



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

Statement Prepared for the January 30<sup>th</sup>, 2013 Hearing of the

Assembly Ways And Means Committee

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Senate Finance Committee

on the

2013 – 2014 Executive Budget Proposal 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 320,000 Empire State residents living with Alzheimer's disease. 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 Coalition is the recognized leader in meeting the needs of individuals with Alzheimer's disease and related dementias and those who care for them.

### **Alzheimer's Funding Request**

We are deeply concerned about the proposal within the Governor's FY 2013-14 Executive Budget to eliminate funding for numerous public health programs in the Department of Health budget and consolidate these programs into six competitive pools. **All funding for community based services to support those living with Alzheimer's disease and their caregivers was eliminated in this proposal.** This includes \$246,000 in funding for the Coalition of New York State Alzheimer's Association Chapters, \$49,000 for the Alzheimer's Disease Community Assistance Program (AlzCAP) and \$295,000 for the Alzheimer's Community Services Program (CSP) to support education and caregiver respite programs. Although this funding was modest compared to the real needs of the New York families affected by Alzheimer's, it was a lifeline for individuals and caregivers struggling to cope with the devastation of the disease.

While we are aware that the intent of this consolidation is to improve contracting efficiency and outcomes for the expenditure of state dollars, we are concerned about the lack of transparency surrounding this proposal. We do not know how much, if any, funding will be invested in programs to support those with Alzheimer's disease. Funding for Alzheimer's related programs will most likely come from the Chronic Disease pot of \$63 million, but we fear at a significantly reduced level. The Coalition will likely have to compete for fewer resources, when we believe the focus of our time and energy should be spent providing services to those living with Alzheimer's disease. We ask that the legislature reject the Governor's proposal to consolidate the funding for public health programs and fight to increase funding for Alzheimer's disease related programs.

### **Funding for AlzCAP**

We ask that the Legislature restore funding for the AlzCAP program and increase the funding line to \$5 million dollars in the SFY 2013-14 Budget. Currently, AlzCAP is funded through the Department of Health —though as noted above this funding is eliminated in the Governor's budget proposal— 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 the past calendar year, the Coalition's chapters provided information and referrals to more than 30,000 people, assisted 37,633 attendees at 5,869 support group meetings, hosted educational programs for nearly 20,000 people and provided care consultations to 8,184 people. These services were provided by the Coalition's chapters with very little financial support from the AlzCAP program. The Coalition strongly believes that a significant expansion of the AlzCAP funding would allow its chapters to reach many more New Yorkers suffering with Alzheimer's disease.

Although the Coalition is sensitive to the State's economic situation, 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.<sup>1</sup> 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. The Coalition's chapters work to provide services to as many impacted people as possible. Unfortunately, the Coalition's resources are already stretched thin as a result of budget cuts and all chapters are struggling to provide services to individuals in their communities impacted by Alzheimer's disease. An allocation of \$5 million in funding is needed to provide critical respite, education and support services to all those individuals with Alzheimer's disease and their caregivers.

An increased investment by New York State in the AlzCAP initiative would also generate Medicaid savings. There is strong evidence that community-based services 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, the median delay in skilled nursing facility placement is 557 days.<sup>2</sup> Based on data from MetLife's 2011 Market Survey of Long-Term Care Costs, the average potential savings per person is \$179,354. The savings to the Medicaid system would more than offset the costs of increased funding for community-based programs, like those offered under AlzCAP, to support individuals and families facing the challenges of Alzheimer's disease.

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 increased risk of nursing home placement or death.<sup>3</sup> A recent study from Harvard University 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. The Coalition believes that increased state funding to support appropriate community based services can help to keep more individuals with Alzheimer's disease at home for as long as possible.

Increasing access to community services for individuals with Alzheimer's disease is also a recommendation of the New York State Coordinating Council for Services Related to Alzheimer's Disease and other Dementias.<sup>4</sup> The Council was created by the Governor and the legislature in 2007. The Council's group of 21 dementia care experts was charged with providing recommendations on policy relating to dementia and improved coordination between public and private agencies to meet the needs of individuals with Alzheimer's disease and other dementias. In the Council's 2009 report to the Governor and the New York State Legislature, the Council recommends "improving access to community services, such as respite, social and medical model adult day care, and support groups, through more outreach and program expansion." In order to implement this recommendation, New York must invest more funding in programs like AlzCAP.

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

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<sup>1</sup> For more information, view the 2012 Alzheimer's Disease Facts and Figures report at [alz.org/facts](http://alz.org/facts)

<sup>2</sup> 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).

<sup>3</sup> Tamara G. Fong et al., 156 *Annals of Internal Medicine* 848, 848-856 (June 19, 2012).

<sup>4</sup> See 2009 and 2011 reports of the New York State Coordinating Council for Services Related to Alzheimer's Disease and other Dementias available here

[http://www.health.ny.gov/diseases/conditions/dementia/reports\\_data.htm](http://www.health.ny.gov/diseases/conditions/dementia/reports_data.htm)

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 a mere \$1.84 per person with Alzheimer's disease.

New York has a strong history of investing in the fight against HIV/AIDS and cancer. New York State's investment in public health was a key factor in diagnosis, treatment and awareness of these diseases. It is now time for New York to invest \$5 million in the AlzCAP program to assist those with Alzheimer's disease and their caregivers.

#### Funding for Disaster Preparedness Training

The impact of Hurricane Sandy has been felt by many New Yorkers and continues to wreak havoc for many of the most vulnerable populations in communities touched by the storm. A disaster situation significantly adds to the stress levels and confusion of individuals with Alzheimer's disease. For people with moderate to severe Alzheimer's disease, a disaster can lead to wandering, agitation and separation from a needed caregiver.

As New York recovers from the devastation of Hurricane Sandy and continues planning for future disasters, the Coalition urges the Legislature to fund emergency preparedness trainings to assist Alzheimer's patients. The Coalition's chapters are uniquely positioned to facilitate trainings around the state to help individuals and their caregivers prepare for emergency situations. Both Florida and Louisiana fund this type of training to ensure that Alzheimer's patients are appropriately cared for in emergency situations. The Coalition asks that the Legislature provide \$1 million dollars in funding for the Coalition to deliver trainings on how to best prepare individuals with Alzheimer's and their caregivers for emergencies. This training would be available to agencies responsible for disaster response, first responders, law enforcement, health care facilities, home health aides and informal caregivers.

#### **Oppose the proposal to eliminate spousal refusal.**

The Coalition is also concerned about the Executive Budget proposal to eliminate spousal refusal in the Medicaid program. Currently, when couples reside in the community and only one spouse requires Medicaid, the sick spouse can apply for Medicaid as a single individual and the other spouse can exercise "spousal refusal," declining to make his or her income and resources available to the sick spouse. The proposal to eliminate spousal refusal in the Executive Budget would eliminate this protection for couples seeking community based services. The budget proposal would not remove the spousal refusal protections for couples seeking placement of a loved one in a nursing home. This elimination of spousal refusal for community based services would mean that both spouses' incomes and resources would be reviewed in determining Medicaid eligibility for home care services. Consequently, a non applying spouse would have to reduce his/her income and assets to the federal poverty level in order for the applicant spouse to receive Medicaid benefits. This policy change would encourage a spouse to place their loved one in an institution, rather than care for the person at home. Although this proposal is advanced to save state dollars it would have the opposite effect by driving up Medicaid costs for nursing home placements.

Moreover, eliminating spousal refusal in the community would violate the Supreme Court's decision in *Olmstead v. LC ex rel Zimring*. The *Olmstead* decision introduced the "integration mandate" which requires states to provide services "in the most integrated setting appropriate to the needs of qualified individuals." The Governor's proposal to allow spousal refusal only in an institutional setting and not in the community would, naturally, have the opposite effect. Individuals would be compelled to leave the community and transfer to a nursing home so that their spouses would be able to survive financially.

Under this proposal of eliminating the spousal refusal for couples seeking care at home, the couple would need to spend down their assets to the \$20,100 asset limit. Further, frequently upon a spouse's death, the income payable to the surviving spouse is significantly reduced due to a reduction in retirement benefits. Elimination of spousal refusal prevents the surviving spouse from protecting assets to produce a sufficient stream of income upon the death of his or her spouse. In contrast, spousal refusal has allowed a healthy elderly spouse to maintain assets that generate income for his or her own living expenses and future long term care needs. We urge that this proposal, which would be detrimental to so many couples, be rejected.

Thank you for the opportunity to present this testimony.

