Alzheimer’s Association and Alzheimer’s Impact Movement Statement for the Record

United States House of Representatives Committee on Energy and Commerce, Health Subcommittee Legislative Hearing on “Legislative Proposals to Increase Medicaid Access and Improve Program Integrity”

April 30, 2024

The Alzheimer’s Association and Alzheimer’s Impact Movement (AIM) appreciate the opportunity to submit this statement for the record for the House Energy and Commerce, Health Subcommittee legislative hearing on “Legislative Proposals to Increase Medicaid Access and Improve Program Integrity.” We are grateful to the Subcommittee and bill sponsors for leading bipartisan bills to strengthen the Medicaid program and ensure our country continues advancing policies that improve the lives of people living with dementia, and their families.

Founded in 1980, the Alzheimer’s Association is the world’s leading voluntary health organization in Alzheimer’s care, support, and research. Our mission is to eliminate Alzheimer’s and other dementia through the advancement of research, to provide and enhance care and support for all affected, and to reduce the risk of dementia through the promotion of brain health. AIM is the Association’s advocacy affiliate, working in a 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 the development of approaches to reduce the risk of developing dementia.

Nearly seven million Americans age 65 and older are living with Alzheimer’s dementia in 2024. Total payments for all individuals with Alzheimer’s or other dementias are estimated at $360 billion (not including unpaid caregiving) in 2024. Medicare and Medicaid were expected to cover $231 billion or 64 percent of the total health care and long-term care payments for people with Alzheimer’s or other dementias, which are projected to increase to nearly $1 trillion by 2050. These mounting costs threaten to bankrupt families, businesses, and our health care system. Unfortunately, our work is only growing more urgent.

According to the Alzheimer’s Association’s 2024 Alzheimer’s Disease Facts and Figures, 24 percent of older individuals with Alzheimer’s or other dementias who have Medicare also have Medicaid coverage, compared with 10 percent of individuals without dementia. For beneficiaries dually eligible for Medicare and Medicaid, the average annual Medicaid payments per person for Medicare beneficiaries with Alzheimer’s or other dementia were 23 times as great as the average Medicaid payments for Medicare beneficiaries without dementia. Much of the difference in payments for beneficiaries with Alzheimer’s or other dementias compared with other beneficiaries is due to the costs associated with nursing home care. Total Medicaid spending for people with Alzheimer’s or other dementias is projected to be $68 billion in 2024.

**Money Follows the Person**
The high utilization rate of long-term care services and nursing home services by people with dementia translates into high costs to the Medicaid program. While it is well known that Alzheimer’s imposes a huge out-of-pocket financial hardship on families, most individuals with Alzheimer’s will spend down their income and assets and eventually qualify for Medicaid.

Extending programs such as the Money Follows the Person (MFP) and spousal impoverishment protections for married individuals receiving Medicaid-funded home- and community-based services (HCBS) will help families and caregivers from becoming poverty-stricken for their loved ones to qualify for long-term care from Medicaid. The MFP program benefits individuals transitioning from institutional settings, such as nursing homes, back into the community, and provides funding and support services to assist with this transition, aiming to promote independence and improve the quality of life for individuals, such as those with Alzheimer’s or other dementia, who may prefer to receive care in a less restrictive environment.

We support extensions and eligibility adjustments for the Money Follows the Person program and protections from spousal impoverishment for married individuals receiving Medicaid-funded HCBS. As the MFP Program is set to expire on September 30, 2027, H.R. 8109 would amend the Deficit Reduction Act of 2005 to make the Money Follows the Person program permanent while also permanently authorizing protections against spousal impoverishment. Medicaid pays for long-term care services and nursing homes for some people with very low incomes and assets, and the high use of these services by people with dementia translates into high costs to Medicaid. These vital extensions aim to prevent families and caregivers from falling into poverty while ensuring their loved ones can access Medicaid-funded long-term care services.

**Protections Against Spousal Impoverishment**

Most people with Alzheimer’s or other dementias who live at home receive unpaid help from family members and friends, while some also receive paid home- and community-based services, such as personal care and adult day care. People with Alzheimer’s or other dementias make up a large proportion of all older adults who receive adult day services and nursing home care.

Between 2010 and 2020, Medicaid spending on HCBS increased from 48 percent to 62 percent of total long-term services and supports expenditures. Increases in spending may have been due to a variety of factors, including more people being diagnosed with Alzheimer’s dementia, more people using home care, an increase in the number of coexisting medical conditions, more intensive use of home care services, and an increase in Medicaid coverage for older adults. However, few individuals with Alzheimer’s or other dementias have sufficient long-term care insurance or can afford to pay out of pocket for long-term care services for as long as the services are needed.

Spousal impoverishment protections are designed to prevent the healthy spouse from becoming financially destitute due to the high cost of home and community-based care services for their partner, such as individuals living with dementia or other conditions requiring extensive care. And, most families lack the means to independently finance long-term services support for someone with dementia. When determining Medicaid eligibility, Medicaid considers the couple’s joint assets and the income of the individual applying. Assets are cash and property holdings, such as 401(k) retirement plans, bank accounts, land, personal property, and anything else an individual owns which can be changed to cash for food or shelter. Income includes pensions or other sources, including money the “healthy” spouse needs to live on. This provision
significantly imperils the financial future of the spouse without dementia, who may need to live years or decades on those retirement savings. To partially remedy this, Congress and the states through the Medicaid program have instituted spousal impoverishment protections.

Medicaid spousal impoverishment rules allow the spouse who remains in the community to keep a certain level of income and assets as their spouse receives Medicaid coverage for long-term care services. This ensures that the spouse receiving care can qualify for Medicaid without leaving the other spouse without the means to support themselves. These protections are crucial for families dealing with dementia or other long-term care needs, as the costs associated with care can quickly deplete savings and assets, leaving the healthy spouse in a precarious financial situation. The Alzheimer's Association encourages states to extend asset limits to the federal maximum to offer maximum protections for families affected by dementia. As the expansion of the spousal impoverishment protection is set to expire on September 30, 2027, H.R. 8110 would amend the Social Security Act to make permanent states’ option to extend protections against spousal impoverishment for recipients of HCBS under Medicaid, such as individuals living with Alzheimer’s or other dementia.

**Conclusion**

The Alzheimer’s Association and AIM appreciate the Committee’s steadfast support and commitment to advancing issues important to the millions of individuals living with Alzheimer’s and other dementia, and their caregivers. We look forward to working with the Subcommittee and other members of Congress in a bipartisan way to strengthen the Medicaid program by making the Money Follows the Person program permanent and extending protections against spousal impoverishment for recipients of home- and community-based services.