

## New York State Office for the Aging Memorandum

**To:** Helen Lamont, Ph.D

**From:** Greg Olsen, Acting Director

**Date:** March 30, 2012

**Subject:** New York State Office for the Aging comments on the Draft Framework for the National Plan to Address Alzheimer's Disease

Thank you for inviting the New York State Office for the Aging (NYSOFA), to comment on the U.S. Department of Health and Human Services, "Draft Framework for the National Plan to Address Alzheimer's Disease." As Acting Director of NYSOFA, the New York State Unit on Aging, I would like to offer for consideration our recommendations to the Draft Framework for the National Plan. These amendments would seek to enhance the role of the aging network in helping to achieve the goals and objectives of the National Plan.

The National Alzheimer's Project Act (NAPA) identifies the urgent need for a national plan to systematically tackle and conquer this fatal illness and scientific research, is the key to finding a cure. NYSOFA supports the efforts of the Advisory Council on Alzheimer's Research, Care and Services which includes, David Hoffman from the New York State Department of Health.

NYSOFA is a member of the New York State Coordinating Council for Services Related to Alzheimer's Disease and Other Dementias, established in 2007, and actively participates in subcommittee activities. In 2011, NYSOFA was awarded a three year Systems Integration Grant from the Administration on Aging (AoA) that provided funding for developing and integrating into service systems, dementia capability - this included care transitions and evidence-based direct services to persons with dementia and their caregivers. In addition, NYSOFA was a recipient of other AoA grants, including Lifespan Respite.

New York State is committed to providing the best possible dementia capable services throughout our aging network. New York will continue efforts to identify best practices and evidence-based interventions that produce positive outcomes impacted by the disease and their caregivers. A recent snapshot of all of NYSOFA's programs/ and services in December 2011, revealed that a significant percentage of the 59 Area Agencies on Aging (AAAs) were serving persons living with cognitive impairments related to dementia.

Of all of NYSOFA's community-based services and supports, social adult day services programs

are uniquely suited to providing care and support to individuals with dementia and their caregivers. In these programs, 65 percent of participants have some form of dementia. The average year of age is 83 of a program participant, who requires hands on assistance with at least two activities of daily living (ADLs). They can remain living in their communities by attending an adult day care center for an average of two years following enrollment in the program. This is one example of a service provided by the aging network that persons with Alzheimer’s Disease and their caregivers rely on.

For the person with Alzheimer’s that lives alone or who does not have a caregiver, the friendly home delivered meal volunteer may be the only daily social interaction they may experience. As noted in the Alzheimer’s Association *2012 Alzheimer's Disease Facts and Figures* report, one in seven persons with this disease lives alone. The case manager who coordinates services for these individuals often identifies signs or symptoms of illness and communicates with health care providers when they emerge. The aging network plays a significant role in providing community-based services and caregiver supports, which routinely interact with clinicians and health care providers. Considering the demographic shift of the next 30 years, it is vital that the aging network be recognized in the plan and that the plan demonstrates an integration of the health care and aging networks.

Please consider NYSOFA’s recommendations for inclusion in the Draft Framework for the National Plan to Address Alzheimer’s Disease:

**1. The Aging Network, as noted below in the following statements, should be identified specifically in the following key provisions of the draft plan.**

This is imperative as the aging network is much more than a support system and is better described as a service system of public and private entities that provide a wide range of services targeted to older adults and their caregivers. Many of the direct services, such as Chronic Disease Self-Management Programs and Adult Day Services are “active treatments” for the participants. Please consider including references to the Aging Network in the following statements:

Page 5: Framework and Guiding Principles – insert:

“Individuals with Alzheimer’s Disease and their caregivers receive assistance from both the clinical healthcare system and support systems, such as long-term care, home care, legal services, aging and other social services. Both the clinical care and support environments need better tools to serve people with Alzheimer’s Disease and their caregivers. Ongoing and future research seeks to identify evidence-based interventions to assist clinicians, persons with Alzheimer’s and their caregivers.”

Page 11: Strategy 1.E: Facilitate translation of findings into medical practice and public health programs –insert:

“Additional steps are needed to highlight promising findings and to facilitate dissemination and implementation of effective interventions to the general public, medical practitioners, the pharmaceutical industry, and public health and aging systems quickly and accurately.”

Page 13: Strategy 2.A: Build a workforce with the skills to provide high-quality care- insert

“The workforce that serves people with Alzheimer’s Disease is diverse and complex. It includes professionals in the aging services network and the licensed health care field - such as primary care physicians; specialists such as neurologists, geriatricians, and psychiatrists; registered nurses and advanced practice nurses; community health workers; social workers; psychologists; pharmacists; dentists; allied health professionals; and direct-care workers like home health aides and certified nursing assistants and, also those who provide consumer directed or informal supports.”

Page 17: Strategy 2.D: Identify high-quality dementia care guidelines and measures across care settings-insert

“These guidelines should be tailored to the stages of the disease and cover the myriad of care settings in which care is delivered, such as in the home, congregate aging service settings, physician offices, and long-term care facilities.”

- 2. The aging network relies on non-pharmaceutical evidence based research to continue generating support for service delivery models used to provide care to persons with dementia and their caregivers.** The aging network needs clinical trials to better demonstrate the effectiveness of the most promising non-pharmaceutical evidence-based interventions.

Page 10: Action 1.B 6: Conduct clinical trials on the most promising lifestyle interventions-insert:

“HHS and its federal partners will continue to conduct evidence based clinical trials to test the effectiveness of lifestyle interventions and risk factor reduction in the prevention of Alzheimer’s Disease.”

- 3. The aging network serves as the foundation on which the Aging and Disability Resource Center (ADRC) is being built to serve as a primary source of information and assistance to persons in need of long term care supports and services.**

Action 2.A. 1: Educate Health Care Providers: insert:

“Health care providers will learn how to manage the disease in the context of other health care conditions, and about the role of the ADRC in linking people to support services in the community”.

- 4. In general, persons with Alzheimer’s Disease and their caregivers prefer to receive community-based long term services and supports as compared to nursing home placements.** Community-based AD care should be routinely referred to in the plan.

Page 15: Action 2. A. 4: Strengthening the direct-care workforce –insert:

“HHS will strengthen the nursing home, aging services and long-term services and supports direct-care workforce through new training focused on high-quality, person-centered care for people with Alzheimer’s Disease.”

Page 17: Strategy 2.D: Identify high-quality dementia care guidelines and measures across care settings-insert:

“These guidelines should be tailored to the stages of the disease and cover the myriad of care settings in which care is delivered, such as in the home, aging service settings, physicians’ offices, and long-term care facilities. These guidelines should also take into account how care might be modified for diverse populations and in the context of co-occurring chronic conditions in people with Alzheimer’s.”

- 5. The following should be added into Strategy 2. D. on page 17 as an additional action item.**

**Adult Day Services implementing evidence-based interventions should be acknowledged as an active treatment for persons with Alzheimer’s Disease.** There is a substantial need for increased access to dementia capable day centers and in the understanding about the effectiveness of this model by primary care physicians. This undertaking can be enhanced through additional evidence based research on this mode of care. In addition, Medicare should be expanded to reimburse for adult day services for individuals with dementia.

Although this process is challenging, NYOSFA is confident that the final adopted National Plan will increase positive outcomes for individuals with Alzheimer’s Disease and their caregivers, as well as, identifying promising treatments for this ailment. On behalf of NYSOFA, I want to express our appreciation for the consideration of these recommendations.