



## **Alzheimer's Association and Alzheimer's Impact Movement Statement for the Record**

### **United States Senate Committee on Aging Hearing on "An Economy That Cares: The Importance of Home-Based Services"**

**March 23, 2022**

The Alzheimer's Association and Alzheimer's Impact Movement (AIM) appreciate the opportunity to submit this statement for the record for the Senate Committee on Aging hearing "*An Economy That Cares: The Importance of Home-Based Services.*" The Association and AIM thank the Committee for its continued leadership on issues important to the millions of people living with Alzheimer's and other dementia and their caregivers. Among other issues, this statement highlights the importance of home- and community- based (HCBS) services..

The Alzheimer's Association is the world's leading voluntary health organization in Alzheimer's care, support, and research. It is the nonprofit with the highest impact in Alzheimer's research worldwide and is committed to accelerating research toward methods of treatment, prevention, and, ultimately, a cure. AIM is the advocacy affiliate of the Alzheimer's Association, working in strategic partnership to make Alzheimer's a national priority. Together, the Alzheimer's Association and AIM advocate for policies to fight Alzheimer's disease, including increased investment in research, improved care and support, and development of approaches to reduce the risk of developing dementia.

#### **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, an estimated 65 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, 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.* Twenty-eight percent of individuals using adult day services have Alzheimer's or other dementias. Ten percent of adult day services specialize in caring for individuals with Alzheimer's disease or other dementias. The median cost of adult day services is \$75 per day, and the cost of adult day services has increased 1.5 percent annually over the past five years.

*Residential care facilities.* Thirty-four 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 \$4,429 per month, or \$53,148 per year, and the cost of assisted living has increased 3.6 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 \$299 per day (\$109,135 per year) and the average cost of a semi-private room is \$263 per day (\$95,995 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 2021, more than 11 million unpaid caregivers provided an estimated 16 billion hours of unpaid care to people with Alzheimer's and other dementias, at an economic value of over \$271.6 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. Approximately 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.

Important provisions within recent legislation would add much needed funds 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 dementias. 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.

### **Conclusion**

The Alzheimer's Association and AIM appreciate the steadfast support of the Committee and its continued commitment to advancing issues important to the millions of families affected by Alzheimer's and other dementia. We look forward to working with the Committee in a bipartisan way to address the challenges facing the dementia community including increasing funding for home- and community-based services.