

February 27, 2025

The Honorable John Thune
Leader
United States Senate
Washington, DC 20510

The Honorable Mike Johnson
Speaker
United States House of Representatives
Washington, DC 20515

The Honorable Chuck Schumer
Minority Leader
United States Senate
Washington, DC 20510

The Honorable Hakeem Jeffries
Minority Leader
United States House of Representatives
Washington, DC 20515

Dear Majority Leader Thune, Minority Leader Schumer, Speaker Johnson, and Minority Leader Jeffries,

We, the undersigned organizations, urge you to oppose and remove the massive cuts to Medicaid and the Supplemental Nutrition Assistance Program (SNAP) in the proposed budget resolution. We are concerned about the negative impact these deep cuts will have on all citizens living with chronic disease and other disabilities, but we are writing to draw your attention to how devastating they will be on those with Alzheimer's disease and related diseases (ADRD), and their family caregivers.

Today there are more than 7 million Americans living with Alzheimer's, with no immediate cure in sight. Of these, as many as 200 thousand are younger than age 65, with what is known as early-onset Alzheimer's disease. Regardless of age of onset, costs of Alzheimer's care are expensive and primarily fall on families (70 percent) and the Medicaid program (16 percent). This is because most care costs are for non-medical (i.e., custodial) services — such as at-home help with bathing, eating, and using the bathroom.

Almost all people living with Alzheimer's are enrolled in the Medicare program. However, due to high out-of-pocket costs and lack of long-term care insurance coverage, about one in four (24%) of those are "dual eligible" and rely on Medicaid coverage. Medicaid covers services that Medicare does not, such as long-term care in nursing homes, assisted living, and at-home care. Home- and community-based long-term care helps patients with routine self-care tasks, such as eating, bathing, and dressing, and household activities, such as preparing meals, managing medication, and doing laundry.

More broadly, many of our nation's seniors are living in poverty (10%) or near poverty (22%) and are unlikely to be able to afford paid help. Medicaid coverage helps many of the most vulnerable adults with ADRD in our communities, and its necessity is only going to increase as our population ages. Some states provide vision, dental, and hearing care for adult Medicaid beneficiaries, often the only way adults may obtain that coverage. Medicaid also

covers premiums, deductibles, co-payments, and out-of-pocket costs for acute care services, which are often cost prohibitive for seniors and disabled adults (e.g. individuals with early-onset Alzheimer's disease) with low or no incomes. In addition—depending on the state—Medicaid may cover in-home physical and occupational therapy, telehealth consults, adult day care programs, medical and nonmedical transportation, emergency call systems (e.g. Lifeline pendants), and respite for family caregivers; as well as incontinence products, shower benches, wheelchairs and other equipment including the cost of home adaptations for people with mobility challenges. In addition, because nearly half (45%) of Medicaid beneficiaries with Alzheimer's live alone, they may not have regular access to unpaid caregiving from a family member.

Perhaps most significantly, wholesale cuts to the Medicaid program will increase costs to states for Alzheimer's-related care. Research cited by the Family Caregivers Alliance shows that when basic assistance for the needs of daily life is not available, frail older adults wind up in high-cost settings—notably hospitals and nursing homes—and overall costs increase. **Home care services are at greatest risk of major cuts because they are optional under Medicaid while nursing home care is mandatory.** According to the 2023 LTSS Expenditure Report, among states reporting, nearly two-thirds of Medicaid funding for long-term care (63%) was spent on home- and community-based services aimed at keeping people of all ages out of institutions.

The cost of care at home is usually significantly lower than in an institution. The Kaiser Family Foundation reports that, in 2023, the national median annual cost of a private nursing home room was \$116,800 annually, while the median cost of a home health aide was \$68,640. Many people with Alzheimer's disease in nursing homes do not need to be there, but they are placed there due to prohibitive costs related to home care for families paying out of pocket.

The eligibility criteria for receiving Medicaid-covered home- and community-based services vary by state. The proposed sharp cuts to Medicaid supported by some in Congress and included in the current bill text will put states with higher aging populations at a disadvantage. Required cuts to Medicaid would accelerate over time, just as an increasing number of baby boomers will begin to need home- and community-based services.

This will not only put their physical and financial health in jeopardy but will also increase costs to states as care gets shifted to high-cost settings such as emergency rooms and nursing homes. On behalf of the millions of American families facing Alzheimer's disease and related dementias, we implore you to oppose and remove proposed Medicaid cuts.

We also *oppose* any cuts to the Supplemental Nutrition Assistance Program (SNAP). SNAP is our nation's most effective tool to fight hunger, reaching over 40 million children, parents, older adults, disabled people, workers, and other low-income people each month, or about 1 in 8 Americans. It is a valuable resource for those who qualify who suffer from ADRD, ensuring that they can access healthy food and do not go hungry. Food insecurity is a major risk factor for older adults with chronic illness. SNAP benefits can also be coordinated with meal delivery services like Meals on Wheels, which provide not only nutritious meals but also crucial social interaction, mitigating the negative effects of social isolation and loneliness that are often associated with cognitive decline.

Thank you for considering our views. We stand ready to work with you to develop policies that will ensure people with ADRD and their family caregivers have access to robust coverage that provides necessary benefits at an affordable price. With questions, please reach out to Scott Frey, Senior Vice President of Public Policy and Government Relations at the Alliance for Aging Research, at sfrey@agingresearch.org.

Sincerely,

Alliance for Aging Research
Your Organization Here

CC: