



New York State Coalition

Statement Prepared for the February 16, 2017 Hearing of the

Assembly Ways & Means Committee

&

Senate Finance Committee

on the

2017-2018 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 ("Coalition") is the leading statewide organization advocating for all New Yorkers affected by Alzheimer's disease and dementia. For more than 30 years, the Coalition's seven statewide chapters have provided care consultations, consumer and professional educational programs, a 24-hour Helpline, safety services and support groups to the 390,000 Empire State residents living with Alzheimer's disease and their 1.1 million caregivers. Alzheimer's is a progressive and fatal disease. There is no cure, and no way to prevent or truly slow its progression. Within the next decade, we expect to see an approximate 20 percent increase in the number of New Yorkers living with Alzheimer's, in large part due to the aging baby boomer population. By 2025, we anticipate as many as 460,000 New Yorkers will be living with Alzheimer's.

We share the Alzheimer's Association mission to eliminate Alzheimer's disease through the advancement of research, to provide and enhance care and support for all affected, and to reduce the risk of dementia through the promotion of brain health. We align with and promote the work of the Alzheimer's Association by increasing concern and awareness, advancing public policy, and enhancing care and support through robust advocacy, partnership and programmatic initiatives.

Funding for 2017-2018

New York now boasts the largest investment in Alzheimer's caregiver support by any state in the nation. For the third consecutive year, since 2015, the executive budget includes approximately \$26.5 million for Alzheimer's Disease Care and Respite Services and additional monies to support greater services for those facing Alzheimer's disease. This includes almost \$5 million for the Coalition's contract with DOH, Alzheimer's Community Assistance Program (AlzCAP), the rest going towards Centers for Excellence in Alzheimer's Disease (CEADs), and for grants to support caregiver support and respite, in addition to administrative and program evaluation costs.

Increase Support for Alzheimer's Community Assistance Program in SFY 2017-18

Based on a longitudinal study by Dr. Mary Mittelman of New York University, community-based caregiver services like those offered through AlzCAP delay skilled nursing facility placement by 557 days.¹ The state's current average nursing home burden is \$130,736.57² per person, annually. Thus, by investing in Alzheimer's caregiver support, the state sees an average potential Medicaid savings per person of \$199,506.26 in that time period. Multiplied by just one tenth of New Yorkers with Alzheimer's, the state will save \$7,780,441,140 annually if those folks do not reside in skilled nursing homes paid by Medicaid. The cost-savings to Medicaid realized from the services provided by Coalition chapters is significant in addressing the public health crisis of Alzheimer's disease. Those affected by Alzheimer's disease require increasing assistance with basic activities of daily life and eventually need around-the-clock care. The Medicaid costs for an individual with Alzheimer's disease is 19 times higher than for someone without the disease.³

The role informal caregivers play in helping to delay institutionalization of an individual with Alzheimer's disease is central to the issue. AlzCAP, the Coalition's sole source contract with the Department of Health, is the key to educating and empowering thousands of New York Alzheimer's

¹ 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).

² Estimated Average New York State Nursing Home Rates, https://www.health.ny.gov/facilities/nursing/estimated_average_rates.htm.

³ Hurd, Martorell, Delvande, Mullen & Langa, Monetary Costs of Dementia in the United States, New England Journal of Medicine 368: 1326-34 (2013).

caregivers to delay skilled nursing facility placement for their loved ones and *reduce the Medicaid burden*. Since the increase in 2015, programs and services to all affected by Alzheimer's and dementia delivered through AlzCAP include:

- Almost 7,000 care consultations offering critical, in-depth, personalized meetings for those facing decisions and challenges pertaining to the diagnosis of Alzheimer's disease or a related dementia.
- Caregiver training and community education to more than 29,000 attendees in every county of the state, in several different languages.
- More than 2,700 support group meetings.
- More than 34,000 calls to our free, 24 hour-a-day, 7 day-a-week Helpline.
- Staff have met with and reached more than 800 physicians.
- Reaching nearly 48,000 people at conferences and health fairs.

Too often, studies show, people do not understand Alzheimer's and the importance of early diagnosis and care planning. According to the 2015 Behavioral Risk Factor Surveillance System survey data, 11% of New Yorkers 45 and older report confusion or memory loss, but more than half of them have not spoken to a physician about it.

In 2016, in coordination with DOH and pursuant to the NYS Alzheimer's Disease Plan⁴, the Coalition commenced a limited public awareness effort across the state. Results were immediate and staggering: *calls to the 24/7 Helpline increased 42%, attendance at education programs grew 34%, and just over a month of digital promotion produced three times the typical number of hits to the Alzheimer's Association website.*

To address this public health crisis, we must promote greater understanding of the early warning signs of Alzheimer's disease and the value of early diagnosis and planning – but dedicated funding for public awareness does not exist. The Coalition respectfully requests a \$10 million investment in public awareness through AlzCAP in SFY 2017-18 to launch a large-scale, culturally competent statewide public awareness campaign in coordination with DOH.

Further, to meet the needs associated with increased awareness, the Coalition seeks an additional \$3.5 million for AlzCAP in SFY 2017-18 to grow staff and program services statewide.

Improve Access to Assisted Living for Low-Income Seniors with Alzheimer's and Dementia

Currently, more than 45,000 New Yorkers live in assisted living and approximately 40% of them have some form of dementia. Consistent with industry best practices for those with dementia, the Coalition advocates for optimizing the most appropriate, but least restrictive, residential setting. The NYS Assisted Living Program (ALP), does not offer a comprehensive long-term care solution for NY's aging population. While there are approximately 7,600 ALP beds authorized, they are inconsistently apportioned throughout the state and woefully scarce. The Coalition advocates expanding the Assisted Living Program to allow greater access for low-income New Yorkers with dementia to reduce unnecessary, costly nursing home admissions.

⁴ 2015 Report of the New York State Coordinating Council for Services Related to Alzheimer's Disease and Other Dementias to Governor Andrew M. Cuomo and the New York State Legislature

Seniors with dementia who can no longer afford their private-pay rate while living in an assisted living residence (ALR) usually have no other option than to go on Medicaid, resulting in a move to a skilled nursing facility at considerable cost to NYS. This option is contrary to longstanding public policy to keep people with dementia in a familiar, less restrictive setting. The Coalition supports creating a pilot project to provide voucher payments to private-pay ALRs to retain spend-down residents and mitigate the State's Medicaid burden.

Conclusion

Through AlzCAP and coordinated efforts, the Coalition is helping to achieve New York's Triple Aim – better care, better population health and lower health care costs – through collaborative community work to implement best practices and strategies to promote brain health and reduce healthcare disparities in underserved regions.

New York State is spending \$4.2 billion annually in state Medicaid costs for caring for those with Alzheimer's. Our efforts to empower and enable caregivers and those with dementia to live at home longer (or in the least restrictive environment) helps reduce the Medicaid burden now and into the future.

The Coalition of New York State Alzheimer's Association Chapters is grateful for the current appropriation and looks forward to working together to grow resources and continue to improve the status quo for New Yorkers facing Alzheimer's disease and dementia at home and in assisted living settings.

Thank you again for this opportunity.