



New York State Coalition

Statement Prepared for February 25, 2021

Assembly Ways & Means Committee

&

Senate Finance Committee

on the

2020-2021 Joint Legislative Budget Hearing for

Health and Medicaid

Delivered by Elizabeth Smith-Boivin

My name is Elizabeth Smith-Boivin, Chair of the Alzheimer's Association, New York State Coalition. I appreciate the opportunity to testify virtually today.

For more than 30 years, through our New York State Coalition, made up of our seven chapters, the Alzheimer's Association has provided services to New Yorkers with Alzheimer's disease and all dementias, and their caregivers in all 62 counties in New York State.

During this unprecedented time, those living with dementia and their caregivers continue to turn to the Alzheimer's Association and we continue to support them. The COVID-19 pandemic has only magnified the urgency of our mission, especially the importance of providing and enhancing care and support, which through evidence-based programming helps to avoid unnecessary hospitalizations and emergency room visits, delays nursing home placement by allowing individuals to "age in place", and improves caregiver burden and mental health outcomes, which ultimately provides a cost savings to New York State.

We have taken a number of extraordinary steps to maintain our programming at pre-pandemic levels and offer new activities in response to emerging needs. Since the onset of the pandemic in March, we have served as a frontline, necessary service to ensure our constituents continue to receive care and support for living well with dementia. In the space of less than 72 hours with no disruption in services, we transitioned our entire staff to work remotely without interrupting service, and successfully converted our support groups, education programs and care consultations to a virtual format. In doing so we have expanded our reach dramatically — a strategic priority. Were it not for us, the situation for people with dementia and their caregivers would be dire. For many New Yorkers, we were the only lifeline during this time, whether through our statewide virtual programming where we served over 86,000 individuals or through our 24/7 Helpline which assisted more than 22,000 individuals.

We also have undertaken additional activities in response to pandemic-related needs. Among others, these activities include staff providing wellness check-ins for constituents during the pandemic to offer support; virtual training programs and guidance for professionals including first responders and staff in long-term care settings; and special outreach and programming for underserved and under resourced communities including rural, LGBTQIA+, and communities of color impacted by dementia.

We understand the budget challenges that New York State faces due to the COVID-19 pandemic; however, any budget reductions will further impact our service delivery for people living with dementia and their caregivers who already face significant challenges due to the coronavirus.

COVID-19 continues to disproportionately affect individuals with Alzheimer's and other dementias. Individuals living with Alzheimer's have high prevalence of conditions that are identified as potential risk factors for severe illness due to COVID-19. In New York State, dementia is the 4th highest comorbidity to COVID-19 deaths. Additionally, as published this month in the New York Times, new research found that the risk of contracting COVID-19 was twice as high for people living with dementia than those without it. Furthermore, African Americans with dementia were three times as likely to contract COVID-19

compared to Whites. These findings, though preliminary, suggest a frightening reality of the vulnerabilities associated with living with dementia. It has been speculated since the beginning of the pandemic that – because of the vulnerabilities associated with the disease – individuals with dementia are at an increased risk of contracting COVID-19. published research shows strong, credible data showing a clear connection.

In addition, COVID-19 poses unique challenges for people with dementia and their families. Caregivers may receive less or irregular outside assistance, adding to already-high levels of caregiver strain. Persons living with dementia may have an impaired ability to follow or remember instructions on social distancing and other best practices, thus increasing their risk of contracting COVID-19. People living with dementia may have difficulty adapting to disrupted routines. Wandering, confusion, and disorientation may increase. Cognitive impairment may impede communicating, especially virtually, therefore contributing to social isolation and potentially causing more rapid cognitive decline.

These findings highlight the continued need to protect patients with dementia as part of the strategy to control the COVID-19 pandemic. Meeting constituent demand for services may be effective at preventing or minimizing future burden.

Request:

We are very thankful to Governor Cuomo and the legislature for the 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 which fund our work as well as 3 other critical grant programs by our over 30 community-based grant partners. As we move into the SFY21-22 budget cycle, we ask for your continued support in preserving and maintaining this initiative at its robust funding level of \$25 million. In addition, due to the COVID-19 pandemic, there has been a full cut of \$1.37 million in supplemental Alzheimer's Public Health funding in the budget, in part was funded by the legislature.

We seek a restoration of these cuts totaling \$1.37 million which is critical to maintaining our state's dementia-capable public health infrastructure by providing a two-pronged systems investment focusing on community support while also equipping the medical system to provide early diagnoses, quality care management, and linkages to community services. Services are vital to the local level response including statewide coordination of support, administration, monitoring and evaluation of services to families and the needs of the Alzheimer's community in New York State. Cuts to this funding will cause workforce reductions and stifle New York State's public health approach to providing coordinated treatment and care management for individuals living with Alzheimer's and all forms of dementia statewide.

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 support 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.