FAMILY CAREGIVER ALLIANCE®
National Center on Caregiving

A nonprofit, tax-exempt organization

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National Center on Caregiving:
- *Family Care Navigator*
- *Innovations Clearinghouse*
- *Technical Assistance*

Bay Area Caregiver Resource Center
- *Care Planning*
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Research, Policy & Technical Assistance

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Kathleen Kelly, MPA
Executive Director

Ping Hao, MBA
Board President

April 17, 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: Advisory Council Meeting #4 (April 17, 2012): Presentation Handouts

Dear Dr. Lamont:

I am writing on behalf of family caregivers throughout the United States who are struggling to provide care for their loved ones with Alzheimer's disease and related dementias. The National Center on Caregiving at Family Caregiver Alliance supports many of the recommendations contained in the presentation handout and would like this letter submitted for the formal record.

Long-Term Services and Supports Subcommittee Recommendations

1) HHS should provide Federal Funds to support a state lead entity in every state and territory. This entity would coordinate available public and private LTSS, conduct service gap analysis, identify opportunities for efficiency, and enable ongoing stakeholder input to address needs across all sectors and systems. Bullet point #7: HHS should fully fund the costs of cognitive impairment and caregiver surveillance through the Behavioral Risk Factor Surveillance System (BRFSS) in every state.

FCA: We support using the caregiver module in BRFSS in every state. However, in our communication with states that have included the caregiver module in their BRFSS, not all states had the funding or infrastructure to properly analyze the data after it was collected. Therefore, HHS should also include funding for the analysis of the data after it has been collected.

4) Fully fund Caregiver Supports under AoA. AoA currently has a Caregiver Support Program, a component of which can be expanded to better meet the needs of caregivers of individuals with Alzheimer's disease and other dementias.

FCA: An article in *American Family Physician*, released in 2011, ("Caregiver Care") focused on the importance of caregiver assessment. In it, the authors noted that the National Family Caregiver Support Program (NFCSP) received $154 million in federal funding in FY 2009, "approximately one-twentieth of 1 percent of the value of caregiver contributions." Family Caregiver Alliance strongly supports fully funding this program that helps families navigate the many complexities of long-term care for a loved one.

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5) Assure a robust, dementia capable system of Long Term Services and Supports (LTSS) is available in every state. Bullet Point #6: CMS should provide guidance to all states on adding adult day services as a state optional service under Medicaid.

FCA: Caregivers in California were faced with the elimination of the Adult Day Health Care program (stopped only by a lawsuit) in 2011 because it is an “optional” benefit in Medi-Cal. Given the nature of caregiving for a person with dementia, especially in its advanced stages, services like adult day programs are not “optional” for caregivers. They are vital sources of respite for families who may also be balancing jobs and raising children. Therefore, we believe that the conversation should focus on how to ensure that every family has access to adult day services. When a service like Adult Day Health Care is considered “optional,” it often lands on the chopping block during economic downturns, (as California caregivers experienced in 2011) and families are left to try and piece together alternatives.

12) HHS and State Lead Entities should assure that caregiver physical health/ behavioral health risk is assessed and addressed regularly. Caregiver illness and mortality contribute to the enormous personal and financial cost of Alzheimer’s disease. The health and well-being of a caregiver has a direct impact on the health and quality of life of a person with Alzheimer’s disease.

FCA: While we support assessing caregivers and connecting them with services, we also advocate for a person *and* family-centered approach to care. While the health of the caregiver does have an impact on the health and quality of life of a person with Alzheimer’s disease, the opposite is also true. People who become caregivers face increased risks of depression, stress, exhaustion, cognitive decline, and higher mortality rates. Instead of viewing the caregiver’s needs merely in relation to how this will support their caregiving role, it is also important to recognize caregivers and their health (psychological, emotional, physical, and financial) as a separate priority in addition to the care receiver.

Family Caregiver Alliance is grateful for the opportunity to provide our input on behalf of the over 15 million Americans currently caring for a loved one with Alzheimer’s and related dementias.

Sincerely,

Kathleen A Kelly

Kathleen Kelly, MPA, Executive Director