

# alzheimer's association

## **New York State Coalition**

Statement Prepared for the February 5, 2019

Assembly Ways & Means Committee

&

Senate Finance Committee

on the

2019-2020 Joint Legislative Budget Hearing for  
Health and Medicaid

Delivered by

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My name is Elizabeth Smith-Boivin and I have the pleasure of serving as President of the Alzheimer's Association, New York State Coalition.

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 all 62 counties in New York State. For more than 30 years, the Coalition's seven Alzheimer's Association chapters, thanks in part to generous support from Governor Cuomo and the New York State Legislature, through our Statewide grant, the Alzheimer's Community Assistance Program (AlzCAP), we are able to address the growing public health crisis precipitated by Alzheimer's. We provide evidence-based education and person-centered care and support to New Yorkers affected by Alzheimer's and other dementias through our free in-person and online programs for caregivers, professionals, and the public on a wide range of topics such as early warning signs, diagnosis and the need for caregiver support and respite. We have a diverse and multilingual staff of specialists and master's-level clinicians that can work with New Yorkers in need, in person or over the phone and through our free 24/7 Helpline. These services are available consistently in all 62 counties across the state and provide caregivers with the support they need to avoid premature placement of individuals with Alzheimer's and other dementias into nursing homes or other institutional settings. Our Care Consultants around the state are able to meet with the individuals and family members in our offices, in communities, or in the person's home. 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.

Alzheimer's is a progressive and fatal disease. There is no cure, and no way to prevent or truly slow its progression and in New York State, over 400,000 New Yorkers age 65 and older are living with Alzheimer's disease. 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. Almost two-thirds of individuals living with Alzheimer's are women. In addition to gender differences, Alzheimer's affects racial and ethnic groups disproportionately. Compared to older white adults, African Americans are about twice as likely to have Alzheimer's or other dementias, and Hispanics are approximately 1.5 times as likely. As New York's population ages, with more individuals aging over 65 each day, their risk of getting Alzheimer's and other dementia's increase, more so than any other disease, with a staggering cost of \$4.8 billion in Medicaid dollars alone.

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 complicate 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.

To address this public health crisis, there is an urgent need to promote a greater understanding of the early warning signs of Alzheimer's Disease and the value of early diagnosis and planning. **EARLY DIAGNOSIS SHOULD BE NEW YORK STATE'S FOCUS.**

In 2016, 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.

Based upon recent data from the Behavioral Risk Surveillance System, the premier nationwide health-related survey designed by the Centers of Disease Control and Prevention (CDC), 10.3 percent – one in 10 – of those aged 45 and over in New York State report they are experiencing confusion or memory loss that is happening more often or is getting worse (“subjective cognitive decline”) and more than half with memory problems have not talked to a health care provider. Over 85% of individuals who have memory problems and at least one other chronic condition report it has created “functional difficulties” – that is, caused them to give up day-to-day activities and/or interfered with work or social activities. Evidence indicates that less than half of people with dementia have been diagnosed by a physician. Among older adults, only 35% are aware they have the disease.

**Request:**

We are very thankful to Governor Cuomo and the legislature for their continued investment and support of the Alzheimer's Caregiver Support Initiative, the most progressive investment in Alzheimer's caregiver support by any state in the nation. For the fifth consecutive year, the budget includes approximately \$26 million for Alzheimer's disease programs across New York State in care, support and respite services. We request continued support of this initiative.

In addition, we respectfully request \$3 million dollars in funding as part of the SFY19-20 budget, to pilot a targeted Public Awareness Campaign across New York State, with an emphasis on traditionally underserved and under-resourced communities including communities of color and rural communities, focusing on

the importance and benefits of an Early Diagnosis and the promotion of the New York State supported 1-800 Helpline. Additionally, the need for a comprehensive Public Awareness campaign is highlighted in the CDC's 2018-2023 Healthy Brain Initiative Road Map to Address Dementia and by the New York State Coordinating Council for Services Related to Alzheimer's disease and Other Dementias in their 2017 report to Governor Cuomo and the New York State Legislature.

Early detection of any chronic disease provides the best opportunity to receive better medical care, enhance health outcomes, plan for future needs, and secure medical desires and wishes. The field of public health promotes early detection activities in order to maximize all these possibilities for chronic diseases. Alzheimer's is no different — even without a way to cure or slow the progression of Alzheimer's, early detection allows individuals and their caregivers greater access to available treatments and support services, as well as the opportunity to enroll in clinical trials. With early detection, people living with dementia can also be involved in their own care during the early stages when cognition is least affected, including dictating their medical wishes and financial plans, as well as choosing their medical team providers. Furthermore, an early and accurate diagnosis can save money for both individuals and the government by reducing visits to the Emergency room as well as admissions and readmissions to the hospital.

### **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.

Our effort to empower and enable caregivers help those with dementia live at home as long as possible and 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 increase awareness, expand resources and continue to improve care and support for ALL New Yorkers facing Alzheimer's disease and dementia.

Thank you again for this opportunity.