



The Honorable Nancy Pelosi  
Speaker  
U.S. House of Representatives  
Washington, DC 20515

The Honorable Kevin McCarthy  
Minority Leader  
U.S. House of Representatives  
Washington, DC 20515

The Honorable Chuck Schumer  
Majority Leader  
U.S. Senate  
Washington, DC 20510

The Honorable Mitch McConnell  
Minority Leader  
U.S. Senate  
Washington, DC 20510

November 5, 2021

Dear Speaker Pelosi, Leader McCarthy, Majority Leader Schumer, and Leader McConnell:

On behalf of the Alzheimer's Association and the Alzheimer's Impact Movement (AIM), including our nationwide network of advocates, thank you for your continued bipartisan leadership on issues important to Americans living with Alzheimer's and other dementia, and their caregivers. We thank you for including additional funding for home- and community-based services (HCBS), making permanent the Money Follows the Person program, reauthorization and modernization of the Elder Justice Act, and other provisions important to people living with dementia and their families in the Build Back Better Act.

An estimated 6.2 million Americans age 65 and older are living with Alzheimer's dementia in 2021. Total payments for all individuals with Alzheimer's or other dementias are estimated at \$355 billion (not including unpaid caregiving) in 2021. Medicare and Medicaid are expected to cover \$239 billion or 67 percent of the total health care and long-term care payments for people with Alzheimer's or other dementia. Total payments for health care, long-term care, and hospice care for these individuals are projected to increase to more than \$1.1 trillion in 2050, not adjusted for inflation. These mounting costs threaten to bankrupt families, businesses, and our health care system. Unfortunately, our work is only growing more urgent.

### **Home- and Community-Based Services: Needs of the Alzheimer's and Dementia Community**

People living with dementia and their caregivers often prefer to keep the individual living in the home for as long as is manageable. In fact, 70 percent of people with Alzheimer's live in the community, and states are driving much of the development of and better access to HCBS. State governments can reduce long-term costs and increase access to person-centered care in home and community settings including respite and adult day, regardless of age or financial status through Medicaid and other state-supported programs.

Several states are implementing innovative solutions to address Alzheimer's in the Medicaid and non-Medicaid spaces by developing critical, cost-effective, dementia-specific HCBS programs. These programs are allowing people with dementia and their caregivers to access services and supports that are uniquely tailored to meet their needs, allowing them to remain in their homes and communities longer and to enjoy a greater quality of life. Medicaid should adopt a core set of home- and community-based services that are specifically designed for people with dementia. A core set of

HCBS, in addition to other services, will allow people with Alzheimer's to continue to remain in their communities and be independent for as long as possible

### **Home- and Community-Based Services: the Impact on Family Caregivers**

While 83 percent of the help provided to older adults in the United States comes from family members, friends, or other unpaid caregivers, nearly half of all caregivers who provide help to older adults do so for someone with Alzheimer's or another dementia. Of the total lifetime cost of caring for someone with dementia, 70 percent is borne by families — either through out-of-pocket health and long-term care expenses or from the value of unpaid care. Alzheimer's takes a devastating toll on caregivers. Compared with caregivers of people without dementia, twice as many caregivers of those with dementia indicate substantial emotional, financial, and physical difficulties.

Caregivers for those living with Alzheimer's — usually family and friends — face substantial challenges. In 2020, more than 11 million unpaid caregivers provided an estimated 15.3 billion hours of unpaid care to people with Alzheimer's and other dementia, at an economic value of over \$257 billion. Of the unpaid Alzheimer's and dementia caregivers, 86 percent have provided care for at least the past year, and well over half have been providing care for four or more years.

Home- and community-based services allow people with dementia to remain in their homes while providing family caregivers much needed support. These services empower caregivers to provide quality care for their loved ones while giving them an opportunity to manage and improve their own health.

Important provisions within the Build Back Better Act add much needed funding to home- and community-based services, permanently authorize protections against spousal impoverishment, and make permanent the Money Follows the Person program. Medicaid pays for long-term care services and nursing homes for some people with very low income and low assets, and the high use of these services by people with dementia translates into high costs to Medicaid. Average annual Medicaid payments per person for Medicare beneficiaries with Alzheimer's or other dementias were 23 times as great as average Medicaid payments for Medicare beneficiaries without Alzheimer's or other dementia. These important programs will help families and caregivers from becoming poverty-stricken in order for their loved ones to qualify for long-term care from Medicaid.

### **Permanent Extension of the Independence at Home Demonstration**

More than 95 percent of people with Alzheimer's disease and other dementia have one or more other chronic conditions. Medicare beneficiaries who have Alzheimer's or other dementia and a coexisting medical condition have higher average per-person payments for most health care services than Medicare beneficiaries with the same medical condition but without dementia. As a result, care coordination — effective communication among medical and community care providers and connecting an Alzheimer patient and his/her family with the services they need — is crucial to providing better medical care and to increasing the opportunity to remain at home. The Alzheimer's Association and AIM have been longtime supporters of the Independence at Home model which provides high-cost Medicare beneficiaries, including those with Alzheimer's, with coordinated, primary care services in lower-cost settings, rather than more expensive institutional settings. The provisions in the Build Back Better Act to make the Independence at Home model permanent will allow people living with dementia to live at home for longer.

## **Palliative Care and Hospice Education and Training**

Alzheimer's is a progressive, neurodegenerative and fatal disease for which there is currently no treatment or cure. Palliative and hospice care can improve both the quality of care and quality of life for those with advanced dementia. A recent study shows that nursing home residents with dementia who receive palliative care at the end of life, compared with those who do not receive such care, are up to 15 times less likely to die in a hospital, nearly 2.5 times less likely to have a hospitalization in the last 30 days of life, and up to 4.6 times less likely to have an emergency room visit in the last week of life. Individuals with advanced dementia who are enrolled in hospice have a lower rate of dying in the hospital, a lower rate of hospitalization in the last 30 days of life, and better symptom management. Additionally, nearly half of all people with dementia die in hospice care. The Alzheimer's Association and AIM support the provisions in the Build Back Better Act that would ensure an adequate, well-trained palliative care workforce through workforce training, education and awareness, and enhanced research.

## **Paid Leave**

As noted above, caring for a person with Alzheimer's or other dementia extends to millions of Americans. It can include providing daily caregiving, participating in decision making, or simply caring about a person living with dementia. Approximately one-quarter of dementia caregivers are "sandwich generation" caregivers - meaning that they care not only for an aging parent, but also for children under age 18. Enabling a family caregiver to take paid family and medical leave when a loved one living with dementia is in need would greatly help ease the financial burden placed on family caregivers.

Paid family and medical leave directly addresses both the needs of individuals living with Alzheimer's and other dementia and their communities of support, including caregivers. In the past decade, nearly one in five workers left the workforce earlier than planned in order to care for an ill spouse or aging family member.

The current lack of a national comprehensive family leave plan when an individual needs time to care for a loved one living with Alzheimer's or dementia is not only an emotional cost for families – it has direct implications tied to the strength of our economy and workforce. The inclusion of paid family leave provisions ring particularly true with the millions of individuals who are caregivers for those living with Alzheimer's and dementia: no American should have to choose between a job and paycheck or taking care of themselves and a loved one.

## **Lifespan Respite Care**

The Alzheimer's Association and AIM have been longtime supporters of the Lifespan Respite Care program and support the inclusion of an additional \$5 million in funding. Lifespan Respite systems require that respite become more accessible and available to all family caregivers. As importantly, Lifespan Respite systems build respite capacity and improve quality by requiring states to focus on respite provider/volunteer training and recruitment, start-up of new respite services, and affordability issues for family caregivers who struggle financially, but are not eligible for any publicly funded respite services. This program is beneficial to the family members, friends or other unpaid caregivers who provide eighty-three percent of the help to older adults in the United States.

### **Older Americans Act funding**

The Older Americans Act (OAA) provides support to America's seniors in their homes and communities by organizing and delivering nutritional programs, in-home services, transportation, legal services, elder-abuse prevention and caregiver support. These programs within the OAA have an enormous impact on dementia caregivers. Compared with caregivers of people without dementia, twice as many caregivers of those with dementia indicate substantial emotional, financial and physical difficulties. These dedicated caregivers would greatly benefit from increased resources, training and support to help them navigate the strain of caregiving and improve their health and quality of life. The Association and AIM strongly support the inclusion of additional funding for the Older Americans Act.

### **Reauthorization and Modernization of Elder Justice Act**

Given the growing population of people living with dementia, police, firefighters, emergency personnel, and social workers will increasingly encounter these vulnerable individuals, and working with them can be fundamentally different from working with other older victims of abuse or exploitation. The trauma of elder abuse can result in premature death, the deterioration of physical and psychological health, destruction of social and familial ties, devastating financial loss, and more. Older adults can be mistreated in multiple settings by family members, friends and neighbors, professionals, and strangers.

The Alzheimer's Association and AIM support the inclusion of the Elder Justice Reauthorization and Modernization Act in the Build Back Better Act, which would advance key solutions to the crisis of elder abuse, neglect and exploitation. It would ultimately create and fund a coordinated elder justice infrastructure in the U.S. These important provisions would greatly enhance adult protective services and the long-term care ombudsman program and create innovative solutions for the long-term care staffing crisis. Additionally, it funds programs that are much needed by older adults including addressing social isolation and loneliness, medical-legal partnerships, and expanding senior legal hotlines.

Again, thank you for your leadership on issues important to Americans living with Alzheimer's and other dementias, and their caregivers. We look forward to working with you on these important provisions in the budget reconciliation process. If you have any questions, please contact Rachel Conant, Vice President, Federal Affairs, at [rconant@alz-aim.org](mailto:rconant@alz-aim.org) or at 202.638.7121.

Sincerely,



Robert Egge  
Chief Public Policy Officer  
Executive Vice President, Government Affairs  
Alzheimer's Association