

June 17, 2025

The Honorable Susan Collins Chair U.S. Senate Committee on Appropriations S-128 U.S. Capitol Washington, DC 20510

The Honorable Shelley Moore Capito Chair U.S. Senate Committee on Appropriations Subcommittee on Labor-HHS S-128 U.S. Capitol Washington, DC 20510 The Honorable Patty Murray Vice Chair U.S. Senate Committee on Appropriations S-128 U.S. Capitol Washington, DC 20510

The Honorable Tammy Baldwin Ranking Member U.S. Senate Committee on Appropriations Subcommittee on Labor-HHS S-128 U.S. Capitol Washington, DC 20510

CC: Members of the U.S. Senate Committee on Appropriations

Dear Chair Collins, Vice Chair Murray, Chair Moore Capito, and Ranking Member Baldwin,

On behalf of the National Alliance for Caregiving and the Act on RAISE campaign, we urge you to protect—and where possible—increase FY 2026 federal funding for critical discretionary programs that support our nation's more than 53 million family caregivers and their care partners. Our organizations represent caregiving, aging, disability, and patient advocacy stakeholders across the caregiving continuum with a common goal of strengthening our nation's first-ever National Strategy to Support Family Caregivers (National Strategy).

Family caregivers are the backbone of our healthcare system, providing an estimated \$600 billion in uncompensated care while serving as essential partners to both patients and healthcare providers. Family caregivers are in every district across the U.S.

As the Labor-HHS Subcommittee and full Appropriations Committee develop and finalize you FY 2026 appropriations proposals, we ask you to prioritize key programs that support millions of family caregivers in every community who provide on-going, complex care for people across the age spectrum – children with complex care needs, young adults with physical disabilities or intellectual disabilities, adults with chronic illness, aging parents and veterans. We also urge you to reject the incredibly harmful cuts to, and elimination of vital and cost-effective caregiver support programs, outlined in the Trump Administration's preliminary FY 2026 budget proposal.

<sup>&</sup>lt;sup>1</sup> Source: Susan C. Reinhard, Selena Caldera, Ari Houser, Rita B. Choula, www.aarp.org/valuing Valuing the Invaluable: 2023 Update Strengthening Supports for Family Caregivers. Washington, DC: AARP Public Policy Institute. March 2023. <a href="https://doi.org/10.26419/ppi.00082.008">https://doi.org/10.26419/ppi.00082.008</a>.



# FY26 Funding Requests: Overview of Critical Caregiver Programs

We encourage appropriators to fund Older Americans Act (OAA) programs—currently administered through the Administration on Aging (AoA) within the Administration for Community Living (ACL)—at levels agreed to in the 2024 bipartisan, bicameral Older Americans Act Reauthorization Act of 2024 (S. 4776) (unless otherwise noted). The Older Americans Act (OAA) is a foundational federal, state, and local program creating in-home and in-community solutions for older adults, people with disabilities, and their caregivers. While OAA is not the only critical federal discretionary program supporting family caregivers, it is a cornerstone of community support infrastructure across the country and is an essential component of implementing the goals included in the National Strategy.

We urge you to consider, at a minimum, the following FY 2026 appropriations levels:

- \$256,069,552 Older Americans Act Title III-E, National Family Caregiver Support Program (NFSCP), including a minimum of \$400,000 for the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregiving Advisory Council
- \$16,000,000 Older Americans Act Title VI-C, Native American Caregiver Support Services (*Note: This amount was agreed to in the House Appropriations Committee Labor-HHS FY 2025 funding bill advanced on July 9, 2024*)
- \$11,000,000 Lifespan Respite Care Program (Note: This amount was agreed to in the Senate Appropriations Committee Labor-HHS FY 2025 funding bill advanced on August 1, 2024)
- \$31,500,000 Programs for Caregivers of People with Alzheimer's Disease and Related Dementias (ADRDs) (Note: This amount was agreed to in both the Senate and House Appropriations Committee Labor-HHS FY 2025 funding bills)

We also urge you to fund the **BOLD Infrastructure for Alzheimer's Act initiatives under the Centers for Disease Control and Prevention (CDC) at \$33,000,000 in FY 26**, which reflects the level circulating in the House Letter to the Appropriations Committee, led by Representatives Tonko and Guthrie.

### Background: Who Are Our Nation's Family Caregivers

Family caregivers are the backbone of our healthcare system, providing an estimated \$600 billion in uncompensated care while serving as essential partners to both patients and healthcare providers.<sup>2</sup> Yet despite their critical role, research shows that one in four caregivers struggles to maintain their own health. This reality not only impacts caregiver well-being generally but also compromises the quality of care they can provide for their loved ones. According to the CDC, between 2015 and 2022, family caregivers showed significantly poorer

<sup>&</sup>lt;sup>2</sup> Ibid 1.



health across multiple measures compared to non-caregivers, with worse outcomes in 13 of 19 key health indicators including smoking, depression, and experiencing chronic conditions.<sup>3</sup>

Millions of Americans provide high-touch, high-impact activities to support older adults and adults living with disabilities. In the nationally representative study, *Caregiving in the U.S. 2020*, conducted by NAC and AARP, research showed there are an estimated 47.9 million people caring for older adults (50+) and adults 18–49 with disabilities. If we add to this the number those who care for children with disabilities, that estimate rises to 53 million Americans, or more than one in five Americans are family caregivers.<sup>4</sup> We only expect to see this number increase in the 2025 study set for release in July 2025.

Research and personal experience support that family caregivers improve the quality of care offered to individuals by providing personalized care, which ranges from support for activities of daily living like bathing or eating to instrumental activities of daily living, such as managing finances. Caregivers are also increasingly responsible for medical/nursing tasks. Research shows that caregiver support can help improve population health and avoid major medical events and costs, such as hospitalization and hospital readmission following discharge.

Although caregivers offer these services without pay, these services are not free. In many cases, caregiving strains family finances and jeopardizes caregiver health, social connections, relationships, and overall wellness. OAA and other **key caregiver support programs** currently administered through ACL and AOA, **have proven to help caregivers provide care for longer** than they otherwise would be able, which can delay or even circumvent the need for costly institutional care for older adults and people with disabilities.<sup>5</sup>

## FY26 Funding Requests: Program Details

As the Appropriations Committee debates funding priorities for FY 2026, we urge you to consider the significant value and importance of modest federal investments in cost-effective discretionary caregiver support programs. We implore you to protect—and where possible increase—funding for services that enhance the health and well-being of millions of families across the country and prevent additional downstream federal spending.

OAA Title III E—National Family Caregiver Support Program and the RAISE Family Caregivers Act:

We request a minimum of \$256,069,552 for the Older Americans Act's (OAA) Title III-E, National Family Caregiver Support Program (NFCSP), which is the amount authorized in the bipartisan, bicameral 2024 OAA reauthorization proposal. NFCSP offers an entry point for identifying caregiver needs and can help to address the need for caregiver

<sup>&</sup>lt;sup>3</sup> Kilmer G, Omura JD, Bouldin ED, et al. Changes in Health Indicators Among Caregivers — United States, 2015–2016 to 2021–2022. MMWR Morb Mortal Wkly Rep 2024; 73:740–746. DOI: http://dx.doi.org/10.15585/mmwr.mm7334a2.

<sup>&</sup>lt;sup>4</sup> AARP and National Alliance for Caregiving, Caregiving in the United States 2020, (May 2020), https://doi.org/10.26419/ppi.00103.001

<sup>5</sup> See https://acl.gov/programs/support-caregivers/national-family-caregiver-support-program.



education, respite, and support. Since 2000, the program has provided grants to states and territories to help older adults and people with disabilities stay in the home as long as possible. The NFCSP offers five core services including information about available services to caregivers; assistance to gain access to services; individual counseling, support groups, and caregiver education; respite care, to allow caregivers to take a break; and other important supplemental services. The NFCSP remains the only nationally administered program to provide supports and services to caregivers of older adults and people with disabilities.

Within the NFCSP, we urge you to continue funding the important and groundbreaking work of the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregiving Advisory Council. First enacted in 2018 and extended in the 2020 OAA reauthorization, these efforts have catalyzed comprehensive strategies to support the broad cross section of the nation's 53 million caregivers. The RAISE Family Caregivers Act supported efforts to develop the milestone National Strategy to Support Family Caregivers to build awareness of and enhance outreach to family caregivers; advance partnerships and engagement with family caregivers; strengthen services and supports for family caregivers; improve financial and workplace security for family caregivers; and develop more data, research, and evidence-based practices to support family caregivers.

# OAA Title VI-C—Native American Caregiver Support Services:

Title VI of the OAA provides grants to eligible Tribal organizations to promote the delivery of home and community-based supportive services, including nutrition services and support for family and informal caregivers, to Native American, Alaskan Native, and Native Hawaiian elders. We ask you to fund these vital caregiver support programs at a minimum of \$16,000,000, which was the level included in the FY 2025 House Appropriations Committee Labor-HHS funding proposal.

### Lifespan Respite Care Program:

The Lifespan Respite Care Program, also administered through ACL, provides short-term care that offers individuals or family members temporary relief from the daily routine and stress of providing care. Additionally, respite care provided through this program can save additional federal dollars by helping to delay, or altogether avoid, out-of-home placements or hospitalizations. Only 14 percent of family caregivers report having used respite care service, despite nearly 38 percent feeling respite would be helpful. We urge Appropriators to, at a minimum, fund this program at \$11,000,000, which reflects current investments, and is the amount included in the current bipartisan reauthorization bills.

<u>Programs for Caregivers of People with Alzheimer's Disease and Related Dementias (ADRDs)</u> and BOLD Act Initiatives:



Within the current ACL and the Centers for Disease Control and Prevention, there are two important programs that support those caring for Alzheimer's disease and related dementias. Alzheimer's Disease Program Initiative (ADPI) supports home and community-based services for people living with ADRD and their caregivers through grants to states, communities, and Tribal entities. To support the important work of ADPI, we request a minimum of \$31,500,000, which was the FY 2025 level agreed to by the House and Senate Appropriations Committees.

Within CDC, the **Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act** Initiatives established an effort within the Centers of Excellence in Public Health Practice dedicated to promoting Alzheimer's disease management and caregiving interventions. **We encourage Appropriators to include \$35,000,000 to support the BOLD Initiatives**—the amount Members of Congress are advocating for in their House-wide letter to the Appropriations Committee.

As you engage in efforts to outline FY026 funding levels for federal discretionary programs, we are eager to work with you to protect the meaningful and fiscally responsible investments in the important initiatives that support family caregivers and strengthen American families. If you have any questions about this letter, please contact Elaine Dalpiaz, Vice President, Government Affairs and Policy at the National Alliance for Caregiving (elaine@caregiving.org).

Sincerely,

Act on RAISE

Easterseals, Inc.

National Alliance for Caregiving Access Living Aging Life Care Association **ALS Association** Alzheimer's Association and Alzheimer's Impact Movement American Association on Health and Disability **American Geriatrics Society** American Society on Aging Arizona Caregiver Coalition, Inc. Association for Frontotemporal Degeneration Association of California Caregiver Resource Centers **Autism Society of America** Benjamin Rose **BWTE** CancerCare CommunicationFIRST Disability Policy Consortium **Diverse Elders Coalition** 



Family Caregiver Alliance

Family Caregiver Center of New Mexico

FamilyMeans

Gerontological Advanced Practice Nurses Association (GAPNA)

Gerontological Society of America

Gimme A Break

Greater WI Agency on Aging Resources, Inc.

Hawaii Family Caregiver Coalition

International Association for Indigenous Aging

Justice in Aging

Lakeshore Foundation

Lindsay Institute for Innovation in Caregiving

Mountain Aging Partners

National Association of Social Workers (NASW)

New Jersey Blind Citizens Association Inc.

North Carolina Caregiving Collaborative

Southeast Michigan Senior Regional Collaborative

The Arc of the United States

University of Miami

**USAging** 

Village to Village Network

Well Spouse Association

Wisconsin Aging Advocacy Network