State Long-Term Care: Recent Developments and Policy Directions

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Preface

State Long-Term Care: Recent Developments and Policy Directions is the first of two reports of an 18-month project funded by the Office of the Assistant Secretary for Planning and Evaluation of the U.S. Department of Health and Human Services. This report provides a thumbnail sketch of long-term care budgets, legislation and planning in the 50 states and the District of Columbia. The goal of the project is to obtain insights into recent state long-term care public policy reforms, as evidenced by their proposed or recently enacted legislation, task forces and budgets.

The focus of this first report is mainly on state legislation, expenditures and policy activity in fiscal year 2001 to provide the most current perspective possible in fast-changing state environments. However, it also previews fiscal year 2002 (when the data were available and appropriate). In some cases, reference is made to prior years to provide context for review and analysis. In the summer of 2003, NCSL will publish a second report that will update subsequent long-term care budgets, planning and implementation strategies in the states.

The fiscal analysis in this report was derived from the responses to a NCSL long-term care expenditure survey sent to legislative fiscal offices in 2001. Twenty-six states responded to the survey. For the other states, fiscal information was gathered from the FY 2000 and FY 2001 Medicaid long-term care expenditures reports compiled by Brian Burwell of MEDSTAT Inc., who uses HCFA 64 reports that the states file annually with CMS (formerly HCFA). While HCFA 64 data are the most accurate available on Medicaid expenditures, there are several important caveats associated with the information. HCFA 64 data are based on date of payment rather than date of service and thus may not accurately reflect the specific services actually delivered in a particular year. In addition, HCFA 64 data are derived from submitted claims and may include some claims that are subsequently disallowed. Finally, HCFA 64 data include only fee-for-service expenditures; any services provided through managed care are not included.

Other fiscal information was gathered from state Web sites and state legislative reports. Information on the number of Medicaid home and community-based waiver programs came from a report for The Kaiser Commission on Medicaid and the Uninsured by Charlene Harrington, *Medicaid 1915 (c) Home and Community-Based Waivers: Program Data, 1992-1999.*

State reporting of long-term care expenditures (primarily Medicaid) can present challenges in conveying an accurate overview of a state's long-term care system. In particular, specific events may distort the picture from one year to the next. For instance, a large increase in nursing home spending may be due to a state's use of a specific strategy to maximize federal dollars, rather than to an increase in the nursing home population or to a sudden surge in nursing home costs in that state. Rates of change in state Medicaid spending for specific services can be due to factors related to state payment policies as well as to real change in service utilization. Therefore, expenditure data need to be considered with caution.

Information on 2001 legislative activities in the states comes from NCSL's Health Policy Tracking Service. The section on long-term care planning was drawn largely from NCSL's "The States' Response to the *Olmstead* Decision: A Work in Progress," published in December 2001, and from information on state Web sites.

Acknowledgements

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Introduction

Long-term care policies and programs are determined in the United States by 50 separate state governments, each with different demographics, economies and political philosophies. For many years, the main direction of long-term care state policy was to support institutionalization of frail elders and people with disabilities. As individuals with disabilities and their families began to advocate and push for greater choice and for increased opportunities to remain in their homes and communities, states began to broaden their focus on home and community-based care services. These programs and services run the gamut from in-home care to adult day services to supportive housing and transportation.

Today, most states are seeking to curb increasing costs for nursing homes that are largely paid through the Medicaid program.[1] States also are expanding the range of home and community-based services (HCBS) that they offer to provide greater options for the elderly, people with physical disabilities, people with mental retardation or developmental disabilities, and other diverse populations with disabilities. The trend toward greater state spending on HCBS encountered a major obstacle in 2001, however, as state revenues began to shrink at the same time as Medicaid spending was rising.

State officials face several major challenges as they try to slow rising Medicaid costs and meet demands from other state services:

- A slowing economy has increased the number of people who are turning to public services for help.
- Shortages of direct care workers have increased pressure on state governments to provide incentives to attract and retain workers.
- Court decisions, most notably the U. S. Supreme Court *Olmstead* ruling, have stimulated many states to increase community-based alternatives to institutionalization for people with disabilities of all ages, particularly people with mental retardation or developmental disabilities (MR/DD).
- There are more frail elderly and people with disabilities who need assistance.

A number of states have used creative approaches to expand the options for frail elders and people with disabilities to receive services and supports that enable them to live in their homes and communities rather than be institutionalized. In the report that follows, the National Conference of State Legislatures (NCSL) traces state long-term care policy developments in 2001, looking backward to the late 1990s and forward to 2002 to add context to the issues discussed in this report.

Fiscal Analysis

Most states have been forced in recent years to grapple with budget shortfalls resulting from declining revenues and escalating costs, particularly Medicaid costs. From FY 2000 to FY 2002, states realized about 5 percent revenue growth, according to the National Association of State Budget Officers (NASBO). Over the same period, NASBO reports that states saw a 25-

percent rate of growth in Medicaid expenditures. Medicaid is second only to education in terms of state spending, accounting for about 20 percent of all state spending. In addition, Medicaid is the single largest source of public funding for long-term care.

NASBO surveyed the states in May 2002 regarding their Medicaid budgets.[2] Of the 49 states that responded to the survey, 39 states had Medicaid shortfalls in FY 2001 and 28 states were anticipating shortfalls in FY 2002. The survey indicated that 47 of the 49 states that responded took action in fiscal 2002 or proposed action in fiscal 2003 to reduce Medicaid expenditures.

NASBO reported that total Medicaid expenditures increased about 10.6 percent in FY 2001 over FY 2000 levels and were estimated to have risen another 13.3 percent from FY 2001 to FY 2002. The federal Centers for Medicare and Medicaid Services (CMS) attributed the expenditure growth to prescription drug spending, nursing home costs, community-based long-term care costs, and payments to health plans.[3]

Institutional and community expenditures. For many years, Medicaid long-term care spending was almost exclusively for institutional services. In FY 1990, more than 90 percent of Medicaid long-term care expenditures was allocated to institutional care (nursing homes and intermediate care facilities for the mentally retarded [ICF/MR] facilities) and only 10 percent to HCBS programs.[4] By 2001, the percentage of Medicaid long-term care dollars for institutional care had decreased to 71 percent and HCBS had risen to 29 percent. Medicaid spending for nursing home care increased by 8.8 percent (from $36.4 billion to $39.6 billion) from FY 1999 to FY 2000, and then by 13.5 percent to $42.7 billion in FY 2001, despite the fact that occupancy has been declining nationally.

Home and community-based services waivers. The Medicaid long-term care benefit that has been growing rapidly in recent years is HCBS waiver programs, which increased from $10.6 billion in FY 1999 to $12.7 billion in FY 2000 (a 14.6 percent increase) and to approximately $14 billion in FY 2001. Implementing Medicaid waiver programs allows states to tap federal matching funds for services that otherwise cannot be covered under the regular state Medicaid plan.

About three-fourths of waiver expenditures in FY 2001 (about $10.5 billion) were allocated to services for people with mental retardation and developmental disabilities. Although the caseloads in many states for MR/DD programs are smaller than for Aged/Disabled programs, the costs are higher because many people with MR/DD receive 24-hour support.

State variations. States differ considerably in their allocation of Medicaid long-term care funds to institutional care versus HCBS. **Vermont** apportioned only 45 percent to institutional care in 2001, for example, and 55 percent to home care. **Washington** allocated 52 percent to institutional care in 2001 and 48 percent to home care. In contrast, **Mississippi** spent 91 percent of its Medicaid long-term care funds on institutional care and only 9 percent on home care.

It should be noted, however, that reviewing state spending on long-term care services from the perspective of Medicaid expenditures distorts the fiscal picture in several states that commit significant state general revenues to home and community-based services (home care and residential services). For example, **Illinois** spent 88 percent of its Medicaid long-term care expenditures on institutional care in 2001 and only 12 percent on HCBS. In addition to the $293 million of

Medicaid money that went to home care in 2001, however, the state also committed $200 million in general revenues for its Community Care Program in FY 2001; this program served 38,000 older adults each month. Although the Community Care Program consists almost exclusively of chore-homemaker support services that may not in and of themselves serve as deterrents to institutionalization, the program nevertheless represents a significant commitment by the state to community services.

State general revenue and federal funds. Several states fund significant HCBS programs from their state general revenues; federal Older Americans Act funds also are a major source of funding. **Indiana** and **Pennsylvania** offer two other examples of the use of non-Medicaid funds for long-term care services in the community. For its home and community-based OPTIONS program in 2000, Pennsylvania provided $175 million in lottery revenue. The state also committed $45 million in tobacco settlement revenue for expanding HCBS in FY 2001-2002 to serve an additional 11,000 people. The state-funded CHOICE program in Indiana, which served more than 12,000 people in FY 2000, was funded at more than $40 million that year.

Another major source of funds for long-term care community services is the Older Americans Act program, under which $1.25 billion in funding was distributed in FY 2001 through Area Agencies on Aging throughout the country. Of that total, about two-fifths was allocated to congregate and home-delivered meals ($530 million) and another $125 million went to the new National Family Caregiver Program, which provides support services such as information and assistance, respite, and education and training to family caregivers.

Legislative Activities

Lawmakers in 2001 pursued long-term care reforms in the context of tight budget constraints and growing concern about health-related expenditures. A number of legislative initiatives involved expanding home and community-based options for people with disabilities. State legislatures also took a number of major actions to regulate nursing homes and assisted living facilities.

Home and community-based services expansions. Perhaps the most ambitious effort took place in **Minnesota,** where the Legislature created a comprehensive framework for reshaping the state's long-term care system, acting on the recommendations of the Long-Term Care Task Force. The legislation resulted in $183 million in appropriations for long-term care reforms for FY 2002-2003, of which more than $75 million was invested in expanding home and community-based service options and $108 million provided cost-of-living increases for nursing facilities and continuing care providers. Increased spending was to be partially offset by $44 million in savings from downsizing the nursing home industry by 5,100 beds.

In **Iowa**, legislators appropriated more than $25 million to fund long-term care development initiatives through the state's Senior Living Trust Fund. The Senior Trust was created to encourage the development of assisted living and community-based services, at the same time decreasing the number of nursing home beds in the state. In addition to providing grants for the conversion of nursing home beds into assisted living, the fund pays for home-delivered meal programs, adult day services and respite care.

The **Maryland** General Assembly created a new program to provide community attendant services and other supports to individuals with physical or cognitive disabilities who qualify for

Medicaid. Participants will be able to obtain services in a variety of settings such as in their own homes or in a supported living environment and will be permitted to hire their own personal assistant.

Pennsylvania lawmakers dedicated a significant portion of the state's tobacco settlement revenue ($45 million) to expand HCBS to 3,000 additional people eligible for Medicaid-funded waiver services. A portion of the funds also will be used to establish a new program to provide HCBS for individuals with low incomes who do not qualify for Medicaid services.

Nursing home quality. Concern about continuing reports of poor quality of care in many of the nation's nursing homes led lawmakers in many states to take actions related to quality improvement. Nineteen state legislatures considered nursing home staffing proposals in 2001. Of these states, **Arkansas** and **Florida** enacted laws to increase nursing home staffing standards beyond previously enacted standards. Both states will phase in staff-to-resident ratios for licensed nurses and nurse aides during the next few years. The **Wyoming** Legislature initiated a study to examine wages and salaries of nonprofessional, direct care workers in nursing homes, assisted living and mental health care facilities, and developmental disability programs.

Several states adopted other measures aimed at improving nursing home quality. **Texas**, for example, became the first state to permit nursing home residents to use video cameras to monitor the care they receive. The "Grannycam" law, as it is known, stipulates that individuals who view a tape that reveals abuse or neglect must report these crimes; it also allows videotapes to be used as evidence in court.

Legislation enacted in **Arizona** allows nursing homes that receive an "excellent" quality rating on the state's annual facility compliance and licensure survey for two consecutive years to receive grant money for quality improvement. **Minnesota** will develop a system of quality profiles for all long-term care providers, while **Texas** will establish pilot centers for advancing quality in long-term care through research, education and outreach programs.

Nursing home liability insurance. Another nursing home issue liability insurance received significant attention from state legislatures in 2001. Nursing homes have faced a growing number of liability cases in recent years, often resulting in costly settlements. With the cost of liability insurance skyrocketing, insurers were pulling out of the market in some states.

In **Arkansas**, lawmakers authorized the state insurance commissioner to establish a voluntary liability insurance pool for long-term care facilities. **Florida** lawmakers added mandatory liability coverage requirements for nursing homes and implemented tort reforms, including caps on punitive damages and attorneys' fees. As of September 1, 2003, the **Texas** Legislature requires nursing homes to maintain professional liability insurance coverage annually of at least $1 million per occurrence of a violation and $3 million total coverage. The Florida and Texas legislation also addressed quality improvements in nursing homes.

Assisted living regulation. A number of state legislatures addressed issues related to assisted living facilities. The **Arkansas** Legislature established licensure and oversight standards for assisted living facilities, provided that facilities currently licensed as residential care facilities could switch all or a portion of their beds to assisted living, and directed the state to apply for a Medicaid waiver to cover assisted living services for at least 1,000 Medicaid beneficiaries.

Alabama legislators enacted several assisted living laws in 2001, following regulatory reforms in 2000 that created a two-tiered assisted living structure with separate standards for facilities that provide care to residents with dementia. The new Alabama laws established licensure standards for assisted living administrators and appropriated $200,000 to fund assisted living inspections. The **Maine** Legislature established a commission to study options for developing high-quality, cost-effective assisted living housing and service programs in community center locations across the state. **New Jersey** lawmakers enacted a policy requiring providers that operate new assisted living or comprehensive care facilities to reserve at least 10 percent of their beds for Medicaid residents.

Long-term care insurance. States have begun taking significant steps to ensure the protection of consumers who purchase long-term care insurance policies, primarily by focusing on premium inflation protection. For example, **Utah** established standards for disclosure relating to federally tax-qualified policies, notification when a policy does not include certain premium inflation protections, and written notification when an insurer denies a policyholder's claim. The Utah legislation also specifies a time frame for delivery of a policy and mandates inclusion of nonforfeiture benefits.

Idaho created a tax deduction for half of a purchaser's long-term care insurance premiums, and **Michigan** required long-term care insurers to define more clearly their assisted living and home care benefits. The **Minnesota** Legislature established standards for rating practices, rate schedule increases, contingent benefits upon lapse, and nonforfeiture benefits.

Long-Term Care Planning

As a follow-up to the 1999 Supreme Court ruling in *L.C. & E.W. vs. Olmstead*, 40 states had task forces, commissions, or state agency work groups assessing their current long-term care systems in 2001. In its interpretation of the Americans with Disabilities Act (ADA), the court ruled that states must provide services in the most integrated setting appropriate to the needs of qualified individuals with disabilities. The ruling directs states to make "reasonable modifications" in programs and activities. Modifications that would "fundamentally alter" the nature of services, programs, or activities are not required.

As a result, the federal government has encouraged states to plan for reforms not only in the health arena but also in the areas of transportation, housing, education and other social supports to fully integrate people with disabilities into the least restrictive settings. Of the 40 states that were reviewing their long-term care systems in 2001, 18 states issued long-term care plans or significant papers addressing options for serving more people with disabilities in home and community-based settings (as of January 2002).

State Olmstead activities. Each state approached *Olmstead* in a different way. Some states developed specific strategies designed for implementation over a number of years, some identified key priorities for more immediate actions, and others set forth broad policy recommendations upon which to base future action. Eight additional states were expected to issue reports in 2002. The recommendations embodied in the reports issued to date included the following:

- Strengthening consumer choice and information;
- Developing a continuum of housing options;

- Addressing transportation barriers;
- Improving quality of care in nursing homes;
- Increasing awareness of home and community-based services;
- Moving toward a long-term care system based on person-centered assessment and planning;
- Ensuring that funding follows the person regardless of whether he or she lives in an institution or in the community; and
- Using Medicaid waivers to expand and create new opportunities for people with disabilities to live in the community.

Plans in four states **Mississippi, Missouri, Ohio** and **Texas** stand out because they contain a clear vision for systems change; include specific strategies and goals; identify the state agencies responsible for each strategy; and include timelines and budgets. For example, Mississippi's 59-page plan contains recommendations for the next 10 years and proposed budgets for FY 2003 to FY 2011 for each recommendation. The 79-page Ohio report contains short-term and long-term recommendations. It contains the proposed executive budget for FY 2002-2003 of $145 million for new initiatives and expansion of programs for people with disabilities.

Study commissions. Not all state long-term care planning in 2001 was a consequence of the *Olmstead* decision. **Minnesota** embarked on a program of comprehensive long-term care reform initiated by the work of a Long-Term Care Task Force that began meeting in 2000. The task force, composed of state legislators and state agency commissioners, issued its report, *Reshaping Long-Term Care in Minnesota,* in January 2001. Its recommendations are limited to the aging population. A number of the task force proposals were enacted into law in 2001. These included funding of community service grants to pay start-up, capital, and other costs of developing supportive housing and home and community-based services and promoting the elimination of excess nursing home beds.

North Carolina offers another example of long-term care planning. In 1999, the North Carolina General Assembly asked the state Department of Health and Human Services to develop a long-term care system that could provide a continuum of care for people with disabilities. The department called on the North Carolina Institute of Medicine to convene a statewide task force to assist in developing the plan. That 49-person task force produced a report in March 2001 containing 47 recommendations that relate to issues of infrastructure, quality, work force and access/financing.

Other. As in the past, some states also continued implementing moratoria on new nursing home beds or continued to administer certificate-of-need laws that effectively restricted the addition of more institutional beds. Others provided financial incentives for divestiture by institutional providers and diversification or reinvestment in home and community-based services.

Future Outlook

Decreasing revenues and rising Medicaid costs caused tight budgets in most states in FY 2001 and continued concern in FY 2002. The effect of these developments on long-term care reforms in the states is uncertain. A number of states have had to consider cost-containment options, many of which affect long-term care programs and services.[5]

Cost containment. As in the past, states are paying particular attention to nursing home costs, which are the largest single item in their Medicaid long-term care package. One strategy involves reducing or freezing rate reimbursement for nursing homes in FY 2002 and FY 2003. **Maine, Illinois, Indiana, Iowa** and **Virginia** reported on the NASBO survey that they were taking such actions or would be in the near future. **Pennsylvania** was revising income eligibility requirements for nursing homes to tighten admissions. Other strategies involved imposing provider taxes and transforming reimbursement systems from cost-based methods to prospective payment systems.

Other cost-containment actions that states were considering in the long-term care area included enhanced estate recovery and asset transfer recoupment from Medicaid beneficiaries (**Kansas, Maine** and **Vermont**), capping the enrollment of some waiver programs (**Kentucky**), placing tighter limits on personal care services (**North Carolina**), and maintaining long-term care per diem prices at FY 2001 levels (**Michigan**).

Systems change. Still, not all state activity in regard to long-term care was restrictive in 2001. With impetus from the *Olmstead* decision and seed money from the Centers for Medicare and Medicaid Services under the Systems Change Grant Program, a number of states were exploring options for helping people in nursing homes make the transition to community settings (if they wished to do so and were found to be capable of living more independently). States also were enhancing personal attendant care options and reforming the delivery of long-term care services.

For example, **Washington** planned to support up to 300 people under age 65 to make the transition out of nursing homes, including partnering with independent living consultants to provide peer support, skills training and advocacy. The **Colorado** Transitions Project will create a state infrastructure for transition efforts and provide choice information to more than 1,200 people in nursing homes, resulting in 130 transitions to the community. **Maryland** plans to coordinate with local housing authorities and housing providers to obtain housing for a minimum of 150 people to leave nursing homes; this program is targeted to individuals with physical disabilities who are age 65 or younger.

States also propose using Systems Change grant money to advance consumer direction in many of their HCBS programs, to develop incentives for recruiting and retaining direct care workers for home care and nursing homes, to improve assessment systems, and to strengthen outreach efforts that will inform people with disabilities about community-based alternatives to nursing homes. The Systems Change Grant Program was allowing states to test new strategies and approaches to their long-term care services.

Conclusion

Several themes emerge from this review of state long-term care actions in 2001. In future months, states are likely to:

- Continue to assess quality of care in nursing homes and assisted living facilities and endeavor to improve quality through more stringent regulation and inspection and through incentives to the facilities to hire more staff and upgrade their training.

- Attempt to enable more people who can live in community settings to move out of nursing homes and ICF/MR facilities. This effort also may force many states to consider housing and transportation issues in conjunction with more traditional long-term care services.

- Consider ways to increase the numbers of direct care workers in long-term care and provide incentives to nursing homes, home care agencies, and other long-term care providers for recruiting and retaining these workers.

- Increase the number of publicly funded programs that allow and encourage consumer direction of services.

- Improve information dissemination to consumers about long-term care options and alternatives.

Uncertainty about the economy may limit state long-term care initiatives that require greater spending in the near future. However, states are showing that they can still design innovative programs and services that expand options for the frail elderly and people with disabilities to live independent lives.

Notes

[1] Medicaid paid for 48 percent of nursing home costs in 2000.

[2] National Association of State Budget Officers. *Medicaid and Other State Healthcare Issues: The Current Situation.* (Washington, D.C.: NASBO/NGA: May 2002).

[3] Cited in the NASBO report.

[4] HCBS refers to three Medicaid programs: Home Health, Personal Care, and Home and Community-Based Waiver programs.

[5] Information on state cost-containment actions comes from the NASBO survey and other sources, which did not become available until after the individual state summaries were completed. Therefore, those state summaries may not include mention of these strategies.

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Alabama

Overview

The long-term care system in Alabama relies heavily upon institutional services, although the state has been making strides toward increasing home and community-based services (HCBS) in recent years. More than 10,000 people were receiving Medicaid waiver services in 2001, compared to about 16,700 people in nursing homes. The state has waiting lists for the waiver programs however, and has not been filling all available waiver slots because of funding difficulties.

Fiscal Analysis

The state spent more than $673.6 million for nursing home care for about 16,700 nursing home residents in FY 2001. (By contrast, Arkansas spent $396.6 million for approximately 14,000 residents.)[1]

Expenditures for the state's Medicaid waiver programs totaled $153 million in FY 2001, more than double the FY 1995 expenditure of $61 million. Highlights of the fiscal picture include the following:

- The largest waiver program, the MR/DD program, has seen major increases in funding since 1995, more than tripling from $38.3 million that year to $106 million in FY 2001. Approximately 4,400 people were receiving waiver services under this program in 2001.

- The state spent about $43.7 million on the Aged/Disabled waiver program in FY 2001, with a caseload of about 5,760 people. (The state had 7,000 slots for this program.)

Legislative Activity

State legislators enacted several laws in 2001 that affected assisted living facilities, following extensive reforms to the assisted living industry in 2000. One measure set licensure standards for assisted living administrators and established a board of examiners for the administrators. Another measure strengthened the Department of Public Health's authority to inspect unlicensed assisted living facilities and established penalties for operating an unlicensed facility.

Regulations issued by the Public Health Department created a two-tiered assisted living licensing structure that established separate standards for facilities that provide care for people with dementia.

Long-Term Care Planning

With a grant from the Center for Health Care Strategies, the *Olmstead* Core Workgroup was formed. The 40-member body is comprised of representatives from state agencies, advocates, providers, consumers, and family members; the Alabama Medicaid Agency serves as the lead agency. The workgroup has four subcommittees: Needs Assessment, Best Practices, Consumer, and Resource Development. Each subcommittee was expected to submit recommendations by Sept. 1, 2001, after which public forums were to be held. The final plan was to be completed in January 2002. Beyond expanding home and community-based care for people with disabilities, the state plans to review its entire Medicaid program during the next few years.

Plans for moving institutionalized disabled people into the community had already begun through a settlement agreement in the *Wyatt vs. Sawyer* lawsuit signed in January 2001. The agreement established specific assessment procedures and called for a plan to be developed to identify people with mental illness and with developmental disabilities. The plan discusses reduction of institutional beds, discharge planning procedures, development of community placement, and certification of providers.

Future Outlook

Two grants totaling more than $3 million under the federal Systems Change Grant Program should help enhance access to community services in 2002 and move people out of nursing homes who would rather live in the community and who are capable of doing so. Alabama expects to use the $2 million Real Choices grant, which the state developed in conjunction with its *Olmstead* planning process, to enhance access to HCBS through improved information dissemination and service coordination. Another goal is the creation and expansion of system-wide opportunities for consumer-directed care.

Specifically, the state plans to develop a community-based information and referral clearinghouse, develop advocacy and informational materials for consumers and family members, and establish an Outreach and Education Unit within the Medicaid Agency's Long-Term Care Division. Training goals include developing a Service Coordination Core Training Module for Medicaid service coordinators, and training and support for person-centered planning for consumers with developmental disabilities.

The other $1 million that the state received will help the state to assist nursing home residents in the Birmingham area to make the transition into the community. A community transitional advocate will assist nursing home residents to plan their move and obtain required supports.

Notes

[1] Expenditure and caseload figures from Burwell using HCFA Form 64 and Harrington HCFA form 372

Alaska

Overview

Although the total numbers are small, Alaska has seen an almost 60 percent increase in the number of people age 65 and older from 1990 to 2000¾from about 22,370 people to 35,700. Still, older people represent only 5.7 percent of the total population, making Alaska the youngest state in the country.

The nursing home caseload has remained relatively constant at about 900 residents, expenditures have risen by about $14 million since 2000 to a projected total of $53.5 million in 2002. During the same period, however, spending for home and community-based services (HCBS) is projected to soar to more than $120 million, largely through dramatically increased spending on the state's four Medicaid HCBS waiver programs.

Fiscal Analysis

The bulk of HCBS spending in Alaska is for the Medicaid waiver programs, particularly for the developmentally disabled. Spending on that program has increased by more than 70 percent from 2000 to 2002, from $26.1 million to a projected $45 million in 2002. Highlights of the fiscal picture include the following:

- Expenditures for the Medicaid Personal Care Program totaled $8 million in 2001 and are expected to increase to $9.2 million in 2002.

- The HCBS waiver program for the elderly was expected to serve about 1,300 people in 2002 at an expenditure total of more than $18 million.

- Spending for the HCBS waiver program for developmentally disabled people constituted about three-fifths of total spending for all waiver programs. The state expected to provide services to more than 600 people in the DD program.

Legislative Activity

The 2001 Legislature adopted a resolution urging the state to disseminate information about the availability and costs of long-term care insurance. However, lawmakers did not enact any other long-term care insurance legislation in 2001.

Long-Term Care Planning

Alaska is building partnerships among various state departments to improve the continuum of care for beneficiaries. During FY 2001, the state authorized funds for planning services for people with disabilities, including home and community-based services.

During FY 2002, the Department of Health and Social Services plans to continue taking public comment on the Comprehensive Integrated Mental Health Plan, *In-Step*, and to use the information to shape the next planning process. The department also expects to contract for a needs assessment to identify the type of services needed to serve as many children and youth as possible within their home communities so that they will not have to go out of state for residential psychiatric treatment services.

Future Outlook

In October 2001, the state implemented a consumer-directed personal assistance program, which gives consumers an option to hire, train and supervise their personal assistants. Changes are also being proposed to the agency-based program, which will result in greater consumer choice and availability of services. The state received a $900,000 Systems Change grant under the Community-Integrated Personal Assistance Services and Supports category, which the state plans to use to improve personal assistance services that are consumer-directed or controlled.

The state will develop statewide training standards and competency testing for personal assistants and will increase training opportunities for these workers. Funds also will be used to implement strategies to increase the recruitment and retention of personal assistants.

The state also received a grant of $1,385,000 from the Systems Change Program in 2002.

Arizona

Overview

The Arizona Long-Term Care System (ALTCS) is the state's alternate system to Medicaid. Arizona has been operating this system since the late 1980s. By 2001, the system was serving more than 29,000 people at a cost to the state of about $568 million.

Fiscal Analysis

The ALTCS is comprised of two populations: elderly and physically disabled (EPD) and developmentally disabled (DD). Each population is contracted for separately. ALTCS is a managed care program that pays its contractors by member month capitation. The capitation amount includes payments for all covered services, including nursing facilities, acute care, and home and community-based services (HCBS). Highlights of the fiscal picture include the following:

- Expenditures for nursing homes for the elderly population totaled $231.5 million in 2000, rising to about $253 million in 2001, and projected to increase to $267 million in 2002. For the developmentally disabled population, nursing home spending remained at about $2 million throughout this period.

- Combined expenditures for HCBS for the elderly and for developmentally disabled people totaled more than $200 million in FY 2001, with more than 80 percent of the total allocated to DD services.

- Spending on services for the elderly rose from $45.1 million in 2000 to $61.5 million in 2001, and was projected to increase further in 2002 to almost $71 million.

Legislative Activity

During 2001, lawmakers approved the creation of a grant program that will allow nursing homes that receive a quality rating of "excellence" on the state's annual facility compliance and licensure survey for two consecutive years to receive grant money for costs related to non-administrative direct care staff. The program will be funded by $1.5 million in tobacco tax revenue.

Long-Term Care Planning

Three state agencies that have been involved in long-term care planning at the behest of the governor released their goals and recommendations in September 2001. The three agencies are the Department of Human Services, the Department of Economic Security, and the Arizona Health Care Cost Containment System (AHCCCS). Each agency developed plans, then consolidated and revised those plans and sought consumer input in regional stakeholder meetings and statewide public forums. Several major issues that emerged from this planning process discussed below:

- *Labor Force Shortages*. According to the plan, solutions to labor force problems will require legislative and fiscal support, changes in credentialing and scope of practice limitations, and an adequate labor market. Proposals include using Medicaid funds to pay spouses and parents as personal care attendants, developing consumer-directed services, and providing pay increases for home and community-based providers.

- *Consumer Education and Information.* The agencies are considering developing and distributing informational materials to help consumers make informed choices, and providing training for consumers and providers. In October 2001, AHCCCS began requiring all contractors to convene member/provider councils to obtain input and feedback on Long–Term Care plans.

- *Consumer-Centered Care Management.* The goal is to provide ongoing training to consumers on consumer-centered care management and to encourage self-advocacy.

- *Provider Networks.* Agencies are conducting an ongoing analysis of the state's service networks, including the development by AHCCCS contractors of formal network development and management plans.

Future Outlook

In her 2002 state-of-the-state speech, Governor Jane Dee Hull (D) proposed that the Arizona Health Care Cost Containment System, in collaboration with business and other public and private agencies, develop a statewide education and public awareness campaign on long-term care. The program would be designed to assist citizens to learn about their long-term care service needs, potential costs and funding mechanisms, and community assistance opportunities.

State officials have indicated that any program or service changes that may come out of the *Olmstead* planning process will need to be–cost neutral.

Arkansas

Overview

Arkansas officials and lawmakers have launched a major effort to respond to the Supreme Court *Olmstead* decision through a planning process aimed at expanding opportunities for people with disabilities to remain in the community.

Although the *Olmstead* planning work continues (see below), legislators have focused on nursing home reform and regulation of assisted living facilities. On the fiscal side, the state appears to have been able to restrain growth in its nursing home resident caseload, although nursing home expenditures have continued to increase significantly. The state currently is serving almost as many people in home and community-based services (HCBS) as in nursing homes, totaling about 9,000 participants in its Medicaid Personal Care and HCBS waiver programs, compared to about 14,000 nursing home residents.

Arkansas also is one of three states participating in a major Medicaid consumer-direction initiative known as "Cash-and-Counseling," sponsored by the Robert Wood Johnson Foundation and the U.S. Department of Health and Human Services. Under this demonstration project, more than 2,000 Medicaid beneficiaries are able to select their own personal care worker and receive cash to pay the worker or use a fiscal intermediary to handle payroll functions. The state currently is seeking to expand the program.

Fiscal Analysis

Institutional caseloads in Arkansas have remained fairly steady since the year 2000 at about 14,000 nursing home residents and about 1,700 ICF/MR residents. During the same period, caseloads have slightly declined for the Medicaid Personal Care program, but have significantly increased for the HCBS waiver programs for the elderly and the MR/DD populations.

The state has made a major commitment to HCBS services through the Personal Care program, which was the fifth highest in the country in 2000 in per capita spending for these services. In 2002, Arkansas spending on HCBS is allocated largely to the HCBS waiver programs ($100.7 million), the Personal Care program ($62 million), and other community-based care ($62 million). Highlights of the fiscal picture include the following:

- Spending for nursing home care was expected to rise from $324 million in fiscal year (FY) 2001 to $426 million in FY 2002, a 30 percent increase. This follows spending increases for nursing homes of only about 4 percent from 1999 to 2000 and about 6 percent from 2000 to 2001.

- Spending for home and community-based care waiver services increased by about $20 million (from $71.9 million to $91.4 million) from FY 2000 to FY 2001, and then by another $9 million from FY 2001 to FY 2002.

- The state expected to spend about $50 million in 2002 on the MR/DD waiver program, and more than $35 million for its Aged waiver program.

Legislative Activity

The two main long-term care issues debated by the legislature in 2001 concerned regulation of assisted living facilities and minimum staffing standards for nursing homes.
Arkansas was one of two states (North Dakota was the other) that established a regulatory framework for assisted living in 2001 by establishing licensure and oversight standards for these facilities. The legislature also required nursing homes to maintain sufficient staff to maintain minimum staff-to-patient ratios, a goal to be phased in during several years. Nursing homes that do not comply with the new ratios will face stiff monetary penalties and may be ordered to stop admitting new residents.

In other actions, the legislature:

- Approved the establishment of a voluntary liability insurance plan for long-term care providers that have difficulty obtaining liability insurance. Coverage will be provided on an occurrence basis, limited to $1 million per occurrence with a $3 million aggregate amount per year.

- Directed the state to apply for a Medicaid waiver to cover assisted living services for at least 1,000 Medicaid beneficiaries.

- Required a study to determine the reasonableness of nursing home rules and regulations; levied a quality assurance fee on nursing facilities, and increased civil penalties for abuse, neglect or exploitation of long-term care facility residents.

Long-Term Care Planning

In May 2000, Governor Mike Huckabee (R) directed the Arkansas Department of Human Services (DHS) to develop a working group to conduct a comprehensive review of the state's existing services for people with disabilities and to identify ways to increase community-based services for this population. On February 15, 2001, the working group delivered a series of recommendations to the governor. The recommendations call upon the state to:

- Identify legislation and funding priorities to improve access to home and community-based services.

- Fund existing developmentally disability waiver programs.

- Give people with disabilities the option of receiving home and community-based services if desired, and develop an assessment program to gauge a person's ability to receive services in the community.

- Organize transition teams to assist people who are making the transition from institutional to community-based care.

The Governor's Integrated Services Task Force was created to replace the working group and to guide implementation of the recommendations. The Department of Human Services hoped that a plan would be completed by spring 2002 so that its recommendations could be reflected in the budget for the 2003 legislative session.

Future Outlook

Arkansas has not been free from the budget difficulties faced by most states in 2001 and 2002. In the fall of 2001, Governor Huckabee announced that $142 million in across-the-board cuts were necessary due to revenue shortfalls. Nevertheless, the state's commitment to expansion of home and community-based care appears to remain strong, as evidenced by increased spending on the state's Personal Care program and HCBS waiver programs for the elderly and for the MR/DD population.

The state also has received almost $2 million from the Systems Change Grant Program in 2001. One grant for $900,000 will be used to develop an advisory council to the Division of Developmental Disabilities. The council, to be composed of consumers and families, will provide guidance to the division and train and support self-advocacy networks. Another activity under this grant calls for developing an advertising campaign and materials for recruiting direct support professionals to provide community-based services.

With the other $1 million grant, Arkansas will address the need for a single point of contact for home and community-based care, timely and flexible eligibility determination, and ease of access to services. Activities under this grant include a feasibility study to integrate Medicare and Medicaid services for senior citizens and training for Department of Human Services staff about available alternatives to institutionalization.

To encourage recruitment and retention of paraprofessional workers, the state proposes to explore the options for providing insurance to these workers and to develop a state worker registry. The state also will create a public awareness campaign to elevate the status of frontline workers with the general public.

The state received additional grants of $598,444 and $360,000 from the Systems Change Grant Program in 2002.

California

Overview

California's governor and Legislature have directed significant attention to nursing home reform and expansion of community-based long-term care during the last two years. Governor Gray Davis (D) proposed an "Aging with Dignity Initiative" soon after he took office to improve services to the elderly. The Initiative included recommendations to improve nursing home care through increased nursing home inspections, focused nursing home quality reviews, and a rapid response system for nursing home complaints. Other parts of the initiative called for higher pay for long-term care workers, caregiver recruitment and training, and a $500 tax credit for family caregivers.

The Legislature subsequently enacted several components of the initiative, with the most contentious issue being minimum nursing home staffing levels (see below). A study by the Department of Health Services (DHS), released in June 2001, did not recommend higher minimum staffing levels, citing lack of "adequate empirical data" to make the case that higher minimums would improve quality of care. (Effective January 2000, the minimum nursing staff requirement had increased to 3.2 hours of direct care per patient day.)

The report proposed, however, that the state address the development and stability of the long-term care workforce and explore facility-specific rate setting instead of the current flat-rate reimbursement system for nursing homes. The state also continued to increase spending for home and community-based care services, with the major focus on the In-Home Supportive Services Program, which serves about 250,000 people annually and is funded through both Medicaid and state general revenues. In March 2001, the governor announced more than $14 million in funding to expand long-term care options for senior citizens. The funding will provide grants for nursing home quality improvement and the development of innovative home and community-based care alternatives.

Fiscal Analysis

California is third among the states in Medicaid spending for nursing home care, with total expenditures expected to reach close to $3 billion in FY 2002. However, the FY 2002 total would be only a 4.3 percent increase over FY 2001 spending.

The next largest long-term care expenditure is for Personal Care, which is budgeted at $1.7 billion for FY 2002. Personal care services are provided through the In-Home Supportive Services (IHSS) Program (Medicaid-funded) and the Residual IHSS Program, which serves people who are not eligible for Medicaid (state-only funded). State-only funds are about 20 percent of total funding under this category. Highlights of the fiscal picture include the following:

- The state was spending close to $700 million for Home and Community-Based Services (HCBS) waiver programs in FY 2001, about 14 percent higher than the previous year (compared to a 19 percent increase for Personal Care during that period).

- More than 80 percent of total HCBS waiver spending went to the waiver program for the mentally retarded/developmentally disabled program (almost $600 million in FY 2001). The program served about 32,000 people in fiscal 2001.

Legislative Activity

The Legislature heatedly debated the nursing home staffing issue in 2001 and in October passed legislation (AB 1075) requiring DHS to develop regulations effective August 1, 2003, that establish staff-to-patient ratios for nursing homes by converting the existing 3.2 hours per patient day into such ratios. The legislation also requires DHS to implement a facility-specific rate-setting system by August 1, 2004. (AB 1075 makes implementation of the staffing ratios contingent upon appropriation in the Budget Act or other statute.)

Other long-term care legislation enacted in 2001 includes:

- Revised standards for adult day centers to improve the qualifications of owners/operators.
- Establishment of a state centralized consumer response unit to respond to consumer inquiries and complaints about long-term care facilities.
- Creation of a $10 million award program for nursing homes that serve a high proportion of Medi-Cal residents. The money must be passed on to exemplary direct care employees in the form of bonuses.
- Development of a plan by the Health and Human Services Agency to improve access to mental health services for individuals with Alzheimer's disease or treatable mental health conditions.

Long-Term Care Planning

The California Health and Human Services Agency Long-Term Care Council has been assigned the central role in *Olmstead* planning and implementation. The council has six work groups that handle such issues as coordination among home and community-based supportive services, creating an inventory of long-term care data, increasing the quality and availability of consumer long-term care information, and other long-term care issues. One work group is focusing on developing and conducting a nursing home assessment and transition pilot project. The council's Web site reports that the state " … plans to take steps to modify the existing assessment process (for nursing homes) to assist individuals who wish to transition into more independent living settings."

The Council held four public forums in different part of the state in 2000 and 2001 to gain input from consumers, family caregivers and others. Recommendations from these forums provided input to the development of grant proposals to the federal government for the Systems Change Grant Program.

Future Outlook

State officials and legislators report that the issues of increasing nursing home staff ratios and providing incentives for recruiting and training nursing home workers will continue to be high priorities, as will initiatives to advance home and community-based care as related to the Supreme Court *Olmstead* decision.

The state received three grants totaling more than $2 million from the Systems Change Grant Program in 2002. Two grants totaling $937,500 will be to assist individuals who wish to leave nursing homes to return to community settings.

Colorado

Overview

Colorado has been making a major effort since the mid-1990s to expand home and community-based services (HCBS) and slow the growth of nursing home use. From 1995 to 1999, the number of nursing home residents decreased by 1.6 percent and the number of nursing home beds increased by only 1.8 percent during that period.

In 1994, the state was allocating 69 percent of its Medicaid long-term care funds to institutional care and 31 percent to HCBS. By 1999, the proportion of Medicaid Long-Term Care funds going to institutions had decreased to 53 percent, and HCBS was receiving 47 percent.[1] Three times as many people with disabilities are being provided services in their homes and in the community than are receiving nursing home services (about 30,000 people in HCBS programs to about 10,000 people in nursing homes).

Fiscal Analysis

Colorado spent $305 million for nursing facility care in FY 1996; that figure had risen to $359.6 million in FY 2001. From FY 1996 to FY 2001, total spending for all the state's Medicaid waiver programs has almost doubled from $166 million to $319.6 million.[2] Highlights of the fiscal picture include the following:

- In 2001, Colorado was operating 10 Medicaid waiver programs, including an Aged/Disabled program and other programs covering peoples with AIDS, brain injury and mental illness and larger programs for the aged and disabled and people with mental retardation or developmental disabilities (MR/DD). Three programs were specifically directed at children with various disabilities and two provided services for people with developmental disabilities, including a Supported Living Services Program.

- The number of people in the state's Aged/Disabled waiver program rose from about 5,000 peoples in 1995 to more than 21,000 in 2001.

- In terms of expenditures, the largest waiver program in 2001 was the MR/DD program at $184 million; the next largest was the Aged/Disabled program at $74.8 million.

Legislative Activity

Legislation enacted in June 2001 creates new quality improvement incentives for nursing homes. One measure allows nursing homes to apply for funding to create "resident-centered" activity programs that focus on enhanced communication and better understanding of resident needs. A second quality improvement initiative requires nursing homes that receive public funding to survey residents to determine their level of satisfaction with the care they receive. Facilities will be required to make their results available to new residents and the public. The law also requires state officials to develop a program to reward providers who achieve the highest quality-of-care standards within their facilities.

In 2001, lawmakers also directed the legislative Colorado Health Care Task Force to study innovative housing options, home and community-based services, and assisted living services for older people who can no longer live independently in their communities. The task force is to identify possible funding sources for these levels of care, and make recommendations to the legislature in 2002.

Long-Term Care Planning

Colorado state officials have been developing a plan to address the problem of individuals receiving care in institutions who are assessed as appropriate for community-based care but are on waiting lists, and individuals with developmental disabilities who are on Medicaid waiting lists. The Department of Human Services has been overseeing the development of the plan in regard to developmental disabilities and mental illness, while the Department of Health Care Policy and Finance has responsibility for the areas of physical disabilities and aging.

The various components have been melded into one plan, which was available for public comment in April 2002.

Future Outlook

Colorado received a $800,000 Nursing Facility Transitions Grant from the federal Systems Change Grant Program, which the state expects to use help 130 nursing home residents make the transition to the community. The Colorado Transitions Project will create a State Transitions Resource Team to oversee the project and establish 10 support networks through independent living centers to coordinate services, referrals and follow-up. The state will provide choice information to more than 1,200 individuals in nursing facilities to reach the goal of 130 transitions.

Notes

[1] American Association for Retired Persons, *Across the States 2000*. (Washington, D.C.: AARP, 2000)

[2] Expenditure and caseload data from Burwell, using HCFA Form 64 and Harrington using HCFA Form 372

Connecticut

Overview

Although Connecticut is spending more than a $1 billion on nursing homes, the growth in this component of the state's long-term care system has been relatively flat during the past few years, as has the number of residents in nursing homes. A moratorium on nursing home beds has been extended until June 30, 2007.

A major state priority has been nursing home reform, with the legislature focused on nursing home staffing. At the same time, the state has devoted considerable resources to home and community-based services (HCBS), particularly on spending for a Medicaid waiver program for mentally retarded individuals, on which the state expects to spend about $360 million in FY 2002.

Fiscal Analysis

The state has been controlling the potential growth of nursing home beds through a moratorium on further construction, and the number of nursing home residents has remained steady at about 20,000. Total expenditures for nursing home care reached $1 billion in 2001 and were expected to remain at a similar level in 2002.

State spending for ICF/MR facilities was expected to reach about $185 million in 2002, with these facilities serving about 1,200 people. Highlights of the fiscal picture include the following:

- The Medicaid MR/DD program is expected to serve about 6,000 people in 2002, an increase of about 1,000 people over the 2000 totals. Expenditures were expected to remain fairly static, however, rising only by about $8.6 million from $349.4 million in 2000 to a projected $358 million in 2002.

- The state reports a considerable caseload in 2001 of about 25,000 people in residential care facilities, at a state cost of about $95 million. These figures cover assisted living facilities, board and care homes, and congregate living settings.

Legislative Activity

In 2001, the Connecticut General Assembly focused on nursing home staffing for the second straight year. Legislation signed into law in July authorizes the state's commissioner of social services to provide rate relief to chronic and convalescent nursing homes and rest homes with nursing supervision to enhance staffing. The commissioner will give priority in the use of funds to facilities with lower staffing levels.

A legislative committee completed a major study of the Medicaid rate setting system for nursing homes. The report recommends more frequent re-basing of rates and use of a simplified case mix system to ensure that the severity of a nursing home resident's needs is factored into reimbursement.

Long-Term Care Planning

A Community Options Task Force, comprised on individuals with disabilities and advocates, was created to help develop a comprehensive long-term care community integration plan. Officials with the Department of Social Services and the Connecticut Council of People with Disabilities are co-chairs of the task force.

The task force, which released a draft plan (*Choices Are for Everyone)* in September 2000, has held public hearings and a forum to gain input on the plan and prepared grant applications to secure funding for community initiatives. The task force also is working with the Long-Term Care Planning Committee, established by the Legislature in 1998 and comprised of legislators and eight state agency representatives.

Choices Are for Everyone outlines the following goals:

- Developing new options related to community integration approved in the 2000 legislative session, such as assisted living services, increased housing options for people with psychiatric disabilities, and pilot programs for seniors and certain people with severe physical disabilities.

- Providing additional services and supports for the future.

- Developing a system for monitoring quality and outcomes.

- Developing targets for deinstitutionalization.

Future Outlook

State officials and legislators have indicated that nursing homes and assisted living issues remain among their major priorities, particularly increased reimbursement for both types of facilities. High–priority issues include tax credit or deductions for private long-term care insurance and increases in long-term care insurance for state employees. The legislature also is interested in authorizing consumer-directed personal care assistant services for the Home Care Program.

Connecticut received two grants under the Systems Change Grant Program, one for $800,000 to facilitate transitions from nursing facilities to independent living in community settings and another for $1,385,000 in the second round of Real Choices grants. The nursing facility grant will be used to identify 150 nursing facility residents who want to return to independent community living and to help them make the transition. The Connecticut Association of Centers for Independent Living will be responsible for the overall management and administration of grant activities, including the provision of financial support for project staff in the five Centers for Independent Living that will implement the project's activities.

Activities under the grant include: 1) designing and implementing an outreach campaign with materials that inform nursing facility residents and their families about long-term care alternatives and 2) developing and implementing a volunteer peer support network to provide technical assistance to people who are making the transition to the community.

Delaware

Overview

Delaware appears to be keeping its nursing home population from growing, but waiting lists exist for community-based programs. Delaware is serving about half as many people in community settings as in nursing homes—about 1,800 people receive home and community-based services (HCBS) compared to between 3,300 to 3,400 nursing home residents. State officials expect that the caseload for HCBS will increase to about 2,200 individuals in FY 2002 but that the nursing home population will remain constant.

Fiscal Analysis

Delaware spent about $100 million for nursing home care in FY 2000, an amount the state estimated would increase to $132.4 million in FY 2002. Expenditures for ICF/MR care were expected to increase only slightly during those years, from $33.2 million to $37 million. Highlights of the fiscal picture include the following:

- For the three HCBS waiver programs (Developmentally Disabled, Elderly and Physically Disabled, and AIDS), the state spent $40.6 million in FY 2000. State officials estimated an increase of almost a third for the three programs in FY 2002, to $53.8 million.

- In terms of expenditures, the largest HCBS waiver program in Delaware is the program for people with developmental disabilities, on which the state spent $31.6 million in FY 2000 and expected to spend $42.4 million in FY 2002.

Legislative Activity

After implementing staffing standards for nursing homes in 2000, lawmakers amended those requirements during the 2001 session. The amendments eliminate the requirement that nursing homes have a nursing supervisor on duty at all times and permit nursing homes to count toward minimum staffing ratios those individuals who have completed all but the final 37.5 hours of classroom and clinical certification training in facility-sponsored certified nursing assistant training programs.

While the state implements these changes, the Division of Long-Term Care Resident Protection is studying Certified Nursing Assistant training programs in the state. The study is examining the percentage of each training program's graduates who passed the CNA certification test, the number of attempts it took each graduate to become certified, and the total number of hours spent in the overall CNA training program. The division also will make a recommendation on whether the state should count nursing assistants in training toward minimum staffing requirements.

Long-Term Care Planning

In May 2000, Governor Ann Minner (D) issued an executive order expressing the state's commitment to providing community-based services for people with disabilities. The executive order required the Delaware Department of Health and Social Services to submit three separate plans for different population groups: people with developmental disabilities and mental retardation, the elderly and people with physical disabilities, and people with mental illnesses.

The plans were issued in the summer of 2001. Each plan became part of the five-year strategic plan of the agency responsible for its management.

Future Outlook

One of the principal issues that Delaware is facing is waiting lists for home and community-based services. Like other states, Delaware is also faced with a shortage of workers for both community and institutional providers.

Delaware received a $1.2 million grant under the federal Real Choice Systems Change Grant Program, which the state plans to use expand the range of assistive technology options and alternatives for people with one or more disabling conditions.
Led by the Delaware Division of Developmental Disabilities Services, a work group comprising key stakeholders developed a three-year plan to expand access to assistive technology. The state plans to conduct a needs analysis and an awareness campaign and training activities for various target groups and to design a tracking system for assistive technology.

Delaware also received two grants in the second round of the Systems Change Grant Program in 2002, one for $270,000 and another for $566,772, to help people make the transition from nursing facilities to the community.

District of Columbia

Overview

The District of Columbia is second only to Mississippi in percent of persons age 65 and older with incomes below 100 percent of poverty, 16.8 percent compared to a national average of 10.1 percent and Mississippi's 17.6 percent ratio.

The District has had high institutional costs in recent years. The city's per capita rate for ICF/MR facilities was the highest in the country in FY 2000 ($122.85) and its per capita rate for nursing homes was the fifth highest that year ($245.34). Because of its high per capita costs for institutional care, the District ranked sixth in the country in per capita long-term care expenditures in FY 2000.

Fiscal Analysis

Ninety-four percent of the District's Medicaid long-term care expenditures went to institutional care in FY 1999, and only 6 percent to home and community-based services, mainly through spending on Medicaid home health services. The city's Medicaid Personal Care Program went from total expenditures of $6 million in FY 1995 to only $1.8 million in FY 2000.

The District applied for and was approved by the federal government in 2000 to operate three Medicaid waiver programs Aged and Disabled, Mentally Retarded, and AIDS. By FY 2001, expenditures for the waiver programs totaled $1.5 million.

Highlights of the fiscal picture include:

- The number of nursing home residents in the District increased by 11.5 percent from FY 1995 to FY 1999 to total about 2,400 persons. However, the number of nursing facility beds per 1,000 of the 65+ population decreased by 4 percent over that period.

- The nursing facility occupancy rate was 93.3 percent compared to a national average of 82.7 percent in 1999.

Legislative Activity

There was no significant long-term care legislation in FY 2001.

Long-Term Care Planning

The Medicaid agency within the Department of Health convened a "Real Choice Systems Change Advisory Committee" to oversee the redesign of the District's long-term care system. The advisory committee includes consumers, providers, and various District government agencies.

The Department of Health's 2002 budget included funding for initiatives aimed at improving long-term care service delivery. Specifically, the Department is designing a resource center to help the city create a service delivery model similar to Wisconsin's Family Care program. The intent is for the model to start with frail elderly people and persons with physical disabilities, and then be extended to people with developmental disabilities and mental illness. The city is also seeking to

expand its 1915c waiver for persons 65 and older to adults under age 65 with physical disabilities, and to provide attendant care and assisted living.

The District recently settled a case, *Evans vs. Williams,* on behalf of individuals with developmental disabilities who were not receiving adequate community supports. The settlement requires detailed actions that the District must take to provide community services, and establishes a set of measurable outcomes to gauge the effectiveness of these services.

Future Outlook

The District received two grants in 2002 from the Systems Change grant program, both of which will be administered by the Department of Health, Medical Assistance Administration. One grant for $725,000 was in the category of Community-Integrated Personal Assistance Services and Supports; the other grant for $1,385,000 was in the Real Choice Systems Change category.

The grants should help the city move forward with its projects to expand home and community-based care.

Florida

Overview

Florida is first in the nation in the percentage of total population that is age 65 and older (18.1 percent compared to the national average of 12.7 percent in 1999). Its allocation of Medicaid long-term care funds is heavily slanted toward institutional care (81 percent institutional compared to 19 percent for home and community-based care services in 1999). However, the state has plans under way to help people make the transition from institutions into the community and to increase home and community-based options for people with disabilities.

In January 2001, Governor Jeb Bush (R) partly unveiled his "elder-friendly" initiative, which called for significant increases in funding for nursing homes and nursing home quality of care reform. The state faced a serious situation in regard to liability insurance for long-term care providers when a number of insurance companies threatened to pull their business out of Florida because of mounting lawsuits against nursing homes. The Legislature took action in 2001 to stabilize financial risks for long-term care facilities and initiated several key quality-of-care actions, including establishing higher nursing staffing standards and creating a trust fund to support quality improvement initiatives in nursing homes and assisted living facilities (see below). The governor signed the legislation into law in May 2001.

Fiscal Analysis

Florida spent almost $2 billion on institutional care in FY 2001, which consisted of $1.7 billion for nursing facilities and $290.5 million for ICF/MR facilities.[1] This total compared to $384 million for home and community-based services (HCBS) that year.

However, given the high proportion of elderly people in the state, Florida had a lower nursing facility bed ratio per 1,000 people age 65 and older in 1999 than the national average (30.3 beds compared to 52.3 beds for the nation as a whole) and a smaller percentage of the age 65 and older population residing in nursing homes than the national average (2.5 percent compared to 4.3 percent nationally).

The state operated seven Medicaid waiver programs in FY 2001. The total $551 million expenditure for waiver programs was triple the amount spent in FY 1995 ($151.4 million). The largest waiver program in terms of expenditures was the MR/DD program, which accounted for $419 million in FY 2001 and a caseload of about 13,000 people.
Highlights of the fiscal picture include the following:

- The state spent $74.4 million on its Aged/Disabled waiver program in 2001, with a caseload of about 13,800 people.

- Although the state's Medicaid Personal Care program was small compared to the HCBS waiver programs, the $17.6 million total expenditure in FY 2001 was almost five times as much as the state spent on the program in FY 1995 when the total was $3.7 million.

Legislative Activity

The Task Force on Availability and Affordability of Long-Term Care, established in 2000, reported recommendations to the Legislature in January 2001. Many of the task force proposals were adopted by the Legislature.

Major legislation in 2001 addressed the liability insurance issue in regard to nursing homes. The measure provided a clearly defined negligence standard, established a claims evaluation process, revised the statute of limitations on when actions could be initiated, and set caps on punitive damages.

In terms of quality of care issues, the Legislature accepted a task force recommendation for higher nursing home staffing standards for direct care workers. The legislation provided for minimum staffing standards of 2.3 hours of direct care per resident, per day beginning Jan. 1, 2002, increasing to 2.6 hours beginning Jan. 1, 2003, and to 2.9 hours beginning Jan. 1, 2004.

Other steps to improve quality included new training requirements for certified nursing assistants, increased penalties for nursing homes with deficiencies, increased reporting requirements for nursing facilities and assisted living facilities, and a study of the use of electronic monitoring devices to monitor quality of care in nursing homes.

Long-Term Care Planning

Florida has developed an *Olmstead* coalition that includes state agencies, consumers and other key stakeholders. Long-term planning and implementation are moving on several different fronts. On one front, the state settled a class action suit in August 2000 (*Wolf Prado Steiman vs. Bush),* agreeing to improve services for individuals with developmental disabilities on Medicaid waiting lists. Under the settlement agreement, if a waiver slot and funding are available, eligible people will be provided the waiver services within 90 days of application.

Other actions the state planned to implement in FY 2001 included doubling the number of developmental disability waiver slots from about 13,000 to 26,000, implementing a nursing home transition grant for people with traumatic brain injuries in nursing homes, and amending the Medicaid state plan to include assisted living. The state also planned to make a demonstration program available statewide on assertive community treatment for people with behavioral health needs.

Future Outlook

The state received a $2 million Systems Change Grant, which it expects to use to expand the implementation of a Clearinghouse on Disability Information. The clearinghouse will be a comprehensive single point of contract system that consumers can use to obtain information about long-term care services and links to state and local resources. The state also will create local grassroots long-term care resource networks in three demonstration areas, which will provide technical assistance and local community resources to address barriers and share best practices.

Another initiative the state will pursue involves the disability and aging communities, housing administrators and providers to increase housing choices for people with disabilities. Through this initiative, Florida hopes to establish partnerships and cross-train on the housing needs of people

with disabilities, develop an effective tool to assess the need for home modifications and assistive technology, and increase the number of Section 8 vouchers for public housing.

Notes

[1] Expenditure and caseload data from Burwell using HCFA Form 64 and Harrington HCFA Form 372

Georgia

Overview

Georgia has the fourth fastest growing population of people age 60 and older and the third fastest growing population of people age 85 and older in the United States. Although the state has been paying for the care of about 28,000 nursing home residents, the caseload for home and community-based care services (HCBS) was expected to reach almost 21,000 people in FY 2002.

Fiscal Analysis

The state expected to spend about $914 million on institutional care in FY 2002, composed of almost $797 million for nursing facility care and $118 million for ICF/MR facilities. The FY 2002 total was $94 million more, or about 11 percent higher than the FY 2000 totals for institutional care ($708 million for nursing facilities and $111.5 million for ICF/MRs).

Although Georgia has been steadily expanding its funding for HCBS since the 1990s, spending for these services still is lagging considerably behind total expenditures for institutional care. The state spent about $160 million for home and community-based waiver services in 2000, for example, and had no Medicaid Personal Care program.[1] However, the caseload for all the waiver programs totaled almost 17,000 in FY 2001, compared to a Medicaid caseload in nursing homes of about 28,000. Highlights of the fiscal picture include the following:

- The state spent $60.7 million in FY 1999 for its MR/DD waiver program.[2]

- The state expanded funding from $64.5 million in FY 2000 to an estimated $76.4 million in 2002 for the Aged/Disabled Medicaid HCBS waiver program, called the Community Care Services Program.

- The state's FY 2002 budget included additional funding to expand the caseload of the Community Care Services Program by another 2,000 people. The budget also included an additional $4 million to provide home and community-based services for another 2,000 people who are not eligible for Medicaid coverage.

Legislative Activity

Lawmakers enacted several nursing home measures in 2001. One new law requires civil monetary penalties against a nursing facility to be suspended if state surveyors do not re-survey the facility within 48 hours from the time a facility completes its corrective plan of action. After the 48-hour period, if surveyors find the facility is not in substantial compliance with standards, state officials may impose penalties from the date penalties were suspended.

Another 2001 law prohibits nursing homes from employing individuals with criminal records determined by a criminal background check. Lawmakers also adopted a resolution urging officials in the Georgia Department of Community Health to provide nursing homes with incentives and wage "pass throughs" to increase the number of nursing staff.

Long-Term Care Planning

The Georgia Department of Human Resources is heading a planning effort to improve access to community services for people with disabilities and has been working with the Georgia Department of Community Health and an *Olmstead* Planning Committee. The planning committee is composed of representatives of a number of state agencies, consumers and family members, advocates, and service providers.

The committee was charged with developing a set of recommended action plans for state implementation to facilitate service delivery in the most integrated setting for people with disabilities. The committee's initial recommendations include establishing a policy that people of all ages with disabilities who can be served in the community not be institutionalized.

Other recommendations include:

- Training treatment professionals to assess and determine the supports needed by each individual to live in the most integrated setting possible.
- Amending the state's Nurse Practice Act to permit nurses to delegate certain nursing tasks to other trained personnel.
- Developing programs to enhance family supports and case management for people with high-end physical and medical needs.
- Supporting legislative and regulatory changes that allow for community living options and increasing flexibility in Medicaid home and community-based waiver programs.
- Maintaining a trained, and competent long-term care provider network.

Future Outlook

The Georgia Division of Aging Services has been awarded an Innovative Program Grant from the U.S. Administration on Aging. The Georgia project will increase service options for consumers by developing five self-directed care voucher projects in rural areas of the state. The project will evaluate caregiver satisfaction with self-directed care by comparing consumers who receive the vouchers and use them to purchase services or supplies to those who receive services through more traditional methods.

Georgia also has received two federal grants in 2001 totaling more than $1 million for nursing facility transitions under the Systems Change program and another $1,385,000 in the second round of grants in 2002. More than $600,000 of the first-year grants will be used to conduct a comprehensive community resource mapping project and workforce development project in 18 county pilot areas to identify barriers and opportunities for increased community services and direct care workers. The project will include the relocation to the community of 24 individuals who presently are residing in nursing homes.

Notes

[1] Burwell figures from Form 64 reports.

[2] Harrington figures from Form 372 reports. More recent figures were not available from the state.

Hawaii

Overview

Hawaii has taken a number of actions in recent years to expand home and community-based services for people with disabilities, particularly for those with mental retardation and developmental disabilities. Hawaii became the first state in the nation to put the concepts of self-determination and person-centered planning into its developmental disabilities law in 1998.

Person-centered planning and self-determination also have been built into the development of a five-year strategic plan for services and supports for people with developmental disabilities and mental retardation that the Department of Health submitted to the Legislature in December 2001. The plan responded both to the *Olmstead* decision and to a lawsuit (*Makin vs. Cayetano)* over waiting lists for community services for persons with developmental disabilities. The state has agreed to fund 700 additional community placements for people with DD over three years.

Fiscal Analysis

Hawaii's spending for ICF/MR facilities has gradually decreased from $11.6 million in FY 1996 to about $8 million in FY 2001. Spending for nursing home care has experienced only moderate increases from about $134.8 million in FY 1996 to $148.3 million in FY 2001.[1]

Expenditures for Medicaid home and community-based waiver services totaled $20 million in FY 1996, rapidly increasing to a total of $51.7 million in FY 2001. Highlights of the fiscal picture include the following:

- Hawaii spent $28.6 on its MR/DD waiver program in FY 2001 and a total of $22.4 million for two Aged/Disabled programs.
- In 2001, Hawaii allocated 74 percent of its Medicaid long-term care money to institutional care and 26 percent to HCBS.
- Hawaii had a nursing facility occupancy rate of 92.2 percent in 1999, compared to the national average of 82.7 percent.

Legislative Activity

The Legislature renewed its efforts in 2001 to address reforms for the state's long-term care system. Lawmakers began the 2001 session by declaring long-term care as their number one priority; in the end however, they were unable to agree on major reform proposals that would have created a unified, state-sponsored long-term care system. Instead, the Legislature approved several resolutions expressing the need to develop and implement a dedicated revenue source for ensuring a comprehensive long-term care structure.

The 2001 Legislature authorized the licensing of home and community-based case management agencies and the certification of community care foster family homes. Lawmakers also created a case management demonstration project. The project will involve home and community-based case management agencies that will locate, coordinate and monitor comprehensive services for Medicaid recipients and other adults in the community.

Long-Term Care Planning

The Hawaii Legislature passed a concurrent resolution in May 2000 to establish an *Olmstead* planning task force. In response, the state set up a planning committee chaired by the directors of the departments of Human Services and Health and the executive director of the Center for Independent Living.

The *Olmstead* planning task force held four meetings and set up four task forces based on different planning areas: 1) assessment, 2) information, 3) finance and 4) infrastructure. The planning committee's top priority was information, which includes developing an awareness of available resources and development of a single point of entry system. The infrastructure task force covers housing, transportation and personnel.

The planning committee has decided to focus on the development of an information portal to expand information dissemination and accessibility to individuals, and on an assessment mechanism to be used as a basis for using the portal. The portal will help people to find and link to available resources.

Future Outlook

Hawaii received a Systems Change Grant for $1,350,000 in the first round of the grants and another $725,000 Personal Assistance Services and Supports grant in the second round. The first grant will be used by the Hawaii Real Choices Partnership, which will involve all key stakeholders in developing a cross-agency Web-based Single Entry Point. The state will establish and support a governing council and workgroups to be chaired by a consumer with at least 51 percent consumer membership.

The goal of the system will be to provide consumers with information about all their available options, including services offered by private and public agencies. The system will include an interactive assessment process to help consumers identify services for which they are eligible; a unified database showing all long-term care services, with open slots listed by geographical location; and a quality assurance component that will identify service gaps by tracking service requests.

Notes

[1] Expenditure and caseload figures from Burwell, using HCFA Form 64 and Harrington, using HCFA Form 372.

IDAHO

Overview

Since FY 2000, Idaho has been steadily increasing the caseloads of the Medicaid Aged and Disabled waiver program and Medicaid Personal Care program. By FY 2002, Idaho had reached the point where the number of people receiving home and community-based services (HCBS) exceeded the number of people in institutional facilities by more than two to one (a total of almost 8,000 people in HCBS compared to slightly less than 4,000 people in institutional facilities).

Fiscal Analysis

The caseload for the Medicaid Aged/Disabled waiver program increased by more than 60 percent from FY 2000 to FY 2002, from 1,380 people to 3,589 people. The caseload for the Medicaid Personal Care program rose by more than 40 percent during the same period, from 2,331 people to 3,295 people.

Expenditures and caseloads for nursing facilities have increased fairly slowly from FY 2000 to FY 2002. Nursing home expenditures climbed by about 10 percent from FY 2000 to FY 2001 ($107.6 million to $119.1 million) and by about 5 percent from FY 2001 to FY 2002 ($119.1 million to $124.3 million). Nursing home caseloads also have shown only small increases, from 3,031 people in FY 2000 to 3,312 people in FY 2002. Highlights of the fiscal picture include the following:

- Expenditures for institutional care totaled $181.5 million in FY 2002, compared to a total of $86.1 million for HCBS ($72.1 million for the two waiver programs and $14.0 million for Personal Care).

- The state's Medicaid Personal Care program was expected to serve 3,295 people in FY 2002, almost 1,000 people more than the FY 2000 total of 2,331 people. Expenditures for this program have decreased, however, from $18.8 million FY 2000 to $14.0 million in FY 2002.

Legislative Activity

In 2001, Idaho became the 24th state to create a tax incentive for the purchase of long-term insurance. A new law established a tax deduction that allows purchasers to claim 50 percent of their premiums paid for a long-term care policy for themselves, a dependent or employees.

Long-Term Care Planning

Idaho is developing a comprehensive, long-term care plan through the Community Integration Committee, composed of representatives from the Idaho Department of Health and Welfare, the divisions of Family and Community Services and Medicaid, other agencies, advocacy groups, and consumers, including the Idaho Commission on Aging. The overall number of consumers on the committee will be increased, so that consumers comprise at least 50 percent of committee members.

The committee is assessing the state's current service delivery systems with regard to community integration, with no projected date for plan completion. Initial findings have focused on issues

that cross disability groups and cover a wide span of community and personal issues such as housing, transportation, medications and community-based supports. Idaho officials believe that crossover issues such as housing and transportation have the greatest effect on successful community living and independence.

Future Outlook

Idaho received a grant for more than $1.1 million from the federal Real Choice Systems Change Grant Program. The state plans to use the money in two phases. The first phase will involve a needs and resources assessment, culminating in a plan for change; the second phase calls for an effectiveness study to test and refine the plan.

Four objectives for the plan include increasing access in all forms, increasing availability and adequacy of services, increasing or maintaining the value of services across the system, and increasing or maintaining the quality of services across the system.

The final product will be a plan for statewide implementation and a monitoring system for continuous quality improvement.

Illinois

Overview

In 1994, Illinois was allocating 92 percent of its Medicaid long-term care funds to institutional care and only 8 percent to home and community-based services (HCBS). In 2001, the distribution of Medicaid funds had not changed significantly: 86 percent to institutional care and 14 percent to HCBS. The state had 74.2 nursing facility beds per 1,000 of the age 65 and older population in 1999, compared to a national average of 52.3 beds.

However, the state estimates that it is providing home and community-based services to about 40,000 people through its state-funded Community Care Program ($205.5 million in FY 2002) and through its Medicaid waiver programs.

Fiscal Analysis

Illinois spent about $2.2 billion on institutional care in FY 2001, consisting of $1.5 billion for nursing facilities and about $669 million for ICF/MR facilities. The nursing home population was about 53,000 people in 2000.[1]

The state spent a total of $348.6 million in FY 2001 for its Medicaid waiver programs. In 1999, the following caseloads were estimated for the largest waiver programs: Aged waiver, about 17,400 people; Physically Disabled waiver, about 12,400 people; and the MR/DD waiver, 7,000 people. Highlights of the fiscal picture include the following:

- Expenditures for nursing homes, which totaled $1.2 billion in FY 1995, increased by only about 2 percent to 3 percent in the late 1990s, until there was a 8.4 percent increase from FY 1999 to FY 2000.

- Of the state's eight HCBS waiver programs, expenditures were highest for the program for persons with physical disabilities, for which spending totaled $87.9 million in FY 2001. The next highest expenditure total was for the Aged program with $70 million in spending.

Legislative Activity

In two major actions affecting long-term care, Illinois lawmakers established new standards for the state's long-term care insurance industry in 2001 and addressed the issue of reimbursement rates for nursing homes. The law on long-term care insurance expands the definition of such insurance to include a policy or rider that provides benefits based on cognitive impairment or loss of functional capacity and establishes provisions for a " … qualified long-term care insurance contract or federally tax-qualified long-term care insurance contract." Insurers must deliver contracts or certificates within 30 days of approval and provide written notification of the reasons for denying coverage within 60 days of receiving a policyholder's written request for such information.

Responding to nursing home industry concerns that the current reimbursement system was not adequately paying facilities for their costs, the legislature approved a measure in June 2001 that requires the state to use more updated cost reports to determine reimbursement levels. Effective July 1, 2001, rates were based on 1999 cost reports rather than on rates set in 1994. The law also

extended the period during which reimbursement for skilled and intermediate care services may include an inflation factor from July 1, 2001, to July 1, 2002.

Long-Term Care Planning

In the spring of 2000, the legislature directed the Department of Human Services to convene a working group to plan for *Olmstead* compliance. Six groups produced broad recommendations in the following areas: financing, universal prescreening and community reintegration, housing, service coordination and public policy, community infrastructure, and best practices.

The highest priorities of the Illinois plan are housing, population identification, consumer education, making the transition from institutions to community care, and assessment and person-centered planning.

Future Outlook

Illinois received an $800,000 Real Choice Systems Change Grant, which the state will use to develop a Community Partner Fund to pay for Community Service Delivery teams in Rockford and southern Illinois. The Department of Human Services will seek to create a systems that fosters ongoing communication between various state agencies and community service delivery agents (CSDAs) in Rockford and southern Illinois.

The CSDAs include area agencies on aging, case coordination units, mental health networks, and centers for independent living. (Case coordination units in Illinois handle case management and preadmission screening for applicants for publicly funded services.) The aim is for CSDAs to be better able to help people who wish to make the transition from institutions to community settings.

Notes

[1] Expenditure and caseload figures are from Burwell using HCFA Form 64 data and Harrington using HCFA Form 372 data

INDIANA

Overview

Since September 2000, Indiana has been moving forward on a number of fronts to expand home and community-based services (HCBS). These steps range from issuing a "Comprehensive Plan for Community Integration and Support of Persons with Disabilities" to appropriating additional funds for the major state-funded HCBS program and adding slots to the Medicaid waiver programs.

Although Indiana allocates only 15 percent of its Medicaid long-term care funds to HCBS — compared to 85 percent to institutional care — the state has a more comprehensive HCBS system than those figures seem to suggest because of significant state funding (more than $40 million in FY 2000) for the Community and Home Options to Institutional Care for the Elderly and Disabled (CHOICE) program.

Fiscal Analysis

Although Indiana had a very high nursing home bed ratio per 1,000 people age 65 and older in 1999 (83.8 beds compared to a national average of 52.3 beds), the state experienced a 2.4 percent decrease in the number of nursing home residents from 1995 to 1999.[1] Expenditures for nursing facilities totaled $817.5 million in FY 2001.[2]

Spending on Medicaid waiver programs has risen sharply from the mid-1990s on, from about $30 million in FY 1996 to about $140.5 million in FY 2001. Still, the caseload for the Aged/Disabled waiver program has remained fairly steady at about 2,300 people and a waiting list for services that has been as high as 2,700 people has existed for some years. In contrast, the CHOICE program was serving about 12,000 people with disabilities in 2000, although it also had more than 7,000 people on a waiting list.
Highlights of the fiscal picture include the following:

- In terms of expenditures, the largest Medicaid waiver program was the MR/DD program with a total of about $120 million in FY 2001; spending for the Aged/Disabled program totaled $17.7 million.

- The CHOICE program has a sliding fee scale that allows people with incomes as high as 351 percent of poverty to receive services before they must pay the full cost of services.

Legislative Activity

The 2001 legislature directed the Family and Social Services Administration to develop a plan to ensure that the agency's programs match individuals' needs as closely as possible. The plan must consider expanding or implementing assisted living, adult foster care, faith-based assistance, philanthropic assistance, and long-term care programs and funding. The plan must include a detailed listing of specific care options that would comprise a continuum of care from least to most restrictive, the availability of federal waivers for these services, and a timeline for securing additional waivers or waiver amendments. The plan also must indicate the amount of additional investment that would be required to eliminate waiting lists for HCBS.

Another measure enacted in 2001 allows the state to provide a self-directed option for people who are receiving in-home services under Medicaid programs or the CHOICE program. Legislators also created a Governor's Commission on Caregivers to study and develop recommendations for recruitment and training of workers in long-term care facilities. Due to report by Oct. 1, 2002, the commission specifically will examine the availability of and need for workers, barriers to increasing their supply, and the adequacy of existing training programs.

Long-Term Care Planning

In June 2001, the state released what it termed the "First Edition" of its "Comprehensive Plan for Community Integration and Support of Persons with Disabilities." The plan includes a "Going Forward" section that outlines further steps that need to be taken beyond the 2002-2003 biennial budget. Six policy directives guide the priorities of the plan. They are:

- Enable individuals to receive the type of services they desire in the setting they prefer (consumer choice);
- Provide information, assistance and access to consumers to increase their opportunity for informed choice;
- Support the informal network of families, friends, neighbors and communities;
- Strengthen quality assurance, monitoring systems, complaint systems and advocacy efforts;
- Increase system capacity for provision of high-quality care; and
- Create a coordinated workforce development system that recruits and supports direct care staff.

The plan calls for the creation of the Real Community Choice Commission to provide ongoing oversight and to act as a leadership resource. The commission will consist of stakeholders and consumers of the plan.

Future Outlook

Although the state received federal approval for a total of 12,500 waiver slots for the Aged/Disabled waiver program in 2003 (an increase of 10,000 slots), it is unclear how quickly the state will begin moving people off the waiting list for the services because of rising Medicaid costs, which the state is trying to curb. The legislature approved 822 additional slots for the Aged/Disabled waiver program for FY 2002, and an additional 813 slots for FY 2003. An additional $6 million for each year of the biennial budget was also appropriated for Indiana's in-home services program, including $3 million for the CHOICE program.

Indiana also had submitted a proposal to CMS to replace the ICF/MR waiver, which had about 2,500 funded waiver slots in FY 2001, with a DD waiver to become effective in October 2001. The new DD program was slated to incorporate the existing caseload from the ICF/MR waiver and expand to 5,649 slots by FY 2004.

The Family and Social Services Administration plans to refine the Comprehensive Plan with a "Second Edition" and further successive editions to ensure that the planning effort is moving forward.

Indiana has received almost $2.9 million in federal Systems Change Grants Program funds. Of that total, the state received $770,000 in the first round of the grant program in 2001 for nursing facility transitions. The funds will be used to identify appropriate candidates for participation using the preadmission screening process, minimum data set assessment data, and outreach. The state hopes to develop appropriate housing options, a specialized case management system to aid in transition, and local coalitions for diversion and deinstitutionalization activities.

Notes

[1] American Association for Retired Persons, *Across the States, 2000* (Washington, D.C.: AARP, 2000)

[2] Expenditure and caseload figures from Burwell using HCFA Form 64 and Harrington using HCFA Form 372

Iowa

Overview

Iowa ranks fourth in the country in the proportion of people age 65 and over to the total population with almost 15 percent (compared to a national average of 12.4). State officials appear committed to continuing to build on recent initiatives to provide expanded home and community-based care (HCBC) options for elderly people and people with disabilities.

In 2000, the legislature established the Comprehensive Senior Living Program, which is intended to create a comprehensive, long-term care system that is consumer-directed, balanced in offering both institutional and non-institutional services, and supportive of the quality of life of Iowans. One component of this program is the Senior Living Trust Fund, which generates funds for development of alternative services for elderly and disabled people who are either in nursing homes or are at risk of placement in nursing homes. The trust provides assisted living, home-delivered meals, adult day care, and respite care to nearly 12,000 elderly people.

In his 2002 state-of-the-state speech, Governor Thomas Vilsack (D) announced his intention to continue providing options to the elderly and people with disabilities through the Senior Living Trust Fund.

Fiscal Analysis

The two major Medicaid home and community-based waiver programs in Iowa are the program for mentally retarded people and the elderly program, each with about 3,300 participants in 2001. Each of these programs is expected to increase its caseload in 2002 to about 4,500 people.

- State spending on nursing homes was expected to reach almost $383 million in 2002 and serve 29,000 people. Another $115 million was projected for ICF/MRs in 2002.

- Funding for the Medicaid HCBC waiver program for mentally retarded people was expected to total more than $80 million in 2002, about four times more than the other five waiver programs combined. The average monthly caseload for this program has been steadily, increasing from about 3,000 people to an expected 4,400 in 2002.

- The state expects to spend about $21 million in 2002 for waiver services for the elderly.

Legislative Activity

The 2001 General Assembly appropriated funding for the development and implementation of the Comprehensive Senior Living Program. The funding was to be used to recruit and retain nurse aides; provide adult abuse detection, training and services; convert nursing facilities to assisted living programs; provide home and community-based waiver services; and implement a case-mix reimbursement system for nursing facilities.

Also in 2001, lawmakers established an oversight system for all adult day services in the state, to be implemented by July 1, 2002. The system will include requirements for operating adult day services, a formal investigation system for consumer complaints, and a coordinated plan for using available funding sources for adult day services.

Long-Term Care Planning

The Department of Human Services held public meetings throughout the state in 2000 to gain input on improving community services for the elderly and people with disabilities. In June 2000, the legislature authorized creation of the Mental Health and Developmental Disabilities Service Task Force to recommend ways to improve service delivery for people with disabilities. The task force report was released in June 2001.

Future Outlook

The Senior Living Trust has awarded 34 grants totaling $10.6 million to facilities to provide a greater range of choices for assisted living for the elderly. The Department of Human Services has announced that it expects to award another $80 million in grants during the next three years "to expand the options available to seniors." With the commitment from the governor and the legislature, Iowa appears prepared to continue its current initiatives for an extensive network of home and community-based care services in the state.

Iowa also received a $1,025,000 grant in 2001 under the federal Real Choice Systems Change Grant Program and an additional $360,000 in the second round of the grants in 2002. With the $1 million grant, the state plans to set up systems to identify all people with disabilities currently living in institutional settings and those at risk of entering institutions. Iowa will train community living specialists to assist consumers with transition activities and support them in community living.

Other components of the project include providing information to individuals with disabilities and their families about resources, services and supports. The state also plans to design an individualized, consumer-centered process to assess individual preferences and abilities that will allow consumers to make informed choices about where they will live and the services they will receive.

Kansas

Overview

Although the number of nursing home residents in Kansas has been slowly declining, expenditures for nursing homes have continued to climb, from about $287 million in FY 2000 to a projected $324 million in FY 2002. During the same period, however, the state has been steadily increasing its spending for long-term care services in the community to the point that its home and community-based services (HCBS) spending soon could equal its expenditures on institutional care. In addition, Kansas was providing long-term care services to an almost equal number of people in the community as in nursing homes¾about 12,000 in each setting.

Fiscal Analysis

The state's spending on nursing home care in FY 2000 totaled almost $287 million compared to about $259 million for HCBS waiver programs. The state expected to reduce its nursing home population by almost 300 people by FY 2002 as it increases its waiver caseloads during the same period by about 1,800 people. Highlights of the fiscal picture include the following:

- Officials expected nursing home expenditures to reach $324 million in 2002, about a 13 percent increase over FY 2000 spending.

- The most costly HCBS waiver program is the Developmentally Disabled program, on which the state spent $157.7 million in FY 2000 for 3,729 people. Those costs are estimated to rise to $178 million in FY 2002.

- The waiver program with the largest caseload was the Frail Elderly waiver, with a FY 2000 caseload of 4,877 at a cost of $43.7 million. The state expected to add another 643 people to this waiver program in FY 2002.

- Expenditures for ICF/MR facilities were expected to increase only slightly from the FY 2000 level of about $66 million to a FY 2002 total of about $70 million. Officials report the anticipated FY 2002 caseload at 529 people.

Legislative Activity

In 2001, the Legislature appropriated funding for an interim study by the Legislative Budget Committee to examine whether the level of care score for entry into a nursing home or to receive in-home services should be raised or was adequate at its current score. The committee must report its findings and recommendations to the Legislature during the second half of the biennial session in 2002.

The 2001 session also directed the Kansas Department of Aging (KDOA) to combine all state general fund programs—including the Income Eligible Program and the Senior Care Act Program—that provide homemaker, chore and attendant care services for people who are not income eligible for Medicaid-funded services.

Long-Term Care Planning

KDOA and the Kansas Department of Social and Rehabilitation Services formed a work group in February 2000, with two subcommittees. One subcommittee was to draft a report on state efforts during the last decade to include people with disabilities in the community, while the other subcommittee was to work on how to best identify people who want to leave institutions to live in the community.

The progress report, expected in early 2002, will outline the activities of state agencies to develop and support a community-based long-term care system that applies to all people with disabilities.

The state formed a consumer task force made up of stakeholders and consumers from the major disability groups¾developmental disabilities, physical disabilities, head injury, mental health, aging, and HIV/AIDS. The task force directed the preparation of a grant application for a Systems Change Grant. The state also plans to continue to use the consumer task force to help with further long-term care planning efforts.

Future Outlook

State officials and legislators report as a high priority continued expansion of HCBS for the elderly and for people with mental illness and developmental and physical disabilities. In addition, KDOA has been given a mandate by the Legislature to expand education efforts to make Kansans aware of the cost of long-term care and to encourage consumers to purchase long-term care insurance at an age when it is affordable.

Kansas received two grants totaling more than $2 million in 2002 under the Systems Change Program. One grant for $725,000 for Personal Assistance Services and Supports is to be administered by the University of Kansas Center for Research Inc.; the other grant for $1,385,000 is to be administered by the Department of Social and Rehabilitation Services.

KENTUCKY

Overview

Kentucky is a poor state, with a high percentage of its elderly living in poverty. The percentage of people age 65 and older who live in poverty in Kentucky in 2000 was higher than the national average–13.2 percent, compared to 10.1 percent for the United States.

Among the state's highest priorities for long-term care reform are authorizing wage pass-through programs for home care and nursing home workers and increasing nursing home staff ratios. Although many states have managed to reduce or at least keep their nursing home populations constant, Kentucky saw a 10 percent increase in nursing home residents from 1995 to 1999.

Fiscal Analysis

Spending for nursing home care in Kentucky has been increasing steadily since the mid-1990s, from about $390 million in FY1995 to almost $554 million in FY 2000. State officials expect those expenditures to reach $570 million in FY 2001 for a nursing home population of about 28,200 people. For ICF/MR facilities, expenditures totaled almost $92 million in 2001 for the care of 1,100 individuals. (No projections were available for FY 2002.) Highlights of the fiscal picture include the following:

- From the mid-1990s to FY 2001, spending on Medicaid home and community-based services (HCBS) waiver programs more than doubled, from $61 million to $158 million.[1]

- The two major Medicaid waiver programs in Kentucky are the MR/DD ($81.5 million) and the Aged and Disabled (about $72 million) programs.

- More than 13,300 people were being served under the Aged/Disabled waiver program and another 1,000 were served under the MR/DD program.

Legislative Activity

The 2001 legislature approved a new law to standardize assisted living and adult day care benefits under long-term care insurance policies. The law establishes that, if a long-term care insurer provides an assisted living benefit, the insurer must cover services in any assisted living community that meets regulatory standards or additional requirements set forth in a long-term care policy approved by the commissioner.

Similarly, any long-term care policy providing coverage for adult day services must cover services received in any adult day care facility that meets regulatory standards.

The legislature directed the Legislative Research Commission to create a Task Force on Quality Long-Term Care to study methods to promote the provision of quality care in long-term care facilities and to enhance quality of in-home and community-based services.

Long-Term Care Planning

An *Olmstead* State Plan Committee began meeting in November 2000 and held a series of public forums. "The Kentucky *Olmstead* Plan: A System of Choices for Citizens with Disabilities," adopted in September 2001, was submitted to the secretary of the Cabinet for Health Services. In the submission, the plan was described as " … the first platform of a sustained development of enhanced supports for vulnerable people."

A central element of the plan is that the state's current home and community-based services system " … is in need of an overhaul ... All services provided to individuals need to be under the control of that individual." The plan includes a set of recommendations in five areas: waiting lists, employment, housing, person-centered funding and transportation. The plan does not include budgets or timelines. However, the report notes two activities for 2002: identification of the "appropriate status" of every program participant and facility resident in the state in regard to the most integrated environment for them, and presentation to them of "informed choice information."

Future Outlook

In his budget message in early 2002, Governor Paul Patton (D) said the Kentucky economy was the worst it had been in at least 20 years, allowing no money for new services in the next biennium. However, in response to a legislative mandate to reduce the backlog of underserved people with mental retardation and developmental disabilities who are eligible for community-based services, he was providing 500 community placements in the current biennium and proposing another 500 in the next biennium.

Kentucky received a $2 million grant in 2001 from the federal Systems Change Grant Program. One project, the Citizen Monitoring Initiative, is targeted to individuals with mental retardation/developmental disabilities in the Supports for Community Living Program. The state will train volunteer advocates, recruit and train two-person interview teams to determine consumer satisfaction, and enhance survey instruments.

Under a Housing/Nursing Home Transition Initiative, the state will develop pilot projects in two regions of the state (urban and rural) to assess the availability of housing and service options for people who are making the transition from institutions. A Workforce Initiative will develop seven curricula to train community-based workers.

Notes

[1] Expenditure figures from Burwell, using HCFA Form 64.

Louisiana

Overview

The percentage of people age 65 and older who are living in poverty in Louisiana was 16.8 percent in 2000, compared to a national average of 10.1 percent. Louisiana was second only to Mississippi for having the highest percentage of its Medicaid long-term care funds go to institutional care in 1999, compared to the allocation for home and community-based services (89 percent institutional, 11 percent HCBS).

The state's nursing home population—at about 28,000 people—far exceeds the number of people receiving HCBC services, which totaled about 5,700 people in FY 2002. In addition, about 8,000 people reside in ICF/MR facilities.

Fiscal Analysis

The state was spending about $500 million on nursing facilities in FY 2000, which rose to about $570 million in FY 2002. Expenditures for ICF/MR facilities remained about the same throughout the FY 2000-2002 period at about $355 million.
Total institutional spending of $925 million in FY 2002 was more than five times greater than the approximately $168 million total for all the home and community-based waiver programs that year. Highlights of the fiscal picture include the following:

- Most of the state's HCBS waiver programs are small in caseloads and expenditures, except for the MR/DD program, which had a caseload of more than 3,600 people in FY 2000 and expenditures of $95 million. The caseload had increased to 4,251 people by FY 2002 and expenditures increased to $146 million.

- Louisiana had a small Medicaid Personal Care program, with expenditures of $4.6 million and a caseload of 420 people in FY 2002.

Legislative Activity

Lawmakers established the Disability Services and Supports Planning Group in 2001 to study and recommend improvements in the state's long-term care system. The group's efforts were to focus on the concepts of informed choice and quality support to individuals of all ages with disabilities. The law authorizes a planning process that will focus on "voice, choice and quality."

Legislators also directed the Department of Health and Hospitals to establish a case-mix reimbursement system for nursing homes, which must be implemented by Jan. 1, 2003.

Long-Term Care Planning

In February 2001, the secretary of the Department of Health and Hospitals met with representatives of the Louisiana People's *Olmstead* Plan, an advocacy group. The objective of the meeting was to begin the process of developing an *Olmstead* plan. To achieve this goal, the advocates and the department proposed legislation in the 2001 Legislature to create a planning process (see above).

Future Outlook

Under the terms of an agreement in August 2001 that settled a class action lawsuit, *Barthlemey vs. Louisiana Department of Health and Hospitals,* the state agreed to greatly expand the number of people who will be served by HCBS waiver programs. By the end of 2005, qualifying applicants will wait no more than 90 days for services in their homes and communities.

The settlement also provides for a new personal care service for Medicaid-eligible adults who otherwise would have to go into a nursing home. In addition to the new services, the state pledged to launch a campaign to inform people about at-home programs and to introduce a simplified application process, including a toll-free number for information about community services.

Louisiana received a Systems Change grant for $1,385,000 in 2002, which should help the state with its planned long-term care activities.

Maine

Overview

A budget crisis in 1993 spurred Maine to review its long-term care system and to plan reform. The state began its efforts by implementing more stringent nursing home admission standards and enacting universal preadmission screening for nursing home placement. In 1996, the governor proposed a Long-Term Care Initiative that called for a significant expansion of home and community-based care. By 1997, more people were receiving care at home than in nursing facilities.

In FY 2001, the state estimated that about 17,000 people with disabilities were receiving home care or assisted living services compared to 8,275 people in nursing homes. The state allocated 60 percent of its Medicaid long-term care funds to institutional care in FY 2000 and 40 percent to home and community-based services (HCBS). Still, the state continues to study its long-term care system, particularly in regard to expanding residential options such as assisted living facilities.

Fiscal Analysis

Although nursing home expenditures took a slight spike upward from FY 2000 to FY 2001 (from $199.6 million to $201.4 million), the state had been decreasing its spending on nursing homes from $213.6 million in fiscal 1996 to the fiscal1999 total of $190 million. The state experienced a 12.3 percent decline in nursing home residents from FY 1995 to FY 1999 and a decrease of 9.2 percent in the number of nursing home beds during that period.[1]

Maine was fifth among the states in both FY 1999 and FY 2000 in spending per capita under its Medicaid HCBS waiver programs ($110.64 per capita in 2000). The state increased its spending on the waiver programs from $64 million in FY 1996 to $152.8 million in FY 2001.[2] Highlights of the fiscal picture include the following:

- The state also has been increasing spending under its Medicaid Personal Care program from $1.4 million in FY 1996 to $5.3 million in FY 2001.

- The caseload for the Aged waiver program in 1999 totaled about 1,400 people and for the MR/DD waiver, about 1,600 people.

Legislative Activity

Maine lawmakers commissioned two long-term care studies in 2001. One measure requires the Long-Term Care Implementation Committee to study and make recommendations regarding barriers to home and community-based care services and reimbursement and staffing issues for nursing homes and residential care facilities. The latter includes the cost of wages and benefits and the effects of staffing patterns on quality of care. The committee was to complete its study by Feb. 1, 2002.

A second law establishes a commission to study options for developing high-quality, cost-effective assisted living housing and service programs in community center locations across the state. Specifically, the commission was to study existing housing and program options for people with disabilities and to propose changes to existing law to adequately compensate providers for the delivery of services that allow consumers to remain in assisted living facilities while aging. Expected to

report to the legislature by December 2001, the commission was to develop a comprehensive plan for assisted living that establishes criteria for admissions.

Long-Term Care Planning

With a grant from the Center for Health Care Strategies and the Systems Change grant program, Maine is embarking on an interdepartmental effort to develop a community integration plan that fills the gaps in the existing services it has developed. The "Plan Development Workgroup for Community-based Living" is made up of representatives from the departments of human services, education, corrections, labor, and behavioral and developmental services.

The workgroup has divided into subgroups on workforce development, coordination among state agencies, and services. A report and recommendations were expected in April 2002.

Future Outlook

Maine officials believe the state has developed a good community services system and plans to use its $2.3 million Systems Change grant to take this system "to the next level." The focus of the project, "Quality Choices for Maine," will be interdepartmental, with the aim of developing a shared interdepartmental vision for serving people with disabilities.

Quality improvement is a key goal of the project. The state hopes to identify and implement quality indicators to measure quality of care and quality of life and to demonstrate the feasibility of interdepartmental collaboration on quality improvement. The state also plans to develop a Web site to provide information about services, resources and eligibility; develop a direct care workers' guild; and conduct two to three demonstrations for improving access to housing services.

Notes

[1] AARP, *Across the States 2000.*

[2] Expenditure and caseload figures from Burwell using HCFA Form 64 and Harrington using HCFA Form 372.

Maryland

Overview

During the last two years, Maryland has begun expanding its Medicaid home and community-based services (HCBS) for mentally retarded/developmentally disabled people and for adults with physical disabilities. Although the state's HCBS spending on older people appears to be relatively small compared to the commitment to these other vulnerable populations, the state plans to significantly increase the caseload of the Medicaid waiver program that serves older adults during the next five years.

Maryland is among the top 20 states in the country in its spending through the Medicaid Personal Care Program, most of whose beneficiaries generally are the elderly. The state also allocates significant state-only funds to residential care, which provided services to an average daily population of about 22,000 people in 2000.[1]

Fiscal Analysis

Maryland spent almost $600 million on nursing home care in 2000, an amount that state officials expect to increase by about $160 million (27 percent) to $755.6 million in 2002. The nursing home population totaled about 25,000 residents. During the same period, the state was spending slightly more than $200 million in state general revenue funds for the care of people in residential care facilities. Highlights of the fiscal picture include:

- Maryland devotes the bulk of its Medicaid HCBS funds to the MR/DD waiver program, on which the state spent $200 million in FY 2000 and almost $227 million in fiscal 2001. Expenditures for this program are expected to reach $246 million in FY 2002.

- A Medicaid waiver program for adults with physical disabilities went into effect on April 1, 2001 (See Legislative Activity, below). The state spent almost $2 million on this program in FY 2001 and expects to spend close to $9 million in FY 2002.

- In July 2000, the state expanded the number of slots for the Medicaid Waiver for Older Adults from 135 people to 1,135 people and expects to increase the slots further to 5,135 after five years.

- The state has been spending about $20 million on services funded through the Medicaid Personal Care program and foresees increasing that amount only slightly to $22.8 million in FY 2002. The program serves about 5,000 people.

- Maryland has a relatively high number of licensed residential facilities (2,800), with an average daily caseload of about 22,000 people. The state is spending more than $200 million in state-only funds for these facilities.

- The state has a state-funded program called "Senior Care," which had a FY 1999 budget of $6.6 million and a total of 3,700 clients during the year (as well as a waiting list of about 1,500).

Legislative Activity

Lawmakers created a new program in 2001 that offers community attendant services to certain physically or cognitively impaired Medicaid beneficiaries as an alternative to nursing home care. The program permits people between the ages of 21 and 59 with severe disabilities to hire their own personal assistant or to use an agency employee. This consumer-direction model allows participants to hire a family member and to receive training on hiring and managing workers and on financial management.

Lawmakers also created two councils in 2001 to help develop and coordinate long-term care services in the state. The Innovations in Aging Services Program and Council is expected to design and test innovative ideas in programs and services for older adults, publicly disseminate the results of these tests, and help meet the need for trained personnel to serve the elderly.

Lawmakers also created the Maryland Caregiver Support Coordinating Council to coordinate statewide planning, development, and implementation of family caregiver support services. The council is to solicit caregiver concerns through surveys, public hearings and a telephone hotline, and to develop a model family caregiver support program that incorporates best practices from existing programs in other states.

Long-Term Care Planning

In July 2000, Governor Parris Glendening (D) created the Community Access Steering Committee to make recommendations to enhance community-based services for individuals with disabilities of all ages. The steering committee organized into four task forces: mental health, Medicaid, developmental disabilities and systems integration. The Medicaid task force focused on community-based services for people with physical disabilities. The system integration task force reviewed crosscutting issues that affect all disability populations, including housing, workforce development and transportation.

The committee's goals were to build community capacity, help people currently in institutions to move to the community, and help people stay in the community. The steering committee issued its final report on July 13, 2001. Its broad–based recommendations did not include funding amounts, the agencies responsible for implementing the recommendations, or timelines.

The recommendations address: 1) raising compensation for direct care workers; 2) increasing affordable and accessible housing; 3) pooling funding on a regional basis for more accessible transportation; 4) creating a fund for people who are making the transition from institutions into the community; 5) expanding Medicaid waiver programs and changing Medicaid eligibility criteria; 6) promoting education and counseling on community options; and 7) expanding crisis response and respite programs.

Future Outlook

Maryland has received four grants totaling more than $2.6 million under the federal Systems Change Grant Program. In 2001, the state received two grants totaling $1,250,000 for nursing facility transitions and a grant for $1,250,000 for four initiatives to increase access, service availability and quality in the state's long-term care system. In 2002, the state received another grant for $360,000 to be administered by the Department of Health and Mental Hygiene.

One nursing facility grant will be used to conduct outreach to nursing facility residents who want to understand service options and relocate to the community. The project will provide face-to-face counseling and will develop curriculum to empower people with disabilities to advocate for themselves. Under the other nursing facility project, the state will develop a "Home Team" for coordination with local housing authorities and housing providers, outreach workers and case managers to obtain housing for a minimum of 150 Medicaid beneficiaries with physical disabilities who are age 65 or younger.

The $1,025,000 grant will be used for four initiatives:

- Implementation of a pilot project to provide outreach and information about community-based long-term care options to people with disabilities being discharged from hospitals.
- Activities designed to attract and retain long-term care direct care workers.
- Development of a managed care demonstration program to provide coordinated services to children with serious emotional disturbances.
- Development of quality indicators for long-term care services, a comprehensive satisfaction survey, and establishment of a quality measurement and improvement process.

Notes

[1] Residential care includes financial support for people living in board and care homes, assisted living facilities, domiciliary care, or similar residential care or congregate living settings.

Massachusetts

Overview

Settlement by the state of two lawsuits involving people with mental retardation in nursing homes in recent years (*Rolland vs. Cellucci* and *Boulet vs. Cellucci)* has resulted in increased funding by Massachusetts for community residential placements and in-home services since 2000. As part of the *Rolland vs. Cellucci* settlement, community residential placements and other supports were provided for 425 people with MR/DD from 2000 to 2002, with a commitment to place 150 additional people in the community each year through 2007. The state also committed to spend $114 million for the development of group homes and interim at-home services during fiscal years 2002 to 2006 for people covered under the *Boulet vs. Cellucci* settlement.

In August 2001, Governor Jane Swift (R) announced $8 million in funding for elder care providers designated for initiatives to create, expand and improve long-term care services. Grants are available to providers who serve low-income elderly people, to renovate physical space to expand or develop new programs for the elderly, or to purchase or upgrade medical equipment.

Fiscal Analysis

Massachusetts spent $1.4 billion on nursing home care in FY 2001, about the same amount as was spent in FY 1995. ICF/MR expenditures have been decreasing since FY 1995, from $357.4 million that year to $211.8 million in FY 2001.

Despite holding the line on institutional spending, however, the state still was allocating about 67 percent of its Medicaid long-term care funds to institutional care in 2001, compared to 33 percent for home and community-based services (HCBS). Highlights of the fiscal picture include the following:

- The state spent about $508 million for Medicaid HCBS waiver programs and $241.5 million for Medicaid Personal Care in FY 2001.

- More than 98 percent of total waiver expenditures were allocated to the MR/DD program ($500 million out of $508 million in FY 2001); the caseload for the MR/DD program in 1999 was about 11,000 people and for the Aged program, about 5,000 people.

- The Massachusetts Home Care Program, which is funded by state general revenues, provided services to 40,000 people in 2000.

Legislative Activity

No significant long-term care laws were enacted in 2001.

Long-Term Care Planning

In July 2001, Governor Swift directed the executive offices of Health and Human Services, Elder Affairs, and Administration and Finance to work with an advisory group of disability advocates and providers to help craft a comprehensive plan that ensures that people with disabilities can live and receive services in the most appropriate community setting. Plan development and implementa-

tion includes review of existing resources for people with disabilities, identification of disabled populations based on their current settings, and establishment of standards for providing enough information on placement options for people with disabilities to make informed decisions.

The group also was expected to analyze the financial effects of policy changes and to recommend steps to ensure quality of service delivery. The advisory group held five public hearings statewide in the fall of 2001. The plan is expected in June or July 2002.

Future Outlook

Massachusetts received more than $2 million in Systems Change Grants from the Centers for Medicare and Medicaid in 2001 and another $360,000 in 2002. The state planned to use $770,000 (a Nursing Facilities Transition grant) to begin moving up to 300 people with developmental and physical disabilities in the Worcester area out of nursing homes into community settings.

Another $1,025,000 will be used to implement interagency policy coordination and program development through an Interagency Steering Committee and a Working Group for Community Long-Term Care. The establishment of a Consumer Task Force will help ensure consumer input into policy evaluation and the design and implementation of infrastructure changes. The state hopes to develop a streamlined functional assessment, eligibility determination and service coordination system, and to field-test models of coordinated, culturally appropriate community-based long-term care services.

Michigan

Overview

Michigan has been actively working in recent years to move people with mental illness or developmental disabilities out of institutions into the community. The state is providing home and community-based services to this population through a 1915(b) (c) waiver combination, which allows the state to deliver a uniform package of home and community services through a managed care approach.

Michigan contracts with 48 county-based Community Mental Health Service Programs (CMHSP), which receive capitated payments to provide health services and supports for persons with mental illness, developmental disabilities and addictive disorders. The state's managed care plan requires each local CMHSP to make consumer-managed and directed services and supports available. The state maintains that self-determination is central in Michigan to the transition to a managed care system for persons with developmental disabilities.

Fiscal Analysis

Although nursing home expenditures have been climbing in Michigan from almost $1 billion in FY 1995 to $1.7 billion in FY 2001.[1] Expenditures for ICF/MR facilities, which reached $519 million in FY 1997, have been declining in subsequent years as those funds have been decentralized to the CMHSPs to support more community-based options for persons with mentally illness or developmental disabilities.
Highlights of the fiscal picture include the following:

- Spending for HCBS waiver programs has steadily risen from $120.5 million in FY 1995 to $412 million in FY 2001.

- The state's largest Medicaid waiver program in terms of caseload appears to be the Aged/Disabled waiver known as MI Choice, with about 11,000 participants and approved slots of 15,000. However, expenditures for the MR/DD waiver program totaled about $224 million in FY 1999 compared to $16.7 million for the Aged/Disabled waiver.[2]

- Spending for the state's Medicaid Personal Care program increased from $163.3 million in FY 1995 to about $183 million in FY 2001.

Legislative Activity

The 2001 Legislature established additional requirements for long-term care insurers that offer home care and assisted living benefits. The law requires long-term care policies that provide these benefits to define the benefits in "plain English" and specify exactly which services are covered. The legislation also places restrictions on the ability of insurers to limit or exclude home health benefits from long-term care policies.

In late December 2001, legislators approved a bill that directs the state to convene a work group that will clarify terms used for nursing home inspections and investigations. The work group also must develop clinical process guidelines that address such issues as bed rails, adverse drug effects, falls, pressure sores and pain management, among others.

Long-Term Care Planning

In July 2000, the Michigan Long-Term Care Work Group, composed of state legislators and state officials, released a report, "Michigan LTC Report and Recommendations." The work group recommended four models to be tested in selected regions of the state beginning in 2001 that build on capitated payment systems.

One model, Long-Term Care HMOs, would provide all health and long-term care services to individuals under a capitated payment system. Another model, Regional Provider Organizations, would consist of partnerships among multiple provider organizations that would use an integrated delivery system under capitated payment. The other models are a Virtual Organization model, an electronic communication network linking corporation partners to deliver services; and a Care Coordination model, which would build on the existing network to integrate delivery of health and long-term care services.

Legislators set aside $10 million in tobacco settlement funds to be used to implement some of the recommendations of the Michigan Long-Term Care Workgroup, and Governor John Engler (R) awarded $7.4 million of that money in May 2001 for 48 "Long-Term Care Innovations" projects that address specific parts of the new integrated service delivery systems. Planning continues with these funds and the Systems Change Grant money the state received in 2001 (see below).

Future Outlook

The Department of Community Health received 216 applications from 169 organizations for the Long Term Care Innovation Grants. The department selected 48 proposals for funding. The proposals included projects that addressed long-term care staffing needs (nine grants), integrated systems models (seven), public education (five), Alzheimer's and dementia disorders (four), MI Choice access (four), and housing (three).

Michigan plans to use its $2 million Systems Change grant to build on its plan for developing an integrated long-term care system. The Systems Change project has three components: The LTC Outcomes and Evaluation Systems (OES) Initiative, the Virtual Organization Initiative, and the Consumer Cooperative Initiative.

The state plans to develop a model for vertically integrated outcomes and evaluation systems across state and local agencies and to improve outcomes through the use of quality indicators across long-term care settings. The Virtual Organization Initiative will use modern information technology and systems design to enable consumers to use telephone or Web technology to identify and arrange services, communicate needs and satisfaction with services, and use assistive technologies. Through consumer cooperatives, the state will establish a process to ensure consumer control over access and management of services. The cooperative will allow members to design and obtain the services they prefer.

In March 2002, six Medicaid recipients and five advocacy organizations sued the state, alleging that Michigan is violating the Americans with Disabilities Act and the 1999 U. S. Supreme Court *Olmstead* ruling by forcing Medicaid beneficiaries with disabilities to receive care in nursing homes rather than in the community. The focus of the lawsuit is MI Choice, the Medicaid waiver program that allows disabled residents to receive in-home care rather than being institutionalized. In October 2001, the state froze enrollment in the program at 12,000 in response to a $23 million

budget deficit. Lawyers for the plaintiffs content that the state is discriminating against disabled Medicaid recipients by forcing them into nursing homes. The suit aims to restore MI Choice to its original enrollment capacity of 15,000 beneficiaries.

Notes

[1] Expenditure and caseload figures from Burwell using HCFA Form 64 and Harrington using HCFA Form 372.

[2] Michigan did not report separate spending figures for the aged/disabled waiver in FY 2000 or FY 2001.

Minnesota

Overview

Minnesota has embarked on a program of comprehensive long-term care reform sparked by the work of a Long-Term Care Task Force, which began meeting in 2000. The task force, which was composed of state legislators and state agency commissioners, issued its report, *Reshaping Long-Term Care in Minnesota*, in January 2001. A number of its recommendations were enacted into law by the 2001 Legislature.

Although state officials estimate that the nursing facility caseload will drop from 26,449 in FY 2000 to 24,762 in FY 2002, nursing home expenditures will continue to increase, although at a slow pace. State officials report that from FY 2000 to FY 2002, the caseload for its largest home and community-based services (HCBS) waiver program (for people with developmental disabilities) will almost double.

Fiscal Analysis

Minnesota's institutional spending totaled almost $1 billion in FY 2000 and was expected to pass that mark in FY 2002, with expenditures of more than $895 million for nursing facilities and about $170 million for ICF/MR facilities. At the same time, the state was spending almost the same total (an estimated $942 million in FY 2002) on a combination of Medicaid home and community-based care services under its waiver programs and Personal Care program.

In addition, the caseloads for institutional facilities were expected to decrease, and caseloads for the state's three largest HCBS waiver programs were expected to increase by more than 10,000 people. Highlights of the fiscal picture include the following:

- Expenditures for nursing facilities totaled almost $848 million in FY 2000, increasing by 3.4 percent to almost $877 million in FY 2001, and then by 2.1 percent to more than $895 million in FY 2002.

- State officials reported that spending for the HCBS waiver program for people with developmental disabilities should increase by 57 percent from FY 2000 to FY 2002, from about $400 million to $629 million. The caseload was expected to increase from 8,094 people to 15,419 people.

- Expenditures for the HCBS waiver program for the elderly were expected to increase from $40.8 million in FY 2000 to $68.0 million in FY 2002 with a caseload increase of 1,245 people during that period.

- Expenditures for the HCBS waiver program—"Community Alternatives for Disabled Individuals"—for people under age 65 who need nursing facility care, were expected to increase from $22.3 million in FY 2000 to $38.8 million in FY 2002, with a caseload increase of 1,745 people (from 3,898 people to 5,643 people).

- The state's Medicaid Personal Care program had expenditures of $115 million in FY 2000, increasing to $176 million in FY 2002.

Legislative Activity

Following the recommendations of the Long-Term Care Task Force, the Legislature in 2001 created a comprehensive framework for reshaping the state's long-term care system. Key components of the legislation included expanding options for home and community-based care services, encouraging the voluntary closure of nursing homes, and making information and assistance more readily available for people and their families who are seeking long-term care services. Other legislative initiatives seek to improve the quality of nursing home care and promote a stable, long-term care workforce.

The legislation resulted in $183 million in appropriations for long-term care reforms for fiscal 2002-03. Of that total, $108 million will provide cost-of-living increases for nursing facilities and continuing care providers. The state expects increased spending to be offset by savings of $44 million from downsizing the nursing home industry by 5,100 beds, or more than 10 percent.

Some of the specific measures include:

- Funding of community service grants to pay start-up, capital and other costs for developing supportive housing and home and community services in areas where current resources are inadequate to meet needs.

- Promoting the elimination of excess nursing home beds and generating funds to expand non-institutional long-term care services.

- Funding for long-term care providers who develop best practices and innovation in providing services and requiring profiles on providers that capture information on the quality of care provided.

- Expanding the Senior Link Age Line with a new interactive Web site and redesigning long-term care consultation (formerly called preadmission screening) to better help consumers and their families make decisions.

- Creating loan forgiveness and scholarship programs for direct care workers and high school internship programs for work in long-term care.

- Developing a case-mix reimbursement system for nursing homes.

Long-Term Care Planning

The Long-Term Task Force was not created in response to the *Olmstead* decision. Its recommendations, therefore, are limited to the aging population and do not cover other populations in need of long-term care services. When the task force made its recommendations, it developed a framework that included 48 strategies under six major policy directions. Those policy directions include:

- Maximize peoples' ability to meet their own long-term care needs.
- Expand capacity of community long-term care system.
- Reduce state's reliance on the institutional model of long-term care.
- Align systems to support high quality and good outcomes.
- Support the informal network of families, friends and neighbors.
- Recruit and retain a stable long-term care work force.

Future Outlook

The Long-Term Care Task Force was expected to reconvene in 2002 to evaluate the results of the 2001 legislative session and to address future initiatives. The task force set benchmarks to measure the state's progress in rebalancing the long-term system, improving information and quality, supporting family caregivers, helping people to take care of their own needs as much as possible, and making jobs in long-term care more competitive.

Minnesota received a total of $3.2 million in Systems Change grants in 2001, of which $900,000 was to be used to increase the use of consumer-directed options for personal care assistance (PCA) services and to address a worker shortage problem that affect the availability of PCA. The state will develop consumer-initiated partnership and support networks through which consumers will access each other's natural supports— such as families and neighbors—to provide PCA services and back-up options.

With a $2.3 million grant, the state plans to develop a model for consumer-driven quality assurance and quality improvement. The state will recruit and convene a 15-member quality design commission; 51 percent of members will be consumers. Another initiative will be the creation of a model for information, referral and assistance and three regional I & A networks.

Minnesota also received a second-round grant of $400,000 for nursing facility transition activities.

Mississippi

Overview

Ninety-one percent of Mississippi's Medicaid long-term care funds were allocated to institutional care in 2001; only 9 percent went to home and community-based services (HCBS). Those percentages had hardly changed since 1994, when the allocations were 97 percent institutional to 3 percent HCBS.

Although the state had 10,000 slots for its Medicaid Elderly and Disabled waiver program in 2001, only about 6,600 people were receiving services and more than 3,300 people were on a waiting list for services. Only 10 people were receiving services under an Assisted Living waiver program that has 500 slots, and a 400-slot Traumatic Injury/Spinal Cord program had no participants in 2001.

In June 2000, Governor Ronnie Musgrove (D) named the Division of Medicaid as the lead agency to work with five other state agencies to develop a comprehensive plan for addressing the issues related to the *Olmstead* decision. A task force, called "Mississippi Access to Care" and formed in October 2000, was composed of state agencies, advocacy groups, consumer groups, providers and consumers. The 59-page report, issued Sept. 30, 2001 (see below), proposes substantial increases in the number of people to be served by HCBS during the next five to 10 years.

Fiscal Analysis

Expenditures for nursing homes totaled $415.7 million in FY 2001, an 8.3 percent increase from the FY 2000 level. [1] With about 13,000 nursing home residents and 198 nursing homes, the state had the second highest nursing home occupancy rate in the country (93.7 percent) in 1999. [2]

Spending for ICF/MR facilities, which increased by about 10 percent each year from FY 1997 to FY 2000, totaled $170 million in FY 2001. Mississippi was eighth in the country in terms of per capita spending for ICF/MR facilities. Highlights of the fiscal picture include the following:

- Mississippi increased its spending on Medicaid HCBS waiver programs from $3.7 million in FY 1996 to $48.6 million in FY 2001. The 2001 total was more than double the $21.9 million FY 2000 total.

- Despite its increased spending for waiver services, the state was third lowest among the states in expenditures per capita ($17.01) for these programs. In terms of HCBS expenditures per people 65 and older, Mississippi ranked 50th in 1999 at $62 per person.

Legislative Activity

The Mississippi Legislature passed a bill in March 2001 that mandated the development of a comprehensive state plan to provide services to people with disabilities in the most integrated setting possible. The "Mississippi Access to Care" (MAC) task force issued its report to the Legislature on Sept. 30, 2001 (see below).

The Legislature also strengthened the state's elder abuse law by expanding the statutory definitions of abuse, neglect and exploitation of vulnerable adults and by mandating immediate report-

ing of suspected abuse. The legislation also establishes monetary penalties for perpetrators and for those who fail to report abuse and requires criminal background checks for newly hired employees in long-term care facilities.

Long-Term Care Planning

The task force report contains recommendations through FY 2011. The plan consists of four areas: system modifications, primary support services, other community-based services, and implementation and review.

Under system modifications, the plan proposes the development of a multi-agency tracking system of services being provided and of an electronic service resource directory listing all available services. The report also calls for establishing a statewide toll-free assistance line and public education initiatives related to Mississippi Access to Care. The plan outlines strategies to respond to people who wish to leave institutional settings and the establishment of a single-point-of-entry system. The goal of the plan is to have community services for all disabled people by June 2011.

Future Outlook

The MAC plan proposes significant increases during the next ten years in the number of people receiving HCBS. The increases proposed during the next five years include: 1) Elderly and Disabled waiver program (750 additional people per year), 2) Independent Living waiver program (500 additional people per year), and 3) Assisted Living waiver (100 additional people per year). By 2011, the report calls for expanding supported living services to individuals with MR/DD from 400 people to 800 people; adding 17 more group homes for individuals with serious mental illness; serving an additional 1,600 individuals in the MR/DD waiver; and identifying and moving 1,035 individuals to the community from institutions.

Mississippi also received a Real Choice Systems Change grant in 2002 for $1,385,000, which will be administered by the Department of Mental Health.

Notes

[1] Expenditure figures from Burwell using HCFA Form 64.

[2] AARP, *Across the States 2000.*

Missouri

Overview

Although Missouri has had a high ratio of nursing home beds to its elderly population compared to the national average (73.8 beds per 1,000 people age 65 and older to 52.3 beds nationally in 1999),[1] the state has also been rapidly expanding the number of people served in the community. The number of people receiving home and community-based services (HCBS) reached a total of more than 31,000 in 2000 compared to a nursing home population that totaled about 26,000 people.

A 15-member Home and Community-Based Services and Consumer Directed Care Commission, created by executive order in April 2000, issued a series of recommendations in December 2000. The state's long-term care planning work and legislative activities have revolved around these recommendations since the report was issued. For example, the 2000 legislature enacted a law requiring that an individual eligible for Medicaid-funded nursing home care be given the opportunity to have those Medicaid funds follow the person to the community to be used for the personal care option that best meets the individual's needs.

Fiscal Analysis

Missouri was able to limit increases for nursing homes to 1.8 percent from FY 1998 to FY 1999 ($696.5 million to $708.9 million) and to 2.4 percent from FY 1999 to FY 2000 ($725.6 million). However, the state reported a 43.5 percent increase from FY 2000 to FY 2001, with expenditures reaching $1 billion in FY 2001. Expenditures for ICF/MR facilities increased from $156.5 million in FY 1996 to $184.6 million in FY 2001.[2] Highlights of the fiscal picture include the following:

- From FY 1996 to FY 2001, Missouri steadily increased its spending on its Medicaid HCBS waiver programs ($173.6 million to $296.6 million) and also more than doubled its spending on the Medicaid Personal Care program during that period ($63.7 million to $150.4 million).

- The largest Medicaid waiver program in expenditures was the MR/DD program at $218 million in FY 2001 out of a total of $296.6 million for all waiver programs (about 73 percent). The largest waiver program in terms of caseload was the Aged/Disabled program with about 23,000 participants, compared to about 8,000 people in the MR/DD program.

Legislative Activity

The legislature took several actions in 2001 to help people who want to move out of nursing homes to transfer to community settings. Examples include creating a $125,000 fund to assist individuals who are making the transition from an institution, and ensuring that training will be provided for staff and individuals who are interested in transferring to the community.

The legislature also passed a bill to phase in increases in income limits for Medicaid eligibility over three years, from the SSI rate ($537 per month for an individual in 2001) to 100 percent of the Federal Poverty Level. Another legislative action mandated that the state's Division of Aging estab-

lish specific requirements for dementia training for workers who provide dementia care in a variety of long-term care settings, from nursing homes to home health agencies and adult day care programs. The legislature also appropriated a $1 per hour increase for aides who care for people with mental retardation and developmental disabilities.

Long-Term Care Planning

Since the Home and Community-Based Services and Consumer Directed Care Commission issued its plan, the governor has formed a new commission to continue the work and implement the plan. Missouri continues to devote planning and resources to ensure that the state's long-term care infrastructure and process reflect consumer choice and consumer input. The state is moving ahead with efforts to help those in institutions make successful transitions to community living.

Future Outlook

Missouri's $2 million grant under the Real Choice Systems Change Program, entitled "Flexible Choices for Independence," a project that will focus on helping people with disabilities to live in the most integrated community setting and exercise meaningful choices about their lives.

The state will study length of hospital stays and the number of people transferred from hospitals to nursing homes, who stay longer than anticipated. Using the results from this study, the state will conduct a pilot program that attempts to address each of the factors found in the study. The aim is to determine the most effective strategies to facilitate community living.

Notes

[1] AARP, *Across the States 2000.*

[2] Expenditure and caseload figures from Burwell using HCFA Form 64 and Harrington using HCFA Form 372.

Montana

Overview

In recent years, the Montana Legislature has increased funding to reduce the wait for community services that 1,000 people with disabilities in the state currently face. The legislature also has increased direct care wages during this period.

The state's nursing home population has remained steady at about 5,300 residents, although the ICF/MR caseload totals only 120 people. Montana is one of only a few states where state officials expect nursing home expenditures to decrease, from $115.8 million in FY 2000 to about $110 million in FY 2002.

Fiscal Analysis

In FY 2001, Montana was seventh among the states in per capita spending ($26.08) for its Medicaid Personal Care program. Total spending reached $23.6 million in FY 2001 and was estimated to increase to $27.1 million in FY 2002. The state was spending a higher amount on home and community-based services (HCBS) however, through its Medicaid waiver programs, which totaled $58.6 million in FY 2001.[1]
Highlights of the fiscal picture include the following:

- Montana's largest HCBS waiver program in terms of expenditures is the MR/DD program with spending totaling $36.7 million in FY 2001 and a caseload of about 1,000 people.

- State spending for the Elderly and Disabled waiver program was about $21 million in FY 2001, serving about 1,500 people. The total caseload was 1,686 in 2001, and the state hoped to increase the number of participants to 1,770 in 2002 and to 1,861 in 2003.

- Montana instituted an intergovernmental transfer program in 2001 from 32 counties in the state to increase funding by $20 million for nursing homes that are facing severe financial problems.

Legislative Activity

The Legislature directed the Department of Public Health and Health Services and the Board of Pharmacy to allow long-term care facilities to donate unused prescription drugs to community pharmacies that serve uninsured and indigent patients when the drugs are not considered dangerous or controlled substances.

The Legislature also authorized long-term care facilities to use safety devices such as side rails, tray tables and seatbelts to reduce a resident's risk of falls or injury. Facilities may initiate the use of such devices if a resident or resident's family member requests them and provides informed consent for their use.

The Legislature also directed the state to adopt rules in 2001 to promote more consistent regulation of intermediate and skilled nursing care facilities. New rules will define terms used in the survey and a certification process for these facilities, including actual harm; potential for more than minimal harm; and avoidable, unavoidable and immediate jeopardy.

Long-Term Care Planning

In August 2001, the Senior and Long–Term Care Task Force became the first of five Montana task forces to release a plan addressing long-term care reform. The seven-page document outlines the key elements essential to an effective plan, the importance of these elements, and preliminary ways to address them. The recommendations will be incorporated into a future comprehensive plan to be developed by the Department of Public Health and Health Services.

The recommendations have five elements: 1) ensure stakeholder involvement in plan development and implementation; 2) correct unjustified institutionalization; 3) increase access to and availability of services; 4) promote informed choice; and 5) assure quality care. On the issue of inappropriate institutionalization, the task force recommended that the Senior and Long Term Care Division develop a method to identify and assess the needs of individuals in institutions and in the community.

Future Outlook

With nursing home caseloads remaining steady and the state expanding the caseloads for home and community-based waiver services, Montana appears to be in position to reduce its waiting lists for community services. The state has planning work under way with its five task forces, and progress has been made in implementing the first recommendations of one of the five groups, the Senior and Long–Term Care Task Force.

Montana received a $850,000 grant from the federal Systems Change Program under the Community-Integrated Personal Assistance Services and Supports component of the program. In collaboration with two area agencies on aging, the state will develop a program to attract older workers to the direct care pool. The state also plans to create Attendant Center for Communication, Education and Support Services (ACCESS) as a central point for recruitment, training and education in addressing workforce issues. Consumers, advocates, family members and providers will participate in the project. The state also received a $1,385,000 Systems Change grant in 2002.

Notes

[1] Expenditure and caseload figures from Burwell, using HCFA Form 64 and Harrington, using HCFA Form 372.

Nebraska

Overview

Nebraska ranked fourth highest among the states in 1999 in number of nursing home beds per 1,000 people age 65 and older. The state had 79.5 beds per 1,000 people 65 and older compared to a national average of 52.3 beds. However, state officials estimate that the nursing home population should drop by almost 1,000 people between FY 2000 and FY 2002, and the number of people provided home and community-based services (HCBS) should increase by about 500 people during that period.

The Governor, Mike Johanns (R), has requested significant increases in spending for HCBS for people with mental illness or developmental disabilities.

Fiscal Analysis

Spending for nursing facility care was expected to almost double between FY 2000 and FY 2002, from about $146 million to $277.6 million. During the same period, the state projected the number of nursing home residents to drop from 8,960 people to 8,025 people.

The largest Medicaid waiver program in terms of caseload is the Aged and Disabled program with 3,260 people in FY 2000 and a projected 3,594 people in FY 2002. Expenditures for this program were estimated to increase by about 70 percent over that period, from $23 million to $39.5 million. Highlights of the fiscal picture include the following:

- The state's MR/DD waiver program had a caseload of 2,226 people in FY 2000, increasing only slightly to 2,400 people by FY 2002. Expenditures for the program also were increasing slowly, from $78 million in FY 2000 to $82 million in FY 2001 and $84 million in FY 2002.

- Nebraska also operated a Medicaid Personal Care program, with expenditures of $7.2 million in FY 2001.[1]

Legislative Activity

The Legislature in 2001 rearranged how Nebraska would spend its share of the tobacco settlement. Provisions of this measure pertained to certain long-term care programs as well as to public health and biomedical research. The Tobacco Settlement Trust Fund had a balance large enough, according to state officials, to create a sustainable health care endowment consisting of money from the tobacco settlement and intergovernmental transfer payments received by the state from government nursing facilities.

As enacted, the following long-term care services would receive funds from the endowment fund: $6.5 million in each of FY 2002 and FY 2003 for development of community-based mental health and substance abuse services, including intermediate-level residential care services; $3 million in FY 2002 and $5 million in FY 2003 for services to individuals with developmental disabilities who are on the state waiting list for services; and $1.06 million in each of FY 2002 and FY 2003 for statewide respite care services.

Long-Term Care Planning

The state is approaching the planning process by focusing on improving the processes and applications of existing policies and on developing plans for each individual who is receiving long-term care services. Individual treatment teams and service coordinators identify potential issues and make decisions based on their evaluation of each case.

Agencies within the Department of Health and Human Services have made budget requests to deal with the issues raised in the *Olmstead* decision, but have not necessarily identified the requests as directly related to that decision.

Future Outlook

Nebraska received a $2 million grant from the federal Systems Change Grant Program. The state's goals for the grant include implementing a consumer-directed model of services coordination and service delivery and improving consumer access to information about supports and services. The state proposes to implement a consumer-directed philosophy across populations–children and adults of all ages with physical disabilities, developmental disabilities or behavioral health problems.

Notes

[1] Burwell figures from HCFA Form 64.

Nevada

Overview

Major reforms in long-term care planning and budgeting for home and community-based services (HCBS) were initiated in Nevada in 2001. In response to a proposal in the governor's budget, the 2001 Nevada Legislature approved funding for a long-term strategic plan to ensure the availability and accessibility of a continuum of services to meet the needs of people with disabilities.

The approved budget included new funding for independent living assistance for people with disabilities and an 88 percent increase of Medicaid home and community-based waiver services (HCBS) for people with physical disabilities. The budget also expanded the Medicaid Community Home-Based Initiative Program by 34 percent, doubled the capacity of the Medicaid Group Care Waiver for the Elderly Program, and expanded the Homemaker Program by 16 percent.

Fiscal Analysis

Nevada had a low nursing facility occupancy rate in 1999 (70.7 percent compared to 82.7 percent nationally) and a low number of nursing facility beds per 1,000 of the age 65 and older population (25.1 beds per 1,000 compared to 52.3 beds nationally).

With only about 2,400 nursing home residents and 2,800 people receiving HCBS, the state appeared to be making significant gains toward a balanced long-term care system. However, the state ranked 49th in per capita spending for HCBS waiver services in 2001, and 75 percent of its Medicaid long-term care funds went to institutional spending.[1] Highlights of the fiscal picture include the following:

- Nevada increased its spending on nursing homes from $63 million in FY 1996 to $92 million in FY 2001, but had much slower growth in ICF/MR expenditures, which rose only from $23.7 million to $28.9 million.[2]

- Medicaid HCBS waiver expenditures more than tripled between FY 1996 and FY 2001, from $8 million to $27.5 million, although the FY 2001 figure was still only one quarter of the spending on institutional care.

- The caseload for the Frail Elderly waiver program was about 1,300 people and for the MR program, about 1,100 people.

Legislative Activity

The 2001 Legislature mandated that all Nevadans who require assistance with daily activities such as bathing, toileting and eating must be identified and that planning for their needs must begin. The law also established a consumer-directed Personal Assistance Council to guide the state's efforts in providing access, consumer choice and systems change related to all personal assistance services.

Another 2001 law directs Nevada's Legislative Committee on Health Care to study alternatives to institutionalization for long-term care services. The committee will identify and evaluate long-term care alternatives and determine the costs, quality considerations, personnel and funding mechanisms to implement these alternatives.

The committee also will explore opportunities for federal waivers to integrate Medicare and Medicaid services and to eliminate the spend-down process for nursing home residents.

Long-Term Planning

Nevada received a grant for almost $656,000 through the federal Systems Change grant process. The state plans to develop interdisciplinary strategies to remove barriers to consumer-preferred personal assistance services (PAS) models and to develop strategies and structures for ensuring consistent consumer involvement in systems and policy development related to PAS. Another activity under the grant will be the creation of a PAS Web site for consumers that will offer tips on service management, resource and service access information, and benefits counseling.

Future Outlook

Nevada received a $1,385,000 second-round grant through the Systems Change program in 2002. In addition, Governor Kenny Guinn (R), in his 2002 state-of- the-state address, proposed doubling the funding to help physically disabled people stay in their homes. He said that the proposed increases in services for people with developmental disabilities would eliminate all waiting lists for this group.

The governor also proposed the creation of an Office of Disability Resources, which would combine several existing services in one location. He said the office would create a long-range plan " … to better provide services to individuals of all ages with disabilities."

Notes

[1] American Association for Retired Persons, *Across the States, 2000.* (Washington, D.C.; AARP, 2000).

[2] Expenditure figures from Burwell using HCFA 64 data.

New Hampshire

Overview

During the 1990s, New Hampshire began significant efforts to expand community-based services for people with disabilities, particularly for those with developmental disabilities who had been on waiting lists for long periods. In 1997, the legislature required full funding of the waiting list for developmental services to be part of the Department of Health and Human Services' budget. Further, in 1998, the legislature established an oversight committee to review the allocation of developmental services waiting list funds.

Although the average waiting time for community services began to decline in the late 1990s (from 302 days in 1997 to 160 days in 2000), the legislature created a study committee in the 2000 session to consider proposals to reduce the developmental services wait list to zero and allocated $4.5 million for salary increases for direct care providers of people with developmental or acquired brain disorders.

Fiscal Analysis

New Hampshire significantly controlled its Medicaid-funded nursing home expenditures in the late 1990s and drastically cut its spending on ICF/MR facilities during the decade. The state had only a 0.6 percent increase from FY 1999 to FY 2000 ($212.9 million to $214.3 million) and a decrease of 2.1 percent from FY 2000 to FY 2001 ($214.3 million to $209.8 million). Expenditures for ICF/MR facilities decreased from $3.3 million in FY 1995 to $2.1 million in FY 2001.[1]

In 2001, the state was allocating 60 percent of its Medicaid long-term care funds to institutional care and 40 percent to home and community-based services (HCBS). Highlights of the fiscal picture include the following:

- New Hampshire increased its spending on HCBS waiver programs from $97.7 million in FY 1996 to $137.7 million in FY 2001. About 87 percent of the waiver expenditures went to the MR/DD program.

- The state has a small Medicaid Personal Care program, which had total spending of $3.4 million in FY 2001.

Legislative Activities

The 2001 legislature required the Department of Health and Human Services to submit a plan to reduce the waiting period for developmental services to 90 days over a five-year period. The final plan, "Renewing the Vision: New Hampshire's Plan to Provide Essential Community Supports for Individuals with Developmental Disabilities," was submitted to the legislature in November 2001. The legislature also appropriated $5 million to serve developmentally disabled people on the waiting list for community services and $3 million for people with acquired brain disorders.

Lawmakers also directed the Department of Health and Human Services to develop a rate-setting structure for nursing home reimbursement and established a long-term care rate advisory committee to make recommendations for changes to the department. The department must report these recommendations to the governor and the legislature by Sept. 1, 2002, and at least every two years thereafter.

Long-Term Care Planning

In 2001, New Hampshire received a total of almost $4 million in three grants from the federal Systems Change Grant Program. The state proposes to use the largest grant ($2.3 million) " … to improve health and long-term care service systems and supports for people with disabilities and long-term illness to live in the community … " through a project entitled "Facilitating Lifespan Excellence" (FLEX). The proposal, developed collaboratively by the disability and aging communities, will develop several projects designed to fill identified gaps or weaknesses in the current infrastructure of long-term supports. The projects then will be implemented in one model community or region.

New Hampshire also has received a $770,000 Nursing Facility Transitions Systems Change grant, which it plans to use in a three-year program to help older adults with mental illness and other disabilities make the transition from nursing facilities to community settings in the Concord community and statewide. The project, called "Wrap Around Services," will provide services and housing for the individuals who are making the transitioning to the community. One step of the project involves developing a Medicaid Mental Health/Home and Community-Based waiver application and other funding options for housing, social, adult daily living and mental health needs.

Another $900,000 Systems Change grant will be used by the state to develop a model consumer-directed personal care service provider program. The goal of the project is to create comprehensive cross-disability and cross-age-group access to consumer-directed personal care. New categories of eligible consumers will include people on the state's Elderly and Chronically Ill Medicaid waiver, and children with special health needs. The project will also expand the availability of direct care workers.

Future Outlook

With its legislative initiatives and federal grants, New Hampshire is engaged in significant planning efforts to develop community-based services for people with disabilities. The state continues to work to reduce the developmental disability waiting list for people living at home who are waiting for community services and to divert people from nursing homes.

Notes

[1] Expenditure figures from Burwell using HCFA Form 64 data.

New Jersey

Overview

New Jersey has embarked on a number of long-term care initiatives in recent years, ranging from a nursing home diversion program that has seen about 2,500 people moved out of institutions to the community to a Cash-and-Counseling demonstration project to allow about 2,000 Medicaid beneficiaries to direct their own care. The state also has one of the country's largest well-funded respite programs–funded through casino revenues–for family caregivers.

The state has about 33,000 people in nursing homes and ICF/MR facilities, but it also is serving almost as many people in the community through Medicaid and state-funded home and community-based care services (HCBS).

Fiscal Analysis

Total long-term care expenditures were expected to increase from $2.6 billion in FY 2000 to $2.9 billion in FY 2002. Actual long-term care spending between 2000 and 2001 increased about 5 percent. Compared to a $1.7 billion expenditure for institutional care (nursing facilities and ICF/MRs) in 2002, the state expected to spend about $1 billion for HCBS. Highlights of the fiscal picture include the following:

- Although nursing home expenditures have risen from about $1.2 billion in 2000 to $1.3 billion in 2002, the caseload has remained fairly steady at 29,000 residents.

- A total of about 16,500 people are being served by the Medicaid HCBS waiver programs for the Aged/Disabled and for MR/DD participants. Another 15,500 people are participating in the Personal Care program.

- The state was spending more than $500 million for HCBS waiver programs in FY 2001, with over three-fifths of the money going to the MR/DD program. Another $200 million was being spent on Personal Care services, and $100 million went for other community-based care services.

Legislative Activity

In August 2001, lawmakers approved a measure that establishes new Medicaid requirements for assisted living providers in the state. The law requires new assisted living residences or comprehensive personal care homes¾including existing facilities that add new beds¾to reserve at least 10 percent of their beds for Medicaid residents. However, the law also provides that the commissioner of Health and Senior Services may waive this requirement if sufficient Medicaid beds exist.

The 2001 Legislature also appropriated funding to address nursing home reimbursement rates and directed state health officials to implement policies that restrict an individual's ability to manipulate Medicaid rules to avoid paying costs associated with long-term care services.

Long-Term Care Planning

An *Olmstead* Stakeholders' Task Force has worked on a plan to guide the state's actions during the next five years to help people with disabilities remain in or return to the community. The task force recommendations were expected to build on actions already under way in the state, such as assessments of individuals in psychiatric and developmental facilities and bridge funding and support for people moving from nursing homes to the community. The report was expected in early 2002.

Future Outlook

The fiscal picture was bleak for New Jersey in early 2002. Incoming Governor James McGreevey (D) told the Legislature on February 11 that the state was facing a $3 billion budget shortfall for the remainder of the fiscal year at the end of June 2002 and that another $6 billion shortfall was expected for the fiscal year beginning July 1.

New Jersey received a $2 million grant under the federal Systems Change Grant Program in 2001, which the state planned to use to develop community housing options for residents of developmental centers, psychiatric hospitals and nursing facilities. The state will create an interactive housing web site for use by people of all ages with disabilities and will hold a statewide housing summit to showcase innovative practices and to stimulate creative planning for future housing options.

Another initiative under the grant will be to provide seed money for innovative housing projects through a competitive bid process. The state also plans to develop and pilot a personal care assistant registry and rapid response back-up system for personal care assistance.

New Jersey also received two grants totaling $1 million in the second round of the Systems Change Grant process in 2002 for nursing facility transition projects.

New Mexico

Overview

New Mexico made significant progress in expanding HCBS in the 1990s. The percentage of Medicaid long-term care funds that the state was allocating to HCBS increased from 21 percent in 1994 to 55 percent in 2001. One of the reasons for the shift was the decline in the Medicaid long-term care funds that the state was allocating to ICF/MR facilities, with expenditures decreasing from $31.8 million in FY 1996 to $18.4 million in FY 2001 for these facilities.

New Mexico is one of only seven states that have closed large, publicly funded institutions for people with mental retardation and developmental disabilities. The state continues to provide long-term care services through small ICF/MR facilities and has greatly expanded spending on its MR/DD waiver program (see below). New Mexico ranks in the top 10 percent nationwide in terms of per capita spending on individuals with developmental disabilities.

However, the state also has had long waiting lists for its Medicaid home and community-based services (HCBS) waiver programs for elderly and disabled and for people with developmental disabilities, with the numbers reaching as many as 5,000 people in total waiting for community services in 2001.

Fiscal Analysis

Spending in New Mexico for nursing facilities, which totaled $120.2 million in FY 1996, rose to $165.8 million in FY 2001. The state experienced an increase of almost 7 percent in the number of nursing home residents between 1995 and 1999.[1]

Total spending for all HCBS waiver programs in New Mexico doubled from FY 1996 to FY 2001, from $92 million to $159.7 million. New Mexico drastically increased its spending on its MR/DD waiver program from only $3.6 million in FY 1992 to almost $134 million in FY 2001.[2] Highlights of the fiscal picture include the following:

- The number of people being provided HCBS services (about 1,400 people in the Elderly and Disabled waiver program and 2,500 people in the DD program) was close to equaling the number of Medicaid-covered nursing home residents in 2000 (approximately 4,350 people).

- New Mexico initiated a Medicaid Personal Care program in September 1999 and, by February 2001, had 2,200 people covered by the program. Expenditures for FY 2001, totaled $65.6 million.

Legislative Activity

The 2001 Legislature appropriated an additional $9 million in state funds for the Medicaid MR/DD waiver program, which would allow the program to increase the number of people served under that program by 500 people by FY 2002. Of the $9 million, $1.7 million was to be used to address reimbursement rates for providers.

Long-Term Care Planning

New Mexico has had a Managed Long-Term Care Advisory Committee since March 1997 that is composed of consumers, advocates and providers. State agency officials participate in the group's meetings but have no vote. The advisory committee and the Department of Human Services developed a centralized intake and screening system called Long–Term Care Link, which went into operation in December 2000. The system provides a single point of entry into the state's long-term care system.

New Mexico has applied to the federal government for approval of a program the state calls "Global Funding." Funding for nursing homes and HCBS would be combined into one funding stream, which would follow an individual to the most integrated setting appropriate to the individual's needs.

Future Outlook

A lawsuit was filed in federal court (*Lewis vs. New Mexico)* on behalf of 3,000 individuals with developmental disabilities in nursing facilities who are on waiting lists for community placements. New Mexico received a grant for almost $1.4 million from the federal Systems Change Grant Program, which will be administered by the Medical Assistance Division of the Department of Human Services. With these funds and the additional funds appropriated by the Legislature, New Mexico is addressing the waiting list issue. The question will be whether the state is moving fast enough to satisfy the courts and the plaintiffs.

Notes

[1] American Association for Retired Persons, *Across the States 2000.* (Washington, D.C.; AARP, 2000).

[2] Expenditure and caseload figures from Burwell, using HCFA Form 64 and Harrington, using HCFA Form 372.

New York

Overview

From 1995 to 1999, New York experienced a higher percentage increase in nursing home beds than the national average (10.1 percent compared to 3.2 percent nationally) and a larger increase in the number of nursing home residents than the national average (8.7 percent compared to 1.0 percent nationally).[1] The number of Medicaid nursing home residents totaled almost 85,000 people in 1999.

However, with almost 20,000 people being served in the state's Elderly and Disabled HCBS waiver program (called "Long Term Home Health Care") and 38,700 people in the state's MR/DD program, New York had a sizeable HCBS caseload. The state also manages the largest Medicaid Personal Care program in the country.

Fiscal Analysis

New York led all the states in per capita spending on nursing homes in FY 2001, with $336.24 per capita. Spending for nursing home care totaled $6.4 billion, which was $2.7 billion higher than the next closest state (Pennsylvania). The state also had the highest total and per capita expenditure in the country for ICF/MR facilities at $2.2 billion and a per capita rate of $113.59.[2]

However, the state's spending on HCBS waiver programs more than doubled from FY 1996 ($914.4 million) to FY 2001 ($2 billion). Total expenditures for the state's Medicaid Personal Care program were almost $1.9 billion, with a per capita rate of $98.35. Highlights of the fiscal picture include the following:

- In 2001, New York allocated 61 percent of its Medicaid long-term care expenditures to institutional care and 39 percent to HCBS.
- About 98 percent of the state spending on HCBS waiver programs went to the MR/DD program in 2001, with a total of $1.9 billion out of $2 billion.
- The state's spending on the Personal Care program stayed fairly static throughout the late 1990s. The state spent about $1.6 billion on the program in FY 1996, then spending decreased to $1.55 billion in FY 1997 and gradually increased during the next few years to reach almost $1.9 billion in FY 2001.

Legislative Activity

There was no significant long-term care legislation in 2001.

Long-Term Care Planning

In the late 1990s, New York initiated a Managed Long-Term Care program. Currently, the state is operating seven demonstration projects plus an additional 24 managed long-term care plans. The state expects to serve 50,000 people through these programs. As of early 2002, New York did not have an *Olmstead* Planning Commission.

Future Outlook

In 2002, Governor George Pataki (R) proposed legislation to ensure that residents of adult care facilities receive quality care and are placed in homes that do not have outstanding serious violations that directly affect the health, safety or welfare of residents. The measure also would prohibit referrals to adult care facilities that do not have valid operating certificates, increase fines for violations related to care, and require additional discharge planning requirements for patients released from inpatient facilities licensed or operated by the Office of Mental Health or the Office of Alcoholism and Substance Abuse Services.

The governor also announced the award of $3.1 million in grants to 14 nursing homes to conduct innovative projects aimed at improving the lives of residents with Alzheimer's disease and other forms of dementia.

New York also received a Systems Change grant in 2002 for almost $1.4 million.

Notes

[1] American Association for Retired Persons, *Across the States 2000* (Washington, D.C.; AARP, 2000).

[2] Expenditure figures from Burwell using HCFA Form 64.

North Carolina

Overview

In 1999, the North Carolina General Assembly asked the Department of Health and Human Services (DHHS) to develop a long-term care system that could provide a continuum of care for people with disabilities. DHHS asked the North Carolina Institute of Medicine to convene a statewide task force to assist DHHS in developing the plan. The task force of 49 people included representatives of county commissions, local governments, long-term care providers and industry associations, consumer advocacy groups, and businesses.

"A Long-Term Care Plan for North Carolina: Final Report," submitted to the legislature in March 2001, contains 47 recommendations relating to issues of infrastructure, quality, work force and access/financing. In response to the study, the DHHS secretary in 2001 established the position of assistant secretary for long-term care, responsible for interagency long-term care planning and coordination of the work of a Long-Term Care Cabinet.

The report includes policy statements and strategies as well as required appropriations for FY 2002 and FY 2003. Several recommendations related to adult care homes were implemented in 2001.

Fiscal Analysis

North Carolina allocated 63 percent of its Medicaid long-term care expenditures to institutional care and 37 percent to home and community-based services (HCBS) in fiscal 2001.

Nursing home expenditures rose only by 4.4 percent from FY 1998 to FY 1999 ($778.9 million to $812.8 million) and by an even smaller 2.4 percent from FY 1999 to FY 2000 ($812.8 million to $832.7 million). The total for nursing homes in FY 2001 was $876 million.[1] Expenditures for ICF/MR facilities had similar small percentage increases in the late 1990s: a 0.9 percent increase from FY 1999 to FY 2000 ($393.4 million to $396.9 million) and a 0.8 percent from FY 2000 to FY 2001 ($396.9 million to $400 million). Highlights of the fiscal picture include the following:

- Spending on HCBS waiver programs increased from $170.6 million in FY 1996 to almost $455 million in FY 2001.
- About 27,000 people were residents of nursing homes in 1999, compared to about 16,400 people receiving services under HCBS waiver programs.
- North Carolina doubled spending on its Medicaid Personal Care program from FY 1996 to FY 2001, going from $108.6 million to $221.2 million. The state ranked fifth among the states in FY 2001 in its Personal Care per capita spending.

Legislative Activity

In response to the recommendations of the long-term care task force (see above), the legislature took several actions in 2001 to address issues related to assisted living. First, the legislature approved a measure requiring adult care homes to report costs for residents in special care units separately from costs associated with other residents. The law also directs DHHS to develop a reimbursement system for special care units.

A second law directs the department to develop an assessment instrument that will enable residents of adult care homes to evaluate the extent to which a home is providing quality care. The department will test the instrument in selected adult care homes during 2002 and report findings to the Study Commission on Aging by Nov. 1, 2002.

Other 2001 laws direct the state to regulate adult care homes under the state's certificate of need program and require nursing facilities in the state to post information on staffing.

Long-Term Care Planning

The Long-Term Care Task Force proposed the creation of a long-term care cabinet within DHHS to finance, regulate or provide long-term care services. The task force also recommended the creation of a uniform entry system for consumers to obtain long-term care services.

Task force recommendations on quality included increased Medicaid funding for personal care services in homes, adult care homes and nursing homes, with the increases to be used for enhancing wages, benefits and/or shift-differential payments. The report also proposed funding for continuing education and paraprofessional development in addition to a career ladder for long-term care paraprofessionals. (North Carolina is putting substantial emphasis on recruiting and retaining direct care workers as an important step in improving the quality of long-term care services in the state.)

Future Outlook

North Carolina received a $1.6 million Systems Change grant, which the state intends to use on a direct care workforce recruitment and retention initiative. Grant activities will focus on developing a career ladder for direct care workers, implementing public education and awareness efforts to promote recruitment and retention of direct care workers, and designing a consumer-directed care model.

The state proposes to examine options for increasing the availability and affordability of health care insurance coverage for direct care workers, as well as other benefits such as flexible work schedules, child and eldercare, and participation in retirement and other benefit plans. Other steps include developing competency-based training models with related wage recommendations that recognize incremental development of specialized competencies, such as working with people with complex medical needs or with dementia.

Notes

[1] Expenditure and caseload figures from Burwell, using HCFA Form 64 and Harrington, using HCFA Form 372.

North Dakota

Overview

North Dakota relied heavily on the use of nursing home care for the first half of the 1990s, but established a moratorium on construction of new nursing home beds beginning in 1995. The state had 76.3 beds per 1,000 of the age 65 and older population in 1999, compared to a national average of 52.3 beds per 1,000; the nursing home occupancy rate was 92.2 percent, compared a national average of 82.7 percent in 1999.

A Task Force on Long–Term Care Planning made up largely of state agency representatives has been meeting periodically since 1995 to review the state's long-term care system and make recommendations for changes. The group issued reports in June 1996, June 1998 and November 2000 (see below).

Fiscal Analysis

Spending for nursing home care has been steadily increasing, from $115.7 million in FY 2000 to an estimated $146.2 million in FY 2002, for a nursing home population that has remained fairly constant at 3,700 people. Although expenditures for home and community-based services (HCBS) have increased from $29.1 million in FY 1996 to $49 million in FY 2001, the number of people served by these programs has increased only slightly, from about 2,000 people in 1995 to 2,600 people in 2001.[1] Highlights of the fiscal picture include the following:

- North Dakota has three Medicaid waiver programs: Aged/Disabled (called Service Payments for Elderly and Disabled or SPED), Mentally Retarded/Developmentally Disabled and Traumatic Brain Injury.

- The MR/DD program constituted 90 percent of total Medicaid waiver spending for the state in 2001 ($44 million of a total $49 million). More than 80 percent of the caseload for the Medicaid waiver programs was in the MR/DD program in 1999.

- North Dakota began implementing a Medicaid Personal Care program in FY 2001, with expenditures of $1.3 million covering 483 people. The state projected spending to increase to $4.2 million in FY 2002.

Legislative Activity

In 2001, the legislature took several actions to improve quality of care in nursing homes and to clarify standards for basic care facilities and assisted living facilities.
("Basic care" is defined in North Dakota as 24-hour care in congregate settings for Medicaid-eligible aged, blind and disabled individuals who need assistance with activities of daily living, but whose condition is not serious enough to warrant nursing home care.)

One measure enacted in 2001 established that basic care facilities provide a higher level of care than assisted living facilities by making response staff available around the clock to meet the scheduled and unscheduled needs of residents or that provide Alzheimer's, dementia or special memory care. The law creates separate standards for assisted living through a new registration process. Under the new standards, assisted living facilities must provide living units that include individual support services to accommodate resident needs and abilities.

Another measure enacted in 2001 appropriated funds from intergovernmental transfer funds to provide loans for remodeling nursing, basic care and assisted living facilities. Those funds also were used to enhance wages for nursing home and basic care facility employees who provide direct care for patients and as matching funds for nursing facilities with student loan programs for nurses. The law also allocates funds that the Department of Human Services may use to provide financial incentives to nursing homes to reduce bed capacity and directs the Legislative Council to conduct a statewide needs assessment to determine the needs of the state's long-term care system.

Long-Term Care Planning

As part of its periodic long-term care planning process since 1995, the Department of Human Services organized an internal work group in January 2000 that consisted of division directors representing Medicaid, aging, mental illness and substance abuse, developmental disabilities, and children and family services. After four public hearings via interactive video networks, the group released an *Olmstead White Paper* in November 2000. The recommendations included a request to the governor to appoint a commission to develop definitions and a comprehensive state plan. The group also proposed the development of nursing home alternatives and the creation of a preassessment screening process before admission to a nursing home.

Governor John Hoeven (R) formed a Governor's Commission on *Olmstead,* charged with developing a plan and recommendations before the legislative session in 2003. The commission is expected to expand on the *Olmstead White Paper.*

Future Outlook

North Dakota applied for but was not awarded a grant under the federal Systems Change Grant Program, but did receive a $20,000 *Olmstead* Financial Support Award from the Center for Mental Health Services. After assessment of the present nursing home population, the Governor's Commission reapplied for the second round of grants in the Systems Change program, and was awarded $900,000.

Notes

[1] Waiver expenditure and caseload figures from Burwell using HCFA Form 64 data and Harrington using HCFA Form 372.

Ohio

Overview

Ohio has been engaged in a major effort since the 1990s to limit institutionalization and to expand home and community-based service (HCBS) options for people with disabilities. The state has, for example, increased the number Medicaid HCBS waiver program slots from about 11,000 in FY 1992 to nearly 38,000 in FY 2000, a 242 percent increase. A moratorium on new nursing home and MR/DD beds has been in place since 1994.

Acting on the recommendations of a task force called "Ohio Access," the legislature appropriated funds in the 2002-2003 biennial budget to add almost 5,000 new slots for the state's Medicaid HCBS waiver programs (see below).

Fiscal Analysis

Despite the growth in home and community-based care services in Ohio in the last decade, spending for institutional care still greatly outpaces spending on community services. The state spent $3.1 billion for institutional care in FY 2001, which consisted of about $2.3 billion for nursing home care and $787 million for ICF/MR facilities. In contrast, Ohio spent only about $480.6 million for HCBS waiver programs that year.

Ohio was providing care for more than 55,000 people in nursing homes in 1999, and 44.6 percent of people age 65 and older in poverty were Medicaid nursing home residents that year (compared to a national average of about 30 percent). However, the FY 2002-2003 biennial budget contains about $145 million for new initiatives and expansion of existing programs for Ohioans with disabilities. Highlights of the fiscal picture include the following:

- The PASSPORT waiver program, which has 24,000 slots for people age 60 and older who otherwise would need nursing home care, will increase by 1,300 slots in FY 2002 and by1,600 slots in FY 2003.

- The Individual Options waiver program, which serves 3,300 people who otherwise would require institutionalization in a facility for the mentally retarded, will receive funding for an additional 500 slots in both FY 2002 and FY 2003.

- The Home Care waiver program, which has slots for 8,200 disabled people under age 60 or people of any age with a chronic, unstable condition who require nursing care, will receive an additional 500 slots in both FY 2002 and FY 2003.

- The state is establishing an Ohio Success pilot program to fund up to $2,000 each in transition costs for 75 people in FY 2002 and 125 people in FY 2003 moving from nursing homes to the community.

Legislative Activity

Major legislative actions related to long-term care reform in 2001 involved the additional funding outlined above. These short-term priorities from the Ohio ACCESS Task Force, which focus on

expanding waiver programs, were endorsed by Governor Bob Taft (R) and submitted to the General Assembly in the 2002-2003 executive budget.

Long-Term Care Planning

Created by executive order in June 2000, the Ohio ACCESS task force issued its report and recommendations entitled "Ohio Access for People with Disabilities," in February 2001. The task force gave priority to the needs of people with developmental disabilities and people with physical disabilities, with the goal of developing strategies to move people with these disabilities out of institutions.

The cornerstones of the Ohio Access vision are consumer self-determination and a person-centered planning approach with assistance from family, friends and caregivers. The three "guiding principles" in the report are:

- **Increase community capacity** by improving current delivery systems to assist families, communities and government in meeting their responsibilities.

- **Prioritize resources** by developing a process to determine where reform is most needed and by seeking cost efficiencies and appropriateness of care, particularly in institutional settings, to make more dollars available to support community-based care.

- **Assure quality and accountability** by assuring clinical, programmatic, and fiscal accountability and compliance at federal, state, local and provider levels.

Future Outlook

The thrust of Ohio Access is the development of a comprehensive state policy centered around the concept of community-based services. As stated in the Ohio Access plan, achieving a balanced and sustainable delivery system requires "comprehensive structural reform."

The policy envisions a "sustained reduction of institutional capacity and funding," so that some funding can be shifted to community settings. Another component of the policy strategy calls for overcoming federal policy constraints such as being able to provide home and community-based services without a federal Medicaid waiver so the state can eliminate bureaucracy and time delays in program implementation. In terms of workforce shortages, the plan recommends that the state encourage the creation of demonstration projects to increase workforce efficiency, and examine the use of payments to family members and other informal caregivers for some services.

When Governor Taft created the Ohio Access task force, he requested recommendations for improving services for people with disabilities during the next six years. Ohio policymakers have determined that a six-year plan is needed to achieve long-term care reforms because of budget constraints " consistent with a slowing economy and the urgency of the need to address school funding." Long-term planning also is needed, policymakers say, because many of the barriers facing reform have developed and existed for many years and, in some cases, are beyond the state's control.

The long-term recommendations in the Ohio Access plan focus on labor issues. Budgets for the long-term solutions and the agencies responsible for them were not detailed in the report issued in February 2001.

Ohio received two grants totaling almost $2 million in 2002 under the federal Systems Change Grant Program. Both grants were to be administered by the Ohio Department of Job and Family Services.

Oklahoma

Overview

Oklahoma has focused in recent years on increasing home and community-based services (HCBS) and improving quality of care in nursing homes. The number of elderly people receiving HCBS through the state's Medicaid Aged/Disabled waiver program has climbed from only a few hundred people in the mid-1990s to more than 11,000 currently. Combined with the other Medicaid waiver programs and the Medicaid Personal Care program, the total number of people receiving HCBC in 2002 far exceeds the number of people in institutional care in the state.

The Oklahoma Health Care Authority began to implement nursing home quality-of-care initiatives in 2000. The state now requires nursing home providers to submit monthly quality-of-care reports. Higher staffing standards became effective in September 2000 that require one aide to every eight residents during the daytime shift and one aide to 12 residents during the evening shift. The state also has begun collecting a fee per patient day from long-term care facilities to be placed in a revolving fund used to pay for a higher facility reimbursement rate and to help meet the increased staffing requirements.

Fiscal Analysis

State spending on nursing home care has been increasing rapidly since FY 2000, although the number of residents has been decreasing slightly. Expenditures for nursing home care totaled about $303 million in FY 2000, but were projected to rise by more than 45 percent to almost $442 million in FY 2002. During the same period, the number of nursing home residents was expected to drop from 16,077 to 15,702 individuals. Oklahoma had the fourth lowest nursing home occupancy rate in 1999, 71.1 percent.

Oklahoma operates four Medicaid HCBC waiver programs, three of which cover people with mental retardation. In terms of caseload, the largest waiver program is the Elderly and Adult Physically Disabled program (ADvantage Program) with almost 7,800 people in FY 2000; it is expected to increase to about 11,250 people in FY 2002. Highlights of the fiscal picture include the following:

- Expenditures for all the Medicaid waiver programs totaled $171.2 million in FY 2000, which were expected to increase by about $100 million to $270 million in FY 2002. About three-quarters of the total went to the largest mental retardation waiver program.

- Spending for the Medicaid Personal Care program increased by about one-third from $35.4 million in FY 2000 to $46.5 million in FY 2002; the caseload increased from about 6,600 people to almost 8,300 people.

Legislative Activity

The Oklahoma Legislature addressed several issues in 2001 applicable to long-term care providers. Lawmakers provided protections against certain types of abuse or financial exploitation of vulnerable adults in long-term care settings. Workers may face a $1,000 penalty or imprisonment for verbally abusing a person under their care. The law also provides that caregivers in nursing homes, assisted living centers, home health agencies and adult day centers commit a misdemeanor offense if they solicit or accept any item worth more than $1 from a person under their care.

Another measure requires long-term care providers to implement, by July 1, 2002, a uniform assessment tool for determining the needs of clients. The law further directs the Oklahoma Health Care Authority (the state's Medicaid agency) to establish a case-mix reimbursement system for long-term care providers by Nov. 1, 2003. Lawmakers also created a task force to study the recruitment and retention of staff in nursing and specialized facilities; a report of its findings was scheduled for Feb. 1, 2002.

Long-Term Care Planning

The Oklahoma Health Care Authority has been coordinating meetings of an informal group of 15 to 20 people who meet monthly to identify activities to support integrated service settings. Aging representatives in the group include nursing home association representatives, the director of the Aging Services Office, and a representative from the agency that manages the state's major aging waiver program.

Although the group does not expect to issue a formal plan, it issued a status report in June 2001, according to advocates involved in the planning process. That report outlined issues, set forth general recommendations, and identified future directions.

Future Outlook

Oklahoma received an $850,000 Systems Change grant, which the state will use to develop and support consumer-directed personal assistance services. The Department of Human Services (DHS) proposes to offer greater consumer/community control in the design, implementation and quality monitoring of personal assistance services.

DHS administers the ADvantage Program and Ability Resources is an independent living center (ILC) that has been a case management provider for the program. The grant project will include development of ILC-based intermediary services organizations to serve as consumers' business agent and consultant for employer responsibilities. The project also will recommend Nurse Practice Act language that supports appropriate delegation of nursing tasks to unlicensed staff or to family and friends who have received training from a registered nurse.

The state also received a second-round Systems Change Grant of $1,385,000.

Oregon

Overview

Oregon has long led the country in regard to having an extensive and comprehensive system of home and community-based services (HCBS) for persons with disabilities. While its nursing home population *and expenditures* have been declining, the number of persons served in the community has been steadily increasing, particularly with its Medicaid Aged and Disabled waiver program, which is currently serving almost 28,000 persons.

Fiscal Analysis

The state's spending on HCBS far outpaces its expenditures for institutional care. In 2000, Oregon spent about $422 million for HCBS Medicaid waiver programs and Medicaid Personal Care compared to $267 million for nursing homes and ICF/MR facilities. The state projects spending almost three times as much on HCBS in 2002 than on institutional care. Highlights of the fiscal picture include the following:

- State officials estimate expenditures of $585 million for HCBS in 2002, compared to $204 million for institutional care. The total for institutional care is expected to be almost $63 million less than that spent in FY 2000.

- Although spending on the state's MR/DD and Aged/Disabled waiver programs were almost equal in FY 2000 at about $200 million each, expenditures are increasing faster for MR/DD services. In FY 2002, the state estimates expenditures of approximately $313 million for the MR/DD program, compared to $257 million for Aged/Disabled.

- The caseload for the Aged/Disabled waiver program was expected to increase from 23,125 in 2000 to almost 28,000 in 2002; the caseload for the MR/DD program was expected to increase from 6,044 to 6,609 during the same period.

- The state estimates that the nursing facility caseload will decrease from 6,644 in 2000 to 5,871 in 2002. Spending also is expected to decrease from $242 million to $191 million, which would make Oregon unique as a state that is experiencing *declining* expenditures for nursing home care.

Legislative Activity

The 2001 Legislative Assembly approved a measure that authorizes nursing home, residential care and assisted living facilities to employ out-of-state licensed nurses for temporary assignments of up to 60 days during periods of temporary staffing shortages.

Long-Term Care Planning

Oregon launched a Medicaid research and demonstration project in fall 2001, the Independent Choices Program, to offer people with disabilities additional choice and control over their services. Under this program, the state will send monthly cash payments to participants' bank accounts. Participants will be responsible for managing personal care and related services within the monthly allotment.

Future Outlook

Oregon's efforts related to expansion of community-based care currently focus on people with developmental disabilities. As an outgrowth of legislation enacted in 1999, the state developed a six-year plan that has as its goal the elimination of the waiting list for community-based services for people with developmental disabilities. The state has agreed to create 50 new placements annually for the next six years, and will increase the availability of personal care and respite services.

With a $2 million Systems Change Grant, Oregon will pilot a consumer-run brokerage in one county, and will assist in the development and strengthening of drop-in centers to demonstrate new models of consumer-directed choice. A grant coordinator and two housing staff will coordinate the efforts of four main workgroups composed of consumers, family representatives, stakeholders and agency staff in implementing 24 specific goals identified in the grant. The state also will develop a statewide recruitment effort for personal assistants.

Pennsylvania

Overview

Pennsylvania has allocated a significant portion of its tobacco settlement funds to expand home and community-based services (HCBS), with the expectation that the state would be able to serve an additional 11,000 people with the funds. The state's plans included creating a new "Bridge" program for people who are not financially eligible for Medicaid but need long-term care services and enhancing the state's lottery-funded OPTIONS program through cost sharing for certain individuals.

Under the "Bridge" program, eligible individuals will pay for a portion of the services they receive until their resources are reduced to Medicaid eligibility, at which point their services would be covered by Medicaid. The OPTIONS program will be changed through implementation of state-wide cost sharing. Those whose incomes exceed 125 percent of poverty ($923 a month in 2002) will be expected to share in the cost of services on an income-related, sliding fee scale. The funds received through the cost-sharing system will be used to cover more people.

The OPTIONS program previously had no financial eligibility requirements, but about 13,000 people were on waiting lists for OPTIONS and Medicaid waiver program services in 2001. Several lawsuits involving people with disabilities and community placement had been filed.

Fiscal Analysis

Pennsylvania has increased its spending on its waiver programs by more than $100 million each year from FY 1996 through FY 2001, reaching a total of almost $879 million in FY 2001. The state more than doubled the number of MR/DD clients receiving HCBS from about 5,500 people in FY 1995 to approximately 12,000 people in 2000.[1]

The number of nursing home residents increased only fractionally between FY 1995 and FY 1999 (0.6 percent), and the percent increase in nursing home beds over that period was close to the national average (3.9 percent compared to the national average of 3.2 percent).[2] However, the state had the second highest total and per capita nursing home expenditures in the country in 2001, with total spending at $3.7 billion and per capita spending at $299.83. Highlights of the fiscal picture include the following:

- In FY 2001, state spending on ICF/MR facilities had dropped to $486 million from $554.6 million in FY 1996.
- Spending for HCBS waiver programs, which had totaled $307.8 million in FY 1996, shot up to $878.7 million in FY 2001.
- The largest HCBS waiver program was the MR/DD program, with expenditures totaling $714 million in FY 2001.

Legislative Activities

In 2001, the Legislature appropriated $45 million from tobacco settlement money for home and community-based services in FY 2001-2002. About 40 percent of the funds were to be used to expand Medicaid waiver program services, particularly the MR/DD program. The other 60 percent of the tobacco appropriation went to the Options program and the creation of the new "Bridge" Program.

Long-Term Care Planning

The state created a Home and Community-Based Services Project in the spring of 2000, which brought together officials from various state agencies that administer HCBS. The aim of the project is to create a seamless system of home and community-based services for consumers, share information and ideas across program areas, and coordinate resources across program areas and agencies.

Future Outlook

Pennsylvania began a five-year plan in 2000 to reduce the waiting list for community services for people with mental retardation and developmental disabilities. The governor has proposed increasing HCBS funding for MR/DD programs in the FY 2002-2003 budget. With these actions and the tobacco settlement funds, the state appears to be committed to expanding community services to more people with MR/DD in the next few years.

Notes

[1] Expenditure and caseload figures from Burwell, using HCFA Form 64 and Harrington,, using HCFA Form 372.

[2] American Association for Retired Persons, *Across the States 2000.* (Washington, D.C.: AARP, 2000).

Rhode Island

Overview

Rhode Island was among the top 10 states in 2001 in terms of allocation of Medicaid long-term care funds to home and community-based services (40 percent compared to 60 percent for institutional care). The national average that year was 29 percent for home and community-based services (HCBS).

Spending on Medicaid HCBS waiver programs almost doubled from FY 1996 ($90.2 million) to FY 2001 ($164.8 million). The state led all other states in 2001 in per capita spending for HCBS with $155.73 per capita.[1]

Fiscal Analysis

The state spent $244.3 million for nursing home services and $7.1 million for ICF/MR facilities in 2001. ICF/MR expenditures had decreased dramatically over five years, from $34 million in FY 1996 to a total of only $7.1 million in FY 2000.

With about 6,000 slots for its five HCBS waiver programs, the state was serving almost as many people in the community as in its nursing homes, where the number of Medicaid residents was about 6,700 in 2000. Highlights of the fiscal picture include the following:

- The largest waiver program in terms of caseload was the MR/DD program with 3,300 participants in 1999, followed by the Aged/Disabled program with about 1,650 participants.

- The largest waiver program in terms of expenditures was also the MR program with $97.4 million in FY 1999, about 70 percent of total HCBS waiver expenditures of $151 million. The state spent another $63.7 million that year for a Special Care waiver program for children.

Legislative Activity

The 2001 General Assembly created a joint legislative commission to study the state's long-term care system. The commission was to examine issues relating to chronic care and disease management of acute and long-tem care services, reimbursement rates for nursing homes and other long-term care providers, and regulation and reimbursement for assisted living services. The legislature also directed the Department of Human Services to obtain federal approval to expand waiver program caseloads so that an additional 180 individuals could receive coverage for assisted living services, including 50 people with Alzheimer's disease or other dementia.

Lawmakers also approved a $3.71 per day per resident increase in Medicaid reimbursement for nursing facilities, in addition to the scheduled inflationary increase that took effect on July 1, 2001. The additional reimbursement was to be used to increase wages and/or staffing, cover the costs of payroll taxes and workers' compensation, and enhance existing benefits or provide new ones.

Long-Term Care Planning

Rhode Island received a Systems Change Grant for $539,730 that the state intends to use in connection with the development of its program for children with special health needs, a project called "Comprehensive Evaluation, Diagnosis, Referral, and Reevaluation" (CEDARR). With the grant funds, the state plans to design and implement a consumer-directed Personal Assistance Services and Support Program that will maximize control and choice for children with special health needs and their families.

Future Outlook

Rhode Island dramatically decreased its Medicaid spending on ICF/MR facilities during the 1990s to the point where those expenditures constituted only 1 percent of the state's allocation of Medicaid long-term care funds in 1999, down from 13 percent of the allocation in 1994. The state more than doubled its spending and tripled its waiver program caseloads during those years for community services for people with mental retardation or developmental disabilities.

The state continues to review its long-term care policies and programs and to expand its waiver caseloads. In addition, Rhode Island currently is engaged in a major initiative to develop consumer-directed personal care services for children with special health needs.

Notes

[1] Expenditure and caseload figures from Burwell, using HCFA Form 64 and Harrington, using HCFA Form 372.

South Carolina

Overview

South Carolina is facing a substantial waiting list problem for its Medicaid home and community-based services (HCBS) waiver program for elderly and disabled people; the list contains names of about 4,000 people. Although the state has been providing HCBS to almost 17,000 people, it also has an institutionalized population (nursing facility and ICF/MR facility) of about 20,000.

The South Carolina Home and Community-Based Services Task Force, created by the governor through an executive order in November 2000, issued a report with comprehensive recommendations in August 2001. These recommendations address the issue of moving people with disabilities from institutions to community settings whenever appropriate and possible (see below).

Fiscal Analysis

The state spent $324 million on nursing facility care in FY 2000, an amount estimated to increase to $376.2 million (a 16 percent increase) in FY 2002. Compared to most states that are seeing (or actually are planning for) reductions in nursing home caseloads, South Carolina officials are predicting an increase of more than 1,000 people in the state's nursing homes, from about 17,100 people to about 18,200 people in 2002.

During the same period, state officials expect expenditures for ICF/MR facilities to remain relatively constant, however, at about $165 million. Caseloads for ICF/MR facilities also are expected to remain constant at about 2,300 people. Highlights of the fiscal picture include the following:

- The state spent a total of about $224 million in FY 2001 on its five Medicaid HCBS waiver programs. The largest program in terms of expenditures is the MR/DD program, which totaled $127.6 million in FY 2001, constituting about 57 percent of the waiver total of $224 million that year.[1]

- South Carolina's spending on its Medicaid Personal Care program totaled $6.9 million, but state officials forecast that spending for this program will decrease to $4.7 million in FY 2002. Caseloads are estimated to decrease from 1,779 people to 1,300 people.

Legislative Activity

No significant long-term care legislation was enacted in 2001. State officials and lawmakers say that the state's high priorities include reimbursement rates for nursing homes, long-term care insurance for state employees, changes in minimum requirements for long-term care insurance, and raising Medicaid eligibility requirements for long-term care and Medicaid estate recovery rules.

Long-Term Care Planning

The final report issued by the South Carolina Home and Community-Based Services Task Force includes a catalogue of existing services, including their budgets and waiting lists, and comprehensive recommendations for people in institutions and those people who are at risk of institutionalization. Some recommendations have rough timelines, but none of the recommendations includes budgets.

The task force recommends that all people living in institutions who wish to be moved to a community setting be moved within a year of plan implementation. To offer choices of care settings to people with disabilities, the Task Force proposes:

- The development of an independent assessment process to offer people opportunities to live in a home or community setting, and

- The development of a comprehensive, statewide crisis intervention and support system to prevent unnecessary institutionalization.

Specific recommendations call for increasing the number of housing units in community settings for people moving from institutions to the community. For example, the plan proposes increasing community housing options by 300 units in each of the next two years and expanding funding for assistive technology and home modification.

Future Outlook

South Carolina has received a $2.3 million grant from the federal Systems Change Program that the state plans to use to develop a project called "Options for Community Living." One component, "SC Access" will develop, implement and maintain a database of comprehensive information and assistance for people with disabilities of any age. The other component of the project, "SC Choice," will create the infrastructure to support more consumer-directed services in two pilot areas of the state.

The state also received a $600,000 Systems Change grant in 2002 for nursing facility transitions.

Notes

[1] Burwell figures from Form 64 and Harrington figures from Form 372. State officials did not provide waiver figures.

South Dakota

Overview

South Dakota experienced a decrease in the number of nursing home residents from FY 1995 to FY 1999 (-8.2 percent) and a decrease in the number of nursing home beds during that period (-4.3 percent). Still, the nursing home population has remained fairly steady at about 4,000 residents since 1999, and the nursing facility occupancy rate is high compared to the national average (91.6 percent occupancy for South Dakota compared to 82.7 percent nationally in 1999). However, the state also has been steadily increasing funding for Medicaid home and community-based waiver services (HCBS) since 1995.

Fiscal Analysis

Nursing home expenditures increased only very gradually during the late 1990s. From FY 1996 to FY 1997, for example, the increase was only 1.4 percent ($98 million to $99.4 million), and another 1.4 percent from FY 1998 to FY 1999 ($102.4 million to $103.8 million). Spending for ICF/MR facilities decreased from about $31 million in FY 1995 to almost $18 million in FY 2000.

Although the state's allocation of Medicaid long-term care dollars to nursing homes changed only slightly–from 60 percent in FY 1994 to 59 percent in FY 1999–its allocation to ICF/MR facilities dropped from 22 percent to 11 percent during those years.

- Funding for HCBS waiver programs reached $53.6 million in 2000, with almost all the money going to services for the MR/DD population. About 1,800 people receive services under the MR/DD waiver program, and 685 people receive services under the Aged waiver.

- South Dakota has a small Medicaid Personal Care Program, with expenditures of about $1 million to serve about 720 people.

Legislative Activity

No significant long-term care legislation was enacted in 2001.

Long-Term Care Planning

State officials believe the state has adequate mechanisms in place to determine the appropriateness of placements in institutional facilities. The state uses an annual service plan review mechanism to determine the appropriateness of continuing placement at state developmental disability facilities, and periodic reviews are conducted by placement boards for people committed to mental health facilities.

Future Outlook

Although South Dakota was facing revenue shortages and budget gaps in 2002, Governor William Janklow (R) appeared confident that the state could make up the deficits through transfers from reserves. No major long-term care initiatives appear to be planned.

Tennessee

Overview

Tennessee has moved from a very modest home and community-based services (HCBS) system in the mid-1990s—when the state was spending only about $21 million for community services—to a point in FY 2000 when HCBS expenditures totaled more than $200 million. State officials estimate that HCBS spending will total more than $300 million in FY 2002. These expenditures and waiver caseloads remain very small, however, compared to the more than $800 million the state estimates spending for nursing home care in FY 2002.

Fiscal Analysis

The state spent almost $859 million for nursing home care for about 26,000 residents in FY 2000, but projected expenditures to drop to $807 million in FY 2002 for about 25,700 residents. Although the ICF/MR facility caseload was also expected to drop during that period (by more than 1,000 people from 1,616 people to almost 1,500 people), ICF/MR expenditures were estimated to increase slightly, from about $215 million to about $230 million in FY 2002.

Although total spending for all HCBS was expected to reach about $315 million by FY 2002, this amount was only about one-third of the more than $1 billion the state would spend on institutional care that year ($807 million for nursing homes and $230 million for ICF/MR facilities). Highlights of the fiscal picture include the following:

- The largest HCBS waiver program (MR/DD) accounted for more than four-fifths of total waiver expenditures. Tennessee spent $203 million for this program in FY 2000 and expected to spend $273 million in FY 2002.

- The state spent $5.3 million of state-only funds in FY 2000 for family caregiving/respite care programs, an amount that the state estimated to increase to $6.7 million in FY 2002. The state expected to provide services to more than 4,500 people in these programs.

Legislative Activity

The legislature created the Tennessee Commission on Aging and Disability in 2001 to plan, develop, and administer programs and services for elderly and disabled people. The commission will:

- Function as the sole state agency for planning and administering activities related to the Older Americans Act;

- Provide a comprehensive and coordinated service system for the state's aging population, giving high priority to individuals in greatest need;

- Conduct studies and research into the needs and problems of the aging; and

- Provide a system of home and community-based long-term care services that is responsive to the needs of all people with disabilities, regardless of age, disability or economic status.

Long-Term Care Planning

In March 1999, the Tennessee Long-Term Care Services Planning Council, a broad-based group of public—and private-sector policymakers, providers and advocates, released the Tennessee Comprehensive Plan for the Delivery of Long-Term Care Services to Elderly and Disabled People. The plan focused on extending and expanding home and community-based services to people with disabilities and the frail elderly.

Most discussions in the state have dealt with funding levels for community-based care. Several bills that were considered by the legislature in 2001 focused on support for family caregivers, waiting list reduction, and expanded Medicaid waivers.

Future Outlook

Although the state is serving more than 4,500 people in its MR/DD Medicaid waiver program, the waiting list for the program numbers some 700 individuals. The state also is maintaining a waiting list for its much smaller Elderly and Disabled waiver program, which currently serves only a few hundred people.

The state received a grant of almost $1,769,000 from the federal Systems Change Grant Program, which will address housing and support services issues for people with serious and persistent mental illness. The state will hire four consumer housing specialists in four communities (Chattanooga, Jackson, Memphis and Nashville). Another activity will be the development of a housing resource Web site and hardware installed at community drop-in centers to promote access to the Web site.

The state also received a second-round Systems Change grant in 2002 for $725,000 for Personal Assistance Services and Supports.

Texas

Overview

Texas has been engaged in a major long-term care planning process since 1999 to expand home and community-based services (HCBS) for people with disabilities. Although the state already has a considerable network of community services, it also has had long waiting lists for those services and a large nursing home population.

A number of legislative actions in 2001 help deal with some of the problems addressed by the planning process and a comprehensive long-term care reform plan issued in January 2001 (see below). The Legislature provided funds to expand the state's six Medicaid waiver programs. An Interagency Task Force on Care Settings for People with Disabilities will continue to monitor the implementation of the plan.

Fiscal Analysis

Texas ranks among the top 10 states in the country in total spending on nursing home care, with expenditures totaling $1.6 billion in FY 2001 and anticipated expenditures of $1.8 billion in FY 2002. However, in terms of per capita spending on nursing homes, Texas ranks among the bottom 10 states. Caseloads stayed fairly constant at about 65,000 residents from FY 2000 to FY 2002.

Although spending for care in ICF/MR facilities was estimated to increase by almost a $100 million from FY 2000 to FY 2002 (from $633.5 million to $729.7 million), state officials projected that caseloads would decline slightly. The ICF/MR caseload was 12,864 in FY 2000, and the state hoped to reduce that number to 12,564 in FY 2002.
Other highlights of the fiscal picture include the following:

- Texas has a large Personal Care program, which is both Medicaid–and state-funded. Funds from both sources totaled $427 million in FY 2000, and are projected to increase to $479 million in FY 2001 and $556 million in FY 2002.

- The number of Medicaid-eligible people receiving services under the Personal Care program was expected to increase substantially from FY 2000 to FY 2002, increasing from about 64,800 people to 75,700 people in 2002. The caseload for the state-only funded program was expected to total 10,000 by 2002, up from 8,300 in 2000.

- Although the caseload for the state's Aged and Disabled Medicaid waiver program is much larger than the caseload for the state's three MR/DD waiver programs (28,000 people compared to about 6,500 people), expenditures appear to be relatively similar. Figures for the Aged/Disabled program are available only for 1999, when spending reached about $267 million.[1] Spending for the three MR/DD programs totaled about $230 million in FY 2000 and was estimated at about $296.5 million in FY 2002.

Legislative Activity

The Texas Legislature took a number of actions in 2001 that affected long-term care, particularly concerning the state's assisted living and nursing home industries.

In regard to assisted living providers, the Legislature:

- Required state officials to give providers prior notice and an opportunity for a hearing before denying, suspending or revoking a license for violations of licensing standards.

- Prohibited the state from assessing administrative penalties that exceed $1,000 unless a facility fails to maintain a correction.

- Permitted providers to retain residents whose health conditions have declined if the resident, the resident's physician and the provider agree that the resident can be cared for adequately.

- Established an assisted living fund for facilities in emergency situations.

- Prohibited providers from employing individuals with a criminal history indicated on a background check.

State lawmakers also enacted several major nursing home measures in 2001.

- Required nursing homes to carry liability coverage of at least $1 million per occurrence and $3 million aggregate on a claims-made basis, effective Sept. 1, 2003, and provided that for-profit facilities might obtain coverage through the Texas Medical Liability Insurance Underwriting Association if no other coverage is available.

- Approved legislation allowing nursing home residents to monitor their care with electronic monitoring devices, such as video cameras. Residents may operate these devices if they obtain consent from roommates and alert others to the monitoring by placing a sign on their door. (Texas becomes the first state to allow these devices.)

- Created new training requirements for nursing home inspectors.

The Legislature also provided for the establishment of pilot centers at two state universities for advancing the quality of long-term care. The pilot centers will identify, develop and evaluate consumer-centered clinical and quality-of-life assessment and care protocols. They also will evaluate 1) the role of reimbursement and financial incentives in improving care in long-term care facilities and 2) the role of telecommunications technology for improving care in remote or underserved areas.

Long-Term Care Planning

Created by executive order in September 1999, the 12-member Health and Human Services Commission issued a comprehensive long-term care reform plan ("Promoting Independence") in January 2001. The commission arrived at its recommendations with guidance from the Promoting Independence Advisory Board, consisting of providers, state officials, and people with disabilities and their representatives.

The lengthy plan includes an inventory of available services, state budget requests and proposed statute changes, and identification of the agencies responsible for implementing the recommendations, primarily the Department of Human Services and the Department of Mental Health and

Mental Retardation. The plan includes recommendations to expand all waiver programs, increase outreach to people with disabilities about community care options, help nursing facility residents make the transition into the community, provide temporary rent subsidies for consumers who are awaiting federal housing assistance, train staff, and implement a data collection system.

Future Outlook

The "Promoting Independence" plan makes multiple recommendations that affect the state's long-term care system. The plan also coordinates the efforts of the many state agencies that provide long-term care services in Texas. The plan has ambitious goals for making community placements possible for hundreds of residents of nursing homes or ICF/MR facilities and for reducing waiting lists for Medicaid HCBS. The state agencies involved in the planning process submitted budget requests for additional funding in the next biennium (2002-2003). With completion of the Promoting Independence Plan, the state intends to continue to identify individuals who are living in institutions but who prefer community-based services, helping these individuals make the transition into the community, reducing the waiting lists, and coordinating all long-term care services and supports to improve services for people with disabilities.

Texas received a grant for about $308,000 through the federal Systems Change Program in 2001, which the state will use to expand outreach efforts to identify people with disabilities in nursing homes who want to make the transition into the community. Texas also received a second-round Systems Change grant for $1,385,000 in 2002.

Notes

[1] Aged/Disabled waiver program figures from Harrington, using 1999 Form 372.

Utah

Overview

Utah is experiencing a slight decline in number of nursing home residents, from 3,444 people in FY 2000 to 3,279 people in FY 2002. Through a long-term care managed care demonstration project, the state helped 160 Medicaid clients to make the transition from acute care hospitals or nursing homes to home and community-based arrangements. This project will continue through March 2003, with the potential to serve up to 500 enrollees at any given time.

With a caseload of almost 3,700 people in the state's Medicaid MR/DD waiver program and 900 people in the Elderly waiver program, the state currently is serving more people with home and community-based services (HCBS) than with institutional care. Between FY 2000 and FY 2002, the state added 500 people to the MR/DD waiver program.

Fiscal Analysis

Expenditures for the MR/DD program, the state's largest waiver program, totaled almost $77 million in FY 2000, increasing to $82 million in FY 2001 and to more than $90 million in FY 2002. The state spent a total of about $4 million in FY 2000 for the other three waiver programs (the elderly, people with physical disabilities age 18 and older, and people with brain injury). State officials estimated that amount to increase in FY 2002 to $5.5 million. Highlights of the fiscal picture include the following:

- State spending on nursing home care was expected to remain fairly constant, at about $90 million during the FY 2000 to FY 2002 period.

- Utah has a modest Medicaid Personal Care program with expenditures of between $500,000 and $600,000, which serves a caseload of about 135 people.

Legislative Activity

The Utah Legislature instituted significant reforms in 2001 for the state's long-term care insurance industry. Lawmakers enacted numerous protections for individuals who purchase long-term care policies, including requirements that insurers disclose whether policies are federally tax-qualified or protect against premium inflation. The law also mandates that insurers deliver long-term care policies within 30 days of the purchase date and provide a written explanation to a policyholder within 60 days of a claim denial.

Long-term care insurers must offer nonforfeiture benefits and a contingent benefit upon lapse when an individual declines nonforfeiture benefits but faces substantial rate increases. Long-term care insurers also cannot condition an individual's eligibility for benefits on prior institutionalization, except when determining eligibility for waiving premiums, post-confinement, post-acute or recuperative benefits.

Lawmakers also repealed the state's $1.83 per-patient-day nursing home tax. The tax was intended to generate funds for quality improvement initiatives and workforce development in the long-term care industry.

Long-Term Care Planning

In 1997, the Utah Health Policy Commission established the Long-Term Care Technical Advisory Group to address concerns about the state's long-term care system. The group produced a set of recommendations after gathering information from the public and those with experience in long-term care. The Health Policy Commission conducted a Comprehensive Long-Term Care Public Policy Study.

In September 1999, key state agencies created a long-term care network task force to address issues raised by the *Olmstead* decision and to extend the state's work on community-based services to broader population groups and infrastructure needs. The task force issued a draft plan and received public comment during November 2001.

Under a state legislative initiative and a grant from the Center for Health Care Strategies, the state is providing residents of nursing homes and ICF/MR facilities with information about alternative home and community-based care programs and is offering individualized assessment and support for possible transition to the community. These education outreach activities are expected to continue.

Future Outlook

Although Utah has been expanding the caseload for the MR/DD waiver program, the program still has a large waiting list for services. Reduction of the waiting list remains a priority for the state. New funds allocated by the Legislature during the last several years continue to be used to further extend waiver services. Planning for the use of funds allocated during the 2001 legislative session is under way, although statewide budget reductions make actual use of these funds uncertain.

Utah received two grants in 2002 under the federal Systems Change Grant Program. One grant for $400,000 will be administered by the Utah Independent Living Center to facilitate transitions to the community for certain nursing home residents. The other grant for $1,385,000 will be administered by the Utah Department of Human Services.

VERMONT

Overview

Vermont has been steadily expanding its home and community-based services (HCBS) while decreasing institutional care. In 2001, Vermont allocated 55 percent of Medicaid long-term care funds to HCBS and 45 percent to institutional care.

The state has implemented a range of activities during several years related to downsizing institutions and expanding home and community-based care services. No institutions exist for individuals with developmental disabilities, and all nursing facility residents have been assessed for community-based service options.

Fiscal Analysis

State officials projected the nursing home facility caseload of 2,381 residents in FY 2000 to decrease to 2,234 residents in FY 2002. Expenditures for nursing facility care were estimated to climb slightly, however, from $79 million to $91 million during those years. From 1995 to 1999, Vermont experienced a 12.3 percent decline in the number of nursing home residents, compared to a 1 percent increase nationally.

Total expenditures for Medicaid HCBS waiver programs—about $78 million in FY 2000—were estimated to reach almost $85 million in FY 2001 and $95.6 million in FY 2002, thus exceeding expenditures for nursing homes. Caseloads for the four HCBS programs were expected to increase from a total of about 2,400 in FY 2000 to almost 2,900 in FY 2002. Highlights of the fiscal picture include the following.

- Vermont's largest Medicaid waiver program in terms of both expenditures and caseload provides services for people with developmental disabilities. State officials estimated that expenditures for this program would increase from $63.7 million in FY 2000 to $67.9 million in FY 2001 and to $74.6 million in FY 2002. The caseload is projected to increase by 165 people, from 1,668 in FY 2000 to 1,833 in 2002.

- The state spent $11.8 million on its Medicaid Aged and Disabled waiver program in FY 2000 for services for 650 people. Total expenditures were expected to increase to $17.4 million for 870 people in FY 2002.

- Vermont operates the Medicaid-funded "Enhanced Residential Care" program for people at risk of institutionalization. Ninety people were in the program in FY 2000; officials expected the number to increase to 140 in FY 2002. (Other residential care homes in Vermont are group living arrangements where residents who do not need nursing home level of care receive help with daily activities such as bathing and dressing.)

Legislative Activity

The legislature increased reimbursement rates to long-term care providers. Specifically, to increase participation by residential care home providers, the legislature raised reimbursement rates in the Assisted Community Care Services Program. At the same time, the Department of Aging and Disabilities increased reimbursement rates for residential care homes by increasing the rate in the

Enhanced Residential Care Waiver program. The legislature also approved increases in nursing home and home health provider rates, especially targeted to wage enhancements for staff.

Long-Term Care Planning

Through the various home and community-based care programs that Vermont is either creating or expanding, the state has reached the point where it is serving more people with disabilities in the community than in institutions. Some of the state's accomplishments include:

- Closing the last developmental disability facility in 1993;
- Having only 150 people in the state mental hospital;
- Creating home and community-based care waiver programs for all populations;
- Moving 100 people from nursing homes to HCBS waiver programs; and
- Managing home and community-based services and nursing homes for the elderly in a single budget so that the savings can remain in the system.

Future Outlook

Vermont planned to implement a "Participant-directed Attendant Care" program under the state's Medicaid Personal Care Program in January 2002. The state received a $2 million grant from the federal Systems Change program in 2001. Vermont's Department of Aging and Disabilities, Division of Developmental Disabilities, and the Division of Mental Health plan to work collaboratively to increase community integration and promote choice and control for elders, younger adults with physical disabilities, people with developmental disabilities, and adults with severe mental illness. The state also plans to develop a pilot project to provide direct funding for supports and services to people with developmental disabilities and their families.

Vermont also intends to use the grant funds to develop a paraprofessional organization to help create a stable, well-trained and well-compensated workforce.

Virginia

Overview

Virginia reduced institutional developmental disability placement by 30 percent during the last three years. The state has also put $20 million into the mental health system. The state has also seen a decrease of 3.4 percent in the number of nursing home residents from FY 1995 to FY 1999.

Virginia almost doubled its spending on HCBS waiver programs from FY 1996 to FY 2001, and more than tripled its caseload for the MR/DD waiver program.

Fiscal Analysis

Nursing home expenditures, which totaled $393 million in FY 1996, increased to $528 million in FY 2001. Spending for ICF/MR facilities increased by about $34 million during that period, from $153.7 million to $187 million.

From FY 1996 to FY 2001, Medicaid waiver programs expenditures increased from $146.3 million to about $289 million. The biggest increases came in the MR/DD program, which went from $53.9 million in FY 1996 to $181.5 million in FY 2001. Highlights of the fiscal picture include the following:

- Spending for the Aged/Disabled waiver program increased only slightly over the five year period from FY 1996 to FY 2001, from $78.2 million to $86.2 million.

- About 5,400 people received services under the MR/DD waiver program, while approximately 10,000 persons were covered in the Aged/Disabled waiver program. These figures compare with about 18,000 nursing home residents.

- The state allocated 71 percent of its Medicaid long-term care funds to institutional care in FY 2001 and 29 percent to home and community-based services.

Legislative Activities

The 2001 General Assembly continued reforms of the assisted living and long-term care insurance industry that began in 2000. A new law clarifies that current regulations authorizing assisted living facilities to provide a safe, secure environment for residents with serious cognitive impairments refers to residents diagnosed with a primary psychiatric diagnosis of dementia. Lawmakers also enacted legislation that requires long-term care insurers to disclose their rating practices to consumers.

Long-Term Care Planning

The Department of Medical Assistance Services, a Consumer Task Force, and other organizations and agencies worked together to develop a grant application for the federal Systems Change program to improve HCBS in the state. As of late 2001, Virginia did not have an *Olmstead* Planning Committee. However, meetings were being held in the state to discuss creating such a commission.

Future Outlook

Virginia received a $1,025,000 Systems Change grant, which the state plans to use to develop a paperless assessment process for persons seeking Medicaid waiver services. The state also will try to assist consumers in making long-term care choices and improve access to services through an interactive Web site and an introductory video on available resources and services.

Through an agreement with the Virginia Institute for Developmental Disabilities at Virginia Commonwealth University, the state will provide training on consumer-directed services as included in the state's waiver programs. Another project under the grant calls for the development of performance, outcomes and satisfaction measures for continuous quality improvement and use.

WASHINGTON

Overview

During the 1990s, Washington expanded home and community-based services (HCBS) and downsized institutions. The state's allocation of Medicaid long-term care expenditures went from 78 percent institutional, 22 percent HCBS in 1994 to 52 percent institutional and 48 percent HCBS in FY 2001. The nursing facility occupancy rate in the state in 1999 was 81.3 percent, and only 3.2 percent of the age 65 and older population resided in nursing homes that year compared to the national average of 4.3 percent. The number of people receiving long-term care services in the community is more than double the number of people in nursing homes.

Fiscal Analysis[1]

For the FY 2001-2003 biennium, the Legislature approved $17.3 million in new spending for community services, which consisted of:

- $10.5 million to provide community placements for 80 individuals with developmental disabilities who currently reside in institutions,
- $3.2 million to establish a 35-bed chemical dependency involuntary treatment program in eastern Washington,
- $1.5 million to expand behavior rehabilitation services for youth who might be at risk of institutionalization,
- $1.1 million savings by providing community option program services for clients on the medically needy program, which will create opportunities for some nursing home residents to move to other settings if desired, and
- $1 million to serve clients with mental illness, currently in state psychiatric hospitals, in other settings.

Washington spent about $153 million on its Medicaid Personal Care program and $516.6 million on its Medicaid HCBS waiver programs in FY 2001. From FY 1996 to FY 2001, the state almost doubled its expenditures on the Personal Care program and almost tripled its expenditures for the waiver programs. Highlights of the fiscal picture include the following:

- Nursing home expenditures totaled $614 million and ICF/MR facilities totaled $130.6 million in FY 2001. The state experienced about a 23 percent decline in the number of nursing home residents from 17,500 residents in 1994 to a total of about 13,500 in February 2001.

- The number of people covered by the state's Medicaid Aged and Disabled Waiver program totaled almost 23,000 in FY 2000, and in the MR/DD Waiver program, almost 5,000.

Legislative Activity

The Legislature took a number of long-term reform actions in 2001. Lawmakers established minimum qualifications for adult family home providers, for example, and eliminated the state's moratorium on adult family home licenses. The law also reforms the inspection process for adult family homes by requiring state officials to provide written notice to homes within 10 working days if violations are found during an inspection. (Adult family homes in Washington are licensed

to care for up to six people in a private home setting with staff available 24 hours a day. About 3,260 people were living in these homes in 2001.)

Lawmakers also expanded the financial eligibility requirements for individuals to qualify for Medicaid home and community-based waiver services by raising the threshold to 300 percent of the Supplemental Security Income level (or $1,635 in 2002). Although Washington was approved for 44,680 slots for the Community Options Program Entry System (COPES), only about 23,000 people were receiving COPES services in 2001.

The Legislature also established the Joint Legislature Task Force on Nursing Homes in 2001. Task force members will examine: 1) key issues in the delivery of nursing home care in various areas of the state; 2) alternative approaches for linking case-mix scores with service hours and costs; 3) reports on nursing home access, quality of care, quality of life, and employee wage and benefit levels; and 4) rebasing alternatives for nursing home reimbursement. The task force is scheduled to make its recommendations by Dec. 1, 2003.

Long-Term Care Planning

The Governor has designated the state Department of Social and Health Services (DSHS) as the lead agency for *Olmstead* planning. Workgroups are composed of representatives from a number of state agencies. The plan that is emerging from their deliberations is seen as an effort to further coordinate and accelerate the activities that have already been under way to expand home and community-based services.

The planning process is broken into four overlapping phases, which span the period from January 2000 to July 2004. Phase One consisted of setting up the workgroups, holding initial meetings, assessing current policies and programs, and developing budget requests for the FY 2001-2003 budget (see above). Phase Two (July 1, 2001 to June 30, 2002) activities include implementation of Phase One initiatives funded during this time frame, data collection to aid in developing new budget requests, stakeholder interaction and performance measurement.

Phases three and four, which will take place during the FY 2003-2004 period, will involve soliciting input, developing proposals, preparing budget requests, and implementing steps using current funding and subsequent appropriations.

The DSHS intends to include in its planning all people with disabilities, regardless of age or physical or mental condition. The planning process also is focusing on institutional residents who wish to live in the community and who are able to do so, as determined by treatment professionals, as well as community residents at risk of institutionalization.

Future Outlook

Faced with class action lawsuits on behalf of people with mental illness and individuals with developmental disabilities, the state is under pressure to make progress in advancing its community-based agenda. There are some significant barriers to complete success, including the problems of achieving sufficient funding for community projects. Affordable, accessible and barrier-free housing and general and special needs transportation also are major issues.

The state has received a $770,000 grant from the federal Systems Change program to help younger disabled and developmentally disabled people make the transition from nursing homes to the community. Washington plans to contract and partner with independent living consultants to provide peer support, skills training, and advocacy. The goal of the project is to support up to 300 people under age 65 as they make the transition from nursing homes. One activity under the project will be to increase the amount of durable medical equipment that is available to people who leave nursing homes so that they have the appropriate type and quality of assistive and adaptive equipment they may need for independent living.

Washington also received a second-round grant for $1,385,000 from the Systems Change Program in 2002.

Notes

[1] Fiscal figures are from Burwell using HCFA Form 64 and Harrington using HCFA Form 372. The figures for nursing home residents in 2001 are from state reports.

West Virginia

Overview

A U.S. District Court ruled in *Benjamin H. vs. Ohl* in 1999 that West Virginia must provide home and community-based services (HCBS) to individuals on waiting lists within 90 days of determination of their eligibility. The court also required the waiting list to move at a "reasonable pace." As a result, state officials established a centralized process to review the waiting lists at the 14 community mental health facilities and the four community developmental disability centers. The FY 2001 budget included a "*Benjamin H.* improvement package" that funded 400 additional MR/DD waiver slots by adding almost $5 million.

The state closed its last MR/DD institution in 1998 and very few ICF/MR beds exist. Expenditures for ICF/MR facilities, which had totaled $53.7 million in FY 1996, had decreased to $47.8 million in FY 2001.

Fiscal Analysis

In 2001, West Virginia was allocating 64 percent of its Medicaid long-term care funds to institutional care and 36 percent to home and community-based care. The state contained nursing home expenditures through the late 1990s, with spending for these facilities increasing by 4.6 percent from FY 1998 to FY 1999 ($262.1 million to $274.2 million), and by only 0.3 percent from FY 1999 to FY 2000 ($274.2 million to about $275 million). Expenditures for nursing homes climbed to $293.2 million in FY 2001.[1]

By contrast, spending for HCBS waiver programs almost doubled between FY 1996 and FY 2001, from $77.5 million to $147 million. Highlights of the fiscal picture include the following:

- The state has a Medicaid Personal Care program, but spending levels for the program reached a high point of $29.8 million in FY 1995 and dropped by a few million dollars each year thereafter before climbing to $26.9 million by FY 2000 and then dropping to $24 million in FY 2001.

- The number of nursing home residents in FY 1999 totaled about 7,500 people. In contrast, about 5,600 people were receiving services under the state's two HCBS waiver programs (Aged/Disabled and MR/DD).

Legislative Activity

The 2001 Legislature created a Care Home Advisory Board to gather information about personal care homes and residential board and care homes. In addition, a new law established an informal appeals process for personal care homes and residential board and care homes to appeal civil assessments, license limitations, and suspensions and revocations.

In other action, the Legislature directed the Joint Committee on Government and Finance to study the creation of an Alzheimer's caregiver assistance program. The committee must submit findings and recommendations to the Legislature in 2002.

Long-Term Care Planning:

A *Olmstead* Task Force created by executive order in September 2000 was scheduled to develop a comprehensive plan by the end of 2001. The task force was composed of people with disabilities and their families, advocates, service providers and various government agencies.

The state's plan will cover people of any age who have developmental and physical disabilities or mental illness. The focus is on people in nursing homes and the two acute-care psychiatric hospitals to determine whether they require that level of care or could be better served in community-based settings. At the request of the governor and the secretary of the Department of Health and Human Resources, the Legislature provided a special appropriation of $500,000 to be used during the planning process to assist in community placement of residents of nursing homes and psychiatric hospitals.

Future Outlook

West Virginia received a grant for $551,678 from the Nursing Facilities Transition component of the federal Systems Change Grant Program. The state's project, "The Transitioning to Inclusive Communities Project," will provide information resources about community choices for people with disabilities in nursing homes or who are at risk of moving to such facilities. The state plans a toll-free phone line, a Web site, training, and a public awareness multimedia campaign.

Other activities for the grant include developing a Consumer Oversight Commission that participates in grant activities, developing and coordinating training for Transition Support teams statewide, and creating a person-centered discharge planning and referral instrument that provides community options and resources. A Life Choices assessment tool will be used for both making the transitioning from and avoiding nursing or congregate facilities.

Notes

[1] Expenditure figures from Burwell, using HCFA form 64.

Wisconsin

Overview

Wisconsin has been engaged for several years in developing the Family Care Program, which will integrate long-term care services at the county level at local Aging and Disability Resource Centers. The core of the program is the pooling of federal and state funds to create an individualized benefit package for each eligible person. The centers not only handle the assessment and determination of eligibility for applicants, but also serve as information and assistance locations for all elderly people and their families, regardless of eligibility for publicly-funded services.

Begun as a pilot program in nine Wisconsin counties, the program has encountered state budgetary problems and may not be able to expand until the state's economy recovers. Expenditures for Family Care's community organizations¾Resource Centers and Care Management Organizations¾totaled $32.2 million in calendar year 2000.

Fiscal Analysis

Despite an extensive commitment over the years to home and community-based services (HCBS) through its Community Options Program (COPs), Wisconsin still is serving most of its long-term clients through nursing home care. The COP program, which is both Medicaid- and state-funded, has had long waiting lists for many years.

The state spent close to $864 million for nursing home care for about 27,000 residents in FY 2000, an expenditure that was estimated to increase to about $1.4 billion in FY 2002. By contrast, spending for the state's two biggest Medicaid HCBS waiver programs¾for the elderly and for people who are developmentally disabled¾totaled about $314 million in FY 2000. State officials do not expect significant increases in spending and caseloads for those two programs in FY 2002. Highlights of the fiscal picture include the following:

- Spending on ICF/MR facilities fluctuated between $114 million and about $118 million from FY 2000 to FY 2002 with caseloads decreasing from about 3,600 in 2000 to an expected 3,300 in 2002.

- The state's Medicaid Personal Care program is serving about 11,000 people. Expenditures are projected to increase by about 45 percent for this program, from the FY 2000 total of $73.6 million to an estimated FY 2002 total of $106.7 million.

- State officials estimate that the caseload for elderly, physically disabled, and developmentally disabled people under the Family Care pilot programs will increase from 853 people in FY 2000 to more than 5,000 people in FY 2002. Officials project that expenditures for this program will increase to $47 million in FY 2001 and then double to almost $94 million in FY 2002.

- At about $210 million, spending for the DD program is approximately twice the spending level for the Elderly program (about $110 million).

Legislative Activity

No major long-term care legislation was enacted in 2001. However, state officials report that raising nursing home staff ratios and expanding regulation of assisted living facilities are among the state's high priorities.

Long-Term Care Planning

The Wisconsin Americans with Disabilities Act Title II Advisory Committee has been reviewing the status of the state's long-term care system and developing recommendations. Phase I was issued in January 2002. Phase II was to begin in April 2002.

The committee's initial recommendations focus on the concept that funding should follow the client in order to maximize consumer choice of care setting. The committee calls for new long-term budgeting methodology that would promote this concept and for the maximization of federal revenue sources to expand home and community-based care. The committee also believes that children's long-term care should be redesigned.

Another Wisconsin organization to address the state's long-term care issues is the Council on Developmental Disabilities, which formed a special committee to address issues that affect individuals with developmental disabilities. The special committee recommends that the state's final *Olmstead* plan require the state to review the status of each person with developmental disabilities living in an institution to determine the person's appropriateness for living in the community.

The special committee also argues that the final plan should determine the need for expanding community services and recommend the amount of funding to accomplish such an expansion. The plan should ensure, the committee says, that provision of services occurs at a reasonable pace.

Future Outlook

As with other states, Wisconsin has had a serious budget shortfall in 2001 and 2002 that has slowed expansion of the Family Care pilot programs to additional counties in the immediate future. It is not certain what effect those fiscal problems will have on reducing the waiting list for COP services, except for the increases expected for the current Family Care pilot programs.

Wisconsin received two grants under the federal Systems Change Grant Program for nursing facility transitions efforts. One grant for $450,000 will be used to facilitate community placement for 210 people with various disabilities who currently are living in nursing facilities. Part of the project will involve training and supporting transition specialists and peer support volunteers.

The other grant for $800,000 will give special emphasis to working with individuals in nursing homes who have developmental disabilities or serious mental illness. This project, "Homecoming II," builds on an earlier "Homecoming" project that focused on individuals with physical disabilities and frail elders. "Homecoming II" will aim at improving community-integrated services in the short term for 400 people who currently are in institutions and, over the long term, through systems changes that will facilitate the relocation of additional individuals in a more systematic way.

Wisconsin also received a Systems Change grant in 2002 for $1,385,000, which will be administered by the Department of Health and Family Services, Division of Supportive Living.

WYOMING

Overview

From 1995 to 1999, Wyoming experienced a 2.7 percent drop in the number of nursing home residents, resulting in a nursing home population of about 1,650 people in 1999. The nursing facility occupancy rate in 1999 was only about 82 percent. With about 2,500 people receiving services in 2000 under the state's Medicaid home and community-based (HCBS) waiver programs, the state was providing long-term care to more people in the community than in institutions.

Lawmakers appropriated nearly $4.5 million in 2001 to expand home and community-based services. Approximately half this amount will be used to add up to 150 individuals to the Medicaid Aged/Disabled waiver program.

Fiscal Analysis

The state spent about $48.6 million for nursing facility care in 2000 and $16 million for ICF/MR facilities, for a total institutional care budget of $64.6 million.[1] That same year, the state spent about $52.7 million on HCBS, of which $48.3 million was for Medicaid waiver programs. Wyoming was allocating about 55 percent of its long-term care expenditures to institutional care and 45 percent to HCBS. Highlights of the fiscal picture include the following:

- The state allocated the bulk of the Medicaid waiver funds to its two MR/DD programs, which received about 90 percent of total waiver expenditures.

- In 2000, Wyoming was ranked eighth among the states in home and community-based waiver services funding per capita.

Legislative Activity

In addition to appropriating additional funds for home and community-based care in 2001, the Legislature initiated a study in the Department of Health to review wages and salaries of paraprofessional direct care workers in long-term care settings, such as assisted living facilities, nursing homes, mental health care facilities and developmental disability programs. Lawmakers have requested that the department recommend an amount of funding that will provide competitive salaries for direct care workers and propose steps to achieve that level of funding.

The Legislature also approved a bill extending the state's moratorium on nursing home beds until June 30, 2003. The same law also increased the personal needs allowance for nursing home residents from $30 to $50 per day. Lawmakers commissioned a study to evaluate the possibility of replacing the current prospective payment system for nursing homes with a case-mix reimbursement system.

Long-Term Care Planning

The draft *Olmstead* plan released April 1, 2001, has four sections: aging, developmental disabilities (acquired brain disorders), developmental disabilities (general) and mental health. Each section makes recommendations in areas such as development of new community services and support

infrastructure and transition services to prepare individuals for a change in placement. Other sections cover the needs assessment process, collection of data on an individualized basis, and collection of outcome data on individuals transitioned to the community.

The Aging Division has established as a priority the promotion of community-based services, when appropriate. The division reported that the following areas needed to be addressed: 1) Medicaid—subsidized assisted living; 2) adult chronic mental illness residential homes; 3) increased senior housing options or group homes for seniors; 4) training for health professionals in person-centered planning and training for service providers; and 5) senior center participation.

The Aging Division proposes allowing clients to choose assisted living facilities (ALF) as their "home" and to receive nursing services in the ALF as long as those services are provided by an outside entity. The Aging Division also may increase the number of HCBS waiver slots.

Future Outlook

One of Wyoming's priorities is to increase access to assisted living facilities. To this end, state officials were planning to apply for a new waiver to cover assisted living services. If approved, the state will use nearly $2.3 million to implement an assisted living pilot project. Wyoming received a grant of $600,000 in 2002 from the federal Systems Change Grant Program.

Notes

[1] Burwell figures from HCFA Form 64 and Harrington figures from HCFA Form 372.

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