



July 23, 2021

The Honorable Julia Brownley
Chairwoman
Subcommittee on Health
Committee on Veterans' Affairs
U.S. House of Representatives
364 Cannon House Office Building
Washington, DC 20515

The Honorable Jack Bergman
Ranking Member
Subcommittee on Health
Committee on Veterans' Affairs
U.S. House of Representatives
3460 O'Neill House Office Building
Washington, DC 20515

Dear Chairwoman Brownley and Ranking Member Bergman:

AARP, on behalf of our 38 million members and all older Americans nationwide, appreciates the opportunity to submit a written statement for the record to the Subcommittee on Health, Committee on Veterans' Affairs for the hearing titled, "Aging in Place: Examining Veterans' Access to Home and Community Based Services."

Caring for our nation's older adults is a vital issue that becomes even more critical as our nation's population ages. Already, over 10,000 Americans turn 65 every day, a group that will represent more than 20 percent of the population in the coming years. From 2015 to 2050, the number of adults age 85 years and older – the age group most likely to need long-term care (also referred to as long-term services and supports [LTSS]) – is projected to more than triple.¹ The vast majority of older Americans say they want to age at home. We must make investments in home and community services so older Americans are able to choose how they live as they age.

Long-term care is a growing and critical need that can define the quality of life for any one of us. It is important to recognize that every individual's needs and circumstances are different, and there is a broad range of caregiving arrangements in this country. Families in search of long-term care services now enter a world that is fragmented, confusing, costly, frightening, under-regulated, and lacking in transparency. Too often, individuals and their loved ones must desperately cobble together a patchwork of care and services they need. Too often, families feel forced into institutional settings, while individuals who end up in nursing homes often yearn to stay in their homes near family and friends. This system is failing American families and it is failing American taxpayers.

AARP's statement will address the importance of supporting family caregivers, expanding access to services that help people live in their homes and communities, and supporting the paid workforce.

¹ AARP PPI, *Across the States 2018*, available at <https://www.aarp.org/content/dam/aarp/ppi/2018/08/across-the-states-profiles-of-long-term-services-and-supports-full-report.pdf>

Supporting Family Caregivers

Family caregivers—broadly defined as including relatives, partners, friends, or neighbors—are the backbone of the care system in this country, and there should be no discussion of caregiving or the care economy that leaves out the 48 million Americans who are providing care to loved ones. They help make it possible for older adults, people with disabilities, and veterans to live independently in their homes and communities. Family caregivers are all ages, races, and ethnicities and cut across all generations and segments of our population. This is physically, emotionally, and financially challenging work family members and others are providing, usually without pay.

Every day, family caregivers help loved ones with tasks such as eating, dressing, bathing, transportation, arranging, directing, and coordinating care among multiple providers and settings (including post-discharge), performing medical/nursing tasks such as wound care, managing multiple complex medications, managing finances, and paying for services to help their loved ones. Six in ten family caregivers are women, four in ten caregivers represent diverse populations, and six in ten caregivers are working, either full- or part-time.²

Family caregivers often take on physical, emotional, and financial challenges. For example, military veteran caregivers consistently experience worse health outcomes, greater strains in family relationships, and more workplace problems than non-caregivers – with caregivers of pre-9/11 veterans being two times more at risk. Veteran and military caregiving respondents report higher levels of need for immediate financial assistance when compared to their non-caregiving peers, according to research by Blue Star Families.

An AARP report found that family caregivers are spending, on average, 26 percent of their income on routine caregiving expenses annually, or \$7,242 every year. Hispanic/Latino and African American caregivers also reported greater financial strain than White or Asian American caregivers. Hispanic/Latino caregivers spent, on average, 47% of their household income on caregiving, and expenses for African American caregivers totaled, on average, 34% of income.³ Family caregivers are also providing about \$470 billion annually in unpaid care to loved ones. Each year \$14 billion in uncompensated care is provided by 5.5 million veteran and military caregivers. On this point, AARP wishes to be crystal clear: if families were not shouldering these caregiving responsibilities, taxpayers would be on the hook for much more costly nursing home care and unnecessary hospital stays.

That is why AARP strongly supports the bipartisan, bicameral Credit for Caring Act (H.R. 3321/S. 1670) introduced by Representative Sánchez (D-CA) and Senators Ernst (R-IA), Bennet (D-CO), Capito (R-WV), and Warren (D-MA). This legislation is a top priority for AARP. We urge Congress to enact this legislation this year. The Credit for Caring Act would provide an up to \$5,000 non-refundable federal tax credit for eligible working family caregivers to help address

² AARP and National Alliance for Caregiving. *Caregiving in the United States 2020*. Washington, DC: AARP. May 2020. <https://doi.org/10.26419/ppi.00103.001>

³ AARP, *CAREGIVING OUT-OF-POCKET COSTS STUDY*. June 2021, available at https://www.aarp.org/content/dam/aarp/research/surveys_statistics/ltc/2021/family-caregivers-cost-survey-2021.doi.10.26419-2Fres.00473.001.pdf

the financial challenges of caregiving. Last year, President Biden also proposed a \$5,000 family caregiver tax credit modeled off of the Credit for Caring Act.

The bill would help working family caregivers offset the cost of some caregiving expenses such as a home care aide, adult day services, home modifications, assistive technology, respite care, transportation, or other supports that help them and their loved ones. The amount of the credit would be 30 percent of the qualified expenses paid or incurred by the family caregiver above \$2,000, up to a maximum credit amount of \$5,000. The tax credit would phase out at higher income levels. The bill, unlike the existing child and dependent care credit, would help family caregivers who care for non-dependents or who do not live with the person they are assisting. Eligible family caregivers caring for loved ones of all ages could receive the credit if the care recipient meets certain functional or cognitive limitations or other requirements certified by a licensed health care practitioner. Blue Star Families, Elizabeth Dole Foundation (EDF), AARP and nearly three dozen other military and veteran service and support organizations support the bipartisan [Credit for Caring Act](#).

Family caregivers also cannot dedicate the time needed to care for loved ones without workplace flexibility and paid family leave. More than a dozen states have already moved ahead with their own paid leave systems. Some employers are beginning to support workers who provide care at home with benefits like flex-time and health counseling. In one survey, 75 percent of corporate benefit managers agreed that “being a more caregiving-friendly workplace would attract and retain talent.” AARP recently endorsed the Building an Economy for Families Act introduced by Chairman Neal (D-MA) that would administer a paid leave program through the Treasury Department. AARP commends Chairman Neal for his thoughtfully designed paid leave proposal which would offer all workers paid family and medical leave. This groundbreaking legislation takes a crucial step in helping caregivers continue to support their loved ones while also protecting their financial security during challenging times. When work conflicts with family obligations, caregivers have to make difficult decisions that can lead to lost wages and missed career opportunities. Caregivers are not only the backbone of our long-term care system, they are a pillar of the paid workforce more broadly and this legislation will help protect them during otherwise uncertain times. We also note the Department of Veterans Affairs (VA) offers various supports to military veteran family caregivers.

Increasing Home and Community Based Services

For most older adults, their preference is to receive care they may need as they age in their own homes and communities, rather than in a nursing home. That's why at AARP, we've made it a priority to ensure people age 50+ are able to find the care they and their family members need, when they want it and in the setting of their choice. AARP has long advocated at the federal and state level for enabling older adults to live in their homes and communities. The COVID-19 pandemic has clearly shown the dangers too often faced by older Americans in institutional care.

In 1999, the U.S. Supreme Court ruled in *Olmstead vs. L.C.* that unjustified institutionalization and segregation of people with disabilities violates the Americans with Disabilities Act. The Court said that people with disabilities have a right to live in the most integrated setting possible.

Thus, the Department of Justice requires states to develop and implement what is called an Olmstead State Plan to fully integrate people with disabilities into community settings.

As a result, since 2013, the majority of Medicaid long-term services and supports (LTSS) spending has been for home and community-based services (HCBS). Prior to this, the majority of funds went to institutional care. As of fiscal year (FY) 2018, 56 percent of Medicaid LTSS dollars were spent on HCBS. However, for older adults and people with physical or other disabilities, only 33 percent of these dollars were spent on HCBS. Medicaid HCBS spending totaled \$92 billion in FY 2018. However, Medicaid retains an institutional bias because it is required by law to cover services provided in institutional care settings while most HCBS are optional.

Several programs and policies are aimed at better balancing Medicaid spending on institutional and HCBS services including:

- providing person-centered counseling through Aging and Disability Resource Center/No Wrong Door systems to people at risk of nursing home placement to provide information about publicly and privately funded HCBS options;
- the Money Follows the Person Rebalancing Demonstration Program, which encourages states to identify people in institutions who want to return to their communities and facilitates their return; and
- rules requiring states to provide financial protections for the spouses of individuals who receive Medicaid HCBS rather than only for those receiving institutional care.

In Medicaid in some states, there are self-direction programs in which the individual receiving services decides how, when, and from whom those services will be delivered. This can include paying a family member or friend to provide care at home. The COVID-19 pandemic led some state Medicaid programs to allow more family members to be hired and paid as caregivers.⁴ The VA includes the self-direction program, Veteran-Directed Care (previously Veteran-Directed Home and Community-Based Services, VD-HCBS). The Program of Comprehensive Assistance for Family Caregivers pays a stipend and provides other support to family caregivers. VD-HCBS has been highlighted by AARP as a promising practice⁵ and an innovation.⁶

⁴ Murray, Kate, Merle Edwards-Orr, Highsmith Rich, Molly Morris and Kathleen Ujvari. *Paying Family Caregivers to Provide Care during the Pandemic-and Beyond*. Washington, DC. Applied Self-Direction and AARP Public Policy Institute, February 4, 2021. <https://doi.org/10.26419/ppi.00127.001>

⁵ Bowen, Christina Neill, Wendy Fox-Grage, Kali Thomas, and James Rudolph. *No Wrong Door: Supporting Community Living for Veterans*. Washington, DC. AARP Public Policy Institute, Providence VA Medical Center and Brown University, November 2017, available at http://longtermscorecard.org/~media/Microsite/Files/2017/2017%20Scorecard/Veterans/AARP1195_PP_NWDandVeterans_WEB.PDF

⁶ Edwards-Orr, Merle and Kathleen Ujvari. *Taking It to the Next Level: Using Innovative Strategies to Expand Options for Self-Direction*. Washington, DC. Applied Self-Direction and AARP Public Policy Institute, April 2018, available at <https://www.aarp.org/content/dam/aarp/ppi/2018/04/taking-it-to-the-next-level.pdf>

Congress Needs to Act

When Medicaid was created in 1965, nursing homes were the only option for a person who needed long-term services and supports. States receive the funding they need to provide nursing home care for those who are eligible, but they can only provide HCBS to a more limited extent in practice. It is long past time to update the law to reflect where and how people want to receive services today. States should be given the ability to use Medicaid dollars for HCBS, just as they do for nursing homes. HCBS are more cost effective—states can serve three people in HCBS for every one person in a nursing home, on average, in Medicaid—and help people live in their homes and communities where they want to be. The change thus makes both fiscal sense and common sense. Individuals who qualify for Medicaid should have a choice between HCBS or nursing facility care and have a choice of providers.

In part to help move toward that change – especially given the devastating impacts of COVID-19 on long-term care facility residents – AARP supports drastically expanding access to home and community-based care under Medicaid and supporting and expanding the direct care workforce. In addition, we need support for family caregivers, such as the Credit for Caring Act, and paid leave policies that give caregivers the workplace flexibility they need to care for their families. All of these policies are essential if we want to build a humane, sustainable system of care that works for every American family. We note that introduction of the Better Care Better Jobs Act (H.R. 4131/S. 2110) is an important first step toward action that is long overdue. Funding for programs such as those under the Older Americans Act is also important, as it helps people live in their homes and communities, and supports family caregivers.

AARP also supports making permanent the Money Follows the Person (MFP) Rebalancing Demonstration Program and the financial protections for the spouses of individuals receiving Medicaid HCBS. In addition, states should fund the services needed to meet individuals' LTSS needs and allow them to remain in the community, offering services in a range of settings. People should have more options to get care at home and in the community.

Eliminate Barriers to Care in Homes and Communities

Greater investments in HCBS will allow more older adults to age in their homes and communities where they want to be, while also helping to alleviate some of the challenges we are facing in our nation's nursing homes. We also should support the workforce that provides these important services. Direct care workers provide the bulk of paid long-term care. Now more than ever, we need more direct care workers, as there is already a shortage that will only grow as the population ages. A shortage of skilled workers makes life difficult for individuals and families searching for quality care, and there is an urgent need to develop an adequate workforce to care for older adults and provide LTSS. It is important to support this workforce through adequate pay and other compensation, paid leave, recruitment, training, and retention. It will require bipartisan work at the local, state, and federal levels and in both the public and private sectors to make sure that our nation's older adults and people with disabilities have access to the quality, affordable supportive services and care they need.

If COVID-19 has shown us anything, it is this: our country's long-term care system is broken, and it is killing older Americans. We know that the pandemic has dramatized the system's poor and unsafe treatment of the neediest and most vulnerable, with older adults and communities of color often experiencing the worst outcomes. We have seen utter devastation in our nation's long-term care facilities. Investments in family caregiver support, HCBS, and the direct care workforce are critical to ensuring more families have access to quality services and supports.

AARP appreciates the Committee's attention to these important issues and the opportunity to submit this statement for the record. We look forward to working on a bipartisan basis with you, the full Congress, and the Administration to better assist older adults, veterans, and people with disabilities. If you have any questions, please feel free to contact me or have your staff contact Rhonda Richards on AARP's Government Affairs staff at rrichards@aarp.org or 202-434-3770.

Sincerely,



Bill Sweeney
Senior Vice President
Government Affairs