State Long-Term Care: Recent Developments and Policy Directions

2003 Update

by

Barbara Coleman
Independent Consultant

and

Wendy Fox-Grage
Donna Folkemer
National Conference of State Legislatures

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- To foster interstate communication and cooperation, and
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Introduction

During the boom years of the 1990s, most states experienced unprecedented revenue growth, enabling many states to increase spending on social programs and initiate new programs, such as prescription drug benefits for senior citizens. The national economy began faltering in late 2001, however, with the result that state revenue collections failed to meet budget forecasts. Spending began to exceed budgeted levels.

By fiscal year (FY) 2002, the record budget shortfalls facing most states threatened to overwhelm all other issues of state governance, including long-term care programs and services. As state budget gaps grew, budget planners, legislators and governors struggled to cut programs and search for new revenue sources.

In addition to the shortfalls resulting from declining revenues, states experienced escalating Medicaid costs. Medicaid, which accounts for about 20 percent of all state spending, is the single largest source of public funding for long-term care. According to the National Association of State Budget Officers (NASBO), Medicaid spending grew by more than 13 percent between 2001 and 2002, the fastest rate of growth since 1992. This reality forced state legislatures and state officials to look for ways to contain Medicaid costs rather than expand services.

Although state policymakers concentrated largely on curbing expanding pharmaceutical programs and optional medical services under Medicaid, long-term care services did not escape the budget axe. States cut, froze or provided only small increases for nursing home reimbursement rates. Other actions involved freezing new admissions to home care programs or restructuring state agency organizations.

Still, despite the gloomy fiscal situation, a number of states moved forward with long-term care planning, implemented pilot programs, and sought creative ways to restructure long-term care services, using federal systems change grants or existing state agency budgets. States used grant funds in particular to move eligible individuals from nursing facilities into the community and to support consumer direction for personal assistance services.

In this report, the National Conference of State Legislatures (NCSL) traces the budget issues that states confronted in 2002 and examines how they addressed those issues. The report also describes long-term care legislation enacted in 2002 and long-term care planning work that is under way in many states.

Budget Issues

Every state constitution, except **Vermont,** requires a balanced budget. As noted in NCSL's February 2003 state budget update, 36 states reported budget gaps midway through FY 2003. Thirteen states and the **District of Columbia** reported no gaps, and **Tennessee** did not provide FY 2003 budget information. As of late January 2003, the cumulative budget gap was about $25.7 billion for FY 2003. NASBO estimated the FY 2004 budget deficit gap at $90 billion.

The states' response took many forms. Tapping "rainy day" funds and tobacco settlement money were among the most prevalent strategies. State policymakers also took the budget axe to the Medicaid program. In January 2003, the Kaiser Commission on Medicaid and the Uninsured reported that, since July 1, 2002, 49 states had made or announced plans to make cuts in their Medicaid programs by limiting eligibility, cutting benefits, or restructuring prescription drug payment and coverage. Another tactic was delaying, cutting or freezing inflation adjustments for Medicaid providers such as nursing homes or home health agencies.

One of the major long-term care targets of state budget-cutters has been nursing home reimbursement rates. For example, **Illinois** implemented a 5.9 percent reduction in its nursing home reimbursement rates, effective July 1, 2002. The 2002 **Kansas** Legislature reduced the Medicaid nursing home budget by $8.9 million. An annual cost-of-living rate adjustment for nursing homes in **Oklahoma** was delayed. The **Rhode Island** legislature in 2002 revoked the $3.71 per resident per day increase in Medicaid reimbursement for nursing facilities that had been enacted in 2001. **North Dakota** legislators appropriated funds to provide incentives to nursing facilities to reduce licensed bed capacity.

Massachusetts enacted a nursing home user fee levied on private-pay nursing home residents, which was expected to generate about $145 million. Although state officials had said the state planned to use $130 million from the tax to increase Medicaid reimbursements to nursing homes, Governor Mitt Romney said he wanted to use those funds for other medical expenses and also wanted to cut $14 million from nursing home rates starting in March 2003. Examples of other budget-tightening actions by states for FY 2003 include the following,

Colorado froze admissions to its state-funded Home Care program.

Kansas capped eligibility for health and homemaking services in its Senior Care program and imposed a freeze on new applicants to its Medicaid home and community-based waiver programs for Frail Elders.

Montana delayed wage increases for direct care workers who provide personal assistance services and for providers of home and community-based waiver and home health services.

Yet, the worsening budget crisis in the states did not totally stymie the ability of some states to improve or expand long-term care options for people with disabilities. In **New York**, media and other reports of widespread problems in adult homes for people with mental illness led to the creation of a special administration task force to review the existing system. The result was a recommendation from Governor George Pataki and the state health commissioner for increased spending on housing and services for the mentally ill, improved case management, and increased advocacy and legal support.

In **Ohio**, a budget plan enacted in mid-2002 that reduced FY 2003 spending by $375 million exempted the Medicaid home and community-based waiver program, PASSPORT, and the Alzheimer's respite program. Although **Tennessee** Governor Phil Bredesen imposed 7.5 percent budget cuts on most state operations, he spared the state's mental retardation agency.

Legislative Activity

Lawmakers were forced in 2002 to pursue long-term care reforms within the confines of tight budgets and growing concern about health-related expenditures. Despite these constraints, lawmakers enacted a number of measures during 2002 that expanded home and community-based options for senior citizens and people with disabilities and expanded protections against abuse and neglect.

Consumer Direction. The **Colorado** legislature created a consumer-directed care program for elderly Medicaid beneficiaries that allows participants to obtain a direct care payment for services. **Florida** lawmakers created a consumer-directed design for a Medicaid home and community-based waiver program under which participants receive a monthly budget allowance to pay for a range of services.

Assisted Living. In several states, lawmakers defined types of assisted housing and required criminal background checks for staff in assisted living facilities. **Colorado** changed the licensing category for personal care boarding homes to assisted living residences and spelled out the kinds of services that must be provided in this type of residence. The **Maine** Legislature established and defined three categories of assisted housing programs: independent housing with services, assisted living services, and residential care facilities. **Rhode Island** amended its existing licensing law for assisted living to specify the level of care appropriate for residents and to require criminal background checks for owners, operators and administrators.

Nursing Homes. Lawmakers continued to focus in 2002 on measures to improve the quality of life in nursing homes. The **Colorado** legislature created a pilot program to survey quality of care and living in nursing homes through the use of a consumer satisfaction survey. **Illinois** lawmakers created the Innovations in Long-Term Care Quality Grants Act for programs that demonstrate creativity in providing services. The grants are to be funded by fines set by previous legislation on nursing homes that provide poor quality care. In **Michigan,** lawmakers required the state to develop criteria to assess the ability of a provider to maintain individuals at the most appropriate level of care and to improve the total quality of care. A bipartisan group of legislators in **Missouri** introduced a package of nursing home reforms in 2003 that includes expanded disclosure and reporting requirements, background checks on some employees, and greater authority for regulators. **New York** lawmakers created the Nursing Home Quality Improvement Demonstration Program to improve the quality of care for residents through an increase of direct care staff in nursing homes.

Staffing issues in nursing homes were also addressed in the **Florida, New Mexico**, and **Oklahoma** legislatures. **Florida** legislators prohibited union organizing activities by a nursing home employee during any time that employee is counted in staffing calculations to meet minimum staffing standards. **New Mexico** legislators called for a study of acuity-based staffing in nursing homes, and **Oklahoma** lawmakers allowed nursing homes to alter their shift ratios and schedules, provided the ratios do not fall below certain minimum standards.

Elder Abuse. Protecting vulnerable individuals against abuse, neglect or financial exploitation

was a concern of many lawmakers in 2002. Twenty-two elder abuse laws were passed in 14 states during the 2002 legislative sessions. Although the bills addressed the issue in different ways, increasing or creating new penalties for the crime of elder abuse was a prevalent trend, as was expanding the definition or categories associated with elder abuse.

The **California** Legislature increased the penalties for elder abuse, added clergy to the list of mandated reporters, and expanded the list of people who may receive and disclose information of suspected abuse. **Maryland** legislators enacted the Financial Crimes Against Vulnerable Adults Act, which allows for penalties of up to 15 years in prison or a $10,000 fine, or both, for such crimes. **New Hampshire** lawmakers defined penalties for neglect of elderly, disabled or impaired adults and added financial exploitation to the offenses for which protective services will be provided. **Utah** modified and strengthened mandatory reporting requirements, and **Vermont** expanded the definitions of "abuse" and "neglect."

End of Life. Legislation on end-of-life issues ranged from a bill of rights for hospice participants to pain management. **California** lawmakers passed a measure allowing individuals who receive hospice services to enter residential care facilities without having to disenroll from hospice. The **Maryland** legislature established the State Advisory Council on Quality Care at the End of Life to study the effects of public policies on the provision of care at the end of life and to advise the legislature on these issues. The **Michigan** Legislature enacted 13 pain management, end-of-life and hospice care bills in 2002. One of the bills creates an advisory committee on pain management that would develop and encourage the implementation of model core curricula on pain and symptom management. In **Minnesota,** legislative activity centered on a hospice bill of rights that spells out 22 rights, ranging from the right to be free of physical or verbal abuse to the right to refuse treatment.

Work Force. Several legislatures addressed work force issues with a view to expanding the pool of direct care workers or upgrading their training. The **Indiana** legislature permitted certain unlicensed workers, to be known as "personal services attendants," to provide health-related services to recipients of home care services. The **Kentucky** legislature required facilities that care for Alzheimer's patients to offer specialized training to their staffs. Lawmakers in **Maine** requested that state agencies review rules regarding the training and certification of unlicensed direct-care staff. The **Massachusetts** legislature funded a rate add-on for wages and benefits of direct care staff of nursing homes or to improve a facility's recruitment and retention of nursing staff. The **Nebraska** Legislature expanded the competency course requirements for medication aides in assisted living facilities.

Long-Term Care Planning

Many states initiated or continued planning efforts in 2002 to assess and evaluate their current long-term care systems. These planning activities stemmed in large part from the 1999 Supreme Court ruling in *L. C. & E. W. vs. Olmstead,* in which the court ruled that states must provide services in the most integrated setting appropriate to the needs and wishes of qualified individuals with disabilities. Before and subsequent to that ruling, many states faced lawsuits from advocacy groups and people with disabilities, who contended that a state's failure to provide them with

community rather than institutional services constituted discrimination under the Americans with Disabilities Act. Many states maintained long waiting lists for community services for people with disabilities because of limited funding and slots in their home and community-based programs.

By 2002, 42 states and the **District of Columbia** had formed task forces, commissions or state agency work groups to review their long-term care programs and, in some states, to develop plans and recommend future actions for expanded community services. Most commissions are broad-based, and their scope of work includes all people with disabilities. Eleven states (**Arkansas, Connecticut, Delaware, Hawaii, Illinois, Kentucky, Massachusetts, Utah, Washington, Wisconsin, Wyoming**) released plans and reports in 2002. However, current budget problems have delayed *Olmstead* plan implementation in many states.

For an example, a 23-member Governor's Integrated Services Taskforce in **Arkansas** released a comprehensive draft plan for long-term care reforms in October 2002. The report recommended providing additional funds for the Medicaid HCBS developmental disabilities waiver program, allowing funds for nursing home residents to be transferred to community care services if a resident relocates to a community setting, and instituting major changes to the state's mental health care system.

In **Washington**, work to develop a five-year plan for people with developmental disabilities began in 1997. The third phase of that planning process culminated in a report *Developmental Disabilities Strategies for the Future*, that was released in December 2002. The report made recommendations on implementation of self-directed services and on the respective roles of residential habilitation centers (institutional centers) and community support services. Examples of other state long-term care plans include the following.

Recommendations by the **Georgia** *Olmstead* Planning Committee in January 2002 led to action in the legislature providing funding in the FY 2003 budget for reducing the waiting list for the Community Care Services Program and for the Mental Retardation Waiver Services Program.

Hawaii issued a long-term care plan that sets five goals, including informing and educating consumers about long-term care choices; supporting individuals in finding appropriate places to live; and assuring adequate housing, transportation and employment for people with disabilities.

The long-term care plan released by **Utah** outlines a course of action in three categories: home and community-based initiatives, cross-agency planning, and individual department and division plans. The recommendations call for identification of problem areas and effective approaches.

Innovations in Long-Term Care Services

Another impetus for state planning activities related to home and community-based care has been the Systems Change Grants for Community Living program, launched in 2001 by the Centers for Medicare and Medicaid Services (CMS) of the U.S. Department of Health and Human Services. Since 2001, CMS has awarded grants totaling about $125 million to 48 states, two territories and the District of Columbia.

Many states began testing innovative ways to deliver community services to people with disabilities. Of particular interest to a number of states was the concept of consumer direction, which these states saw as a way of increasing consumer control over the services they received. **Alaska**, for example, planned to develop a consumer-driven care coordination system. The project would establish a pilot program to develop individual budgets for program participants, and then would place those budgets under their control.

In **North Carolina**, the Department of Health and Human Services planned to use a $725,000 grant to identify provider practices that interfere with consumer direction. Then, the state planned to develop and conduct training and technical assistance with providers to encourage consumer-directed practices. Another part of the project involves creating local demonstration models of consumer leadership that will help build community support for options such as consumer-directed services.

States also were using Systems Change grants and other revenue sources to design programs for moving qualified individuals from nursing homes to community settings. **Rhode Island** was using its System Change grant, for example, to build on its "Date Certain" Nursing Home Transition Program. Grant money is being used to employ service coordinators to help with transition activities and for referrals and communications support. **Nebraska** planned to develop a communication and marketing campaign to help make the public more aware of community alternatives to nursing home placement. The project is using Area Agencies on Aging and specially trained ombudsmen volunteers to help identify and support people in nursing homes who can move to community settings.

Reorganization of State Agencies

Another emerging trend in state long-term care systems in 2002 and 2003 has been reorganization of state human and social services departments and the creation of new offices to deal with long-term care policy. The **Florida** legislature created a new Office of Long-Term Care Policy in the Department of Elder Affairs, for example, to evaluate, improve and coordinate the state's long-term care delivery system. Other state actions included the following.

The **Alabama** Department of Mental Health and Mental Retardation created a new Office of Consumer Empowerment in December 2002 to encourage greater participation in policymaking for people with mental retardation and developmental disabilities.

A major reorganization of the **Alaska** Department of Health and Social Services (DHSS) included a transfer of senior services from the Department of Administration to DHSS in a new Senior and Disabilities Services Division.

The **Iowa** governor transferred authority for inspecting and regulating assisted living facilities from the Department of Elder Affairs to the Department of Inspections and Appeals and appointed a task force to review the mission and responsibilities of the Department of Elder Affairs.

The **South Carolina** Legislative Audit Council recommended in January 2003 that the legislature authorize a single cabinet secretary appointed by the governor to oversee the eight current

health and human services agencies. The Council also proposed placing all senior and long-term care programs (that currently are in three different departments in a newly created agency specializing in senior and long-term care services.

In December 2002, the secretary of the **Washington** Department of Social and Health Services created the Aging and Disabilities Services Administration by merging the Aging and Adult Services Administration and the Division of Developmental Disabilities.

The **Wisconsin** Department of Health and Family Services combined two divisions and a department agency that oversees the new Family Care demonstration home and community-based program in February 2003 to create a new Division of Disability and Elder Services.

Conclusion

Twenty-four new governors took office in 2003. Nearly 1,750 new lawmakers took office in 2003 as well, representing the highest turnover in at least 30 years. What they and their colleagues faced was an unprecedented fiscal crisis. After several years of declining revenues and rising Medicaid costs, almost every state was forced to tighten budgets and trim agency programs and services in FY 2002. Fiscal prospects seem even worse for FY 2003 and FY 2004.

Cost-containment options included many measures that affect long-term care services. Slowing the rate of growth of nursing home reimbursement rates or freezing or cutting those rates had been among the most prevalent belt-tightening tactics in recent years, but in 2002 and 2003 home and community-based services came under the scrutiny of many state policymakers as well.

Nevertheless, many states redoubled their efforts to provide a range of community services for people with disabilities. A successful effort, spurred in part by federal Systems Change grants, was relocating people from nursing homes to community settings if those people sought the move and were assessed as being appropriate candidates for the transition. This movement appeared to be a trend that will continue into the future and that will include providing for Medicaid funding to follow an individual who make the transition from a nursing facility to the community (as has been done in **Texas**),

Another theme that emerges from a review of state long-term activity in 2002 is the increasing use of consumer direction in many HCBS programs. A number of states have been considering ways to more directly involve program participants in the planning and delivery of their services. These efforts also have been facilitated by Systems Change grants. **Nebraska**, for example, involved people all over the state in town hall meetings to obtain their input on consumer-directed services to implement a model that would apply to all populations of people with disabilities.

Long-term care planning is another important trend in the states that is likely to continue in the future. Some state planning groups engaged in a broad review of their long-term care programs and outlined what they thought should be the guiding principles and strategies for a reformed long-term care system. Other state task forces or commissions made detailed recommendations

for change in the immediate and long-range future. In either event, states appear likely to maintain the planning momentum until more favorable economic conditions allow for expansion of long-term care services.

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ALABAMA

Alabama moved forward on a number of fronts in 2002 to improve and expand access to home and community-based services for people with disabilities, particularly for those with mental retardation or mental illness. With impetus from the state's *Olmstead* planning process, Alabama received funds from the federal Systems Change grant program and federal approval of new Medicaid home and community-based waiver programs.

Planning and Reports

The Alabama Medicaid Department has been leading the state's *Olmstead* planning efforts to expand access to home and community-based services for all disability groups. Officials also are involved from the Governor's Office on Disabilities and the departments of Mental Health and Mental Retardation, Human Resources, Senior Services, and Public Health. *Olmstead* subcommittees, composed of consumers, advocates and agency officials, are expected to consolidate their reports into a draft plan by summer 2003. The four subcommittees are: Needs Assessment, Best Practices, Consumer Task Force, and Resource Development and Coordination.

Mental Health

The state continued to implement the provisions of a three-year plan (October 1, 2000 through September 30, 2003) to downsize state-operated psychiatric hospitals and developmental centers, while expanding community-based service options for people with mental retardation or mental illness. The plan emerged from the January 2001 settlement of a lawsuit, *Wyatt vs. Stickney,* which established specific assessment procedures to identify those with mental retardation or mental illness.

This activity was aided by federal approval of a new Medicaid Living-at-Home waiver approval, which became effective in October 2002. The program was expected to support up to 500 individuals with mental retardation during the next three years. The new services include personal care, respite care, in-home residential habilitation, day habilitation, pre-vocational services, supported employment, skilled nursing care, physical therapy, community specialist support, and crisis intervention services.

Assisted Living

The federal government also approved the state's use of Medicaid funds to help pay for people with dementia to stay in specialty care assisted living facilities in the state. The program is expected to pay $2,045 per month for each of 500 residents in the first year, for 650 residents the second year, and for 750 people the third year, with the Department of Senior Services providing $5 million to cover remaining costs. Individuals in the program will be expected to pay about $450 per month.

In another development, the Department of Mental Health and Mental Retardation in December 2002 announced the opening of a new Office of Consumer Empowerment to provide people with mental retardation and developmental disabilities (MR/DD) with additional resources for self-advocacy and self-determination. The goals for the office include greater participation for consumers with MR/DD in policymaking and the development of a consumer-driven support system for training, follow-up and mentoring.

ALASKA

Faced with waiting lists for community-based services for people with disabilities, Alaska engaged in a number of planning efforts in 2002 to advance home and community-based care. The state also is using federal grant funds to develop consumer-directed models of care for some of its programs.

Planning and Reports

Alaska is carrying out long-term care planning through four planning and advocacy boards, funded by the Alaska Mental Health Trust Authority and state general revenue. The four boards worked together to produce a planning document, *In-Step, Comprehensive Integrated Mental Health Plan,* which was released in December 2001. The Alaska Mental Health Board addresses mental illness; the Governor's Council on Disabilities and Special Education handles developmental disabilities; the Advisory Board on Alcoholism and Drug Abuse is responsible for chronic alcoholism issues; and the Alaska Commission on Aging deals with Alzheimer's Disease and related disorders.

The state is crafting a mental health strategy through its Community Mental Health/API Replacement Project that is aimed at better serving individuals with mental health problems. Part of the strategy involves replacing the aging Alaska Psychiatric Institute with a new facility. Components of the project include a single point of entry to assistance and services, enhanced crisis respite, enhanced detoxification treatment, intensive community-based services targeting the highest users of API acute care services, and training.

Home and Community-Based Care

A "Developmental Disabilities Wait List Report" was published in November 2002. Prepared by the Division of Mental Health and Developmental Disabilities, the report noted that 3,552 people were receiving various developmental disabilities services as of June 30, 2002 with 1,233 people on a waiting list. Another report, "Waiting in Line for Treatment," released in February 2002 by the Division of Alcoholism and Drug Abuse, summarized the results of a survey conducted in late 2001. The survey showed that, on any given day, an average of 302 people living in eight Alaska communities signed up for treatment in a program that had no space available for them.

The state received a $1.4 million Systems Change grant from the federal government in 2002 to develop a consumer-driven care coordination system. The project will focus on delivering services using case management models, establishing a reimbursement methodology for individual budgets, and developing a system for purchasing services through fiscal intermediaries or service brokers.

State Administrative Agencies

The new administration of Governor Frank Murkowski in March 2003 announced a major reorganization of the state Department of Health and Social Services (DHSS), an agency of 2,700 employees with a $1.6 billion budget. The move included the transfer of senior services from the Department of Administration to DHSS.

Department officials said the restructuring would make the department operate more efficiently. A new Senior and Disabilities Services Division will provide care for seniors and disabled Alaskans. This division includes the former Division of Senior Services and Adult Public Assistance (formerly

in the Division of Public Assistance) and several other functions from the former Division of Medical Assistance, where Medicaid functions had been centralized. Divisions will have responsibility for their own Medicaid services. A new Behavioral Health Division will include functions formerly in the Division of Alcoholism and Drug Abuse and the Division of Mental Health and Developmental Disabilities.

As it left office at the end of 2002, the Knowles administration dropped plans to issue new regulations that would have sharply curtailed services under a Medicaid home care program for people with mental retardation, severe medical conditions, or developmental or physical disabilities. The Department of Health and Social Services cancelled hearings in November 2002 on proposed new regulations for the program after considerable opposition developed among parents, foster parents and advocates. The changes would have limited some types of home care assistance, added restrictions on foster families, prohibited the purchase of certain types of special equipment, and restricted funds for home modifications. The program cost more than $100 million in FY 2001 and served about 2,700 people.

ARIZONA

Arizona has been expanding home and community-based services (HCBS) in recent years as a proportion of its overall long-term care system but, like many other states, Arizona also is feeling the fiscal pressures of providing HCBS services for growing numbers of people with disabilities.

Home and Community-Based Services

During the 1990s, Arizona's population grew by more than 42 percent. The number of Arizonans age 65 and older increased by 39.5 percent between 1990 and 2000, compared with a national average of 12.4 percent. In her January 2003 budget message, Governor Janet Napolitano said that Arizona was currently taking in the same level of revenues that the state had collected in FY 1999, but it was serving 300,000 more participants in its Arizona Health Care Cost Containment System (AHCCCS), which includes its long-term care program.

Total AHCCCS enrollment as of April 1, 2003, was about 905,000. Of this total, almost 37,000 persons were enrolled in the Arizona Long Term Care System (ALTCS). That number had been 34,334 people in June 2002.

Planning and Reports

Arizona issued a long-term care *Olmstead* planning report in September 2001 that was the combined effort of the Arizona Health Care Cost Containment System (AHCCCS) and the departments of Human Services and Economic Security. Revised work plans for the goals identified in the report were issued in March 2003. Labor force shortages had been addressed in the report, for example, with proposals such as using Medicaid funds to pay spouses and parents as personal care attendants. Although AHCCCS requested approval for that initiative from the Centers for Medicare and Medicaid, that request was denied. However, the Division of Developmental Disabilities (Department of Economic Security) held a roundtable discussion on increasing the network of providers in January 2002. Four priority strategies were developed through this process. The Arizona Legislature approved an allocation to increase rates of providers who were receiving below average negotiated rates, beginning July 2002.

To address the goal of finding providers with an interest in and skills for serving people with serious behavior problems, the Division of Developmental Disabilities implemented a Community Protection Project to increase the focus of placing individuals with significant behavior challenges into the community. Beginning in August 2002, the division initiated new behavioral health services designed to support individuals in the community and reduce or prevent inpatient placements.

The third biennial *Community Based Services and Settings Report* was released in May 2002. The report is a collaborative effort by the Arizona Health Care Cost Containment System, the Department of Economic Security, and the Department of Health Services. The report noted that the percentage of members of the Arizona Long-Term Care System residing in a nursing facility had declined from 58.8 percent in 1998 to 46.6 percent as of January 2002. The proportion of members living in their own homes had increased from 35.9 percent to 40.8 percent during that same period.

In 2000, Arizona began surveying participants in the ALTCS to evaluate consumer satisfaction with the program, known as the Long Term-Care Project. Also that year, the state awarded three

contracts to health plans to provide long-term care services in Maricopa County. In the third phase of the Long-Term Care Project, the state surveyed consumers after they had been given the choice to switch among the three plans to see what, if anything, had changed with their satisfaction levels. Comparisons were made between members who remained with their current health plans and those who switched to another plan.

The report, *Now and the Next Generation: Long-Term Care 2002*, found that consumers in Maricopa County were "extremely satisfied" with their long-term care services, whether or not they had changed health plans. The report noted that more research was needed to determine how much difference choice makes, why new consumers choose one plan over another, and why consumers choose to remain or not remain with their existing plan.

Arkansas

Arkansas state officials took a number of steps in 2002 to improve quality of long-term care services and to increase access to home and community-based care services (HCBS). One effort involved a task force report that recommended increased funding for HCBS for people with developmental disabilities and "money follow the person" policies for nursing home transitions. Another task force proposed ways to increase housing options for people with disabilities.

Planning and Reports

A 23-member Governor's Integrated Services Taskforce (GIST) released a comprehensive draft plan for long-term care reforms in October 2002. Governor Mike Huckabee had authorized the Department of Human Services to appoint the task force in June 2001 after a year of work by an *Olmstead* Working Group. The task force, consisting of consumers, advocates, providers, and agency officials, met from July 2001 through May 2002, and then began writing a plan. Highlights of the plan include the following.

- Assessing all individuals who seek to enter a nursing home to determine eligibility and to inform them of their community options.

- Allowing money that is spent on a nursing home resident to follow the resident after a move to his or her own home or another community setting.

- Providing quicker access to home and community-based services, including a request for an additional $6.4 million for the Medicaid developmental disabilities waiver program.

- Instituting major changes to the state's mental health care system, including funding for adult inpatient acute care, shifting funds to children's outpatient services, and working on commitment laws and insurance parity issues (people with mental illness having the same access to treatment that people with other physical illness have).

Housing for People with Disabilities

The Governor's Task Force on Supported Housing submitted its report on June 6, 2002. The report recommends both using existing housing and creating new housing stock for people with disabilities. The housing task force proposed the creation of a pilot program in cooperation with the GIST to operate in an urban and a rural community. The pilot group would receive assistance to obtain bridge rental subsidies through the state HOME program and permanent subsidies through the local public housing authorities, and would receive assistance to link with service providers.

In September 2002, Governor Huckabee ordered the Department of Human Services to increase staffing requirements in the state's nursing homes, a move facilitated in part by revenue generated from a quality assurance fee (or "bed tax") approved by the legislature in 2001. The fee produced almost $150 million, which was reimbursed to Arkansas nursing homes to improve care.

Consumer Direction

In another long-term care development, the U.S. Department of Health and Human Services approved the state's request to allow all beneficiaries in a Medicaid personal care services demon-

stration program to direct their own services and expenses. Since 1998, Arkansas has operated its Independent Choices Program, which provides cash allowances to 800 participants to hire their own workers, choose the services or supplies they wish, and schedule their services. Another 800 participants have been serving as a control group, using traditional agency services. Now, all 1,600 participants will be allowed consumer choice.

CALIFORNIA

The long-term care system in California was subject to a number of different influences in 2002 and 2003 as a result of the state's major fiscal crisis. Huge budget shortfalls saw California officials reviewing a number of different strategies, which included cuts in 2002 to many services for the elderly, people with mental illness, and other people with disabilities as part of a range of cost-cutting measures. Other strategies called for freezing state agency spending, transferring certain programs to counties, and reorganizing state agencies.

The Budget

On November 26, 2002, Governor Gray Davis issued an executive order directing state agencies to freeze spending where possible and to begin implementing current-year reductions in nonessential functions. Governor Davis announced in January 2003 that his FY 2003-2004 budget proposed $20.7 billion in program reductions, saying that "Nearly every program gets cut." As the centerpiece in the administration's spending plan for FY 2003-2004, Governor Davis proposed a realignment of about 12 percent of state general fund program obligations by shifting those obligations to counties. The state would increase a variety of taxes by a net of $8.2 billion and shift this funding to the counties to cover the costs of the programs transferred to them. Chief among these programs would be 100 percent of the state's cost for Medi-Cal (Medicaid) long-term care (nursing homes), a total cost of $1.1 billion to $1.4 billion.

In its analysis of the administration's budget, the Legislative Analyst's Office (LAO) recommended against legislative approval of the proposed shift, saying that counties " ... would have few tools to manage this major new funding responsibility. Counties would not have authority over major factors driving Medi-Cal long-term costs: provider reimbursement rates, program eligibility, or the decision to place Medi-Cal recipients into nursing homes." However, the LAO said that, since the state's long-term care delivery system was seriously fragmented and lacked coordination, the system " ... would benefit greatly by county coordination and control." The LAO recommended that the Legislature transform the administration's proposal " ... into a plan that phases in over a longer period an integrated system of long-term care, managed by counties."

Another program that the administration proposed shifting entirely to counties is the In-Home Supportive Services (IHSS) Program, for which the county share is currently 35 percent (for the state-funded part of the program). The LAO said the Legislature might consider increasing the county share to 50 percent and giving the counties more control over the program. The LAO also suggested that the Legislature consider eliminating the California Department of Aging and shifting its functions to the Department of Social Services, since both operated programs that support the senior population. The move would eliminate 37 positions and produce a net savings of $3.4 million, the LAO said.

The FY 2002-2003 budget estimated an increase of more than 8 percent in the average monthly caseloads for the In-Home Supportive Services program for a total of 296,800 cases. The budget also supported an estimated 10,000-caseload increase in the number of people with developmental disabilities served by regional centers.

2002 Legislation

In 2002, the Legislature enacted several measures to address long-term care issues. One bill

clarifies the differences between "care and supervision" and "community living support services" in supportive housing to exempt the latter from required state licensing requirements. The bill's author contended that, under current law, when individuals with disabilities were provided supportive living services, confusion could arise about whether they needed a level of care and supervision that would require them to live in a licensed facility. The enacted bill was intended to encourage counties to develop innovative ways to support independent living for people with disabilities.

Another measure allows individuals who receive hospice services to enter a residential care facility without having to disenroll from hospice. Elder abuse also was addressed by the Legislature, with laws to increase the penalties for elder abuse, to add clergy to the list of mandated reporters, to expand the list of people who may receive and disclose information of suspected abuse, and to instruct the Department of Social Services to develop guidelines for adult protective services.

Grant Initiatives

The state received a federal Systems Change grant for $1,385,000 in 2002, which the California Department of Social Services planned to use to develop training, educational materials, and other methods of support to aid participants in the In-Home Supportive Services Program. State officials said that, although the vast majority of Medicaid consumers in the IHSS program recruit, hire, train and supervise their care providers, no statewide assistance or training had been available to support them. Grant funds would be used, they said, to conduct needs assessments of IHSS consumers and providers. Based on those assessments, project staff planned to design or obtain training and educational materials and other supportive resources. As of January 1, 2003, almost all of California's 58 counties had established a public authority that, by law, must make consumer and worker training available.

In May 2002, Governor Davis announced a $10.5 million grant to increase the state's front-line health care work force by up to 2,000 people within the next 20 months. The certified nurse assistant training program uses nursing facilities as training sites.

Colorado

The Colorado legislature enacted a range of long-term care measures in 2002 that included a new consumer-directed care program, expanded services for people with brain injury, changed rules on personal care boarding homes, and established a pilot program on nursing home quality. State fiscal problems caused cuts, however, in the Medicaid long-term care budget, affecting home care services and providers.

2002 Legislation

The legislature enacted a bill that requires the Department of Health Care Policy and Financing to implement a consumer-directed care program for the elderly under which eligible people can receive a voucher to purchase home and community-based services or supports. The voucher amount will be based on the person's historical use of services or a care plan. A physician must certify that the individual is able to direct his or her own care and the individual must demonstrate the ability to manage the financial aspects of that care. The voucher program also covers assisted living. (Another consumer-directed program, the Consumer-Directed Attendant Support Program, went into operation in 2002. Limited to 150 people, the program is open to Medicaid recipients of home care services who must complete training and pass an attendant support management proficiency test to be enrolled.) Other long-term care measures enacted in 2002 include the following.

- Expanded services for individuals with brain injury by allowing them access to "supportive living" services on residential campuses that provide such services.

- Eliminated budget neutrality provisions that require home and community-based services for an individual to be less costly than the average cost of nursing home care.

- Changed the licensing category for personal care boarding homes to assisted living residences. The new rules define an "assisted living residence" as a residential facility that provides room, board and certain services to three or more adults. The services must include personal services, protective oversight, social care due to impaired capacity to live independently, and regular supervision available on a 24-hour basis (not including 24-hour medical or nursing care).

- Created the Assisted Living Residence Improvement Cash Fund to collect civil fines. Funds are used for education, technical assistance, and relocation of residents or closure of a residence.

- Created a pilot program to survey quality of care and living in nursing homes. The consumer satisfaction surveys were to be distributed to no more than 10 percent of residents and their families.

The Budget

The Colorado General Assembly's failure to enact a balanced budget during the 2002 general legislative session caused Governor Bill Owens to order a 4 percent across-the-board cut for state agencies. The result was a $24.5 million reduction in the Medicaid long-term care budget administered by the Department of Health Care Policy and Financing. One example of a program cut

was home health services where reimbursement for a 90-minute visit by a certified nurse's aide dropped from the 2001 rate of $41.12 to $31.06 if the patient was short term and to $39.07 if the patient was long-term. Budget constraints also resulted in a freeze on new admissions to the state-funded Home Care Allowance Program. The freeze went into effect on July 1, 2002.

Grant Initiatives

The Department of Health Care Policy and Financing received a $1.1 million federal Systems Change grant in 2002. The agency planned to contract with the Center for Research Strategies to design and conduct a service capacity survey and a statewide needs assessment for community-based care with an emphasis on rural areas. Activities include developing an education campaign on community-based options, developing recommendations for pilot respite care programs, and improving the mental health assessment tool. A consumer task force will advise the agency staff and subcontractors on all project goals.

Another $725,000 Systems Change grant was awarded to Colorado in 2002 to design and implement a personal assistance services and supports option in which consumers exercise control over their care decisions. The project will provide extensive training through a "train-the-trainer" program so the trainers will become community-based resources for the state, provider agencies, advocacy groups and individuals.

CONNECTICUT

The Connecticut legislature authorized an assisted living pilot program in 2002 and called on the state to develop an Internet Web site of long-term care information for the benefit of consumers. Long-term care planning groups developed recommendations on housing and work force issues and information and assistance for people with disabilities who are making the transition into the community from nursing homes.

2002 Legislation

The 2002 legislature directed the commissioner of social services to establish and operate a pilot program to allow up to 50 people to receive assisted living services, provided by an assisted living services agency licensed by the Department of Public Health. The legislature also called for the creation of a single consumer-oriented Internet Web site to provide comprehensive information about the long-term care options available in Connecticut. The Web site will include direct links and referral information, including private and nonprofit organizations that offer advice, counseling and legal services.

Planning and Reports

The Connecticut Long-Term Care Planning Committee, which is composed of 10 state agencies and key legislative committee members, is charged with developing a long-term care plan every three years. The committee and the Department of Social Services created a Community Options Task Force in 2000 (composed of advocates, other consumer representatives and providers) who met for two years. In March 2002, the three groups released *Choices are for Everyone: Continuing the Movement Toward Community-Based Supports in Connecticut - A Plan in Progress.*

The Long-Term Care Committee is overseeing the implementation of action steps in the *Choices Are for Everyone* plan. The action steps include the following.

- Educating people with disabilities who will make the transition into the community about peer support and support networks.

- Educating architects, housing authorities, builders and local boards about accessibility; reviewing safety codes to ensure safety for individuals with functional limitations; and exploring tax incentives to encourage new homes or renovations to meet minimum accessibility standards.

- Increasing the paraprofessional work force and developing training programs.

- Developing community connections by distributing material to the general public, current residents of institutions and providers of support services; and by establishing networks for people with disabilities who are making the transition into the community.

Transfer of Assets

Following up on legislation enacted in 2001, the Department of Social Services proposed tightening the requirements governing transfer of assets in connection with eligibility for Medicaid coverage for long-term care. Previously, individuals who transferred assets within a 36-month "look-back period" were penalized by the disallowance of Medicaid payment for a prescribed penalty

period, which began on the first of the month in which the transfer occurred. The department proposal, which must have approval from the federal government, would begin the penalty period when a person applies for Medicaid, rather than when he or she actually transferred the money. State officials said that in a random sample of 300 Medicaid applicants for nursing home care, they found that 36 percent of the applicants had improperly transferred assets.

The proposal ran into considerable opposition, however, from the state's congressional delegation, and some state legislators who introduced legislation to block implementation if the plan received federal approval. All members of the congressional delegation urged the Bush administration to deny the application. Opponents contend that the change would penalize people who, in good faith, help out family members.

Delaware

Long-term care activity in Delaware centered around planning efforts to assess the status of the state's home and community-based services and to develop further plans for expanded community alternatives to nursing homes. A federal grant allowed the state to plan to move some people from nursing homes into the community.

Planning and Reports

On the last meeting of the session of the Delaware General Assembly on June 30, 2002, the House of Representatives passed House Resolution 90, which created a Commission on Community-Based Alternatives for Persons with Disabilities. Commission members include representatives of advocacy groups, consumers, and service providers. A report, *A Call to Action: Building a Community-Based Plan for Delaware*, was released in March 2003, listing the following goals to be provided to people with disabilities.

- Establish a systematic, simplified and fair process for assessing individual needs. Create a comprehensive database of the number of people who currently have access to or are waiting for services, and the methods to facilitate this move for individuals who move from one setting to another.
- Provide safe, affordable and appropriate housing and transportation options.
- Create a coordinated, comprehensive and affordable health care system.
- Center quality vocational services and supports around an individual's strengths, preferences and capabilities.

In October 2002, four divisions of the Delaware Department of Health and Social Services released a "Plan for Community-Based Alternatives and '*Olmstead*' Compliance." The four agencies are the Division of Social Services, the Division of Developmental Disabilities Services, the Division of Substance Abuse and Mental Health, and the Division of Service for Aging & Adults with Physical Disabilities.

The report does not include any recommendations, nor does it provide an action plan. Rather, the report provides an overview of the state's progress in providing community-based alternatives and in moving people with disabilities from institutional to community care. For example, the report describes the state's efforts over the years to relocate people with mental retardation/developmental disabilities from the Stockley Center and people with mental illness from the Delaware Psychiatric Center. The population at the Stockley Center has decreased from 555 residents in 1975 to 179 in 2002. From a peak population of 1,530 residents in 1965, the Psychiatric Center population dropped to 248 residents in 2002.

In spring 2002, The Arc of Delaware sued the state, claiming that Delaware had not moved quickly enough to provide group homes and other services for those with disabilities. The organization contended that the state had limited its efforts largely to moving people out of institutions, instead of developing services that would help people remain in their homes. State officials said that about 300 people were on a state registry for residential placements, such as group homes, foster homes or supervised apartments.

Grant Initiatives

The Delaware Department of Health and Social Services received a $566,772 grant from the Centers for Medicare and Medicaid Services to develop a program to move 15 people from nursing homes to community settings. The state also planned to use the grant funds to educate the provider and housing communities about the program.

Home Health

The legislature enacted new standards in 2002 for public health quality assurance in home health agency programs. The law defines a home health agency under Delaware law and spells out staffing standards, permissible services and prohibited practices for these agencies.

District of Columbia

The District of Columbia Department of Health, which is responsible for the Medicaid program for the city, has been overseeing the redesign of the District's long-term care system through a Real Choice Systems Change Advisory Committee since June 2001. The District received two grants totaling slightly more than $2.1 million in 2002 from the federal Centers for Medicare and Medicaid Services to help facilitate this work.

One $725,000 grant is being used to build the infrastructure for a personal assistance services system; to streamline the eligibility determination process; to disseminate information to consumers about home and community-based services; and to recruit, train, and support personal assistants and mentors. The other $1.4 million grant will be used to develop a resource center to serve as a single point of entry that will initially provide frail elderly people and people with physical disabilities with information and access to long-term care services. The resource center will be modeled after the Aging and Disability Resource Center system that has been developed in several Wisconsin counties through the state's pilot Family Care Program. The project also will establish a care coordination system that incorporates financial incentives for providers to increase flexibility, improve quality of life and care, and control costs.

The advisory committee includes consumers, providers and officials from city agencies that provide services to individuals with disabilities. Early activities of the committee have included the expansion of two Medicaid waiver programs, one for the elderly and the other for people with mental retardation and developmental disabilities. The District requested 200 additional waiver slots per year for each waiver for a period of five years. The city also is expanding services under its Elderly/Physically Disabled waiver program to include assisted living and consumer-directed attendant care and is expanding coverage of assistive technology.

FLORIDA

2002 Legislation

In 2002, the Florida Legislature took a number of actions that affected long-term care, from addressing nursing home quality issues to creating a new long-term care policy agency and improving access to services through a statewide information and referral system and a simplified eligibility determination process.

Lawmakers continued to address nursing home staffing standards and liability issues as they had in several previous sessions. On the staffing front, the legislators prohibited union organizing activities by a nursing home employee during any period that the employee was included in staffing calculations to meet minimum staffing standards.

Lawmakers also followed up on the actions they took in 2001 to stabilize financial risk for nursing homes after a number of insurance companies threatened to pull out of the Florida market because of mounting lawsuits against nursing homes. In 2002, lawmakers expedited the availability of general and professional liability insurance for nursing homes by advancing $6 million to capitalize the risk retention group. The legislators also called for a report on the number of notices of intent to litigate received by each nursing home every month, the number of complaints filed each month, and information about the deficiencies cited in the complaints.

Another measure created the Florida Health and Human Services Access Act, which establishes a framework for improvements in access to information about available long-term care services. The legislation calls for the development of an information and referral system using the 211 telephone number, a simplified eligibility determination process, and development of coordinated care management for people with disabilities and their families. The Agency for Health Care Administration was directed to conduct a pilot project to determine the feasibility of integrating state-funded health care benefit eligibility determination with information and referral services.

The Legislature also:

- Directed the Department of Elder Affairs and the Agency for Health Care Administration to develop a model system to move all state-funded services for the elderly in one of the state's planning and service areas to a managed, integrated, long-term care delivery system under the direction of a single entity. All funding for services would be integrated into a single, per-person, per-month payment rate.

- Enacted the Florida Consumer-Directed Care Act, which requires the Agency for Health Care Administration to allow those enrolled in the Medicaid home and community-based waiver programs to direct their own care, if they are able to do so, or to designate an eligible representative. People enrolled in the program will be given a monthly budget allowance, based on their assessed functional needs.

- Established the Office of Long-Term Care Policy in the Department of Elder Affairs to evaluate, improve and coordinate the long-term care delivery system and to make recommendations to increase the availability of home and community-based services.

The new Office of Long-Term Care Policy has a 13-member Advisory Council, which issued its first report in February 2003. The Advisory Council recommended that a template be designed for evaluating all long-term care programs, using a uniform methodology across all components. The next step, the council said, would be an evaluation of the Medicaid waiver programs, to be followed by pilot projects and existing programs.

The council noted that fragmentation of long-term care programs and services would be a major focus for its work because similar services are provided by different programs; multiple state agencies are involved in repetitive or duplicative processes; some segments of the long-term care continuum, such as assisted living and hospice, have as many as four agencies overseeing a portion of their activities; and coordination among state agencies is limited. The report concluded that this fragmentation was the largest single policy issue facing the council.

Georgia

Recommendations from several planning groups about expanding community services for people with disabilities resulted in significant legislative and executive initiatives and funding to move people with disabilities off waiting lists and to revamp community mental health services.

The Budget

In his January 2003 budget message, Governor Sonny Perdue pledged to continue "to work toward full implementation of the *Olmstead* decision." For the FY 2004 budget, he proposed about $4 million to expand waiver services to those waiting for community-based services, and about $9.6 million to support those moving from institutions to community-based settings.

2002 Legislation

A measure enacted by the 2002 legislature expands the Rehabilitation Option under Medicaid to cover more community-based mental health and substance abuse treatment alternatives. The law also increases payment rates to providers of mental retardation services and extends coverage for more community-based services for those with mental retardation. Newly covered services include treatment in community homes with round-the-clock support, family support services, and supported employment or other day services.

Home and Community-Based Services

The expansion of community services for people with mental illness or mental retardation follows upon recommendations of a Blue Ribbon Task Force on Home and Community-Based Services, created by Governor Roy Barnes in 1999. Additional planning and recommendations issued from an *Olmstead* Planning Committee, which included consumers, advocates, providers and state agency officials. The committee made its recommendations in an internal document on January 30, 2002. The governor issued an executive order in June 2002 that charged several governmental council and advisory committees for people with disabilities with ongoing review of state compliance with *Olmstead* requirements. The following initiatives, funded in the FY 2003 budget and implemented on July 1, 2002, were the culmination of these various activities.

- Continued reduction of the waiting list for the Community Care Services Program (822 consumers; $4.1 million) and the mental retardation Medicaid waiver program (507 consumers; $8 million).

- The move of all people under age 21 from state mental retardation institutions into community residential services (65 consumers; $4.1 million).

- Provision of intensive family intervention services for severely emotionally disturbed youth who are at risk of institutionalization and their families (600 families; $3 million).

On January 31, 2003, the Atlanta Legal Aid Society and private attorneys filed a class action complaint in U.S. District Court on behalf of individuals with physical disabilities in nursing homes or who are at risk of nursing home placement. The lawsuit contends that the state has failed to make a "significant effort" to expand home and community-based services. The plaintiffs are on waiting lists for the state's Community Care Services Program and the Independent Care Waiver Programs, the two Medicaid home and community-based services programs in the state for people who do not have mental retardation.

HAWAII

Hawaii broke new ground in 2002 with a long-term care financing program that is intended to ensure universal coverage, but the failure to fund the program left it in limbo until a study is completed about needed tax revenues. An 18-month planning process involving state agencies and consumers resulted in a broad range of recommendations to increase access to home and community-based care.

Long-Term Care Insurance

Hawaii became the first state to create a long-term care financing program when then-Governor Benjamin Cayetano signed legislation on July 1, 2002, establishing the Hawaii Long-Term Benefits Fund to provide a system of universal long-term care in the state. The legislation calls for long-term care taxes to be deposited into the fund to cover benefit payments and administrative costs. People would qualify for coverage if they needed assistance with at least two activities of daily living or were suffering from Alzheimer's disease.

However, a proposal to fund the program through a $10 tax on all Hawaii workers was defeated in the Legislature. Instead, a board of trustees is to conduct a study to determine the amount of tax revenue that the state should place into the fund.

Governor Linda Lingle said in her state-of-the-state address in January 2003 that she would seek a 30 percent tax credit to be phased in over three years to encourage Hawaiians to purchase private long-term care insurance. The 2003 Legislature considered several tax credit measures for those who buy long-term care insurance.

Planning and Reports

The state's Department of Health and Human Services and Department of Health and the Hawaii Centers for Independent Living issued a long-term care planning document on September 13, 2002 after 18 months of work. Individuals with disabilities, advocates, providers, and businesses and government agencies that assist people with disabilities also participated in the planning process. The document, *The Olmstead Plan: State of Hawaii,* describes five goals.

- To inform and educate consumers about their choices and rights involving community living opportunities and services.

- To support individuals in finding appropriate, affordable and accessible housing in a timely manner. This goal involves improving the assessment process, including assessing residents of nursing homes to determine if they should remain in such facilities or move to community settings.

- To facilitate the access of individuals to financial resources for their long-term care and to increase the flexibility available to them in how funds are used, including allowing consumers to direct their own care.

- To ensure adequate housing, transportation and employment for people with disabilities. This goal includes developing and maintaining a suitable work force to assist people with disabilities to live in the community.

- To coordinate a quality assurance program to monitor and assess the state's progress in meeting the goals of the plan.

IDAHO

A new process to assess people with disabilities before delivering services was put into practice through a pilot program in Idaho in 2002 to address concerns about Medicaid caseload increases. Another long-term care development involved legislation governing the transfer of assets prior to qualifying for Medicaid coverage of services.

Developmental Disabilities and Mental Health

Idaho has experienced significant caseload increases in its Medicaid home and community-based waiver program for people with developmental disabilities in recent years. The program served an average of 1,028 people monthly during FY 2002, up 68 percent from FY 2000. This growth led to legislation enacted in 2001 that directs the Department of Health and Welfare to initiate a project intended to manage the growth in Medicaid spending on services for people with developmental disabilities and also to improve the quality of those services. The Developmental Disabilities and Mental Health Service Delivery Project involves several phases, the first of which is to serve adults with developmental disabilities, to be followed by serving adults with mental health issues.

The process requires review and authorization of services for each consumer before services are delivered. The Department began a seven-month pilot program (beginning in October 2001) for adults with developmental disabilities in Region 2 of the state. The project involved 11 developmental disabilities service provider agencies and the care management of 114 consumers receiving services. The department reported that. " ... data shows the pilot was able to slow the growth of expenditures to 1 percent for the seven-month trial period and still maintain a high level of service."

Transfer of Assets

The 2002 Legislature endeavored to plug a loophole in the rules governing the transfer of assets to qualify for Medicaid assistance for nursing home care. The Idaho law provides that any transfer of assets not otherwise permitted by federal law is presumed to be for the purpose of sheltering assets to qualify for Medicaid. The transferred assets will be counted as available in determining eligibility and will subject the applicant to civil penalties, unless the applicant can demonstrate by clear and convincing evidence that the transfer was intended for another purpose.

Illinois

The Budget

Faced with a $5 billion budget deficit for FY 2004, incoming Governor Rod R. Blagojevich in an April 9, 2003, budget address, directed each state agency and department to cut administrative costs by 10 percent on average. For the Department of Aging, he proposed $6.24 million in cuts to come from reductions in administrative costs and a reduction of personnel from 126 to 114. Nonetheless, the Department of Aging budget was to increase by $7.3 million over FY 2003.

The proposed budget did, however, call for increased support for home health programs. Funding was increased by $56 million for the Home Services Program, for example, to help 24,000 individuals with physical disabilities, developmental disabilities, mental illness, AIDs, and traumatic brain injury to remain at home rather than be institutionalized. Medicaid increases proposed by the governor for the Department of Public Aid would allow the state, he said, to reimburse hospitals and nursing homes more promptly than in the past. The goal was payment within 60 days or less. Governor Blagojevich did not propose cutting payment rates for nursing homes.

2002 Legislation

Illinois legislators reacted to state fiscal problems in 2002 by reducing the nursing home reimbursement rate by 5.9 percent, effective July 1, 2002. The legislature also required the state to implement a new payment methodology for the nursing component of a nursing facility's rate, effective July 1, 2003. The Illinois Department of Public Aid must develop the new payment methodology using minimum data set information.

The legislature also created the Innovations in Long-Term Care Quality Grants Act, which requires the director of public health to fund long-term care programs that demonstrate creativity in providing services. The funds to finance the grants will come from fines collected under the Nursing Home Care Act.

Planning and Reports

A State Interagency Team composed of representatives of six Illinois state agencies released its "Community Living and Disabilities Plan" in April 2002. The plan, which establishes a framework to achieve greater integration of people with disabilities into the community, culminated a two-year planning process that involved consumers, family members, service providers and the state agencies.

The plan includes recommended priorities from each of the six agencies involved in the process. The priorities include increased funding for community-based programs and services, improved transitional assistance for people who want to move out of institutions, focus on self-directed care, and increased consumer control. Upon releasing the plan, then-Governor George Ryan created a permanent Disabilities Services Advisory Committee to provide ongoing oversight of the plan and its implementation.

INDIANA

Two Indiana commissions examined issues in 2002 relating to expansion of home and community-based services (HCBS) for people with disabilities and the supply and training of the long-term care work force. The legislature also enacted a measure that would help facilitate the use of certain unlicensed workers in HCBS programs.

Planning and Reports

In July 2002, Governor Frank O'Bannon appointed a 21-member Governor's Commission on Home and Community-Based Services, the purpose of which is to develop short- and long-term strategies to create or expand home and community-based services for people with disabilities. The commission convened five special task forces, each devoted to specific policy areas of concern, and a Consumer Advisory Committee to assist with its work.

The commission issued an interim report on December 23, 2002, with 16 recommendations under five categories: eligibility, streamlining and maximizing funding, provider incentives to increase capacity, consumer education, and consumer choice. Under eligibility, for example, the commission recommended that the state apply spousal impoverishment provisions to the Medicaid Aged and Disabled Waiver Program as is done for Medicaid-funded nursing home care, and raise the monthly income eligibility standard for the waiver program to 300 percent of Supplemental Security Income as is the case for nursing home care. A final report is to be issued in June 2003.

The Indiana legislature established the Governor's Commission on Long Term Caregivers in 2001. The commission convened in 2002 to review information and data related to long-term caregivers, evaluate the adequacy of the state's training programs, and make recommendations to increase the supply. The legislation defined "long-term caregivers" as certified nurse aides, licensed practical nurses, and registered nurses " ... employed in health facilities, home health care, and community-based settings."

Workforce

In 2002, the legislature also enacted a bill permitting certain individuals who are not licensed health care professionals to provide health-related services to individuals who need in-home care services under the state-funded CHOICE program and Medicaid waiver programs. The unlicensed caregiver under this legislation is known as a "Personal Services Attendant." The Indiana Division of Disability, Aging and Rehabilitative Services is developing a registry for personal services attendants. The legislation also provides that hospice and home health agency employees who have received training (which has been approved by the attending physician) from a registered nurse may perform medical activities that have been delegated.

Iowa

Iowa state officials devoted considerable attention in 2002 to reviewing coordination of home and community-based care services for senior citizens across multiple state agencies and the role of the Department of Elder Affairs. Another administrative action involved reorganizing the state's oversight system for assisted living facilities.

The Budget

Iowa's budget crisis caused the state to divert money from the Senior Living Trust Fund to help pay for the state's Medicaid program, which had lost $18 million through budget cuts in 2001. The trust fund pays for services such as home-delivered meals, adult day care and respite care and provides grants to nursing homes to convert beds into assisted living. The governor signed a bill in April 2002 requiring the state to repay the trust money when the state's rainy day fund was restored to its maximum level. (In June, 2002, $13.2 million was transferred to the fund, and another $6 million was transferred in September 2002.)

State Administrative Agencies

The U.S. Administration on Aging awarded Iowa's Department of Elder Affairs a $1.5 million grant in September 2002 to address the complex nature of Iowa's home and community-based service system for senior citizens. Funding for elderly services comes from as many as 17 different sources, with elderly clients required to make a separate application for each program. In addition, each program has specific and different eligibility requirements. Furthermore, the system is not equipped to share information in a confidential way among providers, Area Agencies on Aging, or the Department of Elder Affairs. The first year of the project will deal with research, analysis and development of an enhanced data management system that will address these issues.

Governor Tom Vilsack transferred authority for inspecting and regulating Iowa's 137 assisted living facilities from the Department of Elder Affairs (DEA) to the Department of Inspections and Appeals, the agency that oversees nursing home regulation in the state. The action followed newspaper reports that the Department of Elder Affairs failed to take action against a facility after complaints of numerous instances of resident neglect and allegations that the department created two sets of records on complaints, one with the actual complaints and another set for public release from which those details had been removed.

In July, the governor appointed a Task Force on the Department of Elder Affairs to review the department's mission. The task force issued a report on September 30, 2002, which included among its recommendations that the DEA develop standards and rules for assisted living and adult day care services, including establishing a consumer complaint investigation system. The Department of Inspection and Appeals would be responsible for inspection and regulation functions for those services. Other recommendations called for the DEA to review and streamline Iowa's case management system, focus on developing a seamless system for elders to gain information and a single point of entry system for access to home and community-based services, and allocate more resources to create consumer awareness of the continuum of the long-term care system in Iowa.

Assisted Living

Oversight of assisted living facilities raised another contentious issue during 2002, when the Department of Inspections and Appeals determined that a number of assisted living facility residents

would have to leave certain facilities because the residents required greater care than the facilities were licensed to provide. Inspectors ordered the company that owned the facilities either to seek nursing home licenses for the facilities or to discharge those residents who needed assistance beyond that offered. The company filed a lawsuit, claiming the state was discriminating against people with disabilities by forcing them into nursing homes.

The lawsuit was dropped when the state issued regulations in July that more clearly defined the maximum level of care that could be provided in assisted living facilities. Also, any recommendation by the inspectors that an assisted-living resident might need care in a nursing home would have to be reviewed by a committee composed of a physician and the resident and his or her family. The state would be required to consider the recommendation of the committee before deciding whether a resident needed to be moved to a nursing home.

Kansas

Budget cutting dominated the long-term care agenda in Kansas in 2002. The budget reductions caused increases in waiting lists for home and community-based services as well as legal action from advocates who were fighting proposed reductions in spending. Two legislative reports addressed long-term care insurance, transfer of assets for Medicaid eligibility, and controlling the costs of long-term care.

The Budget

In August and November 2002, Governor Bill Graves called for buget allotment reductions that included a $13.6 million cut from the Department on Aging and a $32.6 million cut in the budget of the Department of Social and Rehabilitation Services. The actions taken included cuts to a Department of Social and Rehabilitation Services program that provides in-home assistance for daily activities, such as bathing and dressing for frail and elderly people. An estimated 350 people who were receiving services no longer were eligible for the program.

The 2002 Legislature reduced the Medicaid nursing home budget by $8.9 million. The Department on Aging was preparing to reduce funding for Meals On Wheels programs. Eligibility was to be capped for health and homemaking services through the Senior Care program. As of December 31, 2002, the number of eligible seniors on the waiting list for the Senior Care program totaled 650. A freeze on new applicants to the Medicaid Frail Elders home and community-based waiver program was instituted in April 2002. At that time, enrollment in the program totaled 5,350. As of January 2003, the waiver program had a waiting list of more than 1,000.

In October 2002, a statewide advocacy organization (InterHab) that represents agencies serving people with developmental disabilities filed a lawsuit against the state for failing to provide adequate funding of community services under the 1996 Developmental Disabilities Reform Act. The advocates contended that the cumulative shortfall in spending since passage of the legislation was at least $300 million.

In further action in January 2003, the organization asked the courts to stop the implementation of emergency budget cuts ordered by Governor Graves. InterHab attorneys said the level of funding already was illegal, with the cuts only making it worse. The lawsuit also said the Kansas Department of Social and Rehabilitation Services failed to give service providers 30 days' notice of the cuts, as required by state law. On February 11, 2003, the court turned down the request for a temporary restraining order.

When incoming Governor Kathleen Sebelius presented her FY 2004 budget, she urged restoration of some of these cuts, including funding of the Senior Care Act, state aid for mental health, and additional funding to help those on waiting lists for home and community-based services.

Planning and Reports

The President's Task Force on Medicaid Reform issued its final report to the 2003 Legislature on March 21, 2003. Long-term care was one of the issues the task force addressed, including a proposal for a statewide public education campaign on the importance of buying long-term care insurance. The task force also recommended a tax deduction and refundable tax credit for long-term care insurance premiums. The task force also proposed a number of legislative and regulatory

changes to tighten transfer of asset requirements for Medicaid eligibility, including increasing the look-back period to 60 months from the current 36 months and supporting legislation that would permit a lien on property of a Medicaid recipient who had been in a long-term care facility for a year or more.

The Legislative Division of Post Audit released a report *Medicaid Cost Containment: Controlling Costs of Long-Term Care*, in August 2002. The report noted that Medicaid long-term care costs had increased by 33 percent from FY 1998 to FY 2001 (from $472 million to $629 million), and that services provided in the community under Medicaid waiver programs accounted for almost 70 percent of that increase. One of the cost containment options identified in the report was limiting the number of people eligible for Medicaid-funded long-term care services by tightening financial and functional eligibility requirements. The other major option noted in the report involves limiting the amount the state pays for long-term care services, including using spending caps per consumer, managing program costs by analyzing key data, strengthening efforts to recoup amounts paid in error, and providing financial incentives for the purchase of long-term care insurance.

Kentucky

Budget shortfalls led to limits being imposed on a number of the state's long-term care services, ranging from nursing home eligibility to personal care services provided in the home. The state moved forward, however, with planning that proposes increasing community options for persons with disabilities over a 10-year period.

The Budget

In January 2003, Governor Paul Patton announced $250 million in Medicaid cuts, about 6 percent of total Medicaid spending. Some nursing home residents were expected to lose Medicaid eligibility when the state began its annual review of resident eligibility beginning in April 2003. The state no longer would cover people with "low-intensity" needs, such as help with daily activities such as bathing and dressing. The changes would apply to nursing home residents or those receiving personal care services at home under the Medicaid program. The state also planned to tighten income limits for some Medicaid recipients in nursing homes or those who apply for coverage.

Planning and Reports

In May 2002, the secretary of the Cabinet for Health Services created the Kentucky *Olmstead* Consumer Advisory Council through an Administrative Order. The mission of the advisory council is to help implement a compliance and systems change plan to meet the broad mandate of the *Olmstead* decision. In December, the Cabinet for Health Services in collaboration with the Advisory Council, released an *Olmstead* Compliance Plan for FY 2002 through FY 2012.

The compliance plan outlines state programs that currently support community-based efforts, makes recommendations, sets goals and strategies for each initiative, and lists challenges with *Olmstead* compliance. The goals of the plan include ensuring that consumers and families have meaningful information about choices that they can understand, that an individual's eligibility and need for services are based on objective criteria, and that plans are developed to move appropriate individuals from institutions into the community. Other goals include making appropriate housing and transportation available and increasing the employment rate for people with disabilities.

In September 2002, a Statewide Transition Committee was formed to develop a uniform process for moving people with mental retardation from ICF/MR facilities to the community when the individual desired the move, the treatment team believed community placement was appropriate, and a slot in the Supports for Community Living (SCL) program was available. SCL is a Medicaid waiver program administered by the Kentucky Division of Mental Retardation.

2002 Legislation

The 2002 legislature required long-term care facilities that provide special care to Alzheimer's patients to offer specialized training to all staff, including training in etiology and treatment, disease stages, behavior management and resident rights. The legislature also authorized the state to develop a Medicaid waiver program to provide services for children with pervasive developmental disorders or autism.

Louisiana

The focus of Louisiana's long-term care activities continues to be on expanding home and community-based services (HCBS) for people with disabilities as part of a settlement of a lawsuit that charged the state with discriminating against people with disabilities through greater spending on institutional-rather than on community-care. As a result, the state has increased funding for HCBS and has engaged in an ongoing planning effort involving state agencies and consumers.

Home and Community-Based Services

As a result of the settlement of the class action lawsuit, *Barthlemey vs. Louisiana Department of Health and Hospitals* in August 2001, the state is in the midst of a four-year, $118 million plan to provide community services to an increased number of people with disabilities. The Legislature approved $83.8 million to expand home and community-based services for FY 2002-2003. The additional funds were expected to provide services for about 1,400 people on waiting lists.

Effective November 1, 2002, the Medicaid home and community-based waiver program for people with mental retardation or developmental disabilities added a skilled nursing service. The service must be ordered by a physician, provided by a licensed nurse through an enrolled home health agency, and meet a medical necessity.

Planning and Reports

Two groups that were created by legislation in 2001 continued to be involved in long-term planning efforts in the state during 2002: the Disability Services and Supports Systems Planning Group and the Consumer Task Force. These two groups were compiling a list of recommendations for state activities through the fall and winter of 2002. In addition, the state was awarded a $1,385,000 federal Systems Change grant in 2002 to support the planning process of the two groups. With the funds, the Department of Health and Hospitals was planning to provide staff, meeting space, educational opportunities, and consultants to support and inform the two groups.

The department also planned to hold a series of public forums in all regions of the state to obtain consumer input. Another activity under the project was developing programming, training materials and project evaluation materials to enable implementation of consumer direction in Medicaid home and community-based waiver programs.

MAINE

The Maine Legislature acted on a number of long-term care issues in 2002, ranging from redefining levels of assisted living services to requiring reviews of reimbursement, training and certification of direct-care staff in the long-term care system. A blue ribbon commission reviewed long-term care financing issues, and a work group on community living issued a draft report on expanding self-directed services and creating a statewide information and referral system on all disability services.

Assisted Living

Major change affecting the state's rules governing assisted living facilities resulted from recommendations from a Commission to Study Assisted Living, which issued its report in December 2001. The commission concluded that the existing licensing requirements for different levels of assisted living could be "confusing and cumbersome and should be streamlined." The Legislature established three categories of assisted housing programs: independent housing with services, assisted living services, and residential care facilities. Housing that provides personal care services but not medication administration or nursing services did not need to be licensed.

The legislation also set reimbursement rate standards for certain facilities. The minimum reimbursement rates for residential care facilities is $433 per month for facilities with up to four beds and $601 per month for facilities of five or six beds. The legislation permits shared staffing between residential care facilities and other levels of assisted housing on the same premises, as long as such arrangements are clearly documented and staffing remains adequate to meet the needs of residents. The effective date of the legislation was October 1, 2002.

Workforce

Lawmakers also directed the Department of Human Services, the State Board of Nursing, and the State Board of Education to review rules regarding the training and certification of unlicensed direct-care staff. Another bill requires the Department of Human Services to review its rules for reimbursing personal care assistant home care services, identify barriers to those services, and revise its rules to improve delivery of those services.

Planning and Reports

The Legislature also established a Blue Ribbon Commission to Address the Financing of Long-Term Care in April 2002. The commission issued an interim report on November 6 supporting a proposed bill-to be considered in the Legislature's Special Session-imposing a licensing fee on nursing facilities and intermediate care facilities. The proposed legislation also would increase reimbursement for long-term care services, provided the fees and reimbursement increases are tied together. The commission proposed continuing its work in 2003 " ... to identify funding and structural issues in long-term care and to propose new approaches to financing."

The Plan Development Workgroup for Community-Based Living, comprised of representatives from five state agencies, issued a draft report on October 2, 2002, *Communities, Individuals and Choices: A Roadmap for Meeting Individual Needs in Integrated Settings and Programs*. The Work group plans to complete the report sometime during 2003. The draft includes recommendations on the following.

- Expanding self-directed services, offering individuals budgets that cover the entire range of home and community-based services needed, and permitting the individual to determine which services to purchase.

- Organizing services around the person served, not for provider convenience, and allowing individuals and families to have the option of having one independent person facilitate service integration.

- Creating a statewide, integrated information and referral system that covers all disability-related services.

- Building respect for direct-care workers through a public relations plan, and exploring increasing the educational and training requirements for certain direct-care services.

- Building standards for quality and accountability into the design of services.

Maryland

The Maryland legislature enacted several long-term care measures in 2002 that related to end of life, elder abuse, and nursing homes, and provided funding for a new Medicaid home and community-based waiver program. The state reported progress on providing community services to people with developmental disabilities who had been on waiting lists.

2002 Legislation

In 2002, the legislature established the State Advisory Council on Quality Care at the End of Life. The council is required to monitor trends in the provision of care to state residents with life-limiting illnesses, study the effects of public policies on the provision of care at the end of life, and advise the General Assembly on legislative proposals on this issue. The legislature also:

- Enacted the Financial Crimes Against Vulnerable Adults Act to curb elder abuse, which allows for penalties of up to 15 years in prison, a $10,000 fine, or both, for such crimes.

- Required social workers to provide all Medicaid-covered nursing facility residents with a one-page information sheet that explains the availability of services under the Medicaid home and community-based waiver program and provides referrals to further information.

- Funded the Community Attendant Services and Supports Medicaid waiver program, which the legislature created in 2001, at $10 million in FY 2002. Services include attendant care, assistive technology, environmental adaptations, a personal emergency response system, and occupational and speech therapies.

Developmental Disabilities

The Waiting List Initiative created by the governor and the legislature to reduce the backlog of 5,000 people with developmental disabilities waiting for community services entered its fifth and final year in 2003. Maryland officials estimated that the initiative will have served 5,977 individuals by the end of 2003, with FY 2003 spending on the initiative exceeding $160 million. From FY 2000 to FY 2003, the budget for the Maryland Developmental Disabilities Administration increased by an average of 9 percent annually as a result of the efforts to expand availability of community services and to increase wages of direct service workers.

MASSACHUSETTS

In 2002, Massachusetts continued to expand community services for people with disabilities who were on waiting lists in compliance with the settlement of *Boulet et al. vs. Cellucci et al.* in December 2000. Under the terms of the agreement, the state was to provide residential services to an additional 300 people during FY 2001, using already appropriated funds. During the next five years (FY 2002 to FY 2006), the state said it would seek enough funding to extend community services to almost 2,000 additional people at the rate of 375 to 400 per year. The legislature approved $36.5 million in new funding for FY 2003 to continue implementation of this program.

Planning and Reports

Planning work also continued in 2002 on ways to build on the work of an *Olmstead* advisory group and a steering committee of agency officials from key human services agencies. The steering committee designated an interagency leadership team to draft a plan with the advisory group. On July 31, 2002, the interagency leadership team (representatives of the executive offices of Health and Human Services, Elder Affairs, and Administration and Finance) issued a report, *Enhancing Community-Based Services: Phase One of the Massachusetts Plan.*

The plan included 62 activities to be implemented in FY 2003. Highlights of phase one activities included the following.

- Continuing to target individuals for community placement when such placements were desired and available;

- Educating residents of institutions about the array of available community-based services and their eligibility for such services, and documenting their preferences;

- Requiring all state agencies that offer long-term care to prescreen Medicaid eligible beneficiaries who are seeking nursing home care for the possibility of community care; and

- Improving the availability of accessible and affordable housing.

Workforce

The legislature appropriated $50 million in 2002 to fund a rate add-on for wages and benefits and related employee costs of direct care staff of nursing homes. The state will require each nursing home to document that the funds are spent only on direct care staff by increasing their wages, hours or benefits or by increasing the facility's staff-to-patient ratio. The funds also may be used to improve a facility's recruitment and retention of nursing staff.

End of Life

The legislature also approved a bill that affects hospice care by updating the statutory definition of "hospice program" to reflect the goal of hospice care to meet the physical, emotional and spiritual needs of both the terminally ill patient and his or her family. The legislation also prohibited unlicensed programs from using the words "hospice" or "hospice program" for marketing or other purposes. Finally, the legislation allows licensed hospices to directly operate general inpatient units under their hospice licenses so that a hospice can continue to provide care when its patients have acute episodes instead of having to admit such patients to a hospital or skilled nursing facility.

Nursing Homes

The state enacted a nursing home user fee to be levied on an estimated 8,000 private-pay nursing home residents, which was expected to generate about $145 million. State officials said the state planned to use $130 million from the tax for its share of increased Medicaid reimbursements to nursing homes, with an equal amount coming from federal matching payments. The tax would be $9.60 per day or $3,504 per year per person for October, November and December 2002.

However, incoming Governor Mitt Romney said he wanted to use those funds for other medical expenses for three months. Moreover, the governor proposed cutting $14 million from nursing home rates starting in March 2003 and announced plans to cut an addition $2 million paid to nursing homes to hold beds for those who need temporary hospitalization. State officials said there were 4,231 empty nursing home beds as of February 2003.

MICHIGAN

The long-term care picture in Michigan was clouded in 2002 by continued shortfalls in Michigan's budget, which forced reductions in Medicaid-funded home and community-based services for people with disabilities. The 2002 Legislature enacted a number of measures dealing with end-of-life issues and quality of life in nursing homes.

The Budget

Michigan's fiscal crisis caused then-Governor John Engler to propose saving $11.6 million in the FY 2003 budget by continuing a freeze on enrollment in the state's Medicaid home and community-based waiver program, MIChoice, that had been first imposed in October 2001. The program, which had a cap of 15,000 people, had enrolled only about 11,000 when the freeze was imposed. Individuals and advocacy organizations challenged the state's freeze in March 2002 through a lawsuit, *Eager vs. Engler and Havemen.*

End of Life

The Michigan Legislature addressed a number of end-of-life issues during the 2002 legislative session, including enacting 13 pain management, end-of-life and hospice care bills. Two bills require the state to produce an informational booklet on pain management and a publication on Michigan's Dignified Death Act, both of which are intended for physicians.

The end-of-life legislative package also contained a bill that creates an advisory committee on pain management. The committee is required to develop an integrated approach to understanding and applying pain and symptom management techniques and to develop and encourage the implementation of model core curricula on pain and symptom management.

Nursing Homes

Michigan lawmakers also enacted eight nursing home laws in 2002. Two bills address more consistent inspection and regulation of nursing homes. Other measures call for the development and adoption of clinical process guidelines and more ease and uniformity to resident complain resolution. One bill requires the state to develop criteria to assess the ability of a provider to maintain individuals at the most appropriate level of care, to improve the total quality of care, to increase compliance with the Supreme Court *Olmstead* decision, and to reduce costs for the state's Medicaid program.

Information and Referral

The state launched a new online service in 2002 to help citizens who need long-term care to determine the most appropriate services for them. By providing their zip code online, individuals are linked to long-term care providers in their community. Individuals are asked a series of 29 questions by means of a self-assessment tool to help them assess their ability to function independently in the community and to direct them to services.

MINNESOTA

Minnesota continued its “Aging Initiative” efforts to expand or develop community long-term care services and its efforts to develop a statewide long-term care information and assistance network for people with disabilities. The Legislature enacted a hospice bill of rights in 2002.

Home and Community-Based Services

The state continued work on the long-term care reforms for the elderly (“Aging Initiative”) proposed by the Long-Term Care Task Force in 2001 and partially implemented by the 2001 Legislature. Those legislative actions included $10 million for community services grants to allow counties to expand or develop new services. As of September 2002, some 100 grants- ranging from $20,000 to $250,000-had been awarded for a variety of projects, from caregiver respite and chore programs to transportation initiatives and home modifications.

In February 2002, the Department of Human Services issued a report, *Keeping the Vision*, that details progress on the Aging Initiative. The report described the results of a survey of Minnesota counties in which the counties were asked to assess the adequacy of 27 long-term care support services in their regions. Three areas deemed inadequate by most counties were transportation, in-home respite and caregiver support, and chore services.

Nursing Homes

Another aspect of the 2001 legislative agenda for long-term care was a Planned Closure program for nursing homes. The legislation provided for an application process for the planned closure of nursing home beds. The process allowed monetary incentives to be paid to nursing homes that closed beds under an approved application, as well as limited funding for county costs related to monitoring the closures and assisting in relocation of residents. Between August 1, 2001, when the program went into effect, and January 6, 2003, a total of 1,089 nursing home beds closed statewide. Another 445 beds had been approved but not yet closed.

The 2002 Legislature required counties to pay 20 percent of the costs associated with caring for disabled people in nursing homes who are younger than age 65 and who stay more than 90 days in the facility. The change took effect on January 1, 2003.

End of Life

The Legislature enacted a hospice bill of rights in 2002 that spells out 22 rights, ranging from the right be free of physical or verbal abuse to the right to refuse treatment. Individuals are to be given written information about their rights in advance of receiving hospice care; to receive care and services according to a plan of care, and subject to accepted hospice standards; and to be told in advance about the services to be provided and the charges for services.

The state is authorized to suspend a hospice caregiver’s license if the patient’s rights are violated. The law also splits state statute so that home care providers and hospice providers are no longer grouped together.

Information and Referral

The Minnesota Department of Human Services awarded a grant in 2002 for coordination of a statewide information and assistance network for people of all ages with disabilities or long-term

illnesses. The network will be a link of the state's eight Independent Living Centers, Senior LinkAge Line, and 211, a health and human services telephone information and referral network. The grant awards of $225,000 per year for two years went to the Options Interstate Resource Center for Independent Living in East Grand Forks to set up the system.

In another action to expand long-term care information sources, the Minnesota Board on Aging launched MinnesotaHelp.info. The Web site provides information on community resources for Minnesotans of all ages, in addition to a special on-line tool to help senior citizens find long-term care assistance. The board partnered with the Minnesota Department of Human Services, Greater Twin Cities United Way 211, and First Call Minnesota, which is answering a new 211 cmmunity rsources phone line.

MISSISSIPPI

The major long-term care activity in Mississippi in 2002 was legislative action regarding reimbursement rates for nursing homes and the development of a single point of entry system for Department of Mental Health services. Work also continued in 2002 to meet the goals of the Mississippi Access to Care plan to expand home and community-based services for people with disabilities.

2002 Legislation

The Legislature authorized a joint study committee in 2002 to consider setting uniform reimbursement rates for nursing facilities. The new law permits the state to establish a Medicare Upper Payments Limits Program for nursing facilities. The state would be allowed to assess each nursing facility to finance the program.

The legislation also specifies that a scheduled 5 percent reduction in reimbursement rates for Medicaid providers will not apply to services in nursing facilities or intermediate care facilities. The reductions also will not apply to case management services and home-delivered meal services provided under the home and community-based service program for the elderly and disabled.

Lawmakers also authorized the Department of Mental Health to develop a single point of intake and referral system within its service areas for individuals with mental illness, mental retardation, developmental disabilities, or alcohol or substance abuse.

Planning and Reports

The Mississippi Access to Care (MAC) plan, developed by several human services state agencies and released in 2001, got a further boost for its recommendations from the Governor's Healthcare Commission, which was established in May 2002. One of the commission's recommendations calls for work to continue " ... toward the goals set forth in the Mississippi Access to Care plan and ... the implementation of these goals at the earliest possible time."

The state's Division of Medicaid is the lead agency for overseeing implementation of the plan's recommendations, which have five- to 10-year timelines for attainment. For example, the plan calls for increasing the number of individuals receiving services under the Elderly/Disabled Medicaid home and community-based waiver program by 750 individuals each year over five years (FY 2003 - FY 2007). That program currently is approved to serve up to 10,000 people; if the goal is reached, the total would be 13,750. For the Mental Retardation/Developmentally Disabled waiver program, the goal is to add 1,600 people by FY 2011 to the current caseload of l,700.

On May 17, 2002, the Coalition for Citizens with Disabilities filed a class action complaint on behalf of five nursing facility residents, alleging that the state's policies result in the unnecessary segregation of people with disabilities in nursing homes instead of making home and community-based services available to them.

Missouri

The governor and legislative leaders in Missouri focused on nursing home reform in 2002 and 2003 to improve quality of care for residents. Their recommendations included greater penalties for infractions and more extensive disclosure and reporting requirements, coupled with eased regulations for facilities that provide quality care.

Nursing Homes

In December 2002, Governor Bob Holden called for sweeping reforms in Missouri laws to protect nursing home residents through a proposed Senior Care and Protection Act. His recommendations included the following.

- Toughening the state's neglect statute to make it easier for the Department of Health and Senior Services to bar individuals who have abused, neglected or financially exploited elders from working in the elder care industry.

- Strengthening civil penalties for poor performance.

- Rewarding nursing homes that consistently provide quality care by reducing red tape for them.

- Requiring nursing home executives to certify the quality of care they provide in their facilities.

- Expanding the statute of limitations from 180 days to two years for initiating complaints that a nursing home resident's rights were violated.

In late February 2003, Republican and Democratic legislative leaders joined to outline measures to improve quality of care in nursing homes. The bill that was enacted on April 30 (SB 556) increases penalties for all violations of nursing home care standards, which Missouri lawmakers said was the first penalty increase in more than 20 years. For the most serious violations, nursing homes could face penalties of as much as $10,000 per day. Any administrator who fails to report abuse or neglect that could result in serious injury to a resident can be charged with a Class D felony. The bill also directs that revenue generated by the fines be used for other programs to help elderly people, including the Meals-on-Wheels program and the Nursing Facility Quality of Care Fund.

The bill also requires more thorough background checks of some nursing home employees and gives state regulators greater access to nursing home records and facilities and the authority to suspend the licenses of nursing homes that refuse entry to inspectors. Nursing homes that provide quality care would be subject to fewer inspections.

The state Supreme Court in December 2002 upheld Governor Holden's action in May, cutting almost $21 million in special nursing home grants. The governor's move was part of a package of spending cuts to balance the state's budget. The state constitution allows governors to withhold appropriated money when revenues fall below projections that are used to develop the budget. Nursing homes argued that revenue for their particular appropriation had not fallen short of pro-

jections, but the court held the nursing home grants were part of the state's general revenue, which had fallen short.

Long-Term Care Insurance

The General Assembly substantially amended the Long-Term Care Insurance Act in 2002. The law requires the insurer of a long-term care contract to state clearly in its enrollment materials whether the contract is intended to be tax-qualified and to state in the policy summary whether an inflation protection option is available under the policy. The issuers also must offer a nonforfeiture benefit and provide a written explanation for a denial of coverage within 60 days.

MONTANA

Montana faced budget problems in 2002 that curtailed some home and community-based long-term care services. Work moved forward, however, on addressing work force shortages through the recommendations of a blue-ribbon task force and, with the help of almost $1.4 million in federal grant money, on improving access, housing and transportation for people with disabilities.

The Budget

Reductions to the FY 2003 budget approved by the Legislature in mid-2002 called for less money to fund modifications to homes and other one-time expenditures that assist people to remain in community settings. Other cuts called for reducing the number of Meals-on-Wheels provided to senior citizens, and delayed wage increases for six months for direct care workers who provide Medicaid Personal Assistance services and for providers of home and community-based waiver and home health services. Spending for mental health services also was reduced.

Workforce

A Blue Ribbon Task Force on Health Care Workforce Shortages issued a report on September 26, 2002. The task force was appointed by Governor Judy Martz in October 2001. The report discussed five major issues: Montana's health care climate, educational opportunities, the health care work environment, reimbursement and compensation, and data collection and analysis.

The task force recommended that the governor direct the departments of Public Health and Human Services and Labor and Industry to educate the general public and policymakers about the need for health care workers, about the diverse opportunities available in the field, and about the value and importance of health care workers to the Montana economy and citizens. Task force recommendations also included calling on health care employers to create a culture in which health care staff are valued and have a voice in shaping institutional policy.

Home and Community-Based Services

A class action lawsuit, *Travis D. vs. Eastmont Human Services Center*, was filed in August 1996 in federal court by the Montana Advocacy Program to seek community-based services for people with developmental disabilities who reside in the two state-run residential facilities. Despite sporadic settlement negotiations between the state and the plaintiffs, there was no resolution of the case as of February 2003.

The Department of Public Health and Human Services developed information for the Legislature regarding income-testing for developmental disabilities services. However, in an October 2002 report by the Children, Families, Health and Human Services Interim Committee, the committee said no changes of this nature were sought by the Legislature "at this time." The committee report added, however, that in the face of litigation and budget cuts, "It may be a proposal that warrants further attention."

Grant Initiatives

The state received a $1,385,000 federal Systems Change grant in 2002 to be used by three programs or divisions within the Montana Department of Public Health and Human Services. The Developmental Disabilities Program will ensure that services are funded for an individual based on the person's needs. Service recipients will purchase and pay for their own services from their choice of qualified providers.

With the Montana HomeChoice Coalition, the Addictive and Mental Disorders Division will coordinate the development and use of accessible and affordable housing in four Montana communities. Montana Vocational Rehabilitation will coordinate with the Montana Transportation Partnership and the Western Transportation Institute to develop and implement a coordinated transportation system in two communities. The system will serve as a replicable model for the state.

NEBRASKA

Although budget shortfalls threatened to limit state spending on long-term care services in FY 2003 and FY 2004, the Nebraska Department of Health and Human Services continued to develop a consumer-directed focus for its home and community-based services. The state also was developing a public information campaign about alternatives to nursing homes for people who need long-term care services.

The Budget

In January 2003, Governor Mike Johanns proposed cutting the state's Medicaid budget by $15 million over two years (July 1, 2003 through June 30, 2005), resulting in the loss of an additional $21 million in federal matching payments. In 2002, the Legislature approved a one-year, half-cent sales tax increase, a one-year 2.2 percent income tax increase, and a two-year 30-cent per pack cigarette tax increase.

Grant Initiatives

The state received a $2 million federal Real Choice Systems Change grant in 2001, which it planned to use to implement a consumer-directed model of services across all populations of people with disabilities. To develop a plan, the state held a two-day consumer-directed services meeting in April 2002. Participants represented various consumer populations, advocates, providers and public agencies.

Eight town hall meetings also were held through the state in the fall of 2002. The purpose of the town hall meetings was to share information, determine the make-up of consumer-directed services, and identify barriers to the provision of consumer-directed services. A consumer task force and steering committee are providing direction and guidance to the project. The Nebraska Department of Health and Human Services is responsible for carrying out and sustaining project initiatives.

Nebraska also received a $600,000 Systems Change grant to develop a communication/marketing campaign to inform the public about long-term care options, particularly alternatives to nursing facility placement. Part of the campaign involves using Area Agencies on Aging to enlist nursing home staff to identify possible candidates who could move into the community. Specially trained ombudsmen volunteers also will help identify candidates and facilitate successful transitions.

Workforce

The Legislature in 2002 increased to 40 hours the competency course required of medication aides in assisted living facilities; it now is the same as for medication aides in nursing homes and in intermediate care facilities for the mentally retarded. The lawmakers also made changes to provisions relating to nursing home administration, including eliminating a required state examination for licensure as a nursing home director and providing for a range of licensure fees.

NEVADA

The work of four strategic planning groups was completed in 2002, resulting in a comprehensive range of recommendations for expanding access to home and community-based long-term care services for Nevada citizens. The final plans established goals both for the near-term and for the next 10 years.

Planning and Reports

Assembly Bill 513 in the 71st legislative session authorized and funded four strategic plan studies to help ensure the availability of community services for vulnerable populations: people with disabilities, senior services, provider rates, and rural health services. The four plans were completed and released in the fall of 2002.

The Nevada Strategic Plan for People with Disabilities included the following recommendations.

- The adoption of a 211 access line/No Wrong Door program, to enable people with disabilities to access information, services and supports;
- The establishment of an Office of Disability Services within the Department of Human Resources;
- Adequate and continued funding to reduce waiting lists and provide necessary waivers;
- Involvement of people with disabilities in policy development and program monitoring; and
- Ongoing collection of data.

The Senior Services Strategic Plan, entitled *Act Now or Pay Later: Ten-Year Targets to Preserve the Health and Independence of Nevada Seniors Health*, contained six over-arching strategies, listed below.

- An information campaign to increase the public's awareness of aging and to educate and empower individuals and their informal support systems to create a positive climate for aging in Nevada.
- A combination of incentives, regulation and advocacy to encourage private-sector initiatives in such areas as development of appropriate housing and transportation services and long-term care insurance.
- A single point of entry system for easier access to information about assistance, care planning and other essential services.
- Changes in reimbursement rates and development of career incentives to encourage and stimulate the recruitment and retention of direct-care workers.
- Increased investment in home and community-based services by accelerating extension of such services to those people who are above the Medicaid income level who are at risk for nursing home care but prefer to remain at home.
- New and timely data collection and analysis.

The strategic plan for senior citizens contains specific goals and target dates by which the goals should be realized. For example, one goal is "More Nevada seniors get the benefits, services, and support they need." The target in the plan is that, by June 30, 2010, " ... 85,000 Nevada seniors and their family members use a single point of entry system to access information and referral for the array of available services."

The Budget

Governor Kenny Guinn proposed raising taxes on businesses, services, cigarettes and liquor to pay for expanding needs and some expanded services. Included among the latter was his plan to increase spending to improve mental health services by about $47 million in FY 2004.

New Hampshire

New Hampshire took several actions in 2002 to improve access to services for people with developmental disabilities (DD) and to place more control in the hands of families who are caring for children with DD. The legislature also addressed nursing home liability issues, assisted living regulation and elder abuse issues.

Developmental Disabilities

In December 2002, New Hampshire became the first state in the nation to receive a federal waiver allowing the state to give families greater control over support services for their children with developmental disabilities. The In-Home Support Program, scheduled to begin March 2003, will provide 200 families with supports and services, such as personal care, respite, environmental and vehicle modifications and service coordination.

Each family's budget will differ, depending on the needs of the child and the family, up to a maximum of $20,000 per year per family. The families will be able to choose which services and providers they want to use. A support broker and a financial management service will assist families and individuals with the program and with handling payroll tasks. The program is under the U.S. Department of Health and Human Services' new Independence Plus initiative.

In a related development, the legislature appropriated $5 million in FY 2002-2003 to serve developmentally disabled people on the waiting list for home and community-based services and $3 million for people with acquired brain disorders. In-coming Governor Craig Benson earmarked an additional $3 million in each year of the next biennium to serve people with developmental disabilities who were on waiting lists.

The situation regarding waiting lists for people with developmental disabilities or acquired brain disorders had resulted in a lawsuit (*Cumming vs. Shaheen)* by an advocacy group (Disability Rights Center), and a class action lawsuit (*Bryson vs. Shumway)* on behalf of 42 adults with acquired brain disorder in nursing homes who are on Medicaid waiver waiting lists.

Planning and Reports

The legislature also established a legislative committee in 2002 to study the development of home and community-based long-term care supports for the elderly and adults with disabilities. The committee must solicit such information from the Department of Health and Human Services, service providers and consumers.

Nursing Homes

The General Court also focused on nursing home liability issues during the 2002 legislative session. The lawmakers established rules for discovery and immunity related to quality assurance programs. The legislation provides that the records of a nursing home or community mental health program's quality assurance program will be discoverable in either of the following cases.

> 1) A judicial or administrative proceeding brought by a nursing home/community mental health program, its quality assurance program, or its board of directors, to revoke or restrict the license or certification of a staff member; or

2) A proceeding alleging repetitive malicious action and personal injury brought against a staff member.

Assisted Living

The state was working on new regulations regarding assisted living facilities in 2002. Lawmakers had enacted a bill that year that established standards for disclosure of information to consumers of costs and services provided by assisted living residences and housing for older people.

Elder Abuse

State lawmakers also enacted two elder abuse laws: one defines penalties for Class A and Class B felonies associated with neglect of elderly, disabled or impaired adults. The other law adds financial exploitation to the offenses that make an individual eligible for adult protective services.

New Jersey

New Jersey expanded opportunities for in-home and community living for people with disabilities in 2002 by increasing assisted living availability and restructuring services for people with developmental disabilities to generate additional funds for such services. The Legislature addressed the issue of information for consumers about the home care workers they employ.

Assisted Living

The state received waivers from the federal government to use Medicaid funding to pay for slots for low-income senior citizens and people with disabilities in assisted living. In January 2002, all 1,500 approved waiver slots for assisted living were filled. Increased state funding of $2.9 million then created an additional 375 assisted living slots, and by the end of the year, 1,875 elderly and disabled people were living in assisted living facilities.

Developmental Disabilities

New Jersey also began a program in 2002 to make broad changes to the state's system of services for people with developmental disabilities. The goal is to shift the state's focus away from developing group homes for this population to providing more in-home services. The state proposed to maximize revenues that could be reinvested in expanded services by:

- Requiring a determination of Medicaid eligibility prior to services being delivered. The state had not been requiring people to be Medicaid eligible prior to receiving services, and therefore was able to claim only 33 percent of the available 50 percent of federal reimbursement. With the change, 50 percent of the cost would be reimbursed from federal funds.

- Applying for an enhanced Community Care Waiver to encompass services to families living at home, including personal care, respite care and assistive devices. Since those services were previously 100 percent funded by the state, New Jersey expected to receive $35 million from a 50 percent match from the federal government.

- Seeking a higher percentage of individual Supplemental Security Income (SSI) contributions for residential services provided the state to more closely match the national average. New Jersey takes 47 percent of an individual's SSI payment toward the cost of care in a residential placement, compared to other states that require 72 percent to 88 percent. The increase could generate an additional $5 million to $10 million annually.

The FY 2003 budget provided $27 million in new funding to improve services to individuals in the state's seven development centers. Increased funding led to the hiring of 750 additional direct care staff for the centers and increased placement of center residents into community homes.

Workforce

The Legislature passed a bill requiring home health agencies and home care service firms to provide patients with information about their employees' background and training in advance of or at the time of their initial visit. Whenever caring for a patient, home health care workers must wear identification tags containing their name and title and, eventually, a photograph. The law also requires that patients receive a copy of the most current edition of the *Consumer Guide to Homemaker-Home Health Aides* published by the New Jersey Board of Nursing.

Planning and Reports

The Governor's Office of Policy and Planning convened an *Olmstead* Stakeholders' Task Force, which was to set forth proposals to guide the state's action during the next five years. Key issues facing the group included 1) identifying ways to move beyond the group home model that is central in developmental disabilities services, and 2) developing strategies to prepare individuals and their families for community placement.

New Mexico

The extensive waiting lists for home and community-based services in New Mexico have caused legislators to propose the creation of task forces to consider expanded community options for people with disabilities.

Home and Community-Based Services

A lawsuit (*Lewis vs. New Mexico Department of Health)* filed in January 1999 by the state's protection and advocacy agency is in federal court. It was filed on behalf of 3,000 individuals with developmental disabilities in nursing facilities or in ICF/MR facilities who are on Medicaid waiver waiting lists for community services or who would benefit from waiver services. In 2002, the state's home and community-based services (HCBS) waiver program for people with developmental disabilities had an approved cap of 3,200, was serving about 2,300 people, and had a waiting list of about 2,600 individuals. The HCBS waiver program for the elderly and disabled had a cap of 1,950 people, was serving 1,500, and had a waiting list of about 2,500.

Planning and Reports

The Legislature approved several measures in 2002 that requested studies of various aspects of the state's long-term care system. One measure requested the Governor's Committee on Concerns of the Handicapped to lead a task force to develop a comprehensive and coordinated state plan in response to the *Olmstead* decision. The Human Services Department and the Health Department were to participate in the task force and were to report to the Legislature on an assessment of people currently in institutional settings in the state and their ability to live in the community instead.

The Legislature also created a Medicaid Reform Committee in 2002 that was charged with reviewing the program's services, delivery, funding and policy. Composed of 12 legislators and 18 public advisory members, the committee held 21 full-day meetings during the year. The committee considered almost 100 short- and long-term cost-cutting strategies, and delivered its report in December 2002.

In regard to long-term care services, the committee said that reconfiguring the long-term care delivery system includes emphasizing home and community-based services that are " ... generally more favorable to the patient and less costly than institutional care." The committee recommended that a cost-benefit analysis be conducted of the Medicaid personal care option with an evaluation of consumer-directed versus consumer-delegated care. Another committee recommendation called for expansion of the PACE program to an urban area beyond the current Albuquerque model and consolidation into one cabinet-level agency of all the long-term care services provided by the Department of Health; Children, Youth and Families Department; Human Services Department; and the State Agency on Aging.

Legislators also requested a study by the Long-Term Care Regulatory Quality Cabinet of acuity-based staffing in nursing homes.

New York

Housing for the mentally ill became a major long-term care issue in New York in 2002 as a result of newspaper stories about poor housing and services in adult homes for this population. The governor and state agency officials took action on a number of fronts to improve community-based services for people with mental illness. The state also began moving in 2002 to considerably increase the number of people with mental retardation and developmental disabilities who would be eligible for home and community-based services.

Mental Health

Governor George Pataki in January 2003 proposed spending at least $80 million on housing and services for residents of adult homes for the mentally ill to replace privately run adult homes, which currently house about 15,000 mentally ill people in the state. In his FY 2004 budget, the governor proposed creating 2,000 units of housing in the immediate future with several thousand additional units in future years. He also proposed continuing to reduce the size of the state psychiatric system and to use the money from closing several facilities to improve local mental health services.

The plan calls for 1) special evaluations of adult home residents to determine whether they can be moved to smaller facilities, and 2) hiring nurses and social workers to improve medication practices and supervision of the residents. A special administration task force, established in May 2002 to review the existing system after a series of newspaper reports detailed widespread problems, had recommended the creation of 6,000 housing units.

The work group's primary focus had been on resident assessments, resident rights, case management, medication management, personal care, coordination of services, and alternative housing options. The state health commissioner and other state agencies announced a series of actions in November 2002, including clinical, psychiatric and functional assessments by health and mental health care providers, improved case management and coordination, enhanced medication management, improved social and recreational services, and increased advocacy and legal support.

Home and Community-Based Services

In August 2002, the state received federal approval for an amendment to its Medicaid home and community-based services (HCBS) waiver program for individuals with mental retardation and developmental disabilities. The action authorized $135 million over three years to support the NYS-CARES program, which is the largest waiver program for this population in the country. Enrollment will be increased by 12 percent to 15 percent to a total of more than 51,000 people within three years.

2002 Legislation

The Legislature passed bills in 2002 providing a tax credit for consumers who purchase long-term care insurance, allowing hospice programs to offer palliative care, and appropriating $25 million to plan and implement a program of expanded in-home, case management and ancillary community services for the elderly.

Lawmakers also created the Nursing Home Quality Improvement Demonstration Program to improve the quality of care for nursing home residents through an increase of direct care staff. The

state also sought to expand and improve the direct care work force through quality improvement projects funded by the state. The state issued requests for proposals for projects that would increase direct care staff, increase training and education, and decrease staff turnover or other efforts at recruitment and retention.

Lawmakers established a task force, the Most Integrated Setting Council, in 2002 to develop and oversee the implementation within one year of a comprehensive, statewide plan for providing services to people of all ages with disabilities in the most integrated setting possible. The legislation requires the state to review existing funding sources for community-based care to increase availability of these services and to analyze ways to organize varied funding streams into a coherent system.

The measure also mandates development of a single assessment process, implemented by one community-based agency using a uniform assessment tool. The council also must contract with an independent organization to conduct an evaluation of the council's plan, to be completed within three years.

North Carolina

In 2002, North Carolina reviewed its programs and services for people with mental illness or developmental disabilities to determine how to better provide community services to those with the most urgent needs. The state also received federal grant money for programs designed to increase consumer choice in services and supports.

Planning and Reports

In October 2002, the North Carolina Department of Health and Human Services published *State Plan 2002: Blueprint for Change*, a major plan to reform the state's system for mental health, developmental disabilities and substance abuse. The target population covered by the plan includes adults and children with mental illness, people with developmental disabilities, and people with substance abuse problems. The document emphasizes eight core functions: screenings, assessment, referral, emergency services, service coordination, consultation, education and prevention.

In 2002, the state was spending more than $1.8 billion annually to provide mental health, developmental disabilities and substance abuse services to more than 300,000 people. Under the plan, system resources will be targeted to those most in need. Priority groups will include people with most urgent needs, people from racial or ethnic minorities with service/support needs, and people with more than one disorder.

The plan proposes focusing more services in local communities rather than in centralized state facilities. A key element of the plan is the local business plan. A local managing entity, such as an area program or county government, will manage the services. The plan also calls for a statewide system contractor to provide referral, crisis hotline services and utilization management.

Adult Day Care

The Legislature in 2002 directed the Department of Health and Human Services to review and report on staffing requirements of adult day care programs and adult day health programs. The bill also decreases the maximum monthly reimbursement rate for residents in adult care home facilities from $1,120 to $1,091, effective October 1, 2002.

Grant Initiatives

The state received two federal Systems Change grants totaling about $1.3 million in 2002, which the state planned to use to connect many of the initiatives already under way to increase options for consumer choice, service, support and self-direction. The Department of Health and Human Services planned to conduct an assessment of state fiscal and regulatory policies, with a view toward initiating statutory and rule changes. The state agency intended to develop and conduct training and technical assistance with agency-based and independent providers to encourage consumer-directed practices. Demonstration models will be established in three communities to increase consumer leadership in local reform efforts.

NORTH DAKOTA

A major Medicaid home and community-based services program for elderly and disabled people was the focus of both budget-cutting actions in FY 2002 and legislative revisions to the state's income and asset tests in the spring of 2003. The state also began a progam in 2002 that provides nursing homes with monetary incentives to close beds.

The Budget

In his proposed budget for FY 2003-05, Governor John Hoeven recommended increasing funding for home and community-based services (HCBS) for elderly and disabled people by $5.4 million, but by mid-April 2003, the House had included a $2.6 million increase while the Senate was recommending a $1 million increase. The state had imposed a freeze in 2002 on new clients for the Medicaid Service Payments for Elderly and Disabled (SPED) waiver program, which had a caseload of about 1,700 at the time of the freeze and about 200 people on a waiting list for services. In an attempt to tighten financial eligibility requirements for the program to save money, the state Senate in the spring of 2003 lowered the asset requirement for eligibility from $50,000 to $25,000. The House restored the $50,000 asset test, but imposed a requirement that people with assets of between $25,000 and $50,000 would have to pay for services on a higher sliding scale, which became the final version of the legislation. Fees also vary depending on a recipient's income.

The FY 2001-2003 biennium appropriation for community-based developmentally disabled services included $164 million for residential and day service providers and family supports and $9 million for supportive services provided by the eight regional human service centers. In FY 2002, almost 2,000 adults and children with developmental disabilities received residential services. About 1,100 people of that total receive supports in their homes, apartments or family foster care homes. State general fund support for services for people with developmental disabilities totaled $53.7 million in FY 2001-2003.

Planning and Reports

The state received a $900,000 federal Systems Change grant in September 2002. Administered by the Governor's *Olmstead* Commission, the grant will help the state evaluate and implement ways of effectively delivering health and human services in urban and rural counties. Special emphasis will be placed on enhancing home and community-based services for people with disabilities. A total of 20 focus group sessions were conducted by the *Olmstead* Commission around the state (two in each of the eight regions of the state and one session on each of the four Indian reservations).

Nursing Homes

In 2001, the Legislature enacted the Nursing Facility Bed Reduction Incentive Program and appropriated $4 million from the health care trust fund to provide incentives to nursing facilities to reduce licensed bed capacity. Through September 2002, the Department of Human Services had paid $3.2 million to nursing facilities to eliminate 270 beds. North Dakota ranked first among the states in terms of nursing home residents per person age 65 and older in 2001; the state also had the third highest nursing home occupancy rate in the country that year. However, the average number of people receiving Medicaid-funded nursing home services in North Dakota decreased from a monthly average of 3,869 in FY 1998 to 3,730 in FY 2002.

Ohio

In January 2003, Ohio officials estimated the state's budget gap at $720 million. Although some home and community-based services for people with disabilities were largely spared from budget cuts in the FY 2003 budget, the state's continuing fiscal problems led to spending reduction proposals for these programs in the FY 2004 budget.

The Budget

When a budget balancing plan was enacted in mid-2002 that reduced state spending by $375 milllion for FY 2003, programs for senior citizens and people with disabilities mainly escaped the budget axe. Funding for the Medicaid home and community-based waiver program, PASSPORT, and the Alzheimer's Respite program were exempted from agency-wide cuts. However, the Department of Mental Health took a 1.5 percent cut, and the budget of the Department of Mental Retardation took a 7.5 percent reduction. (Most state agency budgets were reduced by 15 percent.) Appropriations for FY 2002-03 included the following.

- Adding 1,300 slots in FY 2002 and another 1,600 slots in FY 2003 to PASSPORT, which had 24,000 slots before the additions.

- Adding 500 slots in both FY 2002 and FY 2003 to the Home Care Waiver Program, which provides care to disabled people under age 60 or people of any age with a chronic, unstable condition who require nursing care. The program had 8,200 slots before the additions.

- Adding 500 slots in both FY 2002 and FY 2003 to the Individuals Options Waiver program, which serves people who otherwise would require institutionalization in an ICF/MR facility.

As budget problems continued in 2003, however, even the PASSPORT program was not spared from spending reductions. In March 2003, Governor Bob Taft cut $1.8 million from PASSPORT, resulting in a 20 percent reduction in new monthly enrollments statewide. The governor also proposed freezing Medicaid nursing home reimbursement rates for FY 2004.

Nursing Homes

Ohio lawmakers tackled nursing home liability issues during the 2002 legislative session. The bill that was enacted in August amends various definitions, including tort action and medical claim. The following also must be considered when determining punitive damage awards against a nursing home or residential facility:

- The ability of a facility to pay the award of punitive or exemplary damages based on the facility's assets, income and net worth;

- Whether the amount of punitive or exemplary damages is sufficient to deter future tortious conduct; and

- The financial ability of a facility, both currently and in the future, to provide accommodations, personal care services and skilled nursing care.

The law also prohibits the results of nursing home inspections or investigations or the results of any survey of a nursing facility from being used in court. However, any statement of deficiencies and all findings and deficiencies cited in the statement that result from the survey may be used in a criminal investigation or prosecution.

Developmental Disabilities

Ohio received approval from the federal government in June 2002 to provide Medicaid coverage for home-based care to an additional 2,000 people with mental retardation and developmental disabilities. The expansion was the third increase in available slots since January 2000, bringing the total increase during that period to about 4,500 slots.

In December, the state received federal approval for its new Level One Waiver, which would allow an additional 6,000 people with mental retardation and developmental disabilities to receive in-home care. The 6,000 slots will phase in over three years. Ohio developed the Level One Waiver as part of a redesign of its Medicaid program with services such as respite and home modifications designed to help families keep a person with MR/DD at home.

Legislation was enacted in December 2002 to give the state more authority to regulate homes for the mentally retarded if residents are abused, neglected or harmed. The bill does away with lifetime licenses for private homes and replaces them with permits that expire every one to three years. The changes are intended to help state officials focus their manpower on problem facilities, which would be inspected every year until they improve.

Oklahoma

Although budget shortfalls caused reductions in spending for many long-term care services in Oklahoma in 2002, the state moved forward with a long-term care planning effort that will identify gaps in existing programs and services and recommend options for expanding home and community-based options for people with disabilities. The Legislature also allowed flexible staff scheduling for nursing homes that meet certain staffing standards and addressed elder abuse issues.

The Budget

Faced with severe budget cuts, the Oklahoma Health Care Authority cut services and benefits to thousands of Medicaid recipients for FY 2003. The cuts, which began January 1, 2003, involved home health services and nursing home reimbursements, among others. Additional cuts included the elimination of payments for behavioral and psychological health services in nursing homes. An annual cost-of-living rate adjustment for nursing homes (24 cents per resident per day) was delayed.

Planning and Reports

Lawmakers established the *Olmstead* Strategic Planning Work Group in 2002 to develop a comprehensive strategic plan for providing services to people with disabilities in the most integrated setting. The lead state agencies for the effort are the Office of the Attorney General, the Department of Human Services, the Health Care Authority and the Department of Mental Health. A number of other state agencies also are involved, as are private organizations such as the Centers for Independent Living, the Developmental Disability Council, the Brain Injury Association, and the Oklahoma Mental Health Consumer Council.

The work group will review the state's service delivery system for services for people with disabilities; review existing statutes, policies, programs and funding sources that affect these populations; and identify gaps and barriers in programs and services. The committee is expected to report its findings and recommendations to the Legislature and governor by July 15, 2003, and each July 15 thereafter, as necessary, until completion of the strategic plan.

Workforce

In 2002, the Legislature amended nursing home staffing standards for direct care and 24-hour staffing levels. The bill allows nursing homes and intermediate care facilities to vary the starting times for their eight-hour shifts by one hour before or after the times designated in existing statute without overlapping shifts. Facilities that have complied with shift-based staffing ratios for at least three months are allowed to implement flexible staff scheduling. With the flexible schedule, facilities must maintain a direct care staff-to-resident ratio of 2.86 hours per day per occupied bed; one direct care staff person on duty for every 16 residents at all times; and at least two direct care staff on duty and awake at all times.

Elder Abuse

For the second year in a row, the Legislature addressed the issue of elder abuse. Lawmakers authorized the court to appoint a guardian *ad litem* for a vulnerable adult when a petition is filed alleging that the person has been abused, neglected, exploited or disabled.

Oregon

The top issue for long-term care programs and services in Oregon in 2002 and 2003 was lack of funding as the state grappled with major budget deficits. Still, work continued on developing long-range plans for future services for senior citizens and people with disabilities through the efforts of a task force created in 2001.

The Budget

Oregon voters failed to approve a January 2003 ballot measure that proposed a state income-tax increase to eliminate the state's $482 million deficit. The 2002 legislature had directed the termination of a self-directed support services home and community-based waiver program for people with developmental disabilities if the referendum did not pass. The program was created to respond to the settlement of the *Staley vs. Kitzhaber* lawsuit in December 2000, which called for the state to increase funding for community services for people with developmental disabilities through 2007. The number of people receiving support services was to increase by 4,600 during the agreement's six-year period. In August 2002, the Oregon Advocacy Center warned the state that it would return to court if budget cutbacks caused the state to backtrack on the settlement of the lawsuit.

After the referendum failed, however, the legislature rebalanced the budget in a bill signed by the governor on March 4. That bill restored some of the funds cut or planned to be cut by the Department of Human Services (DHS) through the end of fiscal year 2003. The legislature restored $7.4 million of $11.9 million in planned cuts for the *Staley* settlement. DHS had frozen enrollments on February 1, 2003. Department officials said they anticipated being able to keep the program open through the end of the biennium (June 30) by limiting the growth of new enrollments. In early March, they said they were in negotiations with the *Staley* plaintiffs " ... on possible revisions to the agreement due to the budget crisis."

The outlook for long-term care services remained bleak, however, as budget shortfalls for FY 2003-2005 continued to threaten many programs and services. DHS estimated that major reductions in the governor's proposed budget to programs for people with developmental disabilities included " ... eliminating all non-residential services, impacting 5,500 people who were covered by the *Staley* setlement agreement." The proposed budget also eliminated cost of living adjustments for all long-term care providers, reducing provider reimbursement rates for nursing homes and assisted living facilities, and eliminating the Oregon Project Independence Program.

Planning and Reports

The Governor's Task Force on the Future of Services to Seniors and People with Disabilities, which had been created by executive order on June 30, 2001, issued an initial report in September 2002. The task force was charged with developing a long-range plan on the future of services to senior citizens and people with disabilities and recommending legislative action and levels of funds needed to implement the plan.

The task force said all Oregonians, regardless of their incomes, needed to begin taking " ... personal responsibility for making healthy behavior choices and for planning and preparing for … possible long-term care needs." The group identified eight overarching recommendations that required attention and implementation within the next year. The following were among the recommendations.

- Developing measures to determine whether services in various settings achieve outcomes, promote quality of life and are cost-effective.

- Encouraging personal responsibility by educating Oregonians about the need to engage in healthy lifestyles and planning for future long-term needs.

- Providing information and education on long-term care needs, services and planning, including conducting a public action campaign and expanding education of consumers and families about various long-term care options.

- Increasing system capacity by developing the long-term care work force and providing family caregiver supports.

- Maintaining a safety net for those who cannot afford to pay for their care.

Pennsylvania

The Budget

The FY 2002-2003 budget included an $18.1 million increase in total funds to provide home and community-based services (HCBS) for an additional 1,175 people with mental retardation, $13.4 million in total funds for HCBS services for an additional 479 persons with disabilies and $7.1 million in state funds for community oversight of mental retardation services. The budget also allocated $56.4 million in tobacco settlement funds to provide HCBS for 4,393 older Pennsylvanians.

Four lawsuits have been filed in recent years in Pennsylvania regarding people on waiting lists for Medicaid community services. Settlement of the lawsuit *Delong et al. vs. Houstoun* in April 2002 resulted in the state agreeing to seek funding from the General Assembly to serve 3,382 people in the Person/Family-Directed Supports Medicaid waiver program. Another lawsuit, *Sabree et al. vs. Houstoun*, was dismissed on January 16, 2003. The lawsuit alleged that Pennsylvania had not furnished ICF/MR services to eligible individuals with reasonable promptness. The plaintiffs were people with mental retardation.

Information and Referral

The Office of Social Programs (OSP) of the Pennsylvania Department of Public Welfare began developing a plan to establish regional single points of entry called Community Resource Centers for Persons with Disabilities. These entry points would be responsible for eligibility assessment, service plan development and monitoring, emergency response, and nursing home transition services. The OSP issued a request for bids for the proposed system in October 2002.

Grant Initiatives

A nursing home transition project-called PATH-has been operating in Pennsylvania since July 2001 with funding from the federal Centers for Medicare and Medicaid. The project involves the Pennsylvania Intra-Governmental Council on Long-Term Care; the departments of Aging, Public Welfare, and Health; and consumers. A progress report issued in November 2002 noted that 90 referrals had been received in the 11 months of project operation, with 25 people successfully making the transition from a nursing home to the community.

Workforce

The Pennsylvania Department of Public Welfare initiated a new set of regulations for the nearly 1,800 personal care homes in late 2002. The new rules limit those who can dispense medications, increase training and certification requirements for administrators and staff, and restrict the work that employees younger than age 18 could perform.

RHODE ISLAND

The Rhode Island General Assembly took several actions in 2002 that affect licensing of the assisted living industry and reim- bursement rates for nursing homes. Using federal grant funds, the state also continued efforts to move more people out of nursing homes who could benefit from living in a community setting.

Assisted Living

The General Assembly amended the Assisted Living Resident Licensing Act in 2002. The bill specifies the level of care that is appropriate for assisted living residents. The legislation also requires criminal background checks for owners, operators and administrators of these facilities. (The state previously required background checks only for direct care staff, unlicensed staff and home health care workers.) Residences also are required to implement and maintain a documented, ongoing quality assurance program.

In 2002, the licensing category of resident care and assisted living facilities was changed to "assisted living residence." The rules define "assisted living residence" as a "publicly or privately operated residence that provides directly or indirectly by means of contracts or arrangements personal assistance to meet the resident's changing needs and preferences, lodging, and meals to two or more adults." Other changes included a new section that adds to the contents of a written agreement in the resident rights section and increases training requirements for administrators.

Nursing Homes

The legislature also revoked the $3.71 per day increase in Medicaid reimbursement for nursing facilities that had been enacted in 2001. Lawmakers also enacted a bill that eliminates the requirement that a licensed residential care/assisted living facility must participate in the Medicaid program before it can seek nursing facility licensure.

The state received a $600,000 federal Systems Change grant in 2002 to assist in moving people from nursing homes to the community. Rhode Island officials estimated that about 400 residents of institutions would likely benefit from discharge to a community setting if their needs could be met. The state planned to use the grant to bring in services coordinators from the elderly service network and independent living centers to aid in the transition activities and for referral and communications support. The project, which will build on the state's 1998 "Date Certain" Nursing Home Transition Program, will be directed and monitored by an oversight committee composed of consumers, state agency representatives, private agencies and service providers.

SOUTH CAROLINA

Long-term care actions in South Carolina included gubernatorial and legislative recommendations for reorganizing state human services agencies and legislative measures that affect nursing homes and other community providers. Another long-term care activity involved using federal grant money to develop a program to move some nursing home residents to the community.

The Budget

Due to the state's fiscal problems, the South Carolina Department of Health and Human Services notified Medicaid providers that as of January 1, 2003, the department would implement Medicaid service rate and program reductions. The State Budget and Control Board had imposed 5 percent reductions in the FY 2003 budget on all state agencies.

State Administrative Agencies

On December 13, 2002, in-coming Governor Mark Sanford appointed a 21-member task force to identify reform initiatives to improve the operation of state and local government in South Carolina. The task force report, issued on January 21, 2003, included a recommendation for making three health and human services agencies into cabinet agencies. The three are the Department of Health and Environmental Control, the Department of Mental Health and the Department of Disabilities and Special Needs.

The Legislative Audit Council also released a report in January 2003 on all eight of the state's health and human services agencies. The report recommended that the General Assembly authorize a single cabinet secretary appointed by the governor to oversee all health and human services agencies. The report noted that senior and long-term care programs currently were housed in the Department of Health and Human Services, the Department of Social Services, and the Department of Mental Health. The council proposed placing all these programs in a newly created, freestanding agency specializing in senior and long-term care programs and services.

Nursing Homes

During the 2002 legislative session, lawmakers passed a resolution requiring nursing homes to pay a nursing home franchise fee between February 1, 2002, and June 30, 2003, to maintain their licenses from the Department of Health and Environmental Control. Lawmakers also enacted a bill in 2002 requiring criminal background checks for nursing homes, day care facilities for adults, home health agencies and community residential care facilities.

Grant Initiatives

South Carolina received a $600,000 federal Systems Change grant in 2002 to identify and move nursing home residents who want to reside in the community. The Department of Mental Health and the Department of Disabilities and Special Needs are developing a comprehensive assessment instrument for targeting appropriate transition clients and hoped to assist about 20 residents with community relocation. Another component of the project involved expanding housing partnerships and developing a housing database.

South Dakota

The Budget

In his budget message to the 78th Legislative Session, Governor M. Michael Rounds said his budget reflected his commitment to key segments of the population, which included the "very young and the very old." He called for increased funding for the state's share of federal health care programs, pointing out that the number of disabled citizens, elderly and children enrolled in the Medicaid program "continues to grow."

The governor also proposed to increase funding to address expansion of services for people with developmental disabilities, including slight increases in funding to reduce waiting lists for services. However, Governor Rounds recommended a $13.6 million decrease in funds for the Adult Services and Aging Division, the largest portion of which was a reduction of intergovernmental transfer funds of $19 million (offset by increases in several other programs). The governor's budget proposals included a $1.1 million decrease in clients for personal care, homemaker services, and in-home nursing services under the Adult Services and Aging Division.

Grant Initiatives

The U.S. Department of Health and Human Services awarded a $100,000 grant to the South Dakota Division on Developmental Disabilities of the Department of Human Services. The award was to be used to expand family support services in the state to individuals with developmental disabilities, living in rural and reservation areas, who want to remain in their home communities. The program had been providing services and supports to people caring for a family member with a developmental disability under age 22 and living in the home. The grant will enable the state to expand the availability of these services to include individuals over age 21 with a developmental disability who live in the home in rural areas of the state.

Tennessee

Mental health and mental retardation programs and services were the focus of state efforts in Tennessee to expand community options, particularly housing. The state's housing activities were aided by a $1.8 million federal grant for its Creating Homes Initiative to provide additional housing options for people with mental illness.

The Budget

In explaining his highest priorities as he took office, newly elected Governor Phil Bredesen said his priorities for senior citizens included enforcing regulations to ensure quality and safety of nursing homes. He said the state should " ... punish poor nursing home operators while being careful not to overburden responsible operators who provide quality care." He also proposed expanding home health care opportunities for more aging Tennesseans and expanding home and community-based care initiatives.

Although the governor imposed 7.5 percent budget cuts on most state operations, he spared the state's mental retardation agency. The Mental Retardation Division requested a minimum of $14 million in new funds to comply with court orders. The Arlington Developmental Center in Memphis was under court order to move residents into community homes. However, the division also was under a Department of Justice moratorium on moving any additional residents because the community homes were judged to be inadequate.

Two separate class action complaints (*Brown vs. Tennessee Department of Mental Health and Developmental Disabilities* and *People First of Tennessee vs. Neal et al.*), filed in July 2000 and March 2001, respectively, have been consolidated. The consolidated complaint was scheduled for trial in May 2003. About 2,000 people with developmental disabilities were waiting for home and community-based waiver services.

Mental Health

The Department of Mental Health and Developmental Disabilities announced in 2002 that it was meeting its goals under the Creating Homes Initiative (CHI), which sought to provide about 2,000 permanent housing options for people with mental illness. The agency said that, as of October 2002, funding had been secured for 2,349 new permanent housing options, with more than 1,700 already online. The housing options include home ownership; supervised group housing with 24-hour, on-site care; partially supervised group housing; and private-public market rental housing.

CHI is a grassroots, local community, multi-agency collaboration operated by the Department's Office of Housing Planning and Development. The project received a $1.8 million Systems Change grant from the federal government in 2002 to hire four consumer housing specialists in targeted communities and to develop a housing resource website. The project also involves developing an anti-stigma mass media campaign about mental illness.

Texas

Considerable work went on in Texas in 2002 to provide community options for people in nursing homes, to allow more people with disabilities to manage their own care through consumer-directed programs, and to test new models for long-term care systems change. Yet, large waiting lists for home and community-based services continued to challenge the state to expand its efforts on behalf of people with disabilities.

Consumer Direction

In October 2002, the federal government approved Texas' plan to allow disabled people to use vouchers to obtain services in the Community-Based Alternatives and STAR+PLUS programs. The new program allows participants to employ their own attendants and have some flexibility in setting wage rates. Similar approvals had been obtained in 2001 for the Community Living Assistance and Supports Services program, the Medicaid Home and Community-Based Waiver Program for deaf/blind people, and the Consumer-Managed Personal Assistant Services Program.

The Budget

The Texas Department of Health received funding increases in the FY 2002-03 budget to reduce waiting lists for home and community-based services (HCBS) and for nursing homes. Officials expected the budget increases will allow the number of clients in HCBS waiver programs to increase by about 5,600 persons per year. However, even with those increases, officials said that about 26,000 people would remain on waiting lists for services.

Planning and Reports

The first version of a long-term care reform plan, called Promoting Independence, was delivered to the Legislature in January 2001. The Promoting Independence Advisory Board later was renamed the Interagency Task Force on Appropriate Care Settings for Persons with Disabilities. With coordination from the Health and Human Services Commission, the task force met several times during FY 2002. During this time, the task force monitored implementation of the plan, formed work groups to assist with the overall continued development of the plan, and made further advisory recommendations. The task force released a revised version of the plan on December 2, 2002.

Key to the plan is assisting individuals who seek to move from nursing homes to community settings. Phase one of the plan involved informing nursing home residents about community-based alternative programs, collecting baseline data on nursing home residents, training agency staff, and promoting community awareness of community options. Phase two is being implemented over a two-year period from September 2001 to September 2003. The Department of Human Services is hiring and training relocation specialists, developing an identification process and assessment instrument, tracking data from the relocation specialists, and conducting community awareness activities. Phase three will divert people from institutions by placing additional staff in hospitals and rehabilitation centers for preadmission screening.

On September 4, 2002, 11 individuals and the Arc of Texas filed a class action suit against the Health and Human Services Commission, the Department of Mental Health and Mental Retardation, and the Department of Human Services. The complaint charges that Texas has failed to provide community-based living options and services for people with mental retardation and developmental disabilities. The Medicaid home and community-based waiver program for people

with mental retardation was serving about 4,600 people, with another 17,500 on waiting lists. The Community Living Assistance and Support Services Medicaid waiver program for people with developmental disabilities was serving about 1,800 people; another 7,300 had requested but had not received those services.

State Administrative Agencies

The operations and programs of the Department on Aging came under review as part of the state's sunset process of ongoing reviews of state agencies. As a result of the review, a bill was enacted in 2001 establishing a new long-term care agency to take effect on September 1, 2003, by abolishing the Department on Aging, transferring its programs to the new agency, and renaming the Texas Department of Human Services (TDHS) as the Department of Aging and Disability Services. The bill also consolidated a number of long-term care programs in TDHS and transferred to TDHS several programs from the Texas Rehabilitation Commission and Texas Department of Health.

Many aging advocates opposed the move, so the 77th Legislature passed a bill that requires the Health and Human Services Commission to review the functions of the Department on Aging to determine which functions related to the direct provision of long-term care and to recommend whether any functions should be transferred to the TDHS, provided such a transfer did not conflict with the Older Americans Act. The bill extended the date to September 1, 2005, when the Department on Aging would be abolished.

In the 2003 Legislature, other restructuring bills were introduced to reorganize the state's giant health and human services system. One bill proposes combining 11 agencies into three: a Department of Health Services; a Department of Aging, Community, Disability and Long-Term Care Services; and a Department of Protective and Regulatory Services. The Department of Aging, Community, Disability and Long-Term Care Services would combine mental retardation, nursing homes and other aging services, community-based care, the Texas Rehabilititation Commission, and the Commission for the Blind.

Grant Initiatives

In December 2002, the Health and Human Services Commission announced that the agency would use the almost $1.4 million it had received in federal grants to test models and practices for long-term care systems change in two areas of the state: Heart of Central Texas (13 counties in and around Belton, Killeen and Waco), and Texoma (three counties in and around Sherman/Denison). The project is called Creating a More Accessible System for Real Choice for Long-Term Care Services, or Texas Access Project. The goal is to use "system navigators" to help individuals and families cut through government red tape across agencies and organizations to obtain needed benefits, services and supports.

UTAH

The major long-term care activity in Utah in 2002 was the release of a comprehensive task force plan that outlines an "overall direction and planning process" for public services for persons with disabilities. The report noted that there has been "a significant increase" in the number of people served in community settings in Utah in recent years, although considerable barriers still existed in the state's overall long-term care system.

Planning and Reports

A long-term care task force consisting of a number of state agencies released a *Comprehensive State Plan for Public* Services *in the Most Appropriate Integrated Setting* in November 2002. The plan report notes that, during the last several years, " ... the allocation of public funds has moved dramatically toward the provision of services in non-institutional programs." There has been a " ... significant increase in the number of people served in community settings," the report says, "as well as a significant increase in the percentage of the State Medicaid budget going to community-based services."

The plan outlines a course of action in three categories: home and community-based initiatives, cross-agency planning, and individual department and division plans. The recommendations are largely general in nature, calling for identification of problem areas and effective approaches.

Goals for home and community-based services (HCBS) include, for example, evaluation of existing agency policies and practices relating to current Medicaid waiver programs to determine if an equitable allocation of resources exists among various target populations and equitable access to services among the various programs. Under "cross agency planning," the report calls for designing a model of continuity of care across the long-term care system and integrating self-determination concepts into the system.

Agency plans include development of and implementation by the Division of Aging and Adult Services of the family caregiver support program statewide and development of an online, statewide resource directory. The Division of Mental Health was working on adopting standardized practice guidelines for the assessment of adults and on outlining a process to assess a referral for community placement. The Division of Services for People with Disabilities was focusing on the waiting list issue, including development of a plan to address the immediate needs of people found eligible for services at their entry point to prevent a waiting period that could increase the need for more intrusive and costly services.

Developmental Disabilities

On December 19, 2002, the Utah Disability Law Center filed a lawsuit in U.S. District Court against the Utah Department of Health and the Division of Services for People with Disabilities on behalf of nine individuals and the Arc of Utah in regard to the wait listing of individuals with developmental disabilities for HCBS. About 1,300 people have been determined to have an immediate need for HCBS services, but have been placed on a waiting list.

2002 Legislation

The 2002 Legislature substantially amended the Adult Protective Services Act. The new law modifies and strengthens mandatory reporting requirements and clarifies that protective services for adults is voluntary, unless the adult is vulnerable and lacks the capacity to consent.

Vermont

The Vermont General Assembly addressed two major issues during the 2002 session: elder abuse and home and community-based care. New assisted living regulations defined the nature of the facilities and prohibited the facilities from admitting people with serious medical conditions.

Elder Abuse

The elder abuse law was amended to expand the definition of "abuse" to include sexual activity by a paid or unpaid caregiver and behavior that should reasonably be expected to result in intimidation, fear, humiliation, degradation, agitation, disorientation or other emotional distress.

The definition of "neglect" also was amended to include purposeful or reckless failure or omission by a caregiver to maintain the health or safety of a vulnerable adult or to protect a vulnerable adult from abuse, neglect or exploitation by others. Neglect also would involve failing to carry out a plan of care for a vulnerable adult that could result in physical or psychological harm or a substantial risk of death, or failing to report significant changes in the health status of a vulnerable adult to health care providers or the caregiver's organization.

Planning and Reports

Lawmakers also established an *Olmstead* advisory commission in the Agency of Human Services to determine the barriers that prevent people with disabilities from living in the most integrated settings. The commission will examine the current allocation of resources and identify additional resources needed to ensure that waiting lists for community-based services move at a reasonable pace.

Assisted Living

Assisted living regulations that became effective on March 15, 2003, define "assisted living residence" as a program or facility that combines housing, health and supportive services to support resident independence and aging in place. The rules stipulate that an assisted living facility should not admit anyone who has a serious medical condition or who needs specialized equipment such as ventilators or respirators. However, if a resident developed a need for such equipment, he or she could remain in the facility if it could safely meet the person's needs or those needs could be met by an "appropriate licensed provider."

Virginia

The state's mental health system came under the scrutiny of the Virginia legislature and the governor in 2002 and 2003, with a view to expanding community rather than institutional services. The legislature also mandated the creation of task force to examine the needs of people with disabilities and to recommend ways to expand community options.

Mental Health

Lawmakers approved a measure in 2002 that requires the commissioner of Mental Health, Mental Retardation and Substance Abuse Services to establish state and community consensus and planning teams for any restructuring of the mental health system that involves existing state facilities. Each team would develop a detailed plan to include the types, amounts and locations of new and expanded community services; the transition of facility patients to community services; transition of state facility employees; costs of any proposed structure; and a plan for community education.

Governor Mark Warner proposed a major shift in policy toward community mental health care to the legislature at the beginning of 2003. The governor's proposal, Community Reinvestment Project, would redirect nearly $22 million annually from five state mental health institutions to community service boards, which would use the reinvested funds to offer community care to people with mental illness. Officials said that examples of how the funds might be used included establishing a regional behavioral health authority to manage a community program in a vacant hospital building at Central State Hospital and creating regional jail service teams to provide assessment and limited counseling services.

Long-Term Care Insurance

The General Assembly enacted four long-term care insurance laws in 2002. The major provisions of the laws include the following.

- Benefits for long-term care must be reviewed and approved as set forth in regulations issued by the State Corporation Commission that address long-term care insurance.

- Regulations must establish standards for initial filing requirements and premium rate schedule increases.

- The Department of Human Resource Management must establish a plan for providing voluntary long-term care insurance coverage for employees of local government, local officers and teachers.

Nursing Homes

The 2002 legislature reduced Medicaid reimbursement for nursing facilities, permitted drugs to be transferred between a nursing home and a pharmacy for reuse by the indigent free of charge, and provided for the authorization and acceptance of specific certificate of public need applications for new nursing home beds.

Planning and Reports

The legislature also directed the commissioner of the Department of Mental Health, Mental Retardation, and Substance Abuse Services to convene a task force to develop a plan for serving people

with disabilities and to implement the recommendations of the U.S. Supreme Court *Olmstead* decision. The task force, which is composed of 65 members, including consumers, family members, advocates, providers and representatives of 15 state agencies, must submit its recommendations by August 31, 2003. The group is gathering data on populations and services and examining the needs of individuals with disabilities in housing, employment, prevention and transition services, qualified providers, and waiver programs.

WASHINGTON

In 2002 and 2003, Washington was in the last stages of its five-year plan for restructuring and expanding community options for people with developmental disabilities. The plan included key recommendations on incorporating self-directed services in future programs. On the administrative front, the state revamped its aging and developmental disabilities agencies into a merged Aging and Disabilities Services Administration.

Developmental Disabilities

In April 2001, the parties in the lawsuit *The Arc of Washington State vs. Lyle Quasim* reached a settlement agreement, which depended on the Washington Legislature authorizing an additional $14 million to expand services for people with developmental disabilities. The agreement also stipulated that the Legislature would provide $24 million each year thereafter. The Legislature approved the first phase of the agreement in 2002. However, the District Court rejected the agreement in December 2002. Advocacy organizations had argued that the agreement provided insufficient assurances that the individuals they represented would receive the services they required. Trial is scheduled for October 2003.*

Phase three of the long-range plan for people with developmental disabilities (Developmental Disabilities Strategies for the Future) was released on December 1, 2002. A stakeholder work group was appointed in 1997 to develop plans over a five-year period for the future needs of people with developmental disabilities. Phase one of the plan, released in December 1998, identified unmet needs in five areas: services, case management, quality and accountability, provider stabilization, and administrative infrastructure. The phase two report, issued in December 2000, made recommendations on how to restructure the system to implement choice and self-determination through an individual and family-centered approach.

The phase three report makes recommendations on implementation of self-directed services and on the respective roles of the residential habilitation centers (RHCs)-five centers that are certified either as ICF/MRs or nursing homes-and community support services. Funding for a pilot program for self-directed services in FY 2000 and FY 2001 was not provided. However, the Department of Developmental Disabilities tested some elements of self-determination with people who are moving out of institutions. The Legislature provided funds to move 80 people from RHCs to the community in the 2001-03 biennium. As of November 2002, 54 people had indicated that they wanted to move, and 31 had actually moved as September 2002.

State Administrative Agencies

In December 2002, the secretary of the Department of Social and Health Services created the Aging and Disabilities Services Administration by merging the Aging and Adult Services Administration (AASA) and Division of Developmental Disabilities. AASA had a FY 2001-03 budget of $2 billion, of which about $982 million went to nursing homes for the care of about 13,000 residents and $790 million went to home and community services for about 24,000 clients in FY 2002. (Another 8,000 people resided in community residential settings in FY 2002, which includes adult family homes, adult residential care and assisted living facilities.)

The Division of Developmental Disabilities had a FY 2001-03 budget of about $1.2 billion for services for 33,000 people. Of the total, about $303 million was for the residential habilitation

centers. Another $386 million was for supported living (services people receive in their own homes) or group home programs.

* Human Services Research Institute, February 2003, http://www.hsri.org/docs/litigation021403.pdf

West Virginia

With two federal grants totaling more than $2 million, West Virginia planned to improve community long-term support systems so that consumers had choices of services and the supports they needed for community living. The project's goals are to develop solutions for improved access to transportation, educational supports and services, and employment opportunities with the assistance of a Real Choice Partnership group.

Grant Initiatives

The state received two federal Systems Change grants, totaling slightly more than $2 million, in 2002. With a $725,000 grant, the Center for Excellence in Disabilities at West Virginia University was expected to partner with state agencies, consumers and provider groups to expand personal assistance services and increase participant options for consumer control and direction. The project creates a Consumer/Agency/Services (CAS) Oversight Board that assists with project direction, activities and outcomes.

A $1.3 million grant is being used to develop and maintain an ongoing Real Choice Partnership Group, 60 percent of whom were to be consumers and advocates. The 28-member group planned to meet quarterly to review the activities and recommendations of its four working committees (policy, practice, services and legislative affairs). Consumers will receive self-determination training. Project staff will develop a curriculum and provide consumer-led training. Recommendations will be developed for increasing transportation accessibility, recreational/leisure opportunities, educational supports and services, and employment possibilities.

The Budget

The state was expected to face a $250 million Medicaid budget gap for FY 2004. The Legislature approved a cigarette tax increase, which was expected to generate nearly $60 million in revenues. Governor Bob Wise had pledged that all the money from the cigarette tax would go to Medicaid. That would result in a three-to-one match by the federal government for the Medicaid program.

End of Life

The Legislature in 2002 enacted a measure that allows health care professional licensing boards to develop guidelines for end-of-life pain management. The measure also amends the definition of "accepted guideline" related to the management of intractable pain by adding that such a guideline includes policy or position statements relating to pain management issued by West Virginia boards that have jurisdiction over various health care practitioners.

Nursing Homes

The U.S. Department of Veterans Affairs transferred 5.5 acres of land to West Virginia for a 120-bed nursing home for veterans. Federal grant money was expected to cover about 65 percent of the cost of the $20 million project. The state planned to cover its share of project costs from the state lottery "Veterans Cash" game, which the Legislature authorized in 2001. West Virginia has the highest per capita number of war veterans in the country.

WISCONSIN

Long-term care planning efforts in Wisconsin in 2002 resulted in recommendations for expanding the Medicaid personal care program and for implementing consumer-directed services. An evaluation report on the pilot Family Care long-term care program in five Wisconsin counties showed waiting lists had been eliminated and resource centers under the program were successfully providing centralized information and assistance.

Planning and Reports

Under the direction of the 17-member Wisconsin Council on Long-Term Care, an ADA (Americans with Disabilities Act) Title II Committee has been addressing disability issues in the state. Phase one of the committee's work identified measures to be taken by the state to assist people who currently are living in institutions. Phase one was completed in January 2002 with the release of *Wisconsin's ADA Title II Plan*.

Phase two of the committee's work focused on people who currently are living in the community but who are facing institutional placement unless adequate supportive services become available. The ADA committee investigated three areas: advancing the Medicaid personal care benefit, restructuring the state long-term care budgeting process, and advising the Department of Health and Family Services on the implementation of the phase one and phase two recommendations.

The committee's phase two work was completed in January 2003. Major recommendations involve expanding the Medicaid personal care benefit and pursuing Medicaid waivers to provide maximum flexibility under the program, including consumer-directed services. The committee also calls for monitoring and guiding the use of new funds to implement the phase one and phase two recommendations.

In December 2002, the Wisconsin Legislative Audit Bureau released the third *Implementation Process Evaluation* of the Family Care program, a redesign of the state's long-term care system for the elderly and adults with physical and developmental disabilities that is being operated as a pilot program in nine counties. The report was prepared by The Lewin Group, a national consulting and research firm retained to evaluate the program.

Focusing on program activities through June 2002, the report noted that waiting lists for services had been eliminated in the five pilot counties that have care management organizations. The Lewin Group also report that the resource centers in the pilot counties " ... have emerged as a successful model of centralized information and assistance." (In November 2002, the Wisconsin Council on Long-Term Care recommended that the Family Care program be made available statewide by 2010.)

State Administrative Agencies

The Wisconsin Department of Health and Family Services announced a reorganization of the department in February 2003 to improve the management of long-term care, treatment, and other services for the elderly and people with disabilities. The new Division of Disability and Elder Services will manage the full continuum of community support and institutional care for the elderly and people with disabilities, including people with mental illness and substance abuse problems.

The merger combines the Division of Supportive Living, the Division of Care and Treatment Facilities, and the Center for Delivery Systems Development. The Division of Supportive Living is responsible for providing community-based services for the elderly and people with disabilities and also regulates nursing homes and other facilities that serve these populations. The Division of Care and Treatment Facilities is responsible for state-operated institutions that serve people with developmental disabilities and mental illness. The Center for Delivery systems Development oversees the Family Care program.

Wyoming

The Legislature took major action in 2002 to improve the availability of direct care workers who provide services to people with developmental disabilities by studying their wages and then appropriating funds for wage increases. After the state set minimum wage guidelines, studies showed that wages for direct care workers had risen considerably. Other long-term care activities included the release of a comprehensive plan for expanding home and community-based services for people with disabilities and legislative action to increase penalties for elder abuse.

Workforce

The 2001 Legislature directed the Wyoming Department of Health to conduct a study of wages and salaries of direct care workers. The study, which was submitted to the Legislature on December 1, 2001, included recommendations about additional funds needed to bring salaries up to a competitive level for the FY 2003-2004 biennium and the type of incremental increases that would be needed to allow health care providers to remain competitive.

In response, the 2002 Legislature appropriated $7.6 million in biennial state general funds and $14.8 million in federal funds to improve the salaries of direct care workers in adult developmental disabilities community-based programs. The funds became available beginning in July 2002. Guidelines issued by the Developmental Disabilities Division provided that 100 percent of the funds had to be used for wages and benefits, new staff had to be paid a minimum of $7.50 per hour, and staff with at least 12 months' experience had to be paid a minimum of $8 per hour.

In a November 2002 report to the Legislature on how the funds were used, the Department of Health said direct staff minimum wages had gone from $5.15 per hour to $7.50 per hour or more since July. Average wages had gone from $7.38 per hour to $10.32 per hour. Total compensation for full-time direct care staff, including both wages and benefits, had increased from an average of $9.08 per hour to $13.74 per hour, a 51 percent increase. Turnover dropped by nearly one-third in only the first 90 days after implementation of the salary improvements.

Planning and Reports

The Wyoming Department of Health released a comprehensive plan addressing home and community-based care for people with disabilities in July 2002. The plan consists of four sections: Aging, Developmental Disabilities, Acquired Brain Injury and Mental Health. Each section of the plan consists of nine elements, one of which is "development of new community services and support infrastructure." Under this category, the Developmental Disabilities Division proposed, for example, to serve a total of about 3,500 people by the summer of 2002, to have no waiting lists for services, and to provide a cost-of-living increase for providers in 2002. The Aging Division called for Medicaid subsidized assisted living, adult chronic mental illness residential homes, increased senior housing options or group homes for seniors, and increased training for health professionals and service providers. The Mental Health Division said its priority was for " ... promotion of community-based services, when appropriate, as well as utilization of inpatient hospitalization when necessary."

Elder Abuse

The Legislature in 2002 divided elder abuse into two categories, misdemeanor and felony, based on the intent of the abuse, the severity of the abuse, and any prior knowledge of the mental state of

the person being abused. The penalties range from one year in jail and a $1,000 fine for a misdemeanor to 10 years in prison and a $10,000 fine for a felony.

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Suite 515
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