

June 22, 2017

The Honorable Mitch McConnell  
Leader  
United States Senate  
Washington, DC 20510

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

The Honorable Orrin G. Hatch  
Chairman  
United States Senate Committee on Finance  
Washington, DC 20510

The Honorable Ron Wyden  
Ranking Member  
United States Senate Committee on Finance  
Washington, DC 20510

Dear Majority Leader McConnell, Minority Leader Schumer, Chairman Hatch, and Ranking Member Wyden,

The undersigned organizations are writing to respectfully ask you to support, and build upon, existing state Medicaid expansion, and to oppose efforts to change Medicaid financing by limiting federal funding to states through per capita caps. We are concerned about the negative impact per capita caps will have on all citizens living with chronic disease, but we are writing to draw your attention to how devastating they will be on individuals with Alzheimer's disease and related dementias (AD/ADRD), and their family caregivers.

Today there are more than 5 million Americans living with AD/ADRD, with no immediate cure in sight. Of these, approximately 250 thousand are younger than age 65, with what is known as early-onset Alzheimer's disease.

Care for AD/ADRD is extraordinarily expensive. According to the Alzheimer's Association, total payments in 2017 for all individuals with Alzheimer's or other dementias are estimated at \$259 billion—the first year total costs will surpass a quarter of a trillion dollars. Of these total payments, Medicare and Medicaid are expected to cover \$175 billion, or 67 percent, of the health care and long-term care payments for people with Alzheimer's or other dementias; out-of-pocket spending is expected to be \$56 billion; and, the remaining \$28 billion is “other,” including private insurance, health maintenance organizations, other managed care organizations and uncompensated care.

### **The Importance of Medicaid to People with Alzheimer's Disease and Related Dementias**

According to a Kaiser Commission on Medicaid and the Uninsured (KCMU) analysis of pooled 2010-2012 Medical Expenditures Panel Survey data, almost all (95%) people with AD/ADRD have Medicare. Medicare covers inpatient hospital care, as well as some of the doctors' fees and other medical items for people with AD/ADRD who are age 65 or older or who are younger than 65 and received Social Security disability benefits for at least 24 months. Medicare Part D covers many prescription drugs. Medicare also pays for up to 100 days of skilled nursing home care under limited circumstances.

However, due to high out-of-pocket costs and lack of long-term care insurance coverage, people with AD/ADRD need Medicaid to fill in significant coverage gaps. **KCMU reports that about one in four (24%) adults living with AD/ADRD in the community rely on Medicaid coverage over the course of a year.** 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 provides assistance with routine self-care tasks, such as eating, bathing, and dressing, and household activities, such as preparing meals, managing medication, and doing laundry.

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 AD/ADRD in our communities, and its necessity is only going to increase with the 85 and older age group—the group most likely to need long-term care—increasing by almost 70 percent over the next two decades.

In some states vision, dental, and hearing care is available for adult Medicaid beneficiaries. 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.

Continued Medicaid coverage is necessary to help many of the most vulnerable adults with AD/ADRD in our communities. The KCMU analysis found that, unsurprisingly, given Medicaid's financial eligibility criteria, Medicaid beneficiaries with AD/ADRD are more likely to have low incomes than those who are not covered by Medicaid. Consequently, Medicaid beneficiaries with AD/ADRD have few financial resources available to pay for care out-of-pocket. In addition, because nearly half (45%) of Medicaid beneficiaries with AD/ADRD live alone, they may not have regular access to unpaid caregiving from a family member.

KCMU data also shows that Medicaid beneficiaries with AD/ADRD are more likely to report being in fair or poor health (68% versus 49%) compared to those without Medicaid. Given their reported poorer health status, Medicaid beneficiaries may need more intensive care and/or a broader scope of services to manage their greater health needs. Nearly all Medicaid beneficiaries with AD/ADRD (90%) have multiple chronic health conditions, indicating that they may benefit from care coordination services and/or efforts to better integrate medical, behavioral health, and long-term care services.

### **Per Capita Caps will Kick People with Alzheimer's and Related Dementias Out of Medicaid and Increase Costs to States**

Proposals to change Medicaid financing by limiting federal funding to states through per capita caps would be devastating to people with Alzheimer's disease and related dementias. Those changes would force states to cut eligibility, reduce benefits, and lower provider reimbursement, particularly for AD/ADRD high-cost enrollees who need substantial services under the program.

Medicaid is already a lean program, with spending per beneficiary considerably lower than private insurance and growth in spending per beneficiary slower than private insurance. The program is expected to grow even more slowly in coming years. Since 2010, CBO lowered its Medicaid spending projected for 2011 to 2020 by \$311 billion, or 9.3%. Cuts to the Medicaid program will result in either enrolling fewer people or giving them worse coverage.

Per capita caps will likely increase costs to states for AD/ADRD care. Research cited by the Family Caregivers Alliance shows that when basic assistance for the needs of daily life is not available, frail elders wind up in high-cost settings—notably hospitals and nursing homes—and overall costs increase. Home care services, which help struggling AD/ADRD family caregivers to keep loved ones together, are at greatest risk of major cuts because home care services are optional under Medicaid while nursing home care is mandatory.

According to the 2014 LTSS Expenditure Report, in 2014, for the first time in the Medicaid program's history, more than half of Medicaid funding for long-term care (53%) 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. Genworth Financial reports that, in 2016, the national median cost of a shared nursing home room was \$82,125 annually. The median cost of a home health aide was \$46,332 annually for 44 hours of support each week. Some people with AD/ABRD in nursing homes do not need to be there, they just need some home supports.

The eligibility criteria for receiving Medicaid-covered home- and community-based services vary by state. Many who qualify for such services are among the 11 million older adults who are “dual-eligible,” covered by both Medicare and Medicaid. Most of them do not yet need long-term care, but dual-eligibles tend to have significantly more chronic conditions than those on Medicare alone. According to a report by the Kaiser Family Foundation, 61% of dual-eligibles need at least limited help with activities of daily living compared to just one-third of people who are only on Medicare.

The sharp per capita caps on federal contributions to Medicaid supported by some in Congress will put states with higher aging populations at a disadvantage. Per capita cap proposals ignore the real growth rate in health and long-term care costs and will force all states to tighten eligibility for Medicaid, remove people who currently have coverage from the program, cut services or reduce Medicaid payments to service providers. Impacted Medicaid providers include home care agencies, many of which only pay aides minimum wage. Required cuts to Medicaid would accelerate over time, with most going into effect beginning in 2020, just as many baby boomers will likely begin to need home- and community-based services.

**On behalf of the millions of American families facing Alzheimer’s disease and related dementias, we implore you to build upon, rather than dismantle, Medicaid expansion. Please do not impose per capita caps on Medicaid.**

Per capita caps will leave Medicaid beneficiaries living with AD/ABRD without adequate coverage. 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. We stand ready to work with you to develop policies that will ensure people with AD/ABRD and their family caregivers have access to a robust coverage that provides affordable and comprehensive benefits.

Thank you for considering our views.

Sincerely,

Aging Life Care Association®

Alliance for Aging Research

Alzheimer’s Foundation of America

Alzheimer's Greater Los Angeles

American Academy of Neurology

American Geriatrics Society

American Neurological Association

CaringKind

Center to Advance Palliative Care

Consortium of Multiple Sclerosis Centers

Michael Ellenbogen - International Dementia Advocate & Connector

HealthyWomen

International Organization of MS Nurses

Justice in Aging

LatinosAgainstAlzheimer's

Lewy Body Dementia Association

Medicare Rights Center

National Alliance for Caregiving

National Alliance on Mental Illness

National Association for Home Care and Hospice

National Association of Area Agencies on Aging

National Association of Social Workers (NASW)

National Committee to Preserve Social Security and Medicare (NCPSSM)

National Council on Aging

National Council on Patient Information and Education

National Gerontological Nursing Association

National Hispanic Council on Aging

Social Security Works

The Association for Frontotemporal Degeneration

The Gerontological Society of America

USAgainstAlzheimer's

WomenAgainstAlzheimer's

cc: The Honorable Lamar Alexander, Chairman, Senate Committee on Health, Education Labor & Pensions  
The Honorable Patty Murray, Ranking Member, Senate Committee on Health, Education, Labor & Pensions  
The Honorable Susan Collins, Chairman, Senate Special Committee on Aging  
The Honorable Bob Casey, Ranking Member, Senate Special Committee on Aging  
The Honorable Kevin Brady, Chairman, House Committee on Ways & Means  
The Honorable Richard Neal, Ranking Member, House Committee on Ways & Means  
The Honorable Greg Walden, Chairman, House Committee on Energy & Commerce  
The Honorable Frank Pallone, Ranking Member, House Committee on Energy & Commerce