



the compassion to care, the leadership to conquer

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

Re: National Alzheimer's Project Act (NAPA)

Dear Dr. Lamont:

On behalf of the Alzheimer's Association, Connecticut Chapter, we want to thank you for allowing us to provide public comment on the National Alzheimer's Project Act (NAPA).

The Connecticut Chapter is grateful to the administration for making Alzheimer's disease a national priority. We believe the establishment of the plan is a positive step toward beginning to address many challenges, including quality of care, family and caregiver support and the development of new treatments and early detection diagnosis and interventions.

The National Alzheimer's Project Act NAPA

Much of the draft plan focuses on evaluation and assessment of current programs. While these are valuable steps, we encourage the Administration to quickly move from assessment to action for the families touched by this disease.

The plan identifies several challenges that emerged from the Alzheimer's Association's public input process and outlines a framework to begin the implementation process. Ten key issues include: a lack of public awareness, insufficient research funding, difficulties with diagnosis, poor dementia care, inadequate treatments, unprepared caregivers, ill-equipped communities, mounting costs, specific challenges facing diverse communities and those with younger-onset Alzheimer's.

The Chapter thanks the President for taking immediate action to fight Alzheimer's disease with the historic investment of \$156 million in research funding with the National

Institutes of Health (NIH) and supporting people with Alzheimer's disease and their families in educating the public and providers. On the other hand, statistics suggest \$2 billion will be necessary to find a cure to halt the disease. It is the 6th leading cause of death in the United States and the 5th leading cause of death for those aged 65 and older. Alzheimer's is the only cause of death among the top ten in America without a way to prevent, cure or even slow its progression. Furthermore, deaths from Alzheimer's have increased 66 percent between 2000 and 2008, while deaths from other major diseases, including the number one cause of death (heart disease), decreased. Yet, each of these diseases has received between \$2 to \$8 billion each for the last few years from NIH. Meanwhile, Alzheimer's has been flat-funded at \$595 million. It is clear that research funding has helped lower the death rates for other chronic diseases.

The Association is grateful for the administration's goal to prevent and effectively treat Alzheimer's disease by 2025. However, statistics suggest treatments will need to be accelerated to change the trajectory of the disease or it will triple by 2050.

The plan realizes the need for an adequate supply of culturally-competent professionals with appropriate skills, ranging from direct-care workers to community health and social workers to primary care providers and specialists from the point of diagnosis onward in settings including doctor's offices, hospitals, community-based home care and nursing homes. Further, given the complex care needs of people with Alzheimer's disease, high-quality and efficient care is dependent on smooth transitions between care settings and coordination among healthcare and long-term services and support providers. Provider training is essential to effectively detect Alzheimer's disease and caring for people affected by this devastating disease.

Alzheimer's and the Aging Network

The plan provides for HHS to coordinate with states to develop dementia-capable long-term services and support systems and improve the Alzheimer's disease capability of the workforce in their state aging plans. These strategies may include enhancing Alzheimer's disease competencies among Aging Network staff, developing AD-capable community health and long-term care Options Counseling in Aging and Disability Resource Centers, and linking State Long-Term Care Ombudsmen programs to AD-specific training and resources.

Since much of the work required to support caregivers and the direct-care workforce should and will occur at the local level, the state should develop a state plan to tackle Alzheimer's disease. Currently, Connecticut does not have a state plan to address Alzheimer's disease. The state plan would create the infrastructure necessary to build dementia-capable programs for the growing number of people with the disease.

Understanding the enormous stress the disease places on family members and the healthcare system, developing early interventions is necessary to effectively serve and meet the unique needs of people with Alzheimer's disease and their caregivers.

A comprehensive assessment and strategy to bring local stakeholders together to address the needs of persons with Alzheimer's disease is recommended on the state level. The collection of testimonials through town forums could be gathered identifying and quantifying the number of individuals with Alzheimer's in the state. The forums could provide the opportunity to elicit the opinions of the general public. As achieved on the national level, an advisory council should be formed in Connecticut. Membership should include: key legislative leaders, the Office of Policy and Management representatives, state agency representatives and community-based groups, persons with Alzheimer's family and professional caregivers, health professionals from hospitals and primary care, residential and community care providers and Alzheimer's Association representatives.

With the multitude of issues to examine as part of state plan development, workgroups can be formed to tackle specialty areas of expertise. In fact twenty-three states have published a state Alzheimer's plan to create the infrastructure to build dementia-capable programs for the growing number of people with the disease.

The Alzheimer's Association, Connecticut Chapter appreciates the opportunity to submit these comments on the National Alzheimer's Project Act (NAPA). In summary, the Chapter agrees earlier diagnosis of the disease and coordinated strategies among the Aging Network for long-term services and supports need to be developed on the state level to meet the growing demands of persons with the disease and their caregivers. Finally, accelerated research and funding for a cure is imminently needed to achieve savings in billions of dollars to the health care system.

Sincerely,

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