



Coalition of New York State Alzheimer's Association Chapters, Inc.

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Assembly Ways & Means Committee

&

Senate Finance Committee

on the

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Good afternoon Chairs, and members of the committee. Thank you for allowing us to speak to you today on Alzheimer's disease and the important services we provide to the community.

About the Coalition of New York State Alzheimer's Association Chapters

The Coalition of New York State Alzheimer's Association Chapters advocates on behalf of the 380,000 Empire State residents living with Alzheimer's disease and the caregivers that support them. For over twenty-five years, the seven chapters of the Coalition have provided care consultations, consumer and professional education programs, a 24-hour Helpline, safety services and support groups. These services are available in all regions of New York and provide family caregivers with the support they need to avoid premature placement of individuals with Alzheimer's disease in nursing homes or other institutional settings. The Alzheimer's Association is the recognized leader in Alzheimer's disease, and the Coalition is the only state-wide organization in New York that has the capacity to meet the needs of individuals with Alzheimer's disease and related dementias and those who care for them.

Funding for 2015-2016

This year, Governor Cuomo included an additional \$25 million for Alzheimer's Disease and Respite Care Services. This includes \$4 million for the Alzheimer's Community Assistance Program (AlzCap), \$4 million for Alzheimer's Disease Assistance Centers (ADAC's), and \$16.5 million for grants to support respite and caregiver support, with the remainder going to administrative costs. The Association strongly believes that this significant expansion of the AlzCAP funding will allow its chapters to reach many more New Yorkers suffering with Alzheimer's disease.

Impact of Funding

Alzheimer's is a progressive and fatal disease. There is no way to cure, prevent or truly slow its progression. The increase in funding is a great first step that will position New York to be a leader in the nation when it comes to funding and addressing the problem of Alzheimer's disease. With these funds, the Coalition will be able to expand our regional approach and will provide more resources for

evidence-based training, education, and support programs, as well as offering more one-on-one care consultations that provide individualized education and support. Additionally, with more staff, the Coalition will be able to better serve individuals in the rural areas of the state and address the unique challenges of New York's increasingly diverse populations.

The Coalition currently serves 30,000 New York families each year who are affected by Alzheimer's disease. With increased funding for services, we anticipate serving as many as 60,000 families in the following year and up to 90,000 in subsequent years.

Background for AlzCAP

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 this funding through AlzCAP to support a variety of educational initiatives and caregiver support programs. Specifically, Coalition chapters provide training for volunteers and family members to enable them to deliver proper care to individuals with Alzheimer's disease who live at home, respite programs for caregivers, educational programs for individuals with Alzheimer's disease, care consultations for individuals and families with a member suffering from Alzheimer's disease, and support groups for both individuals with Alzheimer's and their family members.

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.¹ Delaying the need for institutional care for those with the disease can reduce these costs to the Medicaid system. 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

¹ Hurd, Martorell, Delvande, Mullen & Langa, Monetary Costs of Dementia in the United States, *New England Journal of Medicine* 368: 1326-34 (2013).

services such as support groups, education seminars, counseling sessions and telephone support, the median delay in skilled nursing facility placement is 557 days.² The state sees an average potential Medicaid savings per person of \$138,136 in that time period or \$90,520 annually. 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 spend over 1.15 billion hours annually caring for people with dementia. On average, caregivers for individuals with Alzheimer's and other dementias spend 23 hours per week providing care--and one in six spends 40 hours or more per week. This is longer than the average 16 hours per week spent by caregivers of those with other conditions.³ While 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. For 31 percent of Alzheimer's and dementia caregivers, stress is the biggest problem with caregiving, compared with 23.7 percent of caregivers for those with other conditions.⁴ 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 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.

² Mary S. Mittelman et al., Improving Caregiver Well-being Delays Nursing Home Placement of Patients with Alzheimer Disease, 67 *Neurology* 1592, 1592-99 (November 14, 2006).

³ Alzheimer's Caregivers: Data from the Behavioral Risk Factor Surveillance System (BRFSS).

Keeping individuals with Alzheimer's disease connected to appropriate community-based services can also help to avoid unnecessary hospitalizations. Not only do such hospitalizations place a burden on the already financially strapped Medicaid system, they also exact a toll on the individuals with Alzheimer's disease. Indeed, there is new evidence that, for a person with Alzheimer's disease, a stay in a hospital can lead to accelerated mental decline and increase the risk of going into a nursing home or dying. A recent study from Harvard researchers, *Adverse Outcomes After Hospitalization and Delirium in Persons with Alzheimer Disease*, demonstrated that 41 percent of the patients who were hospitalized with dementia experienced accelerated mental decline during the year following hospitalization.⁵ The Coalition believes that the increased state funding will appropriately support community-based services that can help to keep more individuals with Alzheimer's disease at home for as long as possible.

New York State has traditionally been a follower in state funding initiatives to support individuals with Alzheimer's disease. This budget presents an opportunity for the Empire State to be a leader among its peers.

The Coalition of New York State Alzheimer's Association Chapters looks forward to accepting the State's challenge to positively impact the lives of more families than we previously have been able to reach.

Thank you for the opportunity to present this testimony.

⁵ Tamara G. Fong et al., 156 *Annals of Internal Medicine* 848, 848-856 (June 19, 2012).