U.S. Department of Health and Human Services
Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy

CARING FOR FRAIL ELDERLY PEOPLE: POLICIES IN EVOLUTION

CHAPTER 14: UNITED STATES

1996

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CHAPTER 14: UNITED STATES

The United States has been adapting its social and health policy structures for most of the century in response to growth in the numbers of the elderly population. In recent decades, particularly since the enactment of Medicare and Medicaid in 1965. a strong growth in the number of the very elderly, amongst whom chronic diseases and disabilities are the most prevalent. has progressively raised the profile of long-term care policy. The realisation that the demand for these services will continue to increase has led to a series of proposals for reforming long- term care policy in order to accommodate these demands at a reasonable cost.

However, the political debates around these proposals have exposed some wide differences in priorities and values around a number of issues. These include how far the responsibility for covering these risks rests with government at all, how the public share of this responsibility should be allocated between federal and state governments, and the overall urgency of long-term care reform (and associated costs) within the wider health reform agenda. These differences in view have served to derail any specific large scale proposals for reform. It seems likely that in the next few years, long-term care will see only incremental reform to the core legislation, together with continuing new initiatives and experimentation at states level.

In this chapter, the long development of long-term care policy is described, giving particular emphasis to the functioning of the main programmes introduced in the 1960s, and their progressive modification up to the 1990s. Finally, an outline is given of the main reform debates of the late 1980s and 1990s (on which, see also Chapter 19 in this volume, and OECD, 1996).

THE POLICY CONTEXT: DEMOGRAPHIC AND HEALTH TRENDS

In common with other industrialised countries, the United States is experiencing a considerable growth in its older population. In 1900, 4 per cent of the population were aged 65 and over, comprising 3.1 million people. By 1990, this age group accounted for 12 per cent of the population, a total of 32 million people, and by 2030 this proportion is projected to rise to almost 20 per cent of the population, around 65 million people.

More recently, since the 1960s, there has been an accelerated growth of the oldest age group, those aged 85 and over. In the early 1990s this group makes up 1 per cent of the population, or 2.8 million people. Within a decade this age group is projected to rise increase to 4.9 million people, and by 2030 to about 8.6 million, comprising 3 per cent of the population (Olson, 1994, p.25).

The prevalence of chronic diseases and associated disabilities is highest among the oldest age groups, which are now the fastest growing. Success in the prevention, treatment and cure of these chronic diseases, including arthritis, chronic heart conditions, hypertension and rheumatism, has been significantly less than that with the acute and infectious diseases, leading to growing numbers of elderly disabled people in need of some care. In particular, mental disorders such as Alzheimer's disease have become more prevalent. About 1 per cent of those aged 65 and over develop senile dementia every year, and currently slightly over 1 million people suffer from severe dementia, and another three million suffer from lower levels of dementia (*op. cit.*, p.26).

In total, it is estimated that there are around 7 million elderly people in need of long-term care, and that, depending on mortality and morbidity, there will be between 10 million and 14 million in 2020, and between 14 million and 24 million in 2060 (U.S. General Accounting Office, 1994, p.8).

DEVELOPMENT OF LONG-TERM CARE POLICY

The U.S. long-term care system has deep historical roots in "welfare" policy. Care for disabled elderly people has been intertwined with provisions for poverty and dependency generally. It is only relatively recently that disability among the elderly has been viewed as posing "health" or "social service" needs distinct from the needs of poor elderly people without families for sheltered living arrangements or cash payments. (The main developments discussed below are summarised in Table 14.1.)

TABLE 14.1. Chronology of Legislation and Regulations Concerning Long-Term Care

1935	**Social Security Act** (SAA). Introduced Old Age Pensions, and Old Age Assistance payments to low-income elderly. Use of OAA prohibited to pay benefits to inmates of public institutions: credited with encouraging growth of private nursing home industry.
1950	Amendment to SAA to allow public facilities to receive SAA funds and to require licensing of private institutions.
1954	Amendment to health facility capital financing legislation. Enabled use of public funds for construction of public or non- profit nursing homes, thereby defining nursing homes as medical rather than social welfare facilities.
1956	Amendment to SSA authorising federal matching of state funds devoted to social services.
1960	Enactment of programme of Medical Assistance for Aged ("Kerr-Mills"), which introduced concept of "medical indigency", whereby elderly people who had exhausted their capacity to pay for health care could receive help, even if they did not meet low-income criteria for cash assistance.
1962	Enactment of **Title XX/SSBG of Social Security Act**. Consolidated federal matching of state social service expenditures and encouraged provisions for the elderly.
1965	Enactment of **Title 18 (Medicare) and Title 19 (Medicaid) of Social Security Act**. Medicare is a federal tax-funded programme of assistance to all elderly with acute health care costs. Medicaid is a mandatory state programme of help to low-income individuals, which includes help to elderly people who have exhausted their capacity to meet health costs, including long-term care costs.
	Older Americans Act. Title II establishes state and sub-state Agencies on Aging to plan and coordinate services for the elderly.
1972	**Supplemental Security Income** (SSI) replaces OAA.
1974	Enactment of **Title XX of the Social Security Act**, replacing Title XX/SSBG. Raised federal matching of state social services expenditure to 75:25.
	Implementation of "conditions of participation" for nursing homes (with separate provisions governing standards in "skilled" and "intermediate" nursing homes).

TABLE 14.1 (*continued*)	
1980	Amendment of Medicare to extend applicability of Home Health Agency benefits.
	Enactment of "Boren amendment" to Medicaid permitting states to set their own nursing home repayment rates, subject to covering the costs of an "efficiently and economically operated" home.
1981	**Social Services Block Grant** (SSBG) established as amendment to SSA Title XX. Replaced 75:25 social services funding formula with population-based block grant.
	Enactment of home and community-based long-term care (HCBQ waiver option under Medicaid. Permitted to states to use Medicaid funds for home and community-based alternatives to nursing home placement, subject to requirements of cost-effectiveness.
1987	New nursing home quality standards included in Omnibus Budget Reconciliation Act (OBRA). Abolished distinction between "skilled" and "intermediate" facilities and raised overall quality requirements.
	Enactment of new HCBC waiver (1915d) permitting states to take a Medicaid block grant for long-term care, to may be used at the state's discretion to provide services to those meeting Medicaid eligibility conditions (the "Oregon option").
1988	**Medicare Catastrophic Coverage Act**. Broadened Medicare coverage of nursing home costs: these provisions repealed in 1989. Also introduced safeguards for the savings of the spouse of a nursing home resident who applies for Medicaid coverage.
1992	Publication of fully revised "conditions of participation" for nursing homes as required by OBRA 1987.
1993	Budget Reconciliation Act increased "look-back" period governing use of transferred assets for Medicaid purposes to 3 years and closed other loopholes.

Care for dependent elderly people prior to social security

During the Colonial period. dependent elderly people who could not be cared for directly by their own families were "boarded out" with surrogate families (Haber, 1983). The adult children of elderly people were considered financially accountable for paying the costs of such care. In cases where dependent elderly people had no adult children or other family who could assume these costs, churches or municipalities took on the responsibility.

Early in the 19th century, however, ideas about how government should respond to poverty and dependency began to emphasise what was then termed "indoor relief" in institutional settings (Trattner, 1974; Haber, 1983). The principal such institution was the city or county almshouse, of which people aged 60 and older constituted about one fourth to one third of the inmate populations. These older people were generally housed in almshouses as an act of charity, being viewed as too sick and weak to survive outside the asylum.

Later in the 19th century, charitable societies organised programmes to keep the "able-bodied" poor out of almshouses and restore them to self-sufficiency. Specialised institutions such as orphanages and mental hospitals were developed to care for non-elderly dependent populations. As a result, the remaining population of almshouses became increasingly aged -- so much so that, by the end of the century, these institutions had begun to change their names to "homes for the aged and infirm." Welfare authorities actively promoted institutionalisation as the best solution to the problem of the frail elderly poor who lacked families to care for them. Institutionalisation was seen as being more dignified than the alternative of begging in the streets.

However, because a stigma attached to public institutions, religious and other benevolent organisations increasingly established their own old-age homes. Initially most of these homes aimed at keeping "respectable" persons, especially widows and never-married women, from having to experience the "degradation" of the public almshouse. The rise of the modem concept of hospitals as being for the treatment of acute illness accelerated this trend. Hospitals increasingly refused to accommodate chronic, incurable patients, but their sponsoring charitable organisations often built attached or affiliated old- age homes.

The impact of the Social Security Act, 1935

By the mid-1930s, the prevailing philosophy on welfare had changed to an outlook which condemned public institutions and favoured "outdoor relief", preferably in one's own home. The solution to old-age poverty was perceived to be increased income: from tax-financed pensions for retired people, supplemented, if necessary, by means-tested cash assistance that would enable the elderly to remain in their own homes, or at least make their own living arrangements.

The provision of pensions and means-tested cash assistance was partly intended to enable many who could not previously do so to pay fees in privately-run residential care facilities. Moreover, the Federal Social Security Act of 1935 prohibited states from using grants-in-aid under Old Age Assistance (OAA) to pay benefits to or on behalf of inmates of public institutions. Although local authorities did not immediately close their almshouses and old age homes, they were increasingly phased out in favour of privately-run facilities.

Thus, the Social Security Act of 1935 is generally credited by welfare historians with giving rise to the proprietary nursing home industry (Thomas, 1969). Initially, most private, for- profit facilities were small, family-oriented "board and care" homes. They became "nursing" or "convalescent" homes when their proprietors were nurses or doctors who could offer some medical attention in addition to room and board. The Crowing numbers of elderly, sick, homeless persons who needed to be accommodated caused these private, for-profit facilities to grow larger and become more institutional in character.

Growth in voluntary (*i.e.* non-profit) homes for the aged failed to keep pace. Most voluntary facilities were established to provide for members of particular religious, ethnic, or fraternal groups, and, as such, often had various criteria that restricted whom they were willing to admit. Moreover, voluntary facilities had no tradition of accepting public funds. The philanthropic image, both in the minds of the sponsoring organisations and government officials, required that a significant portion of the cost of giving care be borne by the sponsoring organisations. However, the ability of voluntary facilities to expand on the basis of charitable contributions alone was quite limited.

The 1950s and early 1960s: towards a new public policy

By the beginning of the 1950s, public authorities had become alarmed at the growth of the proprietary nursing home sector relative to public and non-profit facilities and attempted to redress the balance. First, in 1950, the Social Security Act was amended to permit public facilities to receive federal OAA funds, and to require licensing of private facilities, which in most states were still unregulated. Secondly, in 1954, the "Hill- Burton" health facility capital financing legislation was amended to make public funds available to construct public and voluntary nursing homes. Even though the amount of Hill-Burton funds actually spent on nursing homes was very small, the significance of incorporating nursing homes into the prevailing hospital-based system of health care should not be underestimated because it transformed them, by definition, into medical facilities. As Vladeck (1980) has put it, "Nursing homes would never again be solely an extension of the welfare system; they now belonged to health policy as well".

However, although federal and state governments were now willing to promote the growth of public and voluntary nursing homes, it was too late. The pattern of dominance by proprietary ownership that prevails to this day had already been firmly established. The 1950s saw a very rapid expansion of nursing home capacity. A 1954 survey of such facilities by the Public Health Services identified either as "skilled nursing homes" or as "personal care homes with skilled nursing" some 9,000 facilities with 250,000 beds. Amendments to the Social Security Act in 1956 increased federal support for OAA and other cash assistance programmes and also established a separate "vendor payment" programme that matched state expenditures for health services to low income elderly, including care in nursing homes and related facilities. By 1960, it is estimated that there were some 10 to 11,000 nursing homes with 400,000 beds (Vladeck 1980).

The "Kerr-Mills" programme of Medical Assistance for the Aged which was enacted in 1960 was essentially an expansion of the vendor-payment programme under OAA. The main innovations were the removal of the cap on availability of federal matching funds and the introduction of the concept of "medical indigency", which meant that payments for health services could be made on behalf of elderly people who had exhausted their capacity to pay privately for care but who were not otherwise eligible for cash assistance on grounds of low income. Kerr-Mills was the immediate predecessor to and, in many of its features, the prototype for the Medicaid prograrnme that, since 1965, has been the major source of public funding for long-term care for the elderly.

1965: the enactment of Medicare and Medicaid

In 1965, Congress enacted Titles 18 (Medicare) and 19 (Medicaid) of the Social Security Act. Both of these programmes included coverage for nursing home care and, for the first time, coverage for home health services -- although Medicare coverage of both nursing home and home health services was limited to short-term, postacute, convalescent and rehabilitative "skilled" nursing and therapies.

Federal legislation had again stimulated the growth of the proprietary nursing home industry. Voluntary homes for the aged could not qualify for Medicare/Medicaid funding because most offered only personal care, not "skilled nursing." Furthermore, the explicit ban on Medicaid payments to "institutions for mental disease" reinforced the movement to "de-institutionalise" mental patients in state mental hospitals by giving states a major financial incentive to transfer elderly people with dementia or psychiatric disorders out of state mental hospitals into private nursing homes in order to access federal matching payments.

Medicare and, especially, Medicaid remain the primary sources of public funding for long-term care services for the elderly, both institutional and non-institutional. However, the 1960s also saw the beginning of Social Security Act (Title XX/SSBG) social services (1962) and Title III, Older Americans Act (1965) funding for non-medical home and community-based services for the disabled elderly. These programmes are described later in this chapter.

SUPPORT FOR LONG-TERM CARE FROM PUBLIC HEALTH PROGRAMMES: MEDICARE AND MEDICAID

The legislative and administrative framework

Medicare is a "social insurance" programme that pays for medical and related care of elderly and disabled Social Security beneficiaries. It relies upon a combination of payroll tax financing for "Part A", which relates to hospital, skilled nursing facility (nursing home) and home health benefits, and voluntary, but heavily tax-subsidised, premiums to cover "Part B", which relates to physician visits and ancillary services. Almost all Americans aged 65 and older are covered by Medicare Part A. For fiscal year 1993, it has been estimated that a proximately 31.3 million persons aged 65 and older had Medicare Part A coverage and about 30.8 million persons aged 65 and older were enrolled in Part B.

By contrast, Medicaid's coverage of medical and long-term care for the poor is often characterised as following a "social assistance" approach. Medicaid is financed jointly out of general tax revenues by the federal government and the states. The federal government matches state expenditures at a rate -- ranging from 50 per cent to 84 per cent -- that provides more generous federal cost-sharing for states whose residents have lower per capita incomes. Eligibility for Medicaid is means- tested and is linked to standards for cash assistance (which vary between states). At state option, the "medically indigent", *i.e.* persons for whom the costs of medical and related services exceed their income and resources, may also be eligible. on condition of "spending-down" their own assets until they have exhausted their ability to pay.

Medicare is a federal programme that is largely administered by private insurance companies under contract as "fiscal intermediaries" for Part A or "insurance carriers" for Part B. Medicaid is jointly administered by the federal government and the states.

Policy-making occurs at the state level within federal mandates established by statute and further spelled out in regulations. The day-to-day operational administration of Medicaid is left largely to the states.

Like Medicare, Medicaid is termed an "open-ended, individual entitlement" programme, because there is no fixed annual appropriation of funds to meet all programme costs. Instead, the statute mandates that any individual who meets the basic eligibility requirements is guaranteed specified benefits (defined in each state's "Medicaid state plan") on the basis of a participating physician's orders or other professional assessment of need for services.

Federal law requires states to cover certain basic services including care in nursing homes and home health services for persons who would qualify for nursing home care. Other services, including home-delivered personal care and other home and community-based services for the functionally disabled, may be provided at state option. As a result, there is considerable variation in Medicaid long-term care coverage across states.

Medicare is the primary source of medical insurance coverage for the elderly. Medicaid supplements Medicare coverage for low- income elderly who cannot afford the co-payments and deductibles for Medicare-covered services and who also cannot afford the "Medi-gap" private insurance that more than two-thirds of all elderly people purchase to cover these costs. In addition, Medicaid is available to help those elderly people who cannot afford high out-of-pocket costs or private insurance coverage for services that Medicare does not cover -- primarily pharmaceuticals and nursing home care.

As of 1991, about 9.5 per cent of the non-institutionalised U.S. population aged 65 and older qualified for Medicaid (Committee on Ways and Means, 1993). However, many elderly Medicare beneficiaries qualify for Medicaid only after they are institutionalised in nursing homes. In 1989 about 13.5 per cent of the elderly were enrolled in Medicaid at some point during the year -- about 4.2 million people.

Coverage of "post-acute" health services by Medicare

Medicare coverage related to long-term care is limited to home health agency (HHA) services and short-term, post-hospital skilled nursing facility (SNF) care.

To qualify for the HHA benefit, elderly people enrolled with Medicare must have a need for home-delivered skilled nursing or therapies (*i.e.* registered nurse visits or visits by licensed physical, speech, or respiratory therapists). Home health aide services to help with personal care and housekeeping may also be provided as long as the beneficiary also requires skilled services. HHA benefits are available to all Medicare beneficiaries solely on the basis of medical need (*i.e.* without a means-test); unlike all other Medicare benefits, there are no co-payments or deductibles required.

The SNF benefit covers short-term nursing home care following a period of hospitalisation. Beneficiaries must have a need for "skilled" nursing care or therapies. A three-day prior hospital stay is required and the duration of the benefit is limited to 100 days (Helbing and Cornelius, 1992).

Both the Medicare home health and skilled nursing facility benefits were originally intended to finance only post-hospital convalescent and rehabilitative care. The objective was to get elderly persons out of the hospital sooner, preferably back to their homes, or, if that was not feasible, to a lower cost, less technically-oriented, recuperative setting.

During the first decade of Medicare, the scale of coverage of post-acute nursing home care was repeatedly reduced via both legislation and regulations. The Medicare Catastrophic Coverage Act of 1988 briefly broadened Medicare SNF coverage, but these provisions were repealed in 1989.

However, in contrast to the SNF benefit, the HHA benefit has relaxed its exclusive focus on post-hospital care. This came about through various legislative and regulatory revisions as well as judicial rulings that required more liberal interpretation of the "part-time", "intermittent", and "home-bound" requirements. The most notable legislative changes occurred in 1980 when the requirement for a three-day, prior hospital stay was dropped, together with a 100-visit limit, co-payment requirements and a prohibition on for-profit home health agencies. The entry of for-profit home health agencies into the market led to significant growth in licensed agencies and subsequent large increases in the use of home health services.

During the early 1980s, Medicare home health expenditures grew very rapidly, due to both the impact of the 1980 legislative changes and as a result of the introduction of the Diagnostically-Related Groups (DRG) system of prospective payments for hospital care. These fixed rate payments created strong financial incentives to shorten hospital lengths of stay and to discharge patients in need of further convalescent, rehabilitative, or terminal care to "post-acute" providers, including home health agencies.

In recent years, the use of Medicare home health services has seen further significant growth. The reasons for this are still not fully understood, but one important factor was the relaxation in coverage rules following the settlement of a major lawsuit (Duggan vs. Bowen) filed by a coalition of home health beneficiaries, providers, and members of Congress. Over the period 1987-1992, the percentage of all those enrolled in Medicare (including both elderly and younger permanently disabled persons) receiving HHA services rose from 4.8 to 6.3 per cent, while the average number of visits per episode of care among users rose from 23 to 57 (Mauser and Miller, 1994; Committee on Ways and Means, 1993; Helbing *et al.*, 1992).

As a result of changing coverage rules, therefore, the Medicare home health benefit has increasingly taken on more of a "long- term" character and has also increasingly been involved in the provision of less skilled "home health aides" rather than the traditional "skilled" services.

Eligibility for help with long-term care costs from Medicaid

Medicaid eligibility rules are extraordinarily complex (for a full account see Gurny *et al.*, 1992). Briefly, individuals are generally eligible for Medicaid-covered services if they qualify for cash assistance on grounds of low income -- Supplemental Security Income (SSI) payments in the case of the elderly disabled (SSI having replaced OAA in 1972). In addition, states may choose, but are not required, to provide coverage to the "medically needy" whose medical expenses exceed their income and savings. In such cases, among which nursing home costs loom large, Medicaid funding covers the shortfall between monthly personal incomes and the relevant costs, no matter what the level of monthly income. As of October 1, 1992, 36 states and the District of Columbia had extended coverage to the "medically needy". In states without "medically needy" coverage, individuals are only eligible for help from Medicaid in paying for nursing home care if their income does not exceed 300 per cent of the level of cash assistance payable through SSI (this varies by states, averaging $1,200 per month).

While living in the community, elderly disabled persons classified as "medically needy" are required to spend-down" to Medicaid eligibility by contributing toward the cost of their medical care all their income above an amount equivalent to the cash assistance benefit level. All Medicaid recipients in nursing homes must "spend-down" their monthly income above a monthly personal needs allowance (currently set at a federal minimum of $30) by contributing toward the costs of care; Medicaid pays the remainder. In addition, nursing home residents must exhaust their assets by paying privately for care prior to becoming eligible for Medicaid. Again, this amount varies by state, falling between $2,000 and $5,000 in savings for one person. However, some assets, such as the home, one car, a burial plot, and some other personal property, are usually exempted from consideration.

Prior to 1988, the income and asset test for married applicants was almost as stringent as that for individuals. However, from 1988, the provisions of the Medicare Catastrophic Coverage Act (MCCA) have allowed the non-institutionalised spouse of a Medicaid recipient in a nursing home to retain more of the couple's income and assets. The purpose of these "spousal impoverishment protections" is to allow the non-institutionalised spouse to maintain his or her accustomed standard of living in the community, and not be reduced to dependency on social assistance as a result of making the required payments for the care of the institutionalised spouse. Such couples are now permitted to divide their assets in half, with the spouse remaining in the community permitted to retain between $12,000 and $60,000. Only the share allotted to the institutionalised spouse must be "spent-down" paying for nursing home care.

During the 1980s, federal and state Medicaid officials grew increasingly concerned about transfers of assets to qualify for Medicaid nursing home coverage. Some elderly people who planned to enter nursing homes and who had substantial savings and property were found to be transferring ownership of their assets before applying for Medicaid. The aim was to evade the Medicaid "spend-down" requirements, and thereby ensure that these assets would pass to heirs instead of being spent on nursing home care.

There is little data on the overall extent of such transfers. However, a 1992 survey of recent nursing home residents in one state asked respondents directly whether they had transferred funds or property to relatives before coming to the nursing home: 22 per cent said that they had. The same survey found that approximately two-thirds of nursing home entrants reported having assets (including savings accounts, life insurance death benefits, vehicles, real estate, stocks, bonds and mutual funds) worth more than $5,000 prior to admission: 39 per cent had assets in excess of $40,000, and 22 per cent had assets worth $100,000 or more (Wetle *et al.*, 1994).

Beginning in 1982, Medicaid legislation attempted to prevent asset transfers prior to nursing home entry. The 1988 MCCA extended the period within which previously-transferred assets would be considered as still available (the so-called "look back" period) to 30 months prior to application for Medicaid nursing home coverage. The law still contained many loopholes, however, and one result was a growing cadre of attorneys specialising in "Medicaid estate planning." The 1993 Budget Reconciliation Act increased the "look-back" period to 36 months and also incorporated other provisions to close loopholes in the law.

For example, states are now required to enact estate recovery laws. These laws enable the recovery or partial recovery of Medicaid expenditures from the estates of deceased nursing home residents. Such laws are considered necessary because, despite "spend-down" requirements, Medicaid-eligible nursing home residents can still have substantial net worth at death. This is because they are permitted to retain ownership of a home so long as they declare in intent to return home to live (regardless of the likelihood that this would occur) or so long as there is a spouse or other protected relative living in the home. In the absence of estate recovery provision, ownership of the home (whose worth may be sufficient to reimburse to Medicaid the cost of several years of nursing facility care) would eventually pass to heirs other than a spouse and escape the Medicaid spend-down net entirely.

Extension of services available under Medicaid

In the earliest years of Medicaid (1965-71), almost the only long-term care services covered were skilled nursing facility (SNF) and home health benefits. These are among the few mandatory benefits that the federal government required states to cover for all those eligible for Medicaid (as contrasted with the many optional benefits that states may or may not choose to cover). Since that time, a number of extensions have been made that have widened the scope of federal matching payments.

Personal assistance services

Medicaid home health benefits may be used by the elderly to supplement the home health care coverage under Medicare. Because the Medicaid home health benefit is very similar to the original Medicare home health benefit, however, most elderly persons in need of home health care have tended to rely primarily on the latter. Use of Medicare is preferable because there is no means-test and no co-payment requirements and because, in most areas of the country, Medicare home health coverage is more generous.

There is one important exception to this pattern. From the late 1960s, the Medicaid system has permitted states to cover personal assistance services in the home. The only limits on state discretion in providing such benefits have been that personal care services have had to be prescribed by a physician, supervised by a nurse, and provided by a qualified individual who is not a member of the recipient's family. Prior to 1980, only a handful of states opted to provide personal care, with New York accounting for three quarters of all Medicaid personal care expenditures (Litvak and Kennedy, 1991).

Since 1980, however, a growing number of states have elected to extend cover to personal care. By 1990, 30 states covered personal care, at a total cost of $1.9 billion. This optional personal care benefit is the single biggest source of funding (both within Medicaid and among all public programmes funding long-term care services) for home-delivered long-term care, particularly for elderly and younger disabled persons who require help with basic activities of daily living such as bathing, dressing, transferring, toileting, and eating. In 1990, the personal care benefit was, for the first time, explicitly incorporated into the Medicaid statute, to clarify the authority of states to allow personal care attendants to accompany clients and provide services outside the home.

Home and community care "waivers"

In 1981, Congress enacted the "home and community-based long-term care waiver option." (This optional benefit is also referred to as the "HCBC", the "2176" or the "1915c" waiver programme). This legislation authorised states to provide a wide variety of home and community-based long-term care services as alternatives to nursing home placement. However, the law stipulated that home and community-based care alternatives must 1915(d) expenditure cap. The main source of nursing home cost increases had been the 1987 federal nursing home reforms that required nursing homes to make "quality of care" improvements, and especially to hire more professionally trained nurses, thus raising Tabour costs. Efforts to have Congress amend the 1915(d) statutory provisions to give HCFA authority to adjust the funding "cap" to account for the increased costs arising from nursing home reform were not successful.

The "frail elderly" provision

In 1990, Congress enacted the "Frail Elderly" provision, also known as "4711", another option within Medicaid allowing coverage of home and community-based long-term care services. Unlike other Medicaid home care optional benefits, services financed under "4711" are only for elderly people. Unique features of the "4711" legislation include eligibility criteria based on "Activity of Daily Living" (ADL) impairment, mandatory case- management, and federal oversight of board and care settings. The "4711" provision has been criticised as being simultaneously under-funded and over-regulatory.

Despite the small amount of capped funding ($580 million over a five year period) and other limitations of the 4711 legislation, its authors stated their intention of establishing this provision in Medicaid as a "foot in the door", to lead eventually to a much broader home care financing reform initiative alone, the lines of the 1990 Pepper Commission recommendations (for details of which, see later.) As of October 1994, only Texas had actually implemented a 4711 programme.

Reimbursement of providers

Medicaid is a "vendor payment" programme, in that payments may not be made directly to individual service recipients, only to service providers. States determine their own methods for provider payment within broad federal requirements.

Payment for nursing home services

Payments for nursing home care from Medicaid and Medicare have always been based on data that providers supply about their actual operating expenses. The methods employed have, however, been progressively developed into a more sophisticated system balancing provider costs, client needs and expenditure control mechanisms.

In the early 1970s Congress passed a law that would have eventually required states to adopt the existing Medicare hospital reimbursement methodology (known as "individual facility-specific retrospective cost-related reimbursement") to establish payment rates for Medicaid nursing homes. However, by the late 1970s, this reimbursement methodology was being held responsible for stimulating very serious inflation in hospital costs (a concern that eventually resulted in a system of prospective hospital payment being adopted for Medicare in 1983). In 1980, therefore, Congress enacted the "Boren Amendment", which permitted states to use whatever methods they chose to establish nursing home payment rates, so long as the resulting rates were sufficient to cover the costs of an "efficiently and economically operated" facility.

This standard permits states leeway in disallowing reimbursement for nursing home costs considered excessive" or "unnecessary". At the same time, it prevents states from setting nursing home payment rates arbitrarily without relationship to the actual costs of providing care and to federal requirements in terms of quality standards. In recent years -- particularly since the passage of nursing home reform legislation in 1987 that raised federal quality standards (for which see later) -- the Boren Amendment has increasingly been the basis of litigation by nursing homes against states for paying what the facilities claim to be inadequate rates.

In the early years following the passage of Medicaid, states tended to be quite unsophisticated in their payment methodologies. This gave rise to a considerable degree of "playing the system" and even outright fraud by nursing home operators. States had a difficult time keeping up with the more unscrupulous operators, and the 1970s saw a series of government investigations and media exposés of nursing home fraud and abuse. By the late 1970s, however, most states had developed payment methods capable of controlling fraud and abuse and had driven blatantly larcenous operators out of the industry. However, this period established a distrusting and adversarial relationship between state rate-setting agencies and nursing homes that continues to the present day (Moss and Halamandaris, 1977; Mendelson, 1974).

Since the late 1970s, most states have chosen to reimburse nursing homes on the basis of a rate-setting methodology known as "individual facility-specific prospective payment". Rates are based on each facility's prior year expenditures, with limits for particular cost items (*e.g.* nursing, administration, physical plant maintenance, etc.) being set according to some per centile of average costs across all facilities. The resulting rates are then projected forward for the payment year according to a fixed adjustment for allowable price inflation. Evaluation research indicates that such reimbursement methods do create strong incentives for facilities to economise, while, at the same time, prohibiting them from generating profits by cutting back on necessary services. The widespread adoption of this payment methodology is credited with holding down annual nursing home cost increases to rates only slightly above general price inflation throughout the 1980s (Holohan, 1985), while, in contrast, cost increases for acute medical services continued to go up at rates considered much more alarming (OECD, 1992).

In recent years, the federal government has sponsored state experimentation with alternative payment methodologies; most notably, "case-mix-related reimbursement" which adjusts payment rates to account for differential needs of patients with different levels of functional disability and types of medical conditions. In several states, the experimentation has concluded and been judged sufficiently favourably that some version of case-mix-related reimbursement has been adopted as the new payment system. There are versions of case-mix reimbursement in use in around one-third of the states (Swan *et al.*, 1993).

Payment for home and community-based services

Reimbursement for home and community-based long-term care services is typically made on a per visit or hourly basis. Medicare reimbursement rates are set nationally (with regional adjustments for labour costs) according to a retrospective, cost-based system (up to limits based on average HHA costs). Under Medicaid, most states aim to set fees based on the lowest payment rate they believe they can offer and still attract an adequate number of qualified providers. States do not necessarily obtain cost data from providers during this process, and in states that use agency services exclusively, competitive bidding has become an increasingly popular method of contracting for home health and home care services, and, therefore, of price-setting.

Federal regulations require home health (*i.e.* professional nursing and therapy) services to be provided only through certified home health agencies. However, for non-technical home care services (especially home-delivered personal care and home-making services) many states authorise the use of independent contractors. These are often recruited directly by home care clients themselves, from among the client's family, friends or neighbours or by advertising in local newspapers. About half of all home and community-based care programmes administered by the states permit the use of independent providers; most of the remainder require the use of certified home health or licensed home care agencies. Sometimes, local social services officials make available to clients lists of qualified individuals who have worked as home care attendants in the past (Litvak and Kennedy, 1990). Most Medicaid -- or other public -- payment to "hands-on" providers of home care services is only just above the minimum wage (about $5 an hour).

Quality standards for long-term care services

The granting of entitlements to services through Medicaid and Medicare has had the effect of involving public authorities closely in the maintenance of adequate standards of care. Arriving at suitable standards has been a long-drawn-out process involving considerable public and political controversy.

Nursing home services

The first set of proposed "conditions of participation" for skilled nursing facility (SNF) were issued in 1969, although the final set of regulations for both SNFs and intermediate care facility (ICF) were not put into effect until 1974. These rules were not revised *in toto* until 1987, and the complete set of revised rules was not finalised until the end of 1992.

The 1970s saw a series of major scandals about nursing home quality that gave rise to highly publicised investigations both by Congress and individual state governments. Often, revelations of fraudulent claims on Medicaid funds by proprietors were intertwined with problems concerning low quality of care, including patient abuse, neglect and mistreatment. During this period, the general public came to perceive many, perhaps even "most", nursing homes as places providing dangerously bad care or -- at best -- mediocre and unreliable care. This is an image that the nursing home industry has still not fully succeeded in overcoming (Moss and Halamandaris, 1977; Vladeck, 1980), and which has continued to influence much discussion about standard-setting.

Opinion remains divided about how effective the implementation of the 1974 SNF and ICF "conditions of participation" were in ameliorating the problem of low quality care. However, there is general agreement that the adoption of the fire safety code standards put an end to the all-too-frequent, multiple-death nursing home fires. However, the adoption of strict fire safety standards led to the phasing out of older facilities, some of which aimed at a "home-like" atmosphere, and their replacement by new nursing homes which were built to the new code, but which tended to look "institutional" and which often resembled mini- hospitals. In recent years, there has been a backlash from advocates for the frail elderlv against the "medical model", and a movement to develop new models of residential care that have desirable safety features but also have a more home-like atmosphere (Lewin-VHI, 1992).

When the Reagan Administration took office in 1981, a task force on deregulation was created, and nursing homes were included on a priority list of industries judged to be in need of regulatory relief. However, while most of the other deregulatory initiatives of the earl Reagan years had substantial public and Congressional support, the deregulation of nursing homes proved highly controversial. By 1984, the attempt to deregulate the nursing home industry had become bogged down in Congressional opposition. A high-profile legal action brought in federal Court in Colorado (the "Smith v. O'Halloran" case), which had begun in 1975 but which was not settled until 1984, also played a significant role in blocking the deregulation process. In this case, the court ruled that the existing nursing home inspection system provided inadequate protection against poor quality care, and that it should be replaced by a survey approach capable of measuring the impact of nursing home care on resident outcomes.

Congress and the Administration agreed on a compromise: the Institute of Medicine (IOM) would carry out a study on improving the quality of care in nursing homes, and subsequent regulatory reforms would be guided by its findings. The IOM report was published in 1986 and the Administration set about drafting new nursing home regulations in light of the report's recommendations. These proposed rules were issued for public comment in November 1987. However, during the consultation process, Congress decided to narrow the discretion available to the Administration in re-writing, the nursing home regulations, by requiring full implementation of the IOM recommendations as a provision of the Omnibus Budget Reconciliation Act of 1987. OBRA 1987 introduced a new set of nursing facility requirements, which abolished the former distinction between "skilled" and (lower cost) "intermediate" facilities in favour of one class of certified "nursing facilities". These new requirements not only raised overall standards, but also substantially reoriented the underlying philosophy of nursing home regulation.

All nursing facilities would now be required to meet or exceed the former "skilled nursing facility" nurse staffing standards. In addition, greater emphasis was to be laced on patients' rights and quality of life safeguards. There would be less emphasis on physical plant standards not directly related to health and safety, on administrative policies and procedures, and on recorded evidence that facilities had complied with regulations (which some critics had termed a process of "paper compliance"). The survey process was to be re-designed to focus much more on patient care outcomes; in particular, measuring the prevalence of negative health status indicators (*e.g.* decubitus ulcers, dehydration, falls and broken bones) which were most likely to reflect poor quality care. In addition, facilities were to be required to institute comprehensive resident assessment and care planning, creating a database that surveyors could use to more accurately evaluate the quality of patient care (Morris *et al.*, 1991). Finally, for the first time, nurses' aides were to be required to have specified training or meet minimum competency standards.

Implementing these reforms again proved to be a lengthy process, although all were eventually published as final rules during the period between the November 1992 elections and the end of the Bush Administration in January 1993. According to Faulkner and Gray's professional newsletter "Long-Term Care Management" (October 29, 1992):

> "Industry and consumer representatives agree that OBRA has succeeded in sharply reducing the use of chemical and physical restraints in nursing home. Before the law's enactment, use of such psychoactive drugs as Haldol was becoming relatively commonplace to keep residents from wandering from their rooms or their beds. As a result, critics said, the nation's nursing homes were filling with silently suffering zombies. Today, the use of chemical and physical restraints is down as much as 50 per cent in some areas, and homes have increased their complement of registered nurses and well-trained nurses' aides. Other accomplishments include improvement in the caliber of rural nursing homes, creation of a uniform set of data on what constitutes quality care, and a renewed emphasis on patients' rights. But moving to the next level of nursing home reform -- where the provision of high-quality care becomes the norm -- may be more difficult, as the coalition of industry and consumer groups that helped push the law to passage is splintering over implementation."

Home and community-based services

The Omnibus Reconciliation Act of 1987 also raised quality standards for Medicare and Medicaid-certified home health agency services. The most important change involved training requirements for home health aides. The same legislation required certification surveys of compliance with HHA Medicare and Medicaid conditions of participation, which surveys were to include face-to-face at-home interviews with a statistically representative sample of HHA clients.

Policy on the supply and use of nursing home services

The infusion of Medicaid money into the nursing home industry from the late 1960s onwards sparked a boom in the building of nursing homes, which in turn led to high rates of growth in state Medicaid budgets for nursing home care. This gave rise to concerns that Medicaid had facilitated a significant increase in the "institutionalisation" of the elderly, a belief that remains widely held by the public and some policy-makers. However, research has since shown that the overall rate of institutionalisation of elderly people did not rise above levels current by at least the 1950s (Office of the Assistant Secretary for Planning and Evaluation, 1981). The major exception was an increase in institutional use among those aged 80 or over, a group whom medical science was now keeping alive in greater numbers but usually in poorer health.

What had changed, however, was the types of institutions to which elderly people were being admitted. It was not that more elderly people were giving up their "own homes" to move into nursing homes, rather that they moved to nursing homes from, or instead of, other forms of institution or group living arrangement. For the most part, this process was the result of a number of deliberate policy shifts: first, the promotion of nursing home use to shorten the average length of stay in hospitals; second, the "de-institutionalisation" of elderly psychiatric patients from state hospitals to nursing homes, together with the diversion of new cases of elderly people with dementia to nursing homes; and third, the closing down of substandard "board and care" facilities, or their upgrading to nursing facilities. Although all these policies were considered desirable in themselves, the sheer magnitude of the numbers of elderly people involved took policy-makers by surprise and fuelled a concerns about potential "over-use" of nursing homes.

Throughout the 1970s, this concern led state and federal Medicaid authorities to impose new systems of "Utilization Review" (UR) to determine whether patients were "appropriately placed" in nursing homes and, if so, at the least expensive level of care sufficient to meet their needs, *i.e.* where possible, in the then-existing "intermediate" nursing facilities. However, since the needs of nursing home residents are subject to change, these systems often required that residents be transferred to other facilities in order to continue to be considered appropriately placed. To the extent that nursing home residents came to view particular facilities as their "homes", or wanted to be in nursing homes that were convenient for family visits, they began increasingly to resist such transfers, through litigation if necessary.

The emphasis of nursing home utilisation policy therefore shifted from concurrent review, *i.e.* determining whether those already in nursing homes were appropriately placed, to pre-admission screening, *i.e.* not allowing those who would require public funding to enter a nursing home to do so unless they met appropriate standards of need. In the early 1980s, states began to adopt screening instruments and point-scoring systems, to be administered by specially trained nurses and social workers, in place of the former process of certification by a physician. Pre-admission screening also became linked to assessment for home care (not necessarily limited to Medicaid-funded services), so that applicants who met the need standard for nursing home placement could remain in the community with home services, if that was their preference, and if sufficient home care could be provided cost-effectively.

States also began to regulate access to publicly funded nursing home care more globally, by limiting the supply of certified nursing home beds. They established planning authorities which were empowered to issue, or to withhold, a "certificate of need" for all new nursing home construction or expansion of existing facilities. To qualify for a certificate, would-be developers now had to present evidence that there was significant unmet need for nursing home care in that area. As of 1989, all but eleven of 51 Medicaid programmes (the 50 states plus the District of Columbia) had adopted "certificate of need" requirements. In addition, many states have announced moratoria, often lasting several years at a time, on all new nursing home construction.

Most states have established target ratios of nursing home beds per 1,000 elderly, and there has been a tendency for "under- bedded" states come up to a ratio closer to the national average by allowing new construction, and for "over-bedded" states to bring theirs down by allowing older facilities to close without replacement. As of 1989, the national average of nursing home beds per 1,000 elderly was 54.9, although at states level this still ranged from a low of 26.4 beds per 1,000 elderly in Nevada to a high of 106.4 in Iowa (Burwell, 1992).

It is notable that opposite perceptions about nursing home access have coexisted in the United States. On the one hand is a widespread belief that nursing home care has been over-used. On the other, there are complaints that a shortage of available beds, and resulting waiting lists, make it hard to get into a desirable nursing home when individuals and families decide that placement is what they want. The wide variations in bed availability at local levels may have provided evidence supporting both views. In total, the national average of nursing home beds per 1,000 elderly people has stayed fairly stable over the past two decades, and the controls introduced in the later 1970s appear to have restricted further growth: the ratio reached a peak of 64 beds per 1,000 in 1976, declining to 53 in 1980, and in 1989 stood at 55 per 1,000 elderly people.

OTHER SOURCES OF PUBLIC SUPPORT FOR LONG-TERM CARE

Support for those in "board and care" homes

Specialised residential care settings that are not certified as nursing facilities are referred to as "board and care" homes, and include a number of different types of setting, including those known as "personal care homes", "domiciliary care facilities" and "assisted living facilities". Elderly residents are expected to pay for these services out-of-pocket, with Social Security, private pension, or other personal income. However, cash assistance payments from either the federal SSI or state supplemental payments (SSP) programmes are a major source of financing of non-nursing home residential care settings for elderly people with low incomes. These payments are made directly to individual beneficiaries, although, in the case of SSP, eligibility for supplemental assistance and the level of payment is often contingent on use of a particular type of licensed residential facility.

In a few states, Medicaid also makes additional payments to board and care facilities, for example, for adult foster homes in Oregon, to provide for personal care services under the "home and community-based services" waivers or the personal care optional benefit. Unlike SSI and SSP payments, however, Medicaid covers only the personal care services that the facility provides over and above the basic rate for room and board.

The regulation of board and care homes is limited to requirements for state licensing. However, under the terms of the Social Security Act, no federal funds for health-related services are to be made to unlicensed facilities or to residents of unlicensed facilities. The ambiguity and resulting difficulty of enforcing this provision has given rise to calls for a more coherent federal policy on the regulation of board and care facilities.

Other funding for home and community-based services

There are several sources of federal and state funding for home and community-based services other than Medicaid. These include:

- the Social Services Block Grant (SSBG), formerly known as Title XX;
- Title III of the Older Americans Act; and
- State programmes without federal funding, which include additional support for
- services for elderly and disabled people who are eligible for cash assistance from the federal SSI programme.

Social Services Block Grant (Title XX)

The origins of the SSBG lie in a 1956 amendment to the Social Security Act (SSA) which authorised dollar-for-dollar federal matching of state funds devoted to social services. Further amendments to the SSA, enacted in 1962, encouraged provision of social services specifically to the elderly. Between 1956 and 1971, federal grants to the states for social services under the public assistance titles of the SSA grew from $194 million to $740 million, and in 1972 rose to $1.7 billion. When projections for 1973 indicated a potential increase to $4.7 billion, Congress imposed a $2.5 billion ceiling on federal expenditure on social services.

In 1974, Title XX of the SSA was enacted to consolidate federal funding of social services, and the share of federal to state funding was increased from 50:50 to 75:25. The amendment also required that 50 per cent of the federal share be used for services to those receiving social assistance (either AFDC: Aid for Families with Dependent Children -- or SSI: Supplementary Security Income) or who were eligible for Medicaid. The remainder of the funding could be used for people with incomes above this level, if they did not exceed 115 per cent of the state's median income.

The Social Services Block Grant (SSBG) was established in 1981 in an amendment to Title XX. The SSBG replaced the Title XX formula of 75:25 federal to state funding with a single grant to each state based on a population formula. The SSBG also reduced federal reporting requirements and eliminated the restrictions on target populations, giving states greater discretion in deciding on whom and on what types of services to spend the funds, but within a fixed total grant.

Title XX was the main source of federal funding for home and community-based long-term care services throughout the 1970s, with most of the expenditure for services to frail elderly people being for home-maker and other domestic services. Following the introduction of the SSBG, states began to rely more heavily on Medicaid as the principal federal source of funding for home and community-based services, because funding opportunities via Medicaid expanded while SSBG funds became more restricted; since 1981, direct cuts and inflation have reduced the SSBG by nearly one-third in real terms. SSBG funds have also been more heavily called upon to serve other populations, for example, child day care for AFDC and other low-income families. Nevertheless, only three states spent no SSBG funds on services for the elderly in FY 1988.

Title III, Older Americans Act

The Older Americans Act was enacted in 1965. Title III established state and sub-state Agencies on Aging to plan and co- ordinate services to the elderly. Services are defined very broadly to include health, continuing education, welfare, recreation, home-maker services, counselling, referral, transport, housing and related services, nutrition services and multipurpose "senior centers".

To receive services funded under the Older Americans Act an individual only has to be aged 60 or older; no means test is applied. However, funding has never been sufficient to support a comprehensive programme of services on a "universal" basis, and targeting on terms other than income (or terms which are a near proxy) has occurred. The Older Americans Act has not been a significant source of funding for long-term care services as such, but Title III has been and remains the major source of finance for services promoting access to the community, such as "senior centers" and transport for both fit and frail elderly people. Title III has also been used to provide support for nutritional programmes, because of concerns that older people living alone, and/or with a low income, might not maintain a healthy diet. In 1989, just over half of all Title III programme funds were used to support nutritional programmes.

More recently, the network of sub-state organisations created by the OAA, the Area Agencies on Aging, has emerged as a focal point of the effort to achieve greater integration and co-ordination of services at the local level, through the creation of "single entry points" to the system for purposes of information and referral, and through assessment and case management activities. This is currently perhaps the most important contribution of OAA- supported activities to long-term care policy.

SCALE AND COST OF CURRENT PROVISIONS

Nursing homes

Number of homes and residents

There were estimated to be about 1.5 million residents of nursing homes on any given day in 1985, and of these slightly over 1.3 million were aged 65 or more. This estimate, derived from the 1985 National Nursing Home Survey, uses a broad definition of "nursing home" which includes non-medical residential care facilities, on condition they have more than 3 beds and supply some "personal care". The survey definition therefore includes virtually all "board and care" homes. It does not include hospitals, mental hospitals, or facilities for the mentally handicapped.

The best measure to differentiate nursing-oriented "nursing homes" from other residential care facilities serving the frail elderly is federal certification as a nursing facility for Medicare or Medicaid. In 1985, 75.6 per cent of "nursing homes" were federally certified nursing facilities. Uncertified facilities tend to be very small, however, and only slightly over 11 per cent of residents (170,000) were in non-certified facilities. Seventy-five per cent of "nursing homes" were private for-profit ventures, 20 per cent were not-for-profit (*i.e.* run by churches or other charitable organisations), and 5 per cent were government-run.

As of 1993, HCFA survey and certification data for nursing homes indicated that there were 16,332 federally certified nursing facilities with 1,656,302 beds. Of these 983 facilities (40,609 beds) were Medicare-certified only, 5,069 facilities (1,040,577 beds) were Medicaid-certified only, and 10,370 facilities (575,116 beds) were certified for both programmes.

Estimates as of 1991, based on the National Provider Inventory, put the combined number of beds per 1,000 elderly in licensed nursing homes and board and care facilities at 61, of which 53 beds were in nursing homes and 8 beds in board and care facilities (Administration on Aging, 1994).

Source and scale of financing

The sources of payment for current residents of nursing homes in 1993 were out-of-pocket payments (42 per cent), Medicaid (150 per cent), Medicare (1 per cent) and other sources (7 per cent) (the latter including other government assistance or welfare, Veterans Administration, charitable support, and private mechanisms such "life care contracts" and private insurance).

In 1989, total national nursing home expenditures (not including facilities for the mentally handicapped) were $36.4 billion, of which $19 billion (52.2 per cent) was paid privately, $14.3 billion (39.3 per cent) by Medicaid, $2.4 billion (6.6 per cent) by Medicare, and $0.6 billion (1.6 per cent) by other public sources.

Resident characteristics

Of nursing home residents in 1993, the average dependency level using ADL measurement was 3.9, out of a total of 6 ADLs measured -- bathing, dressing, eating, transferring, using the toilet room, and continence. About 60 per cent had some mental impairment.

55 per cent of nursing home admissions were from an acute care hospital and 35 per cent of discharges were to hospitals.

Home and community-based services

Access to services

It is estimated from the National Medical Expenditure Survey that, in 1987, formal home and community-based care services were used by about one-third of the 5.6 million elderly people reporting at least one ADL or IADL dependency (Short and Leon, 1990). Home-delivered services (including visiting nurse, personal care attendant and home-maker services, but not including meals-on-wheels) were used by 19.7 per cent of those aged 65 or over who had functional difficulties. More specifically, 8.1 per cent used home-makers from a health care or home care agency, or a helping organisation, or used paid domestic help (*i.e.* self-employed "independent contractors").

With respect to community services, 7.3 per cent of elderly people with functional difficulties regularly attended "senior centers", 6.1 per cent used congregate meal programmes, 6.1 per cent regularly received meals-on-wheels, 5.3 per cent used special transportation services for the elderly or disabled, and about 4 per cent received regular visits from helping organisations or professionals to check up on their well-being. The percentage using adult day care was well under 1 per cent.

Expenditures

Total home care spending on the elderly in 1989 was estimated by the Department of Health and Human Services (DHHS) at $7.6 billion, of which $1.9 billion (25 per cent) was Medicaid- financed, $2.1 billion (28 per cent) Medicare-financed, $2.4 billion (32 per cent) privately financed (out-of-pocket by users), and $1.2 billion (16 per cent) financed by other public programmes (SSBG, state-only programmes, Title III Older Americans Act and Veterans Administration).

Total *public* spending in 1992 on *non-professional* home and community-based services for the disabled elderly has been estimated at $6.4 million, of which 69 per cent ($4.4 billion) was via Medicaid, 10 per cent under the Social Services Block Grant, 8 per cent under Older Americans Act programmes and 11 per cent under state source programmes. This represents a considerable real increase in public expenditure via Medicaid on this component of care within these three years.

Specific types of home and community-based services

a. *Medicare Home Health Care*
During calendar year 1990, 1.8 million of the elderly people enrolled with Medicare used home health services, at a total cost of $3.5 billion. This represented an 88 per cent increase from the total of 957,000 beneficiaries in 1980.

In 1990, 47 per cent of Medicare HHA visits were by registered nurses, 9 per cent by physical therapists, and 41 per cent by home health aides. About two-thirds of agencies supplying services are non-profit agencies and one-third are for-profit agencies.

b. *Medicaid Personal Care Option*
In January 1990, 30 states provided personal care services as an optional benefit under their state Medicaid plans. Of the estimated $1.9 billion spent under Medicaid for all home care services for the elderly in 1989, about $1.2 billion (63 per cent) was spent under the personal care services option. The number of recipients was estimated in 1988 at about 264,000, representing a very high rate of growth since 1980, when there had been 46,000 recipients.

c. *Medicaid Home and Community-based Care Waivers*
In 1989, 36 states operated one or more waiver programmes for elderly and physically disabled people enrolled in Medicaid. Total spending under HCBC waivers reached $943 million in 1989, of which $312 million (33 per cent) was for services for elderly and younger physically disabled people. The majority of expenditure on waiver services was devoted to maintaining mentally handicapped people in the community.

Title III, Older Americans Act

In FY 1989, federal expenditures under Title III were $715.5 million. In lieu of means-testing (which is prohibited under Title III), participants may be asked to make voluntary contributions, and in 1989, these amounted to just over $179 million (mostly for meals). Just over half of all programme funds ($355.3 million) were used for nutrition services. Congregate nutrition services -- meals provided in settings such as senior citizen centres, adult day care programmes and housing projects for the elderly -- accounted for $254.7 million (72.4 per cent), while home-delivered meals ("Meals-on-Wheels") accounted for $100.6 million.

In 1987, amendments to the Older Americans Act allowed funds to be specifically targeted on in-home care for frail elderly people. Expenditure under this provision was $4.6 million in FY 1989.

PRIVATE LONG-TERM CARE INSURANCE

In the last decade, a private long-term care insurance industry has come into being and grown rapidly in the United States. In 1983, only 12 companies offered private long-term care insurance and there were only 50,000 policies in force. By 1990, more than 130 companies were marketing private long-term care insurance and the number of policies sold exceeded 1.6 million. By the end of 1991, more than 2.4 million policies had been purchased, a growth in the market of over 500 000 policies in one year. About 100,000 of these policies were existing life insurance policies which added long-term care coverage in 1991 (Health Insurance Association of America, 1992). At the end of 1992, the number of private long-term care insurance policies purchased had grown to

2.93 million from a total of 135 insurers, representing an average annual increase in policies sold of 29.4 per cent for the years 1987-92 (Coronel, 1994).

Nevertheless, because private long-term care insurance is normally purchased well in advance of the expected risk of nursing home use, it will be many years before benefits paid out under these policies affect sources of payment for nursing home care. Less than 1 per cent of current nursing home expenditures are being financed by private long-term care insurance.

Even in the longer term, the global effects on payment for care will probably be fairly modest. Projection of current trends suggests that between 10 and 30 per cent of the elderly could have private long-term care insurance by the year 2020. If, at the top of the range of estimation, 30 per cent of the elderly have private long-term care insurance in 2020, then aggregate out-of-pocket expenditures for long-term care would be reduced by 6 per cent and Medicaid costs reduced by 3 per cent, by comparison with likely funding patterns if no elderly people had purchased their own insurance. For those holding private insurance, however, the impact of having these policies would be likely to be more substantial: they would be likely to reduce their anticipated out-of-pocket costs for nursing home care by about half.

Partnerships between Medicaid and private insurance

A policy issue of some debate in recent years has been whether the Federal government should allow states to establish "public/private partnerships" which offer Medicaid eligibility incentives for the purchase of private long-term care insurance. In the late 1980s, a private philanthropy, the Robert Wood Johnson Foundation, funded eight states to develop a demonstration project along these lines, but the states were not able to obtain the necessary federal or Congressional authorisations. In 1991, however, Connecticut asserted that a provision in federal law permitting state discretion over aspects of Medicaid eligibility could be interpreted as providing sufficient authorisation for a state to implement a public/private partnership plan as part of Medicaid. Following a legal review, the Health Care Financing Administration agreed that the Connecticut plan could be implemented.

Under the Connecticut partnership plan, those who have purchased private long-term care insurance, who then enter nursing homes (or receive equivalent home care services), and who in time exhaust their private insurance benefits, can receive a credit against their Medicaid spend-down liability. Instead of having to spend-down their savings to the Medicaid allowable asset level (currently $2,000). they can retain an additional amount of savings equal to the amount paid out from their insurance policies. The Medicaid budget can therefore be said to "break even". Connecticut policy-makers believe that the plan builds in an incentive to protect personal assets by purchasing private long-term care insurance, and may reduce the surreptitious transfer of assets to other family members in order to gain Medicaid eligibility. Indiana and California have since implemented similar plans.

In February 1992, New York also amended its Medicaid plan to provide a different form of incentive for the purchase of private long-term care insurance. Under this plan, New York state residents who purchase a minimum amount of state-approved private long-term care insurance (which must provide three years of nursing home coverage, six years of home care coverage or an equivalent combination of both) may obtain immediate Medicaid coverage without spending down any of their assets if their private coverage is exhausted and they still require care.

These partnerships have been the cause of considerable political controversy. Some influential members of Congress have opposed them on the grounds that they allow relatively wealthy elderly people, and their heirs, to benefit from a programme (namely, Medicaid) that was intended to help poor people. In the 1993 Budget Reconciliation Act, these Congressional critics succeeded in limiting Medicaid asset protection for purchasers of private insurance to the six states that already had partnership plans. In all other states, future partnership plans will be subject to mandatory estate recovery provisions. States may still elect to reward purchasers of private long-term care insurance by according them additional relief from Medicaid "spend-down" requirements. but this protection will be limited. While individuals will be able to retain funds and property during their lifetime, these assets may not be given away or bequeathed to heirs.

THE DEBATE ON LONG-TERM CARE REFORM

The U.S. long-term care system has come under increasing criticism from the late 1970s onwards. Concerns about the fragmentation and inadequacy of financing, particularly for non-institutional services, led in the first instance to substantial federal government investment in policy research and demonstrations that would point the way toward suitable reforms in financing and service delivery.

This research on long-term care of the frail elderly has taken four main forms:

a. National surveys of the elderly population in nursing home and community settings, for example, the National Long-Term Care Surveys in 1982, 1984, and 1989. These have enabled the compilation of a substantial national database to be compiled on needs, service and financing patterns, which both provides good information on current trends and allows modelling of the impact of future options.

b. Demonstrations designed to field-test potential new policies and programmes, the largest being the 10-site National Channeling Demonstration, which field tested two models of case-managed home and community-based care as an alternative to nursing homes (see Kemper *et al.*, 1986; and for a critical commentary, Davies, 1994).

c. Evaluations to measure the efficacy of existing policies and programmes in meeting goals, for example, evaluations of the cost-effectiveness of Medicaid waiver services.

d. Issue-oriented studies of various kinds, such as studies of the rate of "spend-down" to Medicaid eligibility among nursing home residents.

Calls for long-term care reform initially focused mainly on a perceived bias toward institutionalisation. Critics maintained that inadequate public funding for home care caused excessive and unnecessary recourse to nursing homes. Recommendations for reform therefore centred on an expansion of funding for home and community-based alternatives to institutionalisation. During the 1980s a number of legislative initiatives to expand home care funding were proposed in the Congress. The closest any proposal came to being passed into law was that of the late Congressman Claude Pepper, who argued for an expansion of Medicare home care coverage as part of the 1988 Medicare Catastrophic Coverage Act.

Although Pepper's initiative failed, the political support he had mobilised among older people was sufficiently compelling for Congress to set up the Bipartisan Commission on Health Care Financing Reform (known as the "Pepper Commission") to study and make recommendations about public funding for long-term care, as well as how to extend acute medical coverage to the estimated 37 million uninsured Americans under age 65. This was an important point in the developing momentum for reforms to the U.S. health system, among which proposals for long-term care reform by now loomed large.

By the time the Pepper Commission began its deliberations, advocates of long-term care reform were no longer quite so exclusively concerned with expanding public funding for home care. The earlier optimism that increased funding for home care would generate savings from reduced nursing home use, thereby allowing new alternative services at no additional budgetary cost, had faded. Findings from the "Channeling" and related demonstration projects, and the experience of the Medicaid waiver programmes, had lowered these expectations (Kemper *et al.*, 1986, 1987; Weissert *et al.*, 1988).

The recognition that nursing homes would remain a very significant part of the long-term care sector, even if other services became more widely available, strengthened support for improved public regulation of nursing homes, one early result of which was the nursing home reform legislation embodied in the Omnibus Budget Reconciliation Act of 1987 (details of which are given earlier).

Criticism of the U.S. long-term care system had also broadened to include the financial problems of elderly people with incomes and savings above Medicaid eligibility levels, who required some protection against catastrophic" out-of-pocket costs for nursing home care. The growing interest in securing protection against the high out-of-pocket cost of nursing home care was first reflected in the emergence of the private long-term care insurance industry in the mid-1980s. Serious consideration was given by federal health authorities during the time of the Reagan Administration to income-related tax subsidies to stimulate the growth of private long-term care insurance and savings plans. However, analyses of the affordability of private long-term care insurance did not support the proposal that tax subsidies would be likely to stimulate insurance purchase or savings that would not otherwise occur. Because of these doubts, as well as anticipated opposition by the Treasury Department on the basis of cost, the Reagan Administration never formally took a position in favour of tax subsidies for private financing mechanisms.

By the late 1980s, most long-term care reform legislation being introduced in Congress included provisions for financing both home and community-based and nursing home care. Representative Stark proposed a comprehensive public insurance to take effect after the first two months of long-term care. However, most legislative proposals introduced in Congress recommended much more limited "front-end" or "back-end" public coverage of nursing home stays; in other words, public funding would be limited to the first six months or one year of nursing home care or, alternatively, would cover only the "catastrophic costs" associated with stays lasting more than two or three years. There were two reasons for these proposed limits on public coverage: one was to lower projected costs, and therefore the taxes needed to finance those costs; the other was to build a political alliance with the insurance industry by guaranteeing it a substantial role.

The Pepper Commission Report

The creation in 1988 of the Bipartisan Congressional Commission on Health Care Costs (more commonly referred to as the "Pepper Commission") was the first serious effort in Congress to achieve a politically viable consensus among both Republicans and Democrats concerning the best approaches for health and long-term care financing reform. However, it did not result in a single consensual report, but a majority report with a number of dissenting minority recommendations (Pepper Commission, 1990).

The main features of the plan supported by the majority of the Pepper Commission included:

- Home care coverage for all elderly and younger disabled persons with severe (3 or more) Activity of Daily Living (ADL) impairments or significant cognitive impairment.
- Coverage of the first three months of nursing home stays with very low cost-sharing.
- Protection of up to $30,000 in savings against "catastrophic" out-of-pocket expenses associated with nursing home stays of over 3 months duration.

The recommendations implicitly preserved a "gap-filling" role for private insurance, but did not include any provisions for tax incentives or other ways of promoting private insurance purchase. The Commission estimated the cost of its long-term care proposals at $42 billion in new public spending, over and above existing Medicaid expenditures for long-term care.

One dissenting Commission member argued in favour of a national health insurance plan, modelled broadly on the Canadian "Medicare" system. There has been a great deal of discussion during the last decade, in policy circles and in the mass media, over whether the U.S. should adopt the so-called "Canadian model" of public financing for health and long-term care (see, for example, Special Committee on Aging, 1984; Kane and Kane, 1985). While the Canadian approach has many admirers in the U.S., not all admirers have advocated a "Canadian model" for the U.S., in the belief that, for better or worse, long-term care reform in the U.S. can only evolve incrementally out of the current system.

In the immediate aftermath of the Pepper Report. Congressional interest in long-term care reform coalesced around two legislative proposals. Support for these proposals polarised along party lines, thus fragmenting the attempt to arrive at a bipartisan proposal. One bill (S. 1668) was introduced in autumn 1991 by the minority (Republican) members of the Senate Finance Committee, and proposed to take public long-term care financing out of Medicaid and create a new "Title XXI" to the Social Security Act. As a "welfare" programme, eligibility for public financing of long-term care would have continued to be means- tested; however, the means test for home and community-based care would have been more generous than under Medicaid, such that access to such services would be expanded. The second part of the Senate Finance Committee minority bill set out a system of public subsidies for private long-term care insurance.

The second bill (S. 2571) was put forward by the majority (Democrat) members of the Senate Finance Committee in April 1992 and essentially contained the recommendations of the Pepper Commission majority report. Initially, this bill contained specific recommendations for financing the expanded public long- term care benefits, including provisions for increases in inheritance tax, in Social Security payroll and self-employment taxes, and in taxes on unearned income (including Social Security benefits, interest on individual retirement accounts and pensions). These revenue-raising proposals proved so controversial that the bill was withdrawn and re-submitted. In the new version, specific tax proposals were replaced with a general statement to the effect that financing must come from taxes that are broad-based, progressive, and that have an equitable impact on every segment of the population.

The Clinton Health Reform Plan

On taking office in January 1993, President Clinton established a health care reform task force, which in turn set up a long-term care working group. This group developed four options for reform for the President's consideration, ranging from inexpensive, incremental expansion of existing Medicaid benefits, coupled with stronger regulation of private long-term care insurance, to comprehensive social insurance coverage of both nursing home and home and community-based services. The

President chose to include the working group's "Option 3" in the health care reform plan announced in September 1993, although the long-term care provisions were entirely separate from the proposals for reform of acute health care funding (for which, see OECD, 1994).

The long-term care component of the President's health reform plan included the following features:

- A new federal and state programme to finance home and community- based services for severely disabled people of all ages.
- Federal regulation of private long-term care insurance and clarification of relevant federal income tax law.
- Modifications to the eligibility rules for Medicaid funding of nursing home care, to make the means-test less restrictive.
- Tax credits for personal assistance services, to reduce disincentives on younger severely disabled people in taking up paid employment.
- A demonstration programme to test methods of integrating acute and long-term care.

The proposed new programme for home and community-based long-term care would have been administratively separate from both Medicare and the private insurance coverage for acute health care that it was proposed to make available through corporate or regional health alliances. It would have been administered by the states, who would have been enabled to offer a wide range of benefits. The flexibility with respect to benefits extended to permitting states to provide cash payments or vouchers to eligible clients in lieu of payments to service providers.

The new programme would have been expected to supersede Medicaid as the main source of finance for home and community-based care for severely disabled people. However, federal matching payments would have continued to be available through Medicaid, at state option, to fund similar services for people whose disability did not meet the criteria for the new programme, on condition that those receiving these services have a low income. Medicaid would have continued to be the major programme providing coverage for nursing home services. All states would have been required to offer "medically needy" coverage. In addition, the President's proposal would have raised the personal needs allowance for nursing home residents from $30 to $50 per month and, at state option, permit nursing home residents on Medicaid to retain up to $12,000 in assets (rather than the current $2,000) (See also Chapter 19 for details of the Clinton proposals).

The American Health Security Act, incorporating the President's health care reform proposals, was introduced in both houses of Congress in November 1993. After considerable debate, relatively little of which focused specifically on long-term care issues, and during which a number of competing health care reform bills emerged, it became clear that there was insufficient consensus in either chamber to pass any new health care measures into law (see OECD, 1996, on these debates). In September

1994, the Senate Majority leader formally abandoned the effort to pass health reform legislation in 1994.

The state of the debate in 1995

In the November 1994 Congressional elections, the Republican Party achieved majority control in both the House and the Senate for the first time in forty years. Based on press reports of exit polling of voters, public dissatisfaction with the President's health reform initiative was among several key factors responsible for the election results. By November 1994, many voters had come to the conclusion that the Clinton health reform plan would have been too extensive an overhaul of the existing health care system and that the government's role under the Clinton plan would have been too intrusive.

The Republicans interpreted their election victory as a mandate from the voters to move forward with the party's proposed legislative agenda, termed the "Contract with America". This outlined legislation that the Republican Congressional leadership was pledged to introduce within the first 100 days of the 104th Congress. Two of the eight proposed bills included initiatives related to long-term care. The proposed "Family Reinforcement Act" would create a $500 annual tax credit for families who brought dependent elderly parents or Grandparents to live in their homes. The proposed "Senior Citizens Fairness Act" included tax incentives for the purchase of private long-term care insurance.

It is noteworthy that the long-term care initiatives proposed in the Contract with America have not been put forward as health care reforms *per se*. Instead, they have been linked to wider philosophical themes that conservative Republicans have emphasised in recent years. One is the idea that public policy interventions are needed to restore "family values" because of the many cultural and other forces that are seen as undermining the family as an institution. Accordingly, the elder care tax credit proposal is part of a package of proposed tax incentives whose stated purpose is to strengthen the family.

Another wider theme is that the "welfare state" should be dismantled or, at least, significantly reduced. Conservative Republicans contend that the size, cost and intrusiveness of government bureaucracy has burgeoned since the 1960s due to a multiplication of programmes aimed at lower income groups. It is further contended that these programmes serve only to reinforce a "culture of poverty" among recipients, while neglecting the needs of the middle class families who are required to pay for the system. The position of the new Republican majority in Congress is that middle class families do not need or want more government benefits, but could purchase the services they need in the market-place, if only the government would "get off their backs", *i.e.*, stop taking so much of their disposable income away in taxes. The proposed tax subsidies for private long-term care insurance follow this line of reasoning, being part of a package of tax breaks for senior citizens intended to leave them with more money with which to take decisions about how to meet their own needs, including those for long-term care.

As of early 1995, the future for reform of the long-term care financing and delivery system is highly uncertain. The long-term care proposals in the Republican's Contract with America are profoundly different philosophically from most of those considered following the Pepper Commission report or in President Clinton's health reforrn plan, and the areas of disagreement between Congressional Republicans and Democrats concerning approaches to long-term care reform have become greater than in the previous Congress.

Major long-term care reform still seems unavoidably linked to the fate of a broader health reform effort to find a way to expand medical cost coverage for the uninsured while controlling the rise in health expenditures. Total annual expenditures for health care (including long-term care for the elderly) now amount to over 14 per cent of the U.S. Gross Domestic Product. Because the likelihood of a continuing political stalemate is so high, and because the focus of debate in Washington is now on cutting taxes, many observers believe that the focus of health reform efforts will shift to individual states.

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