

# HOME CARE AT THE CROSSROADS

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## AN INFORMATION PAPER

PREPARED BY THE STAFF OF THE  
SPECIAL COMMITTEE ON AGING  
UNITED STATES SENATE



APRIL 1988

**Serial No. 100-H**

This document has been printed for information purposes. It does not offer findings or recommendations by this committee.

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U.S. GOVERNMENT PRINTING OFFICE

WASHINGTON : 1988

83-878

## PREFACE

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During 1987, the Senate Special Committee on Aging held three hearings on the issues of quality of and access to home care services for older persons. The committee found that assurance of quality is virtually nonexistent under the various Government programs that provide for home care services. Additionally, the fragmentation of funding sources leads to a fragmentation in services. Those who most need home care services often are those least able to clear the hurdles to obtain assistance.

In a 1986 survey by the National Council on Aging, 65 percent of more than 1,000 home care professionals themselves admitted that quality of care in community based services was a key concern.

Home care today is at a crossroads. Policymakers must choose a course of action that will ensure quality home care and independence for our Nation's older citizens. A continuation down the path of insurmountable barriers no longer can be tolerated.

This report was prepared by committee staff as a follow-up to the hearings and after a re-examination of home care provided under various programs. The committee wishes to acknowledge the following for their thoughtful reviews and comments on the report: Dayle Berke, Bill Dombi, Ruth Galten, Nancy Heyer, Karen Hinick, Ann Howard, Bob Hoyer, Theodora Jay, John Logsdon, Susan Pettey, Richard Price, and Carol O'Shaughnessy.

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## Chapter 1

### OVERVIEW

"The medical system in this country is too fragmented. The support systems are poorly organized . . . My father is dying of heart disease . . . My mother said this is the worst time in her life. The past few years have been a nightmare for her. She is wasting away to nothing . . .

"By finally getting indignant about my father's condition, did we get some real help. He has a visiting nurse every day for an hour, to take his vital signs and care for his legs which have been weeping for over a year. This week a housekeeper aide just started, to help my mother with changing and bathing my father. This service is only for an hour 3 times a week. And now that he's almost dead, they just started sending a physical therapist. It's like Grand Central Station with my mother hopping around like a jack rabbit all day long with no rest at all. At night she is left alone to move him every hour, get him on a bedpan and tend to his every need. She never gets a full night's sleep. The lab technician comes to take blood, every week. The nurses that come are always changing. Think of having strangers flowing in and out of your home every day, plus cooking, cleaning, and all the other responsibilities of caring for a home and a sick husband."

The above quotation from a letter to the Special Committee on Aging summarizes the perception of in-home services from the viewpoint of the patient and the patient's family. They feel that services are difficult to obtain and those that are obtained frequently are fragmented resulting in increased rather than reduced stress. The turnover of home care personnel translates into a stream of strangers, and the family caregiver is left to fill in all the gaps.

In-home services, the various forms of crucial assistance that allow hundreds of thousands of disabled and chronically ill Americans to remain in their communities and out of institutions, is anything but a new phenomenon. For centuries, these services have been provided in communities all over the world, primarily by family members. What is new is the startling increase in the demand for these services. While over 2.1 million patients substituted home care for care in a hospital or nursing home in 1985, it has been estimated that as many as 8 million persons are in need of home care services (NAHC, 1986).

In the early 1980's, more than 80 percent of the caregivers were spouses, children, siblings, or friends of disabled persons, according to the 1982 National Long-Term Care Survey. While the efforts of

the family caregiver are expected to remain a crucial element of in-home services, it is becoming increasingly clear that many family caregivers will have to receive some outside assistance to continue to be the prime source of in-home services.

The development of formal home care services through volunteer or charitable organizations and private-sector efforts is based not only on the need for caregiver respite, but also on sharply rising demand. And trends indicate that the demand will continue to increase as America's population ages.

The oldest age groups (75-84 and 85-plus) are growing faster than any other age group in this country and the risk for chronic illnesses and limitations in functional abilities is greatest in these age groups. While only about 15 percent of those age 65-69 report difficulty with one or more personal care activities, 49 percent of those over 85 report the same (U.S. Senate, 1987-88).

Those who need assistance have limitations in one or more of a number of very basic skills, including dressing, eating, bathing, and toileting. They also have difficulty in the performance of such daily routines as shopping, meal preparation, housework, and taking medications.

Obtaining access to such care is a challenge, not only for the older or disabled person who would benefit from such care, but also for the providers of such care. While there are several funding sources available to pay for formal in-home services, the accompanying regulatory schemes often create bureaucratic barriers to the various types of needed care.

As with the rapid development or expansion of any promising program or service, not all of the problems that accompany such services are apparent initially. While the home care industry has mushroomed in recent years, the development of quality assurance standards and the mechanisms for monitoring and enforcing those standards has not kept pace with this expansion. Other than the Conditions of Participation under Medicare, there are essentially no Federal quality assurance standards for home care.

## Chapter 2

### BACKGROUND

#### ORIGIN AND GROWTH OF HOME CARE SERVICES

Home care includes a variety of skilled and semi-skilled services provided in the home of the beneficiary. Among the more frequently provided medical and health services are nursing, physical, speech, and occupational therapy, home health aide, and homemaker/personal care. In addition, the availability of social services such as case management, housekeeping, home delivered meals, chore, companion, respite care, transportation, and housing assistance frequently determine whether or not a person will be able to remain at home.

Hospital-based home care programs have their roots in the late 18th century when the Boston Dispensary established a home care program primarily for the purpose of training resident physicians. A century later, public health nursing emerged and home care and home visits became a key element of that profession.

Around 1947, the home care concept was adopted by hospitals in New York City and eventually followed by other hospitals which were attracted to the downward pressure these services had on the costs of outpatient services. The insurance industry, too, took note of the decreased costs associated with home care programs and began offering home nursing care to its policyholders in 1909.

A comprehensive home care model was developed in England after World War II and continues today. In time, it was transplanted and adapted to the United States. By the 1950's, home nursing agencies began to augment their services with home health aides and homemakers. Further limited expansion of home care services began after the 1965 passage of Medicare and Medicaid, Titles XVIII and XIX of the Social Security Act.

An unprecedented growth in the home care field is being fueled by a number of sources. For instance, earlier hospital discharges under Medicare's Prospective Payment System have had a significant impact on the demand for post-hospital services. The accelerating aging population and the public desire to find alternatives to institutional care are other factors. Additionally, studies have shown that availability increases utilization (Leader 1986).

But the biggest single reason for home care growth is the simple fact that home care is preferred by 72 percent of the American public over nursing homes for the care of either themselves or a family member who needs frequent medical assistance and housekeeping assistance (Cetron 1986-87).

Between 1966 and 1987, home health care agencies certified by Medicare increased by almost 400 percent—from 1,275 to 5,794. The greatest growth has been among the proprietary or for-profit agen-

cies, largely in response to the 1980 Omnibus Budget Reconciliation Act. This legislation permitted Medicare certification of for-profit agencies in those States that did not have licensing laws. Prior to the act, State licensure, and often certificate of need approval, was required of for-profit agencies. The second largest increase originated with hospital-based programs as discharge planning revealed the need for reliable follow-up care.

Unfortunately, many home care agencies are not certified, although the exact number is unknown. It is estimated that there are approximately 12,000 organizations delivering home care of which only half are certified or accredited (GWU, 1987). Consequently, thousands of home care agencies are operating without meeting even the minimum standards required by Medicare.

## SOURCES OF PUBLIC FUNDING FOR HOME CARE SERVICES

### MEDICARE

The primary Federal source of funding for home care comes from the Medicare Program. Medicare's coverage is focused on acute care, particularly periods of recovery following hospital and surgical care. For Medicare to cover home care, a need for skilled care must be demonstrated in which the beneficiary must be under the care of a doctor, homebound and in need of intermittent skilled nursing care, or physical or speech therapy. Home health aide services are allowable under certain circumstances. Services must be provided by a home health agency certified to participate under Medicare. Home health benefits are reimbursed on a reasonable cost basis; the beneficiary is exempt from any cost-sharing. Since 1982, Medicare also reimburses for hospice benefits which includes support services for a terminally ill patient in the home.

Home care expenditures in fiscal year 1987 under Medicare were \$2.5 billion, 3.3 percent of the overall \$75.1 billion Medicare costs.

### MEDICAID

Medicaid is a combined Federal/State funding source for health care to low-income persons. The Federal Government's share is tied to a formula based on the per capita income of the State. At a minimum, the Federal Government will pay 50 percent of the cost of medical care. Under Medicaid, home health services must include part-time nursing, home health aide, and medical equipment and supplies. At the State's option, it also may cover physical therapy, occupational therapy, speech pathology, and audiology. States are required to provide home health services to categorically needy recipients who are 21 years and older, and to all other Medicaid recipients who are entitled to skilled nursing facility benefits under the State plan. States are permitted to offer home health services to all other recipients.

Prior to 1981, Federal regulations limited Medicaid reimbursable home care services to the traditional acute care model. Congress, in Section 2176 of the Omnibus Budget Reconciliation Act of 1981, authorized the Department of Health and Human Services to expand Medicaid home care services beyond medical or medical-related care by waiving certain Medicaid requirements to allow States to

provide a broad range of home and community-based long-term care services to individuals who would otherwise require institutional care and have it paid for by Medicaid.

The services allowed under the waivers include long-term nursing or therapy for chronic conditions, case management, personal care, homemaker and chore services, adult day health and respite care. Personal care makes up 40 percent of waiver expenditures for aged and disabled clients, followed by case management and homemaker services each of which account for 15 percent of expenditures. The remaining waiver expenditures provide for adult day care (5 percent), home health aide (4-5 percent), respite care (1 percent), and other nonspecified services. In 1987, there were 180 approved waiver programs in 46 States, yet waiver clients accounted for only 3 percent of the entire at-risk population. Five States account for 56 percent of all aged and disabled waiver recipients: Florida, California, Illinois, New York, and Oregon (Burwell, 1987).

The Omnibus Budget Reconciliation Act of 1987 created a new waiver authority under which States can provide home and community-based services to individuals 65 years of age or older by using a different methodology for assuring that costs will not exceed specified amounts.

In fiscal year 1987, the total expended on home care older persons under Medicaid, including the waiver programs, was \$2.1 billion. The Federal share was \$1.1 billion; the States' share was \$988 million.

#### SOCIAL SERVICES BLOCK GRANT PROGRAM (SSBG)

Title XX of the Social Security Act authorized a block grant to States for a wide range of social services to diverse population groups. One of the goals of the program is the prevention of institutionalization.

States receive funds on the basis of the State's population, within a Federal expenditure ceiling. There are few requirements for use of Title XX funds, and States are provided relative freedom to spend Federal social services block grant funds on State-identified service needs. In-home services that may be available include homemaker, home health aide, chore and personal care.

The Omnibus Budget Reconciliation Act of 1981 limited State reporting requirements to reporting on the types of services to be provided and the characteristics of individuals to be served. As a result, qualitative national data specific to the elderly and by service are unavailable. A survey of States conducted by the American Association of Retired Persons (AARP) found that home-based services were the most frequently cited of the SSBG services provided to the elderly in 41 States. At the same time, these States also identified the need for in-home services as largely unmet, many of the States indicating long waiting lists (Gaberlavage, 1987).

The total fiscal year 1988 appropriation for SSBG for all services for all recipients, including home care for elderly, was \$2.7 billion.

#### OLDER AMERICANS ACT (OAA)

Under Title III of the Older Americans Act, in-home services include home-delivered meals, homemaker, home health aide, person-



al care, chore, escort, and shopping services. Although exact data is not available, approximately one-quarter of funds controlled by area agencies on aging is directed at in-home services. Although a sizeable portion of that amount is for home-delivered meals, an almost equal portion is spent for other in-home services.

The Older Americans Act Amendments of 1987 (Public Law 100-175) includes for the first time a separate authorization of funds for nonmedical in-home services for frail older persons.

In fiscal year 1988, \$1.2 billion was appropriated for the provision of all services under the Older Americans Act.

#### VETERANS ADMINISTRATION (VA)

The Veterans Administration also provides services to eligible veterans through its own network of VA hospital-based home care units or through contract with other hospitals. These include skilled treatment services performed by physicians, psychologists, nurses, technicians, and physical therapists.

By the year 2000, approximately 9 million men—two out of every three males age 65 or older—will be veterans and the VA is anticipating dramatic increases in the need for various community-based services. However, this demand will be temporary. By 2010 half of all men over 65 will be veterans and by 2020 the figure will drop to slightly more than one-third.

In fiscal year 1987, the VA spent \$21.1 million on hospital-based home care.

#### STATE PROGRAMS

Besides the State share of Medicaid and Older Americans Act funding, several States provide additional revenues for home care services. For example, Massachusetts uses State funds to pay for its in-home services program. Florida's Community Care for the Elderly program provides State revenues to supplement the in-home services under title III under the Older Americans Act and Medicaid funds (Wood, 1986-87).

State programs, however, often are administered by several State agencies which leads to fragmentation of services.

#### PRIVATE SECTOR FINANCING OF HOME CARE SERVICES

##### HEALTH MAINTENANCE ORGANIZATIONS (HMO's) AND MEDICARE

Health maintenance organizations offer prepaid health insurance coverage of a number of health care services that either are provided directly or arranged by an HMO.

Under Federal rules, HMO's that meet special Federal qualifications are allowed to enroll Medicare beneficiaries as members. These organizations receive a flat fee from the Federal Government for taking care of these Medicare beneficiaries. Some HMO's charge beneficiaries an additional premium for services that Medicare does not cover. HMO's must provide the full range of Medicare-covered basic services that are available in the geographic area. HMO members receive comprehensive doctor, hospital, skilled nursing home, and home health care with few of the out-of-

pocket costs of Medicare, although members generally face restrictions in using providers outside the plan.

Approximately 900,000 of the 32 million Medicare beneficiaries currently are enrolled in more than 150 HMO's.

#### PRIVATE HEALTH INSURANCE

Long-term care policies are offered by about 70 insurance companies which have about 423,000 policies in force (DHHS Task Force, 1987). Four years ago, only 16 insurance companies offered long-term care policies. Nearly 40 States have taken some action to encourage long-term care insurance.

However, few home care benefits, especially those related to custodial or personal care, are included in most long-term care policies. Most plans that cover home care costs require a prior stay in a hospital or skilled nursing facility. This is to reduce the large potential demand for home care among the majority of the covered population that never has been institutionalized (GAO, May 1987).

One reason why coverage of home care is so limited is the difficulty of restricting services that are considered to be noninsurable only to those who need them. These services include personal care, homemaker, and nutritional services. In addition, given the nature of many chronic conditions, many individuals who need long-term care will need it for the rest of their lives, resulting in an open-ended liability for the insurance company. High premiums also would work against private long-term care policies. Additionally, many older people either do not demand such coverage or mistakenly believe they are covered adequately with either Medicare or supplemental policies (Brickfield, 1985; Older Americans Report, July 1987).

There is increasing interest on the part of the insurance industry to develop long-term care policies to adequately address the needs of the elderly. In 1987 several major insurance companies began offering long-term care coverage to large groups such as the employees of the Procter & Gamble Co., the American Express Company's travel related services division, and the State of Maryland. In addition, the General Motors Corp. and the Ford Motor Corp. have agreed in contracts with the American Automobile Workers to develop long-term care benefits pilot programs. Half of 147 companies responding to a national survey said they would probably be offering an employee-financed long-term care benefit within 5 years (Washington Business Group on Health, 1987).

#### LIFE CARE OR CONTINUING CARE RETIREMENT COMMUNITIES

Life care or continuing care retirement communities provide housing, meals, housekeeping, and social activities to older persons, usually in a campus-type setting for the duration of their lives as long as they are residents of the community. Rights and obligations of the resident and the community are set forth in a contract. A resident is required to pay a lump sum entrance fee with monthly payments usually adjusted for inflation. In addition, the resident may receive, when needed, such long-term care services as skilled and intermediate nursing home care, personal care, home nursing,

and speech, occupational and physical therapy (O'Shaughnessy, Price, and Griffith 1987).

The number of life care or continuing care communities is relatively small. An estimated 120,000 persons reside in approximately 683 life care communities in 40 States (AAHA, 1987).

Since life care is a form of risk-pooling in which residents pool their resources and share the risk of future costs of long-term care services, these communities are viewed as a form of insurance. Twenty-one States have passed laws to regulate these communities. The entrance fee and monthly payments are considered to be exorbitant for low- and even middle-income older persons—between \$21,000 and \$100,000 with average monthly payments of \$600 to \$1,100 (AAHA, 1987).

Continuing care retirement communities originally were set up by nonprofit organizations and were popular with middle-income older persons. However, for-profit organizations also are providing such care. And with the income level of new occupants tending to be higher than average, this alternative would not be available to the vast majority of older persons. It may be possible, however, for some older homeowners to pay for continuing care communities with the equity in their homes. This practice is known as home equity conversion.

#### OUT-OF-POCKET

Despite the numerous funding sources mentioned above, most home care expenses still are paid out of individual's pockets. In the 1982 Long-Term Care Survey, 41 percent of 1.1 million persons who received paid care said they were the sole source of payment. The next most frequent sources of payment were Medicare only (8.4 percent) and Medicaid only (6 percent) (Liu, Manton, and Liu 1985).

In 1982, individuals spent \$1 billion out-of-pocket for home care services. Two-thirds of this went for assistance that was provided by nurses' aides or home health aides. This statistic shows that many disabled elderly residing in the community require assistance that is primarily unskilled in nature and generally would not be conventionally covered by either public programs or private third-party payors.

Out-of-pocket expenditures continue to grow. The Congressional Budget Office estimated that \$9.1 billion was spent on certain skilled home health care services in fiscal year 1985. Of this total, \$3.7 billion represented out-of-pocket expenditures (Gordon, 1987).

## Chapter 3

### ACCESS TO HOME CARE

Even though there are sufficient numbers of providers of home care in many areas of the country, many older persons who need home care do not receive these services. Recent regulatory schemes have created excessive barriers to care. One strategy by the Federal Government for controlling costs has been to limit access to home health benefits. Through 10 regional fiscal intermediaries, the Health Care Financing Administration (HCFA) has successfully held down costs via restrictions on home care services.

#### MEDICARE PROGRAM RULES AND REGULATIONS CREATE BARRIERS

In a January 1987 national survey by the General Accounting Office of hospital discharge planners, more than half of all respondents identified Medicare rules and regulations as the biggest barrier to home health care for Medicare beneficiaries. These responses were based on the perception of discharge planners that the Medicare Program changed the way in which individual eligibility and coverage determinations are made and, post-hospital benefits do not cover all of the types of services needed by the elderly, such as homemaker and chore services.

One weakness in recent Medicare eligibility standards is that the social circumstances of patients have not been adequately considered. Many beneficiaries live alone and do not have any other source of help. A major weakness has been the restrictive definitions that the Health Care Financing Administration has applied to Medicare requirements for home health care.

To qualify for home health care under Medicare, a beneficiary must be homebound and in need of intermittent skilled nursing care or physical or speech therapy:

1. *Homebound.*—Homebound has been defined by HCFA as an individual's normal inability to leave home without use of a supportive device such as crutches or a wheelchair, special transportation, bodily assistance, on the advice of a physician. The GAO has repeatedly criticized the homebound and other coverage criteria as difficult to administer because key terms are vague or undefined.

If, for example, a patient is able, although with difficulty, to go to his physician's office for a visit, he is no longer considered homebound. One such Medicare denial was Mr. A who required hemodialysis two times a week which cannot be performed at home. He also had visited a surgeon once a month at which time the physician surgically removed devitalized tissue from gangrenous areas on his feet. His ambulation was very

limited due to the pain he experienced upon walking. However, his ability to walk improved as his feet continued to heal and the physician wrote that "the patient is ambulating well." The fiscal intermediary denied his home care benefits because he was "not homebound."

In other situations, fiscal intermediaries have held that Medicare beneficiaries cannot receive radiation treatment as an inpatient—they must be treated through the hospital outpatient department. However, if the patient has to leave home to receive radiation, they are considered to be not homebound and hence ineligible for home health care.

*2. Intermittent Care.*—Under present guidelines, daily visits are allowed for a maximum of 3 weeks if intensive skilled service is needed. If patients require daily visits for a period lasting beyond 2 to 3 weeks, they become ineligible for reimbursement unless providers demonstrate exceptional circumstances. This often results in premature termination of services. Additionally, if after 2 to 3 weeks of daily care the physician cannot indicate that there will be a declining need for daily services at some point in the future, the beneficiary is ineligible for the home health benefit, no matter how exceptional the circumstances. Retroactive denials of coverage in cases that exceeded the 3-week limit are not uncommon.

In November 1986, some fiscal intermediaries who administer the Medicare benefits began to interpret "daily" as five times a week. The result leaves many beneficiaries without necessary care for the remainder of the week.

In many circumstances where the patient receives supplementary home care provided under any other payment source such as Medicaid or even self-pay, the fiscal intermediary will deny Medicare coverage. The rationale for this is that if a person received care beyond what Medicare will cover, then the person needs more than "intermittent care" and is ineligible for Medicare coverage. Yet with the restrictive interpretations of Medicare's home care benefit, patients and their families are forced to seek other services and sources of payment to avoid institutionalization. Such denials also prohibit development of a combination of skilled and custodial services designed to keep older persons at home.

*3. Skilled Nursing Care.*—Due to Medicare definitions, those needing certain types of professional nursing care may be ineligible for coverage. Skilled nursing care such as monitoring of diet or medication to prevent exacerbations of existing conditions, reinforcing care routines, or identifying health problems is not covered. For example, a physician may order a nurse to draw blood once a month for blood sugar monitoring but fiscal intermediaries will deny reimbursement if the blood sugar of the patient is within the normal range for 3 months. If the blood sugar is abnormal, then the nurse's visits can be reimbursed. Yet the blood sugar would be normal because the nurse is keeping the patient compliant through teaching and monitoring.

In addition, while Medicare reimburses costs for home health aides who help with bathing, eating, and dressing if

these services are "incidental" and "do not substantially increase" the length of the aide visit, reimbursement is not made for such activities as cleaning, shopping, and running errands. These services can be essential to keeping a patient out of a hospital or nursing home.

### THE PROSPECTIVE PAYMENT SYSTEM (PPS) STRAINS THE HOME CARE SYSTEM

One of the greatest pressures on the home care system has come from Medicare's Hospital Prospective Payment System. Under PPS, predetermined fixed payment rates are set for each Medicare hospital inpatient admission based on the diagnosis-related group (DRG) into which that admission falls. This fixed payment is an incentive for hospitals to limit costs spent on Medicare patients either by reducing lengths of stay or the intensity of care provided. As a result, many Medicare patients are being discharged earlier and sicker than they were prior to PPS and in greater need of home care services. The number of hospital patients discharged to home care rose by 37 percent from 1983 to 1986. Yet during the same period, reimbursement denials for home care claims rose by 133 percent (Senate Special Committee on Aging, 1986).

In a survey of 35 home health agencies across the country, 83 percent reported a significant increase in the severity of illness of the patients they served. The survey also showed an increase in the frequency of discharges directly from intensive care units and discharges of post-surgical patients with open or partially healed wounds. More than half of the agencies noted a rise in readmission rates to hospitals, suggesting greater instability in patient conditions. The need for more frequent and longer home health visits also increased. Before PPS, a patient typically required only one visit in the first 2 weeks of care, but now requires as many as 10 visits. Additionally, many visits in the past lasted only 45 minutes to an hour, but delivery of more complicated services now increases some visits to 3-4 hours. (Seifer, 1987)

Early dismissal from a hospital often causes a need for in-home services that are not covered by Medicare. Since Medicare patients before PPS spent more recovery time in the hospital, in-home care services were not as necessary. Early hospital dismissal is adding to the burden not only of elderly individuals in need of medical care, but also on the in-home care system itself.

Studies of social service providers suggest that their budget restraints may limit the availability of long-term custodial care for the frail elderly if social service providers must focus on the needs of a more acutely ill population (GAO, December 1986).

### INCREASE IN HCFA DENIALS FOR HOME CARE

Data from the Health Care Financing Administration show that national rates of denial for home health care claims are increasing. In 1984 denials of Medicare Part A home health bills based on claims averaged 2.5 percent. By 1987, the denials had risen to about 8.2 percent. In 1987, the first year it became official HCFA policy to maintain data based on visits, the denials for visits were lower at 4.4 percent. One visiting nurse association reported that

during a 7-month period between 1986 and 1987 its Medicare visits were cut 50 percent (25,987 visits) due to denials by their fiscal intermediary. These cuts were significant because they occurred in a county where 18 percent of the population is 65 years or older.

Fiscal intermediaries can deny a provider's claim on two grounds: The services were not medically necessary or on technical reasons. Denials on medical grounds mostly are unspecified and the explanations given by fiscal intermediaries are that the visits are "not reasonable and necessary" or constitute "custodial care." Many providers characterize the intermediaries' medical denials as "practicing medicine without a license" (Seifer, 1987).

Denials on technical grounds are based on the fiscal intermediaries' determination that the visit failed to meet a statutory or regulatory requirement other than medical necessity. Two examples are the "homebound" or "intermittent skilled nursing care" requirements. Congress, in the Omnibus Budget Reconciliation Act of 1986 (Public Law 99-509) created a 2.5 percent waiver of liability presumption for technical denials based on the intermittent and homebound requirements for skilled nursing.

Under the waiver, fiscal intermediaries are required to pay all claims on the assumption that the provider is making a good faith effort to check the reasonableness of its claims. However, the overall denial of claims rate must be less than 2.5 percent of the Medicare services rendered. Should an agency exceed the denial limit, it is not reimbursed under the waiver regardless of whether or not it accepted beneficiaries and acted in good faith. However, the waiver does not govern the technical denials which stem from failure to complete paperwork to the satisfaction of the intermediaries. For example, a fiscal intermediary will deny a claim when a Form 485, HCFA's standardized plan of treatment form, signed by the physician was not dated by the physician on the ground of "no physician's orders."

In various memoranda to fiscal intermediaries in early 1987, HCFA ordered fiscal intermediaries to achieve a 5:1 savings/cost ratio in medical review of denials for home health care. This meant that fiscal intermediaries must find \$5 in denials for every \$1 paid for functions such as medical and utilization review and auditing, or risk losing their contracts. Fiscal intermediaries, under stress to meet these quotas, initially targeted those home health agencies considered by the intermediaries to have deficient billing practices. Eventually all home health agencies arbitrarily became vulnerable. In effect, the fiscal intermediaries increased denials based on technical issues and not because the beneficiary did not need the care. HCFA officials subsequently reduced the ratio to 2:1 in April 1987 and did away with it in October 1987.

The Congressional Budget Office in early 1988 revised downward its estimate of Medicare costs for home health care for fiscal years 1988-92. In January 1987, CBO had estimated that Medicare spending for home health services would be \$3.4 billion in fiscal year 1988 and rise to \$5.9 billion by fiscal year 1992. Citing changes in the administration of the benefit, CBO revised its estimates for Medicare home health care costs in January 1988 downward to \$2.5 billion for fiscal year 1988 and \$3.4 billion in fiscal year 1992 (CBO, 1988).

## INCONSISTENT MEDICAID POLICIES

States currently are allowed to apply for limited special exemptions from some restrictive Medicaid regulations through the Section 2176 waivers. Due to the added flexibility provided by these waivers, some States are able to broaden their range of available services to home and community-based long-term care services.

This flexibility, however, increases the vast differences among State-offered programs. For example, only 8 States offer personal care services to the categorically needy; 16 States offer this service to both the medically and categorically needy. Those States that offer services usually place limits on the amount of service; only two States offer unlimited service. Flexibility also means that States may reimburse home health visits at a rate considerably below the cost to an agency, often jeopardizing the ability of some agencies, particularly those in rural areas, to survive.

Additionally, HCFA regulations require States to demonstrate cost-effectiveness. HCFA has become increasingly stringent in its requirements for detailed and specific documentation that utilization of nursing homes by Medicaid recipients actually would increase without the Section 2176 waiver.

### PROVIDER SELECTION

Because of the difficulties home care agencies have in complying with multiple sets of regulations, they may choose to limit their services to one source of payment, thereby limiting the client's ability to receive all appropriate services.

Due to limitations on reimbursement for home health care under Medicare, providers are dropping out of the Medicare Program. In 1986-87, over 200 Medicare-certified home health agencies have withdrawn. In addition, at least two major home health providers with offices in more than three States have ceased participating in Medicare altogether in the past 3 years. Some county health organizations are also withdrawing from Medicare. This leaves the elderly recipient of home care services in underserved areas solely responsible for all the home care bills without any Medicare reimbursement assistance.

Even when providers remain in the program, they are limiting the number of Medicare patients they serve because of the "sentinel effect" of denials; that is, providers who have been subjected to arbitrary denials or are in danger of losing their waiver of liability presumption are likely to restrain from providing services when faced with a case in which coverage is not clear. Rather than providing services and billing Medicare to determine if services are covered, agencies may opt for informing the patient instead that Medicare does not cover the services and requiring the patient to pay for the services out of his or her own pocket. The patient often may decide not to pay or may be unable to pay for the services. Consequently, some patients are going without care to which they may be legally entitled.



## ACCESS TO HOME CARE DIFFERS THROUGHOUT THE COUNTRY

Home care services tend to be less accessible in rural areas than in metropolitan areas. A higher proportion of elderly patients in rural than urban hospitals tend to go home without further care. It is difficult to know if this is due to the presence of family caregivers, unwillingness to seek help, lack of available services, or limited awareness of available services.

Since rural areas tend to have a lower tax base than urban areas, this limits their ability to raise revenue for needed programs. There also tends to be a shortage of trained professionals and other qualified caregivers, which limits the number of people who could receive care.

Targeting home care services to the rural elderly is extremely difficult because of the distances that must be covered. This may be exacerbated by a strong belief in self-reliance and a general unwillingness to seek outside help. Even if rural elderly individuals request assistance, the unavailability of public transportation often poses another isolating obstacle.

## Chapter 4

### PERSONNEL

#### TRAINING OF HOME HEALTH AIDES

The quality of the recruitment, training, supervision, and evaluation is critical to the stability and effectiveness of any home care service. Yet only 13 States have training standards for both minimum hours and curriculum requirements for home health aides (U.S. House Select Committee on Aging, 1986).

Even when training does occur, there is a question of the adequacy of such training. The National League for Nursing recently administered an experimental written examination of home health aides' post-training knowledge and ability to apply basic principles necessary to providing safe patient care to 265 individuals from 19 agencies in 14 States. The results outlined in Table 2 are alarming.

TABLE 2.—*Post-Training Home Health Aides Caregiving Skills*

	Percent
Could not read a thermometer .....	44
Did not know how to take a patient's pulse .....	31
Did not know what to do if a patient stops breathing .....	30
Did not know the proper care for a diabetic .....	45
Did not know how to safely help a stroke victim to walk .....	40
Could not correctly identify low salt foods .....	30
Did not know how to properly monitor a patient's fluid intake .....	46

Source: National League for Nursing, "Home Health Aide Skills Assessment Test," New York: NLN Test Service, 1987.

Even though Congress has mandated training and supervision standards for home health aide services under Medicare, they have not been implemented. Changes in the Social Security Act relating to Medicare in 1980 required home health aides to have "completed a training program approved by the Secretary of the Department of Health and Human Services." Although regulations were drafted by the Health Care Financing Administration to establish a training curriculum for standards in hiring, training, assignment of duties, and supervision, they never were finalized.

In a 1987 hearing held by the U.S. Senate Special Committee on Aging (U.S. Senate, 1987), it was discovered that the Secretary still had not implemented the 1980 Congressional mandate for a home health aide training program.

At the same hearing, the Office of the Inspector General of the Department of Health and Human Services released a study which revealed that Medicare patients' needs for home health aide services are not being met (OIG, 1987). The study showed aides perform most of the assigned personal care services although they perform only half of the needed supportive specialized services representing an extension of nursing or rehabilitation services. These duties in-

clude assisting with dialysis, catheter care, foot soaks, special skin care, and recording intake and output of fluids. Other specialized services involve the taking and recording of patient's temperature, pulse, and respiration along with exercises, ambulation training, and recording progress in activities of daily living. Non-performance of these services could inhibit rehabilitation or allow the patient's condition to deteriorate to the point of readmission to the hospital. The study found that the primary reasons for non-performance of the supportive tasks were the lack of orientation of aides to patients and tasks by supervising nurses as well as the lack of on-site supervision of aides by professionals.

A second finding in the Inspector General's report was an overall lack of standards. The Medicare Conditions of Participation for home health aides lacks standards for recruitment, hiring, and training, according to the report. Additionally, it said the standards for assignment of aides and supervision do not provide sufficiently objective criteria. Further, the standards that are in place can vary sharply from State to State. The report also shows that improvements in Medicare standards are needed to upgrade the quality of care provided by aides and to assure that the estimated \$650 million Medicare will pay for aide services in the current year will not be wasted.

### SUPERVISION AND MONITORING

Because of poor supervision, the potential exists for inadequate care, physical abuse, or theft from the patient. Congressional committees have heard testimony of appalling abuse by individual home care workers. However, abuse and theft do not appear to be the norm in home care; it is most frequently found in institutional settings. One study found that less than 5 percent of home care consumers interviewed reported theft or complained of rough treatment, and one State's survey of abuse complaints by elderly consumers revealed that only 1.5 percent of complaints concerned home care providers (Nassif, 1986-87, U.S. Senate Special Committee on Aging, 1987). Nevertheless, the potential for abuse may increase as demand for these services increases and more unmonitored providers come into the market.

Obtaining home care services in a timely manner is an additional problem. Bedridden patients need assistance with getting out of bed and getting dressed early in the day. Too often, aides are not available when patients need them most, which detracts from the quality and effectiveness of the service. Home care agencies sometimes change the time its workers come to the home without informing the client. This places additional stress on family caregivers who may need to leave work to attend to the patient and on the elderly patients themselves who suffer from loss of care.

### WAGES AND BENEFITS

A number of home care agencies have difficulty recruiting and retaining home health aides because of the low wages and limited benefits they offer. Generally, wages begin at the minimum wage of \$3.35 per hour depending on the agency and labor supply. In

areas where recruitment is very difficult, starting wages are higher.

Home health agencies frequently find themselves competing with fast food chains, often unsuccessfully. Because an aide often has both low prestige and low wages, many prospective home care workers opt for work at a fast food restaurant for equivalent wages and without the difficulties inherent with in-home work or waiting for a deferred salary to begin after training is completed. Some agencies no longer are taking new patients because they are unable to hire enough home health aides.

Benefits to homemaker-home health aides vary, often depending on the number of visits an aide makes for a particular agency. As they are for other industries, insurance rates are increasing for home health agencies, making benefits costly to provide, especially for employees who do not remain with the agency. Minimal benefits consist of the required FICA, worker's compensation, and unemployment compensation. Home health aides often do not receive disability, medical, liability, or life insurance. Other benefits such as a retirement plan, paid annual leave, paid holidays, and paid sick leave also frequently are not offered.

Further, the home care worker is in a situation very different from a similar care provider in an institutional setting—the home care worker has to take the client's home as it is, which may include unsanitary conditions and a lack of adequate facilities for proper performance of tasks. This is an element that the home care worker cannot control and it can add considerable stress to her work. In addition, the aide often must deal with difficult or demanding patients and family members.

These factors are major contributors to the shortage of home care aides to perform various services, particularly the personal care services which are the most needed by elderly with limitations in functional abilities.

## **Chapter 5**

### **ACCOUNTABILITY**

#### **LACK OF CONSUMER INPUT**

A perennial issue in the home care industry is the lack of accountability to the consumers of those services. A major roadblock to a solution is the very limited access to where these services are delivered—the consumer's home. Further, because home care consumers are usually frail, and often live alone, they are particularly vulnerable. Many are too sick to speak out for themselves, and often lack an advocate who can speak on their behalf (U.S. House Select Committee on Aging, 1986).

The present regulatory system contains little in the way of protection or recognition of clients' rights. If quality of care is addressed, it usually is by regulation rather than through the quality of the care actually delivered. There is virtually no client input or client feedback in the determination of what constitutes quality care.

In addition, if home care clients have complaints or problems with the quality of care—or with any aspect of the care they receive—they essentially have no place to turn. Those receiving home care services by definition are ill and dependent upon their caregivers, and therefore are often reluctant to complain, regardless of the situation. It also is difficult for an advocate, if one exists, to visit the client because of where the services are delivered—in the home.

#### **LIMITED PROVIDER ACCOUNTABILITY**

##### **PROFESSIONAL ORGANIZATION STANDARDS**

A few organizations have developed standards of self-regulation through certification and accreditation processes. Skilled nursing services are accredited by the National League for Nursing (NLN). The Joint Commission on the Accreditation of Healthcare Organizations (JCAHO) provides accreditation for hospital-based home care programs and is also developing standards for agencies not run by hospitals. The National Home Caring Council (NHCC) accredits and approves homemaker and home health aide services. However, the number of agencies participating in these programs is very limited—1,000 hospital-based programs have accreditation by the JCAHO, and more than 100 each have been accredited by the NLN and the NHCC.

## FEDERAL STANDARDS

Other than the Medicare Conditions of Participation, there virtually are no Federal standards for home care, and only half of the approximately 12,000 home health care agencies are Medicare certified or accredited. A significant percentage of home care services meet no standards. For example, the Social Services Block Grant Program and the Older Americans Act's laws and regulations do not have any minimum mandatory training and supervision requirements.

## STATE STANDARDS

The other public standards that exist are those developed by the States. Although 35 States licensed home health agencies in 1987, there was no uniformity among licensure laws and State regulations. In a number of States, the frequency of the State visits to the licensed agencies has been declining from once a year to once every 3 years. Additionally, in regulating the health/medical component of home care, many States rely on Medicare regulations for certification of home health agencies, and do not regulate the nonmedical component (Leader, 1986).

State certificate of need requirements for new home health agencies may specify State standards that must be met initially, but do not require monitoring once the agency begins operation.

Nevertheless, some States have developed some creative initiatives to deal with the problems of fragmentation of services, decreasing funds, increasing costs, and accountability. New York has pioneered a "Nursing Home Without Walls" program which assesses the need for, coordinates, and provides a broad range of health, social, and environmental services managed on a 24-hour, 7-day-a-week basis. Tapping a variety of public funding and provider sources, the program provides in a patient's home a broad range of comprehensive long-term care services that otherwise are available only in a nursing home. The cost is about 75 percent of nursing home care (Lombardi, 1986-87).

Some States utilize the diversity of public funding sources to an advantage by creating a continuum of service eligibility for clients. Thus, when a client's eligibility for services under one program leaves off, then those under another program begins (Justice, 1987). Oregon created its Senior Services Division in 1981 which is responsible for both institutional care and all the public financing sources for community-based care, including Medicaid, State general funds, Older Americans Act, and Social Services Block Grant funds.

States increasingly are becoming more adept in regard to managing services capitalizing on the components of case management, preadmission screening, and individual client assessment for care needs in the community. Connecticut contracts with a single statewide case management agency whose sole function is to provide case management services for its home and community-based services program (Burwell, 1986). Oregon allows area agencies on aging to manage its long-term care programs at the local level.

## **Chapter 6**

### **SUMMARY, CONGRESSIONAL RESPONSE, AND CONCLUSION**

#### **SUMMARY**

This report outlines the major issues that need to be addressed to improve access to and the quality of home care services for the elderly. Many older persons are receiving inadequate home care because various funding sources and differing eligibility requirements, often with restrictive interpretations, beget fragmentation of services. Increasing denials of reimbursement result in decreasing acceptance of Medicare patients for in-home services. There also is a lack of adequate public and private funding for the kind of care that many older persons need. In addition, the home care employees, particularly the homemaker and home health aides, frequently are paid very low wages and are undertrained, resulting in frequent absenteeism and high staff turnover.

Few vehicles exist for monitoring in-home services. The Medicare Conditions of Participation require a home health agency's compliance if it wants reimbursement under Medicare and Medicaid. However, the focus has been largely on paper compliance with the rules, not on actual quality of care. State standards, where present, are implemented through licensing and vary widely from State to State. Self-regulation through industry accreditation establishes standards, but the number of agencies covered are relatively few.

#### **CONGRESSIONAL RESPONSE**

Congress recently took steps to correct some of the problems delineated in this report. The Omnibus Budget Reconciliation Act (OBRA) of 1987 (Public Law 100-203) includes a definition of homebound that allows patients to qualify for home health services even if they are able to leave their homes for short periods of time. This legislation also adds substantial quality assurance requirements. For example, new requirements were added to Medicare's Conditions of Participation for home health agencies including protection and promotion of the rights of patients under agency care, provision of services that comply with all applicable Federal, State, and local laws and regulations and with all accepted professional standards and principles, and use of only home health aides who have completed a training program. The training program must meet minimum standards set by the Secretary of Health and Human Services.

The legislation additionally requires surprise surveys of home health agencies about once a year or within 2 months of change in ownership/management or following a significant number of com-

plaints. The inspection process must include actual visits with and interviews of patients. The survey agency also must maintain a toll-free hotline and investigative unit. In addition, OBRA establishes a range of intermediate sanctions and penalties for agencies that are found to be out of compliance.

Another provision requires fiscal intermediaries to furnish the provider and beneficiary with a written explanation of a denial and, reconsiderations must be timely.

The Secretary of the Department of Health and Human Services is required to provide a demonstration project to develop and test alternative methods of paying home health agencies on a prospective basis for services furnished under the Medicare and Medicaid programs.

In addition, the House and Senate versions of the catastrophic health insurance bill contains provisions to expand the number of covered days of daily home health benefits and also clarify the intermittent care requirement.

The Older Americans Act Amendments of 1987 (Public Law 100-175) includes a provision under Title IV authorizing consumer protection demonstration projects for services provided in the home for fiscal years 1989 and 1990. As noted earlier, it also added a new program under Title III of the Act for support of nonmedical in-home services for the frail elderly.

In addition to these legislative actions, the administration is responding to strong congressional pressure by implementing reforms in the coverage criteria used to review home health care and in the evaluation of fiscal intermediaries. Also due to congressional pressure, professional review organizations (PRO's) will receive sufficient funds to begin reviewing the quality of home health and other non-hospital care, as required by laws passed in 1986.

## CONCLUSION

Because of past problems with HCFA's administration of the Medicare home care benefit, Congress will closely monitor HCFA's implementation of the quality and access reforms included in OBRA 1987. These reforms have the potential to make substantive improvements in the Medicare home health program, and Congress can be expected to do everything possible to ensure that its legislative intentions are carried out by HCFA.

Regardless of the success of the OBRA and other legislative provisions, there is little doubt that numerous quality assurance, training, and reimbursement shortcomings will remain. This will be particularly the case as Congress considers ways to finance a comprehensive long-term care benefit in the months and years to come. Such legislation has been already, and will continue to be, drafted in response to the largely unmet home care need. However, there can be no doubt that any program expansion developed to meet this need must ensure that quality care is provided, that the care is provided by adequately trained and paid personnel, and that reimbursement is consistent and sufficient to ensure widespread access to quality home care. Although this is a great challenge, it is a challenge that can and must be met.



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