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February 27, 2025

Sen. John Thune
511 Dirksen Senate Office Building
Washington, DC 20510

Rep. Mike Johnson
568 Cannon House Office Building
Washington, DC 20515

Sen. Charles E. Schumer
322 Hart Senate Office Building
Washington, DC 20510

Rep. Hakeem S. Jeffries
2267 Rayburn House Office Building
Washington, DC 20515

Re: Budget cuts to Medicaid and the Supplemental Nutrition Assistance Program (SNAP)

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

We, the undersigned organizations, urge you to oppose any cuts to Medicaid and the Supplemental Nutrition Assistance Program (SNAP), including those called for in the proposed budget resolution. We are concerned about the negative impact these deep cuts will have on all Americans 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 (ARD), including frontotemporal degeneration and Lewy Body dementia, 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 personal care 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, certain aspects of assisted living, and at-home care. Home- and community-based care helps individuals with routine self-care tasks, such as eating, bathing, and dressing, and household activities, such as preparing meals, managing medication, and doing laundry. [A recent survey of 48 states by KFF](#) found that shortages in home health workers are most likely to be caused by low reimbursement rates. Seventy percent of home health services are currently paid by Medicaid, and cuts of the magnitude proposed would severely compound this problem.

More broadly, [many of our nation's older adults 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 older 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, 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.

We also strongly oppose any additional work requirements that have been proposed. Work requirements would take away coverage and have outsized impact on the ADRD community, as they are problematic for those with [major family caregiving responsibilities and those with chronic illnesses or disabilities](#). The ADRD community cannot be carved out from the harm.

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, 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. [KFF 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 (HCBS) 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. Furthermore, there is already significant unmet need for HCBS and any cuts to Medicaid will only increase the need and lead to more unnecessary institutionalization. On behalf of the millions of American families facing Alzheimer's disease and related dementias, we implore you to oppose any 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

Aging Life Care Association	Disability Rights Idaho
Alliance for Patient Access	Disability Rights Iowa
Alzheimer's Association and Alzheimer's Impact Movement	Disability Rights Maine
Alzheimer's Los Angeles	Disability Rights New Jersey
Alzheimer's New Jersey	Disability Rights North Carolina
Alzheimer's Orange County	Disability Rights Oregon
Alzheimer's San Diego	Disability Rights Pennsylvania
American Academy of Neurology	Disability Rights South Carolina
American Association of People with Disabilities	Diverse Elders Coalition
American Association on Health and Disability	Elder Justice Coalition
American Federation for Aging Research	Georgetown University
American Geriatrics Society	Gerontological Society of America
American Medical Women's Association	Global Alzheimer's Platform Foundation
American Society on Aging	Global Coalition on Aging
Benjamin Rose Institute on Aging	Greater Wisconsin Agency on Aging Resources, Inc.
CareForth	Hand in Hand: The Domestic Employers Network
Caregiver Action Network	Hawaii Family Caregiver Coalition
CaringKind, The Heart of Alzheimer's Caregiving	HealthyWomen
Caring Across Generations	Hilarity for Charity
Center for Caregiver Serenity	ICAN, International Cancer Advocacy Network
Community Legal Aid Society, Inc.	Justice in Aging
Compassion & Choices	Kentucky Protection and Advocacy
Dementia Alliance International	Lakeshore Foundation
Dementia Alliance of North Carolina	LEAD Coalition (Leaders Engaged on Alzheimer's Disease)
Dementia Darling	Lewy Body Dementia Association
Disability Law Center (MA)	Lewy Body Dementia Resource Center
Disability Law Center of Alaska	Lifelines Neuro
Disability Rights Arizona	LuMind IDSC Foundation
Disability Rights California	Lupus and Allied Diseases Association, Inc.
Disability Rights Center – NH	
Disability Rights Florida	

Medicare Rights Center	PHI
MomsRising	Post-Acute and Long-Term Care Medical Association
National Alliance for Caregiving	PrognusUs
National Association of Activity Professionals	RetireSafe
National Association of State LTC Ombudsman Programs	Second Wind Dreams, Inc.
National Caucus and Center on Black Aging	The American Association for Geriatric Psychiatry
National Consumer Voice for Quality Long-Term Care	The Association for Frontotemporal Degeneration (AFTD)
National Consumers League	The Balm in Gilead, Inc.
National Council on Aging	The Ohio Council of Cognitive Health
National Disability Rights Network (NDRN)	University of Pennsylvania
National Indian Council on Aging, Inc.	UsAgainstAlzheimer's
National Respite Coalition	USAging
National Rural Health Association	Virtual Dementia Tour
National Minority Quality Forum	Voices of Alzheimer's
Nevada Disability Advocacy & Law Center	Volunteers of America
National Hispanic Council on Aging	Well Spouse Association
North Dakota Protection & Advocacy Project	Wisconsin Aging Advocacy Network
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Pentara Corporation	

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