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ABSTRACT

The demand for long term care is growing as the population in need of services becomes older and frailer, and as the nature of the family, the economy, and the health care system changes. To investigate the long term care system, its characteristics, trends, financing, policies, availability, and quality of care, 700 health care professionals, patients, families, social workers, state officials, and advocates from eleven states participated in discussions. The results of those discussions showed that long term care is not a program, but an assortment of government and private efforts to meet the needs of chronically ill or disabled people. However, although no explicit public policy exists, in 1980 long term care cost $32 billion in federal, state, and private funds. Families remain the primary provider of health care, with institutional care seen as a last resort. With the decline in Medicaid and Title XX funds, reimbursement is the foremost concern of program administrators. The quality of care directly relates to reimbursement, with nursing home care generally considered to be good. Concern about privacy, independence, food, and personal attention outweigh medical and hygiene concerns. Staffing problems are widespread along the health care continuum, with disenchantment about nursing home licensing and certification very high. Placement decisions based on discharge objectives rather than long term planning are a continuing source of concern for both families and professionals. (BL)

REPORT TO THE SECRETARY
SERVICE DELIVERY ASSESSMENT
OFFICE OF THE INSPECTOR GENERAL
December 1981

LONG TERM CARE

Prepared by
Region X

With Regions
III, IV, V & IX

Service Delivery Assessments are short-term studies of HHS programs and services conducted at the local service delivery level. They are not designed to be statistically valid research studies, compliance reviews, audits, program monitoring activities, or traditional program evaluations. Rather, a service delivery assessment consists of gathering current qualitative information from open-ended discussions with clients and service providers. The knowledge gathered is subjective in nature and is intended as a way for senior-level HHS personnel to obtain the views of the people most directly affected by HHS programs. Assessment results are meant to be used internally by Department managers as an additional source of information which, when combined with others, provides a more complete picture of service delivery.

MAJOR FINDINGS

GENERAL FINDINGS

- Long term care is not a program, but an assortment of government and private efforts to meet the needs of chronically ill or disabled people. There is no explicit public long term care policy. Nevertheless, long term care (excluding income maintenance and informal care by families) cost $32 billion in 1980, of which 42% was federal, 19% was state or local government and 39% was private funding.

- Of the above expenditures, 63% went to nursing homes, 17% to hospitals and 20% to community-based care. Federal, state/local and private outlays all heavily favor institutional care over in-home care, and medical care over social or custodial support services. There is, however, a growing consensus that the institutional/medical model is often an inappropriate and inefficient approach to long term care. Congress and many states seem to be moving toward de-emphasizing the institutional/medical model, in response to public demand.

DEMAND FOR LONG TERM CARE

- Demand for long term care is growing. The long term care population is becoming increasingly older and frailer. The elderly are growing as a proportion of the whole population, and a concomitant growth in the relative size of the long term care population can be expected. Demand for publicly-supported long term care is likely to grow because of inflated costs of health care, decreased full-time homemakers, increased family mobility, precedents set by Medicare and Medicaid subsidies for health care and such special impacts as the aging of the "de-institutionalized" mentally ill.

- Few people know much about long term care until they or their family need it. Misunderstanding of Medicare limitations for long term care coverage and private supplemental insurance coverage is the rule rather than the exception. Remaining in the familiar home setting is virtually everyone's long term care ideal. Boarding homes and other protected living arrangements run a poor second, and nursing homes are at the bottom of most wish lists.

- Families remain committed to caring for their relatives and often perform extraordinary feats before resorting to institutional care. Informal (non-purchased) care probably represents 60-80% of all long term care. Respite, homemaker and other social services would ease the burden of many families. Most people do believe, however, that increased community-based services, if readily available, would encourage potential clients to "come out of the woodwork" and indeed would offset some personal and family effort now being expended. Even though eligible, many people avoid institutional care. Whenever publicly funded, in-home support services are quickly absorbed by this great unmet need.

COSTS AND EXPENDITURES

- Nursing home, hospital and community-based care are all needed at times, and all are part of the necessary continuum of long term care. Both nursing home care and community-based care are usually a "best buy" when they can offset hospital days. Serious hospital backup of patients awaiting a nursing home bed does indeed exist in some places, especially for behavior problems and heavy care patients on Medicaid. Backup is especially acute where public nursing homes are saturated or nonexistent. Relative to each other, neither nursing home care nor community-based care is always a best buy. Cost effectiveness depends on the level and duration of care needed in a given case.

- By themselves, both Medicaid and Title XX long term care expenditures can be expected to decline or at least grow very slowly, because of federal funding cuts and state budget pressures. The possibility of state refinancing of some Title XX services through Medicaid waivers may offset federal dollar savings, however, even without any real growth in current community-based services.

- Reimbursement systems now occupy the forefront of administrative concerns at the delivery level and have major fiscal implications at the national level. Of possible financing alternatives other than reimbursement changes, tax incentives for family care of elderly were the most strongly supported by assessment participants.

QUALITY OF LONG TERM CARE

- Nursing home quality varies dramatically but is generally good, with some exceptions. Once there, people are usually complimentary about staff services. Concern about lack of privacy, independence, food and personal attention far outweighs concern about medical care and hygiene. Quality clearly is related to reimbursement, especially as it affects staffing levels.

- Virtually all nursing homes have staffing problems. Registered nurses are hard to recruit. Sixty-six percent of all nursing home personnel are aides, virtually always at minimum wage levels. Turnover among aides is very high, geriatric training for all staff is very low and physician involvement in nursing homes is sparse. There is a shift of ownership of nursing homes toward proprietary chains, but there are mixed opinions whether this presages good or ill for quality care.

- Community-based care suffers similar staffing problems, but apparently less severely than nursing homes. There are fewer standards and less licensing, monitoring, screening and training in community-based care. Reimbursement is still tied to the medical model, although some medical activities such as monitoring of medications is probably poorer in community-based care. Case management is often poor. Boarding home quality is much lower than nursing home quality. Boarding homes remain largely unlicensed and are increasingly the last resort for Medicaid eligibles, particularly those with mental health problems.

- Especially in nursing homes, there is an extremely high level of disenchantment with licensing and certification approaches to quality assurance. There is a consensus that the current procedures overemphasize quantitative paperwork and physical facility factors and underemphasize patient contact and observation and qualitative aspects of care. These procedures do not discriminate between good and bad homes, and bad homes rarely are closed down. There is strong support for quality assurance approaches that favor sampling and concentration on patient care and that rely on public access to promote quality.

INTRODUCTION

> "Long term care is a bottomless pit. We need all groups to come together to flush out contradictions and to look at the rippling effects of change." (Nursing home administrator)

Persons with long term care needs require varying types and levels of health, social and supportive services for intermittent, extended or permanent periods of time because they have lost some capacity to care for themselves. Long term care includes health, custodial, social, residential, restorative, protective and preventive care. It may be provided formally (i.e., for remuneration) or informally (without compensation).

People in need of long term care are those who cannot perform essential daily self-maintenance activities such as bathing, dressing, eating and toileting. In addition, many people need help with other tasks basic to daily survival and sustenance, such as cooking, cleaning, shopping and transportation. Their inability to care for themselves may be caused by chronic or acute physical or mental health problems or by general debility that commonly accompanies the aging process.

For the purposes of this study, long term care is defined as "an array of helping activities for persons unable independently to perform normal daily functions where this dependent condition is expected to last indefinitely."

In June 1981, Secretary Schweiker directed the Office of Service Delivery Assessment to conduct a national study of long term care. The resulting report treats the subject of long term care under four issue areas:

- overview of the long term care system, including current characteristics and trends,
- proposed or tested financing alternatives and other fiscal policies affecting provision of long term care services,
- availability, accessibility and appropriate placement in the long term care system and
- quality of care.

Discussions were held with approximately 700 people. Fieldwork was conducted in eleven states. Participants included nursing home patients and families, community-based care clients and families, hospital discharge planners and social workers, nursing home administrators and staff, community-based service providers, state officials, local health personnel and general government representatives, special interest advocates and long term care experts.

OVERVIEW OF THE LONG TERM CARE SYSTEM

Families Do All They Can

Long term care traditionally has been a family responsibility in the United States. Most published estimates agree that 60-80% of persons with special needs are cared for by family or friends. These caretakers receive no remuneration for the care they provide.

Clearly, most families do everything they can to keep a member in need of long term care in the home. Although some families are willing to rely on government programs, the consensus of study participants is that most families are committed to caring for their own. Changes have occurred in the family's structure rather than in its commitment. Smaller nuclear families with both spouses working are now the mode. Extended family structures have changed because of heightened mobility and changing lifestyles.

Families experience great stress and guilt when placing a member in a nursing home. As a non-profit nursing home administrator said, "The family usually feels guilty, then feels resigned. Our residents are usually much happier about their placement here than their families are."

Consensus was nearly universal that patients and their families do very little planning and know almost nothing about long term care prior to needing it. Typically, families do not have any sense of the cost, availability or ways to access the long term care system. Patients and families all think that Medicare will cover 100 days in a nursing home. They do not understand the limitations associated with the definition of skilled care. Respondents are extremely critical of the "Medicare Bluebook", HCFA and SSA staff, and physicians regarding the lack of clarity on what Medicare covers in nursing homes. Words used by respondents to describe patient reaction to learning that Medicare would not cover what they expected include: "anger, amazement, flabbergasted, shocked, horrified, stunned, bewildered and hysterical." "One hundred percent think they will get 100 days of Medicare coverage." (Hospital discharge planner)

Study participants in some parts of the country are very critical of the insurance industry for misleading the elderly about nursing home supplemental insurance policies. Most people who purchase supplemental insurance policies for nursing home coverage do not realize that the supplemental policies cover the patient only as long as Medicare coverage continues. Very few people ever collect on these policies.

When asked what can be done to encourage families to provide even more support, study participants most frequently suggested tax incentives at both federal and state levels, similar to those allowed for child day care. The next most frequent suggestion is to provide respite services for families. Respite is viewed as a crucial service to keep families from reaching the crisis state where their long term care member will have to be placed in an institutional setting. Third, participants suggested family education/counseling as a preservative of family support. Families need to learn more about needs of the elderly and how to care for them. They need to know what services are available to piece together a total care approach for their members. This issue is not all one-sided, however. Participants cited many examples of parents resisting support from their children. The reversal of roles is repugnant to many elderly who decry their diminishing independence.

Undoubtedly, families need help to enable them to do as much as possible for their members, whether in or out of institutional settings. One state official echoed the sentiments of most participants when he pleaded, "Don't alienate families by forcing them to provide 100% care or nothing. Let them provide cash or in-kind. Families should be allowed to supplement or help in a patient's care."

Long Term Care Clients Are the Most Vulnerable in Society

Participants in this study overwhelmingly describe long term care clients as being elderly, frail and female. Absence of family, especially spouses and children, is a key indicator that formal long term care, especially institutional care, will be needed. People are remaining at home with greater dependency, more chronic illness and more severe disabilities than in the past. They also are being discharged earlier from acute care hospitals. The result is that patients are much sicker by the time they reach the nursing homes. They also are less alert, experiencing greater mental deterioration and more severe behavior problems than their peers who remain in the community.

In general, long term care clients are getting much older and more dependent. Centenarians are no longer rare. Medical technology has prolonged the lives, but not necessarily the independence, of many aged. The prevalence of chronic diseases and conditions increases with age. The advent of Medicare and Medicaid has provided the elderly a major public subsidy and impetus to use health care services (including long term care), so that the elderly now dominate the long term care population.

The United States population definitely is greying. The age group 65 years and older has been growing faster than any other in America. In 1900, less than 4% of the total population was elderly. By 1970, their numbers grew to 10%. Census projections show the elderly equaling 22% of the total population by year 2030 when the post war baby boom becomes elderly.

A paper developed by the Department's Long Term Care Task Force estimated in 1980 that approximately 30 million Americans (more than 13% of the total population) have some activity limitation, resulting from chronic disease or condition which makes them candidates for long term care. Of this total, approximately 6 million are substantially disabled and represent the hard core of the long term care population. They include approximately 3.6 million who need help with personal care and/or mobility assistance, approximately 1.8 million who live in institutions and approximately .6 million who live in board and care homes and other informal settings.

The long term care population includes special groups whose numbers and special care needs are important considerations when addressing national long term care policies. Approximately 1.7 million people suffer from chronic mental illness, half of whom live in the community but are unable to work and half live in institutions. Approximately 2.8 million Americans suffer from developmental disabilities, of which an estimated 1 million are mentally retarded. Approximately 2 million Americans experience physical handicaps which limit major activity. Some, but not all, of these special groups fall within the estimated 6 million substantially disabled hard core of the long term care population.

Continuum of Care

What kinds of care and services do these 6 million persons need? The spectrum of services needed includes both institutional and non-institutional settings and resources. Individuals may need either increasing or decreasing levels of care as their functional dependency changes. The continuum includes facilities and institutions such as hospitals and nursing homes, community-based services such as home health and chore services, and informal settings such as the family and neighbors.

Of the 30 million candidates for long term care, approximately 1.8 million reside in institutions, primarily in the nation's 18,900 nursing homes. More than 28 million other Americans who suffer some degree of activity limitation due to a chronic condition live in community settings, where there are various types of formal and informal supportive services.

FINANCING LONG TERM CARE

If it were a single program, the long term care federal budget would be larger than that of any federal department except HHS, DoD and the Treasury Department, and second only to OASDI in the HHS budget. Long term care represents about 13.5% of all health expenditures, public and private, or some $32 billion out of $237 billion in 1980. This estimate includes all formal expenditures by government, business, philanthropy and citizens, but excludes any projected value of informal (non-purchased) care by family and friends, which has been estimated at 60% to 80% of actual long term care. The $32 billion estimate also excludes all income maintenance, food stamp and community housing assistance, which total at least an additional $16.7 billion in support to that same long term care population.

Formal Long Term Care Expenditures in Hospital Care, Nursing Home Care and Community-Based Care by Source of Funds - 1980
(in millions)

Source	Hospital	Nursing Home	Community-Based	TOTAL
Medicare	$1,568	$ 455	$1,042	
Federal Medicaid	419	5,694	85	
Federal Title XX			809	
AoA			724	
Veterans Administration	1,562	359	723	
Other Federal	104	21	135	
State Medicaid	354	4,788	73	
State Title XX			420	
Other State	198		211	
Local Government			17	
Insurance	902	129	740	
Business/Philanthropy	29	129	162	
Consumers	209	8,869	1,377	
Total	$5,345	$20,444	$6,518	$32,307
Federal	$3,653	$6,529	$3,518	$13,700
State/Local	$ 552	$4,708	$ 721	$ 6,061
Private	$1,140	$9,127	$2,279	$12,546

(Sources: Combined data from U.S. Budget for FY 1982; U.S. Budget Revision, 1982; Health U.S. 1980; The Book of the States, 1980-81; HCFA publications a, b, c. These statistics involve estimates of the various service populations who receive long term care from each source.)

When based upon recent expenditures, projections for future long term care costs are generally alarming. For example, assuming continuation of the 1979 annual growth rates of 18.3% for nursing homes, 12.1% for hospitals and 11.9% for other long term care (HCFA[b], p.4), long term care expenditures would grow at an aggregate rate of about 16% per year--thus, costs would double every five years. If, however, projections are based on population trends, the figures may appear less startling. The elderly population as a whole will grow at a rate less than 4% per year and the nursing home population less than 5% per year (HCFA[a], pp. 10-13).

Another element in long term care projections should be the relative roles of the three sectors--hospital, nursing home and community-based care--and the degree to which shifts among them may achieve cost efficiencies or expand services to cover unmet needs. Evaluations of current demonstration projects have so far revealed little evidence that expanded community-based care will reduce public aggregate expenditures. Trends should also factor in the shrinking of family size, the relative growth in single or widowed elderly, higher child mobility and employment, improvements in avoiding chronic illness and possible improvements in financial status of the aged (HCFA[a], p. 12).

In summary, cost projections require sophisticated data and methodology. Trends are a function of both costs and utilization, plus other less direct factors. It is fairly obvious, however, that long term care comprises (a) the most rapidly expanding population sector (the elderly) in (b) a process of increased utilization of (c) some rapidly rising health care cost sectors (especially nursing home and hospital care).

Controlling and Refinancing Long Term Care Costs

The Omnibus Reconciliation Act of 1981 made changes affecting long term care, particularly in the Title XX and Medicaid programs. In Title XX, states received additional flexibility along with a reduction in federal funds from about $2.9 billion in 1981 to $2.4 billion for FY 1982. By itself, the Title XX cut could reasonably be expected to result in a reduction of Title XX long term care expenditures proportionate to the cut in other Title XX services.

In Medicaid, Congress decided against a "cap" on federal funding, but imposed limited growth penalties. It also gave states more flexibility to control hospital and physician fees and freedom to buy laboratory services under competitive bids. By waiver, states may limit clients' freedom of choice to certain providers, especially HMOs. Also by waiver, states may spend Medicaid funds for community-based care, including social services such as homemaker and chore services, as an alternative to nursing home care. The continued pressure of inflation against the state share of Medicaid—more than the new penalties—will put severe pressure on state budgets. In most of the states we visited, efforts are underway to control Medicaid growth. These efforts can be expected to constrain Medicaid growth, including long term care expenditure growth.

When the effects of Title XX cuts and the new Medicaid legislation are viewed together, however, the picture changes dramatically. As much as 30% of Title XX expenditures might be construed as long term care. By converting only one fifth (21%) of the existing Title XX services into Medicaid services, states might recoup their losses under the Title XX cuts without expanding 1981 long term care services at all.

This depends, of course, upon how the regulations and procedures for the waivers are handled and how states define service to fit those rules. Not all Title XX clients meet Medicaid income test restrictions. HCFA regulations define the statutory per capita cost limit in such a way as to preclude an overall increase in expenditures for long term care. However, such constraints involve pitting federal estimates against state estimates of what SNF and ICF care expenditures would have been without the community-based care alternatives.

It will be important for HHS to monitor closely the changes in this portion of Medicaid expenditures for the next several years. Unfortunately, refinancing probably will be invisible to HHS, since the Title XX Block Grant legislation virtually eliminated mandatory state reporting under that program.

Financing Alternatives

Participants in the study offered numerous ideas about how long term care financing should be reformed--ranging from very specific to very broad theoretical suggestions. These ideas are discussed briefly under the following groupings: reimbursement, insurance, consumer participation, family participation and tax incentives. Obviously, these suggestions do not cover the full range of possible financing alternatives.

- Reimbursement. Numerous discussions centered on the imposition of reimbursement issues in both nursing home and community-based care. "Almost any alternative reimbursement system would be better than what we have." (RN in nursing home)

  Underlying most reimbursement discussions is concern about inflexibility of payment schemes in relation to the wide variation in types and amounts of care required by patients. Several reimbursement reform approaches are favored. The one most often mentioned is movement toward a point count system which would reward services to heavy care patients over light care patients. Some states are trying point count systems. Opponents say these systems reward them for keeping patients under heavy care and penalize rehabilitation. A second approach favors more standardized and simplified payments, often in conjunction with prospective reimbursement schemes. A third approach being discussed—but nowhere in practice—is payment of providers on outcomes, i.e., whether patients progress better or worse than predicted by some neutral analyst.

- Insurance. Private insurance pays for 6% of all long term care, including 17% of hospital long term care and 12% of community-based long term care, but under 1% of nursing home care. A number of study participants urged greater involvement of private insurers and business/employer funding of long term care.

  Information about private policy coverage is considered proprietary. In the few conversations which the assessment team had with commercial carriers, they were advised that the high probability of institutional care for elderly people would make private long term care insurance too expensive for most people.

- Consumer Participation. Discussion of direct consumer funding of long term care usually centers on deductible and co-payment schemes, both of which are used by private insurance to constrain utilization. In institutional care, however, few people utilize nursing homes out of convenience. Most Medicaid eligibles have spent down their life savings to reach the point of nursing home Medicaid coverage. In a sense, therefore, they have paid the maximum possible deductible or co-payment.

  With respect to co-payments for community-based care, however, they may work as a brake on utilization of long term care services just as they may work to control utilization of other health services. As a utilization control, co-payments probably will not work on those services which, like nursing homes, are already "last resort" services.

- Family Participation. As indicated elsewhere, this assessment revealed a consensus that most families strain their resources to provide long term care to spouses, parents and needy children. Most states have laws controlling the required use of common resources to support one member of a married couple who needs institutional care and forcing "spend-down" before Medicaid may be used. There is Congressional interest in lightening the

burden on non-institutionalized spouses. (Senator Packwood, p. 1039) At least one state is currently considering a law mandating support by certain children of Medicaid-eligible nursing home residents (State Health Notes, p.2). There are, however, administrative and legal complications to mandatory supplementation (Callahan, et al.).

Voluntary supplementation, on the other hand, may be a more popular and reasonable cost-saving move. A number of states allowed voluntary supplementation of nursing home care costs until federal regulations prohibited such supplementation. (Funds donated to Medicaid recipients are construed as income, thereby offsetting SSI/Medicaid public payments.) This assessment revealed some interest among clients, their families and long term care providers in allowing such voluntary supplementation:

> "I think the family support payment issue has not been adequately explored. There are families that are willing to pay $200 for care but can't afford $1,000 a month. They have to pay nothing to get the state to pay the $1,000." (State official)

If one half of those current Medicaid covered nursing home residents who have children received a supplement of $100 per month, and if $30 of that went to offset Medicaid expenses, the federal government and the states would each save about $29 million per year, and nursing homes would have $136 million more each year to spend on improved staffs and services (a "windfall" less than 1% of their operating budgets). The point of contention on this issue is whether nursing homes would in fact improve quality with this windfall, or whether they would simply demand the supplement before admitting Medicaid patients. Given the weakness of federal and state monitoring of quality (discussed elsewhere in this report), government monitoring of marginal quality improvements is not promising. Voluntary supplementation should not be allowed unless accompanied by an effective quality measurement system able to assure better care for more pay.

Tax Incentives. Strong support was expressed by assessment participants for tax incentives to families who care for their parents as an alternative to government-funded long term care. The Secretary has publicly supported this concept (National Association of Counties Meeting, Nashville, 7/15/81).

Current IRS rules (Publication 17, Ch. 19) allow a family to deduct as medical expenses health care outlays and, under some circumstances, nursing home expenditures made on behalf of a relative who (a) is a U.S. citizen, (b) does not file a joint return with a spouse, (c) receives over half his support from the family and (d) has less than $1,000 taxable income for the year.

At that income level, however, Medicaid often cancels out any family-care incentive which IRS deductions may now proffer. To offer a more meaningful incentive, a tax deduction would have to be coupled with a voluntary supplementation allowance and/or would have to apply to care for dependents with higher income than the Medicaid eligibility level. Removal of the IRS requirement to provide one-half of the dependent's support would open up the tax incentive to those families where several children might each supply less than half of the dependent parent's support and care.

As a cost-saving measure, the concept suffers from the same "woodwork" threat that community-based care faces. Far more of the tax relief may go to offset current family expenditures for which there is now no government relief than may be saved in government outlays which would be avoided. Given the interplay with Medicaid and the many possible variations, some fairly sophisticated cost analysis would be required to identify the most efficient tax incentive form.

> Long term care for an individual may include any mix of social and health services including skilled nursing care, therapy, personal care services, homemaker and chore services, emotional, financial, nutrition, or legal counseling, transportation, and even friendly visiting. To obtain the total package of required services today is not easy. Yet the unavailability of one crucial element may mean the person in need of long term care may not be able to remain at home. (Congressional Record, July 24, 1978, p. S.11550)

A true continuum of care creates a set of choices and/or services across a variety of settings. No community or state has a full range of services available and accessible to all who need them. Families and providers are faced with the challenge of patching services together to meet the increasing and decreasing levels of care long term care candidates need as their dependency grows or diminishes.

Service Gaps in the Continuum of Care

Many people who require some form of long term care—particularly non-institutional care—do not receive services. During fieldwork, study participants reported many gaps in service availability in their communities. The most frequently mentioned shortages were respite (temporary relief for the caretaker), adult day health, homemaker/chore and protected living arrangements. Yet, when asked what services are most needed in their communities, participants specified homemaker/chore (31%), protected living arrangements including residential centers, congregate care and foster care (30%), nursing home beds including SNF, ICF, heavy care and Medicaid beds (29%) and adult social and health day care (25%).

Service gaps clearly are attributed to lack of funding, either inadequate third-party reimbursement rates or limited grants-in-aid. As one state official noted, "Both profit and non-profit providers are reliant on federal funds for their survival." The second most frequently cited reason is excessive regulations, especially in communities where SNF, ICF and heavy care beds are in short supply. Government regulations, such as certificate of need, and market conditions, such as high interest rates, reportedly limit supply. In some communities, specific services, such as hospice, respite, adult day health and congregate care, are too new to be fully developed and available. Finally, many services have not been able to keep up with rapidly expanding demand, fueled by the ever-increasing numbers of elderly clients.

The Nursing Home Focus

Between 1960 and 1970, the number of elderly nursing home residents doubled. Following passage of Medicare and Medicaid, there was rapid growth in the nursing home population. Since 1970, types of homes for the aged and dependent have become increasingly medically-oriented. The HHS Working Group on Nursing Home Bed Supply indicated that "it is logical to conclude that the factor most responsible for this has been the large sums of public money available under Medicaid for this type of shelter and care, and the absence of incentives for the development of other types of congregate facilities."

The issue of nursing home bed shortage or surplus is important to the discussion of appropriate placement. If a surplus, do people who live in nursing homes actually need to be there? If a shortage, are patients inappropriately backed up in acute care hospitals? Three out of four study participants who addressed the issue in this service delivery assessment believe that there would

be no hospital back up if the nursing home bed supply were adequate. Some experts argue, however, that expansion of supply without improvement in reimbursement levels might mean that new beds are filled with light care patients from the community, leaving the high cost, heavy care patients still backed up in the hospitals.

The patients who are backed up in hospitals generally are the "heavy care" patients. They are described as the behavior problems and those requiring constant attention such as feeding, turning, lifting and suctioning. Several respondents cited patients being backed up for a year. A state official described one city where "at least 3,000 are backed up at all times at a cost of $150 a day; 1,200 have waited 12 months or longer for placement."

Access to Care

Even when a service is available in a community, it may not be accessible. The service may be in short supply and not have current openings for clients no matter what their ability to pay. Barriers to Medicaid patients gaining access to nursing homes are still very strong in many locations. In areas where the demand exceeds the supply, nursing homes continue to deny admittance to most Medicaid patients whether they are heavy or light care. Most private pay patients ultimately "spend down" and convert to Medicaid status. Thus, the preponderance of Medicaid patients among the nursing home population continues despite selective admission policies of some facilities.

There was no direct evidence in this service delivery assessment that nursing homes actually evict patients when they convert from private pay to Medicaid. There is some evidence, however, that nursing homes do try to get rid of their most difficult patients, e.g., the behavior problems. Although most homes reportedly make efforts to keep these difficult patients, many homes medicate or restrain them or cluster them in special wings. When getting rid of problem patients, homes frequently have them readmitted to acute care hospitals, transfer them to state mental hospitals or transfer them to another nursing home.

Accessibility is also a problem with many community-based services. For example, home health agencies are not in short supply in many areas and may even be in surplus. But home health care is not provided in unlimited amounts under either Medicare or Medicaid. In many states, Medicaid has simply applied the Medicare requirements which means that a client cannot get services even if permanently homebound because the need for "skilled" care is not documented. Some states have added requirements for prior authorization under Medicaid which discourages many home health agencies from dealing with Medicaid at all.

Appropriate Placements

There are times when it is appropriate for a person to be placed in a nursing home, and other times when such a placement is inappropriate even for an individual with identical medical and functional limitations. What makes the difference is the existence of appropriate support systems, be they "natural supports" of relatives and friends or supports created by caseworkers, home health aides, chore workers or others.

Sixty percent of the study participants who addressed the issue believe that less than 30% of patients already living in a nursing home could be placed in a less restrictive setting if necessary support were available. Additionally, 47% said they believe that less than 30% of patients going into nursing homes could be diverted to a less restrictive setting. This may indicate that prescreening and channeling programs are effectively diverting some current placements and/or that patients are sicker at time of admission to the nursing home (and that their independence improves while in the nursing home).

The Woodwork Factor

Appropriate placement hinges on the presence of options—institutional versus non-institutional care, nursing homes versus community services, formal versus informal support systems. A full continuum of formalized community-based services is in short supply throughout the country. Three out of four study participants believe that increased federal contributions to community-based services will result in the woodwork factor. That is, people who have been dependent on family or friends for help plus others who have received no help would "come out of the woodwork" requesting such services unless effective control mechanisms were imposed.

The appropriateness of a service, therefore, takes on a new dimension. If a person is getting adequate care from an informal support system, i.e., family and friends, then it is not appropriate to provide that person with a full array of chore workers, home health aides and transportation assistants who will displace the family and friends. On the other hand, respite will be appropriate for some families to keep them from burning out and giving up.

Client Assessment and Case Management

Assessment tools are used to help providers gain a detailed, comprehensive picture of a client's situation, which in turn suggests the etiology of a problem and the type of plan needed. They are also used to monitor changes in a client at risk over time, with or without provision of long term care services. A single assessment tool may not be able to do all these jobs well.

Case management is a major missing ingredient in the long term care system. Study participants clearly viewed it as "catch as catch can" in their communities. Where case management exists at all, it is described as an "informal" and "hodge-podge" system and applied primarily to Medicaid patients. Medicare and private pay patients reportedly have to rely on their families or an interested staffer in one of the service agencies. Except for the long term care experiments and demonstrations, the approach generally is haphazard at best. As one home health agency registered nurse summarized, "The problem is there's no reimbursement for case management. Since it's expensive and time consuming, no one really does it."

Hospital Discharge Planning and Nursing Home Admissions Practices

The roles of hospital discharge planners and nursing home admissions directors are key to the issues of access and appropriate placement. Although some study participants expressed no concerns about placement practices, many were critical. A hospital discharge planner summarized the views of many, "We place too much emphasis on getting patients out. We place less emphasis on planning. This results in recycling patients back in. All this inappropriate placement costs Medicare more, but not the hospital."

The major complaints among study respondents of the client placement processes are that:

- Nursing homes discriminate against Medicaid patients, especially those requiring heavy care.
- Nursing homes accept private pay patients who should remain in community-based settings.
- Hospitals discharge many patients prematurely, because of utilization review pressures.
- Many discharge planners are poorly trained as well as inexperienced in and/or biased against community based services.
- Most doctors do not cooperate with discharge planners.

QUALITY ISSUES IN NURSING HOMES

Although the quality of nursing homes appears to vary dramatically--"from atrocious to excellent"—reports of outrageous patient abuse, neglect or mistreatment were isolated. In general, study respondents feel that the quality of nursing homes has improved significantly in recent years. Yet cases of fraud continue to surface and state ombudsmen report receiving substantial numbers of documented complaints. Overall, however, the image that most people have of nursing homes is probably worse than the reality. Discussions of quality in nursing homes focus largely on three factors—staffing, regulations and the indignities of institutional life.

Staffing in Nursing Homes

Nearly all nursing home providers (87%) report significant staffing problems. Comments focus primarily on administrators, registered nurses (RNs), aides and physicians. Administrators and supervisors are considered crucial to establishing an overall commitment to quality care within a facility and motivating staff to perform unpleasant tasks. Most of an RN's time is spent on paperwork and supervising the aides. Patients are reported to receive an average of only 12.5 minutes of direct care from an RN every day (Geriatric Nursing, 12/80, p. 216). Most of the "hands on" care in nursing homes is provided by aides. Whereas RNs comprise only 10% of the workforce, aides represent 66% of all nursing homes employees. Aides tend to have limited training and prior experience in health services and relatively little formal education--34% have not completed high school (National Nursing Home Survey, 1977, pp. 17, 22).

- Lack of physician involvement. Physicians were heavily criticized for their lack of attention and sensitivity to patients in nursing homes, as well as a general disinterest in geriatric medicine and chronic disease. Physicians rarely follow their patients to nursing homes, especially if they are on Medicaid. A small group of physicans or the medical director usually assume responsibility for most of the patients in a facility. Visits are often seen as perfunctory at best, i.e. "gang visits."

- Difficulty recruiting and retaining staff. A severe national shortage of RNs has hit the nursing home industry especially hard. DOL statistics project the shortage to be over 140,000 for nursing homes alone (Geriatric Nursing, 12/80, p. 216). Excluding the Pacific Northwest where the RN shortage does not appear to be quite as severe, 88% of the nursing home providers reported difficulties recruiting RNs. "We take any RN who breathes." (Administrator) Nursing homes are increasingly relying on expensive nursing registries to fill temporary vacancies. Use of pool staff is widely critized because these nurses are unfamiliar with a facility's routines and procedures, have no loyalty to the patients, disrupt continuity of care and can be twice as expensive.

  Whereas the major issue with RNs is finding them, the major issue with aides and other nonprofessional staff is keeping them. High staff turnover disrupts continuity of care and disturbs patients. Turnover in nursing homes is reported to be one of the highest for any industry in the country. One state set a standard that turnover not exceed 234% per year. Although 90% of the facilities met this standard, only 16% showed an annual turnover of less than 156%.

  Many feel that the primary problem is that nursing homes cannot compete with the higher wages and broader benefits offered by hospitals. Furthermore, working in a nursing home has no prestige and can be very depressing. Employees are commonly regarded as people who are

unable to find jobs elsewhere. The most common image of the aide is a person who will work for minimum wage at one of the grungiest jobs imaginable. The string of adjectives commonly used by all types of participants to describe work in a nursing home creates a dismal litany: "stressful, exhausting, emotionally draining, thankless, unpleasant, unglamorous."

> "It's bad enough to clean your own baby's diaper. Think of doing it for some smelly old person who isn't even nice to you, and doing it four or five times a day." (Union official, as quoted in Vladeck, 1980, p. 20)

- Training. Strong emphasis was placed on the need for both professionals and aides to receive more training and exposure to geriatric medicine and the needs of the chronically ill. The hospital continues to be the primary training ground, but there is little emphasis on the dynamics and pathology of aging. Many states now mandate at least some training for aides. Although training has good results, it is costly, and turnover remains high.

Massive regulations are no guarantee of quality.

There was a strong message from many participants that while some regulation of nursing homes is clearly needed, governments at all levels have "gone overboard" in their attempts to assure quality through regulation. Several participants said that only one industry in this country is subject to more regulation than nursing homes—the nuclear power industry. Nursing home operators called the licensing and survey process "a farce", "nightmare", "counter productive", "pain in the ___", "performed by incompetent ding-a-lings", "professionals who have forgotten how to be human" and "arrogant nit-pickers" engaged in a "redundant", "duplicative", "highly subjective" activity in which providers are "judged guilty until proven innocent".

- Too much emphasis on the physical plant, rather than actual patient care. Regulators are thought to have lost sight of their goals and to be preoccupied with structural aspects such as the width of doors and the size of baseboards. "You can meet almost every HCFA regulation and not have a single patient in a nursing home." (State official)

  Nursing home participants were especially critical that they are subject to much more structural scrutiny than either hospitals or boarding homes. Noted the director of a public nursing home: "We tried to license some nursing home beds in a hospital that had empty beds. It was an intensive care neurology wing. The hospital was getting $236 a day per bed. Medicaid would have paid $27 a day. We were told we would have to do tremendous upgrading of the wing to get it licensed as a nursing home. Now that's incredible."

- Regulations focus on paper, not patients. Most participants emphasize that the regulatory process has evolved into a paper-ridden exercise which often has little bearing on the actual quality of patient care. Survey teams spend little time talking with patients, their families and staff. Notes a nursing home administrator: "In 1973, our survey lasted one day. The surveyor spent two hours in the office and the rest of the day with patients in the wards. In 1981, the surveyor was here for seven working days, spent 6-1/2 days in the office, and spoke with six patients on the last afternoon."

- Regulatory process does not distinguish between "good" and "bad" facilities. Because inferior homes are reported to meet the paperwork requirements about as easily as homes reputed to deliver superior care, many feel that regulations in such detail and volume are largely irrelevant. Facilities with good reputations and a proven track record should not be subject to the same intensity of surveys and inspections as those with more questionable reputations. "Ease off on the good ones and clobber the bad ones." (State official)

- Difficulty of closing poor quality homes. State licensing and survey teams are generally understaffed and overworked, the tools they use are not their own creation, and the survey/licensing responsibilities frequently are vested in more than one agency, making coordination and consistent interpretation of regulations very difficult. Furthermore, many urban areas are experiencing critical nursing home bed shortages. Officials are said to overlook infractions because there is simply no place to put patients if a facility is closed. In addition, the process for terminating agreements and closing facilities is costly, lengthy, cumbersome and subject to political pressure.

- Public accountability and access to nursing homes. Many noted that quality improves in direct ratio to the de ee of public scrutiny of a facility.

Quality of Care Versus Quality of Life: The Indignities of Institutionalization

Experts express concern about both the medical and psycho-social aspects of nursing home care. Although there was also some concern among study participants about the quality of medical attention in nursing homes—primarily the inappropriate use of medications—a far greater number expressed concern over the lack of sensitivity to the emotional and social needs of patients. Nursing homes are characterized as "impersonal", "boring", "over-medicalized", "sterile" and "too much like hospitals". A more holistic approach, incorporating the medical, social and emotional needs of patients, is needed. "Most of these homes try very hard to keep the patient clean and provide the medical care, but they are not places for someone who is still alert." (Hospital discharge planner)

Even the best nursing homes are still institutions and there are many drawbacks inherent to institutional life. The major complaints of regimented life in an institution include loss of independence, individuality, privacy and dignity. Patients cannot eat when or what they want. Dressing, bathing and even toileting are often on a set schedule. Patients tend to look and act alike—passive, resigned and docile. Furthermore, a nursing home can be a very lonely place, especially for the mentally alert patient who is thrust into a population that is largely senile. Noted a stroke victim: "There's only one other person I can talk to here. I've still got all my marbles, but the rest are veggies. I read a lot—that's what keeps me going."

QUALITY ISSUES IN C MMUNITY-BASED CARE

With the exception of boarding homes, participants were more preoccupied with the availability of community-based care than with its quality. Some suggest this is because community-based care is in its infancy and has not been subject to the same degree of public scrutiny.

Boarding homes. In some regions, especially the East and Southeast, boarding homes are regarded as a public scandal. An inquiry from the Attorney General's office in one state concluded: "In a number of facilities, the living conditions offend basic decency and endanger the well-being and health of residents." Many states only recently have begun to license boarding homes. Even then, regulations are said to be incomplete, vague and unenforceable. In one city, only 52 of more than 1,000 boarding homes have been licensed since the law became effective in June 1980. Fewer than five homes have been closed, despite an abundance of horror stories. Boarding homes have become a dumping ground for deinstitutionalized mental patients. Part of the problem in closing these facilities is that there is nowhere else for residents to go. Many respondents emphasized that nursing homes will not accept most clients living in boarding homes.

Other community-based services. As with nursing homes, there were isolated examples of abuse or neglect, but most felt that the quality of life for clients appropriately placed in the community is superior to life in an institutional setting. For the most part, the longer someone can remain in familiar surroundings, maintain a degree of independence and a normal routine, the better his emotional, mental and physical health will be. Community-based care offers a much greater opportunity for preserving family ties and a social network as well as contact with the community.

- Staffing. Staffing is also a problem in community-based agencies, but not nearly to the degree as in nursing homes. It is easier to attract both professional and nonprofessional staff because wages and benefits are often higher, the hours are better, the jobs are less physically demanding and the clients are generally healthier, happier and more alert. As with nursing home employees, participants stressed the importance of special training for both professional and nonprofessional staff.

  Some suggest that community-based, nonprofessional staff are of a higher caliber than in nursing homes because agencies can be more selective, while others feel that the problems are the same, just less visable because there are fewer employees and nursing homes have been subject to much more public scrutiny. Because choreworkers, home health aides and other nonprofessional staff are not supervised nearly as closely as their counterparts in nursing homes, some participants see a potential for problems with abuse, neglect and errors in judgment. "It's hard to police people working in individual homes." (Health expert)

- Monitoring medications. Misuse or abuse of drugs is seen as a more serious problem for people living at home than in nursing homes. Often prescriptions are not re-evaluated frequently enough, there is no assurance that medications are being taken in accordance with the doctor's orders and there is little monitoring for adverse drug reactions. Patients with chronic problems frequently go from doctor to doctor seeking relief, so they may have several medications for the same problem. Day health centers report this as a major problem. "I make all our clients bring all their pills in once a month so I can see what they're taking, and I've had them come in with shopping bags full of pills. Half my clients don't know what they're taking." (Day health director)

- Inadequate supervision and monitoring of clients. A day health director noted: "Our patients don't require 24-hour supervision, but many need 20." For many elderly and disabled clients, even a daily visit is not enough to assure safety, adequate nutrition and the monitoring of medications. It is common for elderly people to forget to turn off a stove or put out a burning cigarette. Since few service providers work on weekends, many clients must fend for themselves. Isolation of chronic patients is also a common concern. Noted a nursing home RN: "We had one patient we thought could move to a retirement home. One month later they found her in her beautiful room curled up in a ball." Community-based services do not always keep pace with a client's deteriorating health status. Family, friends and service providers without professional health training do not always recognize the early stages of a serious problem, thus delaying medical intervention. Families often resist a nursing home placement longer than they should, to the detriment of both patient and family.

- Inadequate coordination, resources and case management. Inadequate screening, patient assessment, case management and interagency coordination often mean that services do not match a client's needs. Most people with chronic health problems require more than one service. Hospital discharge planners note that most of the services must be in place immediately—waiting lists do not work.

- Lack of standards, licensing and monitoring of community-based agencies. In contrast to the consensus that nursing homes are over-regulated, participants are concerned that licensing and regulation of community-based agencies are minimal or nonexistent. This is a special concern in light of anticipated rapid growth in community-based services.

Impact of ownership and management of long term care services on quality of care.

There is a trend toward increased proprietary ownership and the growth of national chains, especially in the nursing home and home health industries. There is no clear consensus, however, as to whether this is having a positive or negative impact on quality. Some participants argue that chains place too much emphasis on profit, thereby providing only minimal care. Others argue, however, that chains have the benefit of better management, efficiency and economies of scale and can hire better trained and specialized staff.

APPENDIX: ADDITIONAL INFORMATION
PATIENT/CLIENT SAMPLE

Patients in Nursing Homes

Discussions were held with 80 nursing home patients or their families. Nearly all the patients had fairly serious physical disabilities, but were mentally alert enough to participate in a thoughtful discussion. Nearly one-half (47%) reported they were private pay patients, and 50% were on Medicaid. Medicare was paying all or part of the bills of 10% of the patients. Nearly three-fourths (72.8%) were in their 70s and 80s. Prior to admission, one-third had used some type of community-based service. Only 13% felt they might be able to be cared for in a less restrictive environment, and several of these said they would require 24-hour care. Ninety-eight percent regarded the nursing home as their primary residence. Half were living alone when they entered the nursing home, and 93% said they had no surviving spouse. Seventy percent had family living in the immediate community. More than half (58%) reported they have regular visitors at least once a week and another 16% said they receive visitors at least once a month. Nearly all those who reported they seldom or never have visitors also indicated they had no relatives living nearby.

Most patients reported that they entered the nursing home because they could no longer care for themselves at home, had become too much of a burden on relatives, or their spouses died. The most common factors influencing the selection of a particular home were its reputation and proximity to relatives. Other important factors include the staff, religious or fraternal affiliations, appearance, cleanliness and a homelike atmosphere.

Fifty-eight percent of the patients or the families of patients expressed positive feelings about their experiences with nursing homes, 17% were neutral and another 25% were negative. Many said that they didn't like having to be there, but saw no other alternative given their physical condition and inability to live alone. Most of the suggestions for improving life in nursing homes focused on loneliness, inattention from staff and the desire for privacy and better food.

Ninety percent expressed positive feelings toward the staff in their nursing facilities. Words used to describe the staff included "friendly, helpful, very cooperative, interested, understanding, exceptionally good, respectful," and "some of the nicest people you'd ever meet." A few said their care would be better if they received more attention from the staff.

A sampling of comments illustrates the range of patient and family reactions to their nursing home experiences:

- "They treat me like one of the family." (Patient)
- "Any attention we need, we get." (Patient)
- "It is kept clean like home, but it's not home." (Patient)
- "I get bored and the days seem endless." (Patient)
- "I'm not really adjusted to being here, but sometimes something nice happens." (Patient)
- "I hated to give up my belongings. I worked all my life and valued my independence. I cried for the first 1-1/2 years I was here." (Patient)
- "It is a pretty shattering experience when you are faced with the reality of putting a loved one in a nursing home. It's been a long, hard summer." (Family)
- "Financially and emotionally it's cleaned us out." (Family)

Clients in Community-Based Care

Discussions were held with 60 clients or the families of clients receiving a range of community-based services. Nearly two-thirds (63%) were in their 60s and 70s. Three quarters were women, and 42% were living alone. Over half (54%) said they could not continue to live in their current residences without these services. Very few, however, had any idea where they would go if the services were discontinued. One fiftn of the clients had been in a nursing home in the last five years.

Clients who were receiving services that enabled them to remain in their own homes were universally grateful. Clients in boarding homes and other congregate living facilities had some complaints, but preferred this to a nursing home. Very few felt they needed additional services or had suggestions for improvement. Some typical comments:

- "These adult day health centers are like a second home—like a big happy family. Many of these people would go to nursing homes if they couldn't come here. That would be a tragedy." (Female, 76 years old)
- "I love it here. I would be ungrateful to complain about anything. It would be very hard and lonely to be at home without these services." (Client in day care)
- "Before I started coming here, I was always afraid. I'd go nuts with depression." (Client at senior center)
- "She was so unhappy and bored. It was becoming intolerable, and I was so tied down. This gives her an out and lets her associate with folks her own age." (Family of client in day health)

Clients emphatically do not want to go to nursing homes. More than 75% said they hadn't even considered such a move, and most of the others stressed they would resist this as long as possible. "I hope the good Lord takes me before that happens. I will fight to the last before I go to a nursing home." (Client). Of the 13 who had been in a nursing home, only one reported a positive experience. Some typical coments from clients:

- "A very lonely place. People deteriorate there."
- "It makes you listless. You don't care about life."
- "I'd do most anything to avoid it again."

A theme that was common among elderly participants both in and out of nursing homes was that they do not want to live with their children.

- "It isn't good to mix three generations—too much confusion."
- "I don't want to live with one of the kids. I don't think I could stand it, and it isn't right anyway."
- "I didn't want to live with my kids. I would have been lonely with them."

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