



the compassion to care, the leadership to conquer

The New York State Coalition of Alzheimer's Association Chapters is comprised of the seven Alzheimer's Association Chapters serving families in all of New York State. The Coalition is a recognized leader in affecting change by ensuring that the concerns of individuals with Alzheimer's disease and their caregivers are articulated to policy and political leaders. The services provided by the Chapters are available in all regions of New York and are considered to play a significant role in the education and support of caregivers, both family and professionals. The Coalition is part of the national Alzheimer's Association, which is the largest private funder of Alzheimer's research having committed over \$200 million toward research.

There are almost half a million people with Alzheimer's disease and related disorders residing in New York State- helping to care for them are more than two million family caregivers. Studies have shown that some 70-75% of all consumers with Alzheimer's disease are being cared for in the home by families at little or no cost to New York State. As such, a primary focus of the Coalition's advocacy efforts center on the education and support of caregivers, both family and professional. Our work to empower and support caregivers allows them to continue to provide quality care to the ill individual.

The Coalition of New York State Alzheimer's Association Chapters is cognizant of the constraints placed on the state by rising Medicaid costs and the increasing services needs of an aging population, particularly those over 85 years of age. Nevertheless, the long term needs of the growing number of persons with dementia cannot and must not be ignored. New studies predict that the prevalence of Alzheimer's will increase 27% by 2020, 44% by 2025, an astonishing 70% by 2030, and nearly 300% by 2050 (approximately 1.5 million New Yorkers) unless research scientists find a way to slow the progression of the disease or prevent it. As such, people with Alzheimer's and their families and other caregivers must not bear the brunt of any state attempts to contain Medicaid costs.

Our Coalition is advocating for alternative community based services and greater availability of caregiver support services. Such services are designed to enable friends and families caring for a loved with dementia to continue in their role for as long as possible, avoiding the need for placement of someone into an institutional setting. Unfortunately, New York has made little progress in reducing its institutional bias for the aged and disabled community. When comparing Medicaid expenditures in 1998 to spending in 2002, the most recent year for which Medstat data is available, we find that long term care services for seniors and people with disabilities largely remained institutional, only shifting from 69.2% in 1998 to 68.6% in 2002, less than a one percent shift toward community based care.

Funding Request:

The Alzheimer's Coalition has long been advocating for increased funding for programs specifically designed to divert or transition people with Alzheimer's or dementia from unwanted institutional placement. This level of resources would allow Chapters to provide

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caregiver supports and a broad array of home and community based care during the early stages of Alzheimer's and dementia. Access to such services will help family members remain in their roles for a longer period of time and reduce the need for institutional services. Furthermore, ongoing care from informal support networks will reduce pressure on EISEP and Medicaid funded home care and personal care. Medicaid funded long-term care services, such as personal and home care, provide a vital safety net for New York's vulnerable elderly population. To ensure that this critical safety net is available for those individuals most in need, it is necessary to fund Chapter programs that support community based care.

The Coalition requests that the following appropriations be included in the SFY 2008-09 budget:

- \$1 million for the Alzheimer's Disease Community Assistance Programs (AlzCap),
- \$1 million for the Alzheimer's Disease Community Services Programs (ADCSPs)

In addition, the Coalition respectfully requests that a \$250,000 appropriation be included in the Executive Budget for education, support services and early diagnosis related to Alzheimer's disease. This \$250,000 in funding has traditionally been allocated to the Alzheimer's Association on an annual basis to provide outreach services related to prevention and diagnosis of Alzheimer's disease and related dementias. This funding provides critical support to allow the seven Coalition Chapters throughout New York State and the National Contact Center to connect families by providing support 24 hours a day 365 days a year. The services provided by the Chapters and the Contact Center include care and consultation by a licensed social worker, translation services, crisis management and suicide prevention.

Presently, more than seven out of ten people with Alzheimer's disease live at home. Our services have helped to ensure that people with dementia have access to the services they need when appropriate in an effort to keep family members in the home environment for as long as possible. In fact our services have been demonstrated to delay nursing home placement by an average of 521 days. The Coalition's ability to assist families in caring for their loved ones in a community based environment is an effective way to lower state Medicaid costs.

As a result of being directly involved with supporting families and individuals struggling with the disease, the Coalition is keenly aware of the potential implications this disease could have on New York's aging population. Inclusion of funding in the Executive Budget for programs related to Alzheimer's disease will not only generate significant cost savings for the state but will improve the coordination of care for individuals suffering from dementia related illnesses.

One of the primary goals of the Coalition is to help families delay institutionalization of their loved ones. Funding in the Executive Budget will help the Coalition to meet the needs of a vulnerable population in a cost-effective, high-quality manner. We estimate that a \$2,250,000 investment in funding for Alzheimer's disease and related dementias will allow us to serve approximately 25,000 additional families and save precious Medicaid resources. Ultimately providing funding for programs and services to assist families and individuals struggling with Alzheimer's will improve the quality, efficiency and accessibility of health care for patients.