



Formerly Park Slope Geriatric Day Center

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March 29, 2012

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

RE: New York Memory Center comments on the Draft Framework for the National Plan to Address Alzheimer's Disease

Thank you for inviting the public to comment on the U.S. Department of Health and Human Services "Draft Framework for the National Plan to Address Alzheimer's Disease." For over two decades New York Memory Center has been on the front-lines of Alzheimer's community-based care. As a pioneer in Social Adult Day programming and Caregiver Supportive Services we welcome the opportunity to provide recommendations for your consideration.

We believe that the five goals outlined in the plan which form the foundation of the National Plan are ambitious, courageous, and seek to offer a comprehensive and multi-faceted approach. In comparing the National Plan to the most recent work of the three Sub-Committees, we felt the need to underscore a few key recommendations.

While our ultimate goal is a world without Alzheimer's, we recognize the very real possibility that even with increased financial support to drive a targeted research agenda, we may not put an end to this horrible disease by 2025. Moreover, those living with the disease today and tomorrow deserve the best possible care we can offer. We need better care now. We are concerned that the ultimate research agenda will be too narrow in scope and leave research relative to care practices as a back-burner issue, instead of integrated as a significant component.

In innovative Alzheimer's Adult Day Centers around the country, various non-pharmacological approaches to care such as arts-based programming; cognitive stimulation; exercise and movement training; meditation; learning methods; sensory therapy, cognitive training; tailored diets; communication techniques for managing behavioral symptoms; early stage education designed to maximize independence and efforts to reduce excess disability; and caregiver education, coaching, and counseling are practiced with evident increases in quality of life, and evident reductions in challenging behaviors; and with some interventions, short term improvements in cognition, language and learning. These interventions must be recognized as active treatment for Alzheimer's disease and reimbursed by Medicare.

Although these practices emerged as grassroots movements, we now have significant studies that support many of these interventions as evidence-based or evidence informed practices in the care of individuals with dementia and their caregivers. Any plan to invest in research should substantially include non-pharmacological care-based research. Much more research is needed in these areas as positive outcomes are consistently identified by care providers and clinicians as superior to other conventional approaches. We must address the clinical significance of these various approaches to treatment. The small size of most studies, and variability in quality in these areas limits generalization of the results, and discourages widespread practice changes in care settings. What is needed is funding for large, well designed, robust studies in order to influence practice changes nationally.

Today, approximately \$30 million dollars of the \$479 million dollars devoted to Alzheimer's disease research is earmarked for clinical research in Alzheimer's disease care, support and education. We recommend a substantial increase in this area relative to the overall annual research budget. Research based, non-pharmacological, active treatment needs to be implemented as standard practice. Research must seek to understand what care works, why, and to ensure that the best care is widely practiced nationwide.

One agency missing from the list of participating inter-agency departments and government agencies tasked to help support the development of the national plan is the National Endowment for the Arts. We strongly recommend that this agency have an opportunity to weigh in and support efforts in creating this national plan. Recently, this agency partnered with the U.S. Department of Health and Human Services in creating a white paper framing a national research agenda for the arts, health and well-being.

We believe that HHS should provide federal funds to support a state lead entity in every state--- determined by each Governor for the purpose of developing a state Alzheimer's Strategic Plan. We recommend that this lead agency Chair a state inter-agency committee comprised of other departments in state government which impact the Alzheimer's community, labor, other stakeholders, community service providers, caregivers and at least one resident living in the state with capacity who is living with memory loss to serve on this committee. We believe this committee should be tasked to provide annual updates which compare results to planned goals, and made publicly available to the citizens of each state.

We strongly recommend that the plan encourage the development of statewide plans for a full assessment of each state's current service delivery system, and outline a strategic plan for caring for individuals living with Alzheimer's and related dementias now and in the future. The national plan should weigh in on these efforts and seek to reward states for creating and implementing innovative cost savings while improving care outcomes.



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We also believe that Administration on Aging Title III E Caregiver Support Service Programs can be an effective resource in meeting the needs of the Alzheimer's and related dementia community. With increased funding to the States, these programs could provide memory screenings and referrals to local diagnostic centers in order to receive a full differential diagnosis. Moreover, these programs could take a lead role in case management and care coordination, and in helping families with advanced care planning. We recommend that the plan include increased new funding to states within III E that stipulates services for individuals with Alzheimer's disease and their caregivers.

Medicare must provide an Adult Day Services benefit for persons with dementia. Adult Day Care Services provides active treatment for the person with dementia and support for their caregivers. This is particularly vital for the person with the disease that lives alone and/or has no caregiver. Medicaid should include Adult Day Services as a state option. Simply put, public policy discriminates individuals with a dementing disease. Medicare and Medicaid provide coverage for active treatment of medical and functional needs related to disease processes but does not include active treatment for individuals with dementia. These services allow adults with memory loss to be safe, socially connected, and therapeutically supported in order to maintain functional abilities as long as possible and avoid premature institutionalization. Moreover, this provides caregivers needed respite in order to extend their ability to care for their loved ones at home.

The cost savings to our long-term-care system would be tremendous relative to the over usage of home care, and nursing homes. In New York State the average cost for Adult Day Services is approximately \$80 per day--- compared to \$144 a day for home care, and between \$253-376 a day for nursing home care. We must ask ourselves--- why are we--- over-medicalizing long term care services when they are often inappropriate. Adult Day Services provides care in the least restrictive setting and offers a therapeutic oasis where those living with Alzheimer's disease and related dementias can continue to actively participate in the life of a community.

Thank you for the opportunity to share our thoughts and recommendations.

Sincerely,

Christopher Nadeau

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Executive Director

