

**alzheimer's  association**

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**state review 2004**



## State Review 2004

The Advocacy and Public Policy Division's *State Review 2004* provides information about legislative activity on issues of interest to Alzheimer advocates and allies. The report, complete as of November 18, 2004 is not intended to provide an exhaustive list of all legislation related to Alzheimer's disease. Rather, it is designed to furnish advocates with a snapshot of 2004 Alzheimer-related legislative activity and primarily reflects the work of Alzheimer's Association chapter advocates.

During the 2004 Legislative Session, the Advocacy and Public Policy Division received and reviewed an enormous amount of information and attempted to condense it into an easily readable and concise chart. Information obtained from state advocates was verified through Statenet, Illumen, and/or each state's legislative web site.

Thank you to our chapters for their assistance in submitting legislation for this report.

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## highlights from the 2004 legislative session

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In 2004, State Legislatures continued to grapple with increased demand and cost of state services, and the need to regain their fiscal footing. Lawmakers have faced hard choices, none more visibly than in the health sector, which has rapidly become an enormous budget burden. According to the National Association of State Budget Officers' October 2004 report, "Medicaid will become the number one cost facing U.S. State Governments in 2004-5, beating out elementary and secondary education for the first time ever." Going into the 2004 legislative session, 38 states were expecting a Medicaid Budget shortfall for FY05 (beginning July 1, 2004).<sup>1</sup> This is not new and is expected to be a problem in FY06 and beyond.

Governors in several states (New Hampshire, Mississippi, Florida, and Tennessee) have initiated or discussed global waivers for their states; capping Medicaid expenses in order to achieve budget predictability.

As was the case in 2003, the biggest challenge for Alzheimer advocates was in defending against cuts to essential programs and services for people with Alzheimer's and their family members.

The following pages include Alzheimer legislation and advocacy in key topic areas; bills that were signed into law over the past year and other important state initiatives advocates pursued in 2004.

### assisted living

The big story in assisted living reform in 2004 came out of **New York**. Advocates won a sound victory this August with the last minute passage of a large assisted living reform package. The legislation provides the following: a definition of assisted living; uniform admission and discharge policies; strong consumer protections, state oversight; standard contract disclosures; and a comprehensive "Resident's Bill of Rights." Further, the legislation works to ensure the delivery of quality care and the ability to age in place in assisted living facilities in New York State.

A series of articles appeared in the Washington Post, describing the state of assisted living in **Virginia**. H.B. 424, a bill that would require assisted living facilities that choose to serve residents with serious mental illness, mental retardation or substance abuse problems to comply with the State Board of Social Service's regulations governing such placement, recently died in committee. More proposals are expected for introduction during the second half of the session, including a proposal from the sponsor of H.B. 424, as well as an assisted living package from Governor Mark Warner through his budget. Virginia advocates have been involved with the Governor through an Assisted Living Task Force, and have been working with outside interest groups in addition, hoping to take the issue further than what is expected from the Executive and Legislative branches.

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<sup>1</sup>2004 State Health Care Priorities Survey Report. National Conference of State Legislatures and Health Policy Tracking Service. December 2003.

In August 2004, **Missouri** Alzheimer advocates convened a meeting of the Assisted Living Stakeholders Taskforce in an effort to improve the quality of assisted living in the state. The 16 member-organization taskforce, comprised of medical, legal, research, and advocacy expertise, testified before the State's House Interim Committee on Assisted Living in November, 2004. In its final report, the taskforce recommended an improved definition of assisted living, an increase in funding for the office of the Long-Term Care Ombudsman, urged the state to regularly convene state-level hearings and meetings on assisted living issues, and demanded improvement in Public Access to Statutes, Regulations, Survey and Inspection Reports. The report also has recommendations on licensure in assisted living, direct care services, medication management, resident rights, and staffing. The recommendations within this report are expected to become the foundation and framework for assisted living legislation and regulation in the coming session.

## medicaid

In **West Virginia**, Medicaid may be in trouble. Waiver programs there had previously been local county aging programs that performed the waiver interviewing and also provided the care. The Legislature stopped this, and hired an independent contractor to do initial assessment to get rid of any possible conflict of interest. 180 people lost their waivers as a result, but a judge has ordered the state to give back waivers, which will be an expensive process.

Both **Mississippi** and **Tennessee** have proposed changes to their Medicaid laws. Mississippi Governor Haley Barbour (R), successfully garnered a waiver from the Federal Government, and New Hampshire is seeking a similar waiver in return for a promise to rein

in its cost. Tennessee is attempting to rid itself of its TennCare program, which if successful, is likely to become a model for other states looking to cut Medicaid and redefine medical eligibility as a way to address ongoing budget difficulties.

The **Montana Billings-Gazette** wrote in August 2004 that, "Medicaid, the state-federal program that covered 130,000 of Montana's poorest children, disabled and elderly last year, is changing. The number of people eligible for Montana Medicaid has risen in the past year and a half. Costs of health care continue to increase, but federal support for Montana Medicaid is decreasing. Given the certainty of change, Montana policy-makers have an urgent responsibility to carefully consider how policy must be shaped to sustain needed services to the most vulnerable of our citizens. The 2005 Legislature must take action on Medicaid."

## defending state budgets

**California** Alzheimer advocates successfully protected \$377,000,000 for the In-Home Supportive Services Residual Program. Due to their teamwork, they saved the residual program, which enables spouses to be compensated when they provide in-home services for persons with Alzheimer's who are Medi-Cal eligible. Additionally, they protected \$4,923,000 for the Alzheimer's Research Centers. These 10 university-based centers will be able to continue providing state-of-the-art diagnostic and treatment services as well as education, referral and support to families.

In **Illinois**, several programs required great effort just to be held at the Governor's introduced levels, including funding for Retired Senior Volunteer Program, and funding for Senior Prescription Drug Programs. Nursing Homes received a partial

restoration of rate cut sustained in 2002. The *Community Care Program*, which covers case management, the adult day care programs, and the homemaker programs, sustained a 2.25% cut. The effect of the Governor's agreement to increase homemaker rates is still unknown.

The Respite Services line item in the **Ohio** state budget suffered from not one, but two cuts. Initially, an across the board cut to the department of Aging forced the program to sustain a budget trimming. However, when it became clear that the economy would not pick up in the foreseeable future, the Governor ordered departments to cut again. The respite line item was hit with a 7% cut. It is an indicator of the state of the economy when advocates are relieved to just have the two cuts, having spent time and political capital fighting off additional cuts that were proposed. Departments have been told to brace for additional reductions in 2006-7 budget, which have been estimated at 7-13%.

Because of the budget issues in **Kentucky**, funding for full-time ombudspersons in each region of the state and additional staffing in populous areas is at risk after the first quarter of the Fiscal Year. Kentucky advocates are vocal in their support for this program that is so vital to protect long-term care resident rights and resolving complaints.

**Minnesota** advocates avoided some of the more threatening proposals offered by the Governor and state legislators. Among those were Medical Assistance rate cuts for health care services, the repeal of the scholarship program for long-term care workers, the repeal of rate equalization in nursing home billing, and the repeal of the MN Prescription Drug Assistance Program well in advance of discovering how the new federal Medicare law pans out.

**New Mexico** advocates successfully preserved Respite and Educational funds in their budget,

and lobbying efforts in **Pennsylvania** restored Alzheimer's Outreach funding from \$145,000 to \$250,000.

## nursing facility issues

**California** Governor Schwarzenegger signed several bills into law this session. Of note is Assembly Bill 1629, which provides for the imposition of a quality assurance fee on each skilled nursing facility, to be administered by the Department of Health Services. This also provides that the fees assessed be made available to draw down a federal match in the Medi-Cal program or to provide additional reimbursement, and support facility quality improvement efforts in skilled nursing facilities. While the bill did not receive support from the Association, California advocates are currently drafting proposed changes to make the law more Alzheimer friendly, stressing the need for increased accountability.

In **Minnesota**, the Governor signed three bills that could signal increased access to care and quality of care in the future. HF2027 (Chapter 218) is a moratorium exception that allows for the creation of a new nursing facility in Austin, MN, where there will be a 20-bed Alzheimer's special care unit. SF1604 (Chapter 194) directs the Department of Human Services to continue working with other advocacy organizations to reform the nursing home reimbursement system in ways that reward adequate staffing and other measures of quality. Finally, HF 2246 (Chapter 247) makes changes to the Department of Health nursing home inspections, to include more opportunities for members of family councils to be interviewed in the process.

## caregiver support/ respite

In **West Virginia**, advocates passed two new resolutions to study the respite and training issues. Advocates made formal presentations supporting their case to the interim committee that studies passed resolutions that might be turned into formal legislation. For respite care, resolution authors asked for a line item in the Bureau of Senior Services budget be increased to \$1 million. According to supporters, this would offer some Alzheimer respite money to every West Virginia county.

A new law, effective October 2004, establishes the **Michigan** Lifespan Respite Services Program within the Department of Community Health (DCH). The program would seek to encourage and develop a statewide coordination of community respite services by providing: policy and program development support; technical assistance; developing and distributing information; promoting statewide access; and monitoring and evaluating implementation. Additionally it seeks to promote the exchange and coordination between state and local governments, community respite programs, the individuals served by respite programs, and respite care advocates.

In **Illinois**, H.B. 6706 was signed into law by Governor Rod Blagojevich. This bill creates the Family Caregiver Act, to be administered by the Department on Aging, for the purpose of encouraging family members to provide care for their elderly family members. The bill requires the Department to contract with area agencies on aging and other appropriate agencies to provide family caregiver support services to the extent of available funding. The bill amends the Respite Program Act so that the Act applies to "frail or disabled" adults.

The bill defines a "frail or disabled adult" as a person who is age 60 (instead of 55) or older

and who either (i) suffers from Alzheimer's disease or a related disorder or (ii) is unable to attend to his or her daily needs without assistance or regular supervision.

## research funding

Again in **Illinois**, the Association-authored bill, S.B. 2805, stabilizes the overall funding mechanism of the Alzheimer's Disease Centers at Rush Presbyterian, Northwestern Memorial Hospital and the SIU School of Medicine. The measure expands the duties of the Alzheimer's Disease Advisory Committee at the Illinois Department of Public Health. The bill further revises the duties of the Center for Minority Health Services at IDPH to include advocacy and promotion of the increased risk of Alzheimer's disease among minority populations.

**California** Assembly Bill 1799 was signed by Governor Arnold Schwarzenegger (R). The bill extends the Alzheimer's Disease Research Fund tax check-off for 5 more years (until 2010). According to the California Council, this could mean at least another \$2.8 million dollars will be raised for Alzheimer's research in California over the next 5 years. The small grants from the tax check-off contributions awarded to California researchers enable researchers to successfully compete for much larger National Institute of Health grants.

## dementia training

In **Arizona**, Governor Janet Napolitano (D) signed H.B. 2024, allowing the Department of Human Services to monitor and take the necessary actions if training programs in

assisted living facilities do not meet Department rules.

**Nevada** is currently implementing requirements of certain employees of nursing facilities for long-term care, to receive education in the care of persons with dementia (NAC 449.037). The regulations require the Department of Human Resources to develop a plan for increasing the number of beds that are used to provide long-term care to persons with dementia.

**New Jersey** advocates successfully pushed through a new Special Care Unit dementia training law. The law establishes a mandatory training program for long-term care facility staff, in the specialized care of patients who are diagnosed by a physician as having Alzheimer's disease or a related disorder. A long-term care facility will annually provide training to a certified nurse aide, licensed practical nurse, registered professional nurse and other health care professionals, as appropriate, who provide direct care to a patient in the facility who is diagnosed as having Alzheimer's disease or a related disorder.

Additionally, New Jersey advocates worked on Assembly Bill 1816, which requires the Department of Law and Public Safety to establish, by regulation, a policy for local law enforcement personnel in working with the Safe Return program to facilitate the recovery of lost individuals with Alzheimer's disease and related disorders. This bill made it through the Assembly, but became tied up in committee.

## **adult day care**

**California** Assembly Bill 2127 requires a direct services contractor operating an Alzheimer's Day Care Resource Center to be licensed as either an adult day program or as an adult day health care center. It also allows

currently unlicensed Centers operate as though licensed until 2008.

**Rhode Island** advocates successfully lobbied to reverse the Executive Branch's freeze of the co-pay program for home-based and adult day care assistance.

## **advisory boards, commissions, committees**

**California's** State Policy Director has been reappointed to the state's Olmstead Advisory Committee. The Association has been at the forefront of pressuring Governor Schwarzenegger to take a strong leadership role in implementing California's Olmstead Plan.

The **Massachusetts** Chapter received a hard-earned budget item reauthorizing the Governor's Advisory Council on Alzheimer's Disease and Related Disorders,

In **Oklahoma** the Long Term Care Facility Advisory Board, which expired July 1, 2004, was recreated and extended the sunset clause to July 1, 2010.

In **Arizona**, a study committee was established under the Caregiver Wages and Workforce Development Committee. It will aid in developing policy that will introduce additional and better-trained individuals to Arizona's long-term care system.