



The Honorable Debbie Dingell
U.S. House of Representatives
Washington, D.C. 20515

The Honorable Maggie Hassan
U.S. Senate
Washington, D.C. 20510

The Honorable Sherrod Brown
U.S. Senate
Washington, D.C. 20510

The Honorable Bob Casey
U.S. Senate
Washington, D.C. 20510

April 26, 2021

Dear Representative Dingell and Senators Hassan, Brown, and Casey:

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 dementias, and their caregivers. We especially appreciate your work to address the important home- and community-based services (HCBS) needs of individuals living with Alzheimer's and other dementia. We appreciate your efforts to develop and seek stakeholder input on the Home and Community-Based Services Act discussion draft, and we strongly support your goals of increased access to home- and community-based services for Medicaid beneficiaries.

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 dementias. Total payments for health care, long-term care, and hospice care for people with Alzheimer's and other dementias are projected to increase to more than \$1.1 trillion in 2050. 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 care, 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 services, 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

People living with Alzheimer's or other dementias make up a large proportion of all elderly people who receive adult day services and nursing home care. Additionally, 32 percent of individuals using home

health services have Alzheimer's or other dementias. Persons affected by dementia use a wide range of long-term supports and services, for example:

Adult day services. Thirty-one percent of individuals using adult day services have Alzheimer's or other dementias. Overall, 69 percent of adult day services offer specific programs for individuals with Alzheimer's or other dementias. The median cost of adult day services is \$75 per day, and the cost of adult day services has increased 2.9 percent annually over the past five years.

Residential care facilities. Forty-two percent of residents in residential care facilities, including assisted living facilities, have Alzheimer's or other dementias. Fifty-eight percent of residential care facilities offer programs for residents with dementia. The median cost for care in an assisted living facility is \$4,051 per month, or \$48,612 per year, and the cost of assisted living has increased three percent annually over the past five years.

Nursing home care. Forty-eight percent of nursing home residents have Alzheimer's or other dementias. Nursing home admission by age 80 is expected for 75 percent of people with dementia compared with only four percent of the general population. In all, an estimated two-thirds of those who die of dementia do so in nursing homes, compared with 20 percent of people with cancer and 28 percent of people dying from all other conditions. The average cost for a private room in a nursing home is \$290 per day (\$105,850 per year) and the average cost of a semi-private room is \$25 per day (\$93,075 per year). The cost of nursing home care has increased three percent annually over the past five years for both private and semi-private rooms.

Respite. Given the demands on and responsibilities of caregivers, respite is critical to their health and well-being, and may allow individuals with dementia to remain in the home longer. Use of respite care by dementia caregivers has increased substantially, from 13 percent in 1999 to 27 percent in 2015. This is consistent with the growing demand the Alzheimer's Association hears from our constituents. Yet availability of respite programs in the community is limited. We applaud Congress's passage of the *Lifespan Respite Care Reauthorization Act* (S. 995/H.R. 2035) to meet this demand.

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 dementias, 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. Nearly one-fourth of Alzheimer's and dementia caregivers are “sandwich generation” caregivers — caring for both someone with the disease and a child or grandchild.

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.

Medicaid LTSS Eligibility and Services

The strict income and asset limits for Medicaid long-term services and supports (LTSS) eligibility mean that older adults are only eligible if they have low incomes or have already spent down their savings and other assets on their LTSS needs. To avoid the impacts of spend-down on an already vulnerable population, the federal maximum should be the baseline for all states on income, assets, and home equity limits.

In addition to financial eligibility, older adults seeking Medicaid LTSS coverage must also meet functional eligibility criteria, typically by demonstrating a need for assistance with daily self-care. In most cases, individuals seeking LTSS must show that they require an institutional level of care, typically the level of care delivered at a nursing facility. An institutional level of care is required for admission to a nursing facility and for receipt of HCBS, including assisted living and adult foster care. Requiring an institutional level of care does not mean that the individual must then move to an institution; it only signifies the level of care that is required, which may then be provided in the home, community, or institution.

To ensure that individuals with dementia are able to access needed Medicaid long-term services and supports, functional eligibility criteria needs to include and properly weight issues related to cognitive impairment, particularly in regard to prompting, monitoring, and supervision of daily activities.

Workforce

A strong HCBS workforce is needed to ensure quality care. Direct-care workers, such as nurse aides, home health aides, and personal and home care aides provide most of the paid long-term care to older adults living at home or in residential settings. Direct-care workers have difficult jobs, and they may not receive the training necessary to provide dementia care. Turnover rates are high among direct-care workers, and recruitment and retention are persistent challenges. Inadequate education and challenging work environments have also contributed to higher turnover rates among nursing staff across care environments. Studies have shown that staff training programs to improve the quality of dementia care in nursing homes and hospitals have modest benefits. The Alzheimer's Association and AIM support the recommended changes to federal requirements from The National Academies of Sciences, Engineering, and Medicine for general direct-care worker training, including an increase in training hours from 75 to 120, and instructional content with a stronger focus on knowledge and skills related to caring for individuals with Alzheimer's and other dementias.

The Alzheimer's Association and AIM support the enactment of legislation that would enable direct-care workers to provide person-centered dementia care based on thorough knowledge of the care recipient and their needs, advance optimal functioning and high quality of life, and incorporate problem-solving approaches in care practices. We support investing in strengthening the HCBS workforce through increased wages, benefits, support, and career advancement opportunities. This is especially important as the majority of home care workers are disproportionately women of color.

PACE Expansion

One important program available to dual-eligible seniors is the Program of All-Inclusive Care for the Elderly (PACE) model. This model serves individuals who are age 55 or older, certified by their state to need nursing home care, able to live safely in the community at the time of enrollment, and live in a PACE service area. PACE programs are able to provide the entire continuum of care and services to

seniors with chronic care needs while maintaining their independence in their homes for as long as possible. The PACE program includes important services such as adult day care, physical and occupational therapies, meals, medical care, home health care, and others. We urge the Committee to explore options to expand the number of PACE service areas and expand the PACE model to individuals not currently eligible, such as people under 55, and Medicare-only beneficiaries. A dementia-specific PACE program would greatly benefit persons living with dementia and their families as it would allow people to age in place longer and access necessary home- and community-based services.

The Alzheimer's Association and AIM are proud to support the PACE Plus Act (S. 1162) introduced by Senator Casey (D-PA). The PACE Plus Act would strengthen and expand access to the PACE program by increasing the number of PACE programs, expanding the number of seniors eligible to receive PACE, and incentivizing states to grow their PACE programs. We urge Congress to move this important piece of legislation.

Money Follows the Person and Spousal Impoverishment

The Alzheimer's Association and AIM thank you for including extensions and eligibility adjustments for the Medicaid Money Follows the Person (MFP) program and protections from spousal impoverishment for married individuals receiving Medicaid-funded HCBS in the Consolidated Appropriations Act of 2021. 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 dementias. These important extensions will help families and caregivers from becoming poverty-stricken in order for their loved ones to qualify for long-term care from Medicaid. We also urge Congress to make permanent MFP and spousal impoverishment protections so that married couples can afford to stay together at home when one spouse develops a chronic illness or disability.

Underserved Communities

As we work to expand and improve care options, we must ensure that populations who have been historically underserved have access to culturally-appropriate services. According to the *2021 Alzheimer's Disease Facts and Figures*, most studies indicate that older Black Americans are about twice as likely to have Alzheimer's or other dementias as older Whites, and some studies indicate older Hispanics are about one and one-half times as likely to have Alzheimer's or other dementias as older Whites. Yet a study of Medicaid beneficiaries with a diagnosis of Alzheimer's indicated that Black Americans had significantly higher costs of care than Whites or Hispanics, primarily due to more inpatient care and more comorbidities. There may be a variety of reasons for this disparity, such as later-stage diagnosis, delays in timely access to primary care, and a lack of care coordination among them. Furthermore, of Alzheimer's family caregivers in the United States, 10 percent are Black, 8 percent are Hispanic, and 5 percent are Asian. These individuals need access to high-quality, culturally-appropriate services and supports, as stated in Strategy 3A of the *National Plan to Address Alzheimer's Disease*.

Additionally, it is important to include individuals living with younger-onset Alzheimer's disease and other dementias, defined as those who are under the age of 65, in current programs. Individuals living with younger-onset face unique challenges when it comes to family, work, and finances. They may be parenting young children at home, or still be working as the primary income provider for their families. Due to their young age, they may have more trouble receiving an accurate diagnosis, and even family and friends might question their diagnosis. The stigma associated with younger-onset Alzheimer's can have a significant impact on their well-being and quality of life. The services provided under the Older Americans Act (OAA) are particularly helpful for individuals with younger-onset Alzheimer's and related

dementias who need assistance with activities of daily living. Services also provide vital assistance, support, and respite to family caregivers through the National Family Caregiver Support Program and help to maintain the independence of the individual living with the disease. In the 2017 *National Plan to Address Alzheimer's Disease*, the Plan's Advisory Council recommended that Congress amend the OAA to allow additional services to be provided to younger adults living with dementia. With the passage of the reauthorization of OAA, the *Supporting Older Americans Act* (H.R. 4334), key provisions of the *Younger-Onset Alzheimer's Disease Act* (H.R. 1903/S. 901) were included. We urge the Congress to work with the Department of Health and Human Services and the Government Accountability Office to further identify the gaps in needs of individuals living with younger-onset Alzheimer's and other dementias.

Again, thank you for your leadership on issues important to Americans living with Alzheimer's and other dementias, and their caregivers. We appreciate the opportunity to comment on the Home and Community-Based Access Act. If you have any questions, please contact Rachel Conant, Vice President, Federal Affairs, at rconant@alz-aim.org or at 202.638.7121.

Sincerely,

A handwritten signature in black ink, appearing to read 'R. Egge', with a stylized flourish at the end.

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