Care of the Chronically Ill at Home: An Unresolved Dilemma in Health Policy for the United States

KAREN BUHLER-WILKERSON

University of Pennsylvania

The problems of caring for patients with disabling illnesses who neither get well nor die are not new. Such patients have always required assistance at home from family, benevolent volunteers, or paid caregivers. Despite two centuries of experimentation, however, no agreement exists concerning the balance between the public and private resources to be allocated through state funding, private insurance, and family contributions for the daily and routine care at home for chronically ill persons of all ages. This article examines these issues and the unavoidable tensions between fiscal reality and legitimate need. It also uses historical and policy analyses to explain why home care has never become the cornerstone for caring for the chronically ill.

Keywords: Home care, chronic illness, Medicare, nursing.

THE PROBLEMS OF PROVIDING ONGOING CARE TO patients who have disabling illnesses and who neither get well nor die are not new. Chronically ill patients have always needed assistance at home from family, benevolent volunteers, or paid caregivers. However, despite almost two centuries of experimentation with organized efforts to provide daily and routine care at home for chronically ill people of all ages, no agreement has been reached concerning the proper balance between governmental resources and the private resources of family, friends, and insurance.

Address correspondence to: Karen Buhler-Wilkerson, 418 Currie Blvd., Barbara Bates Center for the Study of the History of Nursing, School of Nursing, University of Pennsylvania, Philadelphia, PA 19104 (email: Karenwil@nursing.upenn.edu).

The Milbank Quarterly, Vol. 85, No. 4, 2007 (pp. 611–639)
© 2007 Milbank Memorial Fund. Published by Blackwell Publishing.

In recent years, a vast array of approaches have been proposed to provide and finance home- and community-based care of the chronically ill. In 1990, the (Claude) Pepper Commission (House and Senate Bipartisan Commission on Comprehensive Health Care) recommended expanding home care coverage, which also was included in the Health Security Act proposed by the Clinton administration and in other legislative proposals. Reducing the fragmentation of available services through integration and coordination has been the impetus for social health maintenance organizations (SHMOs), PACE (Program of All-Inclusive Care for the Elderly), various managed care models, transitional care, and state initiatives and waiver programs, along with European models of community-based care. By now, the burden of family caregiving has been studied at length, with numerous suggestions of ways to support families. We now use various algorithms for eligibility, targeting, and titrating care to allocate scarce resources. Both private and public insurers have created financial incentives to contain costs, such as co-pays, deductibles, prospective payment systems, and global/capitated budgets that combine acute and long-term care. Finally, we have interdisciplinary care, practice guidelines, social as well as medical services, uniform clinical records, case management, flexibility of services driven by patients' need, greater involvement by physicians, and an expanded and better trained workforce.

These continuous and repetitious efforts to solve the problems of the chronically ill who remain at home reflect the unavoidable tensions between fiscal reality and legitimate need. Tough political and societal questions are inescapable: Who should get care? For how long should it be provided? Under what circumstances should public funds pay for care? In my earlier work on the history of home care, I argued that the needs of the chronically ill have constantly confounded our ability to develop a comprehensive or informed system of community-based care. In this article, I delve more deeply into this dilemma, using historical and policy analyses to reexamine why home care has never become the cornerstone for the care of the chronically ill.

In the words of historian Charles Rosenberg, "History cannot predict what will happen; it is a more useful tool for predicting what will not happen" (Rosenberg 2006, p. 29). The history of organized home care for the chronically ill makes clear our contemporary policy dilemma—and our seeming inability to answer the questions just posed. The story is fundamental to understanding the goals of chronic care, home care, their

components, and the place of home care for the chronically ill within the larger continuum of health care in the United States. The primary stakeholders in this chronicle of home-based care for the chronically ill have always been women, whether they are family caregivers, paid workers, or the recipients of care. Indeed, our continuing belief that women will always be available to provide such care contributes to the lack of public will necessary to address these questions thoroughly, honestly, and realistically.

The Origins of Organized Home Care for the Sick

In the United States during the early nineteenth century, care of the sick was part of domestic life, and hospitals were places of last resort for those with no alternative. Instead, families hired doctors or nurses to provide care in the patient's home. The earliest-known organized efforts to care for the sick at home (1813) originated in the religious benevolence of wealthy women of Charleston, South Carolina, who entered the homes of the poor and dependent to offer care and domestic comfort. By the 1850s, the records of Charleston's Ladies Benevolent Society (LBS) had documented the central problems of caring for the sick at home, what the members referred to as the "vexed question of chronic patients." Discharging the needy chronically ill may have violated a sense of benevolent duty, but maintaining them in the LBS's caseload threatened the organization's financial viability. Even worse, the LBS found it impossible to identify the most deserving of the chronically ill. Ultimately, it limited care to the acute phase of illness and eventually resorted to obtaining a physician's certification to define medically necessary care. The LBS's efforts to determine how best to deliver home care, especially to the poor and chronically ill, remain an excellent prototype for us as we continue, nearly two hundred years later, to confront care for the sick at home, an enduring problem that clearly transcends time and place (Buhler-Wilkerson 2001).

By the end of the nineteenth century, urbanization, industrialization, immigration, and the constant danger of infectious diseases had transformed most large cities into increasingly unhealthy places to live. The relationship between poverty and illness was indisputable, and the popularization of the germ theory was yet another reason to protect

the public from uncontrolled disease. Motivated by a shared vision of the good society, wealthy women in New York, Philadelphia, Boston, Chicago, and other cities across the United States formed organizations to hire trained nurses to save the indigent from illness and bad habits. By 1909, nearly six hundred organizations were sponsoring the work of visiting nurses, who cared for five major types of patients: surgical, medical, obstetrical, contagious, and tubercular. The work of visiting nurses was financed through donations, subscriptions, endowments, revenues from fund-raising events, and the occasional paying patient. Even so, the image, incentives, and management style of these visiting nurse organizations were appropriate to a charitable cause aimed at doing good, not a well-run business with a product to sell (Buhler-Wilkerson 1987).

Insurance Coverage for Visiting Nurses

The financial circumstances of many visiting nurse organizations were dramatically improved with the Metropolitan Life Insurance Company's (MLI) establishment in 1909 of an insurance payment scheme for home nursing care. Relying on outcomes data based on visits by nurses from New York City's Henry Street Settlement, the MLI was convinced that preventing premature death through home nursing would be a cost-effective social investment. The economic incentives for MLI were obvious. Increasing the life span of its policyholders lowered the number of death claims as well as the cost of premiums, which in turn attracted more policyholders. Such arrangements also meant that without raising additional funds, visiting nurses could extend their services to more working-class patients. Persuaded by the mutual advantages to policyholders, visiting nurses, and the insurance company, in 1911 the MLI extended this program across the country, using the general policy of contracting with existing visiting nurse associations when possible (Hamilton 1988, 1989; Haupt 1937, 1953).

The focus of this coverage was industrial-life policyholders. Industrial insurance, purchased by poor and working-class populations, was known as insurance for the masses. By 1910, 20 percent of the U.S. population had these policies. Industrial life insurance was sold door to door, for a small weekly premium, as a death/burial payment. No medical exam was required, and policies were available to men, women, and children (Dublin 1943). By 1916, 87 percent of policyholders receiving nursing

care were white, and 13 percent were African American. Seventy percent were women, mostly maternity cases. Thirty percent of MLI cases were patients with acute illnesses (pneumonia, tonsillitis, typhoid fever, influenza, pleurisy, injuries, children's communicable diseases), and 9 percent were chronically ill (tuberculosis, cancer, rheumatism, diseases of the veins, organic diseases of the heart, Bright's disease) (Frankel and Dublin 1918).

As the nursing service grew and the MLI accumulated more data, it became obvious that "scientific case management" would be essential if insurance coverage were to be cost-effective. Through a system of constant correspondence, close supervision, and regular inspection, the MLI gradually introduced new management strategies in an effort to eliminate "useless cases," missed opportunities, and wasted effort. The company's goal was for visiting nurse associations and nurses to emphasize acute rather than chronic care, to limit care to a few closely spaced visits (six), and to discharge patients to the care of their families within two weeks. The visiting nurse associations were delighted with the MLI's financial support, but they were less enthusiastic about conducting their work in such a scientific and businesslike fashion (Dublin 1914; Frankel 1913; Frankel and Dublin 1918; MLI 1948).

Although the nurses may have understood the MLI's case management strategy, the desire for quick recovery or discharge to the family for caregiving did not resonate with their priority of care over cost. Given the opportunity, visiting nurses usually provided many visits for long periods—what MLI referred to privately as "excessive" nursing (MLI 1931). Then, to obtain coverage for these practices, nurses would describe patients with chronic conditions who received hundreds of visits as having either a hopeful prognosis or an acute condition. When the patient's diagnosis appeared to be contrived or the numbers of visits per case exorbitant, the MLI referred the record to its Professional Reviewing Unit of experienced nurses. Believing that excessive nursing was costly and did not save lives, the company carefully analyzed visit patterns to uncover these deceptions. Denials for payment varied among agencies but averaged 24 percent of the cases reviewed. While the nurses in the field believed they were simply providing needed care, such maneuvers today would be classified as fraud and abuse (Haupt 1951; MLI 1920, 1931).

By the late 1920s, the MLI was claiming publicly that between 1911 and 1928, the nursing service had saved 350,000 lives and \$70 million

in reduced death claims, and it pronounced the health campaign to be a profitable investment (MLI 1929). Although its agents were not supposed to use the visiting nurse service as a sales argument, it was a valuable privilege for policyholders and, as such, a wonderful form of advertising for the MLI (Taylor 1933). Indeed, the establishment of nursing services by the John Hancock Mutual Insurance Company, as well as West Coast Life, Travelers, and Aetna Life Insurance, in the mid-1920s confirmed the growing popularity of such approaches to the sale of insurance. Hancock and the MLI had the most comprehensive policies, but other companies were competitive as well (John Hancock 1928; Lewenstein 1992).

The Unseen Plague of Chronic Disease

By the late 1920s, the public remained totally unaware of what was later described as the “unseen plague of chronic disease.” Not surprisingly, fewer of the diseases treated at home were the dreaded contagions of the past that often killed patients quickly, and more were chronic illnesses. Consequently, visiting nurses were caring for more and more patients with heart disease, cancer, strokes, diabetes, and arteriosclerosis (Buhler-Wilkerson 2001). Less need for acute care at home and the rise in chronic illness were dramatic changes but were predictable in light of changing morbidity patterns, evolving trends in health care delivery, and changes in demographics. Visiting nurses were not alone in their growing awareness of chronic illness. A small number of influential physicians (including Alan Gregg, Ernest Boas, George Bigelow, and Sigmund Goldwater), as well as Alfred Cohn, a clinical scientist at the Rockefeller Institute, and the MLI’s statistician, Louis Dublin, also were keenly conscious of the implications of chronic illness for health policy, research, systems of care, and financing mechanisms (Boas 1940; Fox 1989, 1993).

Dublin was one of the first to observe the shift to chronic disease because of his analyses of the massive database available to him through the MLI. Since joining the company in 1909, he and his staff of statisticians had tracked the mortality of policyholders. As early as 1925, Dublin was reporting a dramatic transformation in the leading causes of death, which sharply challenged his earlier ideas about the continuous progress of medicine. He predicted an enduring upward trend in mortality from

chronic diseases as the proportion of elderly in the population rose (Boas 1940; Dublin 1940, 1943).

In a desperate search for ways to pay for chronic care, Sophie Nelson, the director of Hancock's nursing service, was commissioned by Boston's visiting nurse organization to test the ability of nurses to cure or retard the progress of chronic illness. Nelson, also an active participant in public health endeavors outside the company, worked with nurse colleagues to address the challenging problems associated with chronic illness. Always interested in the economics of nursing care, Nelson believed that the effectiveness of nursing services ought to be studied, and because no one knew much about the natural history and progress of chronic illness at this time, she undertook this yearlong study herself (Nelson 1929).

The key question was whether a payment system could be established that was stringent enough to avoid paying for long-term personal care (such as assisting with activities of daily living), elastic enough to care for patients with the potential to recover, and humane enough to cover the care of patients requiring skilled care to minimize suffering. Conducted in Boston in 1928, the study compared the outcomes of unlimited care provided by visiting nurses with the outcomes of care restricted by the criteria of insurance coverage (six visits). The results showed that both the limited and unlimited care of the chronically ill produced the same outcomes, suggesting that skilled nursing care of the chronically ill was a "humanitarian contribution but hardly a scientific one" (Nelson 1929, p. 578). From an insurance perspective, the message was clear: the most "expedient" policy was to pay for very limited care for chronically ill patients. The focus was to demonstrate the method of home nursing care and to help the family plan for its own ongoing care of the patient. As for reimbursement, diagnosis and prognosis would dictate the amount of service covered by insurance companies, and Nelson concluded that insurance companies could not carry the load of chronic illness alone (Nelson 1929).

There were, of course, institutional alternatives to community-based care for the chronically ill: hospitals, almshouses, and private nursing homes. Then in 1935, the creation of Old Age Assistance dramatically rebalanced the locus of care for the chronically ill. Although the policy goal was to move the elderly from almshouses to independent function in their homes, the Social Security Act (Old Age Assistance) instead encouraged the incremental expansion of private nursing homes for chronically ill older people. For families unable to provide care at home for dependent

elderly family members, nursing homes offered an institutional alternative. Most important, tax dollars provided the means to finance such institutional care, and the result was a steady increase in the institutionalization of the elderly in some type of “nursing home,” even though most people with chronic disease still remained at home (Boas 1940; Grogan 2006; Schell 1993).

Changing Times, New Challenges

The nursing services of the MLI and Hancock continued to grow until the Depression. The MLI’s nursing service peaked in 1931 with 770,000 policyholders receiving care. With the onset of the Depression, though, policies lapsed, and the cost per nurse’s visit steadily rose. From a life insurance company’s perspective, this combination made visiting nurses seem like a less economically viable method of preventing death or attracting customers (Haupt 1950; Nelson 1953b). Accordingly, an article in the MLI’s *Quarterly Bulletin* (1946) asked the obvious question: “What of the Future?” As predicted, by the 1940s chronic illness accounted for 57 percent of all deaths (Fox 1993). Policyholders lived longer; mortality rates had significantly decreased; and rising affluence made possible the purchase of more health insurance or necessary care. Communicable diseases were no longer the major cause of death, and hospitals’ principal responsibility was caring for maternity and acutely ill patients. With the growing centrality of the hospital, fewer policyholders needed or used the visiting nurse services, and those still seeking the services of a nurse were, most often, the elderly chronically ill (Armstrong and Haupt 1951; Buhler-Wilkerson 2001; Nelson 1953b).

By this time, the MLI was spending \$4 million annually to care for 1 percent of its policyholders. Undeafened by these realities, MLI nurses and statisticians surveyed the public and policyholders about attitudes toward home care (Advertising Research Bureau 1947); studied new methods of financing and managing care; analyzed the problems of caring for the chronically ill (Lanza 1937); scrutinized the cost of a nursing visit; and provided more staff supervision and education (Reid 1942). Experiments with prepayment (in contemporary parlance, “prospective payment”) sharply reduced the number of visits and caused MLI statistician Louis Dublin to remark that “the experiment has thrown tremendous light on the administrative possibilities of decreasing volume of

service to policyholders" (Dublin 1942, p. 2). Much like today, home care providers proved to be exquisitely responsive to changes in financial incentives (Dublin 1942). Despite these efforts, the closure of MLI's nursing service seemed inevitable. With the transformation in the nature of disease from acute to chronic, care by visiting nurses simply made little difference in recovery.

As the MLI's president, Leroy Lincoln, wrote at the time (1950, p. 1), "Our withdrawal from this activity can only be viewed as in harmony with today's changed conditions." In 1953, as the MLI was shutting down its visiting nurse program, a total of more than 100 million home visits had been made to more than 20 million industrial policyholders at a cost of \$116 million (Haupt 1953; Lincoln 1950). Like the MLI, Hancock was experiencing a similar change in social and health care circumstances. With only 0.5 percent of policyholders requesting nursing care, Hancock concluded that funding medical research was a better investment. Even so, between 1925 and 1953, Hancock made 11 million visits to 2 million policyholders, what Sophie Nelson described as a definite contribution to the cause of public health (Nelson 1953a, 1953b).

The Postwar Search for a New Paradigm of Caring for the Chronically Ill

Like his nurse colleagues, Ernest Boas, a prominent physician advocate for the chronically ill, argued that justice and decency demanded community support for those unable to help themselves. Acknowledging that no single approach was entirely satisfactory, Boas believed that communities should establish policies to care for the chronically ill, including the use of hospitals, custodial homes, outpatient clinics, and home care. Haphazard development needed to be replaced by a consistent policy with central responsibility and the authority to offer comprehensive care. Such a vision conflicted with the customary practice of medicine and was considered an affront to patients' individual freedom and choice of provider. Nonetheless, only a reconceptualization of health services for the chronically ill and the identification of new sources of payment would bring about an alternative system of care (Boas 1940).

Boas was not alone in his views. Visiting nurses also believed that the solutions for the seemingly intractable problems caused by chronic illness were (1) assistance with personal care by an aide or attendant under the

supervision of a nurse; (2) boarding out in private homes; (3) temporary hospitalization for special treatments or the transport of treatments from the hospital to the patient's home; and (4) augmenting the family's income by subsidizing earnings or providing a part-time attendant to help with care (Stevens 1928; Wales 1928). Likewise, Dublin agreed that solving the problems of the chronically ill required money, housing, and adequate medical and nursing care, integrated "into one unified structure with health insurance acting as cement binding all the parts together." He believed that the creation of a single coordinated structure for all—sick and healthy, rich and poor—would solve these complex health care problems (Dublin 1949).

In the 1940s, the American Medical Association, American Hospital Association, American Public Health Association, and American Public Welfare Association combined to call attention to the growing problem of the chronically ill (American Medical Association, American Hospital Association, American Public Health Association, and American Public Welfare Association 1947). This joint effort led to the Commission on Chronic Illness, which was created in 1949 to review and assess the problems associated with chronic illness. This massive seven-year undertaking eventually produced a four-volume, comprehensive analysis with recommendations. The commission called for an overhaul in the financing and delivery of health care, noting the current overemphasis on institutional care and the need for plans to allow long-term care patients to live at home. Needed most was the coordination and financing of care at home. Reviewers wondered how this massive reference work would be translated into actual policy, or better yet, reality (Commission on Chronic Illness 1956; Sheatsley 1958). What followed instead were more studies, symposia, and public health monographs, as well as the creation of various planning groups documenting the problems of the chronically ill and making policy recommendations, but little changed (Fox 1993). As Boas had suggested a decade earlier, redesigning the management of the chronically ill was not compatible with the available systems for delivering or financing care (Boas 1940).

The Back-to-the-Home Care Movement

By the 1950s, the increasing need for long-term care, along with the high cost of institutional care, stimulated a renewed interest in care

at home. As if the decades of service by visiting nurse associations had never occurred, the government and the American Medical Association studied home care and, in prestigious medical journals, pronounced its coming of age. With physicians at the helm, the newly reinvented home care movement was declared a dynamic approach to the far-reaching problems of chronic illness. Suddenly, home care was proclaimed a crucial and respected component in the continuum of care (American Medical Association Committee on Indigent Care 1957; Goldman 1952; Kogel and Fraenkel 1953; U.S. Public Health Service 1955).

The origin of this hospital-based back-to-home care movement is generally attributed to the Montefiore Hospital Home Care Program in the Bronx, which opened on January 1, 1947 (Frost and Lynch 1948; Thompson 1950). Acknowledging that the concept of home care was not new, policymakers were enamored with the “completeness and success” of Montefiore’s program. As an editorial in the *American Journal of Public Health* asserted in 1949, Montefiore was seen as a hospital truly “moving into the future” (Editor 1949). Predictably, the physician-inventor of the Montefiore program, E.M. Bluestone, labeled his program the “parent home care program,” the first permanent, organized example of home care. He characterized earlier experiments in home care by visiting nurses as limited and lacking, a lukewarm approach to the problem. Because visiting nurses were not integral to the hospital and fell outside the boundaries of total medical control, the organizations that employed them were “haphazard” and did not have the power, authority, or discipline essential to optimal home care (Bluestone 1954; Cherkasky 1949; Levenson 1984).

Descendants of the Montefiore model were commonly referred to as coordinated home care programs (CHCPs). Although hospitals showed the greatest interest in these programs, they also were administered by visiting nurse associations, health departments, city welfare departments, and private social agencies. The idea of taking the hospital home was described as appealing in its simplicity. Caring for the sick in the security of their home seemed to be a natural and more humane thing to do and would reduce the costs of hospital care. Not surprisingly, the patients reported that they were happier at home as well. The typical patient was a sixty-four-year-old woman with heart disease who was referred for care following hospitalization; she received forty-two visits a year at a rate of 5.7 per month. The average visit lasted thirty minutes. Patients were

usually cared for by three members of the interdisciplinary home care team. But despite such intensive home care, hospital readmissions were nevertheless common (Goldman and Frankel 1959; Munter and Berke 1958; Reid 1954).

Administrators and staff were in near universal agreement that coordinated home care programs would reduce the costs of hospital care. But without any reliable data, such enthusiasm was highly speculative. Few acknowledged a fundamental reality: any economic advantage of home care probably derived from the unpaid contributions of family members, primarily women. Dr. Sidney Shindell of the U.S. Public Health Service was one exception, noting that "care in the home involves assumption on the part of the patient's family of all of the domiciliary functions and cost, as well as a large percentage of nursing functions and cost. It is in these categories that much of the savings occur" (Shindell 1950, p. 659). Of course, only in a fragmented system of health care could this type of cost shifting be considered a form of savings, predicated on the expectation of women's unpaid labor. Predictable difficulties arose as soon as these coordinated home care programs were put to the test. The reduction of the utilization and costs of institutional care remained debatable; identification of the appropriate recipients of home care proved complicated; patients' requirements for personal care and housekeeping services were almost as great as those for medical care; and the control of home care costs proved nearly impossible. Some providers announced that families now had the satisfaction of caring for their own, whereas others recognized that not all families were willing or able to take on the burden of caregiving. By 1964, seventy CHCPs cared for 550 patients. Despite these reservations, supporters of home care later claimed that these experiments were the prototype for what eventually became the Medicare home care benefit (Follmann 1958; Kurlander 1954; U.S. Department of Health, Education and Welfare 1964).

During the 1950s, experiments with home care as a way to reduce the costs of hospitalization were undertaken. By 1959, the Health Insurance Association of America determined that the vast variation in home care made impossible any assessment of its potential to reduce health care costs. Once again, the conclusion was that only in cases of serious illness was home care a reasonable benefit to include in an insurance premium (Follmann 1959).

Devising a Federal Policy for Home Care

Given these realities, the inclusion of home care in any federal health program seemed unlikely. Yet home care appeared, disappeared, and reappeared during the decade of debate that finally resulted in passage of the Medicare and Medicaid legislation in 1965 (Buhler-Wilkerson 2001; Goldman 1952). The events and politics leading to the passage of these federal and state programs have been extensively reviewed by historians. Most telling for the future of home care, according to historian Daniel Fox, was the "consensus that Medicare should not directly address the growing burden of chronic disabling illness" (Fox 1993, p. 74). Fearing loss of support in Congress if the program appeared uncontrollably expensive, the Johnson administration insisted that priority be given to care during acute episodes of illness, and it was only the perceived capacity of home care to empty hospital beds that resulted in its inclusion as a posthospital benefit (Benjamin 1993; Fox 1993).

Backed by popular demand expressed at hearings held across the country by the Senate Committee on the Problem of the Aged and Aging and endorsed by the White House Conference on Aging, a place for home care in any new federal health legislation seemed assured. While congressional testimony between 1961 and 1965 attested to the review and debate of familiar themes and cautions, home care was nevertheless included in every proposed bill. In a now familiar chorus, some warned that the home care benefit contained great possibilities for expansion and substantial increases in cost, while others promised that it would save money. But the ability to save money always assumed, at least implicitly, the availability of unpaid family caregivers who would supplement professional care. Eligibility criteria included a physician's documentation of the medical necessity for and the intermittent skilled care of homebound acutely ill patients following their hospitalization. Payment was to be based on reasonable cost. Acknowledging its restorative and comprehensive focus, care at home was now called *home health care* (Benjamin 1993; Feingold 1966; U.S. Senate Committee on Labor and Public Welfare 1959; U.S. Senate Special Committee on Aging 1961).

Government-sponsored home care programs came to be financed mainly through the federal Medicare program for the elderly, Medicaid (the federal-state cost-sharing program for the medically needy), and

Title III of the Older Americans Act. Consistent with U.S. tradition, this federally financed and regulated pluralism was accompanied by a confusing assortment of payment requirements, eligibility criteria, and systems of reimbursement, as well as coverage limitations that created gaps in services and fragmentation. Medicare services included skilled nursing care; occupational, speech, and medical social services; physical therapists; and home health aides. Initially, home care benefits were optional under the states' Medicaid programs, but in 1971 they were made mandatory. The Medicaid program permitted states to offer a range of optional benefits, which included traditional home care and personal care services. In addition, the Older Americans Act provided a variety of home- and community-based services for the frail elderly, including meals, transportation, homemakers, home repairs, and referral services (Benjamin 1993; Buhler-Wilkerson 1991).

Implementation of the Medicare program marked a new era for home care. At the outset, nearly two thousand agencies were certified to participate in the Medicare program. Medicare's home care outlay was \$46 million, only 1 percent of the program's total expenditures (Ryder, Stitt, and Elkin 1969). But even though the number of home care services grew, families and their physicians often found it to be a less than perfect solution to the health care needs of aging, chronically ill patients, especially in contrast to hospital care, which was much less trouble for most families. Policymakers and third-party payers, who regarded home care as having little intrinsic value, continued to search for evidence of its cost-effectiveness. As always, most care at home was provided by informal support systems, such as family, friends, or neighbors (Spurrier, Johnson, and Manussen 1965; Trager 1971).

Home Care as an Alternative to Nursing Home Care

By the 1970s, discussions of home care entered the debate about long-term care for the elderly. This time, it was examined as a cost-effective substitute for nursing home expenditures. After a decade of study, findings from and the evaluation of demonstration projects were not encouraging. Home care did not significantly reduce hospitalization or the use of nursing homes. Furthermore, families did not have the same goals for home care as payers or policymakers. Rather, they simply sought

relief—as caregivers, paying consumers, and managers of care (Weissert 1997; Weissert, Cready, and Pawelak 1988).

Simultaneously, Medicaid, the means-tested welfare program, was actually offering more extensive coverage for the chronically ill than did Medicare or private insurance. Created to provide care for the medically needy, within a few years Medicaid also was paying for long-term care in nursing homes. By the mid-1970s, states were struggling to get nursing home spending under control. Although financing and services varied from state to state, Medicaid did pay for both institutional and home-based long-term care for the chronically ill poor (Fox 1993; Stevens and Stevens 1974; Vladeck 1980).

Home Care Utilization Expands

Because of declines in the use of home care during the 1970s and the perceived need to lower hospitalization rates, a variety of legislative, judicial, and regulatory changes were introduced, resulting in the exponential expansion of home care benefits. Most important was the Omnibus Reconciliation Act (ORA) of 1980, which removed the limits on the number of home care visits, prior hospitalization requirements, and deductibles. The ORA also permitted the participation of proprietary home care agencies. Definitions of eligibility for service were broadened as a result of two class action suits, *Fox v. Bowen* in 1986 and *Duggen v. Bowen* in 1988 (Benjamin 1993; Mauser and Miller 1994).

Together these events changed the composition of the agencies that provided home services. By the end of the 1980s, one-third of all Medicare-certified home care agencies were for profit, and by 2003, nearly half were proprietary (National Association for Home Care and Hospice 2004). While the hope was that competition would lower costs, traditional nonprofit home care providers argued that the profit motive was antithetical to the altruistic mission of home care. Given the financial incentives for home care, proprietary agencies predictably tended to provide more visits compared with those by nonprofit or governmental agencies. In 1993, for example, proprietary agencies provided beneficiaries with an average of seventy-eight visits per year, whereas voluntary and governmental agencies provided an average of forty-six visits (U.S. General Accounting Office 1996).

Finally, with the introduction of the hospital prospective payment system in the 1980s, hospitals and physicians once again became interested

in bringing the hospital home. As patients were discharged from hospitals quicker and sicker, home care also became more expensive. Well-intentioned nurses and social workers, increasingly skilled at gaming the system in an effort to provide services they considered necessary and appropriate, contributed to the rise in patients' and families' satisfaction with home care, although they did not necessarily improve functional levels and clinical outcomes (Arras 1995; Benjamin 1993; Mundinger 1983). By 1987, 5.9 million individuals of all ages were receiving home care services, at a cost of \$22.3 billion (adjusted for inflation). The government's share of these expenditures, at \$10.3 billion, represented 46 percent of the spending for home care. The remainder was privately financed (out-of-pocket and private insurance) (National Association for Home Care and Hospice 2004; Spector, Cohen, and Pesis-Katz 2004; U.S. General Accounting Office 1996).

Integration of acute and home/community care services became the buzz phrase for the 1990s. Social health maintenance organizations (SHMO), Programs of All-Inclusive Care for the Elderly (PACE), a variety of state initiatives, and even health management organizations (HMOs) attempted to integrate and coordinate care across settings. By experimenting with service delivery and financial models, the hope was that the problems of fragmented services, cost containment, misgivings about social welfare services, restrictive reimbursement, and the burden of family caregiving that were thwarting community-based long-term care might be addressed. In the process, important lessons about integration and financial modeling were learned, but no universally acceptable paradigm of care delivery was found (Eng et al. 1997; Greenlick and Brody 1997; Gross et al. 2004; Stone 1997).

From 1990 to 1996, Medicare's home care expenditures increased by 350 percent. In 1997, an estimated 3.6 million Medicare enrollees received home health care, with an average of seventy-three visits costing \$4,705. It was thus no surprise that by the mid-1990s, Medicare's coverage for home care was considered a benefit out of control. Whether good or bad, during the 1990s, home care was the fastest-growing component of the Medicare program, representing 10 percent of all Medicare costs. Ambiguity over liberalized interpretations of criteria for eligibility and coverage created the opportunity for providers of home care to recast the Medicare benefit. The number of visits nearly doubled as a program specifically designed to meet the needs of short-term acute illness gradually began to provide long-term care to the chronically ill at home. But

just as the Metropolitan Life Insurance Company had, the federal government found home care difficult to manage and control (U.S. General Accounting Office 1996). While presumed reasonable, necessary, and medically appropriate, the expansion of home care was deemed unsustainable, and demands for reform were heard once again (Bishop and Skwara 1993; Conley and Walker 1998; Heger 1996; National Association for Home Care and Hospice 2004).

For policymakers faced with the potential insolvency of the Medicare program, the growth of home care raised the all-too-familiar questions of how much and what kind of home care would be paid for, who should receive it, and who would provide it and for how long. A century of experimentation in home care clearly outlined the parameters of the controversy and its likely outcome. The inability of policymakers to visualize the elements, desired outcomes, or value of home care made it very difficult to decide whether caring for the sick at home was a civic duty or a family responsibility. The very private and unseen nature of care at home caused unease among regulators and policymakers alike. As recognition grew that home care was no panacea in regard to reductions in the costs of health care, the debate was further politicized by charges of overutilization, fraud, and abuse (Olson 2003; Sarraile 1998; U.S. General Accounting Office 1996).

On October 1, 1997, and with almost no awareness on the part of the public, the Balanced Budget Act (BBA) of 1997 radically transformed the Medicare home care benefit enacted in 1965. Designed to eliminate inefficiency, waste, and abuse by limiting the expenditures per beneficiary and the cost per visit, the outcomes of the BBA were swift and dramatic. By 1999, more than three thousand home care agencies (14 percent) had closed; the proportion of beneficiaries using home care had fallen by 20 percent; the number of visits per patient had decreased by 40 percent; and the public spending per enrollee had declined by 52 percent (Spector, Cohen, and Pesis-Katz 2004). As hoped, clearer eligibility criteria moved the Medicare home care benefit away from a long-term personal care service back to a primarily skilled nursing and rehabilitation service. At this point, home care was characterized by fewer services and more family caregiving. Reminiscent of the study by Sophie Nelson, analysis of these dramatic reductions in care demonstrated that they had a minimal negative impact on outcomes (McCall et al. 2001, 2004; Spector, Cohen, and Pesis-Katz 2004). Not addressed, however, was whether or not it would be reasonable to expect the population served

to show improvements in functional status, health status, and symptom relief. Furthermore, the circumstances under which home care was an appropriate publicly funded service remained unknown. But as Nelson concluded in 1928, perhaps in matters of the bottom line, diagnosis and prognosis dictated the amount of service covered (Nelson 1929).

As Medicare-financed home care was being transformed, many states were expanding Medicaid and other local home care programs. Motivated by the need to reduce spending on nursing home care, as well as the recent *Olmstead* decision by the U.S. Supreme Court (1999) mandating the provision of community alternatives to institutionalization for people with disabilities, and the federal government's New Freedom Initiative encouraging states to provide community-based services, home care was once again deemed a more suitable and less expensive alternative to institutional care. Many new programs also provided care for a nonelderly population, including those with mental retardation and developmental or physical disabilities, as well as infants and children on ventilators. Between 1996 to 1999, Medicaid's share of home care spending nearly doubled, from 17 to 33 percent. During this same time, the share of state and local programs increased from 1.7 to 25 percent of expenditures (Spector, Cohen, and Pesis-Katz 2004).

Family Caregiving

Noticeably absent in most analyses during this period was the cost of unpaid care provided by family caregivers (mostly women) to the chronically ill or seriously disabled. In 1997, an estimated 25.8 million informal caregivers (one in five adults) provided approximately 24 billion hours of such care, with an estimated economic value of \$196 billion (Arno, Levine, and Memmott 1999; Wager 2004). More recent estimates give an economic value of \$257 billion for informal care (Gould 2004). Such an investment far exceeds government spending for either home or nursing home care. For the 44 million estimated caregivers in 2004, this remains largely a women's issue. The typical caregiver is a married forty-six-year-old woman with some college education who provides twenty hours of care each week to her mother (National Association for Home Care and Hospice 2004).

Although caregiving can bring gratification, its physical, mental, and economic costs are undeniable. Caregiving today goes well beyond the

routine needs of daily living, often including technically sophisticated medical tasks, as well as the management of family members who are discharged from hospital to home. Family caregiving is complex, costly, and exhausting and may continue for years without assistance or training from professionals (Gould 2004). While this experience is rarely acknowledged by policymakers or shared equally by men, it nonetheless is an essential aspect of health care in the United States (Aronson 1992; Calasanti and Slevin 2001). Family caregiving therefore remains a multifaceted and enormous policy issue (Abel 2000; Olson 2003).

Families have always sought private assistance with these responsibilities. Today, they most often employ home health aides for personal care, nonmedical care, and companionship. Such privately purchased care is not usually directed by a physician or governed by any regulations. Even though such aides are low-wage, unskilled workers earning an average of \$10 per hour, many families cannot afford such assistance indefinitely. Nevertheless, this private-duty market is expected to grow because of the financial prosperity of baby boomers, who can pay directly for the care of aging parents. Aides are available through traditional home care organizations, a rapidly growing home care segment of franchises/chains known as nonmedical private-duty home care, and through the gray market, in which patients and workers are connected by word of mouth or advertising (Montgomery et al. 2005). Many such workers are untrained, unscreened, and unsupervised but desirable nevertheless because they are less expensive and unfettered by regulation, and families have more control over arranging for services that meet their particular needs or wishes (Gross 2007; McMackin 2006; Von Bergen 2007). It is difficult to estimate the number of private-duty organizations, but data from the Economic Census of 2002 documented 17,000 organizations providing home health services, 7,007 of which were certified by Medicare (National Association for Home Care and Hospice 2004; U.S. Bureau of the Census 2002).

Reinventing Home Care's Future

Behind the scenes, as federal bureaucrats and policymakers publicly expressed surprise and gratification for reductions in Medicare spending following the passage of the BBA, they also were repairing some of the legislation's damage to the home care system. For those home care

agencies that survived the first wave of cuts in 1997, the proposed rules for Medicare's new prospective payment system promised a better future for the providers and recipients of home care. As in the past, changes in financing meant yet another reinvention of care at home.

Implemented on October 1, 2000, this payment system was described as the most dramatic change affecting home care services since the Medicare program. The movement of home care from a cost-based payment system to a predetermined payment adjusted to reflect the health conditions and service needs for an episode of care was intended to provide financial incentives for more efficient care delivery. For home care agencies, this meant yet another new set of opportunities and risks. The opportunities provided by this payment system were welcomed by the home care industry, but the failure to manage care and resources efficiently would also risk the agencies' survival (Halamandaris 2006).

Although it is too soon to assess the total impact of this shift in financing, changes in visit patterns, case mix, provision of therapies, and length of service continue. As with the Metropolitan Life Insurance Company, the goal is for an intensive and targeted approach to home care aimed at constraining growth through better management and monitoring. Increases in skilled care, decreases in visits by home health aides, fewer users, and brief episodes of care indicate that these new financial incentives have successfully transformed the Medicare home health benefit away from long-term care and back to a focus on short-term acute care. There appears to have been no significant negative impact on patients' function, health status, hospital readmission, or emergency room use, although a slight increase in patients' dissatisfaction has been reported (Chen 2002; McCall et al. 2001; Schlenker, Powell, and Goodrich 2005; U.S. Department of Health and Human Services 2006).

Always responsive to changes in financial incentives, home care agencies quickly learned that limiting the number of visits and classifying patients in the highest-paying categories could ensure their survival and perhaps even profit. Some organizations have fashioned the prospective payment system's allowance to provide an unlimited number of medically necessary episodes of care into a chronic care benefit for those patients requiring skilled management of their care plan (Chen 2002; Holt 2005; McCall et al. 2003). Predictably, these new payment methodologies and mechanisms require adjustment. Appropriate payment rates (financial margins) are the latest topic in the heated debate between those

providing care and government regulators (Dombi 2004; Halamandaris 2006).

Conclusion: If Home Care Is the Answer, What Is the Question?

In 2007, an article on the front page of the *New York Times* described the crushing burden of indefinite home care expenses frequently faced by families caring for aging, chronically ill family members (Gross 2007). The origins of the vexing problem of caring for the chronically ill can be traced back to the nineteenth-century struggles of the Ladies Benevolent Society. By the early twentieth century, the needs of a growing elderly population prompted decades of research, policy development, experimental models, and proposals for new paradigms of care delivery and financing. However, in the absence of the requisite public will, our stance appears to be one of waiting for a complete breakdown of long-term care before definitive action will be taken in response to the needs of the present and growing aging and chronically ill population.

Even though we may assume that home care could be the cornerstone of any redesigned system of care to meet the needs of the chronically ill, two centuries of experimentation with the mechanisms for delivering and financing that care have left many unresolved questions. As Branch suggested in the 1980s, home care is the answer, but only when the question is carefully phrased (Branch 1985). The history of caring for the sick at home explains much about our current challenges and their possible resolution, but only if we are willing to confront an enduring set of questions with a measured and balanced set of answers concerning a reasonable approach to home care.

Home care will be the answer when the long-term care policy debate moves beyond purely economic analyses of the role of home care in the continuum of care. Today, public financing of long-term care at home needs to be viewed as a matter of quality of life and safety, as well as an investment in greater function and independence. In the final analysis, the ability to save money by using home care as a less expensive alternative for institutional care for the chronically ill will depend on the availability of family members, friends, or volunteers able and willing to house, feed, and meet the medical and psychological-social needs of the chronically ill. Such care comes with a high price for these dedicated

and necessary caregivers and is undervalued by contemporary society. While there are pockets of redesign for care of the chronically ill that move beyond dependence on family caregivers, the gendered nature of our approach to caregiving suggests a belief that women will somehow always be there to provide this care.

Thus, ambiguities about health care at home for the chronically ill in the United States constantly reverberate. Given the public's desire for a uniquely American health care system with expanded coverage and considerable choice, along with minimal increases in out-of-pocket expenses, it is difficult to envision an approach to care at home that would create an universally acceptable balance of self-sacrifice, personal responsibility, and expanded financial resources, both public and private (Berk, Gaylin, and Schur 2006). As always, it remains very difficult to resolve whether care of the sick at home is a publicly funded civic duty or a private family responsibility. Should home care be provided only under the most restrictive of circumstances or whenever it can help? And what is an acceptable trade between the reasonable availability of public funding and the needs or requirements of patients and families to pay? (McCall and Korb 2003).

The history of home care suggests that policymakers and the public believe that the long-term care of the chronically ill is a family responsibility, but one that in some way ought to be socially sanctioned and partially subsidized. Numerous experiments in home care have proved to be too expensive politically or economically to be permanently embedded as a health care benefit for the chronically ill. Furthermore, the history of home care suggests that despite the demography of our aging population and the array of long-term care alternatives, it seems unlikely that home care will become the cornerstone of delivery of care for the chronically ill in the United States. The private, unseen, and seemingly uncontrollable nature of caring for the sick at home, combined with the open-ended nature of chronic illness, make the institutionalization of home care in the continuum of health care essentially untenable in the context of political, social, and economic realities, cultures, and incentives in the United States. At best, what the Heartland Institute calls a good public policy of tough love—individual responsibility for planning and financing old age (read chronic) care, combined with a very targeted public program for the truly financially needy—is likely to remain the “American way” for the foreseeable future (Heartland Institute 2007).

References

- Abel, E. 2000. *Hearts of Wisdom: American Women Caring for Kin, 1850–1940*. Cambridge, Mass.: Harvard University Press.
- Advertising Research Bureau. 1947. *Survey of Metropolitan's Visiting Nurse Services*. New York: Metropolitan Life Insurance Company.
- American Medical Association, American Hospital Association, American Public Health Association, and American Public Welfare Association. 1947. Planning for Chronic Illness: A Joint Statement by the American Hospital Association, American Medical Association, American Public Health Association, and American Public Welfare Association. *American Journal of Public Health* 37:1260.
- American Medical Association Committee on Indigent Care. 1957. Organized Home Care Programs in the United States. *Journal of the American Medical Association* 164:298–305.
- Armstrong, D., and A. Haupt. 1951. A Forty-Year Demonstration of Public Health Nursing by the Metropolitan Life Insurance Company. *Public Health Nursing* 43:41–44.
- Arno, P., C. Levine, and M. Memmott. 1999. The Economic Value of Informal Caregiving. *Health Affairs* 18:182–88.
- Aronson, J. 1992. Women's Sense of Responsibility for the Care of Old People: "But Who Else Is Going to Do It?" *Gender and Society* 6:8–29.
- Arras, J. 1995. *Bringing the Hospital Home: Ethical and Social Implications of High-Tech Home Care*. Baltimore: Johns Hopkins University Press.
- Benjamin, A.E. 1993. An Historical Perspective on Home Care. *The Milbank Quarterly* 71:129–66.
- Berk, M., D. Gaylin, and C. Schur. 2006. Exploring the Public's Views on the Health Care System: A National Survey on the Issues and Options. *Health Affairs* 25:596–606.
- Bishop, C., and K. Skwara. 1993. Recent Growth of Medicare Home Health. *Health Affairs* 13:106.
- Bluestone, E.M. 1954. The Principles and Practice of Home Care. *Journal of the American Medical Association* 155:1379–82.
- Boas, E. 1940. *The Unseen Plague of Chronic Disease*. New York: Augustin Publisher.
- Branch, L. 1985. Home Care Is the Answer: What Is the Question? *Home Health Care Services Quarterly* 6:3–11.
- Buhler-Wilkerson, K. 1987. Left Carrying the Bag: Experiments in Visiting Nursing, 1877–1909. *Nursing Research* 36:42–47.
- Buhler-Wilkerson, K. 1991. Home Care the American Way: An Historical Analysis. *Home Health Care Services Quarterly* 12(3):5–17.

- Buhler-Wilkerson, K. 2001. *No Place Like Home: A History of Nursing and Home Care in the United States*. Baltimore: Johns Hopkins University Press.
- Calasanti, T., and K. Slevin. 2001. *Gender, Social Inequalities, and Aging*. Walnut Creek, Calif.: Altamira Press.
- Chen, V. 2002. Home Health Care: Prospective Payment Reduces Visits While Preserving Quality. *Issue Brief* 1:1–4.
- Cherkasky, M. 1949. Montefiore Hospital Home Care Program. *American Journal of Public Health* 39:163–66.
- Commission on Chronic Illness. 1956. *Chronic Illness in the United States, Care of the Long Term Patient*. Vol. 2. Cambridge, Mass.: Harvard University Press.
- Conley, V., and M. Walker. 1998. National Health Policy Influence on Medicare Home Health. *Home Health Care Services Quarterly* 17:1–15.
- Dombi, W. 2004. Profit Margins Projected to Continue Downward Spiral. *Caring: National Association for Home Care Magazine* 23:34–38.
- Dublin, L. 1914. *The Effects of Life Conservation on the Mortality of Metropolitan Life Insurance Company: A Summary of Experience, Industrial Department, 1914, for Agents, Medical Examiners, and Visiting Nurses*. New York: Metropolitan Life Insurance Company.
- Dublin, L. 1940. Statistical and Social Implications in the Problem of Our Aging Population. Paper given at the University of Pennsylvania Bicentennial Celebration. Dublin Collection, Box 11, National Library of Medicine.
- Dublin, L. 1942. Minutes of Meeting, MLI Advisory Committee, November 20, Metropolitan Life Insurance Collection (MLI).
- Dublin, L. 1943. *A Family of Thirty Million: The Story of Metropolitan Life Insurance Company*. New York: Metropolitan Life Insurance Company.
- Dublin, L. 1949. The Aged—Are We Meeting Their Problems? Speech to the Federation of Jewish Philanthropies of New York, September 21. Dublin Collection, Box 11, National Library of Medicine.
- Editor. 1949. Home Care at Montefiore Hospital. *American Journal of Public Health* 39:224–25.
- Eng, C., J. Pedulla, G. Eleazer, R. McMann, and N. Fox. 1997. Program for All-Inclusive Care for the Elderly (PACE): An Innovative Model of Integrated Geriatric Care and Financing. *Journal of the American Geriatric Society* 45:223–32.
- Feingold, E. 1966. *Medicare, Policy, and Politics: A Case Study and Policy Analysis*. San Francisco: Candler Publishing.

- Follmann, J. 1958. *Voluntary Health Insurance and Medical Care: Five Years of Progress, 1952–1957*. Chicago: Health Insurance Association of America.
- Follmann, J. 1959. *Health Insurance, Nursing, and Home Care: A Study*. Chicago: Health Insurance Association of America.
- Fox, D. 1989. Health Policy and Changing Epidemiology in the United States: Chronic Disease in the Twentieth Century. In *Unnatural Causes: The Three Leading Killer Diseases in America*, edited by R. Maulitz, 11–31. New Brunswick, N.J.: Rutgers University Press.
- Fox, D. 1993. *Power and Illness: The Failure and Future of American Health Policy*. Berkeley: University of California Press.
- Frankel, L. 1913. Visiting Nursing from a Business Organization Standpoint. *Public Health Nurse Quarterly* 5:25–45.
- Frankel, L., and L. Dublin. 1918. Visiting Nursing and Life Insurance: A Statistical Summary of Results of Eight Years. *American Statistical Association Journal* 16:58–112.
- Frost, H., and T. Lynch. 1948. From Hospital to Home Nursing. *American Journal of Nursing* 48:684–86.
- Goldman, F. 1952. Home Care for the Needy and Medically Needy. *Journal of the American Medical Association* 148:1085–87.
- Goldman, F., and M. Frankel. 1959. *Patients on Home Care: Their Characteristics and Experiences*. New York: Council of Jewish Federations and Welfare Funds.
- Gould, D. 2004. Family Caregiving and the Health Care System: Findings from the National Survey. In *The Culture of Caregiving: Conflict and Common Ground among Families, Health Professionals, and Policy-makers*, edited by C. Levine and T. Murray, 15–34. Baltimore: Johns Hopkins University Press.
- Greenlick, M., and K. Brody. 1997. Home Health Services in a Managed Care System: Policy Recommendations from a Program of Research. In *Home-Based Care for a New Century*, edited by D. Fox and C. Raphael, 99–119. Malden, Mass.: Blackwell.
- Grogan, C. 2006. A Marriage of Convenience: The Persistent and Changing Relationship between Long-Term Care and Medicaid. In *History and Health Policy in the United States: Putting the Past Back In*, edited by R. Stevens, C. Rosenberg, and L. Burns, 202–5. New Brunswick, N.J.: Rutgers University Press.
- Gross, D., H. Tempkin-Greener, S. Kunitz, and D. Mukamel. 2004. The Growing Pains of Integrated Health Care for the Elderly: Lessons from the Explanation of PACE. *The Milbank Quarterly* 82:257–82.
- Gross, J. 2007. New Options (and Risk) in Home Care for the Elderly. *New York Times*, March 1, A1, A7.

- Halamandaris, V. 2006. Statement to the U.S. House Committee on Ways and Means. Available at <http://waysandmeans.house.gov/hearings.asp?formmode=view&id=4812> (accessed April 1, 2007).
- Hamilton, D. 1988. Faith and Finance. *Image: Journal of Nursing Scholarship* 20:124–27.
- Hamilton, D. 1989. The Cost of Caring: The Metropolitan Life Insurance Company's Visiting Nurse Service, 1909–1953. *Bulletin of the History of Medicine* 63:414–34.
- Haupt, A. 1937. Nursing and Life Insurance. *International Nursing Review* 11:471–76.
- Haupt, A. 1950. 1909–1952, the Metropolitan Nursing Service. A Memo Announcing Termination, Welfare Division/Nursing Service, MLI Collection.
- Haupt, A. 1951. Professional Reviewing, July 3, Memo, RG 13, Welfare Division, Visiting Nurse Service, MLI Collection.
- Haupt, A. 1953. Forty Years of Team Work in Public Health. *American Journal of Nursing* 53:81–84.
- Heartland Institute. 2007. Bias in Long Term Care Favors Nursing Homes, Government. Available at <http://www.heartland.org> (accessed March 14, 2007).
- Heger, R. 1996. Medicare Coverage for Home Care: Reining in a Benefit out of Control. *National Health Policy Forum Issue Brief* 694:2–7.
- Holt, S. 2005. Executive Director, Visiting Nurse Association of Greater Philadelphia, to E. Richmond, Secretary, Pennsylvania Department of Public Welfare, October 6, Visiting Nurse Association Collection.
- John Hancock Mutual Life Insurance Company. 1928. Visiting Nurse Service Report. Boston: John Hancock Mutual Life Insurance Company Collection.
- Kogel, M., and M. Fraenkel. 1953. Home Care Comes of Age. *Hospitals* 27:49–51.
- Kurlander, A.B. 1954. Problems of Organized Home Care for the Long-Term Patient. *Public Health Reports* 69:823–28.
- Lanza, A.J., Assistant Medical Director, Metropolitan Life Insurance. 1937. Various Nursing Service Problems Report. MLI Collection.
- Levenson, D. 1984. *Montefiore: The Hospital as Social Instrument, 1884–1984*. New York: Farrar, Straus, & Giroux.
- Lewenstein, B. 1992. Industrial Insurance, Public Health Campaigns, and Public Communication of Science, 1908–1951. *Public Understanding of Science* 1:350–54.
- Lincoln, L. 1950. Leroy Lincoln to MLI Field Force, June 30, MLI Collection.

- Mausser, E., and N. Miller. 1994. A Profile of Home Health Users in 1992—Issues in Reforming Home Health Care. *Health Care Finance Review*, fall, 1–13.
- McCall, N., and J. Korb. 2003. The Impact of Medicare Home Health Policy Changes on Medicare Beneficiaries. *Policy Brief*, summer, 1–6.
- McCall, N., J. Korb, A. Petersons, and S. Moore. 2001. Medicare Home Health Before and After the BBA. *Health Affairs* 20:189–98.
- McCall, N., J. Korb, A. Petersons, and S. Moore. 2003. Reforming Medicare Payment: Early Effects of the 1997 Balanced Budget Act on Postacute Care. *The Milbank Quarterly* 81:277–303.
- McCall, N., J. Korb, A. Petersons, and S. Moore. 2004. Decreased Home Care Use: Does It Decrease Satisfaction? *Medical Care Research and Review* 61:54–88.
- McMackin, S. 2006. What Is Private Duty Home Care? An Industry Overview. *Home Health Care Management and Practice* 18:92–97.
- Metropolitan Life Insurance Company (MLI). 1920. Abbreviated Three Month Study Made of Visits Made to Metropolitan Life Insurance Company Patients Not Paid for by the Company. *Public Health Nurse* 12:616.
- Metropolitan Life Insurance Company (MLI). 1929. *Stabilization of Metropolitan Visiting Nurse Service*. New York.
- Metropolitan Life Insurance Company (MLI). 1931. *Home Office Analysis of Nursing Service*. New York.
- Metropolitan Life Insurance Company (MLI). 1948. *Analysis of Volume of Service in Relationship to Cost*. New York.
- Montgomery, R., L. Holley, M. Deichert, and K. Kosloski. 2005. A Profile of Home Health Workers from the 2000 Census: How It Can Change What We Know. *The Gerontologist* 45:593–600.
- Mundinger, M. 1983. *Home Care Controversy: Too Little, Too Late, Too Costly*. Rockville, Md.: Aspen Publication.
- Munter, E., and M. Berke. 1958. The Care of the Long-Term Patient: A Review of the Administration of Present Programs. *Journal of Chronic Disease* 7:144–77.
- National Association for Home Care and Hospice. 2004. *Basic Statistics about Home Care*. Washington, D.C. Available at <http://www.nahc.org> (accessed April 1, 2007).
- Nelson, S. 1929. Study of Chronic Illness: Carried on by the John Hancock Mutual Life Insurance Company and the Community Health Association of Boston, Mass. *Public Health Nurse* 21:577–78.
- Nelson, S. 1953a. Final Report Visiting Nurse Service Year 1953: Total Summary Cases, Visits, Cost, 1925–1953. Boston: John Hancock Mutual Life Insurance Company Collection.

- Nelson, S. 1953b. Twenty-Eight Years and Eleven Million Visits. *American Journal of Nursing* 53:1469–70.
- Olson, L. 2003. *The Not So Golden Years: Caregiving, the Frail Elderly, and the Long-Term Establishment*. Lanham, Md.: Rowan and Little.
- Reid, M. 1942. *Evaluating the Service of the Nurse: A Handbook for Staff Nurses and Supervisors*. New York: MLI Collection.
- Reid, M. 1954. Nursing in New York City's Home Care Program. *Nursing Outlook* 2:530–32, 591–93, 647–49.
- Rosenberg, C. 2006. Anticipated Consequences: Historians, History, and Health Policy. In *History and Health Policy in the United States: Putting Back the Past*, edited by R. Stevens, C. Rosenberg, and L. Burns, 13–31. New Brunswick, N.J.: Rutgers University Press.
- Ryder, C., P. Stitt, and W. Elkin. 1969. Home Health Services—Past, Present, and Future. *American Journal of Public Health* 59:1720–29.
- Sarraille, W. 1998. The Home Care Industry Faces Mounting Allegations of Fraud. *Journal of Long Term Care* 17:10–18.
- Schell, E. 1993. The Origins of Geriatric Nursing: The Chronically Ill Elderly in Almshouses and Nursing Homes, 1900–1950. *Nursing History Review* 1:203–16.
- Schlenker, R., M. Powell, and G. Goodrich. 2005. Initial Home Health Outcomes under Prospective Payment. *Health Services Research* 40:177–93.
- Sheatsley, P. 1958. Chronic Illness in the US. Vol. 4, Chronic Illness in a Large City: The Baltimore Study. *Journal of the American Statistical Association* 53:769–72.
- Shindell, S. 1950. A Method of Home Care for the Prolonged Illness. *Public Health Reports* 65:651–59.
- Spector, W., J. Cohen, and I. Pesis-Katz. 2004. Home Care Before and After the Balanced Budget Act of 1997: Shifts in Financing and Services. *The Gerontologist* 44:39–47.
- Spurrier, R., R. Johnson, and A. Manussen. 1965. Challenge to Nursing in Medicare. *American Journal of Nursing* 65:68–75.
- Stevens, H. 1928. Round Table on the Care of the Chronic. *Public Health Nurse* 20:541–42.
- Stevens, R., and R. Stevens. 1974. *Welfare Medicine in America: A Case Study of Medicaid*. New York: Free Press.
- Stone, R. 1997. Integration of Home and Community-Based Services: Issues for the 1990s. In *Home-Based Care for a New Century*, edited by D. Fox and C. Raphael. Malden, Mass.: Blackwell.
- Taylor, M. 1933. *The Social Cost of Industrial Insurance*. New York: Knopf.
- Thompson, J. 1950. The Home Care Program of Montefiore Hospital: The First Two and One Half Years. Master's thesis, Yale University.

- Trager, B. 1971. Home Health Services and Health Insurance. *Medical Care* 9:89–98.
- U.S. Bureau of the Census. 2002. 2002 Economic Census, Home Care Services. Available at <http://www.Census.gov/prod/ec02/ec0262a1ust.pdf> (accessed April 1, 2007).
- U.S. Department of Health, Education and Welfare. 1964. *Coordinated Home Care Programs: 1964 Survey*. Washington, D.C.: U.S. Government Printing Office.
- U.S. Department of Health and Human Services. Office of Inspector General. 2006. *Effect of the Home Health Prospective Payment System on the Quality of Home Health Care*. Pub. no. OEI-01-04-00160. Available at <http://www.oig.hhs.gov> (accessed April 1, 2007).
- U.S. General Accounting Office. 1996. *Medicare: Home Health Utilization Expands While Program Controls Deteriorate*. Available at <http://www.gao.gov/cgi-bin/getrpt?HEHS-96-16> (accessed June 25, 2007).
- U.S. Public Health Service. 1955. *A Study of Selected Home Care Programs*. Pub. no. 447. Washington, D.C.: U.S. Government Printing Office.
- U.S. Senate, Committee on Labor and Public Welfare. 1959. *Hearings before the Committee on Problems of the Aged and Aging*. Washington, D.C.: U.S. Government Printing Office.
- U.S. Senate, Special Committee on Aging. 1961. *The 1961 White House Conference on Aging: Basic Statement and Recommendations*. Washington, D.C.: U.S. Government Printing Office.
- Vladeck, B. 1980. *Unloving Care: The Nursing Home Tragedy*. New York: Basic Books.
- Von Bergen, J.M. 2007. Health Care Comes to Your Door: Older Population, New Issues. *Philadelphia Inquirer*, March 11, C1, C8.
- Wager, D. 2004. The Financial Impact of Caregiving. In *Always on Call: When Illness Turns Families into Caregivers*, edited by C. Levine, 136–48. Nashville: Vanderbilt University Press.
- Wales, M. 1928. Round Table on the Care of the Chronic. *Public Health Nurse* 20:464–66.
- Weissert, W. 1997. Home Care Dollars and Sense: Prescription for Policy. In *Home-Based Care for a New Century*, edited by D. Fox and C. Raphael, 121–33. Malden, Mass.: Blackwell.
- Weissert, W.G., C.M. Cready, and J.E. Pawelak. 1988. The Past and Future of Home- and Community-Based Long-Term Care. *The Milbank Quarterly* 66:309–88.

Acknowledgments: The author thanks her colleagues Patricia D’Antonio, Christopher Feudtner, Joan Lynaugh, Neville Strumpf, Ruth Schwartz-Cowan, and Susan Reverby for their critical reviews of drafts of this manuscript.