) that would benefit mostly the elderly and be financed mostly by younger people.

The opposite view, which became embodied in the administration's plan, was that the government should take the lead in ensuring care for all disabled people, regardless of financial need, by providing non-means-tested services. Non-means-tested strategies were the only approach that guaranteed that everyone would have coverage for long-term care services. Welfare strategies assume that only a relatively small proportion of the population will need public asistance, but that is not the case in long-term care. Universal coverage would end the distinction that makes heart attacks (covered by Medicare) on a non-means-tested basis, while help for Alzheimer's disease (covered by Medicaid) is only available after impoverishment.

To proponents of universal coverage, the generational and income equity arguments about long-term care were greatly overstated. About a third of people eligible for services under the plan would have been under the age of 65 (U.S. Department of Health and Human Services 1994a). In addition, nonelderly informal caregivers would benefit from a program that helped disabled older people. Moreover, the bulk of incremental expenditures would have been for people with modest incomes. Fully 70 percent of people with severe disabilities had incomes below 200 percent of the federal poverty line (U.S. Department of Health and Human Services 1994a).

Design Issues for a Non-means-tested Home- and Community-based Services Program

Once it became clear that the administration was going to propose a non-means-tested home- and community-based services program for long-term care, numerous program design issues had to be decided, including who was going to run the program, what standards would govern eligibility, which services would be covered, how costs could be controlled, and how it would be financed.

Role of the States. While funding would overwhelmingly be federal, there was early consensus in the long-term care workgroup that the new services program should be largely designed and administered by the states. The option of designing and running the program at the federal level, perhaps as part of Medicare, was never seriously considered. As a traditional acute-care insurance program, Medicare was thought to be overly rigid and bureaucratic and too medically oriented to operate a flexible home- and community-based services program.

This emphasis on state involvement was a major departure from earlier social insurance proposals for long-term care, which used states for administration but retained policymaking at the federal level. To the workgroup, states seemed the logical level of government to take the lead because they, not the federal government, had the operational expertise for managing long-term care. States regulate the supply and quality of care, set reimbursement rates, write contracts with providers, process claims, and coordinate the care of clients. Moreover, as one workgroup member put it, “My bias is that long-term care is so idiosyncratic that the decision making has to be as close to the individual as possible.”

While program design was firmly placed at the state level, financing was to be overwhelmingly but not totally federal. Federal funds would be allocated according to need and then drawn down on a matching basis, with the federal match rate set at 28 percentage points above the existing Medicaid levels, up to a high of 95 percent. This matching structure was established because the workgroup believed that the states would not be prudent financial managers unless they were at some financial risk.

The introduction of a matching structure, however, raised several problems. Since federal funds had to be matched, there was the possibility that some states might choose not to use all of the federal funds available. However, the federal contribution rates were so high that the workgroup believed advocacy groups would force states to spend their full allotment. An additional problem was that the flexible benefit and the lack of reliable information on how much states were already spending on home- and community-based services for the eligible population meant that states would have had little trouble refinancing existing services if they wanted to, using the new funds to reduce state spending rather than to expand services.

Functional Eligibility Criteria. All programs need criteria for establishing who is eligible for services and who is not. There was a consensus in the workgroup that eligibility for the program should be limited to individuals with fairly severe disabilities. But what measures should be used? For the older population, the standard for measuring disability was difficulty with the activities of daily living (ADLs)—e.g., eating, bathing, dressing, transferring, and toileting—but this measure did not capture all types of disability. In particular, ADLs by themselves excluded some people with relatively severe cognitive impairment (such as Alzheimer's disease) who needed substantial supervision but not necessarily a lot of hands-on care. But measuring cognitive impairment was and is much less standardized than ADLs and was potentially subject to manipulation by applicants. Nonetheless, it was critical to cover people with Alzheimer's disease because this population had substantial long-term care needs, and the Alzheimer's Association was well organized. Ultimately, it was decided that to be eligible for the program, individuals had to require hands-on or stand-by personal assistance, supervision, or cues in three of five ADLs; present evidence of severe cognitive or mental impairment; have severe or profound mental retardation; or be a child under the age of six who otherwise requires hospital or institutional care (U.S. Department of Health and Human Services 1994b).

These criteria raised three troublesome issues. First, while all state home-care programs used similar kinds of measures, the research literature showed wide variations in estimates of the number of people with disabilities, based on which survey was used and the way in which the questions were asked (Wiener, Hanley, Clark, et al. 1990). According to one participant, "There was a snow job on ADLs in the sense of overstating how precise they could be in differentiating those people who would be eligible and those who would not. It was very important to sound and behave as if we really could objectively and definitively estimate the number of people eligible and their costs."

Second, the inclusion of cognitive impairment as an eligibility criterion opened the door to potentially expensive coverage of a large number of people with severe mental illness. "We tried to include chronic mental illness where appropriate," said one workgroup member, "but not end up being the mental health program."

Third, in an effort to develop a level of impairment that was comparable to that proposed for the older population, the qualifying level for people with developmental disabilities was set at having "severe or profound" mental retardation. The problem was that states already were running programs that had much less strict functional eligibility requirements for this population. "The mental retardation/developmental disability advocates were worried about being screwed by inclusion in a larger program because their programs have been so generous in so many states," recalled one workgroup member.

Entitlement and Flexible Services. A crucial issue was how to balance the desire for a flexible set of services with the desire to have an "entitlement" to benefits. Many members of the workgroup began the program design process with the traditional insurance concept of an entitlement to a defined set of benefits, which was how Medicare, Social Security, and Medicaid operated. An "entitlement" establishes a legal obligation on the part of government to provide a defined benefit to individuals who meet established criteria regardless of the budget impact. Under an entitlement, public resources automatically flow to individuals in need and are distributed equitably because governments are required to treat people in the same circumstances in the same way. None of this is true with block grants or appropriated programs, where funding may fail to adjust to changes in the size of the needy population or to the cost and use of services, causing some needy people to be denied assistance (Burtless, Weaver, and Wiener 1997; Estes and Linkins 1997).

Beyond this philosophical debate, data from the major demonstration of expanded home-and community-based services for the severely disabled elderly (the so-called channeling demonstration) had found that 80 percent of expenditures were for a narrow set of services: home health aid, homemaker/personal care, and skilled nursing (Corson, Grannemann, and Holden 1988). Thus, it initially seemed simple to establish an entitlement to personal care and perhaps a few other services.

For workgroup members focusing on younger people with disabilities, the range of services to be provided and the tailoring of benefits to individual needs and preferences was anything but straightforward. They argued that younger people with disabilities needed an exceptionally broad range of services; to them, almost nothing could be excluded.[1] As one workgroup member saw it, "For the elderly, the goal of long-term care has largely been to keep people safe, clean, and reasonably well fed. Younger people with disabilities rejected these goals as far too narrow and wanted whatever it took to participate in normal life. For younger people with disabilities, there is less of a distinction between life and long-term care." Advocates for this group also insisted on the power to hire, direct, and fire their own workers, rather than having to go through an agency, and they wanted to experiment with providing cash rather than services.

The basic dilemma was that the broader the set of covered benefits, the more difficult it is to provide them as an individual entitlement. As one participant put it, "How do you make people entitled to everything and still live within some kind of budget?" The workgroup struggled with whether the concept of a "capped entitlement program" (a concept which was also being applied to acute care) made sense or whether it was oxymoronic.

Unable to resolve the dilemma, the workgroup abandoned the effort to define benefits and the individual entitlement to services, giving states extremely broad flexibility in establishing what services would be provided. In return, individuals were entitled only to an assessment, a plan of care, and services on a funds-available basis. States would have to offer personal care, but the plan did not say how much. Moreover, in a further acknowledgement of the influence of younger people with disabilities, the plan required states to offer a consumer-directed option, where clients could hire, direct, and fire workers, and the states could offer cash grants rather than services, if they so desired.

By not establishing an entitlement or a defined benefit, the workgroup gave up a lot of the classic notions of "social insurance," retaining only the element of a non-means-tested program. One workgroup member joked that the Clinton long-term care plan was not social insurance, but "a friend of social insurance." Although the lack of an entitlement disappointed advocates for older people, so long as the total amount of new money was large and the program was non-means-tested, they were willing to go along.

Expenditure Controls. Previous efforts to enact public insurance programs for long-term care had failed partly because of concerns about how much it would cost. The first concern was over the absolute level of expenditures required, which in all cases was large. The second fear involved the uncertainty inherent in the expenditure estimates, with the worry that no matter how careful the estimates may be, they would prove to be too low. The continual upward revision of cost estimates of the prescription drug benefit in the Medicare Catastrophic Coverage Act of 1988 weighed heavily on the minds of policymakers.

Once it became clear that the Administration was going to propose global budgets for acute-care insurance, it quickly became a foregone conclusion to the workgroup that the long-term care program would be budgeted as well. An explicit expenditure cap on the new public long-term care program, combined with no individual entitlements, would come close to guaranteeing that spending did not exceed a preestablished amount.

In place of an open-ended entitlement, the workgroup developed cost estimates based on a budget consistent with meeting the needs of the eligible population. "The program was capped as a budget controller," noted one workgroup participant, "but the notion was that it would be 'fully funded' so that there would not be any real difference between the capped amount of dollars and an entitlement." Thus, cost estimates included high levels of utilization, generous reimbursement rates, and extensive program participation among the eligible population. To be conservative, the cost estimates assumed no acute-care or nursing-home savings from the expansion of home care. The Health Care Financing Administration actuaries, the Office of Management and Budget, and the Congressional Budget Office accepted the workgroup's estimates of the program expenditures for long-term care with few questions, while heavily scrutinizing the Clinton plan's acute-care cost estimates.

Opponents of a budgeted approach feared that, once capped, expenditures would not rise with inflation, population, experience, or need. Fixed-budget programs lack the automatic engine of spending increases inherent in entitlement programs. Supporters of the fixed budget hoped that the middle class would lobby for funding increases. But states worried that federal funds would not keep up with demand and force them to spend more than their allocation.

Financing. Like other aspects of the Clinton health plan, the long-term care component did not have a specific source of financing. The strategy was to add up all of the federal costs and compare them to the federal savings, principally from Medicare and Medicaid, and new federal revenue from a tobacco tax and other sources, making sure that they were equal. It was politically important to the Administration that the sum of the costs of the new long-term care benefit and the new prescription drug benefit for older people equal or exceed the Medicare savings. As one high-level official put it, "Magaziner was adamant that Medicare savings go to benefits for the Medicare population."

This financing strategy raised some problems. First, concerns were raised as to whether the Medicare and Medicaid savings were too large and whether tobacco revenues were too unstable. Second, the lack of dedicated financing for long-term care (as well as for other benefits) meant that services were potentially vulnerable to future budget cuts because benefits were not linked to a specific financing source. Third, the lack of designated financing sources exposed the entire plan to the charge that it was financed by "smoke and mirrors."

Long-Term Care Stakeholders' Perspectives

While the plan was being developed, and afterward as it went through Congress, the views of long-term care stakeholders—states, elderly and disability consumer advocacy organizations, nursing home and home-care provider associations, and the health insurance trade association—were consequential for the plan. While many groups supported the long-term care component of the Clinton health plan, there was not the energetic support that was anticipated. In addition, disagreements over the acute-care component of health reform drained resources, enthusiasm, and attention away from long-term care.

The States

State governments, especially state units on aging, generally were supportive of the Clinton long-term care plan, but higher-level state executives (e.g., governors and budget directors) had significant reservations, particularly about the potential fiscal impact. The financial risks for the states, combined with the lack of fiscal relief, meant that state budget officials had little reason to champion the plan.

From a design perspective, state units on aging supported the plan's overall approach for service provision. On a means-tested basis, several states had already implemented this kind of flexible program, and state officials on aging believed that the states rather than the federal government should be the focal point for long-term care reform. States considered the Health Care Financing Administration to be hopelessly bureaucratic in a way that was detrimental to long-term care.

States particularly supported the effort to expand home- and community-based services to allow for the coverage of a wide range of services. "Without a lot of rules and requirements," said one state official, "you could put together cost-effective service packages that would work for people. . . . You have to have service flexibility." States were also comfortable with the notion of a single program serving both older and younger people with disabilities, since about one-third of the states already had such programs.

While there was support for the goals of the reform, state officials were uniformly concerned about the fiscal impact on the states. State officials—especially in New York—feared that the long-term care benefit would be perceived as an individual entitlement, even if the bill said it was not. In its congressional testimony, the National Governors' Association expressed concern that "federal participation, though significant, is limited, while the state financial exposure may not be" (Campbell and Dean 1993).

The final fiscal issue for the states concerned the allocation of the new funds among the states. A few states were spending so much money on home- and community-based services that the Clinton plan did not add as much to their level of resources as they thought was necessary for them to meet the need. Anxiety was especially strong in New York (represented by Senator Daniel Patrick Moynihan, chairman of the Senate Finance Committee), which had nearly a third of the nation's Medicaid home-care expenditures in 1993 (Pear 1993; Liska, Bruen, Salganicoff, et al. 1997).

Advocacy Groups

Elderly Advocacy Groups. The main elderly advocacy groups that were involved in the long-term care reform effort were AARP, the Alzheimer's Association, and the Long-Term Care Campaign. Other advocacy groups with a focus on aging that were named as involved in the process were the National Council of Senior Citizens (a union-based organization that was influential in the original passage of Medicare), the National Council on the Aging, United Seniors Health Cooperative, the Older Women's League, and the Leadership Council of Aging Organizations (a coalition of national organizations on aging). Families USA (formerly named the Villers Foundation), which had helped found the Long-Term Care Campaign, made a conscious decision to withdraw from the long-term care issue and concentrate virtually all of its resources on obtaining health care for the uninsured.

If long-term care was added to obtain the enthusiastic support of older people and their advocacy groups, it failed. One health reform advocate, recalling the "terrible disappointment" in the White House about how seniors' organizations received their proposal, described the situation thus: "Whenever we had discussions about the 'E' word [endorsement], they could never do it. When they testified, they said, 'We like this but. . . .' This let the press say the aging organizations had real problems with the plan."

The largest advocacy group for the elderly, AARP, played a central role in the design of the long-term care component of various bills and was consulted frequently by the White House, members of Congress, and the press. However, AARP opted to emphasize educating its members about the provisions of various reform proposals that emerged in 1993 and 1994, in the hopes of building broader public support before endorsing any particular plan. Indeed, AARP never did endorse Clinton's Health Security Act, although it did take out full-page newspaper advertisements in support of bills sponsored by House Speaker Richard Gephardt and Senate Majority Leader George Mitchell, but not until a few days before health reform collapsed.

AARP's leaders were strongly committed to universal health reforms, but the organization's polls and focus groups showed that its members wanted to understand the proposals better before the association made a formal judgment. In addition, the AARP leaders hoped—perhaps naively—that the legislative process would produce a bipartisan proposal, which AARP could then actively support. The organization's stance was a response to the strong criticism from members and others of its support of the earlier Medicare Catastrophic Coverage Act of 1988, which was repealed in 1989 after a storm of protest from the elderly.

Besides the fear of repeating what happened with the Medicare Catastrophic Coverage Act of 1988, other reasons also led elderly advocacy groups to withhold enthusiastic endorsements. The president's plan was less comprehensive (especially in its lack of nursing home coverage) and a lot less like traditional social insurance than the more liberal organizations wanted. Furthermore, it was difficult to explain to older people exactly what benefits they would receive because those would vary by state.

Another obstacle was that concerns about acute-care reform, including Medicare, diverted the attention of elderly advocacy groups away from promoting long-term care and lessened their support for health care reform in general. The Clinton plan's inclusion of substantial cuts in

Medicare and Medicaid, which then were far larger than anything ever enacted (although they proved to be roughly the size of the expenditure reductions in the Balanced Budget Act of 1997), were generally opposed by groups representing older people.

There were other acute-care issues, as well. Even though Medicare was explicitly excluded from the president's new system of managed competition, advocacy groups devoted a lot of time and energy to preserving the Medicare fee-for-service system and ensuring freedom of choice of providers. Moreover, as the acute-care benefits for the non-Medicare population grew richer, a new concern was that the elderly would actually end up with fewer health care benefits than other Americans. Finally, many elderly advocacy groups, including the Older Women's League and the Gray Panthers, were strongly committed to a single-payer system and were disappointed that the President's acute-care approach depended on private insurance.

Disability Groups. Groups representing younger people with disabilities, such as the ARC (formerly the Association for Retarded Citizens) and American Disabled for Attendant Programs Today (ADAPT), were highly energized by health reform. As heavy users of both acute-care and long-term care services, younger people with disabilities had major stakes in what was proposed in both arenas. In addition, large proportions of people with disabilities were uninsured. Following the enactment of the Americans with Disabilities Act in 1990, younger disabled people made health and long-term care reform a major priority and pushed themselves into the political process, largely through the Consortium for Citizens with Disabilities (CCD), a coalition of more than 100 organizations.[2] Having done so, they found the Administration, which hoped that disability groups would be vocal advocates of its health reform plan, receptive to their concerns. Elderly advocacy groups were also receptive to their involvement, partly because they wanted to portray long-term care as a problem that affected all age groups, not just older people. Together with elderly advocacy groups, they crafted a joint agenda for long-term care reform.

Younger people with disabilities achieved a strong consensus on the need to redress the institutional bias in current policy. "Our position," reported one participant, "was that new money needed to be spent on home- and community-based care." For the disability groups, the major issues in designing the home-care program involved ensuring that the initiative served people of all ages, used eligibility criteria that spanned all types of disabilities, and covered a broad array of services so that the diverse needs of the disabled population could be met. By pushing these issues, the disability groups had a profound impact on the design of the Clinton long-term care plan.

Like the aging organizations, the disability groups supported the plan, but there were always many seemingly never-ending concerns, which frustrated the White House team enormously. "There was no way to satisfy the disability community," said one government official. "No matter what you did, it wasn't enough." As was the case for the elderly, the media interpreted their reservations as an absence of support.

Although CCD brought a degree of consensus and discipline to the demands of disability groups, they remained fragmented in many ways. First, the disability groups were distracted from concentrating on long-term care by acute-care issues—such as the coverage of rehabilitation services and durable medical equipment under both private insurance and Medicare, risk adjustment, managed care, and the "unevenness" of their coverage under Medicaid. Second, groups representing people with disabilities needed to work out competing and conflicting issues among and between themselves, in addition to hammering out accommodations with the aging community. This was a formidable task because of the number of different disabilities, each of whose conditions, needs, and organizations were steeped in different terminologies and philosophies. The new proposal threw all of the categorical groups into one program, "disrupting all of the existing service and financing arrangements." Third, there also were power struggles between consumers and providers, principally about which types of services would be covered and who would provide them. According to one disability representative, different professional "guild" members actively lobbied to make sure their services were covered.

Provider and Corporate Groups

Nursing Homes. In general, the nursing home industry opposed the Clinton plan, although there was somewhat of a split between the American Health Care Association (AHCA), which predominately represents for-profit companies (although some nonprofit facilities are members as well), and the American Association of Homes and Services for the Aging (AAHSA), which represents nonprofit facilities. AHCA worked behind the scenes with other groups opposing the proposal, but it did not want to irritate the administration by publicly opposing the plan. On the other hand, AAHSA supported "some good things" in the plan.

From the perspective of the nursing home industry, the long-term care proposal did nothing to improve their position while it generously funded their home-care competitors and emphasized expanding public programs over the private insurance they preferred. The few nursing home changes that were included would have slightly increased the number of people receiving Medicaid nursing home benefits, which would have had a financially negative impact on the industry since Medicaid pays less than private-pay residents. While not explicitly promising to cover nursing home care under a future public plan, the Administration consistently portrayed its proposal as a first step in a larger reform agenda for long-term care.

The industry resented what it saw as a bias against nursing home care in the funding emphasis on home- and community-based services. AHCA opposed the long-term care proposal because it focused on only "one part of the continuum—home- and community-based care—not assisted living and nursing home care" (Willging 1993). Moreover, AHCA feared that "because of the proportionately larger federal match for the new home- and community-based program, states might be tempted to deinstitutionalize Medicaid beneficiaries—even beneficiaries who would not be well or cost-effectively served in a home or community setting" (Willging 1993). On the other hand, AAHSA supported the expansion of home care.

In addition, both AHCA and AAHSA believed that the future of financing reform lay with greater reliance on private long-term care insurance rather than on the expansion of public programs (Willging 1993). As one industry observer put it, "There was a tremendous amount of fear, a huge amount of paranoia, about expanding public programs. From the provider perspective, public payment is so poor. The advantage of private long-term care insurance is that it [gives] more money to providers without requiring additional public resources." Another observer noted that the industry "cannot see how Medicaid can continue to be the prime source of financing for long-term care" because of the financial burden on individuals and governments.

The nursing home industry also had problems with the acute-care component of the Clinton plan, both as providers and as employers.

As providers, AHCA was concerned about the global expenditure caps that limited aggregate health expenditures to a predetermined level. "It was a cost-containment policy that was ultimately going to squeeze the nursing home industry," said one lobbyist, "even if initially the global budget did not cover long-term care."

As employers, for-profit nursing home providers also were apprehensive about the cost of having to provide employee health insurance under the acute-care portion of the Clinton plan. Nonprofit providers were less concerned because the vast majority of facilities already provided health insurance to their employees. For nursing homes, the central question was whether Medicaid would pay for the increased costs of health insurance, something that was not certain.

Home Care Agencies. The National Association for Home Care (NAHC), the main home health trade association, was very supportive of overall health care reform as well as of the long-term care component. However, while it supported expansion of the home-care benefits, NAHC worked very hard to defeat proposals to establish a 20 percent coinsurance for Medicare home health benefits and to reduce reimbursement cost limits (National Association for Home Care 1999). Some groups in the home-care industry, including for-profit trade associations, opposed the Clinton plan, mostly because of the Medicare cuts for home health, requirements to pay for employee health insurance, and concern about the impact of managed care (Pyles 1993).

Even though NAHC supported the administration's long-term care proposal, they disagreed with some elements of the plan. For example, NAHC believed in a uniform national program like Medicare and thought that the emphasis on states was a mistake. According to one industry official, "the program with the least fraud is Medicare, while the Medicaid program is not well watched." A uniform federal program would also eliminate undesirable state variations in services and spending.

Insurance Industry. The insurance industry played a major role in defeating Clinton's overall health reform proposal, but they did not give much attention to long-term care. Instead, they were concerned primarily with much bigger acute health insurance issues, including health alliances, rate caps, price controls, and community rating (Johnson and Broder 1996; Skocpol 1997; Aaron 1996). The industry did support most of the long-term care insurance provisions, particularly proposals to clarify the tax status of long-term care insurance products and to allow the expansion of public/private partnerships for long-term care insurance. Not surprisingly, however, the industry preferred less stringent standards for insurance products.

The Health Insurance Association of America (HIAA), the major trade association, opposed expanding any public program for home care that was not based on financial need, even though the President's plan left institutional care and home care for less severely disabled people available for private insurance coverage. On broad policy grounds, HIAA contended that a better use of limited public dollars was to encourage private insurance.

From a marketing and operational perspective, the new home-care program would complicate private long-term care insurance, partly because of the uncertainty it introduced. Sales might be depressed because people could think that the new program covered all of long-term care, or that it eventually would. "Insurers did not want to be dependent on a program that the Congress could change at any time, and preferred to keep public and private roles separate," said an industry observer.

Health Reform Unravels in Congress: Salvaging Long-Term Care

As Congress sought to devise a health care plan that would receive widespread support, political pressures forced a reduction in the overall cost of health reform, and with it, the size of the long-term care program. Funding for long-term care was cut back, both to reduce the overall size of the bill and to provide funding for health care for the uninsured. Nonetheless, all of the major bills reported out of Senate and House committees and developed by the Democratic leadership contained significant new funds for home- and community-based services, albeit less than that proposed by President Clinton.

Inclusion of Long-Term Care

At the outset of the health reform debate, some Democrats in Congress were concerned that the Administration would be taking on too much by including long-term care. According to Senator Rockefeller, "what we don't know is how much long-term care we can afford to include—politically or financially" (American Healthline 1993). Nonetheless, congressional Democrats recognized the political importance of long-term care and no one in a leadership position publicly opposed its inclusion.

Throughout the health care reform debate, Congress focused primarily on the issues of funding universal coverage and controlling health care costs. Long-term care did not take center stage. Members of Congress who opposed health reform believed that it was not "politically smart" to attack expansion of long-term care services, particularly when there were so many other problems with the President's proposal. There was enough ammunition around employer mandates, cost containment, benefit requirements, and subsidies that it was not worth antagonizing the aging community.

Although several major Democratic congressional figures were interested in long-term care, there were none for whom long-term care was a "make or break" issue that would determine whether he or she would support health reform. As a result, long-term care was not a major bargaining chip.

From the Republican perspective, as one congressional staffer described it, "long-term care was not a central part of the discussions about health care reform." Republicans were opposed to the creation of a new entitlement program and favored means-testing, which made the new long-term care program unpalatable. Where long-term care did enter the picture for Republicans was with regard to the tax clarification of long-term care expenses and the tax treatment of long-term care insurance.

Setting the Boundaries of the Debate

Several reform proposals that were not reported out by any congressional committee still received consideration and added to the debate on long-term care. To the left of the Administration's proposal was the single-payer plan (the American Health Security Act of 1993) proposed by Representative Jim McDermott (D-Wash.) and Senator Paul Wellstone (D-Minn.). This plan would have covered extensive nursing home and home-care benefits on a non-means-tested basis, making it far more generous than the administration's plan (Health Section 1994; Kaiser Commission 1994).

To the right of the Administration were the Managed Competition Act of 1993 proposed by Representatives Jim Cooper (D-Tenn.) and

Senator John Breaux (D-La.), and several Republican proposals, including the Health Equity and Access Reform Today Act of 1993, put forward by Representative William Thomas (R-Calif.) and Senator John Chafee (R-R.I.). The Cooper-Breaux plan actually would have phased out federal Medicaid funding of long-term care and made it entirely a state responsibility (Health Section 1994; Kaiser Commission 1994). The long-term care portions of the Republican proposals for health reform, such as the Thomas-Chafee plan, focused on clarifying the tax status of private long-term care insurance and establishing minimum federal standards for them. The Thomas-Chafee bill also would have allowed tax-favored medical savings accounts to be used for long-term care expenses (Health Section 1994; Kaiser Commission 1994).

Committee Deliberations

Several committees did report out bills for consideration on the House and Senate floor. Between June and August 1994, legislation from the Senate Labor and Human Resources, Senate Finance, and House Ways and Means Committees, as well as from Senate Majority Leader George Mitchell (D-Me.) and House Speaker Richard Gephardt (D-Mo.) was either reported out of committee or placed on the House or Senate floor for debate. (Although the House Energy and Commerce Committee actively debated health reform, it was unable to muster a majority to report out a bill.) Table 2 summarizes the long-term care portions and the associated cost estimates of these legislative proposals.

On June 9, 1994, the Senate Labor and Human Resources Committee reported out a health reform bill (S. 1757) sponsored by Senator Kennedy that included a substantial home-care program, regulation of private long-term care insurance, and the Life Care Act. The Life Care Act would have established a voluntary, self-funded public long-term care insurance program for extended nursing home stays. Life Care was estimated to save the federal government $3.7 billion over five years by moving some expenditures from Medicaid to the new program (Kassner 1994; U.S. Senate, Labor and Human Resources Committee 1994).

Politically, Democrats on the committee assumed, as one congressional staffer stated, that "the addition of long-term care would strengthen the bill, unless the costs of the program were so high that it jeopardized the success of the entire package." Committee Republicans agreed to the home-care program (although they wanted it to be means-tested) and insurance regulation pieces of the legislation, but opposed the Life Care Act. The bill was approved by the committee in an 11–6 vote. The long-term care portion of Kennedy's bill was estimated to cost $49.6 billion over five years, some $7.1 billion less than the Clinton Plan (Kassner 1994; U.S. Department of Health and Human Services 1994a).

Following closely on the action of the Senate Labor and Human Resources Committee, the House Ways and Means Committee reported out its version of health reform (H.R. 3600) on June 30, 1994. Before being voted on by the full committee, the bill first made its way through the Ways and Means subcommittees, most notably, the Subcommittee on Health led by Representative Pete Stark (D-Calif.). According to one congressional staffer, the Subcommittee on Health viewed the long-term care component of the bill as a "residual part of the package." Given this assessment, only long-term care insurance regulations were included in the measure voted out by the subcommittee on March 23, 1994. It was at the full committee level, led by the new chair, Representative Sam Gibbons (D-Fla.), that more comprehensive long-term care provisions, including a copayment for Medicare home health and a home- and community-based care program were added (U.S. House of Representatives 1994; Pear 1994). The Congressional Budget Office estimated the cost of the Ways and Means Committee's long-term care component at $40 billion over five years, less than both Kennedy's and the administration's plans (Cloud 1994; U.S. Congressional Budget Office 1994).

As the committees moved closer to developing legislation that might eventually be approved by Congress, cost pressures made it harder to maintain a costly long-term care component. Up until almost the very end, only tax clarification for long-term care insurance was included in Chairman Daniel Patrick Moynihan's plan for the Senate Finance Committee. Just one day before the committee approved its draft bill (S. 1775) on July 2, 1994, an amendment by Senator David Pryor (D-Alaska) that added a block-grant program for home and community care for people regardless of age or income was adopted on a vote of 16–4 (U.S. Senate Finance Committee 1994; Rubin 1994a; 1994b). After a seven-year phase-in beginning in fiscal year 1998, annual federal costs for long-term care were estimated to reach $15.4 billion in fiscal year 2004 (Kassner 1994).

The final action taken on health reform involved House Speaker Gephardt and Senate Majority Leader Mitchell in August 1994, each

TABLE 2
Long-Term Care Benefits and Costs by Major Reform Proposals

	President Clinton	Senate Labor and Human Resources	House Ways and Means	Senate Finance	Speaker Gephardt	Senator Mitchell
Action taken	September 1993: Plan introduced	June 9, 1994: Kennedy bill approved	June 30, 1994: Gibbons bill approved	July 2, 1994: Moynihan bill approved with amendments	August 3, 1994: Gephardt bill introduced	August 3, 1994: Mitchell bill introduced
Benefit proposed	New home- and community-based care benefit for persons with severe disabilities, regardless of age or income; and standards for long-term care insurance	New home- and community-based care benefit; Life Care Act; voluntary public insurance program to cover extended nursing-home stays; standards for long-term care insurance	Subcommittee on Health included long-term care insurance regulation only; full Committee added new home- and community-based care benefit	Block grants for community and home health care for the disabled included in an amendment by Sen. Pryor	Combined House Committee bills; new home- and community-based care benefit; standards for long-term care insurance	Combined bills reported by Senate Finance and Labor and Human Resources; included long-term care program, Life Care Act, and standards for long-term care insurance

Annual cost	Federal spending to begin at $4.5 billion in FY 1996; phased in to $38.3 billion in FY2003	Federal spending to begin at $3.9 billion in FY 1996; increasing to FY2003 when it will be fully funded at $33.6 billion	Federal spending to begin at $3.2 billion in FY 1997; phased in to $12.1 billion in FY2003	Federal spending to begin in FY1998; increasing to an annual federal cost of $15.4 billion in FY2004	Federal spending to begin at $1.7 billion in FY 1998; increasing to annual federal cost of $22.6 billion in FY2004	Federal spending to begin at $1.8 billion increasing to annual federal cost of in FY1998; $15.4 billion in FY2004
Cumulative cost	$56.7 billion over 5 years.	$49.6 billion over 5 years.	$40 billion over 5 years.	$21.2 billion over 5 years.	$24.2 billion over 5 years.	$21.2 billion over 5 years.

Sources: Clinton Health Security Act; Kassner 1994; S. Rept. 103-317; CBO markup; H. Rept. 103-601 (Part 1); S. Rept. 103-323; S. 2357; Clymer 1994; Gephardt amendment to H.R.3600.

of whom struggled to construct a bill that could draw the votes needed to pass. In the House, Speaker Gephardt put forward a version of the Administration's proposal that included a Medicare home health copayment and a scaled-back community-based care benefit that was estimated to cost $24.2 billion over five years (Rubin 1994c). In the Senate, the Mitchell plan (S. 2357) brought together the draft measures approved by the Senate Finance and Senate Labor and Human Resources Committees. The long-term care component of Mitchell's plan was estimated to cost $21.2 billion over five years (Clymer 1994; Rubin 1994d). Lacking majorities in both houses, a vote was never called for either bill, marking the end of comprehensive reform efforts.

Conclusions

Long-Term Care Policy since 1993–1994

Although efforts at comprehensive health reform failed in 1994, health policy has continued to be on the national political agenda, but in a very different form. With the Republican takeover of both houses of Congress in 1995, the health policy debate shifted away from issues of universal coverage to whether existing programs, especially Medicare and Medicaid, should be radically changed and expenditures cut back.

The collapse in 1996 of Republican efforts to transform public programs ushered in the current period of incremental change in health care policy, including the Health Insurance Portability and Accountability Act of 1996 (HIPAA) and the Balanced Budget Act of 1997 (BBA). While the HIPAA and BBA included some important long-term care provisions—such as tax clarification and regulation of private long-term care insurance, reimbursement changes to Medicare home health and skilled nursing facilities, and repeal of federal standards for Medicaid nursing home reimbursement—long-term care largely has been "off the radar screen," as several study informants put it. Long-term care activity and innovation continue to occur, but at the state rather than national level. Federal proposals now focus largely on tax incentives for purchasing private long-term care insurance, education about the need for long-term care, and limited efforts to help caregivers (e.g., respite care, most recently under reauthorization of the Older Americans Act, and tax credits for people with severe disabilities).

Although a major component of retirement security, the policy debates on the future of Medicare and Social Security have given little attention to long-term care. In a major departure from their 1993–1994 position, AARP and other elderly advocacy groups have made prescription drug coverage a much higher priority than expanding long-term care services. President Clinton, the Republican Congress, and both presidential candidates in the 2000 election shared this priority.

Implications for the Future

Informants were generally cautious in drawing implications from the experience of 1993–1994 for future efforts to reform long-term care. The potential lessons are necessarily qualified by whether the context and elements of any future debate on long-term care will be totally different (in fiscal, political, and policy terms) than that of the 1990s. Nevertheless, several themes and cautionary tales emerge from this study that may inform future action.

First, expansion of long-term care services is a popular idea. Long-term care was often described as one of the initiatives (albeit relatively neglected) that *helped sustain* commitment to health reform, even though it did not generate a groundswell of support by advocates for older people. Among long-term care activists, there was a consistent belief that "there was always more public support for long-term care than for larger health reform." The fact that a public program for long-term care would not displace existing private-sector insurance gave it a certain advantage over the Clinton proposals to extend coverage for acute care.

On the other hand, long-term care policy is largely about money—that is, how much are we willing to spend? While long-term care is in many ways politically popular, it is also expensive and adds substantially to the costs of health reform, which helped to drag it down in 1993–1994. Many participants in the process observed that the long-term care needs are so great and the current system so inadequate that to do any significant reform requires spending billions of dollars.

Second, being part of a very large, comprehensive heath care proposal did not necessarily aid long-term care reform. Although long-term care reform "tried to get on the big train," it got lost in the larger health care reform effort. Interest-group representatives, including elderly and disability advocates, all agreed that "long-term care went down with the larger ship." One elderly advocate put it this way: "You have to be careful what you hitch your wagon to." Clinton's health reform plan did not stand much of a chance of passing because of the political environment and the contents of the plan itself. Reform of long-term care may need to go its own way and not be part of health care, Medicare, or Social Security reform. The main drawback of such a separate strategy is that it gives up any offsetting savings from other programs that might help finance it.

Third, although inclusion of long-term care in the reform package had a clear political goal of increasing public enthusiasm for health reform, several key decisions undercut its political support, although there was no unanimity on these points. The states were concerned about their potential financial liability in long-term care and would not have received fiscal relief for it under the Clinton proposal. For elderly advocacy organizations, the lack of a defined benefit and individual entitlement was a major obstacle in explaining what people were going to get, while, at the same time, the Medicare cuts that the administration proposed distracted attention and resources from promoting the long-term care plan. Similarly, the Medicare cuts for home health somewhat splintered the home-care industry, leading some groups to oppose the Health Security Act.

Fourth, health reform—including long-term care—generally neglected certain political prerequisites. President Clinton could not create a winning majority in the context of inevitable divisions. The expectation that major reform legislation could be passed without significant bipartisan support in Congress was not realistic. An advocate for the elderly recounted, "We did not work with the Republicans at all; the sense was that we could do it without them." However, bipartisanship in such a comprehensive reform may be a fantasy—and was not achieved when Medicare and Medicaid were passed, either. There is also the need for a champion for whom long-term care is *the* issue. As one long-time participant in health reform noted, "When Representative Claude Pepper died, we lost our voice. For many years, we sought someone with his commitment, but we never identified a true successor." Furthermore, informants suggested the need for a stronger public education effort to convey the urgency of the problem and explicate policy solutions. Said one respondent, "Ultimately, in the case of acute health insurance, most of us are covered. In the case of long-term care, almost nobody is covered and they do not know it."

Fifth, the legacy of the long-term care reform of 1993–1994 includes some important changes in the way long-term care is conceptualized. The conflict between individual entitlement and service flexibility that dominated the design of the Clinton long-term care plan forced a rethinking of traditional social insurance concepts, at least as they applied to long-term care. The plan's emphasis on states as the level of government that should have major responsibilities for designing and administering long-term care is consistent with the recent trend of devolving responsibility for social programs from the federal government to state governments. However, the Clinton plan met the bottom-line requirement of many advocates that there be no means-testing in long-term care.

Another legacy has been the uniting of advocacy organizations for older people and younger people with disabilities around the idea of intergenerational and cross-disability solutions to the long-term care problem. This new political alignment has been sustained in the postreform period and successfully defended Medicaid against the proposed block grant. Other significant changes are that the long-term care reform process contributed to a new paradigm that seeks to counterbalance the bias and limits of categorical and institutional thinking, as well as the overprofessionalization and overmedicalization of long-term care.

Final Thoughts

The recent trend toward incremental health care reforms has generated significant debate within the long-term care policy community. Advocates of incremental change note—some ruefully—the difficulty, if not impossibility, of any reforms that are seen as "big governmental programs." One congressional staffer said bluntly: "We learned a comprehensive proposal will not fly. You need to introduce incremental pieces to get anything accomplished." Thus, most groups for the elderly and disabled supported President Clinton's very modest 1999 and 2000 proposals for tax credits for people with severe disabilities and small expansions of respite care. Even the Long-Term Care Campaign, founded initially to promote social insurance for long-term care, has endorsed tax credits and Medicaid reforms—proposals that it previously would have dismissed as woefully inadequate, if not wrongheaded. Politically, almost anything that puts the issue on the agenda and adds to the pot of money for long-term care now appears to be acceptable to advocacy groups.

More subtly, the contemporary "small steps" approach is accompanied by a profound shift in the framing of the options. Traditional social insurance for long-term care in the mold of Medicare and Social Security is no longer actively debated, as it was in the late 1980s and early 1990s, a result of the more conservative political environment and the deconstruction of the concept by the Clinton long-term care proposal. Nevertheless, there remains a small contingent that advocates for single-payer plans for universal health care on a social insurance model that includes long-term care.

So what are the prospects for long-term care reform in the near term and in the more distant future? For the more distant future, few observers doubt that when the baby boom generation needs long-term care, it will be a major domestic policy issue. While demography is not destiny, the baby boomers are likely to set the policy agenda (Friedland and Summer 1999).

For the nearer term, the political salience of long-term care is less certain. While the baby boom generation is not yet using long-term care, many of their parents are. One congressional staffer noted that, "because the baby boomers are now caring for their parents, they are going to drive interest in this issue in a way that hasn't been the focus before, and they will also think about the need for long-term care for themselves." On the other hand, informants also expressed pessimism about the possibility for progress relating to long-term care due to its public or private cost, the competing desire for tax cuts, the funding and financing problems currently evident with Medicare and Social Security, and the lack of consensus in the policy community.

Long-term care will be on the national political agenda, but the terms of the debate are likely to be very different than they were in 1993 and 1994. Changes in fiscal circumstance (positive and negative), health and long-term care costs, and political attitudes will all shape any future debate on long-term care.

ENDNOTES

1. For example, one listing of the components of personal assistance services included personal services relating to the activities of daily living, giving medications and injections, menstrual care, and operating and maintaining equipment, and providing assistive technology devices and services, household services, life support services (e.g., money management, home management, positive behavior management, and companion or roommate services to provide supervision), communication services (e.g., assistance with interpreting, letter writing, and the use of communication devices), securityenhancing services (e.g., monitoring alarms), mobility services in and out of the home, work-related support services, service coordination, assistive technology services, and emergency services. "Personal Assistance Services," memo, March 28, 1993.

2. Members of the consortium included ARC, the United Cerebral Palsy Association, the Paralyzed Veterans of America, the National Association of Developmental Disability Councils, the World Institute on Disability, the National Council on Independent Living, the National Association of State Directors of Developmental Disability Services, the National Association of Protection and Advocacy Systems, ADAPT, the Bazelon Center, the National Alliance for the Mentally Ill, and the American Psychological Association.

References

Aaron, H.J., ed. 1996. *The Problem That Won't Go Away: Reforming Health Care Financing*. Washington, D.C.: Brookings Institution.

American Healthline. 1993. Long-Term Care. *America Healthline* (March 19).

Burtless, G., R.K. Weaver, and J.M. Wiener. 1997. The Future of the Social Safety Net. In *Setting National Priorities: Budget Choices for the Next Century*, ed. R.D. Reischauer, 75–122. Washington, D.C.: Brookings Institution.

Campbell, C., and H. Dean. 1993. Impact of Health Reform on the Economy and Employment. Testimony for the National Governors' Association before the Committee on Ways and Means, U.S. House of Representatives, December 15.

Clinton, B., and A. Gore. 1992. *Putting People First*. New York: Times.

Cloud, D.S. 1994. Gibbons' Compromise Health Bill Gets Good Marks from CBO. *Congressional Quarterly* (June 11):1527–9.

Clymer, A. 1994. Senate Optimists Offer Some Hope for a Health Bill. *New York Times*, September 12.

Cohen, M., S.S. Wallack, and N. Kumar. 1992. Financing Long-Term Care: A Practical Mix of Public and Private. *Journal of Health Politics, Policy and Law* 17:403–23.

Cohen, M.A., E.J. Tell, J.N. Greenberg, and S.S. Wallack. 1987. The Financial Capacity of the Elderly to Insure for Long-Term Care. *Gerontologist* 27:494–502.

Corson, W., T. Grannemann, and N. Holden. 1988. Formal Community Services under Channeling. *Health Services Research* 23:83–98.

Crown, W., J. Capitman, and W.N. Leutz. 1992. Economic Rationality, the Role of Private Long-term Care Insurance, and the Role for Public Policy. *Gerontologist* 32:478–85.

Estes, C.L., and T. Bodenheimer. 1994. Paying for Long-Term Care: Private Insurance or Social Insurance? *Western Journal of Medicine* 160:64–9.

Estes, C.L., and K.W. Linkins. 1997. Devolution and Aging Policy: Racing to the Bottom in Long-Term Care? *International Journal of Health Services* 27:427–42.

Friedland, R.B. 1990. *Facing the Costs of Long-Term Care*. Washington, D.C.: Employee Benefit Research Institute.

Friedland, R.B., and L. Summer. 1999. *Demography Is Not Destiny.* Washington, D.C.: Gerontological Society of America-National Academy on an Aging Society.

Gallup Organization. 1993. *Public Attitudes on Long-Term Care, 1993*. Survey prepared for the Employee Benefit Research Institute. Washington, D.C.: Gallup.

Health Section, Education and Public Welfare Division. 1994. *Summary Comparison of Selected Health Care Reform Bills*. Washington, D.C.: Congressional Research Service Report for Congress.

ICR Survey Research Group. 1993a. *Long-term Care Survey*. Prepared for American Association of Retired Persons. Media, Pa.: International Communications Research.

ICR Survey Research Group. 1993b. AARP Finds Americans Want Long-term Care as Part of Health Care Reform. *AARP News* (November 11).

Johnson, H., and D.S. Broder. 1996. *The System: The American Way of Politics at the Breaking Point*. Boston: Little, Brown.

Kaiser Commission on the Future of Medicaid. 1994. *Summary of Major Health Care Reform Legislation*. Washington, D.C.: Kaiser Health Reform Project.

Kane, R.A., and R.L. Kane. 1987. *Long-Term Care Principles, Programs and Policies*. New York: Springer.

Kassner, E. 1994. Comparison of Long-Term Care Proposals. Internal working document. Washington, D.C.: AARP.

Kemper, P., R. Applebaum, and M. Harrigan. 1987. Community Care Demonstrations: What Have We Learned? *Health Care Financing Review* 8(4):87–100.

Liska, D., B. Bruen, A. Salganicoff, P. Long, and B. Kessler. 1997. *Medicaid Expenditures and Beneficiaries: National and State Profiles and Trends, 1990–1995* (3rd ed.). Washington, D.C.: Kaiser Commission on the Future of Medicaid.

Lucas, D. 1996. Managed Competition with Prefunding: The Solution to Long-term Care? *Milbank Quarterly* 74: 571–99.

Magaziner, I. 1993. Preliminary Work Plan for the Interagency Health Care Taskforce. Memo. Washington, D.C.

National Association for Home Care. 1999. Legislative and Regulatory Advocacy FAQs. Available at http://www.nahc.org/NAHC/FAQ/legreg.html (accessed September 17).

Pear, R. 1993. Moynihan Criticizes Clinton Format for Paying for Home Care. *New York Times* (December 30):16.

Pear, R. 1994. Panel's New Leader Offers a Health Program. *New York Times* (June 7):A16.

Pyles, J.C. 1993. Testimony of the National Home Health Services Alliance at the Hearings on Health Care Reform: The President's Health Care Reform Proposals. Subcommittee on Health, Committee on Ways and Means, U.S. House of Representatives, November 2.

Rivlin, A.M., and J.M. Wiener. 1988. *Caring for the Disabled Elderly: Who Will Pay?* Washington, D.C.: Brookings Institution.

Rubin, A. 1994a. Moynihan Plan a Starting Point. *Congressional Quarterly* (June 11):1526.

Rubin, A. 1994b. Big Decisions Now on Shoulders of House, Senate Leaders. *Congressional Quarterly* (July 9):1866–7.

Rubin, A. 1994c. Key Provisions of the Gephardt Plan. *Congressional Quarterly* (July 30):2143.

Rubin, A. 1994d. Mitchell Aims for 95 Percent. *Congressional Quarterly* (August 6):2205.

Skocpol, T. 1997. *Boomerang: Health Care Reform and the Turn against Government*. New York: W.W. Norton.

U.S. Bipartisan Commission on Comprehensive Health Care. 1990. *A Call for Action, Final Report*. Washington, D.C.: Government Printing Office.

U.S. Congressional Budget Office. 1994. H.R. 3600, Health Security Act as Amended by the House Committee on Ways and Means—Preliminary. Washington, D.C.: CBO.

U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging, and Long-Term Care Policy. 1994a. *Cost Estimates for the Long-Term Care Provisions Under the Health Security Act*. Washington, D.C.: Government Printing Office.

U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging, and Long-term Care Policy. 1994b. *Summary of Long-term Care Provisions under the Health Security Act*. Washington, D.C.: Government Printing Office.

U.S. House of Representatives, Ways and Means Committee. 1994. *Committee Report 103-601*. Washington, D.C.: Government Printing Office.

U.S. Senate, Finance Committee. 1994. *Committee Report 103-323*. Washington, D.C.: Government Printing Office.

U.S. Senate, Labor and Human Resources Committee. 1994. *Committee Report 103-317*. Washington, D.C.: Government Printing Office.

Weissert, W.G., C.M. Cready, and J.E. Pawelak. 1988. The Past and Future of Home and Community-based Long-term Care. *Milbank Quarterly* 66:309–88.

Wiener, J.M. 1996. Managed Care and Long-term Care: The Integration of Financing and Services, *Generations* 20(2):47–52.

Wiener, J.M., and R.M. Hanley. 1992. Caring for the Disabled Elderly: There's No Place Like Home. In *Improving Health Policy and Management*, eds. Stephen M. Shortell and Uwe E. Reinhart, 75–105. Ann Arbor, Mich.: Health Administration Press.

Wiener, J.M., R.J. Hanley, R. Clark, and J.F. Van Nostrand. 1990. Measuring the Activities of Daily Living: Comparisons across National Surveys. *Journal of Gerontology: Social Sciences* 45:S229–37.

Wiener, J.M., L.H. Illston, and R.J. Hanley. 1994. *Sharing the Burden: Strategies for Public and Private Long-term Care Insurance*. Washington, D.C.: Brookings Institution.

Wiener, J.M., C.M. Sullivan, and L.M.B. Alecxih. 1995. Catastrophic Costs of Long-term Care for Elderly Americans. In *Persons with Disabilities: Issues in Health Care Financing and Service Delivery*, eds. J.M. Wiener, S.B. Clauser, and D.L. Kennell, 182–212. Washington, D.C.: Brookings Institution.

Willging, P. 1993. Testimony before the U.S. Senate Labor and Human Resources Committee, November 11.

Zedlewski, S.R., and T.D. McBride. 1992. The Changing Profile of the Elderly: Effects on Future Long-term Care Needs and Financing. *Milbank Quarterly* 70:247–75.

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Address correspondence to: Joshua M. Wiener, Health Policy Center, The Urban Institute, 2100 M Street, NW, Washington, DC 20037 (e-mail: jwiener@ui.urban.org).

Appendix

Long-Term Care Provisions in Clinton's Health Security Act

The Clinton health plan, introduced in September 1993 as the Health Security Act, promised universal, mandatory acute-care coverage by 1998 of all citizens and legal residents who do not receive Medicare through a system of subsidized private group health insurance. The costs were to be contained through managed competition and global budgets. The program would be administered by states and purchasing alliances, and financed through a combination of individual, employer, and federal payments, augmented by state contributions for low-income people and small employers.

The long-term care portion of the proposal included four key elements:

- A large, capped matching-grant program to the states to cover home- and community-based services for people with severe disabilities, regardless of age or income;
- Tax clarification of, and federal standards for, private long-term care insurance;
- Minor liberalization of Medicaid nursing home coverage; and
- A tax credit for personal assistance services.

Table 3 gives a summary of cost estimates for each element of the Clinton plan's long-term care proposal.

Home- and Community-based Services

The centerpiece of the long-term care proposal was a capped matching-grant program to the states for home- and community-based long-term care services for people with severe disabilities, regardless of age or financial status. The program was intended to serve 3.1 million people with disabilities and would have been designed and administered almost entirely by the states. People having problems with three or more activities of daily living (ADLs), severe cognitive impairment, or severe or profound mental retardation, and severely disabled children under age 6, would have been eligible for the program. Individuals would not

TABLE 3
Summary of Additional Federal Expenditures under the Health Security Act (in billions)

	FY1996	FY1997	FY1998	FY1999	FY2000	Total
New home- and community-based services program	$4.5	$7.8	$11.0	$14.7	$18.7	$56.7
Tax incentives for private long-term care insurance	$0.1	$0.4	$0.5	$0.7	$0.8	$2.5
Medicaid nursing home coverage	$0.4	$0.5	$0.5	$0.5	$0.5	$2.4
Tax credit for personal assistance services	$0.1	$0.1	$0.1	$0.1	$0.1	$0.5
Total	$5.1	$8.8	$12.1	$16.0	$20.1	$62.1

Source: U.S. Department of Health and Human Services, March 1994.

have been legally entitled to benefits, but rather to an assessment, a care plan, and services on a funds-available basis. States would have been given the opportunity to provide an extremely broad array of home- and community-based services, but they would have had to fund at least some personal assistance services and would have had to offer clients the option of a consumer-directed system of care. Individuals with incomes in excess of 150 percent of the federal poverty level would have been required to pay a portion of the cost of their services on a sliding-scale basis. Funding for the program would have been overwhelmingly federal, with the state match set between 5 and 22 percent of total spending. The program would have been phased in over a seven-year period, with fiscal year 2003 being the first year of full funding—at which point federal expenditures would have totaled $38.3 billion. Federal funding between fiscal year 1996 and fiscal year 2000 would have totaled $56.7 billion.

Private Long-Term Care Insurance

The Health Security Act sought to improve the standards and accountability of private long-term care insurance policies by establishing uniform national standards for policies and requiring nonforfeiture benefits, the mandatory offer of inflation protection, and improved premium stability. In addition, the tax status of private long-term care insurance was clarified in ways favorable to the industry. The Health Security Act would have permitted individuals to deduct payments for long-term care services and insurance premiums under the individual income tax medical expense deduction. In addition, it would have excluded long-term care insurance premiums paid by an employer from taxable income and would have allowed employers to deduct their contributions as a business expense. While this portion of the long-term care program did not require any additional federal funds, it would have resulted in lower tax revenue. Therefore, it was estimated that approximately $2.5 billion in lost tax revenue would be incurred over a five-year period.

Medicaid Nursing Home Coverage

The plan would have required states to raise the personal needs allowance of nursing home residents from $30 to $50 a month (fully paid by the federal government), required state Medicaid programs to establish programs for medically needy nursing home residents if they did not already offer such benefits, and given states the option of increasing the financial resource limit for individuals in institutions from $2,000 to $12,000. An additional $2.4 billion in federal funds was estimated to be spent on Medicaid institutional residents between fiscal year 1996 and fiscal year 2000.

Tax Credit for Personal Assistance Services

The Health Security Act would have provided a nonrefundable tax credit to people with disabilities for up to 50 percent of their personal assistance expenses, up to the lesser of $15,000 or the individual's earned income. The tax credit was to be phased out for individuals with incomes over $50,000. An estimated $0.5 billion in tax credits for personal assistance expenses for employed persons with disabilities was expected to be incurred over the five-year period.

Other Provisions

In addition to those four key provisions, the Health Security Act also authorized demonstration programs that would test the effectiveness of various approaches to financing and providing integrated acute and long-term care services.