



Coalition of NYS Alzheimer's Association Chapters Budget Advocacy 2014

Issue #1: Increase Funding for the Alzheimer's Disease Community Assistance Program (AlzCAP)

Message:

Currently, AlzCAP is funded through the Department of Health and it supports the delivery of community based services to help individuals and families struggling with Alzheimer's disease. The Coalition receives funding through AlzCAP to support a variety of educational initiatives and caregiver respite programs. In 2013, the Coalition's chapters provided information and referrals to nearly 20,000 people, and had 29,009 attendees at early stage and caregiver support group meetings. The Coalition's chapters hosted educational programs on a range of relevant topics for 25,648 people including caregivers, members of the public, individuals with dementia and medical professionals. The Coalition chapters also provided over 7,000 care consultations to individuals in need of assistance.

The time has come for a significant increase in state funding to ensure appropriate services are provided to this vulnerable—and growing population. Currently there are more than 320,000 New York residents living with Alzheimer's disease. By 2025, it is estimated that approximately 350,000 New Yorkers will suffer from this disease, a sharp increase over the current number. And while these numbers are significant, they do not include the nearly 1 million informal and unpaid caregivers in New York providing care to individuals with Alzheimer's disease.

Services provided by Coalition chapters are critical in addressing the public health crisis of Alzheimer's disease. Those affected by Alzheimer's disease require increasing assistance with basic activities such as eating, bathing, dressing, and toileting. Individuals eventually need around-the-clock care. The cost of Medicaid for an individual with Alzheimer's disease is 19 times higher than for someone without the disease. These costs to the Medicaid system can be reduced by delaying the need for institutional care for those with the disease. There is strong evidence that community-based services, like those that the Coalition chapters provide through AlzCAP, delay nursing home placement and reduce the state's Medicaid burden. A research study by Dr. Mary Mittelman of New York University's Langone Medical Center concludes that, with use of community-based caregiver services such as support groups, education seminars, counseling sessions and telephone support, the median delay in skilled nursing facility placement is 557 days. Based on data from MetLife's 2011 Market Survey of Long-Term Care Costs, the average potential Medicaid savings per person is \$179,354 in that time period. The savings to the Medicaid system would more than offset the costs of increased funding for community-based programs to support individuals and families facing the challenges of Alzheimer's disease.

The role informal caregivers play in helping to delay institutionalization of an individual with Alzheimer's disease is critical. In New York State over a million caregivers provided more than 1,142,000 unpaid hours of care to individuals with Alzheimer's disease. The total value of this unpaid care exceeds \$14 million dollars. While these caregivers often take on these tasks willingly, the demands of caregiving can take a toll on their health, compromising their ability to care for themselves and their family members. Those who care for someone with Alzheimer's or another dementia are 3.5 times more likely than caregivers of people with other conditions to say that the greatest difficulty associated with caregiving is that it creates or aggravates their own health problems. Ensuring that caregivers have access to necessary support is crucial to help prevent caregiver burnout. While caregivers are providing care, services like support groups- can lessen feelings of depression and stress and help delay nursing home placement. Part of the Coalition's work is making sure that caregivers receive the support they need from local chapters. Every chapter offers a variety of support groups and other services to help caregivers cope with the stress of their undertaking. Ensuring that caregivers receive the services they need to continue to providing quality care to a family member is another way to keep individuals with Alzheimer's disease out of institutional settings and reduce Medicaid costs.

New York State lags behind other states of comparable size in funding initiatives to support individuals with Alzheimer's disease. Over the past five years California has invested \$28 million in Alzheimer's initiatives, and Florida has invested over \$100 million for Alzheimer's disease prevention and outreach services. In that same time period, Ohio has invested \$43 million and Texas, over \$16 million. Currently, the New York State budget allocates \$557,200, a mere \$1.74 per person with Alzheimer's to support the delivery of community based services for those with Alzheimer's disease. New York should be a leader in responding to this public health crisis, just as it has been in the past when facing the HIV/AIDS epidemic.

The Ask: Please advocate with the Governor, the Division of Budget and the Department of Health for increased funding of \$5 million dollars for the Alzheimer's Community Assistance Program (AlzCAP) in the upcoming budget.

Issue #2: Funding for a Public Awareness Campaign

Message: Individuals with Alzheimer's disease must be connected to appropriate medical care and community-based services. Timely diagnosis gives people with the condition and their families time to plan and prepare for the future, leading to more positive outcomes for both. Unfortunately, many New Yorkers are not aware that they have dementia and are letting their symptoms go untreated.

Raising the public's awareness about the signs of dementia can encourage families to seek assessment, reduce isolation and help link people in need to accurate information, resources and services. The New York State Department of Health should sponsor a public awareness campaign to educate the public about the warning signs of the disease. This campaign should also provide information on how the public can connect with providers like the Coalition's chapters. The Department has run similar successful awareness campaigns on anti-smoking initiatives, cancer awareness and the importance of prenatal care.

Data from the 2011 Behavioral Risk Factor Surveillance System found that 10.6 percent of New Yorkers aged 60 and over report that they are experiencing confusion or memory loss that is happening more frequently or is worsening. For those with worsening memory problems, four in ten say it has interfered with household activities and/or work activities. Alarmingly, nearly 80 percent of these individuals have

not talked to a healthcare professional about their symptoms. Talking about memory problems and possible cognitive decline with health care providers leads to earlier diagnosis, which in turn enables individuals and their families to plan for the future and allows for the better management of co-occurring chronic conditions.

Both the National Plan to Address Alzheimer's Disease and the New York State Coordinating Council for Services Related to Alzheimer's Disease and other Dementias plan recommend that a public awareness campaign be undertaken to facilitate timely diagnosis and intervention. Additionally, the Centers for Disease Control and Prevention (CDC) and the Alzheimer's Association recently collaborated to develop the Health Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013-2018. One of the key recommendations within the report is to "identify and promote culturally-appropriate strategies designed to increase public awareness about dementia, including Alzheimer's disease, to reduce conflicting messages, decrease stigma and promote early diagnosis." The sooner an individual with Alzheimer's disease can be connected to support services, the sooner he or she can begin planning for their long term needs. A coordinated public awareness campaign must be undertaken to ensure that individuals are made aware of the signs of Alzheimer's disease and the resources available to them.

The Ask: Please advocate with the Governor and the Commissioner of Health to include **\$500,000 dollars for an Alzheimer's disease Public Awareness Campaign** in the upcoming budget.