Testimony of Stephanie Monroe

"Caring for America: Legislation to Support Patients, Caregivers, and Providers."

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Good morning, Chairman Eshoo, Ranking Member Guthrie, and Members of the Committee. Thank you for the opportunity to share information about challenges that caregivers and their loved one's face in navigating Alzheimer's Disease.

My name is Stephanie Monroe. I am Director of Diversity and Access at UsAgainstAlzheimer's as well as Executive Director of AfricanAmericansAgainstAlzheimer's. I am a 25-year veteran of Capitol Hill, and a current caregiver for my 88-year-old mother and 84-year-old father who is living with Alzheimer's.

Despite my being an attorney, my brother being a physician, and my sister being a professional educator - our family was caught completely underprepared for my father's diagnosis of Alzheimer's more than 8 years ago. It took going to several doctors before we received the correct diagnosis, navigating a system that felt ill-prepared and even biased against sharing that diagnosis with us, and uninterested or ill-equipped to provide the care plan and support my parents and I needed. We received the diagnosis, were referred to a neurologist and sent along our merry way.

You may ask how it was that I, as an Alzheimer's professional, was so ill-prepared. I would respond that no matter what your credentials and head knowledge are, few are prepared for the shock that follows when you learn that this stalworth figure who has been leading your family is on a journey to that may end with complete dependence. He's your dad, and life as you know it has just changed dramatically.

Where do you start? Aside from medications you've been given - what do you expect? How will you manage increasing care needs? Can your parents safely remain at home and for how long? What do you do when you're not financially prepared? How do you manage medication with memory loss, the need for transportation when your dad can't, and your mom doesn't drive? How do you manage all this from a distance?

In essence- you aren't prepared. You don't even know what you don't know. You don't know what resources exist and whether they would even be helpful. You don't seek "caregiver support" because, just as a parent doesn't consider themselves to be a childcare provider, you don't consider yourself to be a caregiver. You are the son, daughter, or spouse of a loved one fulfilling a promise of love, respect and honoring your elders.

To be clear I am not suggesting caregiving is a burden- in fact for many it is a blessing and an honor. But it is challenging on a day-to-day basis to assume these roles with little support (financial or emotional) and virtually no access to training.

Although I am but one person before you, I speak on behalf of the millions of caregivers facing similar challenges.

Overview:

To put things into perspective, currently, an estimated 6.2 million Americans aged 65 and older are living with Alzheimer's. By 2025 that number is expected to increase to 7.2 million and by 2060 expected to nearly double to 13.8 million in America. The annual costs, driven extensively by out-of-pocket caregiving assistance, currently exceed $305 billion.

What's more is the impact this disease is having on Black and Latino populations with Blacks being at least twice as likely to develop Alzheimer's than non-Hispanic whites, and Latinos more than 1.5 as likely. The impact on women is also significant as women are more likely than men to develop Alzheimer's and two-thirds of America's caregivers are also women.

With more than 16 million Americans providing billions of hours of unpaid care to family and friends living with Alzheimer's and other dementias, the need for action is now.

I am here today to urge consideration of the bills on the agenda as a lifeline for caregivers who unfortunately are often forced to deny their own health and wellbeing while caring for others. Too often this results in physical and emotional deprivation sometimes resulting in the caregiver becoming sicker and dying sooner than the loved one with Alzheimer's.

Importance of Alzheimer's Caregiver Support Act:

The Alzheimer's Caregiver Support Act authorizes the Secretary of Health and Human Services to award grants to public or nonprofit private health care and social service providers described for the purpose of expanding training and support services for families and unpaid caregivers of people living with Alzheimer's disease or a related dementia.

Recipients include health care organizations; community health centers, senior centers, area agencies on aging, community-based organizations, and others with proven track record of reaching and serving communities.

The legislation before you today will provide training and support services to those providing unpaid care to patients with Alzheimer's disease or a related dementia and requires the Secretary of Health and Human Services to coordinate with the Office of Minority Health and the Office of Women's Health to ensure that women, minorities, and other underserved communities are not left behind.

Recent surveys conducted by UsAgainstAlzheimers found that:

- Stress was a key challenge on their journeys. Other challenges included no time for self (63.5%), uncertainty about the future (50.0%), concerns about financial status (46.1%), not getting enough sleep (44.2%), and unable to leave home (42.3%).

- Caregivers reported how few received training and information related to caregiving, and on the quality of that training. Non-Caucasian Alzheimer's/dementia caregivers are not receiving the training and supports they need from their own and their loved ones' healthcare providers, and the training that is accessed is often inadequate.

- For those who did receive training, half (50.0%) did not receive it at the appropriate time and fewer than half (42.9%) felt the training addressed all the situations that they faced

- When asked if their own healthcare provider had ever given help or advice about being a care partner, or suggested where you might get help? 74% said no.

- The majority of caregivers reported that their own healthcare provider knows they are caregivers but 74% report receiving no help or advice about being a care-partner or suggestions of where they can receive help.

- For those who received training more than half say it wasn't at the right time, so it did not help when they needed it most.

I would like to thank Reps. Waters and Smith for their leadership in introducing the Alzheimer's Caregiver Support Act and for their passion in working to improve the lives of those impacted by Alzheimer's disease.

H.R 3297: Workforce Development and Diversity:

The need for a qualified, well-trained, and diverse workforce is essential. Many communities, especially those in rural and high Alzheimer's Disease prevalence areas struggle to find the specialists (the neurologists, psychiatrists, and geriatricians) needed for care. The lack of specialists and primary care doctors who are fluent in Spanish is also challenging and prevents those who are Spanish speaking from accessing the care they need.

Lack of culturally appropriate resources for dementia diagnosis and care is a key reason why African Americans and Hispanics with dementia are less likely than White people with dementia to have a formal diagnosis and are more advanced in their disease when they are diagnosed. To close this gap, we must invest in training programs that graduate qualified, culturally competent primary care doctors and specialists who can meet the needs of older adults especially those from underserved communities who are at higher risk of developing cognitive impairment and are willing to serve communities where they are.

H.R. 3297 would do just that by incentivizing practice in communities that are traditionally underserved and increasing the number of providers who have the individual skills, cultural competencies, and capacity to provide dementia care services. There is a need for investment in capacity and coordination of community health centers and/or older adult day centers that provide direct services within underserved communities, with specific strategies for improving access to brain health services and dementia assessments.

Finally, I'd like to mention three additional policies, that if changed would be of enormous help to caregivers, their loved ones, and others who may develop AD in the future.

H.R. 3352: The CHANGE ACT

I mentioned that my father was seen by several doctors before receiving a diagnosis. The diagnosis cam when he was 76 years of age. Until I requested it his doctors had not proactively screened him despite him having annual wellness visits and being on Medicare. Thru science, we have learned that brain changes related to Alzheimer's can begin 20 years before symptoms. Had routine screening been offered, or a PET scan, perhaps he would have been diagnosed sooner, offered treatment sooner, and allowed my family those additional years to plan and to interact with him to preserve memories.

Early and accurate diagnosis of dementia is central to improving the delivery of health services and care, yet studies have found that approximately 40 percent of patients with dementia are unrecognized in the primary care setting and when diagnosed by a physician, are not told of that diagnosis.

The Change Act would improve the Welcome to Medicare and Annual Wellness Visit preventive benefits and ensure Medicare providers fulfill the detection of cognitive impairment requirement in a more effective manner by requiring providers to use screening tools designed to detect cognitive impairment and signs of Alzheimer's or dementias in the early stages. The legislation directs the Centers for Medicare and Medicaid Services (CMS) to require the use of cognitive impairment detection tools identified by the National Institute on Aging during the Medicare Annual Wellness Visit and would add detecting cognitive impairment as a requirement of the "Welcome to Medicare" benefit. It also includes payment measures which incentivize the detection and diagnosis of Alzheimer's disease or related dementias and discussion of appropriate care planning services, including potential for clinical trial participation.

Paid Leave as an Important Caregiver Support

Expansion of paid family leave, currently being considered by Congress, is an essential workforce support and an equity issue for dementia care and services. We know that people from minoritized backgrounds are more likely to rely on family caregiving and they are also less likely to hold a job that provides paid family and medical leave.

More than 102 million people – 77 percent of workers – do not have paid family leave through their employer to care for a new child or a loved one with a serious health condition such as Alzheimer's or to address their own medical issue.

Paid family and medical leave could be a critical support for dementia caregivers and patients. Adult caregivers of loved ones living with Alzheimer's disease or other types of dementia who have access to paid family and medical leave have reported a positive impact not only on being able to take their loved ones to their medical appointments, but also on their own health and own emotional well-being.

We urge Congress to include a robust, equitable, and just national policy to ensure America's caregivers are not forced to choose between work and caring for their own or their loved one's serious medical condition.

Support a National Alzheimer's Prevention Goal

Recent research confirms that as much as 40-percent of dementia, which ranks the top of fears of aging Americans, could be delayed - and in some cases prevented - by early intervention to address risk factors such as hypertension, diabetes, depression, physical inactivity, poor nutrition, smoking, hearing loss, traumatic brain injury, sleep, and social isolation and loneliness.

This is a hopeful message that not many Americans or health providers are aware of. That's why I urge the committee to ask the Department of Health and Human Services (HHS) to establish an ambitious national goal to prevent Alzheimer's disease and related dementias. This call for a national prevention strategy is widely supported. More than 190 national organizations, including the including Volunteers of America, the American Federation of Teachers, American Heart Association, National Urban League, YMCA of the USA, AARP, UnidosUS, the National Kidney Foundation, the Southern Christian Leadership Conference, HADASSAH, the Milken Institute and others are calling for a national dementia prevention goal and a plan to reach that goal that includes metrics to measure progress along the way, and a focus on healthcare equity that recognizes the disproportionate impact of this disease on communities of color and women.

This concludes my testimony. I am happy to answer any questions.