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January 29, 2020

The Honorable Lance Robertson
Administrator and Assistant Secretary for Aging
Administration for Community Living
Department of Health and Human Services
330 C Street, SW
Washington, DC 20201

Dear Administrator and Assistant Secretary for Aging Robertson:

AARP, on behalf of our nearly 38 million members and all older Americans nationwide, appreciates the Administration for Community Living's (ACL) leadership on implementation of the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act. The current ACL request for public input is an important opportunity for family caregivers, organizations, and others to provide feedback to assist the Family Caregiving Advisory Council in developing its initial report and to inform the development of the national family caregiving strategy and plan future activities. Over 40 million family caregivers are assisting their loved ones and need commonsense solutions to make their lives a little bit easier.

We officially responded through the online form to ACL's request for input. AARP's three submissions to the input request are included below. While AARP's submissions reflect particular issues and priorities we want to bring to the Council's attention, they do not reflect a finite list of issues or recommendations that AARP may engage on or support going forward. We understand the Council will consider many important issues and recommendations in its work. Given the diversity of family caregivers and the individuals they are assisting, it will also be important for the Council's initial report, the strategy, and recommendations to reflect and address the diverse needs of all family caregivers, consistent with the definition of family caregiver in the RAISE Family Caregivers Act.

AARP fought hard to enact RAISE, and we have also been working to extend the current three year sunset date for RAISE to give the Council and ACL additional time to do their important work to better recognize and support family caregivers.

Below are the questions in the request for input and AARP responses.

Alabama | Alaska | Arizona | Arkansas | California | Colorado | Connecticut | Delaware | District of Columbia | Florida | Georgia | Hawaii | Idaho | Illinois | Indiana
Iowa | Kansas | Kentucky | Louisiana | Maine | Maryland | Massachusetts | Michigan | Minnesota | Mississippi | Missouri | Montana | Nebraska | Nevada
New Hampshire | New Jersey | New Mexico | New York | North Carolina | North Dakota | Ohio | Oklahoma | Oregon | Pennsylvania | Puerto Rico
Rhode Island | South Carolina | South Dakota | Tennessee | Texas | Utah | Vermont | Virgin Islands | Virginia | Washington | West Virginia | Wisconsin | Wyoming

AARP Response One

One pressing family caregiving need/concern I would like to see addressed is:

There is a need to better recognize, include, and support family caregivers in health and long-term services and supports (LTSS) contexts (as well as other areas). Often family caregivers (as defined in the RAISE Family Caregivers Act) do not self-identify. They see themselves as simply helping a family member, friend, or neighbor. Family caregivers' involvement in their loved ones' care can be critical to the health and well-being of both the caregiver and the person they are assisting. Health care and LTSS providers and systems must engage and support the person needing and receiving services, and they should also appropriately do the same for caregivers. Family caregivers provide help with daily tasks, such as dressing, bathing, transportation, arranging 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 provide critical support to their loved ones and in doing so 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. According to research by AARP and others, half of family caregivers perform medical/nursing tasks for individuals with challenges in physical, cognitive, and behavioral health, but they are largely on their own in learning to perform medical/nursing tasks they find difficult to do, such as managing incontinence and preparing special diets. Appropriate instructions, guidance, and support are important and can help with the stress, emotional and time-consuming challenges that can come with performing medical/nursing tasks. Caregivers may often perform such tasks after a loved one's discharge from a hospital or from rehabilitation. Such transitions in care—especially from one physical place to another—often involve family caregivers.

It is important to appropriately recognize, include, and support family caregivers in the care of their loved ones. Health care, social service, and other providers may not be aware of caregivers' involvement, the role(s) they play in a loved one's care, and thus may not communicate and coordinate with them appropriately. This lack of awareness and coordination could affect the individual's health outcomes, create unnecessary stress, frustration, and confusion and cost precious time for the caregiver(s), as well as limit the effectiveness of the individual's service or care plan. If health care and other providers appropriately communicate and coordinate with family caregivers—as well as the person receiving services—it could benefit everyone involved.

Family caregivers are a diverse group, as are the individuals they are supporting. To meet the needs of individuals and family caregivers, strategies, tools, and approaches must meet family caregivers where they are and engage them in ways that resonate with and are helpful to them. Engagements and interventions should be culturally competent and accessible in languages individuals use, available to caregivers of all ages caring for loved ones of any age and across different relationships and geographic locations, and available to caregivers assisting loved ones with chronic or other health conditions, disabilities, or functional limitations. To accomplish this,

an array of strategies and public and private partners are needed—both traditional and non-traditional.

I would like to offer this specific recommendation to address my need/concern:

Strengthen recognition, inclusion, and support of family caregivers, including in Medicare.

- Identify family caregiver(s) and their contact information in electronic and paper health/LTSS records of the person they are assisting so family caregivers can appropriately be part of their loved one's care team if a care or service plan depends on having a family caregiver. In some cases, this may mean identifying a primary family caregiver and/or other caregivers who take on particular roles or assist their loved ones with specific tasks. Caregiver identification facilitates engagement, communication, and coordination with the caregiver assisting their relative or friend, as well the provision of caregiver support. The individual (or their representative or guardian, if appropriate) would be given the opportunity to identify their family caregiver(s).
- Include screening to identify family caregivers as part of the Welcome to Medicare preventive visit and Medicare annual wellness visits. This could help family caregivers identify themselves, include their caregiver status in their own health record, and flag this information for their health care professional, as caregiving can affect a caregiver's health. In cases where a caregiver and care recipient have the same provider, it may also inform a provider that one of their patients has a caregiver. Screening could identify a caregiver assisting a loved one, and in some cases also identify that the caregiver herself or himself has a caregiver assisting them.
- Strengthen, expand, and financially incent the use of caregiver assessments to connect caregivers with the supports that best meet their needs, produce better outcomes for care recipients, and prevent or delay nursing home placement. This includes using family caregiver assessments in public programs, health care and LTSS, as appropriate, especially when a care or service plan relies on a family caregiver. Update caregiver assessment tools to include medical/nursing tasks, capture the complexity of care, and ensure they are culturally competent. Identify and develop consensus on the top questions providers should routinely ask of family caregivers.
- Allow Medicare to pay for family caregiver education and training as part of the services a beneficiary receives post-discharge, such as through Medicare billing codes. For family caregivers assisting a loved one after a hospital or post-acute care discharge, having the information, guidance, and training they need could make a big difference in the outcomes, health, and well-being of the Medicare beneficiaries and the caregivers themselves.
- Improve discharge planning to better include and support family caregivers across settings. While progress has been made with hospitals at the state level, continued progress is needed, including with discharge from other settings, such as post-acute care and LTSS. Public and private sector efforts can help better identify, include, inform, prepare, support, and coordinate with caregivers who are engaged in a loved one's care after discharge and could help improve outcomes and reduce caregiver stress and worry.

- Improve family caregiver education and training that many family caregivers need to provide the best support for their loved one. Provide broad basic caregiving education earlier (including before people are caregivers), so they know there is help and where to go for it. When family caregivers need information and resources, they should be easy to find and accessible. Use technology to make Aging and Disability Resource Centers (ADRCs) more accessible and mobile with real time, 24/7 access where not already available. Develop a list/template for local use for caregivers of where to go for resources, including neutral parties for credible information and where a caregiver can speak to someone directly. Improve awareness and current availability of public and private resources for caregivers. Provide information, education and culturally competent and relevant training such as on medical/nursing tasks and daily activities in hospitals, provider offices, community based organizations, simulator labs, nursing homes, and rehab centers.
- Develop and use quality measures regarding family caregivers' experience with care/providers. In Medicare, other public programs, and the private sector, develop and use appropriate quality measures of family caregivers' experience with care and/or health care/LTSS providers. Quality measures help focus provider attention on specific aspects of care and outcomes. Such measures would encourage a person- and family-centered approach to care that involves the individual and their family caregiver, as appropriate.

The recommendation addresses needed actions that pertain to: the greater adoption of person/family-centered care; assessment; service planning and/or delivery; care transitions/coordination; and information, education, referral, training and advance planning.

AARP Response Two

One pressing family caregiving need/concern I would like to see addressed is:

While many family caregivers find caregiving to be an enriching experience and a source of deep satisfaction, they can spend significant time, energy, and emotion in assisting their loved ones and sometimes they need a temporary break to ensure their own health and well-being, prevent caregiver burnout, reduce stress, work, and enable them to continue in their caregiving role. Caregivers help make it possible for older adults, veterans, and people with disabilities of all ages to live independently in their homes and communities. About 41 million family caregivers provide about \$470 billion in unpaid care annually. On average, caregivers spend about 24 hours a week caring for their loved one, but about 30 percent of caregivers provide, on average, 62 hours of care weekly and some provide assistance 24 hours a day, 7 days a week.

Respite care provides family caregivers with vital temporary relief from their caregiving responsibilities and is one of the most commonly requested caregiver support services. Respite can allow a family caregiver much needed time to go see their own doctor, run errands, go to work, and take care of themselves (ultimately helping them to better assist their loved ones). Family caregivers may not know what respite care is, that it is an option, or where or how to find it. Respite can be hard to find in some areas. Some programs offering respite may have limits on the services provided or focus on serving specific targeted populations, so they may not be able to provide all the respite a family caregiver needs or serve all populations needing respite.

Caregivers assisting individuals with complex needs or conditions, certain conditions, or who require specialized care may have difficulty finding respite providers who are appropriately trained to meet the specific needs of their loved ones. It is also important that respite is provided in a culturally competent manner, so that it meets the diverse needs of the family caregivers and their loved ones. In addition, respite may also be unaffordable for some families.

Respite is one of the important support services provided in the National Family Caregiver Support Program (NFCSP) under the Older Americans Act (OAA). People age 80 and older are among the most likely to need help to live in their homes and communities, and the age 80-plus population is projected to increase by 54 percent from 2019 to 2030, from about 13 million to about 20 million. Funding for OAA programs has not kept pace with inflation and increased demand. While the age 60 and older population has grown by 63 percent since 2001, OAA funding in FY 2019 was only 22 percent above the FY 2001 funding level. When adjusted for inflation, total OAA funding over this time period has declined by 16 percent. Additionally, over the next decade, family caregivers will likely face greater strains as the number of family caregivers is not expected to keep up with the large number of older adults needing care, underscoring the need for greater investments in OAA programs, such as the NFCSP. NFCSP is effective in reducing caregiver burden and in helping caregivers continue providing care to their loved ones for longer.

The Lifespan Respite Care Program helps family caregivers caring for loved ones regardless of age or disability, including by providing respite services, training respite workers and volunteers, providing information about and assistance in accessing services, and better coordinating services. Respite can extend the time an individual is cared for at home, potentially delaying costly institutional care and saving taxpayer dollars. Bipartisan legislation to reauthorize the program through Fiscal Year 2024 and authorize increased funding, the Lifespan Respite Care Reauthorization Act (S. 995/H.R. 2035), is pending in Congress. The bill passed the House and passed the Senate Health, Education, Labor, and Pensions Committee with amendment. Funding for this program has significantly lagged behind authorized levels and need. These are just two programs that increase access to and provide respite in which funding has not kept up with need. Among other programs, respite can be provided under Medicaid waivers and short-term inpatient respite care is covered under the Medicare hospice benefit.

I would like to offer this specific recommendation to address my need/concern:

Expand respite access so family caregivers can rest and recharge.

- Establish a Medicare respite benefit. This could help provide some critical relief to the family caregivers of Medicare beneficiaries, potentially extending the ability of caregivers to assist beneficiaries at home and delay more costly institutional stays or unnecessary and costly hospital care.
- Enact the Lifespan Respite Care Reauthorization Act (S. 995/H.R. 2035).
- Increase funding for the National Family Caregiver Support Program, Lifespan Respite Care Program, and respite more broadly. Additional resources for respite programs would enable more families to access this important service, including families and individuals with more specialized needs and in areas where respite is more scarce.
- Ensure access to adult day care as one form of respite.

- Expand respite access and eligibility through Medicaid waivers (including for the pre-Medicaid population), technology, and mobile respite. Medicaid waivers could provide targeted respite and care coordination for family caregivers, including for individuals not yet eligible for Medicaid, to help divert those at risk of institutionalization from eventually needing full Medicaid benefits. Examples include Washington State’s 1115 Waiver and a waiver under development in Oregon. Technology and mobile respite should be explored for how they could expand access to respite services.
- Educate the public on respite through multiple channels. Increased understanding of what respite is, how it can help family caregivers, and how and where they can find respite can help increase access to available respite.
- Share and scale innovative respite practices. If a particular respite approach works well in one community or for certain populations, it could potentially benefit additional communities and families.
- Incent the private sector to provide respite. Help ensure the private sector is aware of the need for respite and potential opportunities to serve caregivers in their communities and more broadly.
- Think differently about respite. Respite may be available in ways we do not traditionally consider. Thinking more broadly about respite may open new doors and allow more caregivers to rest and recharge in new and different ways.

The recommendation addresses needed actions that pertain to: respite options; the greater adoption of person/family-centered care; service planning and/or delivery; and information, education, referral, training and advance planning.

AARP Response Three

One pressing family caregiving need/concern I would like to see addressed is:

Some family caregivers can face significant financial challenges resulting from their caregiving responsibilities and need financial relief. Many individuals and families have difficulties saving for their own major life expenses and retirement, and ensuring their own financial security. Most are probably unaware of the potential financial costs they may incur in caring for a loved one with a chronic or other health condition, disability, or functional limitation.

Caregiving is costly both in terms of direct expenses and potential income and retirement savings foregone. According to AARP research, family caregivers spent nearly 20 percent of their income, on average, in 2016 providing care for an adult relative or friend. This equates to nearly \$7,000 paid out-of-pocket on caregiving expenses 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. More than three in four family caregivers (78 percent) are incurring out-of-pocket costs as a result of caregiving. Paying for caregiving expenses can mean using savings, cutting back on the caregiver’s own health care, or reducing/stopping saving for their own retirement. These out-of-pocket costs are on top of the estimated \$470 billion family caregivers provide annually in unpaid care. In addition, family caregivers (ages 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.

Individuals who need long-term services and supports (LTSS) can face an array of costs that vary depending on the type, amount, and duration of support individuals need. While people with LTSS needs are of all ages, people are more likely to need LTSS as they age. Providing services that enable individuals to live in their homes and communities—where people want to be—is generally more cost-effective than institutional care. According to Genworth’s Cost of Care Survey, 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 not often factored into retirement planning and can occur earlier in one’s life, add up the longer a person needs assistance, and are too often unaffordable. Some families who pay out-of-pocket for their loved one’s services and supports can be overwhelmed and the expenses can affect their future financial well-being. Medicaid is a vital safety net for those with limited incomes and resources who meet functional eligibility requirements.

However, 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.

Some tax provisions can help some individuals with the high cost of care, but individuals using the medical expense deduction may soon face tax increases without congressional action on a permanent solution. An estimated 4.4 million Americans with high health and LTSS costs claim the medical expense deduction at the 7.5 percent income threshold. Seventy percent of Americans claiming the deduction have incomes between \$23,100 and \$113,000. Without action by Congress, the income threshold for the deduction will increase to 10 percent in 2021, effectively raising taxes on millions of Americans—including older adults and people with disabilities—with high health care costs.

There are also gaps in whom federal tax credits currently assist. Some federal tax provisions, such as the child and dependent care credit, focus on caregivers who are assisting dependents and individuals who live with them. However, family caregivers may often assist loved ones who are not dependents and do not live with them. Long-distance family caregivers have higher out-of-pocket costs than caregivers generally. Individuals and families need more public and private sector solutions to assist with the high cost of care and services and make them more affordable and accessible.

I would like to offer this specific recommendation to address my need/concern:

Assist family caregivers with the financial challenges of caregiving.

- Make the medical expense deduction permanent at the 7.5 percent threshold for all taxpayers by enacting S. 110/H.R. 2073. This would help prevent a tax increase on millions of Americans and assist with costs such as home care, assisted living, prescription drugs and insulin, transportation to medical care, long-term care services (including insurance premiums), and nursing home care.
- Enact a federal family caregiver tax credit, such as the Credit for Caring Act (S. 1443/H.R. 2730), and state caregiver tax credits or caregiver grants. The Credit

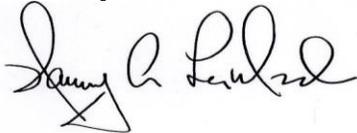
for Caring Act would provide a new federal tax credit of up to \$3,000 annually for eligible working family caregivers to help address the financial challenges of caregiving. The bill would help eligible family caregivers caring for loved ones of all ages offset the cost of some caregiving expenses such as a home care aide, adult day care, home modifications, assistive technology, respite care, transportation, and 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. State caregiver tax credits or grants for caregivers would help ease their financial concerns. One recent state example is the Family Caregiver Grant Program in Arizona that would provide up to \$1,000 to help caregivers of adults afford home modifications and assistive technology.

- Take other steps to assist with the financial challenges of caregiving. Individuals and families need more public and private solutions to assist with the high cost of care and services and make them more affordable and accessible. Solutions of varying sizes are needed in both the short- and long-term to assist family caregivers, older adults, and people with disabilities.

The recommendation addresses needed actions that pertain to: financial security; service planning and/or delivery; and respite options.

We appreciate the consideration of AARP's submissions. We look forward to continued work with ACL, the Council, other federal agencies, Congress, states, and other public and private sector partners to help make recognition and support of our nation's family caregivers a national priority and ensure they receive the tangible and meaningful support they need. If you have any additional questions, feel free to contact me or Rhonda Richards on our Government Affairs staff at r-richards@aarp.org.

Sincerely,



Nancy A. Leamond
Executive Vice President and Chief Advocacy & Engagement Officer

CC: RAISE Family Caregiving Advisory Council Members