



ALZHEIMER'S ASSOCIATION, NEW YORK STATE COALITION

Testimony on FY 2026-27 Executive Budget Proposal

Joint Budget Hearing on Health & Medicaid

New York State Senate Finance Committee:
Chair, Senator Liz Krueger
&

New York State Assembly Ways & Means Committee
Chair, Assemblymember J. Gary Pretlow
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Thank you for the opportunity to submit testimony for today's Joint Legislative Budget Hearing on Health and Medicaid.

The Alzheimer's Association is the leading voluntary health organization in 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 thirty years.

Biomarker Precision Testing

In 2024, the Legislature passed, and Governor Hochul enacted, a law which requires health insurance policies and Medicaid to cover biomarker precision medical testing for diagnosis, treatment, or appropriate disease management. This historic law can improve the health outcomes of New Yorkers and help identify and diagnosis Alzheimer's disease – for which there is currently no cure. There is no single test that can determine if a person is living with Alzheimer's or another dementia. Physicians use diagnostic tools combined with medical history and other information, including neurological exams, cognitive and functional assessments, brain imaging (MRI, CT, PET) and cerebrospinal fluid or blood tests to make an accurate diagnosis.

The Food and Drug Administration has cleared the first blood test to aid in diagnosis of Alzheimer's disease. The test detects amyloid plaques, a hallmark of Alzheimer's disease, through a blood draw. This test is less invasive, more affordable, and more accessible than the other more commonly used diagnostic tools. Scientific advancements in biomarker testing must be made available to the general public in order for the full extent of their benefits to be realized. Insurance coverage for all kinds of biomarker testing must keep pace with innovations and advancements in treatment.

It was unfortunate to see the Executive Budget propose rolling-back Medicaid coverage of precision biomarker testing - *Part M: Managed Care Related Proposals of the Health and Mental Hygiene Article VII Legislation*. This is the kind of short-sighted move that will only cost the state significantly more on the back end. Alzheimer's disease already accounts for \$6.8 billion in Medicaid costs, so reducing the easiest form of diagnosis from that state's tool kit to save \$50 million is by our estimation, pennywise and pound foolish. Biomarker testing could democratize the diagnosis of Alzheimer's disease but by rolling back Medicaid coverage, the Executive Budget harms the very people the state claims it wants to help in its Prevention Agenda 2025-2030: New York State's Health Improvement Plan. Therefore, the ***Coalition respectfully requests that the Legislature stand with the New Yorkers living with Alzheimer's and those***



yet to be diagnosed, oppose this harmful proposal and continue to its long-held tradition of tearing down barriers to access and reject it from the Final Budget.

Alzheimer's Community Assistance Program (AlzCAP)

According to the Alzheimer's Association's 2025 Facts and Figures Report, approximately 427,000 individuals aged sixty-five and older are living with Alzheimer's in New York State. This prevalence underscores the critical need for enhanced support services. Alzheimer's disease impacts people in all of New York's sixty-two counties and every single one of your legislative districts.

The same report highlights that 656,000 family caregivers in New York provided 893 million hours of unpaid care in 2025, valued at \$22.6 billion. Over half of these caregivers are living with chronic health conditions, reflecting the significant personal toll of caregiving.

AlzCAP was originally designed to provide evidence-based education and support services to individuals living with dementia and their caregivers, in an effort to postpone or prevent costly nursing home placements and the data suggests that this approach works. Despite the critical services these programs provide, the increasing prevalence of Alzheimer's disease necessitates additional resources to meet the growing demand and yet, there has been NO increase in AlzCAP funding in 10 years. Investing in this program not only improves the quality of life for those affected but also has the potential to reduce long-term healthcare costs by delaying the need for more intensive care services. In 2025, the cost of caring for those with Alzheimer's and other dementia is estimated to cost New York's Medicaid program \$6.8 billion, with this figure projected to grow as New Yorkers age and more individuals are diagnosed.

Furthermore, in the last iteration of the AlzCAP grant's Request for Proposals, an additional and important priority was added and that was the provision of Brain Health and Risk Reduction education for all New Yorkers. This addition is consistent with the NYS Coordinating Council for Alzheimer's Disease and Other Dementia's (Coordinating Council) top priority; *Risk Reduction and Early Detection/Diagnosis of Alzheimer's and Related Dementia*. ***Therefore, the Coalition respectfully requests that the Legislature include an additional \$3 million in funding for AlzCAP in the Final Budget to help the state meet its caregiver demands.***

Centers for Excellence for Alzheimer's Disease (CEADs)

Similarly, the Centers for Excellence for Alzheimer's Disease (CEADs) offer comprehensive evaluation, diagnosis, and treatment services, serving as innovative leaders in the management of Alzheimer's disease. Now that there are new, disease targeting FDA treatments for people in the earliest stage of Alzheimer's, the need for the CEAD's diagnostic services are more critical than ever and again, in keeping the with the Coordinating Council's top priority.



The CEADs were intended to serve as diagnostic hubs but are currently bogged down with waiting lists that in some circumstances are more than one year, 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 to those 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 diagnosis took so long that you are now ineligible for treatment is beyond heartbreaking. New Yorkers deserve better.

We cannot be the nation's leader in healthcare, if we cannot get individuals screened in an appropriate amount of time! Alzheimer's disease is expensive and 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. ***Therefore, the Coalition respectfully requests that the Legislature include an additional \$3 million in funding for the CEADs in the Final Budget to help alleviate the wait time and ensure New Yorkers have an early and accurate diagnosis.***

Increased investments in both the AlzCAP and CEAD programs would enable them to expand their reach, improve service delivery, support more individuals and families affected by this devastating disease, ensure that more people (including those that are disproportionately impacted by dementia) have access to FDA approved treatments and educate ALL New Yorkers about this importance of brain health. 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.

Special Needs Assisted Living Voucher Program for Persons with Dementia

New York's Medicaid spending is unstable without finding substantial savings, fortunately for the Legislature there is a program that is already in place, which is supported by the individuals it serves, and popular with the industry providers. The Special Needs Assisted Living Residential (SNALR) Voucher Program for Persons with Dementia was established in the 2018-19 Enacted State Budget as a demonstration program and was permanently moved into statute in the 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 Medicaid.

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; however, 200 vouchers for the entire state of New York is woefully inadequate. The Coalition believes it is time to expand this program and offer its savings and support to more New Yorkers; therefore, ***the Coalition respectfully requests that the Legislature increase the number of vouchers in the program from 200 to 500 in the Final Budget.*** This investment 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.



Establish a Special Needs Assisted Living Demonstration Program

We believe it is in the best interest of the state, caregivers, and—most importantly—individuals living with Alzheimer’s disease or other dementias to ensure access to a broad range of care options. Under the current framework, Medicaid-eligible individuals with specialized dementia-related care needs have limited choices. For many New Yorkers, once remaining at home is no longer feasible, a nursing home becomes the only option.

Establishing and funding the demonstration program outlined in S.8635 (Fernandez) / A.9418 (Paulin) would create a Special Needs Assisted Living Demonstration Program authorizing up to three assisted living programs statewide to serve individuals with special needs, including, but not limited to, those with dementia or cognitive impairments. We believe that piloting this program would quickly demonstrate significant cost-effectiveness and generate substantial Medicaid savings for the state. Beyond potential cost savings, this person-centered program would allow individuals with dementia to receive care in the least restrictive setting possible. Therefore, ***the Coalition respectfully requests that the Legislature establish and fund the Special Needs Assisted Living Demonstration Program, as outlined in S.8635 (Fernandez) / A.9418 (Paulin), in the Final Budget.***

Alzheimer’s disease is terminal and expensive. The disease’s impact on the state budget is immense; however, the Legislature can reject unnecessary barriers to diagnosis, invest in existing programs that are popular with individuals living the disease and their caregivers, AND save the state money.

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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