

Dr. Bruce Chernof  
Chairman  
Commission on Long-Term Care

Dr. Mark Warshawsky  
Vice Chairman  
Commission on Long-Term Care

August 16, 2013

Dear Dr. Chernof and Dr. Warshawsky:

On behalf of the millions of families affected by Alzheimer's disease, thank you for the opportunity to comment on ways to improve our nation's system of long-term services and supports (LTSS). The Alzheimer's Association® is the world's leading voluntary health organization on Alzheimer's care, support and research.

Today, there are more than 5 million Americans in the United States living with Alzheimer's disease. Alzheimer's is the sixth-leading cause of death in the United States, and the only cause of death among the top 10 without a way to prevent, cure or even slow its progression. According to a study published in the *New England Journal of Medicine*, Alzheimer's is the most costly disease in the United States and is set to increase like no other. This year, Alzheimer's and other dementias will cost the United States an estimated \$203 billion, 70 percent of which will be borne by Medicare and Medicaid. By 2050, this number is expected to grow to more than \$1.2 trillion. Alzheimer's disease also affects certain segments of the population disproportionately compared to other groups. Data indicate that older African Americans, Hispanics and individuals with Down syndrome are more likely to have Alzheimer's disease than older whites in the general population. Furthermore, there are currently 200,000 individuals with younger-onset Alzheimer's who are under age 65. Unless action is taken to improve the LTSS system, public and private costs will become unsustainable and outcomes for certain populations will continue to worsen.

On average, people with Alzheimer's disease will spend 40 percent of their time with the disease in the most severe stage, making them high users of long-term care. They often require assistance with activities of daily living (ADLs) such as dressing and bathing, and instrumental activities of daily living (IADLs) such as food preparation and medication management. As the disease progresses into the final stages, individuals lose their ability to communicate, fail to recognize loved ones and become bed-bound and reliant on around-the-clock care. Compared to only 4 percent of the general population, 75 percent of the people with Alzheimer's will be admitted to a nursing home by age 80. Additionally, among all nursing home residents, more than 64 percent have been diagnosed with Alzheimer's or another dementia. Consequently, average, annual per-person Medicaid spending on seniors with Alzheimer's and other dementias is 19 times higher than average, annual per-person Medicaid spending across all seniors without dementia. Furthermore, at least 74 percent of people with dementia have multiple chronic conditions which complicates their care and drives up costs. Individuals with Alzheimer's disease utilize LTSS at a higher rate than the general population, and any recommendations to Congress must account for the complexity of providing care for this population.

What's more, statistics show that a significant portion of people with Alzheimer's disease and other dementias are dual eligibles. Nationally, according to data from the Medicare Current Beneficiary Survey, 30 percent of individuals with Alzheimer's or other dementias are on both Medicare and Medicaid, compared to 11 percent of seniors without these conditions. Evidence also shows dual eligible individuals are among the costliest to the nation's health care and long-term care systems. Individuals with dementia incur high health care and long-term care costs, both public and private. Changes to the LTSS system should focus on improving the quality of care for these individuals as a strategy to reduce overall spending on LTSS.

The long-term care burden of Alzheimer's also extends to the millions of Americans caring for those with the disease. In 2012, more than 15 million unpaid caregivers provided over 17 billion hours of care valued at more than \$216 billion. Alzheimer's caregivers report higher levels of stress, depression and worse health outcomes when compared with caregivers of individuals who do not have dementia. Alzheimer's and dementia caregivers incurred \$9.1 billion in additional health care costs last year. While unpaid caregivers can benefit from home and community-based services such as respite care, adult day centers and home care, the lack of financing options means many must pay out-of-pocket and cannot afford these costs over time.

Given these facts, we urge the Commission to consider the following recommendations as you develop recommendations to improve the organization, provision and financing of the long-term care system:

- **Improve awareness of available LTSS among individuals with Alzheimer's disease, their families and caregivers, and health care providers.**

Many individuals and their families are unaware that LTSS are available in their communities to help and support them as they navigate this devastating disease. This is especially true for those who are disproportionately affected by the disease, such as the younger-onset population, racial and ethnic minorities, and individuals with Down syndrome and other developmental disabilities. Programs and services accessed through community-based organizations, such as the Alzheimer's Association, local Area Agencies on Aging, and Aging and Disability Resource Centers, provide valuable lifelines for individuals, their families and caregivers. Respite care, caregiver training, counseling and nutrition programs are just a few examples of the critical supportive services that can be accessed locally by individuals and families facing Alzheimer's disease. However, a federal task force on populations disproportionately affected by Alzheimer's disease identified a lack of knowledge of, and access to, LTSS as a major problem currently facing these populations. Therefore, we recommend that the federal government work to encourage states to educate all health care providers and supportive services on what LTSS are available in their communities and how their patients, as well as their families and caregivers, can access those services.
- **Fully support families and caregivers of those with Alzheimer's disease and other dementias.**

As we have described above, the stress and pressure of providing care for a loved one with Alzheimer's disease can have a large impact on family caregivers. The Commission should recommend that the federal government work with state and local partners as well as the Aging Services Network to identify and implement caregiver interventions that have been shown to reduce stress and depression. Reducing caregiver burden has been shown to improve the quality of care received by those with Alzheimer's disease, allowing them to remain in the community longer, avoiding expensive institutional care which is driving LTSS spending. The *National Plan to Address Alzheimer's Disease (National Plan)* echoed this

sentiment, recommending that caregivers be linked to supportive services such as respite care and other interventions shown to decrease caregiver burden. We also recommend that caregiver health be assessed and addressed regularly to avoid potential problems. For example, the Advisory Council on Alzheimer's Research, Care, and Support recommended that health care providers ask caregivers about their own health whenever they accompany a loved one with Alzheimer's disease to a health care appointment. This allows the provider to assess the health of the caregiver and provide referral to health care services, if needed.

In addition, the Commission should recommend that Congress fully fund existing federal programs which have proven successful in providing these types of supportive services, such as the National Family Caregiver Support Program (NFCSP) which is administered by ACL/AoA. The NFCSP provides crucial funding for states to inform caregivers about available services, assist caregivers in accessing services, provide individual counseling and support groups, conduct caregiver training and provide respite care. These services have been shown to reduce caregiver stress, anxiety and depression – allowing caregivers to avoid more costly care settings, such as nursing homes. Additional funding for programs like the NFCSP would allow them to be expanded to better meet the needs of Alzheimer's and dementia caregivers, which could help to mitigate health system costs in other areas.

- **Encourage states to expand access to home and community- based LTSS.**

Congress and CMS should encourage states to expand access to Home and Community-Based Services (HCBS) by taking full advantage of existing programs such as the Balancing Incentive Program and Community First Choice Option. Medicaid HCBS help states provide necessary and vital services such as medical care, respite care, case management and assistance with ADLs to an array of individuals, including persons with dementia. Without access to these services in a home or community setting, many people would have to receive those services in a residential facility, which is often a more costly option, both to the state and to families. An estimated 60-70 percent of older adults with Alzheimer's disease and other dementias live in the community, where their care needs are primarily met by family members, relatives and friends. Some of these individuals could remain in the community longer if they received HCBS necessary to meet their needs and support their caregivers. Expansion of access to HCBS could provide some cost savings to the states' Medicaid programs, as well as enhance the quality of life for individuals living with dementia, allowing them to remain with or among family and friends.

- **Ensure appropriate training for the direct care workforce across settings to create a more dementia-capable LTSS system.**

Current federal regulations are extremely limited in requiring dementia-specific training for the direct care workforce caring for individuals with Alzheimer's disease and other dementias, and state laws vary widely. Contributing to the inadequate delivery of LTSS as identified by the Advisory Council on Alzheimer's Research, Care, and Support is the current lack of training on Alzheimer's and dementia care for practitioners (e.g., physicians, nurse practitioners, physician assistants). This lack of training affects the quality of care received by all individuals with dementia. But, a recent HHS report highlights the elevated concerns for populations disproportionately affected by Alzheimer's disease, including people with younger onset dementia, racial and ethnic minorities, and people with Down syndrome and other intellectual disabilities. Proper training for facility and home care staff can improve outcomes for those with dementia and prevent the overutilization of more expensive care, such as premature entry into a nursing home and unnecessary hospitalizations and emergency room visits. We ask the Commission to recommend that Congress work with states to require training on

Alzheimer's disease care and support in any curriculum for health care professionals that will be treating adult populations. Certification, recertification and continuing education programs concerning the management and treatment of dementia should be made available.

Section 6121 of the Affordable Care Act (ACA) requires that all certified nursing aides (CNAs) employed by nursing homes receive training on care for persons with dementia during their required 12-hour annual training. As this provision is fully implemented, we would urge the Commission to recommend that CMS establish survey guidelines that will accompany this new requirement to ensure that all CNAs are appropriately trained in dementia care as recommended in the Alzheimer's Association's *Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes*. In addition, federal agencies should work with state, local and private sector organizations to enact policies that ensure adequate training for direct care workers who care for individuals with Alzheimer's disease and other dementias in settings beyond nursing homes (e.g., assisted living facilities, adult day centers, hospice).

- **Support state and local strategies to develop dementia-capable LTSS systems for those with Alzheimer's disease and their caregivers.**

Congress should act to ensure that HHS works with states to designate lead entities on Alzheimer's disease to coordinate activities across state agencies. The federal government should provide funding to these state lead entities to allow them to facilitate development of dementia-capable systems, coordinate available public and private LTSS, analyze existing gaps in service, identify opportunities for efficiency, and enable ongoing stakeholder input to address the needs of individuals. This recommendation was initially proposed by the Advisory Council on Alzheimer's Research, Care, and Services; the 2013 update to the *National Plan* also calls for strengthening the ability of state and local governments to provide dementia-capable services to the Alzheimer's-affected population.

We appreciate your leadership on this important issue. The Alzheimer's Association stands ready to assist the Commission in developing sustainable solutions to the problems facing the long-term care system. Please contact Rachel Conant, Director of Federal Affairs, at [RConant@alz.org](mailto:RConant@alz.org) or 202-638-7121, if you have any questions or if we can be of assistance.

Sincerely,



Robert Egge  
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Alzheimer's Association