March 22, 2022

The Honorable Bob Casey
Chairman
Special Committee on Aging
U.S. Senate
G31 Dirksen Senate Office Building
Washington, DC 20510

The Honorable Tim Scott
Ranking Member
Special Committee on Aging
U.S. Senate
G31 Dirksen Senate Office Building
Washington, DC 20510

Dear Chairman Casey and Ranking Member Scott:

AARP, on behalf of our 38 million members and all older Americans nationwide appreciates the opportunity to submit a written statement for the hearing on “An Economy That Cares: The Importance of Home-Based Services” This hearing is part of a long-overdue and important conversation on improving long-term care in this country.

Families in search of long-term care services, including care at home, now enter a world that is confusing, costly, frightening, under-regulated, and lacking in transparency. Too often, those 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. Finding care at home is extremely challenging: families often must desperately cobble together a patchwork of care and services they need. This system is failing American families and it is failing American taxpayers.

The problems we are seeing today are only the tip of the iceberg. These challenges only get worse as our population ages. Long-term care is a growing and critical need that can define the quality of life for any one of us and will be increasingly sought after in the coming years.

We must provide greater support for family caregivers who are often the first line of assistance for their loved ones, make important investments and policy changes to give more people more affordable options to get care at home, and secure a strong, sufficient, and stable 21st century paid workforce to assist older adults and people with disabilities. We need solutions that meet people where they are and meet the everyday needs of individuals and families nationwide.

Home Care

After a lifetime of hard work and contributing to our society, America’s seniors deserve to live with independence, security, and dignity. AARP is fighting for older adults to have high-quality, affordable options when it comes to long-term care—especially care at home. In a recent AARP survey, three-fourths of adults age 50-plus told us they wish to remain in their current homes and communities for as long as possible.
It is long past time for Congress to address Medicaid’s institutional bias and to greatly expand investments in and access to home care, which allows older adults to live where they want to – in their homes and communities. Investing in home care, called home and community-based services (HCBS), will help get individuals the services and supports they need, where, when, and how they need them. Providing necessary home care can also reduce the challenges facing some family caregivers and enable them to return to the paid workforce and improve their financial security. Investing in home care will also reduce the need to build more institutions that are expensive for consumers and for public budgets.

To understand the impact of Medicaid home care, consider the experiences of just two family caregivers out of millions.

Susan, 66, from South Carolina, pays out of her own pocket for full-time care to keep her adult son, who is blind and has cerebral palsy, out of a nursing home. If Susan’s son was eligible for and in a nursing home, Medicaid would pay for it. But because she and her son want him to live at home, she applied for more help through Medicaid home care. She did that in 2017, and she has still not received assistance. She is now number 3,089 on that waiting list. Even though her son is eligible to receive Medicaid home care services, Susan returned to work after retiring because she has to pay out-of-pocket for care her son needs at home. She worries about the future.

Chuck, 68, from New York, applied for Medicaid home care to help him care for his elderly mother and an older brother who has schizophrenia, diabetes and nerve damage that limits his mobility. Four times a week, an aide arrives to provide critical help with cleaning, bathing and other household needs that allows Chuck to keep his family under one roof.

While Chuck’s story shows the clear benefit of Medicaid home care, Susan’s experience is all too common. More than 800,000 individuals are on waiting lists for home care, and the wait often takes years. There is great variation in Medicaid across and even within states in terms of eligibility, benefits, and access.

It is also important to help individuals transition out of institutions into the community, as under the Money Follows the Person Rebalancing Demonstration Program, which AARP supports extending and making permanent. We also support making permanent financial protections for the spouses of individuals receiving Medicaid home care.

This bias toward nursing homes not only hurts families, it flagrantly wastes taxpayer dollars. On average, Medicaid can serve about three people in their homes and communities for the cost of one person in a nursing home.

We must also ensure that individuals and families who do not rely on Medicaid can access the supports and services they need to live and get care at home. Now more than ever, we need to prioritize making home care options more affordable—and available—so nursing homes aren’t seniors’ only choice.
Supporting Family Caregivers

Over 48 million family caregivers providing care to loved ones are the backbone of the care system in this country. They help make it possible for older adults, people with disabilities, and veterans to live independently in their homes and communities. These caregivers are all ages, races, and ethnicities and cut across all segments of our population. This is physically, emotionally, and financially challenging work family members and others are doing, often without pay. An economy that cares must include and support family caregivers.

A 2021 AARP report found that family caregivers are spending, on average, 26 percent of their income on caregiving expenses, or $7,242 annually. They are providing about $470 billion annually in unpaid care to loved ones. 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 sponsored by Senators Ernst, Bennet, Capito and Warren. The legislation is a priority for AARP, and we urge Congress to enact it. The Credit for Caring Act would provide up to a $5,000 non-refundable federal tax credit for eligible working family caregivers to help address the financial challenges of caregiving. AARP also supports the family caregiver tax credit passed by the House Ways and Means Committee last year that is consistent with the Credit for Caring Act. In 2020, President Biden also proposed a $5,000 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, home modifications, assistive technology, respite care, 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 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 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.

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 supports enacting a new federal paid family and medical leave program to care for a family member, a new child, and one’s own medical needs. AARP will also continue to support state action to drive progress on paid leave policies and strengthen existing programs.

Finally, the expected release this summer of the national family caregiving strategy under the RAISE Family Caregivers Act (P.L. 115-119) can serve as a catalyst for meaningful and tangible outcomes that improve support for caregivers. The strategy will identify actions that
communities, providers, government, and others are taking and may take to recognize and support family caregivers. We must also make improvements in Medicare to better support such caregivers.

**Paid Direct Care Workforce**

Direct care workers provide the bulk of paid long-term care. These workers hold a variety of job titles, including personal care assistants, home care aides, and certified nursing assistants (CNAs). They work in diverse settings, including private homes, adult day centers, nursing homes, assisted living residences, and other residential care settings. Older adults and people with disabilities rely on the vital support provided by this workforce to enable them to live in their homes and assist with tasks such as eating, bathing, and dressing.

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 long-term care. Direct care workers play a critical role in the success of states’ long-term care systems, but low wages, few benefits, poor working conditions, and few advancement opportunities have led to dangerous staffing shortages. Many workers are forced to work multiple jobs in multiple facilities just to make ends meet. As we have seen during the COVID-19 crisis, when coupled with an infectious disease outbreak, the status quo is a deadly mix.

Unbelievably, many of these direct care workers lack basic benefits such as paid sick or family leave. During the pandemic, there were numerous reports of staff being forced to work while sick, or not having access to paid time off, to care for themselves or loved ones. Policymakers should not, therefore, have been surprised when long-term care facilities became ground zero for the pandemic, as staff and residents got sick and died at an alarming rate.

The workforce challenges in long-term care are a serious threat to the lives and safety of older Americans who receive that care. It is important to support this workforce through adequate pay and other compensation, paid leave, recruitment, training, good working conditions, and retention. We note that an investment in Medicaid home care would also support the workforce that provides these critical services. We also appreciate the Administration’s recent commitment to establishing minimum staffing standards in our nation’s nursing homes that participate in Medicare and Medicaid.

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 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, home care and more home care options, and the direct care workforce are critical to ensuring more families have access to quality services.

Quality long-term care should be within the reach of any American who needs it, whatever their age, income, race, ethnicity, geographic location, and more. AARP looks forward to working
with you and the Administration to help ensure these important investments to help older adults and people with disabilities live in their homes. If you have any questions, please feel free to contact me or have your staff contact Rhonda Richards at rrichards@aarp.org

Sincerely,

Bill Sweeney
Senior Vice President
Government Affairs