NASUAD
National Association of States
United for Aging and Disabilities

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March 30, 2012

Helen Lamont, Ph.D.
HHS Office of the Assistant Secretary for Planning and Evaluation
Room 424E, Humphrey Building
200 Independence Avenue, SW
Washington, DC 20201

[Submitted Electronically]

Dear Ms. Lamont,

The National Association of States United for Aging and Disabilities (NASUAD) appreciates the opportunity to comment on the Department of Health and Human Services (HHS) Draft National Plan to Address Alzheimer's Disease, as published on February 22, 2012.

NASUAD represents the nation's 56 state and territorial agencies on aging and disabilities. As part of the National Aging Network, each of our members oversees the implementation of the Older Americans Act (OAA), through funds awarded by the Administration on Aging (AoA). Additionally, many member-states also serve as the operating agency for Medicaid home and community based services (HCBS) waivers that serve older adults, and in some cases, individuals with disabilities. The Association's principal mission is to design, improve, and sustain state systems delivering home and community based services and supports for people who are older or have a disability, and their caregivers.

The enactment of the National Alzheimer's Project Act (NAPA) on January 4, 2011, has created a long-overdue opportunity to focus the nation's attention on Alzheimer's disease, and the Association applauds the Administration's recognition of both the vital need to address the many challenges facing people with the disease, their families, and caregivers; and the urgency with which this must be done. Additionally, we find the Draft Plan's guiding principles, which seek to optimize existing resources and improve and coordinate ongoing activities, to support public-private partnerships, and to transform the way we approach Alzheimer's disease, to be an appropriate reflection of the ambitious, yet attainable, goals embodied by the plan itself.

Guided by a vision of a nation free of Alzheimer's disease, the Draft National Plan to Address Alzheimer's Disease outlines goals, strategies and actions that directly affect the Aging Network. Consequently, NASUAD respectfully submits for your consideration the following comments and recommendations.

Action 2.A.5: Strengthen state aging workforces.
NASUAD applauds the Department's efforts to strengthen state aging workforces that are "capable and culturally competent" through AoA. While implementing this action, it is important that efforts to improve state strategies do not further burden states' abilities to apply for and utilize funds from AoA. States should maintain flexibility to implement strategies that address the unique needs of the state populations through their state infrastructures.

Action 2.A.6: Support state and local Alzheimer's strategies.
NASUAD applauds states for recognizing the need to develop comprehensive plans to address Alzheimer's disease, but we are concerned that these plans are being conceptualized and developed without involvement from the Aging Network. State agencies on aging and disabilities play a critical role in the oversight and delivery of services that are designed to support older adults, including those with Alzheimer's disease, in their homes and communities. For these reasons, NASUAD recommends that state agencies on aging and disabilities, and other relevant stakeholders, should be involved at all stages of Alzheimer's state plan development.

Additionally, in accordance with the Older Americans Act, state agencies must develop a State Plan on Aging, which is envisioned by AoA as a comprehensive plan document that articulates the direction in which state long-term care efforts are moving, key strategies to address the strong desires of the rapidly growing new generation of long-term care consumers to be served in their homes and communities, and how the state will address the challenges of America's budgetary constraints and competing priorities in today's society. Given these existing requirements, State Plans on Aging may be the most appropriate place for states to describe their short and long-term strategies for addressing Alzheimer's disease. The integration of Alzheimer's state plans into State Plans on Aging would align with the need for a holistic approach to combatting the disease itself, as well as AoA' s intent that State Plans serve as valuable tools for planning and tracking all of the state's efforts on behalf of older adults.

Action 2.B.1: Link the public to diagnostic and treatment services.
NASUAD supports the Department's approach of expanding linkages between existing disease support and community information centers supported by AoA and the National Institutes of Health (NIH). In order to successfully connect members of the public with the necessary services and supports, NASUAD recommends that HHS also examine the capacity of these existing structures, particularly those within the Aging Network, such as ADRCs, I&R/A, and SHIPs, to ensure that these resources are adequately funded to meet the needs of this growing population.

Action 2.C.2: Enhance assistance for people with AD and their caregivers to prepare for care needs.
NASUAD recommends that any strategy to strengthen the Aging Network's capacity to provide families and people with AD access to appropriate services and specialized long-term care planning should be implemented in such a manner that does not overly burden these existing systems. Rather, any approach should provide the Aging Network with the necessary resources to meet these unique needs and to develop innovative practices for doing so. In addition, HHS should compile an inventory of tools to assist caregivers from federal and state agencies, as well as patient advocacy organizations, and make these tools readily available within the next year for distribution through the Aging Network.

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Action 2.F.2: Implement and evaluate new care models to support effective care transitions for people with Alzheimer's disease.
NASUAD supports the Department's recognition of the potential for the ADRC Evidence Based Care Transitions program to implement evidence-based care transition models that meaningfully engage older adults, individuals with disabilities, and their informal caregivers. Throughout this evaluation process, NASUAD recommends that HHS consider the impact that additional resources could have on the ability of ADRCs to build their capacity and successfully support effective care transitions for people with Alzheimer's disease.

Action 2.F.3: Develop an AD-specific toolkit on care transitions.
NASUAD recommends that this toolkit be developed in consultation with state agencies on aging and disabilities, and be available for distribution throughout the Aging Network within the year.

Action 2.H.2: Identify steps to ensure access to long-term services and supports for younger people with AD.
NASUAD supports the proposed collaboration between the Administration on Aging (AoA), the Office on Disability, and Administration on Developmental Disabilities (ADD) to address access to long-term services and supports across the lifespan, and believes these agencies should be consulted as stakeholders throughout the plan's development and implementation.

Action 3.A.1: Identify culturally sensitive materials and training.
NASUAD supports HHS efforts to give caregivers the information and training that they need in a culturally sensitive manner, and recommends that plans to do so include input from the Aging Network. To facilitate the identification and distribution of culturally-appropriate materials to caregivers, NASUAD recommends that within the year, HHS should convene an expert panel to develop an inventory of culturally-sensitive materials and trainings that are currently available, and identify gaps that should be filled by government and patient advocacy organizations.

Action 3.A.2: Distribute materials to caregivers.
NASUAD recommends that HHS utilize its current inventory of federal agency programs and materials and make these resources readily available to all caregivers through the Aging Network.

Action 3.B.2: Identify and disseminate best practices for caregiver assessment and referral through the long-term services and supports system.
NASUAD recommends that HHS distribute the identified best practices in a manner that recognizes the variance in long-term services and supports systems across, and within, states. Since what may be a promising practice in one state may be ineffective in another, NASUAD encourages HHS to recognize the importance of state flexibility in meeting the unique needs of individuals within each state.

Action 3.B.3: Review the state of the art of evidence-based interventions that can be delivered by community-based organizations.
NASUAD recommends that this action include identifying interventions that are successful in improving the health and wellness of people with Alzheimer's disease and other dementias. Many successful evidence based programs have been proven to work for both people with Alzheimer's

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and other dementias, so it is important that the evaluation of such programs not be limited to only Alzheimer's specific interventions.

Action 3.B.4: Develop and disseminate evidence-based interventions for people with Alzheimer's disease and their caregivers.
To successfully implement the strategies defined in Action 3.B.3, NASUAD recommends that HHS quickly work to ensure that more people with Alzheimer's disease, and their families, have access to successful evidence based intervention programs. There are existing programs that NASUAD recommends HHS should expand as part of this effort:

- Older Americans Act - Reauthorization of this legislation would ensure grants to states for community planning and social services, research and development projects, and personnel training in the field of aging. Funding should also be increased for the programs funded by the Act.

- Lifespan Respite Care Act – Reauthorization of this legislation would authorize grants to statewide respite care service providers. Grants can be used for various purposes, including training and recruiting workers and volunteers, training family caregivers and providing information about available services. Additional funds should be allocated to the Act.

- National Family Caregivers Support Program - At a minimum, funding levels should meet the recommended levels of the President's FY12 budget ($192 million). This program provides grants to states and territories to pay for a range of programs assisting family and informal caregivers to care for loved ones at home and for as long as possible.

Action 3.B.5: Provide effective caregiver interventions through AD-capable systems.
As HHS works to connect caregivers with appropriate supportive services, NASUAD recommends that HHS build upon the existing capacity of ADRCs to serve as "No Wrong Doors" through which individuals, their families, and caregivers can access available services and programs.

Action 3.B.6: Share lessons learned through VA caregiver support strategies with federal partners.
NASUAD recognizes and applauds the successes of the VA in providing home and community based care, and realizes the importance of sharing lessons learned from the implementation of these programs across agency and state lines. NASUAD recommends that the quarterly meetings identified in this action step commence as soon as possible, so that important information is gathered and shared not only among federal programs, but also throughout the Aging Network.

Action 3.C.1: Examine awareness of long-term care needs and barriers to planning for these needs.
Once HHS completes this barrier-identification process, NASUAD recommends that HHS work with federal stakeholders, including CMS and AoA, as well as state and local agencies on aging, to develop and implement solutions to the identified obstacles.

Action 3.C.2: Expand long-term care awareness efforts.
In looking to expand public outreach and awareness about Alzheimer's disease and the importance of long-term care planning, NASUAD recommends that HHS build upon the successes of the Aging

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Network in providing outreach and education, such those achieved by ADRCs, I&R/A, SHIPs, and state and local agencies.

Strategy 3.D: Maintain the dignity, safety and rights of people with Alzheimer's disease.
To successfully implement this strategy, NASUAD recommends that HHS consider implementing the Elder Justice Act (EJA), as established by the Affordable Care Act (ACA). The EJA fully realizes the need to protect our most vulnerable citizens from financial exploitation, as well as from physical and emotional abuse and neglect, and it creates structures and programs for doing so. Though the EJA was signed into law in 2010, it has yet to receive any federal dollars. Without a strong financial commitment to address the growing problem of abuse and neglect among older adults, it will be impossible to fully secure the dignity, safety, and rights of people with Alzheimer's disease. NASUAD recommends that HHS work with Congress to fully fund the Elder Justice Act.

Action 3.D.1: Educate legal professionals about working with people with Alzheimer's disease.
NASUAD recommends that these efforts take into consideration the existing framework and resources for legal services that are available through the OAA. Additionally, training should be offered to legal professionals throughout the Aging Network, and the curriculum should address the importance of cultural competence. Training should also be extended to state Adult Protective Services workers as well as to other individuals as appropriate.

Action 3.D.2: Monitor, report, and reduce inappropriate use of anti-psychotics in nursing homes.
To leverage existing successful systems, NASUAD recommends that federal and state representatives from AoA' s National Long-Term Care Ombudsman Program be involved in this collaborative effort.

Action 3.E.1: Explore affordable housing models.
NASUAD recommends that this action include the evaluation of innovative interventions aimed at helping older adults and individuals with disabilities, including those with Alzheimer's and other dementias, remain in the community rather than in institutional settings. With a focus on programs and strategies undertaken by AoA, state agencies on aging and disabilities, and area agencies on aging, NASUAD recommends that HUD and HHS work with the Aging Network to identify innovative practices, barriers to success, and solutions to these barriers.

New Recommendation: ***Ensure adequate resources for programs and services supported by AoA's Alzheimer's Disease Supportive Services Program (ADSSP).***
ADSSP's focus is to expand the availability of diagnostic and support services for persons with Alzheimer's disease and other dementias and their caregivers, as well as to improve the responsiveness of the home and community based care systems to persons with dementia. The program focuses on serving hard-to-reach and underserved persons using proven and innovative models. In order to achieve Goal 3 in the Draft Plan, funding for ADSSP should be increased rather than reduced so that evidence based programs can continue to support the growing number of people with Alzheimer's disease and other dementias and their families at the community level.

New Recommendation: ***Include services for mental and behavioral health services.***
Mental and behavioral health services must be included in the wide array of necessary health services available to individuals with Alzheimer's and other dementias, their families, and their

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caregivers. Mental and behavioral health providers should be represented on interdisciplinary health care teams that work with these individuals, their families, and caregivers in primary care, institutional, and home and community based settings. Cognitive impairment alone does not preclude the ability to benefit from various forms of effective behavioral and mental health interventions.

Action 4.A.1: Design and conduct a national education and outreach initiative.
NASUAD recommends that HHS use existing "No Wrong Door" systems, such as ADRCs, to link individuals to accurate information, resources, services, and supports, in a manner that recognizes the potential need to enhance the capacity of ADRCs.

Action 4.B.1: Convene leaders from state and local governments.
NASUAD recommends that HHS include state directors on aging and disabilities in this collaboration, as well as state long-term care directors.

On behalf of NASUAD, I thank you for the opportunity to comment on the Draft National Plan to Address Alzheimer's Disease. We look forward to continuing to work with HHS to develop an approach that seeks to achieve the vision of a nation free of the disease, while maintaining the dignity and independence of older adults, individuals with disabilities, their families, and their caregivers. Please do not hesitate to contact me at mroherty@nasuad.org, or Lindsey Copeland, NASUAD's Director of Policy and Legislative Affairs at lcopeland@nasuad.org to further discuss any of these issues.

Sincerely,

Martha A. Roherty
Executive Director

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