



## New York State Coalition

Statement Prepared for the January 25, 2016 Hearing of the

Assembly Ways & Means Committee

&

Senate Finance Committee

on the

2016-2017 Executive Budget for Health and Medicaid

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## **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 over 1 million 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 2016-2017**

For the second year in a row, Governor Cuomo included approximately \$26.5 million for Alzheimer's Disease and Respite Care Services and additional monies to support greater services for those facing Alzheimer's disease. This includes almost \$5 million for the Alzheimer's Community Assistance Program (AlzCAP), \$4.5 million for Alzheimer's Disease Assistance Centers (ADACs) (now referred to as Centers for Excellence in Alzheimer's Disease (CEADs)), and \$16.5 million for grants to support respite and caregiver support, with the remainder going to administrative costs. The Coalition avers that this significant expansion of the AlzCAP funding will continue to 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 cure, and no way to prevent or truly slow its progression. New York's leadership in supporting Alzheimer's caregivers in 2015 was historic, and the results are already impressive. The increase in funding has allowed the Coalition's chapters and subcontractors to expand our regional approach and is providing more evidence-based training, education, support programs, one-on-one care consultations than ever before. The increase in staff statewide has positioned the Coalition to better serve individuals in the rural areas of the state and address the unique challenges of New York's increasingly diverse populations, and the increased public awareness efforts are facilitating the outreach.

## **Background for AlzCAP**

AlzCAP is funded through the Department of Health and 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 programs for caregivers and those with Alzheimer's and related dementias to coach them through the journey. Services include evidenced-based educational programs for community members and professional groups, one-on-one care consultations, a 24 hour, 7 day a week helpline (1-800-272-3900), support groups and safety services. Alzheimer's Association training for volunteers and family members enables them to deliver proper care to individuals with Alzheimer's disease who live at home, navigates healthcare, financial and legal planning, and offers resources and support at every level.

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.<sup>1</sup> 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 services such as support groups, education seminars, counseling sessions and telephone support, the median delay in skilled nursing facility placement is 557 days.<sup>2</sup> The state's current average nursing home burden is \$128,709<sup>3</sup> per person, annually. Thus, by investing in Alzheimer's caregiver support the state sees an average potential Medicaid savings per person of \$196,415 in that time period. Multiplied by just one quarter of New Yorkers with Alzheimer's, and the state will save \$12,227,355,000 annually if those folks are kept out of skilled nursing homes paid by Medicaid. Clearly, the savings to the Medicaid system more than offset the costs of increased funding for community-based programs to support individuals and families facing the challenges of Alzheimer's disease.

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

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

<sup>3</sup> Estimated Average New York State Nursing Home Rates, [https://www.health.ny.gov/facilities/nursing/estimated\\_average\\_rates.htm](https://www.health.ny.gov/facilities/nursing/estimated_average_rates.htm).

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.<sup>4</sup>

While caregivers often take on caregiving tasks willingly, the demands of caregiving can take a toll on their own 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 have aggravated health problems.<sup>5</sup> 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.<sup>6</sup> Ensuring that caregivers have access to necessary support is crucial to help prevent caregiver burnout.

In 2015, studies revealed that only 45% of patients are given their Alzheimer's diagnosis.<sup>7</sup> Explanations vary as to why this is, some say a lack of promising treatments offer little hope to patients and families and others cite the stigma associated with this disease. Failing to provide patients with a diagnosis however, precludes them from participating in necessary research and the ability to plan for the personal and financial changes that lie ahead. In keeping with the triple aim to improve health outcomes for New Yorkers, the Coalition is committed to working with medical professionals to ensure they are aware of the robust menu of services and supports the Alzheimer's Association chapters have to offer statewide. Greater public awareness efforts are underway and chapters are already reporting significantly increased contacts and inquiries.

The services provided by the Coalition chapter attempts to lessen the caregiver burden in a variety of ways. 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 and each chapter offers one-on-one care consultations by Master's level social workers -- one of the most effective means to coach caregivers and connect them with appropriate resources.

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. There is new evidence that, for a person with Alzheimer's disease, a stay in a hospital can lead to accelerated mental decline and increased

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<sup>4</sup> Alzheimer's Caregivers: Data from the Behavioral Risk Factor Surveillance System (BRFSS).

<sup>5</sup> Alzheimer's Disease Caregivers Fact Sheet, March 2015.

<sup>7</sup> Alzheimer's Association Facts and Figures, March 2015.

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.<sup>8</sup> Increased funding from New York State will appropriately support community-based services that can help to keep more individuals with Alzheimer's disease at home for as long as possible.

The Coalition of New York State Alzheimer's Association Chapters is grateful for the increased appropriation to expand our services and encourages continued investment to positively impact the lives of families in every corner of the state who are facing and Alzheimer's diagnosis. Further, we are committed to working with the medical community to communicate the importance of early and accurate diagnosis and support the triple aim to improve healthcare across New York.

Thank you for the opportunity to present this testimony.

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<sup>8</sup> Tamara G. Fong et al., 156 *Annals of Internal Medicine* 848, 848-856 (June 19, 2012).

