



New York State Coalition

Statement Prepared for the February 12, 2018

Assembly Ways & Means Committee

&

Senate Finance Committee

on the

2018-2019 Joint Legislative Budget Hearing for
Health and Medicaid

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Thank you for the opportunity to present testimony today.

Alzheimer's is a progressive and fatal disease, and the 6th leading cause of death in the United States. There is no cure, and no way to prevent or truly slow its progression. Currently, there are approximately 390,000 New Yorkers with Alzheimer's and by 2025, we anticipate as many as 460,000 New Yorkers will be living with this brain disease. Nationally, the number of people with Alzheimer's is projected to sharply increase from more than 5 million today to as many as 16 million by 2050, as the 78 million Baby Boomers mature and reach the age of highest risk.

The Alzheimer's Association, New York State Coalition ("Coalition") is the only statewide organization supporting, representing and advocating for all New Yorkers with Alzheimer's disease and their caregivers in every county of New York.

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, New York expects to see an approximate 20 percent increase in residents 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 this brain disease.

Annually, the annual per-person Medicaid spending on seniors with Alzheimer's and other dementias is 19 times higher than average, annual per-person Medicaid spending across all seniors without dementia. Furthermore, at least 74 percent of people with dementia have multiple chronic conditions, which complicates their care and drives up costs. Seniors with Alzheimer's and other dementias have, on average, twice as many hospitalizations each year and four times as many skilled nursing facility stays as seniors without Alzheimer's.

Our SFY 2018-29 requests seek to mitigate costs the state may spend unnecessarily on behalf of those with Alzheimer's and dementia and focus on programs that are innovative and supportive -- keeping those with Alzheimer's disease at home, or in the least restrictive, cost effective residential setting.

For more than 30 years, the Coalition's seven Alzheimer's Association chapters have offered expert in-person support to Empire State residents living with Alzheimer's disease and their 1.1 million caregivers. Services include care consultations; caregiver, professional, community and gatekeeper educational programs; a 24-hour Helpline and expert information and referrals; and support groups to ensure New Yorkers receive the vital care and support they deserve. The chapters offer services in all of New York's 62 counties. Further, reaching diverse and historically underserved communities is rooted in our values and critical to program success. Cultural competency, sensitivity, awareness and outreach are ongoing priorities.

We align with and promote the work of the Alzheimer's Association by increasing concern about Alzheimer's disease and awareness of resources and services available to all affected, advancing related public policy and enhance care and support through statewide initiatives. Through our efforts, we aim to reduce caregiver burden, improving quality of life, and delaying unnecessary hospitalizations and long-term care placement of New Yorkers with dementia.

New York boasts the largest investment in Alzheimer's caregiver support by any state in the nation. For the fourth consecutive year, the executive budget includes approximately \$26 million for DOH Alzheimer's disease programs to support statewide care, support and respite services and additional monies to support NYSOFA services for those facing Alzheimer's disease and dementia. This total allocation includes monies for the Centers for Excellence in Alzheimer's Disease, Alzheimer's Caregiver Support Initiative and related initiative to benefit those in underserve communities, and almost \$5 million for the DOH's Alzheimer's Community Assistance Program (AlzCAP) – the Coalition is not only the current, but the long-time and successful primary subcontractor.

Increase Support for Alzheimer's services in SFY 2018-19

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. The state's current average nursing home burden is approximately \$137,438 per person annually. By the age of 80, 75 percent of people with Alzheimer's will have been admitted to a nursing home, compared with just 4 percent of the general population. More than 60 percent of seniors living in a nursing home have moderate or severe cognitive impairment.

In 2016, New York State spent 70% of Medicaid dollars (4,453,801,673) on those with Alzheimer's and related dementias in a nursing home, compared to the total amount of \$6,391,025,875 spent on nursing home care.

Alzheimer's Disease Community Assistance Program – AlzCAP

The role informal caregivers play in helping to delay long-term placement of individuals with Alzheimer's disease is clear. AlzCAP, the Coalition's sole source contract with the Department of Health, is the key to educating and empowering tens of thousands of these caregivers -- cost-savings to Medicaid realized from the Coalition's chapter services significantly addresses the public health crisis of Alzheimer's disease.

Since the Fall of 2015, AlzCAP programs and services to all affected by Alzheimer's and dementia include:

- Almost **14,000 care consultations** offering critical, in-depth, personalized meetings for those facing decisions and challenges pertaining to the diagnosis of Alzheimer's disease or dementia
- **Caregiver training and community education to more than 48,000** people in every county of the state, in several languages
- More than **5,000 support group** meetings for Alzheimer's, caregivers and those in the early stage of the disease
- More than **52,000 calls to our free, 24-hour, 7 days-a-week Helpline**. This Helpline is staffed by Master's level dementia care specialists, who are trained to respond to all calls whether in need immediate support, crises situations, or local resources and supports available – wherever the caller resides.
- **Staff outreach and education to more than 1,500 physicians**

- Reaching nearly **77,000 people at conferences and health fairs**

In 2016, in coordination with DOH and pursuant to the NYS Alzheimer's Disease Plan, the Coalition commenced a limited public awareness effort across the state in 2016. 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, there is an urgent need to 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 2018-19 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 \$5 million for AlzCAP in SFY 2018-19 to grow staff and program services statewide.

Assisted Living Voucher for those with Dementia

Among residents of assisted living, 42 percent have Alzheimer's or another dementia. In the Executive Budget, the Governor has also provided for a demonstration project to offer up to 200 vouchers to individuals with dementia who are currently living in an assisted living facility. These vouchers would cover up to 75% of the average regional private pay rate. This rate is still being determined, but as it is, we encourage the legislature to eagerly support this initiative to keep people with Alzheimer's and related dementias in the most preferred and most appropriate residential setting, reduce unnecessary moves which can be detrimental to those with dementia, and utilize this option which will significantly the Medicaid burden to the state.

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. In 2017, New York State spent \$4.6 billion in annual State Medicaid costs to care for those with Alzheimer's disease. By 2025, that number is expected to increase by 33 percent.

Our efforts to empower and enable caregivers to help those with dementia live at home longer greatly reduces the Medicaid burden now and into the future. The Alzheimer's Association, New York State Coalition 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.

Thank you again for this opportunity.