November 26, 2019

The Honorable Richard Neal
Chairman
Committee on Ways and Means
U.S. House of Representatives
1102 Longworth House Office Building
Washington, DC 20515

The Honorable Kevin Brady
Ranking Member
Committee on Ways and Means
U.S. House of Representatives
1139 Longworth House Office Building
Washington, DC 20515

Dear Chairman Neal and Ranking Member Brady,

AARP, on behalf of our 38 million members and all older Americans nationwide, appreciates the Committee holding its recent hearing, “Caring for Aging Americans,” and the opportunity to submit a written statement for the hearing record. Caring for our nation’s older adults is a vital issue that becomes even more critical as our nation’s population ages. 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.

Caring for America’s older adults, and the critical role of family caregivers, covers many important areas. For these written comments, AARP will focus on supporting family caregivers, and access, quality and affordability of services for both for post-acute care and long-term services and supports (LTSS).¹

America’s population is aging and becoming more diverse. The age 65+ population is projected to almost double from 48 million in 2015 to 88 million in 2050. Over that same timeframe, racial

¹ LTSS consist of a broad range of day-to-day help needed by people with long-term conditions, disabilities, or frailty. This can include personal care (bathing, dressing, toileting); complex care (medications, wound care); help with housekeeping, transportation, paying bills, and meals; and other ongoing social services. LTSS may be provided in the home, in assisted living and other supportive housing settings, in nursing facilities, and in integrated settings such as those that provide both health care and supportive services. LTSS also include supportive services provided to family members and other unpaid caregivers. AARP Public Policy Institute (PPI), Picking Up the Pace of Change, 2017: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers, available at http://www.longterm_scorecard.org/~media/Microsite/Files/2017/Web%20Version%20LongTerm%20Services%20and%20Supports%20State%20Scorecard%202017.pdf. See also AARP PPI, Long-Term Services and Supports Fact Sheet, available at https://www.aarp.org/ppi/info-2017/long-term-services-and-supports.html.
and ethnic minorities are projected to increase from 22 percent to 39 percent of the age 65+ population. From 2015 to 2050, the age 85+ population—the age group most likely to need LTSS—is projected to more than triple. According to AARP’s Home and Community Preferences Survey, the vast majority of adults age 50-plus—more than three out of four people—want to remain in their community as long as possible. Supporting our nation’s family caregivers and ensuring a sufficient, competent, and stable workforce to care for older adults and people with disabilities will continue to have growing importance as our nation’s population ages.

Supporting Family Caregivers

Family caregivers—broadly defined to include relatives, partners, friends, or neighbors—help their loved ones live independently in their homes and communities. Forty-one million family caregivers provide an estimated $470 billion annually in unpaid care to their adult loved ones. Everyday 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 and managing multiple complex medications, managing finances, and paying for services to help their loved ones. Family caregivers save taxpayer dollars by helping to delay or prevent more costly nursing home care and unnecessary hospital stays.

Family caregiving touches everyone—just about everyone has been, is, or will be a family caregiver or will need the assistance of one in the future. They spend on average 24 hours a week caring for their loved one; almost one-third provide an average of 62 hours of care a week. Six in ten are women, and the same proportion are working, either full- or part-time. Nearly one in ten family caregivers are over age 75. One in four is a Millennial, and Millennials are also the most diverse generation of family caregivers and more likely to be working than other generations.

These caregivers often take on physical, emotional, and financial challenges. They commonly report experiencing emotional strain and mental health problems, especially depression, and often have poorer physical health than non-caregivers. They also find it difficult to navigate a fragmented system, find the information and resources they need, and coordinate care. In addition, “[h]alf of family caregivers are performing medical/nursing tasks for individuals with challenges in physical, cognitive, and behavioral health…Caregivers are largely on their own in learning how to perform medical/nursing tasks they find difficult to perform, such as managing

---

3 Ibid.
incontinence and preparing special diets.” Caregivers may often perform medical/nursing tasks after discharge from a hospital or from rehabilitation.

In terms of financial challenges, family caregivers (age 50 and older) who leave the workforce to care for a parent lose, on average, nearly $304,000 in wages and benefits over their lifetime. These estimates range from $283,716 for men to $324,044 for women. Evidence suggests that caring for aging parents in midlife has a greater economic impact on female caregivers’ retirement years than on male caregivers’ retirement years, and may substantially increase women’s risks of living in poverty and receiving public assistance in old age. In addition, an average family caregiver spent nearly 20 percent of their income, or nearly $7,000, on out-of-pocket costs related to caregiving, such as home modifications, care at home, and transportation. Long-distance caregivers averaged over $11,900 in annual expenses and caregivers of persons with dementia averaged almost $10,700.

While progress has been made, family caregivers need better recognition and support. That need is the major reason Congress enacted, and the President signed into law, the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act (P.L. 115-119) to require the development of a strategy to recognize and support our nation’s family caregivers. The Act created an Advisory Council that will issue an initial report that includes an evaluation of how family caregiving impacts Medicare, Medicaid, and other federal programs. We expect this report could offer important guidance to Congress and other policymakers as we examine how to best support this nation’s family caregivers. AARP encourages the Committee to enact legislation to support family caregivers within its jurisdiction, including improvements to Medicare and tax relief.

The financial burden family caregivers face is a prime reason why Congress needs to act to extend the medical expense deduction at the 7.5 percent income threshold before the end of the year. Without action, individuals who depend on the medical deduction to help pay for LTSS needs, prescriptions, doctors and hospitals, hearing aids and glasses, and more will see their taxes go up.

AARP is also pleased to support the bipartisan Credit for Caring Act (H.R. 2730), sponsored by Representatives Linda Sánchez and Tom Reed, that would provide a new federal tax credit of up to $3,000 annually for eligible working family caregivers to help address the financial challenges of caregiving. The Credit for Caring Act could help eligible family caregivers caring for loved ones of all ages offset the cost of some caregiving expenses such as a home care aide, adult day

11 The term “family caregiver” is specifically defined under RAISE.
care, home modifications, assistive technology, respite care, transportation, or other supports that help their loved ones. Unlike the existing child and dependent care credit, this new credit would help family caregivers who do not live with the person they are assisting or who care for non-dependents.

The needs of family caregivers are often intertwined with the needs of their loved ones. AARP believes there are multiple opportunities to help support family caregivers of Medicare beneficiaries and Medicare beneficiaries themselves, including but not limited to:

- designing and conducting a Medicare pilot project to test supports for family caregivers of Medicare beneficiaries that help family caregivers and can demonstrate measureable savings in Medicare through improved care and outcomes for Medicare beneficiaries;
- routinely identifying family caregivers as part of the health risk assessment during Welcome to Medicare preventive visits and annual wellness visits;
- establishing a Medicare respite benefit;
- allowing Medicare to pay for family caregiver education and training as part of the services a beneficiary receives post-discharge; and
- including family caregiver experience, as appropriate, in experience of care measures.

With the recent flexibility provided to Medicare Advantage (MA) plans to offer more supplemental benefits, some plans are covering some LTSS benefits, such as in-home support services, as well as some family caregiver supports, such as respite care, counseling, and skills training. While these benefits should help beneficiaries and their family caregivers, it is still early in the implementation of these supplemental benefits, so it remains to be seen how insurers will respond broadly to this emerging innovation. For example, these benefits may change annually and may only be available to beneficiaries who meet certain eligibility criteria. We urge the addition of similar innovations within traditional Medicare as well to encourage access to comparable benefits for all Medicare beneficiaries.

Supporting family caregivers is also more broadly part of a person-and-family-centered approach to services. “Person-and-family-centered care (PFCC) is an orientation to the delivery of health care and supportive services that addresses an individual’s needs, goals, preferences, cultural traditions, family situation, and values… Services and supports are delivered from the perspective of the individual receiving the care, and, when appropriate, his or her family.”

**Access, Quality, and Affordability of Post-Acute Care Services and Hospice**

Medicare beneficiaries receive post-acute care often—but not always—after discharge from a hospital or other post-acute care setting. Post-acute care is provided by skilled nursing facilities (SNFs), inpatient rehabilitation facilities, long-term care hospitals, and home health agencies (HHAs). Post-acute care can be vital for improving and maintaining function. Hospice care is provided when a Medicare beneficiary is certified as being terminally ill (life expectancy of six

---

months or less) by their doctor and the hospice doctor. Under hospice, the beneficiary receives palliative care instead of curative care for their terminal illness and related conditions.

CMS is implementing new payment systems for both skilled nursing facilities and home health agencies, the Patient Driven Payment Model (PDPM) and Patient-Driven Groupings Model (PDGM), respectively. We urge the Committee to monitor implementation of these payment systems and how they impact beneficiaries, beneficiary access to care, and whether they create financial incentives to under-supply services or limit care. It is also important for CMS to monitor these issues and quality of care, so that they can identify, quickly understand, and address any emerging problems that affect the provision of care.

Post-acute care involves transitions from one setting of care to another. These care transitions—admissions and discharges—are critical times for both the Medicare beneficiary and their family caregivers. Communication and coordination are essential to ensure a smooth transition of care. Family caregivers of Medicare beneficiaries often play a vital role in supporting, coordinating, and even providing care at these times, including at discharge. As we noted previously, this is a time when education and training for the caregiver are important and Medicare could better support family caregivers, potentially helping to improve outcomes for beneficiaries. Testing the various Medicare Compare tools with family caregivers of Medicare beneficiaries would also be helpful, as family caregivers may be assisting their loved ones in selecting a SNF, HHA, hospice, or other provider.

In the post-acute care area, AARP urges the committee to act on two bills currently pending before the Committee. First, AARP supports the Improving Access to Medicare Coverage Act (H.R. 1682), sponsored by Representatives Joe Courtney and Glenn Thompson, that would count the time a Medicare beneficiary spends in observation status toward the three-day inpatient hospital stay requirement for Medicare coverage of SNF care. Individuals in observation status are classified as hospital outpatients, not as inpatients, so time in observation does not count toward the three-day stay requirement. This is despite the fact that persons in observation status may stay in a hospital bed overnight or for periods of time as long as several days and receive care that may be indistinguishable to them from inpatient care. Thus, some Medicare beneficiaries may fail to qualify for Medicare coverage of SNF care even though they have spent more than three days in the hospital in observation or a combination of observation and inpatient care. These beneficiaries may be faced with paying thousands of dollars in surprise medical bills for the full cost of their SNF care or the denial of appropriate SNF care due to lack of Medicare coverage. In some cases, Medicare beneficiaries may forego the necessary follow-up care they need, such as therapies in SNFs, due to the cost of care.

Second, AARP supports the Home Health Care Planning Improvement Act (H.R. 2150), sponsored by Representatives Jan Schakowsky, Earl Carter, Ron Kind, and Mike Kelly, that would allow nurse practitioners, clinical nurse specialists, certified nurse-midwives, and physician assistants to order Medicare home health services. This would ensure that patients who access care from these providers are able to directly receive their referrals for home health care from their provider, rather than having to find a physician who will see them to order home health. Current policy forces the provider to locate a physician to make the referral, an often difficult task in shortage areas such as rural regions. It creates a barrier to care for consumers that
can result in extended hospital stays or unnecessary nursing home admissions. In addition, it can result in an inappropriate or inadequate referral if the physician has no previous knowledge of this person and may be more costly. The needed change in this bill would improve access to important home health services, and potentially prevent the need for many hospital, sub-acute care facility, and nursing home admissions—all of which are costly to the consumer and the taxpayer.

As the Committee examines hospice care, AARP would also urge the committee to examine discharges from hospice of individuals who are long-term terminally ill and still living. As best as we can tell, there is a lack of good data on this issue, including the prevalence of patterns and reasons for such discharges; whether beneficiaries with long-term terminal illnesses and their families understand the reasons for being discharged and their rights; and the effect these discharges have on subsequent access to hospice. We appreciate the Committee’s interest in hospice and urge the Committee to secure additional information and data so that policymakers can better understand the issue and determine what, if any, action may be appropriate.

Finally, quality of care for individuals and their families is important across settings. The Government Accountability Office (GAO) and Department of Health and Human Services Office of Inspector General (OIG) have issued recent reports about deficiencies in care and abuse, particularly regarding nursing homes and hospices. AARP has been deeply concerned over reports and evidence of dangerous conditions in nursing homes across the country. Ensuring the health, well-being, quality of care, and safety of nursing home residents is critically needed. While CMS has taken some positive steps, such as the use of a consumer alert icon in Nursing Home Compare for nursing homes cited for incidents of abuse, neglect, or exploitation, AARP is concerned with regulatory and administrative actions taken by CMS over the last couple of years that could weaken the quality of care and quality of life for our country’s approximately 1.3 million nursing home residents. Strong quality standards are vital to the residents of nursing homes and their families. They are particularly important as these facilities serve a population with increasingly complex care needs, including the nearly half of nursing home residents who have Alzheimer’s or another dementia.13 AARP believes strong enforcement of regulations that impact residents’ health, safety, and well-being is essential and should be continued.

We are concerned that CMS has taken steps to delay implementation and enforcement of nursing home quality standards; reduce civil money penalties (CMPs); allow the continued use of pre-dispute arbitration agreements for nursing homes; and propose regulatory changes that would take steps back for residents and their families, including in areas such as grievances and psychotropic and anti-psychotic drugs. We appreciate the Committee’s interest in ensuring the quality of care and well-being of nursing home residents and encourage the Committee to continue and further its work in this area.

Access, Quality, and Affordability of Long-Term Services and Supports

Fourteen million adults in the United States needed LTSS in 2018, 7.9 million of whom were over age 65+ and 6.1 million of whom were ages 18-64. Of these individuals, 90 percent lived in the community, while 10 percent received nursing home care. This is another example of the strong preferences of individuals to live in their homes and communities. The vast majority of people who need help with daily activities rely on unpaid assistance from family caregivers, as discussed previously. Without this support, many of these individuals would be without the critical support they need to live in the community. AARP urges a person-and family-centered approach to LTSS.

When family caregivers are not available or unable to offer the assistance an individual needs, many people hire a direct care worker. However, many face challenges in finding a qualified, skilled, and affordable paid care worker who can meet their needs. They may also have difficulty in finding health care providers, especially in rural or underserved areas, including health professionals that are specifically trained to meet the unique health care needs of older adults. The current need for culturally competent providers and care will only grow as the population becomes more diverse.

The cost of LTSS varies depending on the type, amount, and duration of support individuals need. Individuals are more likely to need LTSS as they age. In 2018, only 2 percent of individuals ages 18-49 needed LTSS. This increases to 5 percent for ages 50-64, 8 percent for ages 65-74, 17 percent for ages 75-84, and 42 percent for ages 85+. In 2019, the national median annual private pay costs for individuals were as follows: 30 hours per week of care by a home health aide is about $35,900; a private, one bedroom in an assisted living facility is about $48,600; and a private room in a nursing home is about $102,200. These costs are significant on their own, and they add up to even more the longer a person needs assistance. These are potential costs that many individuals may not have factored into their retirement planning and cannot afford.

Many people think that Medicare covers LTSS, but Medicare only pays for short-term skilled nursing facility care focused on rehabilitation and for limited home health care. While MA plans may cover some supplemental benefits that could include some LTSS, these are limited benefits that are not currently widely offered and can change annually. Unpaid family caregivers are often the first line of assistance for those needing LTSS. When individuals need additional care, they often pay out-of-pocket from their income and savings—as they are able—for home care or other services. As noted earlier, family caregivers may also pay out-of-pocket to assist their loved ones, but the costs can be overwhelming for families and impact their future financial security. Individuals may also turn to programs under the Older Americans Act, Department of

---

15 Ibid.
Veterans Affairs, state-funded LTSS programs, or other public and private resources in their communities.

Some individuals—about 7.5 million—have private long-term care insurance to assist with their costs, including traditional long-term care insurance (LTCI) or hybrid LTCI policies that link LTCI with life insurance or an annuity. LTCI policies most often cover home care, assisted living, and nursing home care. The high cost and complexity of these policies, and concerns about premium increases that have occurred over the last several years, are among the factors that affect consumer demand. Individuals who already have LTSS needs are not able to purchase policies. LTCI consumer protections, including premium rate stability and inflation protection, are important for individuals who have policies, or are considering purchasing policies, and their families. As it undergoes a transformation, the LTCI industry is working to develop more affordable and flexible products.

In general, once individuals’ needs exceed the ability of family caregivers or the costs of services and supports have depleted their personal resources, they turn to Medicaid as a vital safety net. Over 17 million seniors and children and adults with disabilities rely on Medicaid for critical health care and LTSS. Medicaid covers an array of LTSS, including home and community-based services (HCBS) that vary greatly by state, and care in nursing homes and other institutional settings. To be eligible for Medicaid LTSS, individuals must have limited income and resources and meet functional eligibility requirements. It is important to note that most older adults will not rely on Medicaid, but for those who do, it is vital.

It is important to note that many individuals find themselves stuck in the middle—not eligible for Medicaid, but also not having enough money to pay for all the services they need. This leaves them scrambling—sometimes with the help of families and sometimes on their own—to figure out if and how they can get the help they need to live at home or receive services in another location.

Nationally, about $235 billion was spent on paid LTSS in 2017, of which Medicaid paid about 57 percent. Out-of-pocket costs comprise about 23 percent of paid LTSS, private long-term care insurance 4 percent, and 16 percent is other public and private sources. As a point of comparison, family caregivers provided $470 billion in unpaid care in 2017.

Medicaid also has a long-standing institutional bias. When Medicaid was created in 1965, nursing homes were the only option for a person who needed LTSS. States receive the funding

---

19 Ibid.
20 Ibid.
23 Ibid.
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 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.

About half of states are using managed care in Medicaid to provide LTSS to older adults and people with disabilities. This change provides important opportunities to ensure the engagement of consumers and family caregivers in the process, expand HCBS, support family caregivers, ensure strong consumer protections, and robust oversight, monitoring, and accountability. Individuals dually eligible for Medicare and Medicaid also face unique challenges as they navigate and receive their care through two programs. Both the federal government and states should continue and build on their current efforts to provide these individuals with coordinated, quality, accessible, seamless, and easy-to-understand care and experiences.

Support for family caregivers is an important part of LTSS and a high-performing state LTSS system, as is affordability and access, choice of setting and provider, quality of life and quality of care, and effective transitions. The discussion of quality in post-acute care above is also relevant to LTSS. Individuals and their families need and deserve quality of care and quality of life whether they are in their own homes, assisted living, nursing homes, or other settings. Depending on the location and payer, the state and federal governments may have different roles in terms of quality, oversight, and enforcement, but the need for quality is constant regardless.

**Conclusion**

As the Committee and federal policymakers consider caring for aging Americans and possible solutions, we suggest they incorporate existing insights, learnings, and promising practices from states and localities, as well as other federal programs. Both private and public – as well as bipartisan – solutions are needed, and there is no one silver bullet. Instead, there are multiple solutions of varying sizes that are needed both in the short- and long-term. AARP has suggested some solutions to assist older adults and people with disabilities in this statement, but more are needed. Some will require thinking differently. Some will require sustained engagement, persistence, and commitment. However, the driving force for solutions should be how they help individuals and families who are trying to get the care or services they need for themselves or their loved ones.

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 and people with disabilities.

---

nationwide. 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,

[Signature]

Bill Sweeney
Senior Vice President
Government Affairs