Testimony Submitted by the National Alliance for Caregiving – April 9, 2025
Jason Resendez, President and CEO

Subcommittee on Labor, Health and Human Services, Education and Related Agencies
Committee on Appropriations - United States House of Representatives

Administration for Community Living and Centers for Disease Control and Prevention
Department of Health and Human Services

Chairman Aderholt, Ranking Member DeLauro, and members of the Subcommittee, on behalf of the National Alliance for Caregiving, a national membership-based organization focused on building health, wellness, and financial well-being for America's 53 million family caregivers we appreciate the opportunity to provide written testimony for inclusion in the written record of the U.S. House of Representatives Committee on Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies Public Witness Day Hearing on April 9, 2025.

The National Alliance for Caregiving (NAC) is a catalyst for change, transforming how the United States recognizes, supports, and values the fifty-three million family caregivers providing complex care. Through our nationally recognized caregiving research and advocacy, we drive policy, system, and culture change to elevate family caregivers as a national priority. As you consider FY 2026 appropriations, we ask you to prioritize Older Americans Act and other critical discretionary programs within the U.S. Department of Health and Human Services (HHS) that support millions of family caregivers in communities across the country.

We encourage appropriators to, at a minimum, fund Older Americans Act (OAA) programs—currently administered through the Administration on Aging (AoA) within the Administration for Community Living (ACL)—at levels that were agreed to in the 2024 bipartisan, bicameral Older Americans Act (OAA) Reauthorization Act of 2024 (S. 4776).

Specifically, for key national caregiver support programs across AoA's and ACL's program portfolios, we ask that you 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 Caregivers 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)*
- $11,500,000 - 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 ask that you fund the BOLD Infrastructure for Alzheimer's Act initiatives under the Centers for Disease Control and Prevention (CDC) at $33,000,000, which reflects the level included in the 2024 bipartisan reauthorization that was signed into law on December 11, 2024.

Background

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.[1] 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. In fact, according to the CDC, between 2015 and 2022, family caregivers showed significantly poorer 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.[2]

Millions of Americans provide high-touch, high-impact activities to support older adults and adults living with disabilities. Many of you and your colleagues share in the challenges of caregiving. We applaud the Members of Congress who have spoken openly about their own caregiving journeys.[3] In our nationally representative research study, *Caregiving in the U.S. 2020*, conducted in partnership with AARP, we estimate there are 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 fifty-three million Americans, or more than one in five Americans are family caregivers[4]

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. According to research from *Caregiving in the U.S. 2020*, six in ten family caregivers assist with medical and nursing tasks such as injections, tube feedings and changing catheters. Four in ten caregivers are in high-intensity caregiving situations, the proportion of caregivers (31 percent) who reported difficulty in coordinating care among healthcare providers is growing.

Research has also shown that caregiver support can both 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 can strain an individual's finances, their health, their social connections and relationships, and even their overall wellness.

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[1] AARP Public Policy Institute, Valuing the Invaluable: Strengthening Supports for Family Caregivers (March 2023), https://www.aarp.org/content/dam/aarp/ppi/2023/3/valuing-the-invaluable-2023-update.doi.10.26419-2Fppi.00082.006.pdf

[2] 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.

[3] Next Avenue, Members of Congress Share their Caregiving Stories, (November 2017), https://www.forbes.com/sites/nextavenue/2017/11/10/members-of-congress-on-their-caregiving-challenges/

[4] AARP and National Alliance for Caregiving, Caregiving in the United States 2020, (May 2020), https://doi.org/10.26419/ppi.00103.001

The Administration for Community Living has noted that caregiver support programs can enable caregivers to provide care longer, which can help older adults and people with disabilities to delay or even avoid the need for institutional care.[5]

OAA Title III E—National Family Caregiver Support Program:
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 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 Caregivers Council. First passed 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 fifty-three 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

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Lifespan Respite Care Program:
The Lifespan Respite Care Program, also administered through the Administration for Community Living, provides short-term care that offers individuals or family members temporary relief from the daily routine and stress of providing care. Additionally, respite care proved 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 your Subcommittee to, at a minimum, fund this program at

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[5] See https://acl.gov/programs/support-caregivers/national-family-caregiver-support-program.

$10,000,000, which reflects current investments, and the amount included in the 119th Congress reauthorization bill.

Programs for Caregivers of People with Alzheimer's Disease and Related Dementias (ADRDs) and BOLD Act Initiatives:
Within both the Administration for Community Living and the Centers for Disease Control and Prevention, there are two important programs that support those caring for Alzheimer's disease and related dementias. Alsheimer'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 your Subcommittee to include $33,000,000 to support the BOLD Initiatives, which was the amount included in the most recent reauthorization, which was signed into law last year.

In closing, these vital federal efforts and programs support millions of family caregivers across the country and have a profound impact on the quality of life of millions of older adults, individuals with disabilities, and their caregivers. They reduce caregiver depression, anxiety, and stress, enabling caregivers to provide care longer and thereby avoiding or delaying the need for costly hospital and institutional care. They offer a way for family and friends to take a break from care and to be present with the people they love.

On behalf of myself, the National Alliance for Caregiving and family caregiving advocates across the lifespan in every community across the U.S. I encourage you and your Subcommittee to support FY 2026 funding levels for these programs that recognize and respect the immense contribution of caregivers to society. Thank you again for all you have and will do for children with complex care needs, older adults, individuals with disabilities, and their family caregivers.