



The Honorable Bernie Sanders
Chairman
Senate HELP Committee
U.S. Senate
Washington D.C. 20510

The Honorable Bill Cassidy, M.D.
Ranking Member
Senate HELP Committee
U.S. Senate
Washington D.C. 20510

July 19, 2024

Dear Chairman Sanders, Ranking Member Cassidy, Chairman Casey, Ranking Member Braun, Senator Collins, Senator Kaine, Senator Markey, and Senator Mullin:

The Alzheimer's Association and Alzheimer's Impact Movement (AIM) appreciate the opportunity to provide comments on the staff-level bipartisan discussion draft to reauthorize the Older Americans Act (OAA). We are pleased to see the draft includes several provisions that are critical to persons living with Alzheimer's and dementia, their families and their caregivers.

The Alzheimer's Association is the leading voluntary health organization in Alzheimer's care, support, and research. The Alzheimer's Impact Movement (AIM), the advocacy arm of the Alzheimer's Association, is a nonpartisan, nonprofit organization and works in strategic partnership with the Alzheimer's Association to make Alzheimer's a national priority. Today, there are nearly 7 million Americans living with Alzheimer's. As the size and proportion of the United States population age 65 and older continue to increase, the number of Americans with Alzheimer's and other dementias will grow: 13 million people 65 and older may have the disease by 2050. It is important to work to ensure that there is infrastructure in place to support the growing number of people living with Alzheimer's, their families, and their caregivers.

Section 201 - Administration

Older Americans Tribal Advisory Committee

One in 5 Native American adults aged 45 and older reports experiencing memory or thinking problems that might be a sign of dementia. Native Americans are more likely to develop Alzheimer's or other forms of dementia than White or Asian Americans. At the same time, American Indians overall have less access to healthcare and health services and are less likely to be diagnosed once they show symptoms, creating unique challenges in addressing Alzheimer's and other dementias. In addition, Native American cultures hold great esteem for Elders and are more likely to take care of their Elders at home. This may create stress for caregivers.

We support the Committee's inclusion of language to develop an Older Americans Tribal Advisory Committee. We encourage the Committee and the Secretary of the Department of Health and Human Services to ensure that this program is not duplicative of the work currently being done with the federal government and to work with stakeholders to develop this Advisory Committee.

The Alzheimer's Association partners with several organizations to better serve all communities in the United States, including the National Indian Council on Aging (NICOA), to promote Alzheimer's awareness and care and support resources to American Indian individuals from 574 tribes across the country.

The Indian Health Service (IHS), an agency within the Department of Health and Human Services, provides a comprehensive health service delivery system for approximately 2.6 million American Indians and Alaska Natives who belong to 574 federally recognized tribes in 37 states. Its goal is to raise the health status of American Indians and Alaska Natives to the highest possible level. The Alzheimer's Association and the IHS will work together to address and improve the health and well-being of American Indians and Alaska Natives living with Alzheimer's disease and all other dementias and their caregivers.

In 2019, the Alzheimer's Association and the CDC collaborated on the The Healthy Brain Initiative (HBI) Road Map for Indian Country, the first-ever public health guide focused on dementia in Native American communities. Success stories highlight how tribes can utilize the Road Map to improve health outcomes. The International Association for Indigenous Aging (IASquared) is a partner of the HBI and serves as a hub of information and resources on Alzheimer's and other dementia serving Indian country.

Legal Assistance Training Resources Relating to Elder Abuse Provisions

Elder abuse is the intentional or negligent act by any person that causes serious harm to an older adult. This harm may be physical, mental, emotional, sexual, and/or financial. As many as 62 percent of persons living with dementia experience psychological abuse and as many as one-fourth have been physically abused. Additionally, one study found that 60 percent of elderly victims of sexual abuse have cognitive impairment. Nearly one-third (31 percent) of adults with dementia have experienced more than one form of abuse.

In 2020, the Promoting Alzheimer's Awareness to Prevent Elder Abuse Act (P.L. 116-252) was signed into law. Individuals living with dementia often have difficulty understanding or explaining situations. Common behaviors experienced by individuals living with Alzheimer's and other dementias could be viewed as uncooperative, disruptive, or combative unless professionals have training on the unique needs of someone living with dementia. This law addresses this need and will improve interactions between justice personnel and our constituents. This bipartisan bill was consistent with the *National Plan to Address Alzheimer's Disease* and helped ensure greater success for the Department of Justice's efforts to combat elder abuse, neglect, and financial fraud targeting seniors. During the implementation of the OAA Reauthorization, Long Term Care Ombudsman programs should look at the implementation of PAAPEA.

Addressing Mental Health and Substance Use Disorders and Cognitive Impairments of Older Individuals

The Alzheimer's Association and AIM support the ability of the Assistant Secretary to designate an officer or employee to be responsible for the administration of services for mental health and substance use disorders, and cognitive impairments to serve as an effective and visible advocate within the Department of Health and Human Services. The Advisory Council on Alzheimer's

Research, Care and Services would be a good resource for the designee of the Assistant Secretary as they administer services for cognitive impairment.

We suggest adjusting the language on page 11 line 10 to add in risk reduction. It would read “involving education about and prevention, detection, and treatment of mental health and substance use disorder and *adding risk reduction for* cognitive impairment, including age related dementia, depression, and Alzheimer’s disease and related neurological disorders with neurological and organic brain dysfunction. ”

Section 203 - Interagency Coordinating Committee on Healthy Aging and Age Friendly Communities

Social isolation

The Alzheimer’s Association and AIM appreciate your commitment to supporting individuals facing social isolation. Social isolation is an issue within the aging community as a whole, and particularly in the Alzheimer’s and related dementias community. Studies have found that support groups can decrease social isolation and increase social support, the ability to accept the diagnosis, cope with symptoms, improve quality of life, and enhance family communication. (Alzheimer’s Association *Dementia Care Practice Recommendations*, 2018).

The [Alzheimer’s Association Public Health Center of Excellence on Risk Reduction](#) highlights the importance of social engagement on older adults. Social engagement is defined as meaningful and sustained contact with at least one other person that is intrinsically and mutually beneficial pertaining to a common interest, activity or goal. Research suggests that loneliness can shorten a person’s life by an estimated 15 years - the equivalent to smoking 15 cigarettes a day. Social engagement is considered a key component of successful aging and an integral part of overall health. Although it may have less enduring impacts in midlife, social engagement appears to minimize dementia risk in older adults. Social engagement is the converse of social isolation.

Section 306 - Supportive services and senior centers; home modifications

We strongly support the change in language that strikes “mentally impaired older individuals” and inserts “older individuals with cognitive, physical, or mental impairments” in paragraph 18 of Section 321(a) (42 U.S.C. 3030d(a)). The inclusion of person centered language decreases the stigma surrounding individuals experiencing cognitive impairment, including those with Alzheimer’s disease or other dementia.

Section 310 - National Family Caregiver Support Program

We also support the inclusion of language promoting taking into account linguistic and cultural differences in the National Family Caregiver Support Program. The need for culturally informed theories, research frameworks, and services for people living with dementia and their caregivers is pronounced. Cultural values may influence disparities in perceptions and use of support among caregivers across diverse racial and ethnic contexts. For example, underutilization of needed services on the part of Latino dementia caregivers may be due to culturally incongruent expectations on the part of health care systems and providers that assume that families are the predominant/only support network for Latino individuals with dementia.

Black/African-American dementia caregivers' needs include greater education about dementia treatment, diagnosis, and care strategies; navigating what is often perceived as a “broken” health care system; improved access to affordable transportation and health care services; greater education about navigation of family conflict; increased availability of respite support; better communication about dementia within the Black/ African-American community; and increased availability of financial/legal planning. We applaud the committee for noticing the need for culturally competent care and encourage the committee to continue to promote this care in all aspects of the Older Americans Act. When culturally competent care is present, there is an increase in the utilization of services, providing better health care outcomes.

Section 401 - Direct care workforce resource center

We appreciate the commitment of the Committee to better support the direct care workforce and encourage work in this space. As the prevalence of Alzheimer's disease increases, so does the need for more members of the paid workforce to be knowledgeable and skillful about working with a diverse population of people living with dementia, as well as with their families. Turnover rates for direct care workers are high — estimated at 77% annually for those providing home care and 99% for nursing assistants in nursing homes.

The Alzheimer's Association has prioritized ensuring direct care workers and professional care providers are knowledgeable about how to care for people living with dementia. The Association's Alzheimer's and Dementia Care ECHO Program connects multidisciplinary dementia care experts with professional care providers in a free continuing education series of interactive, case-based video conferencing sessions. Project ECHO aims to improve health outcomes through a team-based approach while reducing geographic barriers and the cost of care. This dementia care training series from the Alzheimer's Association is one of the first in the country focused on improving access to quality dementia care in the long-term setting.

Each weekly session includes a short lesson on a particular aspect of dementia care, followed by a case discussion from a participating long-term care setting. Unlike a typical webinar, the program enables content experts to mentor and train professional care providers on the most up-to-date best practices for caring for those living with Alzheimer's and other forms of dementia. The ECHO program emphasizes high-quality, person-centered care in community-based settings, with topics including care planning, activities of daily life and understanding dementia-related behaviors.

Section 402 - Falls prevention program

The Alzheimer's Association and AIM are supportive of the inclusion of falls prevention programs in the OAA Reauthorization. People with dementia are at risk of falling because of their neurological impairments in perception or cognition and changes in motor function, stance or gait, which can lead to progressive loss of physical functioning. Falls are associated with a variety of contributing factors, some of which are characteristics of the individual resident, and some of which are characteristics of the environment. Individual risk factors include depression, fatigue, prolonged immobility, and a history of falls. Environmental risk conditions include a confusing environment and clutter, improper footwear, lack of stable furniture, inadequate lighting, and weather conditions. The use of certain medications may also increase the risk of falls by contributing to such conditions as fatigue or confusion, perceptual disturbances,

dizziness and altered muscle tone. The consequences of falls include broken bones and bruises, concussions, and fear of falling that can limit an individual's willingness and ability to stay mobile.

In 2018, the Alzheimer's Association released the updated [*Dementia Care Practice Recommendations*](#) for quality care practices based on a comprehensive review of current evidence, best practice and expert opinion. The Recommendations are intended for professional care providers who work with persons living with dementia and their families in residential and community based care settings. Underlying the practice recommendations are person-centered approaches to dementia care, involving tailoring care to the abilities and changing needs of each individual. One of the priority areas where intervention can make a significant difference in an individual's quality of life is falls.

The Alzheimer's Association care goals for individuals at risk for falling are to promote safety and preserve mobility by reducing the risk of falls and fall-related injuries, and to minimize fall-related injuries by avoiding physical and chemical restraints. The recommended dementia care practices include assessment, staff approaches for facilities, and environment approaches.

Title VIII - Miscellaneous

Section 812 - RAISE family caregivers

We strongly support and urge adoption of the proposed five-year extensions for the RAISE Family Caregivers Act (Sec. 812).

As part of a coalition, we requested during the previous request for information period that lawmakers ensure Older Americans Act reauthorization extends authorities and funding for the RAISE Family Caregivers Act to advance cross-cutting, national efforts to improve support for family caregivers. The RAISE Family Caregivers Act supported efforts to develop the milestone 2022 National Strategy to Support Family Caregivers, which reflects a whole-of-government approach to:

- Achieve greater 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.

For millions of Americans caring for individuals with Alzheimer's and other dementias the emotional, physical, and financial costs can be overwhelming. Caregivers of people with dementia report higher levels of stress, depression, and worse health outcomes than those providing care to individuals without dementia. Unpaid caregivers provided an estimated 18.4 billion hours of care last year, valued at nearly \$350 billion. We appreciate the prioritization of this important program. We applaud lawmakers for including these long-term extensions for RAISE through the OAA to align with the future OAA reauthorizations. This approach will ensure that the National Strategy is updated on a biennial basis to reflect changes in the caregiver landscape.

Subtitle B - Studies and Reports

We are also pleased to see the continuation of studies and reports that promote the wellbeing of older Americans. Reports such as the GAO Report relating to health outcomes for older individuals living with or near family members and reports from the White House Conference on Aging are instrumental to ensuring the success of these programs, and for measuring their positive impact on Older Americans, including those living with Alzheimer's Disease and other dementia.

Section 831 - White House Conference on Aging

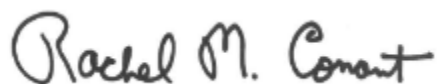
We appreciate the draft text's inclusion of a 2025 White House Conference on Aging and are particularly interested in the goal of development recommendations to guide the Federal Government in creating policies that serve older individuals. While we applaud the creation of the White House Conference on Aging, we encourage the committee to amend the language on page 73 to include not just the 'prevention of' but also include "mitigation or remediation of...". Many individuals are already experiencing the issues mentioned in this section, including abuse, disease, injury, and social isolation. While it is important that the White House Conference on Aging work to reduce the prevalence of these issues, they must also work to decrease the severity of these issues for those already experiencing them. We urge lawmakers to consider including authorized funding for this important event.

Title IX - Authorization of Appropriations

As the committee works to solidify and increase the infrastructure for older Americans, their caregivers, and their families, we strongly urge the Committee to ensure that funding levels authorized and appropriated will be increased proportionally to reflect the strengthening of these vital programs.

Thank you for the opportunity to comment. The Alzheimer's Association and AIM would be glad to serve as a resource for the Committee as it considers these important issues and how they relate to individuals living with Alzheimer's and related dementias. Please contact Sarah Osuna, Associate Director, Congressional Affairs, at 202-638-7041 or sdosuna@alz-aim.org if you have questions or if we can be of additional assistance.

Sincerely,



Rachel Conant
Senior Vice President, Federal Affairs, Alzheimer's Association
Executive Director, Alzheimer's Impact Movement

CC: Chairman Bob Casey
Ranking Member Mike Braun
Senator Susan Collins
Senator Ed Markey
Senator Markwayne Mullin