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Alzheimer's Association, New York State Coalition

Testimony on the FY 2024-25 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 Helene Weinstein

January 23, 2024

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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.

Alzheimer's Community Assistance Program (AlzCAP)

The Coalition receives support for these activities from the Alzheimer's Community Assistance Program (AlzCAP), funded by the NYS Department of Health (DOH). AlzCAP is a statewide program providing a comprehensive array of community-based services for individuals with Alzheimer's disease and other dementias and their caregivers.

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. Over the course of the last six years, 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. Even through the height of the COVID-19 pandemic, the Coalition and its staff deftly pivoted to offering virtual options and continued serving individuals living with Alzheimer's disease and other dementias and their caregivers.

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, provide the state vital and robust personto-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 capacity.

The Coalition is respectfully requesting that the Legislature increase funding for the program to \$7 million. Currently there are over 425,000 New Yorkers living with Alzheimer's disease and that number is expected to grow to 460,000 by 2025. 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. During her Executive Budget address, Governor Hochul put out the call to save an additional \$1 billion in Medicaid costs. 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 Therefore, additional investment in the program will continue to bare out savings in the state's ballooning Medicaid budget.

Special Needs Assisted Living Voucher Demonstration Program for Persons with Dementia

Additional Medicaid savings can be found in the Special Needs Assisted Living Residential (SNALR) Voucher Demonstration Program for Persons with Dementia. This program, established in the 2018-19 Enacted State Budget, 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.

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

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The Executive Budget proposes to move the voucher program from its current demonstration phase to a permanent program. **The Coalition fully supports this decision.** While making the program permanent is welcome, the fact is there has been a waitlist for a voucher since 2021 and the state paused any additional additions to the waitlist in 2023. The popularity and need for the program is undeniable. **Therefore, 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.

Alzheimer's disease is terminal and costly. The disease's impact on the state budget is immense; however, the Legislature has the ability to invest in two programs that are popular with individuals living the disease, their caregivers, and save the state money. By increasing funding for the Alzheimer's Community Assistance Program to \$7 million and increasing the number of Special Needs Assisted Living Residential vouchers to 500, the state can address the demands of the disease and save money in its Medicaid budget.

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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