NEW DIRECTIONS

FOR STATE LONG-TERM CARE SYSTEMS

Second Edition

by

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Acknowledgments

The author would like to thank the many state officials who were extremely helpful and wonderfully patient in providing information on their state long-term care systems. I am also grateful to PPI's Sharon Hermanson and Natalie Graves Tucker for their valuable contributions to the report. I appreciate the thoughtful review of the paper by Donna Folkemer, Wendy Fox-Grage, Carolyn French, Enid Kassner, Glenn Koocher, and Robert Mollica.

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Foreword

Publicly funded long-term care in the United States today consists of 50 different state and five U.S. territory systems that vary considerably in services, financing methods, and eligibility standards. In the absence of a national long-term care program, the states continue to be the major decisionmakers in long-term care: setting policies, regulating care, and controlling resources.

Until the 1990s, a state's long-term care system consisted largely of care in a nursing home. States are required to help pay for nursing home care for Medicaid-eligible adults and those who become eligible after they have depleted their assets paying for such care. Although states are not obligated under Medicaid to offer home and community-based care, changes in federal Medicaid policies in recent years have allowed the states more flexibility, and thus have encouraged states to expand home and community-based care services. A number of states have also allocated significant state general revenue funds for home care services.

Medicaid is the largest public source of long-term care expenditures. About 76 percent of Medicaid long-term care spending covers care in institutions — nursing homes and intermediate care facilities for the mentally retarded. Many states have been looking for ways to control the rapidly rising costs of such care, and to offer alternative forms of long-term care. Several states have been notably successful in developing balanced and comprehensive long-term care systems that include nursing home care, residential services, and home care services.

This report revises information presented in the 1996 AARP publication, *New Directions for State Long-Term Care Systems, Volume 1: Overview*. Material in the original report has been updated or replaced by more recent examples of state long-term care systems. New sections have been added on state demonstration projects to integrate health and long-term care services and state programs for consumer-directed care.

States serve as laboratories for reform. States that have revamped their long-term care systems to provide a range of options for consumers contribute ideas and information to other states. The challenge for researchers is to help fill the gaps in knowledge about the most effective state strategies for developing comprehensive long-term care systems. The challenge for states is to provide consumers with affordable quality long-term care in the home, the community, or in nursing homes.

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Executive Summary

Background

The country's long-term care system is actually 50 different state and five U.S. territory systems. In the absence of a national long-term care program, states have developed their own long-term care programs and services, using federal Medicaid and Older Americans Act funds and state general revenues.

The largest source of public funds to pay for long-term care is the Medicaid program. In 1997, 35 percent of total Medicaid expenditures went to long-term care services. During the late 1980s, Medicaid long-term care costs grew at a rate of 20 to 25 percent a year. Since more than four-fifths of that spending had been going to nursing home care, states began taking a hard look at how they could control the rate of increase in these expenditures.

Many state officials believe they can restrain the growth in publicly funded nursing home costs by expanding home and community-based care (HCBC) services. These officials reason that many persons enter nursing homes because of a scarcity of other care options, not because they need skilled nursing care. States believe they can provide HCBC services at a lower cost per capita than they would spend for nursing home care. Long-term care recipients also prefer home to institutional care, according to surveys, giving states another incentive to augment HCBC services.

Purpose

A number of states have demonstrated that a state's long-term care system can be transformed from almost total dependence on nursing home care to a more comprehensive system that offers a variety of care options. This report provides information on these long-term care models to encourage similar efforts in other states.

States learn from each other. State officials frequently exchange ideas and strategies with each other. This report is intended to contribute to that process. Another goal is to help consumers understand the key components of state long-term care systems and how those elements need to be linked to create a comprehensive range of service and financing options. This information can help consumers advocate in their states for the development or expansion of long-term care options so that more people will be able, if they wish, to remain in their homes and communities as they age.

Methodology

The report draws on the programs and experiences of a number of states that have been leading the way in recent years in building comprehensive long-term care systems. The emphasis of this report is on "comprehensive" systems because limited reforms, such

as controls on the expansion of nursing home beds, can create greater difficulties for people seeking long-term care if other service options are not available.

The author selected the states featured in this report mainly to be illustrative of various approaches to organizing, financing, and delivering long-term care services. Oregon is highlighted frequently throughout the report because the state was the first to envision and develop a long-term care system based primarily on the theory that people wanted and should be offered "the least restrictive setting" (the state's term) for their care. The result in Oregon has been the growth of a wide range of in-home and community services for persons needing long-term care.

The other states discussed in this report demonstrate a specific strategy for organizing their long-term care systems or a new direction for their long-term care programs and services. The author also selected states from different regions of the country, from large and small states, and from rural and urban areas.

The author collected information for the report from state annual reports, from telephone interviews with state officials, and from other state summaries on specific programs. The report also draws extensively on Medicaid expenditures data reported by the states to the US Health Care Financing Administration, as compiled by Brian Burwell of the MEDSTAT Group in Cambridge, Massachusetts.

Principal Findings

From 1987 through 1997, Medicaid spending on home and community-based care services rose from about $2 billion to $13.6 billion — more than a six-fold increase. Over the same period, Medicaid expenditures for institutional care (nursing facilities and intermediate care facilities for the mentally retarded) slightly more than doubled from $19 billion to $40.8 billion.

Over this decade, many states adopted comprehensive long-term care plans that called for developing, expanding, and coordinating home and community-based services as alternatives to nursing home care. The following are examples of state strategies that many states have combined to create long-term care systems that respond to consumer needs and demands.

- In 1995, 45 states regulated the growth of nursing home beds either through a certificate of need process, a moratorium, or both. Many states also restricted rate reimbursement increases and controlled access to nursing home care.

- While home and community-based care claimed only a 10 percent share of Medicaid long-term care dollars in 1987, that percentage had increased to about 24 percent in 1997. States used federal Medicaid and Older Americans Act funds and state general revenues to expand home and community-based care services.

- States have moved toward a single state agency approach to managing and operating all home and community-based care services regardless of funding source. This consolidation helps to reduce the fragmentation that resulted from having long-term care services scattered throughout state government.

- Many states have created single entry point agencies at the local level for screening, assessment, and care management to help consumers identify the most appropriate services for their needs and help arrange the services.

- States are encouraging the development of supportive residential housing for older persons such as congregate housing, board and care facilities, and assisted living facilities.

- By 1998, two states (Minnesota and Texas) had initiated demonstration projects to integrate acute and long-term care services and financing for persons dually eligible for Medicare and Medicaid. Several other states have been developing plans for such projects.

- States have provided funds to persons with disabilities to manage their own care through self-directed care programs.

Conclusion

Many states are broadening the scope of publicly funded long-term care services beyond traditional and costly nursing home care in an effort to control the growth in Medicaid long-term care spending and to offer consumers greater choice of services. States are also consolidating formerly fragmented programs into more easily accessible financing and delivery systems.

Evidence of these shifts comes from rising Medicaid and state expenditures for home and community-based services and structural changes in state management of long-term care programs and services. Still, progress in building comprehensive long-term care systems at the state level has been slowed by gaps in the research about the most cost-effective strategies. These gaps leave many policymakers reluctant to increase spending too rapidly on HCBC services. Some policymakers are uncertain about whether they will be substituting HCBC services for costly nursing home care or adding additional HCBC recipients while nursing home costs continue to rise.

Cost is a legitimate concern for advocates and consumers as well as policymakers and researchers. State models need to be tested, comparative studies need to be conducted, and outcomes need to be assessed. But a debate over costs could paralyze further progress in developing a rational long-term care system in this country. Many vulnerable people will go without services if cost effectiveness is the only issue.

States must move ahead in developing long-term care systems that offer a range of services in various settings so that the millions of people who need long-term care have access to the most appropriate and affordable services. Important lessons can be learned from the long-term care models that have *already* been developed. These models demonstrate a broad range of options that have been explored and implemented.

This report has sought to highlight some of these models. State officials must be willing to experiment and innovate as have the states mentioned in this report and others. At the same time, researchers need to continue their search for quantifiable data on cost-effective methods and successful outcomes.

NEW DIRECTIONS

FOR STATE LONG-TERM CARE SYSTEMS

I. INTRODUCTION

States have been facing tough budget and fiscal decisions in recent years. One of the biggest challenges has come from the federal-state Medicaid program, the major public source of funding for health and long-term care for persons of low income. In most states, spending on long-term care services comprises between 30 and 50 percent of total Medicaid expenditures.

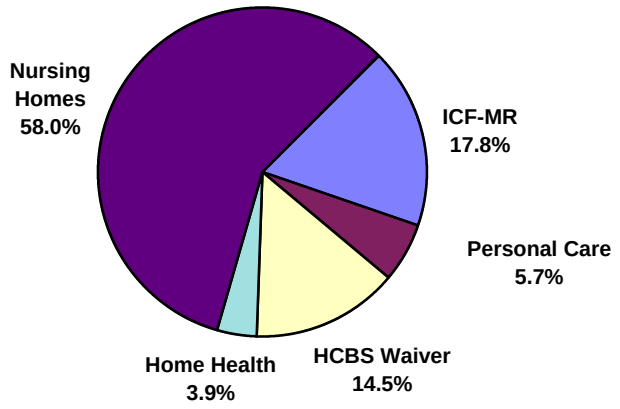
Medicaid has been one of the biggest and fastest growing programs in state budgets. Between 1988 and 1992, total Medicaid spending grew at over 22 percent a year (Holahan and Liska 1997). That spending growth has slowed; increases have averaged 9.5 percent each year between 1992 and 1995 (Holahan and Liska 1997).

While total Medicaid spending increased by only 4 percent from fiscal 1996 to 1997, Medicaid *long-term care* spending increased 9.3 percent over that period. That was the highest annual rate of growth in Medicaid long-term care spending since fiscal 1992 (Burwell 1998).

- Medicaid spent almost $56.1 billion for long-term care services in 1997, about one third of total Medicaid expenditures that year.

- About 76 percent of those Medicaid dollars ($42.5 billion) in 1997 went to nursing homes and intermediate care facilities for the mentally retarded (Burwell 1998). (See Figure 1.)

Figure 1
Medicaid Expenditures for LTC Services, 1997*
(Total Expenditures = $56.1 billion)



Source: Brian Burwell, The Medstat Group, 1998.
*Does not add to 100% because of rounding.

Nursing home care is costly. Many nursing home residents are severely disabled or cognitively impaired with high-cost care needs, and nursing homes have to be staffed and equipped for 24-hour care. However, home care advocates contend that other nursing home residents do not need skilled nursing home level of care and could be cared for at home. They also claim that home care can be much less costly because family and friends often provide the bulk of the care, perhaps supplemented with paid services.

State officials also point to cost savings in home care versus nursing home care. For example, Indiana officials estimated that Medicaid paid on average about $36,400 a year for a nursing home resident in 1996, compared to $8,122 on average for a person receiving home care services under a Medicaid home and community-based care "aged and disabled waiver"[1] program (Indiana Family and Social Services Administration 1997). Similarly, Maine officials said that the annual cost for a Medicaid nursing home resident was $22,570 in 1996, but only about $7,650 for a person receiving Medicaid services under the elder and adults waiver program (Maine Department of Human Services 1997).

It should be noted, however, that per capita costs may be much higher for certain groups of home care beneficiaries than in the examples noted above. For example, the annual Medicaid cost for an autistic individual receiving HCBC waiver services in Indiana was about $28,828 in 1997.) Although the amounts vary considerably from state to state and from one beneficiary group to another, all states spend less per capita for home and community-based care than for nursing home care.

Thus, states have a major financial stake in limiting construction of new nursing home beds, controlling the use of nursing home care, and promoting use of home and community-based care (HCBC). This has led a number of states to begin testing new and innovative ways to provide inexpensive, quality long-term care services for people in their homes or in residential settings, such as adult foster homes or assisted living facilities.

This report describes the steps a number of states have taken to begin revamping their publicly funded long-term care systems. Generally, this has meant controlling the growth of nursing home use while increasing expenditures for home and community-based services. But it also involves restructuring state long-term care financing and delivery systems to improve access to and coordination of services.

The report reviews efforts by states to:

- control spending on nursing home care;
- expand the use of home and community-based care services through the federal-state Medicaid program and state general revenues;

[1] States receive a waiver of certain Medicaid requirements to provide a range of services for persons who would otherwise require institutional care. "Aged and disabled" is one category of beneficiaries; others include persons with AIDS, persons with traumatic brain injuries, and technology dependent children.

- encourage the development of residential settings, such as adult foster care homes and assisted living facilities;

- consolidate and coordinate long-term care services and financing at the state level;

- create a single point of entry at the local level that, at a minimum, provides information and referral, screening, and care management;

- integrate health and long-term care services for persons eligible for Medicare and Medicaid through a managed care approach using capitated payment systems; and

- provide more opportunities for persons with disabilities to choose, purchase, or manage their own care.

II. CONTROLLING SPENDING ON NURSING HOME CARE

Background

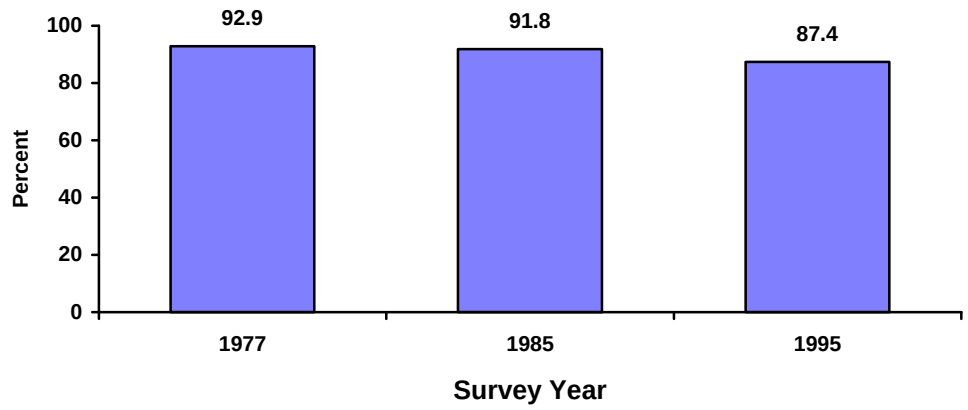
Each state's Medicaid program must pay for nursing home and home health care for eligible persons, and has the option to cover other long-term care services. Federal law provides that individuals can qualify for Medicaid assistance for the cost of nursing home care if their income and assets fall below specific state-set limits, and they meet state standards for medical, functional, and cognitive impairment.

The availability of Medicaid funding was a key factor in the growth of nursing home care in the 1970s and early 1980s. Other factors included the aging of the American population, shortened Medicare-covered hospital stays due to the introduction of the prospective payment system in 1983, and the lack of affordable alternatives.

The number of nursing homes increased from 15,700 in 1973-74 to 19,100 in 1985. But by 1995, the total had decreased by 12.6 percent to 16,700 facilities, as reported by the 1995 National Nursing Home Survey (Strahan 1997).

The Survey also reports a decline over the 1985-95 decade in the number of nursing home beds per 1,000 persons age 65 and over, from 56.9 beds per 1,000 in 1985 to 52.6 beds in 1995. Bed occupancy rates also decreased over the period, from 91.8 percent in 1985 to 87.4 percent in 1995 (Strahan 1997). (See Figure 2.)

Figure 2
Bed Occupancy Rates in Nursing Homes



Source: Centers for Disease Control; National Center for Health Statistics.

State Strategies

States have various options for controlling nursing home growth. States can limit the number of nursing home beds that are available, or they can tighten the eligibility requirements for Medicaid coverage of nursing home care — or they can do both. But if they adopt these strategies without also developing home care services or supportive housing, people who need formal long-term care services and public dollars to pay for services could be left without any assistance.

A. Restricting the growth of nursing home beds

Certificates of need and moratoria -- States can require nursing homes to obtain a certificate of need (CON) that demonstrates a need for additional beds before they can build a new facility or expand the number of beds in an existing facility. States can also impose a moratorium on new bed construction. In 1996, 45 states regulated the growth of nursing homes or nursing home beds either through a certificate of need requirement, a moratorium, or both (Anderson and HCIA 1996).

A recent study looked at the effect of state certificate of need and moratoria policy on change in nursing home bed growth over a 13-year period from 1981 through 1993. The study found that while some states had high bed growth rates over this period (such as Florida, New Mexico, and North Carolina), other states had little or no bed growth (including Colorado, Minnesota, Oregon, and Wisconsin). The study was able to show, the researchers said, an association between CON and moratorium restrictions and lower growth in bed stock (Harrington et al. 1997).

Controlling the use of beds – A number of states have been offering incentives to nursing homes to develop new uses for some of their beds, or take beds out of circulation ("bank" the

beds) for a time. For example, the Nebraska legislature passed a bill in April 1998 to create a $40 million trust fund for loans and grants to nursing homes willing to convert units to assisted living or to build new units for that purpose. Maine provides another example:

- To encourage nursing homes to convert beds to a residential level of care, the Maine legislature in 1996 eliminated the requirement that nursing homes obtain a CON for this shift in the use of the beds. (A "residential level of care" in Maine refers to facilities that provide personal care services, such as boarding homes, rather than a nursing home level of care.)

- The legislature also allowed nursing homes to bank unused beds and then bring them back into operation under an expedited CON approval process if the facility could later show need for the beds. (Maine bases its nursing home reimbursement rate on a 90-percent-or-higher bed occupancy level, giving facilities with lower occupancy rates a financial incentive to bank the unfilled beds.)

B. Restricting access to nursing homes

Expanding preadmission screening to all nursing home applicants — Most states screen Medicaid applicants to nursing homes to ensure that the applicants meet the state's financial, medical, and functional eligibility standards for Medicaid coverage of their care. In recent years, some states have extended the preadmission screening process to private-pay individuals. State officials reason that people who pay their nursing home bills out of pocket will exhaust their resources within a short period of time because of the high costs of nursing home care. Those individuals might then qualify for Medicaid coverage. If the screening process determines that a person's needs could be met through home care services, the state can then advise the person of alternative home and community-based care services.

It can be politically difficult for a state to institute mandatory preadmission screening for all nursing home applicants. States want to adopt such systems as a way of directing persons to home and community-based care services if screening and assessment of need determines that the individual does not need nursing home level of care. Nursing home providers in some states have opposed mandatory preadmission screening as taking away from individuals their right to choose nursing home care if they are willing and able to pay for such services. Some providers have also contended that many persons cannot be safely cared at home despite the findings of the assessment procedure.

Illinois is an example of a state where controversy arose over the imposition of a mandatory preadmission screening process. In 1995, the Illinois legislature mandated a preadmission screening process for all nursing home applicants age 60 and over, regardless of income. Individuals retain the right to choose nursing home care, even if the evaluation does not substantiate a need for that level of care. However, if after entering a nursing home, an individual exhausts his or her resources and still fails to meet the Illinois Medicaid standard of impairment, the individual could then be denied Medicaid coverage (Illinois Department on Aging 1996 and 1998).

The Illinois law went into effect on July 1, 1996. The state nursing home industry tried unsuccessfully in 1996 to get the law repealed. In its first annual report on the screening program, the state reported that the average monthly Medicaid nursing home caseload dropped by 1,053 residents from FY 1996 to FY 1997 (Illinois Department on Aging 1997).

C. Rate-setting arrangements

Each state sets its own Medicaid reimbursement rates for nursing home care, which gives states options for managing or restraining spending growth. A state can freeze rates or peg increases to a national index of nursing facility cost increases, although these are generally short-term strategies that cannot be continued indefinitely. Forty-six states used varying prospective payment methods in 1996 that set rates in advance, by setting a flat rate for groups of facilities or groups of clients or by setting rates for each facility based on historical costs and other factors. One state (Nebraska) used a retrospective reimbursement system that pays nursing homes for the costs incurred in the previous year. The remaining four states used a combination of prospective and retrospective systems (Harrington et al. 1998).

Within these reimbursement systems, many states use case-mix reimbursement methods that base a portion of the total reimbursement rate on direct resident care costs.[2] A higher rate is paid for a resident who requires more nursing care than for a resident who requires less care. Use of case mix methods does not necessarily lead to cost savings, but is believed to be useful in influencing nursing homes to accept individuals with higher levels of disabilities.

If nursing facilities objected to a state's Medicaid reimbursement policies, the facilities could sue the state under the terms of the Boren Amendment. This law required states to set reasonable and adequate reimbursement rates for nursing homes that were operating efficiently and economically.

The Balanced Budget Act (BBA) of 1997 repealed the Boren Amendment. Governors fought for repeal to give them greater flexibility to slow the rate of growth of nursing home reimbursements. However, the impact of repeal is not yet clear. States must provide justification for the rates they set for nursing homes, publish the proposed rates with an explanation of the methodology used, and give the public reasonable opportunity for review and comment.

Advocates for nursing home residents also have two major concerns about repeal of the Boren Amendment: 1) facilities that are forced to tighten their budgets may reduce expenditures for direct patient care, thus lowering the quality of care, and 2) nursing homes might try to attract more private-pay applicants, thus limiting access by poor persons.

[2] Direct care accounts for between 40 and 60 percent of the total reimbursement rate. The remainder includes capital costs and indirect costs, such as laundry and general administration.

Selected State Examples

The following describes the actions by two states to slow the number of admissions to nursing homes and thus slow the rate of growth of spending for nursing home care.

Oregon

Oregon public officials and advocates have long contended that, if a state provides a sufficient number of home and community-based care alternatives to nursing home care, individuals and their families will overwhelmingly choose those alternatives. If that happens, state officials say, fewer people will enter nursing homes, and the number of nursing home beds will shrink — without the state's needing to take drastic actions to curtail nursing home use.

In 1982, the state adopted the principle that nursing homes were to be placements of "last resort." During the 1980s, the state developed a number of home and community-based care programs, from assisted living to adult foster care to home care programs. The state combined a number of strategies, which included:

- Gaining approval from the federal government for the first Medicaid waiver that allowed the state to provide a range of Medicaid home and community-based services to persons at risk of having to enter a nursing home.

- Implementing a statewide system of screening for all nursing home applicants — private-pay as well as publicly funded applicants to ensure that they needed nursing home level of care.

- Using the certificate-of-need system to set a target range for nursing home bed capacity from 35 to 45 beds per 1,000 persons age 65 and older. The range allows for variations in demand factors in different regions of the state. In 1996, the ratio of nursing home beds per 1,000 was 32.4, one of the lowest ratios in the country.

In 1980, the number of Medicaid residents in Oregon nursing homes totaled about 8,000. In 1996, that total had dropped to about 7,100. (Over the same period of time, the number of Oregonians age 85 and over had increased by over 40 percent.) The number of nursing home facilities dropped from 193 in 1981-82 to 161 in 1995 (Graves and Bectel 1996; Kutza 1993).

At the same time, Oregon encouraged the development of alternative residential settings for people needing supportive housing, such as adult foster homes and assisted living facilities. Today, about 5,000 Medicaid beneficiaries live in adult foster homes out of a total of about 15,000 persons in about 6,500 homes; another 1,000 Medicaid beneficiaries live in about 50 assisted living facilities. (The state's Medicaid home and community-based waiver programs cover the costs of services for the Medicaid beneficiaries in these residential settings.)

The state spent $153.9 million for Medicaid coverage of nursing home care in fiscal 1992. Nursing home care expenditures have risen by only 2 to 3 percent over subsequent years,

with the fiscal 1997 amount ($169.2 million) 2.6 percent over the fiscal 1996 total ($164.9 percent). Nationally, Medicaid nursing home costs rose between 7.2 percent and 7.9 percent from fiscal 1993 through fiscal 1995, dropping to 2.2 percent between fiscal 1995 and 1996 and then increasing by 4.8 percent between fiscal 1996 and 1997 (Burwell 1998).

Maine

A 1993 budget crisis forced Maine to review its long-term care spending patterns. The governor and legislature agreed that one major step would be to cut nursing home admissions by 10 percent. The strategy involved:

- targeting nursing home services only to people with the most severe disabilities or medical needs;
- providing incentives to nursing homes to convert some beds to lower levels of care;
- increasing appropriations for home care services; and
- developing additional residential care beds (Goldberg, Fralich, and Pears 1996).

As shown in Table 1, Medicaid expenditures for nursing facilities dropped from $240 million to $202 million and the number of Medicaid residents declined by almost 1,000 from fiscal 1995 through fiscal 1997. Over the same period, spending on the Medicaid home and community-based "elder and adults" waiver program increased by over $3 million. An additional 2,028 persons received home care services under the two waiver programs and two Home-Based Care programs from 1995 to 1997.

Table 1
Maine Long-Term Care Expenditures FY 1995 & 1997

	FY 1995			FY 1997		
	Total Expenditure	**Clients**	**Per Capita Cost**	**Total Expenditure**	**Clients**	**Per Capita Cost**
MEDICAID						
Nursing Facilities	$239,648,555	9,945	$24,097	$202,292,500	8,963	$22,570
Residential Care	$16,711,742	2,174	$7,687	$24,555,594	3,017	$8,139
Waiver: Physically Disabled	$1,993,971	183	$10,896	$5,062,143	269	$18,818
Waiver: Elder & Adults	$7,080,916	1,052	$6,731	$10,272,214	1,343	$7,649
GENERAL FUND						
Home Based Care: Elder & Adults	$4,671,076	1,296	$3,604	$6,747,308	2,899	$2,327
Home Based Care: Physically Disabled	$1,475,077	125	$11,801	$2,484,207	173	$14,360

Source: Maine Department of Human Services, 1998.

III. EXPANDING HOME AND COMMUNITY-BASED CARE SERVICES

Background

National spending for Medicaid-financed home and community-based care (HCBC) services (home and community-based waiver services, personal care, and home health) totaled $13.5 billion in fiscal 1997 — more than double the $5.8 billion Medicaid spent on these three services in fiscal 1992 (Burwell 1998). The $13.5 billion was composed of:

- $8.1 billion (60 percent) for home and community-based care waiver services,[3]
- $3.2 billion (24 percent) for personal care, and

[3] The $8.1 billion reflects total expenditures for various target populations in waiver programs: elderly and disabled, mentally retarded/developmentally disabled (MR/DD), persons with AIDS, etc. About 80 percent of the total is spent on services for MR/DD beneficiaries (Lakin et al. May 1998).

- $2.2 billion (16 percent) for home health services.

Twenty-three states devoted more than 25 percent of their Medicaid long-term care dollars to home and community-based services in fiscal 1997. Oregon outpaced all the other states by allocating 50.3 percent of its total Medicaid long-term care spending for home and community-based care (Burwell 1998).

Thirty-one states and the District of Columbia provided personal care services as an optional Medicaid benefit in fiscal 1997. New York State spent about half ($1.6 billion) of the national total of $3.2 billion for personal care. California, Michigan, Texas, New Jersey, and North Carolina spent close to another billion (Burwell 1998).

Another significant source of funds for home and community-based care services in recent years has been state general revenues. Many states have developed state-funded programs so that they can provide services to persons whose incomes exceed Medicaid limits or whose functional impairments are less severe than required for Medicaid coverage. General revenues also allow states more flexibility in designing programs and selecting services to offer (Kassner and Williams 1997).

In 1996, 32 states reported operating one or more state-funded programs that provided a single home and community-based service for older persons. Examples include a nutrition program or case management or homemaker services. Thirty-nine states reported having one or more state-funded multi-service home and community-based programs. State spending for multi-service programs ranged in amount from about $317,000 for the Community Home-Based Initiatives Program in Nevada to the $290.5 million In-Home Supportive Services Program in California (Kassner and Williams 1997).

State Strategies

States have used the Medicaid personal care program and home and community-based waiver programs in a variety of ways:

- To provide a range of services that include respite, homemaker, transportation, adult day care, home modification, emergency response systems, and nutrition programs.

- To set income eligibility standards for waiver services as high as 300 percent of the monthly Supplemental Security Income level, $1,482 monthly in 1998.

- To allow persons to qualify for certain Medicaid services if their medical expenses force them to “spend down” their income to the “medically needy” level.

- To offer waiver or personal care services to eligible older persons in residential care facilities, such as assisted living facilities.

- To protect the spouses of persons receiving home and community-based care from impoverishment. States are required to allow the at-home spouse of a Medicaid nursing home resident to retain a share of the couple's income and assets.

Selected State Examples

The following section describes the efforts of three states to craft more extensive home and community-based care programs using a combination of Medicaid and state funds.

Oregon

In 1981, Oregon adopted a set of principles to guide its long-term care efforts. These principles, incorporated into law, provide that older people will receive care "at the least cost and in the least confining situation" (Oregon Senior and Disabled Services Division 1981).

- Oregon began its community long-term care efforts in 1975 with a $500,000 state-funded program called Oregon Project Independence. In 1981, Oregon became the first state to receive approval from the federal government for a Medicaid waiver program for aged and disabled persons.

- In the mid-1980s, Oregon was providing home and community-based long-term care services to about 14,000 people. The number had grown to about 24,000 by 1997.

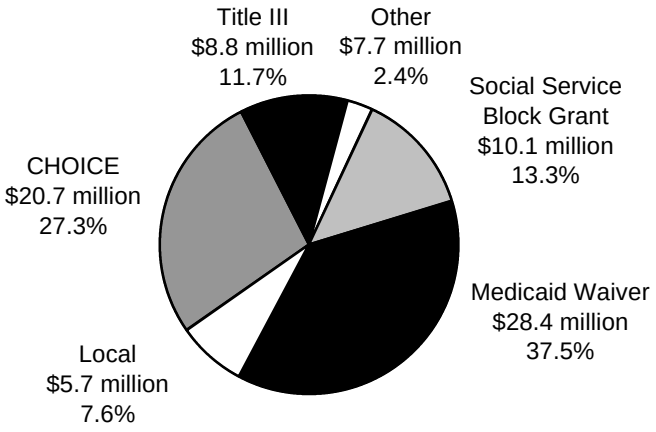
- By the end of 1997, the state was serving over 76 percent of its Medicaid long-term care clients in home and community-based care settings (Auerbach, 1998; Alecxih, Lutzky and Corea 1996).

Indiana

In the 1980s, older Hoosiers of low income had few choices if they needed long-term care assistance. Either they relied on family support that enabled them to remain at home, or they went into a county home or nursing home. County homes provided room and board for poor older persons.

This situation began to change when the Indiana General Assembly in 1989 established a pilot program called CHOICE (Community and Home Options to Institutional Care for the Elderly and Disabled) in two areas of the state. The legislature expanded the state-funded program to all 92 counties in 1992 (Indiana Family and Social Services Administration 1997).

Figure 3
Total Long-Term Care Expenditures in Indiana
(by funding source*)



Source: Indiana Family and Social Services Administration, 1997
*Percentages do not add to 100% because of rounding.

CHOICE serves people of all incomes who need not give up their assets to participate (although more than three-fourths of program participants in 1996 had incomes below $15,000 a year). The program uses a sliding fee schedule for persons whose incomes exceed 150 percent of poverty. Functional eligibility criteria are also more liberal than the Medicaid requirements for the aged and disabled waiver program: inability to perform at least two activities of daily living (ADLs), such as bathing, dressing, toileting, or transferring, rather than three ADLs for the waiver program.

- After five full years of operation (fiscal 1992 through fiscal 1996), the CHOICE program was serving about 5,400 persons a year, with a waiting list of over 2,300 persons.

- The state estimated that the total average cost of CHOICE services for an individual in 1996 was $582.81 per month. The state's cost to maintain a person in a nursing home in 1996 was $1,134.69 a month (total federal-state cost: $3,031.50 per month.)

- Indiana spent almost $75.8 million on in-home services in 1996, almost 65 percent of which was allocated for CHOICE and four home and community-based waiver programs. (See Figure 3.)

Arkansas

In 1996, about 361,000 Arkansans were age 65 or older — 14.4 percent of the state's population, the seventh highest percentage in the country (Bectel and Tucker 1998). Arkansas

ranked third highest among the states for percentage of persons age 65 and over with incomes below the poverty level in 1993-95 (U.S. Administration on Aging 1997).

Those two figures suggest that demand for long-term care services is also likely to be high. Arkansas has met that demand largely through nursing home services. In 1996, Arkansas had 68.5 beds per 1,000 persons age 65 and older compared to a national average of 49.1 beds per 1,000. Still, Arkansas has also been trying in recent years to counterbalance that institutional bias by expanding the use of the Medicaid personal care program for older persons of low income. One study of state long-term care systems ranked Arkansas ninth among the states in terms of its progress toward a system that emphasizes home and community-based services over nursing home care (Ladd 1996).

- Arkansas ranked second in the country (behind New York) in spending per capita on Medicaid personal care in fiscal 1997, at $23.83 per capita.

- The state provided personal care services to 13,663 older persons in fiscal 1997, with expenditures totaling about $59.8 million.

- Arkansas' total Medicaid spending on personal care services in fiscal 1996 was eleventh highest in the country, exceeded only by states with much larger populations, such as New York, California, and Texas.

- Arkansas also operates a Medicaid home and community-based services waiver program, ElderChoices, which the state began in July 1991. The program served 5,900 beneficiaries in fiscal 1997 and cost $12.6 million (Arkansas Department of Human Services 1998).

IV. DEVELOPING RESIDENTIAL OPTIONS

Background

More than 28 percent of persons age 65 and over lived alone in 1990 (Bectel and Tucker 1998). Persons living alone who have difficulties with activities of daily living may not be able to get the help they need, unless they have family or community supports. They may be afraid to remain in their homes, even if they want to avoid a nursing home.

An important alternative for these frail elderly persons can be supportive housing — housing with services. Many states are exploring a variety of ways to expand the supply of supportive housing for older persons, which includes congregate housing, board and care homes, and assisted living facilities. Definitions of supportive housing are continually shifting. Some of the basic differences among these types of housing are described below.

Congregate housing

Congregate housing generally refers to residential buildings with separate apartments and shared dining facilities and other community space. Congregate housing typically includes a program of supportive services, such as housekeeping and transportation plus one meal a day. This type of supportive housing does not usually include personal care or protective supervision. Residents are typically living independently but with access to specified services.

Board and care homes

Board and care homes may, depending on state regulations, also be referred to as residential care homes or facilities, sheltered care facilities, personal care homes, or adult foster care. These homes often offer a home-like setting, providing rooms (often semi-private), shared common areas, meals, protective oversight, and some measure of help with activities of daily living. Currently, about one-half of board and care residents have low incomes, which means that the facilities often rely on the public benefit checks (often Supplemental Security Income) of the residents for payment of room and board charges (Clemmer 1995).

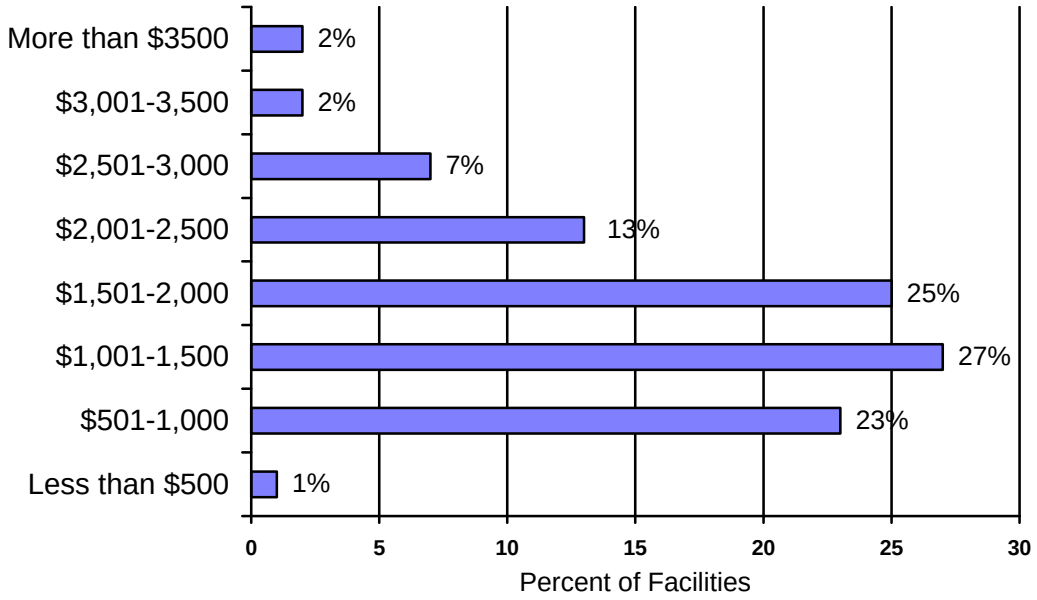
Assisted Living

An assisted living facility is a residential setting that provides or coordinates personal care services, 24-hour supervision, scheduled and unscheduled assistance, social activities, and some health-related services. Typically, assisted living facilities house fewer than 100 residents, have apartment-like rooms (often private, with bedroom, bath, and kitchenette), and have central dining facilities and activity rooms.

Assisted living is the fastest growing type of senior housing. In the absence of federal regulation or guidelines, states are grappling with how to protect individuals and ensure residents' safety and quality of care, while allowing providers flexibility for innovation and individuality. As of June 1998, state legislative activity included:

- twenty-two states with assisted living regulations;
- five states with regulations drafted as a result of authorizing legislation;
- seven states with assisted living services covered under existing board and care regulations;
- three states with assisted living pilot projects; and
- fourteen states studying the issue (Mollica 1998).

Figure 4
Average Monthly Rent and Fees in Assisted Living Facilities



Source: AHCA, Survey of Assisted Living Facilities, 1996.

Most assisted living facilities are private pay. The majority charge between $500 and $2,000 per month, depending on the size of a unit, services, and amenities. (See Figure 4.) Oregon has developed an assisted living model that combines Supplemental Security Income (SSI) and Medicaid (through the use of Medicaid waivers) to cover the cost of services for low-income residents who are nursing home eligible. In 1998, 28 states covered services in assisted living or board and care homes, and seven other states had plans to do so (Mollica 1998).

State Strategies

Encouraging the development of supportive housing is a key component of a state's strategy to build a multifaceted long-term care system. Many states are trying to reduce the need for additional nursing home beds by encouraging the development of new types of supportive housing. Some states have coupled limits on nursing home beds with incentives to nursing homes to convert beds to lower levels of care or to developers to build new residential units. States may offer housing loans, grants, and subsidies for these types of developments.

Selected State Examples

Oregon

Oregon has pioneered the development of a range of long-term care housing options that include assisted living and adult foster care facilities. There were almost 15,000 beds/units available in these residential settings in 1998, compared to about 14,100 nursing home beds.

- Oregon began licensing adult foster homes (nonmedical living arrangements with five or fewer residents) in April 1986. Oregon recruits homes for participation in the adult foster home program, trains staff, and encourages family members to run the homes.

- The state had licensed 2,023 adult foster homes with 9,055 beds as of March 1998. The Medicaid waiver program paid for in-home services for over 5,000 residents of adult foster homes in 1997.

- During the 1988-89 period, the state designed an assisted living program as a licensed category, reimbursable under the state's Medicaid waiver programs**.** The state had licensed 98 assisted living facilities with 5,792 units by April 1998 (Oregon Senior and Disabled Services 1998).

Florida

With one of the highest concentrations of older people in the country, Florida has been trying in recent years to curtail nursing home admissions by placing people in supportive residential housing, such as assisted living facilities (ALFs), extended congregate care facilities (ECCs), and adult family care homes.

- ALFs offer personal care and other services in a group setting. As of April, 1998, Florida had licensed 2,094 ALFs, with about 67,000 beds. About 84 percent of the ALF beds are private-pay, with the rest supported by Supplemental Security Income with state supplementation.

- The number of assisted living beds is fast approaching the number of nursing home beds in the state, which totaled about 73,000 in 1998.

- The Extended Congregate Care program went into effect in December 1992. As of April 1998, the state had licensed 224 ECC facilities. This form of supportive housing provides a greater range of nursing services than a person may receive in an assisted living facility.

- Florida had licensed 365 adult family care homes with a total of 1,391 beds as of April 1998. Adult family care homes provide room, board, personal services, health monitoring, and general supervision for one to three older persons or disabled adults in a family-type setting (Florida Agency for Health Care Administration 1998).

V. CONSOLIDATING STATE LONG-TERM CARE SYSTEMS

Background

A completely coordinated long-term care system does not exist in most states today. An array of state and federal programs are administered by different state and local agencies.

Services are delivered by state and local agencies, private nonprofit organizations, and private-sector providers.

Many long-term care experts believe that states could make more effective use of limited public dollars for long-term care if they would develop a cohesive policy for long-term care and administer that policy through a single agency. But consolidation can be difficult to achieve. State agencies generally have their own constituencies in advocate and provider groups and also in the legislature. Also, each agency is likely to resist loss of budgets and staffs.

- Several states have created cabinet-level departments on aging, while other states have created a single aging entity (bureau, department, or division) within an umbrella agency that manages social services and welfare programs.

- The long-term care component that has been most effectively consolidated in most states today is home and community-based care services. Most departments on aging began their existence by administering Older Americans Act social and nutritional programs for older persons. Now those departments are administering all federally and state-funded home and community-based care programs for older persons.

- Medicaid agencies are generally responsible for the development of financial and functional eligibility criteria for Medicaid coverage of nursing home care. (Under the Medicaid waiver programs, participants must also meet these nursing home standards, although the programs themselves may be managed by an aging agency.)

- State health departments typically license, regulate, and set payment rates for nursing homes and other long-term care facilities.

State Strategies

States use a variety of models for administering long-term care financing and services. Increasingly in recent years, states have been consolidating previously scattered long-term care programs and services into one department of aging. For example, the New Jersey governor created the Department of Health and Senior Services in 1996. The new department consolidated 20 state and federal programs previously run by four departments. In 1997, the West Virginia legislature dissolved its Commission on Aging and the State Office of Aging, and created a new cabinet-level Bureau of Senior Services, reporting directly to the governor.

Selected State Examples

Oregon

Under a legislative mandate in 1981, Oregon began to bring all long-term care and services into a single agency, which became the Senior and Disabled Services Division of the Human Resources Department. The agency was created by merging the functions of the previous state aging agency with the long-term care unit of the state Medicaid agency.

Only two long-term care activities had been left out in the 1981 reorganization — a federally mandated review process for nursing homes seeking Medicaid certification, and nursing home licensure. In 1985, the Division became responsible for the Medicaid certification review and in 1987 for survey and licensure functions. The agency also administers Older Americans Act programs, all the state's Medicaid-funded long-term care services (including Medicaid payments to nursing homes), and cash assistance and food stamps for older persons.

Kansas

During the early 1990s, Kansas commissioned several studies of its long-term care administrative structure. At that time, responsibility for major long-term care services was mainly divided between the Department of Social and Rehabilitation Services (SRS), which houses the Medicaid agency, and the Kansas Department on Aging (KDOA).

In 1996, the legislature mandated the transfer of specific programs from SRS to KDOA, effective June 30, 1997**.** At that time, the Department on Aging was administering Older Americans Act services and the state-funded Senior Care Act Program for persons age 60 and over who needed in-home services and who had incomes at 150 percent of poverty or higher. Table 2 depicts the range of responsibilities assumed by KDOA after the consolidation.

The programs administered by KDOA now range from assessment and case management to state- and Medicaid-funded home care programs and nursing facility services payment. (SRS retained responsibility for determining financial eligibility for Medicaid services.)

Table 2
Kansas Department On Aging Services
(after transfer of programs)

Program	Target Population & Eligibility	Services
Medicaid Home & Community Based Service Waiver for the Frail Elderly	• Ages 65 and older • Meet Medicaid LTC threshold criteria* • Meet Medicaid financial eligibility criteria • Consumers help pay for services if countable income >$658 per month	• Adult day care • Sleep cycle support • Personal emergency response • Health care attendant • Wellness monitoring • Respite care
CARE Assessment	• All ages • Must be seeking nursing facility admission • No income requirement	• Individual assessment, referral to community-based services, appropriate placement in LTC facilities
Nursing Facilities (NF)	• Ages 65 and older • Meet Medicaid NF-LTC threshold criteria • Meet Medicaid financial eligibility criteria	• 24-hour skilled nursing care
Income Eligible Program	• Ages 60 and older • <150% of poverty • Meet LTC threshold eligib. for HCBS-FE waiver • Voluntary donation	• Non-medical attendant care • Homemaker • Income Eligible individualized tailored services
Senior Care Act	• Ages 60 and older • Cannot access any other programs • Targeted to >150% poverty • Sliding fee scale	• Attendant care, homemaker, adult day care, respite, chore services, transportation, assisted living, case mngmt
Case Management, State Funded	• Ages 60 and older • No income test • At risk for nursing home care	• Assessment, coordination, resource development, care planning, advocacy
Targeted Case Management	• Ages 65 and older • Meet LTC threshold eligibility • Meet Medicaid financial eligibility criteria	• Assessment, coordination, resource development, care planning, gatekeeping, advocacy

*Impairment in Activities of Daily Living (bathing, dressing, etc.) and Instrumental Activities of Daily Living (shopping, medication management, housekeeping, etc.)

Source: Kansas Department on Aging, 1998

VI. ESTABLISHING A SINGLE POINT OF ENTRY SYSTEM

Background

Many state aging units delegate responsibility for the administration of home and community-based care services to local agencies around the state: Area Agencies on Aging, county agencies, or private, nonprofit organizations. These designated agencies are often referred to as "single points of entry" through which individuals enter the state's long-term care system. The responsibilities of a single point of entry agency may be only to provide information and referral on long-term care services in the community. But many states assign greater authority to these local agencies, including allowing them to authorize the allocation of public long-term care dollars and to direct people to home and community-based care services.

In many states, single point of entry agencies conduct preadmission screening and assessment for nursing home applicants, or contract with other local agencies for these services. The preadmission screening and assessment process evaluates a person's long-term care needs. If a case manager concludes that a person does not need nursing home level of care or will not meet Medicaid functional eligibility requirements, the care manager will advise the individual of home and community-based care options, and help develop a plan of care. If a person meets the Medicaid criteria for nursing facility admission but would like to receive home care services, some case managers are able to authorize HCBC waiver or state-funded services.

By directing people away from nursing homes if they do not need that level of care, a single point of entry system may help to conserve public long-term care dollars. By providing information on other long-term care options and helping to steer people to those services, a single point of entry system helps people stay in their homes or in their communities.

Single point of entry systems vary from state to state. No one system can serve as a model because states vary in demographics, geography, and state and local government structure. Creating a single point of entry system can spark controversy among government agencies, social service providers, and advocacy organizations because the single point agencies generally become "gatekeepers" for long-term care services. As such, the single point agencies have considerable control over the allocation of dollars for services.

State Strategies

Selecting a local or regional organization to serve as a single entry point can be a sensitive issue, and result in heated competition from existing local agencies. The following are illustrative of the range of approaches that states have taken:

- Oregon allows Area Agencies on Aging (AAAs) to be designated if they wish. If they decline, local offices of the state Senior and Disabled Services Administration serve as the single entry point agency.

- Massachusetts has had an aging network for years made up mainly of Home Care Corporations (HCCs), with which the state's Executive Office of Elder Affairs has contracted to provide social support services for older people. Recent state legislation has expanded the role of the HCCs into "Aging Services Access Points" or points of entry into community-based long-term care services.

- The single point of entry in Indiana is the care management system operated by the state's 16 AAAs.

Selected State Examples

New Jersey

New Jersey has developed a system called NJ EASE (Easy Access Single Entry). Using a planning grant from the Robert Wood Johnson Foundation, the state has established working models of single entry systems in seven counties with another six counties expected to be in operation by the end of calendar year 1998 (of a total of 21 counties in the state).

The county authority (e.g., Board of Chosen Freeholders or County Executive) designates a county agency to take the lead in designing and operating the system. The lead agency identifies other agencies that can help the county provide a full range of core services. (Core services include information and assistance, outreach, benefits screening and counseling, comprehensive assessment, care planning, care management, and reassessment.) Counties must use existing funds from the Older Americans Act, Medicaid, and state and county programs to cover the costs of the new single entry point system.

One example of the models being developed is Atlantic County, which is using the county's Division of Intergenerational Services as the lead agency. The division, in turn, has contracted with two nonprofit agencies and one municipal office to provide outreach and care management services for older people in two municipalities and one rural area in the county (New Jersey Department of Health and Senior Services, 1998).

Colorado

Colorado began planning its single point of entry system in the late 1980s. Implementation began in 1992 and was completed throughout the state by July 1, 1995. The system called for county commissioners to group their counties into districts, with each district responsible for designating a single point of entry agency (now known as Options for Long Term Care (OLTC) agencies).

The OLTC agencies are varied and include county social service departments, county health departments, area agencies on aging, and private nonprofit agencies. The main responsibility for these agencies has been to provide case management services for Medicaid and private-pay individuals. In May 1997, the Colorado legislature provided funding for a project to expand the role of OLTC agencies to include services for persons in nursing homes. Three OLTC

agencies (in Denver and Jefferson and El Paso counties) were selected for a new two-year project to identify nursing home residents who could be relocated to less restrictive settings (Colorado Department of Health Care Policy and Financing 1997).

VII. INTEGRATING HEALTH AND LONG-TERM CARE

Background

Several states have begun to develop service delivery and financing systems that integrate health and long-term care services and financing for persons dually eligible for Medicare and Medicaid. Generally, a managed care organization receives a capitated (or fixed) payment per enrollee through the pooling of Medicare and Medicaid funding to provide a full range of medical and social services for the enrollees.

Many states already require Medicaid-eligible families with children to participate in managed care programs. States have been slower to enroll persons with disabilities in these plans because of uncertainty about costs and the complexity of design issues.

In 1995, about six million persons were enrolled in both Medicare and Medicaid at some point in the year. The 16 percent of Medicare's beneficiaries who were also Medicaid eligible accounted for 30 percent of Medicare spending. While dually eligible individuals constitute about 17 percent of the Medicaid population, they account for about 35 percent of total Medicaid expenditures (HCFA 1997).

Various public and private organizations have been experimenting in recent years with ways of providing integrated care, and have been testing different models in different types of settings. An integrated managed care system was pioneered in 1983 by On Lok Senior Health Services in San Francisco. The Program of All-inclusive Care for the Elderly (PACE) developed from that project to become one of the first federally-managed demonstration projects to provide a comprehensive program of health and long-term care services for dually eligible persons who require nursing home care.

The PACE program was authorized by Congress in 1986 as a demonstration project; the Balanced Budget Act of 1997 made the program permanent. PACE sites provided services to almost 5,000 individuals during 1996. At the end of 1996, 26 PACE sites were operating in 16 states. PACE participants receive assessment, care planning, and services from an interdisciplinary medical and social work team, with the services generally provided at an adult day health care center (National PACE Association 1997).

State Strategies

Thirteen states[4] have been developing programs to integrate health and long-term care services for dually eligible persons. Policymakers reason that bringing health and long-term care

[4]Arizona, Colorado, Florida, Minnesota, Oregon, Texas, Wisconsin, and six New England states working jointly (Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, and Vermont).

services into an integrated system for dually eligible beneficiaries will not only improve care coordination but also help restrain costs.

Although state demonstration projects share a common objective to serve dually eligible beneficiaries, the characteristics of each program differ. (See Table 3.) For example, the Arizona program integrates *Medicaid* health and long-term care, but *Medicare* still operates separately. Medicare services are, however, usually provided by the Medicaid contractor, which facilitates limited integration. On the other hand, Mesa County, Colorado is an example of a fully integrated program, which combines Medicare and Medicaid health and long-term care services through the Rocky Mountain health maintenance organization in Mesa County.

Table 3
Summary of Selected Programs Serving Dually Eligible Beneficiaries

	Target Population	Scope of Service	Voluntary or Mandatory	Statewide?	Status
Arizona Long-Term Care System	Nursing facility eligible elderly, physical or developmentally disabled	Primary, acute and long-term care	Mandatory for Medicaid	Yes	Operating since 1989
Colorado Int. Care and Financing	Medicaid beneficiaries, including dually eligible	Primary, acute and long-term care	Voluntary	No	Waiver approved July 1997
Minnesota Senior Health Options	Elderly dually eligible	Primary, acute and long-term care	Voluntary	No	Operating since 1997
PACE	55+ years, nursing facility eligible	Primary, acute and long-term care	Voluntary	No	On Lok since 1983; replication sites since 1990
Texas Star+Plus	Elderly and disabled, including dually eligible	Primary, acute and long-term care	Mandatory for Medicaid	No	Waivers approved January 1998

Source: National Academy for State Health Policy, 1997.

Selected State Examples

Minnesota (Senior Health Options)

Minnesota has been enrolling Medicaid beneficiaries, including older persons, in managed care *health* plans since 1985 through its Public Medical Assistance Program (PMAP). Some of these enrollees have also participated in a Medicare plan operated by their PMAP.

After years of planning, Minnesota became the first state to receive Medicare and Medicaid waivers to integrate acute and long-term care for dually eligible older people. The

waivers allow the state to combine the purchase of both Medicare and Medicaid services into one contract managed by the state.

- The program, called Minnesota Senior Health Options (MSHO), began operating in the seven-county Minneapolis-St.Paul metropolitan area in January 1997.

- The state estimates that about 15,000 dually eligible older persons live in the designated area. As of May 1998, about 2,400 persons had enrolled in MSHO.

- Enrollees are entitled to receive all Medicaid services previously provided under PMAP, plus all Medicare services under Parts A and B. Plans are also providing extended home care benefits to persons eligible for nursing home care.

- Plans are also financially responsible for the first 180 days of care in a nursing home for those who enroll in Senior Health Options while still living in the community. They continue to coordinate care after 180 days, and the nursing facility is paid a per diem fee-for-service amount for services covered by Medicaid (Minnesota Department of Human Services 1997).

Texas

On January 20, 1998, HCFA approved a health and long-term care integration project called STAR+PLUS for Harris County (Houston) Texas. The project serves about 60,000 aged and disabled Medicaid beneficiaries in Harris County, about half of whom are dually eligible.

Participants may choose from three health maintenance organizations (HMOs), two of which also have Medicare managed care contracts. The program offers unlimited prescriptions for dual eligibles who choose one HMO for both Medicare and Medicaid. The traditional Texas Medicaid prescription limit is three per month.

All participants are assigned a Care Coordinator, an HMO employee who is responsible for coordinating health and long-term care services. The Care Coordinator develops an individual plan of care with the individual, family members, and provider, and can authorize services for the individual.

Long-term care services provided by the HMOs include day health care, personal assistance, and nursing facility care. Additional services are available to persons enrolled in the state's Community Based Alternatives Medicaid waiver program, which include adult foster home services, nursing services, respite care, and minor home modifications.

VIII. CREATING CONSUMER-DIRECTED PROGRAMS

Background

A number of states have created consumer-directed programs that permit persons with disabilities or their families to manage their own long-term care services. The funding sources are generally either Medicaid personal care or waiver program funds or state general revenues. States hope to save money by using such programs because program participants can purchase services directly and need not go through provider agencies, which adds overhead costs. Self-directed care is also very popular with many young adults with disabilities who want the freedom to select their personal care worker and direct the assistance provided by that worker.

Several studies of these programs have been conducted. In one study, researchers surveyed Medicaid beneficiaries who received home care services in Maryland, Michigan, and Texas. The purpose of the research was to determine how consumer choice affected Medicaid beneficiary satisfaction with their lives and their aides (Tilly, forthcoming).

The authors constructed an index of choice, and compared the responses of participants who had little or no choice regarding their home care workers to the responses of participants who had a great deal of choice. Ninety-two percent of beneficiaries with the greatest amount of choice in home care said their aide was very concerned about their well being, compared with 74 percent of those with some element of choice and 63 percent of those with no choice. Seventy-six percent of those who had a high level of choice said the presence of their aide made them feel safer at home, compared to 47 percent of those with little or no choice (The Commonwealth Fund 1993).

The study reported that state programs providing beneficiaries with the greatest flexibility and choice in regard to personal care services ranked highest among the beneficiaries in terms of improving their quality of life. A key factor was the ability to select one's own home care aide (The Commonwealth Fund 1993).

State Strategies

States employ a variety of consumer-directed cash payment models, with variations on the age of the recipient, nature of disability, provider to be selected, hiring and firing practices, reporting requirements, and other issues.

The Robert Wood Johnson Foundation is collaborating with the US Department of Health and Human Services to support a multistate demonstration and evaluation of a "cash and counseling" program. Arkansas and New York were selected for the project in 1996 and Florida and New Jersey in 1997. The program has given the four states planning grants to experiment with giving cash to Medicaid beneficiaries with disabilities. The beneficiaries will choose their own long-term care arrangements, and receive counseling on how to manage a cash allowance, including selecting and working with a personal assistant.

Selected State Examples

Colorado

The Colorado Home Care Allowance is one of the earliest state models of cash grants to individuals to purchase long-term care services. The state-funded program began in 1979 as an added cash grant to the state's Old Age Pension Program.

- Services are targeted to persons who are financially needy and unable to meet their physical or personal care needs themselves. About 67 percent of the clients are age 60 and older.

- Payments are made directly to clients for purchase of services from relatives, friends, or agency providers.

- State officials estimate that the program will serve 5,735 persons in fiscal 1997-98. Program beneficiaries receive a monthly amount based on functional needs, with the amounts ranging from a minimum of $123 for a person with low levels of need to a maximum of $358 for high levels of need. The average monthly payment in fiscal 1996-97 was $214.04; the average is expected to be $222.99 for fiscal 1997-98 (Colorado Department of Health Care Policy and Financing, 1998).

Michigan

Michigan began operating its Home Help Program in October 1980 as part of its Medicaid Personal Care optional benefit program. Counseling services are provided locally by adult services workers of the state Family Independence Agency. In addition to conducting a needs assessment, the adult services worker develops a service plan with the individual.

- As of March 1998, the program had 36,355 enrollees, about half of whom were age 60 and older.

- Enrollees receive an average monthly payment of about $307 in 1998.

- Enrollees are free to choose their own providers from available family members (about 47 percent of all providers), and friends and neighbors (47 percent). Public and private service agencies make up the remaining 6 percent (Michigan Department of Community Health 1998).

IX. CONCLUSION

A state faces a daunting task in developing a comprehensive long-term care system that offers choice to consumers and cost savings to the state. Many states have chosen to reorganize services or expand services gradually. A governor might transfer certain home and community-

based care programs from a Medicaid agency to an aging agency. A state legislature might increase expenditures for state-funded home care. A state regulatory agency might adjust the reimbursement rates paid to nursing homes to control increases in payments.

Most of the states discussed in this report have, however, chosen to adopt more comprehensive strategies to tie together financing and delivery components of long-term care. These strategies are based on the premise that controlling the use of nursing home care can promote choice and independence only if home and community-based care alternatives are available and affordable. Creation of a single point of entry system will help improve access to services only if case managers have programs and providers to whom they can refer their clients.

Evidence that many states are expanding home and community-based care service options and increasing spending on these services comes from Medicaid spending reports and from recent surveys of state general revenue funding of HCBC services. Medicaid spending for home and community-based care has more than doubled in the last decade as a proportion of Medicaid expenditures for long-term care. Nonetheless, Medicaid spending for institutional care ($42.5 billion) was still more than three times higher than Medicaid spending on home and community-base care ($13.5 billion) in fiscal 1997.

Progress in expanding home and community-based care services has been slowed by gaps in the research about the most cost-effective strategies. These gaps leave many policymakers reluctant to increase spending too rapidly on HCBC services. Some policymakers are uncertain about whether they will be substituting HCBC services for costly nursing home care or adding additional HCBC recipients while nursing home costs continue to rise.

Cost is a legitimate concern for advocates and consumers as well as policymakers and researchers. State models need to be tested, comparative studies need to be conducted, and outcomes need to be assessed. But a debate over costs could paralyze further progress in developing a rational long-term care system in this country. Many vulnerable people will go without services if cost effectiveness is the only issue.

States must move ahead in developing long-term care systems that offer a range of services in various settings so that the millions of people who need long-term care have access to the most appropriate and affordable services. Important lessons can be learned from the long-term care models that have *already* been developed. These models demonstrate a broad range of options that have been explored and implemented.

This report has sought to highlight some of these models. State officials must be willing to experiment and innovate as have the states mentioned in this report and others. At the same time, researchers need to continue their search for quantifiable data on cost-effective methods and successful outcomes.

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