



Alzheimer's Association, New York State Coalition

**Testimony on the FY 2025-26
Executive Budget Proposal**

Health/Medicaid

**Submitted to:
New York State Senate Finance Committee
Chair, Senator Liz Krueger**

&

**New York State Assembly Ways and Means Committee
Chair, Assemblymember J. Gary Pretlow**

February 11, 2025





Thank you for allowing us the opportunity to submit testimony for today's Joint Legislative Budget hearing on Health and Medicaid.

The Alzheimer's Association is a worldwide voluntary health organization dedicated to Alzheimer's care, support and research. Our mission is to lead the way to end Alzheimer's and all other dementia — by accelerating global research, driving risk reduction and early detection, and maximizing quality care and support. Our vision is a world without Alzheimer's and all other dementia.

The Alzheimer's Association, New York State Coalition (Coalition) is the only statewide organization supporting all New Yorkers affected by Alzheimer's disease and all other dementia. Its members, the seven Alzheimer's Association chapters in New York State, have delivered in-depth, expert services and education to constituents for more than 30 years.

According to the *Alzheimer's Association's 2024 Facts and Figures Report*, approximately 427,000 individuals aged sixty-five and older are living with Alzheimer's disease in New York State. This prevalence underscores the critical need for enhanced support services. Alzheimer's disease impacts all of New York's sixty-two counties and every Senate and Assembly District. The same report highlights that 543,000 family caregivers in New York provided 879 million hours of unpaid care in 2024, valued at nearly \$19 billion. Over half of these caregivers are living with chronic health conditions, reflecting the significant personal toll of caregiving.

We are writing to respectfully request an ***increase in funding for the New York State Centers for Excellence for Alzheimer's Disease (CEADs) Program by \$3 million, an increase in funding for the Alzheimer's Community Assistance Program (AlzCAP) by \$1 million, and an increase in the number of available vouchers for the Special Needs Assisted Living Residential (SNALR) Voucher Program for Persons with Dementia to 500.*** These three programs are essential in providing support and care to the growing number of New Yorkers affected by Alzheimer's disease and other dementias.

Centers of Excellence for Alzheimer's Disease (CEAD)

The New York State Department of Health funds ten regional medical centers under its Centers of Excellence for Alzheimer's Disease (CEAD) program. Currently, the funding allocated to the ten CEADs is \$4.7 million, split between the institutions. This paltry sum is meant to cover the costs associated with diagnosing Alzheimer's disease and related dementia (ADRD), coordinating treatment for those diagnosed with ADRD, training physicians & health care professionals, and promoting primary care physicians to deliver cognitive screenings in community-based settings. This funding is insufficient to meet the current needs of the State.

We have entered a new era of treatment for Alzheimer's disease; however, these new FDA-approved treatments require an early and accurate diagnosis. Obtaining said diagnosis in New York State, regardless of socioeconomic status, is difficult. The CEADs were intended to serve as diagnostic hubs but are currently bogged down with months-long waiting lists, that oftentimes force patients to go out of state for a diagnosis. The unfortunate reality of these new Alzheimer's treatments is they can only be prescribed in a narrow window of impairment. Waiting months for an appointment can potentially push an individual beyond that window and render them unable to receive treatment. Alzheimer's disease is horrific enough but the thought that waiting for a diagnostic appointment took so long that you are now ineligible for treatment is beyond heartbreaking. New Yorkers deserve better.

The Coalition is respectfully requesting that the Legislature increase funding for the CEAD program by \$3 million.

The New York State Coordinating Council for Alzheimer's Disease and Other Dementia, the statutory body that facilitates interagency planning and policy, reviews specific agency initiatives for their impact on services related to the care of persons with dementia and their families, and provides a continuing forum for concerns and discussion related to the formulation of



a comprehensive state policy relating to Alzheimer's disease and services for persons with incurable dementia has long indicated that the CEAD funding was insufficient and inhibiting the institutions ability to provide the necessary diagnostic services.

The Coalition agrees with the Coordinating Council. The CEADs have done great work with their current allocation; however, the science around Alzheimer's is changing rapidly and that includes treatment options. It is in the best interest of the State of New York to have the best clinical diagnostic options available for people with cognitive impairment. We cannot be the nation's leader in healthcare, if we cannot get individuals diagnosed in an appropriate amount of time. Alzheimer's disease is expensive, its cost to the state is immense. New and future treatments offer the ability to address this disease earlier and potentially save the state money by keeping individuals home longer, staving off a nursing home placement.

Alzheimer's Community Assistance Program (AlzCAP)

AlzCAP is designed to postpone or prevent nursing home placements and provides a comprehensive array of community-based support services to individuals living with dementia, caregivers, and communities that are disproportionately impacted by dementia. The Coalition currently receives \$5 million in AlzCAP funding from DOH to:

1. Promote greater understanding of Alzheimer's and other dementia, and the importance of early and accurate diagnosis;
2. Provide individualized care planning to individuals and families affected by Alzheimer's and other dementia;
3. Offer support groups, a free 24/7 Helpline, caregiver and community education to provide necessary information, and guidance and connection to resources;
4. Partner with houses of worship, senior centers, first responders, pharmacies, cultural organizations, financial planners, lawyers and many others to raise awareness of the Alzheimer's public health crisis and the services available through the Alzheimer's Association and trusted partners; and
5. Hire talented, committed and diverse staff to serve all New Yorkers affected by Alzheimer's and other dementia.

The partnership between the Coalition and DOH via AlzCAP has been a successful one. The Coalition has been able to provide the state with boots on the ground programs and services across all of New York's 62 counties. The Coalition's successes can be seen in its reach and deliverables. Between 2018 and 2022 the Coalition and its staff ensured individuals living with Alzheimer's disease and other dementias and their caregivers received the following critical care:

- **36,086** Care Consultations;
- **8,197** Support Group Sessions, serving **42,103** individuals;
- **3,309** Caregiver Education and Training Programs, serving **29,990** individuals;
- **105,299** referrals and follow up calls from our 24/7 Help line;
- **3,070** Community Education Programs, serving **55,933** individuals;
- **1,148** Health Fairs, serving **60,296** individuals; and
- Training for Important Constituencies (individuals trained)
 - Medical Practices: **10,958**
 - Professionals from Health Systems/Long-Term Care Industry: **20,334**
 - Faith-Based Community Leaders: **11,637**
 - Gatekeepers: **15,305**
 - First Responders: **5,929**



The data supports the fact that the Coalition and its staff, year after year, have provided the State with vital and robust person-to-person programs and services. While the Coalition continues its efforts to meet all goals, the current economic landscape and its funding level, along with the anticipated increase in Alzheimer's cases in New York, do not allow the Coalition to keep pace with the increased demand for these critical services without adding more staff via additional funding.

The Coalition is respectfully requesting that the Legislature increase funding for AlzCAP by \$1 million.

Currently there are approximately 427,000 New Yorkers living with Alzheimer's disease and that number is expected to grow to 460,000 by the end of the year. The State of New York has the second highest rate of prevalence of Alzheimer's disease in those 65 and older in the nation – Bronx County has the highest rate of prevalence of any county in the country. There are also an estimated 563,000 informal family caregivers in New York, who themselves are at risk of poor health outcomes; 28% have depression and 17% are in poor physical health. These are the individuals and families who need these services and a lack of additional funding may negatively impact health outcomes for both those living with Alzheimer's and their caregivers.

Alzheimer's disease is a public health crisis in New York and the longer the state decides to underinvest in care and support services, the worse the outcomes will be for individuals living with the disease and their caregivers. Governor Hochul has completely reorganized CDPAP to find \$500 million in Medicaid savings, if her budget team had looked in the successes of AlzCAP, they would have found that according to the University of Albany School of Public Health, AlzCAP has saved the New York \$400 million in Medicaid-paying nursing home placements.¹ This is a real saving. Not only is the state of New York saving millions of dollars, but individuals are staying home and receiving the person-centered care they need and deserve. Therefore, additional investment in the program will continue to bare out savings in the state's ballooning Medicaid budget.

Special Needs Assisted Living Voucher Program for Persons with Dementia

Additional Medicaid savings can be found in the Special Needs Assisted Living Residential (SNALR) Voucher Program for Persons with Dementia. This program, established in the 2018-19 Enacted State Budget as a demonstration program, was permanently moved into law in last year's 2024-25 Enacted State Budget. This program authorizes the Department of Health to issue up to 200 vouchers to subsidize up to 75% of the average monthly cost of a SNALR. This allows individuals living with Alzheimer's or another dementia to remain in the most integrated setting possible, out of a nursing home, and off the Medicaid rolls.

While making the program permanent was a welcome decision, the fact is there has been a waitlist for a voucher since 2021, and there even was a pause instituted in 2023 that kept people from being added to the waitlist. The popularity and need for the program is undeniable.

The Coalition is respectfully requesting the Legislature increase the number of vouchers in the program from 200 to 500.

This investment in the program will save the state money in its Medicaid program, while also ensuring those living with the disease are not prematurely admitted to a nursing home due to financial considerations.

Investing in these programs not only improves the quality of life for those affected by ADRD but also has the potential to reduce long-term healthcare costs by delaying the need for more intensive care services. The cost to New York's Medicaid system for caring for those with ADRD is estimated to be \$5.453 billion, with this figure projected to grow as New Yorkers age and more individuals are diagnosed.

¹ https://www.health.ny.gov/diseases/conditions/dementia/docs/eval_rpt_y1_rpt_3.pdf





Alzheimer's disease is terminal and costly. The disease's impact on the State is immense; however, the Legislature has the ability to invest in three programs that are popular with individuals living the disease, their caregivers, and save the state money. We urge you to consider the profound impact that ***increasing funding for the CEADs by \$3 million, increasing funding for AlzCAP by \$1 million, and increasing the number of SNALR Vouchers to 500*** would have on individuals, families, and communities across New York State. By strengthening these programs, we can provide essential support to those affected by Alzheimer's disease and work towards a future where this condition no longer poses such a significant burden.

The Coalition is dedicated to ensuring all New Yorkers living with Alzheimer's disease or another dementia have access to robust programs that help alleviate both the caregiver and financial burden the disease places upon them and their families. By investing in these programs the Legislature can help accomplish that goal.

Thank you for your time and consideration.

Respectfully Submitted:

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