

An Historical Perspective on Home Care Policy

A. E. BENJAMIN

University of California—Los Angeles

ALTHOUGH THE WAYS IN WHICH WE THINK ABOUT home care and the character of its public and private support have changed significantly over time, the history of home care in the United States suggests continuity as well. Barely a century ago virtually all medical care was provided in the home, first by family members and other “natural” caregivers, and later by physicians making house calls. With the emergence of modern scientific medicine and the hospitals in which it is practiced, the importance of home care waned as people sought care in hospitals and physicians’ offices. The rise in chronic illness attracted attention to the idea of caring for persons in their homes, and models of organized home care were developed in a few cities. Not until the marketing of private health insurance after World War II, and especially the passage of Medicare and Medicaid in 1965, was home care again to be considered a part of mainstream health care.

Because home care seems to have been “rediscovered” since 1965, and especially during the last decade, there is little in the health services literature that puts home care in historical perspective. This article represents an initial attempt to fill that gap. Although I will be considering policy developments since the 1965 Social Security amendments, I will devote some attention to earlier forces that seem important to under-

standing that landmark legislation and subsequent events. Any attempt at history is selective and interpretive, particularly in the case of the home care story, because it is a modest and often fragmented part of a much larger history of health care in the United States. Several broad themes characterize the development of home care policy both before and after 1965.

Throughout the era of modern medicine, home care has been considered a residual set of services, to be provided after other care was delivered and to persons whose conditions were not amenable to mainstream medical intervention. Consequently, home care policy has suffered from an absence of consensus about its principal goals, the essential elements of comprehensive home care, and the place of these services in a continuum of care. In large measure, consensus has been difficult to achieve because of the presence of two different models of home care: the medical-postacute and the social-supportive. Whereas the former was relatively well defined and articulated, the latter was much less so.

For about 75 years, the legitimacy of home care has depended almost exclusively on its relation to inpatient, acute, and nursing-home care. The rationale for home care has long rested upon rhetorical claims that it would relieve utilization and costs of institutional care. The sorting out of claims about the impact of home care has been a major feature of recent policy debate. This dependence on institutional performance has served both to maintain the policy salience of home care and to undermine its legitimacy.

Policy thinking about home care has been shaped not only by relations to institutional care, but also by various environmental factors. The entrance of the federal government into health care financing opened up what had been a very limited debate about public models of community care for the sick and chronically ill and drew policy attention to home care. Recent fiscal crises in government, along with dramatic increases in health care costs, have forced a reexamination of traditional approaches to delivering care, enhancing the policy visibility of home care. Profound demographic changes have increased the demand for home care and brought it more firmly into the mainstream of health care reform.

In what follows, I will present a brief historical overview of the rise, decline, and reemergence of home care as a service model prior to 1965, with primary attention to the period immediately preceding the 1965 amendments and to forces that shaped home care benefits under Medi-

care and Medicaid. I will then trace major developments in public policy regarding home care since the mid-1960s and conclude with some observations about persistent themes and unresolved issues in home care policy in the 1990s.

Home Care Before 1965

Prior to the turn of the century, most sickness, birthing, and dying in America took place within the household among family members (Risse, Numbers, and Leavitt 1977; Reverby 1987). The earliest care was provided by immediate family and neighbors. By the mid-nineteenth century, care at home included house calls by growing numbers of physicians. By the late nineteenth century, the emergence of modern science, along with important social and economic changes like urbanization, industrialization, and immigration, had shifted medical care away from the home into the hospital and physician's office (Starr 1982; Rosenberg 1987; Stevens 1989). In support of this shift, medical leadership enumerated the limitations of the home as a site for modern medical practice, although physician house calls continued (albeit in declining numbers) until the 1950s. Some advocates called for a hospital in every community (i.e., near to every home) and touted these institutions for their comfort and hospitality (i.e., their homelike qualities), but the home was quickly becoming irrelevant as a medical care site, and by 1930 most medical care was delivered elsewhere.

Changing social and economic conditions also were stimulating development of other models of home care. Epidemics of infectious diseases were especially devastating as the expanding population became more urbanized. With increasing immigration and growing public concern about health, public health activity aimed at families at home began to expand with both voluntary and government support. Emphasis was placed on instruction in prevention and hygiene and on direct patient care by nurses (Reverby 1987; While 1987).

By World War I, steadily growing numbers of persons with chronic illness, especially the aged, were presenting additional problems for public health officials and others. Care of the chronically ill had become a problem: for physicians, who could do little to treat illnesses like heart disease and cancer; for voluntary hospitals, which found that their beds were occupied by the incurable chronically ill despite determined efforts

to screen out patients who ostensibly undermined hospital capacity to provide beds for the potentially curable; for local and state governments, whose public hospitals bore the brunt of chronic care demands; and of course for increasing numbers of the chronically ill themselves.

Beginning in the 1920s, new interest in home care was stimulated as a few foundations and several prominent physicians and public health officials became interested in the treatment of chronic illness (Fox 1988, 1989). The prevailing view was that the demands of the chronically ill were compromising the capacity of hospitals. Much of the ensuing study and debate addressed the question of which setting(s) to recommend as the appropriate alternative to the acute care hospital. For decades to come, efforts to find alternatives to institutional care would motivate home care policy development and reform.

Two reports were especially visible and influential in framing the debate on the role of the home in care of the chronically ill. The first, using data from New York City, was critical of contemporary home services and concluded that specialized chronic disease hospitals were preferable for most chronically ill (Jarrett 1933a; Boas and Michelsohn 1929; Boas 1930). Current programs (e.g., visiting nurses) seemed to focus more on providing medically related care to convalescent patients, especially children, than on providing the mix of skilled nursing and "custodial" care required by chronically ill adults. Also, there were numerous problems associated with family care in the home setting. For example, because of wide variations in educational levels, language, and culture, providers doubted the efficacy of training family members to assume nursing and personal care roles. They described the urban apartment disdainfully as having poor lighting and ventilation and inadequate space. The toll of home care on the family (e.g., strained relations) and on the patient (e.g., guilt, despair, loss of status) was documented at length (Boas 1930).

In the 1930s and 1940s, health professionals (most visibly, physicians and social workers) were ambivalent about the home as a site for care. Indeed, some critics of home care also maintained that it could lead to substantial reductions in health care costs by reducing utilization of inpatient beds by the chronically ill and saving hospital days (Jarrett 1933b; Jensen and Weiskotten 1944). During this period, home care became defined as a less expensive alternative to hospitalization, as well as a means to other positive outcomes. Proponents argued that most patients and their families preferred to live and receive care at home and

that, once cared for at home, chronic patients were happier, less anxious, and better prepared to manage their illnesses (Bardwell 1930; Epstein 1930; Jensen and Weiskotten 1944).

Between the world wars, interest in chronic care revived the study and analysis of home care models, although programmatic reform tended to be modest and confined to a few urban centers. Often featured in discussions of home care were a few hospitals and prominent physicians, who emphasized it as a means to relieve hospitals, and social workers, who stressed the importance of trained attendants and visiting housekeepers in care at home. Both perspectives received additional attention following World War II from the Commission on Chronic Illness, whose work began in 1946 as the Joint Committee on Chronic Disease and concluded with a published report in 1956 (Commission on Chronic Illness 1956).

The commission emphasized the role of the private physician in home care, as well as the importance of various roles played by nurses (e.g., personal care, teaching, emotional support). In addition, the report noted a widespread lack of appreciation for the role of homemaker services for the chronically ill. The 1956 report attributes a pivotal role to these services, arguing that for many long-term patients, homemaker services (including personal care, household tasks, and emotional support) could make the difference between being cared for at home and being forced to accept care in an institution (American Hospital Association et al. 1947; Commission on Chronic Illness 1956).

The primary recommendation of the report for home care concerned its organization. It drew heavily from a commission survey of model home care programs, most notably the one at Montefiore Hospital in New York City. Recognizing that home care involved a diversity of programs and services, the commission called for "organized home care programs" that offered a full range of services coordinated by a single agency or institution (U.S. Public Health Service 1955). Such programs were characterized by centralized responsibility, coordinated care planning, and a team approach to services (Commission on Chronic Illness 1956). Montefiore was one of 30 or 40 programs operating in the mid-1950s, but it clearly set the standard for what a program should include. Montefiore's was a postacute program serving many elderly and others following hospitalization. A range of services was available under a physician's plan of care, including physician (house calls), nursing, social work, housekeeping, transportation, medications, and other benefits. This and

many other organized home care programs were hospital based and physician directed, so that institutional and professional interests as well as client needs helped shape these programs.

Federal Funding for Home Care Prior to 1965

Federal activity in health care grew on several fronts following World War II, primarily addressing the supply of health care resources (Brown 1988). Introduction of a national health insurance proposal in 1949 (Marmor 1973) began a debate about health insurance and about a federal role in financing health care that led to the 1965 amendments establishing Medicare and Medicaid. In this policy context, both home and nursing-home care were considered minor issues. From the late 1940s to the mid-1950s, no provision for home care benefits was included in prominent proposals for federal financing of health care for the elderly (U.S. Congress 1963-64). By 1961, this situation had changed for several reasons. A new Democratic administration had renewed the health insurance debate, fears about excessive hospital costs had become a central issue, and home care was considered to be one tool for controlling hospital spending. Home care had now acquired a modicum of legitimacy in insurance circles because of the visibility and respectability of organized home care programs and because a few Blue Cross-Blue Shield plans had introduced home care coverage.

Congressional testimony during this period highlighted some now familiar themes in debates about the role of home care. The American Nurses Association cited the need to create an expanded network of home care agencies whose bedside nursing and health care teaching services would directly reduce the number of patients in institutions. Even the American Medical Association, which for decades had opposed publicly financed health insurance, offered its version of support for community-initiated and privately financed home nursing and homemaker services as a means to reduce utilization of hospitals (and nursing homes). Whereas medical interests emphasized the importance of medical supervision, social service interests emphasized the need for collaborative approaches to home care and stressed the importance of home supportive (especially homemaker) services (U.S. Congress 1961b).

The prevailing view of home care within private insurance circles re-

mained cautious and ambivalent. On the one hand, home care was seen as a potential component of modern and continuous medical care, as a reasonable response to growing concern about the unnecessary use of hospital facilities, and as therapeutically and psychologically beneficial to many patients. Moreover, evidence from a New York Blue Cross experiment in the mid-1950s seemed to prove that early discharge and home care nursing effected cost savings for selected hospital patients (Follmann 1963). On the other hand, there were numerous doubts and concerns. Insurers worried about the "public" and "indigent" character of much home nursing care, most notably that provided by visiting nurse associations (VNAs) and local health departments. Companies questioned whether demand was substantial, and particularly whether the middle class was interested in home care. Beyond a few innovators, it was unclear whether physicians and hospitals accepted home care. A host of concerns was voiced about traditional, typically voluntary home care agencies, including their non-business-like character, the lack of uniform definitions of services and visits, and the absence of modern cost-accounting methods. The result was that, although home care coverage was available from some insurers, in 1960 there was no widespread conviction about its necessity or about any prevailing model of coverage. The most active experimentation with home care services occurred within Blue Cross-Blue Shield plans in New York, Michigan, and several other states (Follmann 1963).

The link between home and hospital care was made explicit under many Blue Cross-Blue Shield plans, both because the hospital reference helped to establish boundaries around eligibility, particularly with respect to chronic illness, and because hospitals represented what was considered good quality care, involving trained personnel and established protocols. The home was a setting that did not readily accommodate review or monitoring, and insurers (steeped in a medical perspective) were uneasy about underwriting care by nurses acting alone without an institutional or medical attachment. One solution to this "problem" was to endorse only home care attached to hospitals, which insured institutional oversight. Another was to require that any authorized home care be provided under a plan approved and reviewed periodically by a physician. This approach was common among Blue Cross plans by the late 1950s and was incorporated into Medicare in 1965.

The hospital connection also made insurer exclusion of the chronically ill a more straightforward task. This was achieved by requiring that

home care reimbursement be authorized only within a given number of days following hospital discharge, and by limiting coverage of home visits, sometimes explicitly tying the number of visits to the number of "unused" hospital days. Setting limits based upon the presumed interaction of institutional and noninstitutional care became fundamental to home care insurance coverage. Formulas were designed to encourage the use of home care as a substitute for inpatient care and to moderate the risk of unlimited care at home. From the perspective of the Blues, home care—especially for the chronically ill—looked like a "bottomless pit," even in the 1950s.

The process by which the 1965 Social Security amendments took final shape has been described well by others (Marmor 1973; Myers 1970), as have the ways in which nursing-home policy emerged from battles over other issues (Vladeck 1980; Smits, Feder, and Scanlon 1982). No comparable analysis of home care coverage is available. Interviews with some participants suggest that decisions regarding key home care provisions were made by the small cadre of Social Security Administration (SSA) officials leading the fight for King-Anderson (H.R. 3920) and that they looked in two (now familiar) directions for help: (1) organized home care programs, particularly Montefiore; and (2) Blue Cross plans. SSA seems to have drawn some inspiration from Montefiore and substantive assistance from Blue Cross.

SSA representatives visited the Montefiore program and met with its leadership in the late 1950s and subsequently. Despite their admiration for the New York program, they foresaw many problems in incorporating an organized home care model into prospective federal legislation, foremost of which were administrative feasibility and costs. Several problems were identified. Because private insurers had little experience with chronic illness, SSA could find no generally accepted models for determining when a given service should be covered or not. Montefiore was seen as providing little help on this because its program not only was oriented to the chronically ill, but also was flexible and comprehensive, raising SSA concerns about the future costs of home care. Montefiore's willingness as well to provide homemaker services to its clients would lead, in SSA's opinion, to all older persons needing or requesting it, with the result that public care would be substituted for existing private care. Again, in the SSA view, this was administratively unfeasible unless coverage was limited to brief acute episodes and chronic care was excluded. Although physician house calls were effectively ignored, the

issue of appropriate supervision of home care workers worried SSA officials. The answer, borrowed from Blue Cross and commercial insurers, was found in a physician plan of treatment and periodic medical certification of need.

Montefiore had established an overall daily rate for home care based on their service experience; it was implemented in a setting with relatively flexible funding. SSA officials were uneasy about lack of clarity regarding units of service (e.g., visits of variable lengths), wide variations in utilization that were not readily explainable, and the general absence of a "rational unit of payment." In light of this, SSA extended to home care the fee-for-service, cost-based reimbursement method it had borrowed from Blue Cross and embraced for hospital care.

SSA officials also worried about the cost associated with the continuous care that Montefiore provided its clients, some of whom had lengths of stay of two years or longer (Follmann 1963). They believed that longer-term home care would be more costly than institutional care and that only episodic or intermittent care at home was economically feasible. Furthermore, if a patient was mobile enough to leave home to seek care, then that would surely be less expensive than bringing care into the home. The answer was to be found in ensuring that only persons unable to seek less costly care outside the home (i.e., the "home-bound") would qualify for more expensive home care.

Planners at Social Security believed that they were not denying care to anyone, but instead were providing care in the least costly setting. They also understood that it might reduce both institutional utilization and overall health care costs, especially if the family could share the care burden. Implicit in this perspective was the proposition that for home care to be cheaper, it needed to take full advantage of the fact that unpaid family care was always less expensive than professional care at home.

Between 1961 and 1965, there was an increasing political need to demonstrate the noninflationary character of publicly financed hospital insurance. The notion of home care as a posthospital benefit was perfectly consistent with the conception of organized home care, which still had its young roots in public and community hospitals. If home care was to be sold as a mechanism to contain hospital costs, then surely its beneficiaries should have recently occupied a hospital bed. By 1965, this came to mean a hospital stay immediately prior to initiating home health care services.

Federal planners embraced Montefiore's coverage of a range of services, but this was effectively limited to benefits covered in Blue Cross plans. Included were nursing visits, the three established home therapies (physical, occupational, and speech), medical social services, and what was now to be termed "home health aide" care (personal care plus limited homemaker), along with medical supplies and appliances. The physician, although rarely in the home, would establish a care plan and provide the medical supervision consistent with the medical, postacute character of the new benefit.

Home care was something more than an afterthought in deliberations about Medicare. It was an explicit, but primarily symbolic, component of a budgetary strategy designed to convince critics that publicly financed hospital expenditures would not go through the roof. By contrast, home care remained truly an afterthought in Medicaid deliberations prior to 1965. Larger issues involving an expanded federal-state program as an alternative to the administration's federal health insurance bill dwarfed concerns about the role of services at home for the poor.

The larger history of Medicaid has been described elsewhere (Stevens and Stevens 1974; Vladeck 1980). Old Age Assistance (OAA) had been part of the Social Security Act of 1935 and, despite widely varying and often inadequate cash assistance levels, OAA had made it plausible for the low-income older person to consider self-care at home rather than at the county nursing home. The 1950 amendments permitted, for the first time, federal matching of direct payments by state and local welfare agencies to providers of health services (or vendors) for OAA recipients. As the movement to win support for hospital insurance under Social Security for the elderly gained momentum, opponents sought to develop a viable alternative (Stevens and Stevens 1974). That alternative was framed as the Kerr-Mills Act of 1960 and was added to the Social Security amendments of that year.

Kerr-Mills (P.L. 86-778) created a new federal-state program, Medical Assistance for the Aged (MAA), which expanded the existing vendor-payment program under OAA. Like its predecessors Kerr-Mills fell well short of its legislative goals. Most states failed to expand medical coverage for the elderly, and this failure set the stage for the passage of Medicaid in 1965. Kerr-Mills was important to home care in two ways. First, it approved a relatively wide array of services, including "home health services," for federal cost sharing because its framers sought to

render Medicare unnecessary and make a narrow hospital insurance benefit package seem inadequate by comparison. Second, the legislation made federal cost sharing contingent upon state coverage of both institutional and noninstitutional services (U.S. Congress 1961a). This provision reflected fears about the sharply rising costs of institutional care and (possibly) about the inclusion of proprietary nursing homes as vendors (Vladeck 1980). It also acknowledged the success of advocates in making the case for the savings potential associated with home care services.

Kerr-Mills had provided incentives for states to subsidize costly institutional care rather than other types of health services (Stevens and Stevens 1974). States could meet the noninstitutional services requirement by including them in state enabling legislation and regulations. This did not compel them, however, to spend heavily (or much at all) on these services, as would become apparent under Medicaid. Title XIX (Medicaid) mandated five basic services and ten optional services, including noninstitutional services like home health care and private-duty nursing care. With minimal planning, a relatively varied menu of services for low-income, chronically impaired persons had been defined and financed.

1966–1975: Hope Springs Eternal

The decade following the 1965 amendments was dominated by efforts to clarify and fix ambiguities in the 1965 law, to address unresolved issues, and to expand the supply of home care and, to a lesser degree, access to it. The Social Security amendments of 1967 moved home health care from optional to mandatory among Medicaid benefits (Greenfield 1968). The 1972 amendments to the act, which extended Medicare coverage to the nonelderly with disabilities and to persons with chronic renal disease, also streamlined the terms of Medicare program participation for home care agencies and eliminated part B coinsurance requirements for home health users. Amendments to the Social Security Act in 1974 created the social services block grant program, consolidating various social service programs under a new title XX. Although its component programs had traditionally served families with children, title XX did provide limited home care coverage to the adult chronically ill, including the elderly (Callender and LaVor 1975). Beyond these offi-

cial actions, significant changes in health care were occurring that would alter the context within which home care was considered and set the stage for later debate about issues that had long defied easy resolution (Brown 1988).

Most fundamentally, home care was still a very small ticket item for public and private insurers. As a result, only a small cadre of analysts, administrators, and legislators paid it much heed. Professional home care interests remained localized and fragmented, despite periodic national meetings, and represented something less than a strong and coherent voice in the federal policy arena. Home care discussions were dominated by medical perspectives and a posthospital model, although less visibly by physicians and hospital administrators, who, now that they received federal reimbursement, had much larger fish to fry. Home care continued to be defined as an alternative to institutions and as a mechanism for reducing the costs of caring for the elderly and disabled.

Still, developments during the years following 1965 established a new era in health care and had important implications for home care policy. Most important, home care had now become a federal issue, at least to the extent that in a very short time Medicare had become the single largest payer for home care services and found itself addressing a series of basic policy questions: which services? for which persons? how intensively? for how long? Congressional and administrative staff became the key players in debates over issues large and small, most typically over specific programmatic issues that mirrored far larger ones. Medicare's resolution of these issues defined (or confirmed) a model of postacute home care that was to be dominant for years to come.

In the mid-1960s, it had been possible to muster broad-based support for the passage of health care financing legislation, in part because the economy was in exceptional health and federal revenue coffers were overflowing. By the early 1970s the fiscal implications of these new federal commitments had become clearer amid growing concern with inflation and the health of the economy. Although concerns about a crisis of rising health care costs were still diffuse and there was little consensus on solutions (Brown 1988), it was apparent to many that expenditures for institutional care were at the root of the cost problem. Trends in hospital costs continued to be an issue, as they had been prior to the passage of Medicare. Rapidly rising expenditures for nursing-home care were almost entirely the result of the 1965 amendments, as played out first through Medicare and later through Medicaid (Vladeck 1980).

Whereas the burden of health care costs on the elderly had provided the rationale for Medicare and, less directly, Medicaid, now the burden was being shared in a significant way by the public. Widely publicized scandals in the nursing-home industry, beginning about 1970 and continuing throughout the decade, set the stage for supporters of home care. The case could soon be made that home care was an alternative, not only to hospitalization, but also to nursing-home use (U.S. General Accounting Office 1974).

Health policy makers in the period immediately following World War II had been preoccupied with expanding the supply of health care resources and services, and the result was dramatic growth in the number of hospital beds, medical personnel, and research activities (Brown 1988). Only in the decade following 1965 did policy attention turn to the supply of home care, and supply issues dominated public debate about home care during this period. If home health care was to slow the rise in institutional expenditures under Medicare and Medicaid, it would need to be sufficiently available to be utilized.

After steady early growth, by the late 1960s utilization of home health services under Medicare had declined sharply despite rapid program enrollment of aged and disabled beneficiaries. The number of Medicare home health visits fell by 44 percent between 1969 and 1971 and did not return to 1969 levels until 1975. Medicaid home health reimbursements rose between 1969 and 1971, then declined by 15 percent in the next two years. The number of certified home health agencies remained essentially the same during this period, and more than half of the nation's counties reportedly had no agency operating in them (Callender and LaVor 1975). These patterns for the most part were blamed on the restrictiveness of the benefit, stringency of administration by fiscal intermediaries, and failure of SSA to tackle these problems (U.S. General Accounting Office 1974).

The 1972 amendments had tried to relax requirements for home health agency participation in the program as well as to remove ostensible barriers to utilization (e.g., the part B coinsurance requirement). Acknowledging the impact that skilled care requirements were having on access, the amendments also authorized demonstration projects to determine the suitability of coverage for homemaker services, lack of coverage for which was believed to constrain home care use (U.S. Congress 1972). Home health care expansion and personnel training resources in very modest amounts were authorized by the Health Revenue

Sharing and Nurse Training Act of 1975 (P.L. 94-63). Subsequent congressional hearings and reports continued to cite other administrative issues, including the stringency of the provider certification process, wide variations in intermediaries' interpretation of program coverage, and frequent denials of reimbursement (Callender and LaVor 1975). Many of these issues have been addressed over time, and beginning in 1975 both provider participation and beneficiary utilization began to rise steadily. More fundamental issues regarding the medical character of the benefit, with its skilled, intermittent, and homebound requirements, were also aired regularly, but not resolved. In administering Medicare, the primary focus of SSA was to enhance administrative uniformity and fairness, not to debate the narrowness of the benefit.

Debate could not be avoided, however, because agencies within the federal Department of Health, Education and Welfare (DHEW) were divided regarding the future of home care under the Social Security Act. For example, the Public Health Service (PHS), which had supported early studies of chronic illness in the 1940s, now supported expansion of home health eligibility and services, including coverage for some homemaker services. Although expansionist, PHS maintained its historical allegiance to medical necessity and a strong role for physicians in determining need for and scope of care. PHS was aligned with the committees on aging in both houses and with the Administration on Aging, a social service agency that did not yet consider home care a priority. Relative to their agency and congressional peers, PHS and its allies were considered the home care "zealots" of their period.

At the other extreme was the SSA, whose focus was administrative reform to ensure consistent intermediary practices. SSA was committed foremost to protecting the health or medical character of Medicare, which meant opposition to any expansion of what were described as "domestic" (e.g., homemaker) services. While acknowledging the important role of the physician in making initial recommendations, SSA was also determined to strengthen the role of intermediaries in approving and denying reimbursement claims. This cautious and conservative approach was shared with key staff on congressional appropriations committees, who worried about the fiscal integrity of the Medicare program. Similarly, the Social and Rehabilitation Service (SRS), which administered Medicaid, proposed to expand home health care services under Medicaid, but was reluctant to endorse any expansion of homemaker or other social services.

Key staff in the office of the Assistant Secretary for Planning and Evaluation (ASPE) in the mid-1970s can best be described as both advocates and realists. Although their longer-term agendas included expanded, publicly funded home care for the chronically ill elderly, their analysis of contemporary issues was critical of exaggerated claims for the benefits of home care. ASPE cited a number of issues: little agreement on care goals or appropriate service populations, few data on costs and benefits, little consistency regarding service definitions, and a paucity of useful evidence to support or illuminate claims for substitution. In a widely discussed background paper, Callender and LaVor (1975) identified long- and short-term models of home care, as well as three levels of care (basic, intermediate, and intensive). They highlighted tensions between medical and social conceptions of care, suggesting, for example, that supply issues were partly the result of congressional and SSA efforts to shield medical care from participation by social service agencies. They pointed also to the frequency with which SSA officials were careful to describe the duties of a home health aide as comparable to those of a nurse's aide in a hospital, again to reinforce the medical character of the benefit. Examination of home health care under private insurance revealed coverage that was uneven and limited and in almost no case broader than Medicare's (Callender and LaVor 1975).

Debate over the relative merits of the two models of home care defined in the 1965 amendments was taking place in the context of Medicare and Medicaid and, most visibly, within Medicare. The "Medicare model" was designed to provide short-term postacute care primarily through skilled services; any supportive services were incidental to skilled care and could only be provided in tandem with it. The "Medicaid model" allowed states to provide preventive, skilled, and nonskilled care to low-income, chronically ill persons (Comptroller General of the United States 1974). The Medicaid statute defined eligibility solely in terms of nursing-home eligibility, but included no prior hospitalization, homebound, or need-for-skilled-care requirements in the law. The Medicaid model implied longer-term services for persons with various acute and chronic care needs. This kind of benefit flexibility was anathema to SSA and, until the late 1980s, irrelevant in practice in a majority of states, which used restrictive Medicaid reimbursement to limit home health availability and various benefit restrictions to curb the use of nonnursing services by the elderly and disabled (Callender and LaVor 1975).

The 1972 amendments had authorized new studies, experiments, and demonstrations related to services not currently covered by Medicare (section 222). These provisions, along with those in the 1965 amendments permitting "waivers" under Medicaid (section 1115), extended a tradition begun by the Commonwealth Fund and other foundations a half century earlier to support new approaches to provision of chronic care. PHS had supported small demonstration programs following World War II, and this approach singularly appealed to numerous policy makers. Experimenting with alternatives to institutional care permitted persons who were concerned with fiscal integrity issues to examine actual programmatic experience and costs, but on a conservative scale; it gave advocates the opportunity to build their case more emphatically and concretely; and it provided time for further debate on the issues to those who were ambivalent.

In mid-1974, DHEW awarded contracts for six section 222 experiments in homemaker and medical day care services and selected a firm to evaluate them. Findings from a number of other modest home care demonstrations funded under Medicaid since 1966 were difficult to interpret because of a variety of methodological limitations. Nonetheless, the demonstration project provided an arena for provision of social as well as medical services and a crucible for testing the extent to which "alternative" services like home care substituted for institutional use. In subsequent years, these demonstrations would provide an important vehicle for considering home care outside the confines of the Medicare model. At least partly because of Medicare's sudden prominence as the largest health care financing program, in many policy eyes home care had become equated with Medicare's limited, postacute home health benefit for (primarily) persons over 65 years of age. Only later would less restrictive models for the chronically impaired elderly and nonelderly command serious policy attention.

1975-1982: Conflict, Debate, and Legislative Action

By the mid-1970s, those concerned with the availability of home care were encouraged by the fact that expenditures under Medicare and Medicaid were accelerating; home care costs roughly doubled in each program between 1975 and 1978 (Comptroller General of the United

States 1977; Pillemer and Levine 1981). Still, conviction remained widespread that public home health care benefits were too restrictive and that more home care agencies and personnel were needed to stem the rising tide of demand for institutional care. The doubts about home care as an alternative began steadily to shift to nursing homes as, by 1975, their growing costs were becoming an acknowledged problem. Medicaid nursing-home expenditures were to triple in the next decade, and by 1975 nursing-home outlays represented about 40 percent of all program spending (Gornick et al. 1985). The state budget crises of the late 1970s and the looming federal deficits that materialized in the 1980s added weight to expectations about substituting home care for nursing-home care.

An important 1977 report from the Congressional Budget Office (CBO) argued that a disproportionate amount of service funds for the elderly and disabled was going to nursing homes, and claimed that an estimated 20 to 40 percent of nursing-home residents could be cared for less intensively in other settings (Congressional Budget Office 1977a). The report described several reform options, including federal long-term-care insurance and consolidation of all relevant program funds under a single federal agency. The most incremental and least expensive option involved liberalization of home care benefits under Medicare and Medicaid (Congressional Budget Office 1977a). In this context the report suggested expanding Medicare's "skilled care" definition and eliminating the "homebound" requirement. Despite its endorsement of home care as an alternative, CBO warned that home care could be as expensive per unit (day) as nursing-home care. The report cautioned that existing research on home care costs was inadequate, while citing some evidence that the relative costs of home versus nursing-home care might depend on level of disability (Congressional Budget Office 1977b). By this time, the analysts were becoming far more cautious in their claims for home care than their congressional employers.

By the late 1970s, home care had become a part of the new debate about "long-term care" for the elderly. Projections about accelerated growth in the aging population were being generated by the U.S. Bureau of the Census (1984), while national survey data on the prevalence by age group of activity limitations due to chronic conditions were being reported by the National Center on Health Statistics (Rice and Feldman 1983). It was now well understood that the doubling of the population over age 65 between 1940 and 1970 was but a prelude to the growth an-

ticipated in the next half century, and that the fastest growth would occur among the very old, who were the frailest and neediest (Health Care Financing Administration 1981). In the early 1970s the newly coined term "long-term care" was generally equated with nursing-home care. By 1975, those in government most interested in aging had broadened the term to include a range of health, social, residential, and income benefits related to care of the chronically ill. (This broad conception of chronic care was characteristic of reform discussion in the 1920s and 1930s, but receded during the health insurance debate of the 1950s and 1960s.) Whereas home health care financed by Medicare continued to receive considerable administrative and legislative attention, a significant portion of the home care debate had now shifted to the long-term-care arena. When long-term care was the subject, the excesses of "inappropriate" nursing-home utilization and the need for more home care generally were emphasized (Congressional Budget Office 1977b).

This was also the period when home care lost its innocence. Home care had come to be represented as a cluster of services whose prospective benefit was inestimable if only enough could be provided to the elderly and disabled. During the decade following the 1965 amendments, home care expenditures had actually declined, but now spending seemed to take off. In an inflationary environment when hospital and nursing-home expenditures were climbing at an unnerving rate, home health expenditures were also increasing rapidly under Medicare. Although this trend was a source of substitutional hope, it also began to produce fiscal anxiety (U.S. General Accounting Office 1979). The most dreaded theme of the period probably was "uncontrollable spending" for public programs (Derthick 1975).

This concern was in no way relieved by other developments in the home health industry. By 1975, a series of congressional hearings had begun to unearth evidence that all was not well within the growing ranks of home health providers. In language reminiscent of continuing hearings about nursing-home scandals, testimony warned of the entry of profit-making agencies into the market, both as proprietaries and as nonprofits established by proprietaries. Under Medicare regulations, reimbursement was allowed for proprietaries only in states that licensed them. Because half the states did not, proprietaries could enter those markets only through spin-off nonprofits (U.S. General Accounting Office 1979). In congressional hearings, proprietary agencies were harshly described as "an unusual concentration of real estate manipulators and

quick-buck artists" (U.S. Congress 1975). Senator Chiles of Florida, where proprietaries seemed to be thriving, decried agencies that had clearly been ripping off the Medicare system and lamented increased patterns of overutilization, padded costs, and hidden profits (U.S. Congress 1975).

To make matters worse, the General Accounting Office cited continuing lax administration of the home health benefit. Wide variations in decisions by fiscal intermediaries, approval of questionable claims, and frequent overpayments continued to be an issue (U.S. General Accounting Office 1979). In this context other assessments pointed to the growing competition faced by traditional (and less expensive) home health providers like VNAs from new entrants into the field (including hospital-based agencies), whose higher charges exerted upward pressure on program expenditures (Office of the Inspector General 1981). Home care, once considered a cottage industry run by well-intentioned nurses and social workers, was now big business and, like the nursing-home industry, seemed to be tainted by corruption and mismanagement. The integrity of providers and the quality of the care they were selling had now become a public policy issue.

In the eyes of many long-term-care analysts, home care had not only lost its innocence, but also its simplicity; it had now become a perplexing and complex topic. A report in 1981 by the U.S. Health Care Financing Administration (HCFA) concluded that most home care would not substitute for expensive nursing-home care, but would largely serve new populations. As a client's disability level increased, so would the likelihood that home care would be more expensive than nursing-home care (also see Congressional Budget Office 1977b). Weissert and his colleagues (1980) analyzed data from recent demonstration programs and found that, although client contentment and satisfaction improved, broadened coverage of homemaker services was not associated with significant improvements in client function and significantly increased the costs of care.

Another theme long implicit in the home care debate now became an explicit issue for federal analysts. The importance of family and friends as informal caregivers for the elderly and disabled was now widely acknowledged. Various studies had indicated that 60 to 80 percent of care received was being provided informally (1981), and some efforts to estimate the relative costs of home versus nursing-home care now included shadow prices for the services of family and friends (Congressional Budget Office 1977a). A dilemma recognized a half-century earlier, but not

explicitly addressed in subsequent public policy debate, now entered the home care (and broader long-term-care) discussion. On the one hand, it was predicted that for a variety of reasons the ability of families to continue to care for the elderly and disabled might decrease in coming years, causing the need for formal services to grow. On the other hand, little was known about the extent to which expanded home care benefits would lead to a reduction in care provided informally. Demonstration projects to date had tried to examine changes in utilization of formal (home care) services. None had explored the extent to which new benefits might supplement or supplant current informal care.

The increasingly complex topic of home care had, by the late 1970s, become a subject for much study as Medicare analysts scrutinized the role of home health care within the rapidly growing title XVIII program, and long-term-care analysts considered the role of home care within a broader long-term-care benefit, for which various options were being discussed. All of this was complicated by a profound shift in federal and state budget politics (from expansion to tax reduction and deficit management) and in attitudes toward the role of government signaled by Carter policy and the election of President Reagan in 1980. While key members of Congress, agency staff, and others were convinced that real long-term-care reform was needed, the prevailing mood in the Reagan administration was fiscal restraint, reinforced by distrust of carryover bureaucratic staff members with the necessary experience and expertise to design feasible reform measures.

Although there was little consensus about the necessity or direction of federal long-term-care reform, between 1978 and 1982 the various factions agreed on several new policy initiatives. First, two new demonstration strategies would be adopted: the National Long Term Care Channeling Demonstration authorized in 1979 and the Medicaid (section 2176) Waiver Program in 1981. Second, the Medicare home health care benefit would be liberalized in ways recommended in a controversial 1979 report by DHEW, called the H.R.3 report. Third, a new hospice benefit with a strong home care component would be authorized under Medicare in 1982.

Earlier demonstration programs had been disappointing principally because they involved one-time, single-site projects that yielded few generalizable lessons and had limited program impact beyond single communities. Although demonstrations would seem to be a straightforward way to evaluate new approaches, as well as symbols of program re-

solve and initiative, the approval by Congress in 1979 of the Channeling Demonstration followed a complex struggle within the administration about next steps in services for the elderly. The first result was a multi-site, case-managed service demonstration to run through 1985 and to be designed and evaluated with a methodological rigor unknown to earlier projects.

Another quite different demonstration approach was enacted into law under section 2176 of the Omnibus Budget Reconciliation Act (OBRA) of 1981. Realists among congressional and agency staff had been disappointed with the evolution of Medicaid long-term-care policy, which had been heavily influenced by Medicare values and was oriented toward medically related services delivered in an institutional setting (Laudicina and Burwell 1988). Earlier Medicaid demonstrations authorized by section 1115 of the 1965 SSA amendments had been limited in scope and duration and had no impact on most elderly and disabled recipients. Reformers sought and got something broader, namely, a benefit waiver that broadened the scope of allowable state Medicaid program activity. Specifically, section 2176 permitted states to receive federal matching funds under Medicaid for a variety of home and community-based services provided to persons who otherwise would require nursing-home placement.

The additional flexibility available to the states under the waiver program was intended to permit state programs to innovate by expanding the range of covered services and targeting the populations most in need. The budget reconciliation process put a damper on expected innovation by requiring budget neutrality, namely, that state program expenditures were not to increase as a result of the waiver. On balance, the 2176 program in its early years had little impact because HCFA was stringent in approving waivers and in monitoring their administration, most states were cautious in designing waiver programs, and relatively few persons received home and community-based services through the program (Holahan and Cohen 1986; Laudicina and Burwell 1988).

Beginning in the early 1970s, when a decline in Medicare home health use was the primary problem, and continuing through the late 1970s, when escalating hospital costs renewed the search for alternatives, various voices within government had identified a series of changes in the Medicare home health benefit that would liberalize its use (Callender and LaVor 1975; LaVor 1979; Congressional Budget Office 1977b). Given the extent of agreement about the need to modify various provisions of

the benefit, it is surprising that congressional action did not occur until 1980. In light of estimates about the potential costs of liberalizing benefits, it is surprising in the restrictive budget environment of the period that any action was taken. As it turned out, with one exception the subsequent impact of the legislation was probably overestimated by most of those involved (Pillemer and Levine 1981).

The Omnibus Reconciliation Act (ORA) of 1980 contained several Medicare amendments designed to remove selected limitations in the original law. First, the act removed existing limits on the number of allowable home health visits (at the time 100 visits each were permitted under parts A and B). Second, the amendments eliminated the existing (three-day) prior hospitalization requirement for home health benefits under part A. Third, the deductible (\$60) was eliminated under part B. Fourth, the amendments eliminated the requirement that for-profit (proprietary) home health agencies only be certified for program reimbursement in states that licensed these agencies. Architects of these amendments hoped that the changes would encourage expanded use of in-home care and discourage institutionalization.

Although dropping the prior hospitalization requirement had symbolic significance, maintaining the skilled care requirement meant that nearly all who qualified were recovering from an acute episode serious enough that hospitalization had been necessary. One feature of the ORA amendments that was to have a notable effect on the home health care market opened up Medicare participation to proprietary home health agencies. By mid-decade, the number of for-profit agencies receiving Medicare reimbursement would increase six-fold (Benjamin 1984). There was considerable worry and some evidence (never entirely convincing) that proprietaries delivered more expensive care and were less likely to accept Medicaid clients than other agencies (Pillemer and Levine 1981; Benjamin 1986). Arguments about the place of profit in home care would become even more relevant later in the decade, as the number of proprietaries grew to one-third of all Medicare-certified home health agencies (Silverman 1990; Kenney and Dubay 1992).

Two other legislative developments in 1982 were to have implications for the role of home care in publicly financed health care programs. The first was the passage of Medicare amendments in 1982 that authorized Medicare reimbursement for hospice care for the terminally ill under the Tax Equity and Fiscal Responsibility Act (TEFRA) of 1982 (P.L. 97-242, section 122). The hospice story is an extraordinary one because in less

than five years hospice services had gone from uncovered and unnoticed to mainstream benefit under Medicare (albeit with a sunset clause that was later dropped). Effective lobbying by hospice interests led to authorization of a large-scale Hospice Demonstration Program, initiated in 1980. The most prominent component of the hospice model was home care, and savings were to be gained from a reduction in inpatient hospital use by the terminally ill. Without the benefit of evaluation data, which was still several years away, and without hearings in the Senate, a Medicare hospice benefit was authorized (Mor 1987). This hospice legislation created a new arena of home care activity, attracted considerable public attention, and deflected pressures for more fundamental reform. These pressures were soon to be rekindled, however, because TEFRA 1982 also called for changes in the way hospitals were reimbursed under Medicare. This would generate new interest in what happened to the elderly and disabled outside the hospital.

1982–1990: Keeping Home Care on the Policy Agenda

The period between 1979 and 1982 had been one of action and promise for federal home care policy. The Channeling Demonstration, Medicaid 2176 Waiver Program, and the hospice benefit under Medicare were initiated, and the Medicare (ORA) amendments of 1980 had been designed to ease the restrictiveness of the home health benefit. Although the following years would see a new wave of demonstrations and legislative proposals, along with improvements in federal data on chronic care needs and refinements in interpreting past research on home care outcomes, the sense in the late 1970s of the inevitability of long-term-care reform was now replaced in the 1980s by the political necessity to contain health care costs (and public expenditures generally), including those for home care.

Developments in home care policy in the 1980s can best be understood within the larger context of the politics of spending cutbacks, limited government, and competitive solutions that characterized this period. Within the temper of the times, expanded and costly health care coverage, including reforms in long-term care, did not seem politically feasible. However, the place of home care within reform discus-

sions would become more central during this period, while the extent of actual programmatic commitment to home care would grow only incrementally.

For understanding home care, the definitive policy event of the 1980s was the authorization of the Medicare prospective payment system (PPS) for hospitals under TEFRA in 1982. Discharge incentives for hospitals (and physicians practicing in them) were significantly altered, as was conventional thinking about the centrality of the hospital within the care system (Gornick and Hall 1988; Ruther and Helbing 1988). Attention was now focused on the posthospital experience. Even where home care was available, before PPS there were few incentives for physicians and hospitals to consider utilizing it because both were reimbursed for all of the days patients remained in hospitals (Steel 1991). With prospective payment, hospitals now faced discharge incentives whether home care was available or not. As the length of Medicare hospital stays declined, it also became clear that shortened stays were the result of reimbursement reform, and not of home care "substitution" (Weissert 1991).

In a period in which tinkering with current home care benefits was to prevail over framing basic reform, costs and quality were the most prominent and frequently aired themes. By mid-decade, home health care was being described as the "fastest growing" service under Medicare. Program payments had passed \$1.0 billion by 1982 and \$2.0 billion by 1989 (1990). Medicaid expenditures for home care, barely half a billion in 1982, had more than quadrupled by 1988 (Reilly, Clauser, and Baugh 1990). These were, in Washington parlance, "real numbers," which meant that spending growth would need to be monitored and slowed, even as concerns grew about the elderly being "dumped" at home by hospitals without adequate posthospital care (Estes and Binney 1988).

Federal officials and the home health lobby spent much of the decade contesting two initiatives that addressed home health costs issues. Section 223 of the 1972 Social Security amendments (P.L. 92-603) had authorized establishment of cost limits for Medicare reimbursement (LaPorte and Rubin 1979), but until the late 1970s there had been no effort to specify and implement them. Under pressure to gain control over home health costs, HCFA in mid-1979 defined initial cost limits by visit type. The home health industry devoted considerable energy through the late 1980s to pressuring HCFA to revise the methodology used and

to loosen the cost limits. In 1982, P.L. 97-414 instructed DHHS to undertake demonstration projects to test alternative reimbursement methodologies for home health agencies. Home health care had been spared immediate conversion to prospective payment because no one knew how to implement prospective payment for long-term care and because retrospective reimbursement per visit with cost limits had been workable. A reimbursement demonstration had been opposed by the largest home health association, canceled by the Office of Management and Budget, and was finally launched in 1988. Development of a patient classification (case mix) system for home health is an essential element of the demonstration program (Williams 1986).

Although the costs of home health care became a prominent public issue in the 1980s, the rate of growth in Medicare home health utilization and expenditures actually slowed between 1983 and 1987, then began to accelerate again. Analysis of these patterns suggests that, although the percentage of beneficiaries using home health services within 60 days of hospital discharge grew steadily after 1983 (Gornick and Hall 1988), hospital admissions dropped and home health visits per user flattened in mid-decade, and actually declined among those over age 80 (American Association of Retired Persons 1991). Various explanations are offered for these trends, principally that the effects of ORA (1980) and TEFRA (1982) had already been absorbed by 1985 and that more stringent interpretation by HCFA of eligibility in 1984, as well as the tightening of reimbursement ceilings in 1985, began to constrain utilization. Another round of federal efforts to loosen program regulations began in 1987 under pressure from providers and Congress.

Issues of quality in home care had been aired in the mid-1970s and did not disappear in the 1980s. Reports continued to be heard of problems ranging from home care workers failing to appear on time and sitting down on the job to theft, fraud, and abuse. Critics understood the dual challenge of monitoring care delivery in a field that had grown rapidly in recent years in essentially an invisible setting (U.S. Congress 1986). Greater administrative and professional attention has been given to developing "quality assurance" procedures, and federal research funds have been allocated to examine quality and outcomes issues in home care, mirroring broader interest in health outcomes research. Nearly all of the long-term-care bills introduced during this period included provisions related to home care quality (O'Shaughnessy and Price 1989). OBRA 1987, whose regulatory provisions most visibly ad-

dressed nursing-home quality, contained very similar language (involving training, inspections, and sanctions) aimed at home health agencies. Although nursing-home issues provided the impetus for this legislation, inclusion of home health was now much more than an afterthought.

Other developments in the 1980s generally served to strengthen the role of home care within contemporary thinking about health policy, even while issues concerning appropriate public roles in long-term care continued to complicate the debate. Under pressure from the Reagan administration, federal policy makers turned away from the public sector and looked to the private sector for long-term-care solutions (U.S. Health Care Financing Administration 1984). Of particular significance in this context was the rapid growth in the market for private long-term-care insurance in the 1980s (Meiners 1984). Whereas in the decades prior to 1965 the experience of private insurers had helped to shape the provisions of Medicare posthospital benefits, in recent years these insurers have confronted a new set of market challenges. Although only about 3 percent of the elderly currently have long-term-care insurance (Wiener and Harris 1990), recent growth in the number and variety of policies has been significant (Rivlin and Wiener 1988).

Paradoxically, the primary criticism of the home care features of many policies has been that they too closely approximate Medicare's home health provisions and, in some cases, retain coverage restrictions dropped by Medicare following the 1980 ORA reforms. Most such insurance has restricted home care benefits to skilled care following a hospital or nursing-home stay, and episodes of care of long duration have frequently not been covered (U.S. General Accounting Office 1987; Wiener and Harris 1990). Still, private insurers have steadily modified their offerings during the last decade in an effort to expand their market penetration. Like the framers of Medicare in the 1960s, they have generally concluded that home health care services must be included to offset incentives to enter and remain in institutional settings. Although home health care as an "alternative" is now integral to "long-term care" insurance, coverage of nonmedical, supportive home care services of extended duration remains the exception rather than the norm.

Two other developments suggest that home care achieved a new level of legitimacy during the 1980s. Simply put, hospitals and physicians are interested once more in care at home, and not simply as a result of PPS. Hospitals have moved into the home health business on a large scale;

only free-standing proprietaries grew faster in number in the last decade. Hospitals have also been involved in the marketing and provision of "high-technology" home health care as part of what might reasonably be described as exporting the hospital room to the home.

The role of physicians remains considerably more ambiguous. Although some physicians were investing in proprietary home health agencies, others began to talk about a revived role for "house calls" in community medicine (Sivek 1985; Council on Scientific Affairs 1990; Steel 1991). The reintroduction of physician home visits for selected populations and conditions probably makes good social and clinical sense. Viewed more cynically, efforts by hospitals and physicians to expand their roles in the home may also be interpreted as the self-interested pursuit of new reimbursement opportunities and a diversion from designing effective chronic care at home.

Another development has had a significant effect on the changing visibility and legitimacy of home care, and this involved data collection and research. In mid-decade, an era of small studies and sketchy findings about home care seemed to draw to a close with publication of the long-awaited evaluation report from the Channeling Demonstration (Kemper 1988). The findings were summarized well by Weissert, whose stature in the field is unmatched despite his penchant for synthesizing and communicating bad news:

These studies found home care was used mostly by those not at risk of entering a nursing home, costs increased with provision of home care, and benefits of home care are few and fleeting. (Weissert 1991, 68)

Publication of new research findings along with several widely read syntheses of research on home care (Hughes 1985; Hedrick and Inui 1986; Kane and Kane 1987; Weissert, Cready, and Pawelak 1988) all pointed to the need to understand home care in terms other than as a cost-saving alternative to institutional use. Rather, it was suggested that home care could be redefined as a sensible benefit preferred by many persons and their families, to be sold politically in terms that avoided "the cost-effectiveness trap" (Weissert 1985).

In part because of the availability of various federal data sets related to home care needs and use, the range of policy scholars working on home care issues expanded significantly during the 1980s. At the beginning of

the decade, it was difficult to find anything published on home care in major journals outside of nursing and social work. Today, research on home care involves scholars from diverse disciplines who publish their results in the mainstream health journals. Although this shift was in large measure inspired by the rapid growth of Medicare posthospital expenditures and accompanying federal research support, professional interest in broader home care issues has found a place on the health services research agenda.

These and other developments meant that despite the weight of the ongoing budget crisis and a steady conservatism in domestic policy, long-term-care reform became increasingly visible on the congressional agenda during the latter half of the 1980s, and the role of home care became more prominent. This was due in part to a political struggle to determine which party could be most responsive to the elderly and in part to the persistence of home care's reputation in Congress as a cheaper and better alternative. A range of bills was introduced, primarily with Democratic sponsorship, and all combined nursing-home and home care coverage in some fashion. None was more prominent than the Medicare Long-Term Home Care Catastrophic Protection Act of 1987 (H.R. 2762), not to be confused with the Catastrophic Coverage Act.

This bill sought to establish a home care benefit under Medicare for the chronically disabled of all ages, based upon inability to perform two "activities of daily living" (ADLs). The sponsor, Congressman Claude Pepper, publicly demanded that this expanded home care benefit be included in what was to become the Medicare Catastrophic Coverage Act of 1988 (P.L. 100-360). Determined efforts by fellow Democrats, who feared that the additional costs and controversial financing (i.e., removing the cap on income subject to the Medicare portion of the payroll tax) would threaten passage of the broader bill, succeeded in defeating the Pepper Bill in June 1988.

The Catastrophic Coverage Act was approved by Congress in the same month. Although it contained no long-term home care provisions, the act included three provisions that involved incremental changes in the Medicare home health benefit. First, it loosened limits on intermittent care by extending coverage "provided on an intermittent basis. . . to 38 consecutive days" (P.L. 100-360). Second, it introduced coverage of limited respite care in the form of up to 80 hours per year of in-home care for chronically dependent persons, in order to provide

a respite (break) for informal caregivers. Third, the act extended Medicare coverage of home intravenous drug therapy services, supplies, and equipment. Significantly, the act also included provisions to establish a U.S. Bipartisan Commission on Comprehensive Health Care, which was charged with, among other things, making recommendations on comprehensive long-term-care services for the elderly and disabled.

In its final report, that commission integrated the primary features of the Pepper Bill into its long-term-care provisions. In addition to protection against the costs of nursing-home care, the commission recommended that a broad array of home care services be available to all persons with severe disabilities, regardless of age. In response to reservations as old as American welfare policy, the commission recommended relying upon case managers to develop and oversee care plans, in order to “ensure that home care services support but do not replace family care giving and are managed in a fiscally responsive manner” (U.S. Congress 1990). Whereas the Pepper Bill set the level of disability at two ADLs, the Pepper Commission chose to be more restrictive (and less costly) with a standard of three ADLs, estimating that 4.1 million persons would qualify. (Both the commission report and the Pepper Bill also include serious cognitive impairment as a basis for eligibility.) On a related front, OBRA 1990 authorized home and community-based services as an optional (nonwaiver) benefit for Medicaid eligibles unable to perform two ADLs without assistance (Lipson and Laudicina 1991). That ADL levels had become a subject of disagreement among policy makers indicated that disability assessment has gained legitimacy and that the policy debate had begun to move beyond age and income in considering eligibility for public benefits.

Two other points must be made about the work of the Pepper Commission. First, according to observers there was little or no debate about the inclusion of broad home care benefits, including personal care, homemaker/chore, shopping, respite, and other services. In this context (which included little attention to—or agreement about—financing) an integrated medical and social home care model emerged as a primary component of a long-term-care service package. Second, although nearly everyone agrees that the commission’s various recommendations are unlikely to be acted upon by Congress or the administration anytime soon, they nonetheless represent an important blueprint and source of legitimacy for future action.

Conclusions

The purpose of historical analysis is to put current events in a broader context and to develop a better understanding of factors influencing those events. When viewed historically, what is striking in the current home care debate is the persistence of themes that have their roots in the emergence of modern medicine nearly a century ago. Development of home care policy continues to be constrained by the view that home care is a residual set of services, at least somewhat apart from mainstream health care. Home care policy still suffers from an absence of consensus about its principal goals, elements, and place in a continuum of care. Health care financing and medical practice continue to emphasize a postacute model of care, although attention is beginning to shift. Past associations between the social-supportive model and the welfare poor, as well as persistent myths about the presumed costs of public financing for supportive care, continue to restrain enthusiasm for this model. The rationale for home care remains dependent upon claims for the impact of home care on institutional use and costs.

Recent developments also suggest that policy thinking about home care is no longer characterized simply by the ambiguity and uncertainty of past decades. This is a matter of degree, however, because many of the same issues that have constrained policy development historically have not disappeared, but rather have been recast over time. After nearly three decades of federal financing under Medicare and Medicaid, home care is no longer widely perceived as residual. A growing range of interests now supports proposals to provide a variety of home care services to the acute and chronically ill as a right, based on need rather than previous or anticipated service history. Yet political and professional conviction about the need for comprehensive home care services is far from universal. Among others, some elected officials remain preoccupied with the nursing-home problem and fear the costs of home care, and many physicians remain unaware of or indifferent to patient care needs at home.

There is now a growing consensus about the essential elements of a comprehensive home care model that integrates current postacute, social-supportive, and hospice models in a flexible manner. Yet categorical programs and priorities continue to dominate the current delivery of home care. The development of consensus about definitions of home care is complicated by the persistence of limited models, particularly the

postacute home health benefit under Medicare and many private insurers. While the signal home care development of recent years has been the growth of interest in the social-supportive model (primarily through federally financed demonstrations, their evaluation, and the ensuing debate), familiar doubts continue to persist about public financing for supportive care. For example, despite evidence to the contrary from the Channeling Demonstration and elsewhere, many policy makers continue to fear that if public financing for chronic home care increases, the result will be vastly expanded demand for home services and the collapse of informal care provision by family and friends. Although we still have relatively few data about precisely who demands home care and under what circumstances, concerns about public financing of supportive home care extend beyond a dispassionate weighing of the evidence. Other issues related to defining and monitoring home care quality are currently being addressed in federally supported demonstrations and research. Some policy makers continue to be troubled by fears of scandal as attendants and homemakers enter the homes of hundreds of thousands of chronically ill persons, although evidence of quality problems in formal home care is relatively scant.

Part of the problem in developing a consensus about the essential elements of comprehensive home care lies in persisting uncertainty about the goals of social-supportive home care. This model involves various rehabilitation goals for many users, but is also concerned with providing maintenance and support services, with slowing decline where possible, and providing comfort where decline is inevitable. Maintenance goals continue to suffer from medical disdain, lack of political appeal, and a close association with uncompensated care by families and friends. This remains the case despite wide experience demonstrating that trained personnel can ease the burden on informal caregivers and provide significant relief and comfort to the chronically ill and their families.

No theme in home care's recent history is stronger than its reliance for legitimacy on reducing the use and costs of inpatient acute and nursing-home care. In the last decade, the most consistent theme in home care research has been that home care does not reduce institutional utilization or expenditures. Although much remains to be learned about whether and how home care may affect overall costs for specified subsets of persons in need, it is no longer easy to make public claims about the potential "savings" to be had from home care. Curiously, these claims persist (especially among elected officials) and, indeed, they still seem

important to keeping home care on the policy agenda. This is so primarily because the rising costs of health care plus relentless budget crises in government apparently require that any prospective reforms (especially nonmedical ones) be linked with reduced costs to the treasury. For home care, despite the mounting evidence to the contrary, these traditional claims continue to have symbolic significance.

Since the turn of the century, health professionals and others have argued about the appropriateness of the home as a locus of care. In recent years, the home generally has become less suspect as a care site. Advances in medical technology and the rush of hospitals to enter the home care business have enhanced the legitimacy of postacute home care in the eyes of the medical profession. This cuts both ways, however, because while home care gains legitimacy, it is the postacute perspective that is strengthened. These developments in turn may make it more difficult to shift resources to social-supportive care or to expand that care outside medical auspice.

The current fiscal context of reform, including the burgeoning costs of health care and the decline in the economy, suggests that home care is likely to remain salient in the reform debate for the foreseeable future (Congressional Budget Office 1991). Inexorable changes in demographics, with growing numbers of frail elderly, persons with AIDS, and children and adults surviving with disabilities, suggest that both economic and political demand for publicly financed comprehensive home care is likely to grow. Increasing demand may make it easier for elected officials to support expanded funding for home care because it is preferred by significant numbers, even as claims fade regarding its impact on institutional expenditures.

Paradoxically, although home care has been considered residual and dependent, reform also has been constrained because home care historically has been associated with a range of policy issues extending well beyond illness. The passage of the Social Security Act in 1935 assured a guaranteed income for most retired persons, giving these persons most likely to be affected by chronic illness the resources to remain at home in old age. Successful home care implies adequate income, housing, transportation, and health care. Consequently, larger issues of life quality and the role of the welfare state are inherent in public policy commitments to services at home.

Reports from the Pepper Commission and Physicians for a National Health Program (Harrington et al. 1991) are the two most prominent

examples of recent proposals to expand the federal role in long-term care, and comprehensive home care benefits are featured in both. Although long-term-care reform probably is not imminent, many observers consider reform likely in the next decade. For a host of reasons, including emergence of various consumer constituencies that prefer home care (Litwak and Kennedy 1991; U.S. General Accounting Office 1989; Benjamin 1988), future reform is likely to include comprehensive home care across traditional eligibility categories. How the public sector addresses home care issues—and not nursing-home ones—is at the heart of the contemporary policy challenge in long-term care.

References

- American Association of Retired Persons. 1991. *Medicare's Home Health Benefit: Eligibility, Utilization, and Expenditures*. Washington: AARP Public Policy Institute. (Issue brief)
- American Hospital Association, American Medical Association, American Public Health Association, and American Public Welfare Association. 1947. Planning for the Chronically Ill. *American Journal of Public Health* 37:1257-66.
- Bardwell, F. 1930. Public Outdoor Relief and the Care of the Aged in Massachusetts. In *The Care of the Aged*, ed. I.M. Rubinow, 54-64. Chicago: University of Chicago Press.
- Benjamin, A.E. 1984. *Understanding State Variations in Home Health Utilization and Expenditures Under Medicare*. San Francisco: University of California, Aging Health Policy Center.
- . 1986. Determinants of State Variations in Home Health Utilization and Expenditures Under Medicare. *Medical Care* 24:535-47.
- . 1988. Long-term Care and AIDS: Perspectives from Experience with the Elderly. *Milbank Quarterly* 66:415-43.
- Boas, E. 1930. The Care of the Aged Sick. In *The Care of the Aged*, ed. I.M. Rubinow, 39-46. Chicago: University of Chicago Press.
- Boas, E., and N. Michelsohn. 1929. *Challenge of Chronic Disease*. New York: Macmillan.
- Brown, L.D. 1988. *Health Policy in the United States: Issues and Options*. New York: Ford Foundation.
- Callender, M., and J. LaVor. 1975. *Home Health Care Development, Problems, and Potential*. Washington: Department of Health, Education and Welfare.
- Commission on Chronic Illness. 1956. *Chronic Illness in the United*

- States*. Vol. 2: *Care of the Long-Term Patient*. Cambridge: Harvard University Press.
- Comptroller General of the United States. 1974. *Report to the Congress, Home Health Care Benefits Under Medicare and Medicaid*. Washington: Department of Health, Education, and Welfare.
- . 1977. *Home Health—The Need For a National Policy to Better Provide for the Elderly*. Washington.
- Congressional Budget Office. 1977a. *Long-Term Care Actuarial Cost Estimates*. Washington.
- . 1977b. *Long-Term Care for the Elderly and Disabled*. Washington.
- . 1991. *Policy Choices for Long-Term Care*. Washington.
- Council on Scientific Affairs. 1990. Home Care in the 1990s. *Journal of the American Medical Association* 263:1241-4.
- Derthick, M. 1975. *Uncontrollable Spending for Social Services Grants*. Washington: Brookings Institution.
- Epstein, A. 1930. Facing Old Age. In *The Care of the Aged*, ed. I.M. Rubinow, 77-82. Chicago: University of Chicago Press.
- Estes, C.L., and E. A. Binney. 1988. Toward a Transformation of Health and Aging Policy. *International Journal of Health Services* 18:69-96.
- Follmann, J.F. Jr. 1963. *Medical Care and Health Insurance: A Study in Social Progress*. Homewood, Ill.: Richard D. Irwin.
- Fox, D.M. 1988. Health Policy and Changing Epidemiology in the United States: Chronic Disease in the Twentieth Century. In *Unnatural Causes*, ed. Russell C. Maulitz, 11-31. New Brunswick: Rutgers University Press.
- . 1989. Policy and Epidemiology: Financing Health Services for the Chronically Ill and Disabled, 1930-1990. *Milbank Quarterly* 67:257-87.
- Gornick, M., J.N. Greenberg, P.W. Eggers, and A. Dobson. 1985. Twenty Years of Medicare and Medicaid: Covered Populations, Use of Benefits, and Program Expenditures. *Health Care Financing Review* (suppl.):13-59.
- Gornick, M., and M.J. Hall. 1988. Trends in Medicare Use of Post-Hospital Care. *Health Care Financing Review* (suppl.):27-38.
- Greenfield, M. 1968. *Medicare and Medicaid: The 1965 and 1967 Social Security Amendments*. Berkeley, Calif.: Institute for Governmental Studies.
- Harrington, C., C. Cassel, C.L. Estes, et al. 1991. A National Long-term Care Program for the United States: A Caring Vision. *Journal of the American Medical Association* 266:3023-9.

- Hedrick, S.C., and T.S. Inui. 1986. The Effectiveness and Cost of Home Care: An Information Synthesis. *Health Services Research* 20:851-80.
- Holahan, J.F., and J.W. Cohen. 1986. *Medicaid: The Trade-off Between Cost Containment and Access to Care*. Washington: Urban Institute Press.
- Hughes, S.L. 1985. Apples and Oranges? A Review of Evaluations of Community-Based Long-Term Care. *Health Services Research* 20:461-88.
- Jarrett, M.C. 1933a. *Chronic Illness in New York City*. Vol. 1: *The Problems of Chronic Illness*. New York: Columbia University Press.
- . 1933b. *Chronic Illness in New York City*. Vol. 2: *The Care of the Sick by Different Types of Voluntary Agency*. New York: Columbia University Press.
- Jensen, F., and H.G. Weiskotten. 1944. *Medical Care of the Discharged Hospital Patient*. New York: Commonwealth Fund.
- Kane, R.A., and R.L. Kane. 1987. *Long-Term Care: Principles, Programs, and Policies*. New York: Springer.
- Kemper, P. 1988. The Evaluation of the National Long-Term Care Demonstration: 10. Overview of the Findings. *Health Services Research* 23:161-74.
- Kenney, G.M., and L.C. Dubay. 1992. Explaining Area Variation in the Use of Medicare Home Health Services. *Medical Care* 30:43-57.
- LaPorte, V., and J. Rubin. 1979. *Reform and Regulation in Long Term Care*. New York: Praeger.
- Laudicina, S.S., and B. Burwell. 1988. A Profile of Medicaid Home and Community-based Care Waivers, 1985: Findings of a National Survey. *Journal of Health Politics, Policy and Law* 13:525-46.
- LaVor, J. 1979. Long-Term Care: A Challenge to Service Systems. In *Reform and Regulation in Long Term Care*, eds. V. LaPorte and J. Rubin. New York: Praeger.
- Lipson, L., and S. Laudicina. 1991. *State Home and Community-Based Services for the Aged Under Medicaid*. Washington: AARP Public Policy Institute.
- Litwak, S., and J. Kennedy. 1991. *Policy Issues Affecting the Medicaid Personal Care Services Optional Benefit*. Oakland, Calif.: World Institute on Disability.
- Marmor, T.R. 1973. *The Politics of Medicare*. Chicago: Aldine.
- Meiners, M.R. 1984. *The State of the Art in Long-Term Care Insurance*. Rockville, Md.: National Center For Health Services Research.
- Mor, V. 1987. *Hospice Care Systems: Structure, Process, Costs, and Outcome*. New York: Springer.

- Myers, R.J. 1970. *Medicare*. Homewood, Ill.: Richard D. Irwin.
- Office of the Inspector General. 1981. *A Service Delivery Assessment*. Washington.
- O'Shaughnessy, C., and R.J. Price. 1989. *Long-Term Care Legislation: Summary of Selected Bills*. Washington: Congressional Research Service.
- Pillemer, K.A., and A.S. Levine. 1981. The Omnibus Reconciliation Act of 1980 and Its Effects on Home Health Care. *Home Health Services Quarterly* 2:5-39.
- Reilly, T.W., S.B. Clauser, and D.K. Baugh. 1990. Trends in Medicaid Payments and Utilization. *Health Care Financing Review* (suppl.): 15-33.
- Reverby, S. 1987. *Ordered to Care: The Dilemma of American Nursing, 1850-1945*. New York: Cambridge University Press.
- Rice, D.P., and J.J. Feldman. 1983. Living Longer in the United States: Demographic Changes and Health Needs of the Elderly. *Milbank Quarterly* 61:362-96.
- Risse, G.B., R.L. Numbers, and J.W. Leavitt. Eds. 1977. *Medicine Without Doctors: Home Health Care in American History*. New York: Science History Publications.
- Rivlin, A.M., and J.M. Wiener. 1988. *Caring for the Disabled Elderly: Who Will Pay?* Washington: Brookings Institution.
- Rosenberg, C.E. 1987. *The Care of Strangers: The Rise of America's Hospital System*. New York: Basic Books.
- Ruther, M., and C. Helbing. 1988. Use and Cost of Home Health Agency Services Under Medicare. *Health Care Financing Review* 10:105-8.
- Silverman, H.A. 1990. Use of Medicare-covered Home Health Agency Services, 1988. *Health Care Financing Review* 12:113-15.
- Sivek, J. 1985. House Calls: Current Status and Rationale. *American Family Physician* 31:169-74.
- Smits, H.L., J. Feder, and W. Scanlon. 1982. Medicare's Nursing-Home Benefit: Variations in Interpretation. *New England Journal of Medicine* 307:855-62.
- Starr, P. 1982. *The Social Transformation of American Medicine*. New York: Basic Books.
- Steel, K. 1991. Home Care for the Elderly: The New Institution. *Archives of Internal Medicine* 151:439-42.
- Stevens, Robert, and Rosemary Stevens. 1974. *Welfare Medicine in America*. New York: Free Press.
- Stevens, Rosemary. 1989. *In Sickness and in Wealth*. New York: Basic Books.

- U.S. Bureau of the Census. 1984. *Projection of the Population of the United States by Age, Sex, and Race: 1983 to 2080. Current Population Reports*, series P-25, no. 952. Washington: U.S. Department of Commerce.
- U.S. Congress. Senate Special Committee on Aging. 1961a. *State Action to Implement Medical Programs for the Aged: Staff Report*. Washington.
- . Senate Special Committee on Aging. 1961b. *The 1961 White House Conference on Aging: Basic Policy Statements and Recommendations*. Washington.
- . House Committee on Ways and Means. 1963–64. *Medical Care for the Aged*. Hearings, 88th Congress, first and second sessions, on H.R. 3920. Washington.
- . 1972. *Summary of Social Security Amendments of 1972*. Washington.
- . Senate Special Committee on Aging. 1975. *Proprietary Home Health Care*. Washington.
- . House Select Committee on Aging. 1986. *The "Black Box" of Home Care Quality*. Washington.
- . House and Senate Bipartisan Commission on Comprehensive Health Care (Pepper Commission). 1990. *A Call For Action*. Washington.
- U.S. General Accounting Office. 1974. *Home Health Care Benefits Under Medicare and Medicaid*. Washington.
- . 1979. *Home Health Care Services—Tighter Fiscal Controls Needed*. Washington.
- . 1987. *Long-Term Care Insurance: Coverage Varies Widely in a Developing Market*. Washington.
- . 1989. *Health Care: Home Care Experiences of Families with Chronically Ill Children*. Washington.
- U.S. Health Care Financing Administration. 1981. *Long Term Care: Background and Future Directions*. Washington: Office of Policy Analysis.
- . 1984. *Long-Term Care Financing and Delivery Systems: Exploring Some Alternatives*. Washington.
- U.S. Public Health Service. 1955. *A Study of Selected Home Care Programs*. A Joint Project of the Public Health Service and the Commission on Chronic Illness. Washington: U.S. Department of Health, Education, and Welfare.
- Vladeck, B.C. 1980. *Unloving Care*. New York: Basic Books.
- Vladeck, B.C., and G.J. Alfano. 1987. *Medicare and Extended Care: Issues, Problems, and Prospects*. Owings Mills, Md.: National Health Publishing.

- Weissert, W.G. 1985. Home and Community-Based Care: The Cost-Effectiveness Trap. *Generations* 10:47-50.
- . 1991. A New Policy Agenda for Home Care. *Health Affairs* 10:67-77.
- 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.
- Weissert, W.G., T.H. Wan, B.B. Livieratos, and J. Pellegrino. 1980. Cost-Effectiveness of Homemaking Services for the Chronically Ill. *Inquiry* 17:230-43.
- While, A.E. 1987. The Early History of Health Visiting: A Review of the Role of Central Government (1830-1914). *Child: Care, Health and Development* 13:127-36.
- Wiener, J.M., and K.M. Harris. 1990. Myths and Realities: Why Most of What Everybody Knows About Long-Term Care Is Wrong. *Brookings Review*.
- Williams, J.L. 1986. *Medicare Home Health: Ready for the Future?* Cambridge, U.K.: Commonwealth Fund. (Draft)

Acknowledgments: The author gratefully acknowledges the support of the Milbank Memorial Fund through its Health Policy Review on Households and Health Services. Additional support was provided by the Koret Foundation through a Koret Faculty Research Award to the Institute for Health and Aging, University of California, San Francisco, where this paper was completed.

Address correspondence to: A. E. Benjamin, PhD, Associate Professor, School of Social Welfare, University of California, 247 Dodd, 405 Hilgard Avenue, Los Angeles, California 90024-1452.