



John K. Holton, Ph.D., Director

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March 28, 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 Plan

Dear Ms. Lamont:

As Director of the Illinois Department on Aging, I am writing in support of the proposed National Plan for Alzheimer's and Related Disorders (ADRD) that would promote an earlier diagnosis of the disease, improve strategies for long term services and supports, and accelerate the search for a cure.

The Illinois Department on Aging was created by the State Legislature in 1973 for the purpose of improving the quality of life for Illinois' senior citizens by coordinating programs and services enabling older persons to preserve their independence as long as possible. It is the single State agency authorized to receive and dispense Federal Older Americans Act funds and is mandated to provide a comprehensive coordinated service system for the State's 2.2 million older persons, giving high priority to those in greatest need. I appreciate the opportunity to comment on the proposed goals, strategies and actions that directly affect the Aging Network, caregivers and persons with Alzheimer's and related dementia.

According to the Illinois Department of Public Health, an estimated 222,300 individuals in Illinois are living with Alzheimer's disease with a direct and indirect financial toll of \$5.2 billion. More than 70% of those suffering from Alzheimer's disease are living at home.

Caregivers of persons with Alzheimer's disease are more likely to assist care recipients with Activities of Daily Living (ADLs) than caregivers of other persons.⁽¹⁾ Caregivers often help to manage other serious medical conditions in addition to Alzheimer's, and because Alzheimer's and other dementia usually progress slowly, most caregivers spend many years in the caregiving role.⁽²⁾ In 2006 the Family Caregiver Alliance and National Family Caregiver Association reported an estimated 1.2 million family caregivers in Illinois were providing 1.3 million hours of care to family members. As the baby boom generation enters the age of greatest risk for Alzheimer's, by 2025 their number in Illinois is expected to increase to over 239,000.

Thirteen Area Agencies on Aging and statewide service providers comprise the Aging Network in Illinois, which effectively links older persons with needed services. The National Family Caregiver Support Program (NFCSP), implemented through the Aging Network, provides five basic service categories to family caregivers including: information about services; assistance in accessing services; counseling; support groups and training/education; respite care; and, supplemental services.

In FY 2011, 66,132 Illinoisans received assistance through services of the NFCSP. Additionally, 493,313 individuals received assistance through supportive and nutrition services of the Older Americans Act.

Respect for yesterday. Support for today. Hope for tomorrow.

The proposed National Plan for Alzheimer's and Related Disorders contains thoughtful recommendations which address the immediate and long-term needs of caregivers, providers and individuals affected by Alzheimer's disease. The Aging Network in Illinois is committed to providing services to Alzheimer patients, their families and caregivers through a number of programs which support the five goals of the National Plan.

- Public Education and Outreach: Through Title III-B efforts under the Older Americans Act and Title III-E programs of the National Family Caregiver Support Program the Aging Network provided education and outreach on aging issues and available resources to 6,429 individuals in FY 2011. Additionally, the Department collaborates with many professional organizations to provide education and training opportunities. Examples include the Annual Elder Rights Conference; Senior Expos; Area Agencies on Aging sponsored Lunch and Learn/Brown Bag events; Caregiver Conferences; AIRS (Alliance of Information and Referral Systems) training; the Illinois Department of Children and Family Services Older Caregiver Training.
- Outreach to healthcare providers: Home and community-based resources are critical to ensure that persons living with Alzheimer's disease are adequately and safely cared for in their homes as long as possible and contain the cost of health care. The Illinois Department on Aging sponsors many conferences and workshops for professionals including the Community Care Program/Case Coordination Unit Annual Supervisor Conference convening supervisors from case coordination units and home care agencies; the Annual Governor's Conference on Aging and Illinois TRIAD comprised of state and local law enforcement agencies and other professional organizations. The Department also promotes the use of the Administration on Aging's National Alzheimer's Call Center by caregivers and encourages referrals by AAAs and providers.
- Expanded support for people with Alzheimer's disease and caregivers in the community: The Department has aggressively pursued funding to expand and enhance services for caregivers. In 2009 the Administration on Aging awarded the Department a three year Lifespan Respite grant which has enhanced access to and improved awareness of respite services. The Department has established a statewide Caregiver Advisory Committee which convenes regularly to discuss caregiver issues, share resources and best practices and review caregiver programs and is establishing protocol to implement an effective service delivery system through Aging and Disability Resource Centers/Coordinated Points of Entry.
- Improved data collection and analysis: The Department works closely with the thirteen Area Agencies on Aging to collect data for NAPIS reporting as well as reviewing current caregiver assessment tools.

In 2009, the Illinois Department of Public Health published the "Alzheimer's Disease and Other Related Dementia State Plan - Senate Joint Resolution 43 - Report to the Governor and General Assembly." Recommendations in this report are reflected in the National Plan and include:

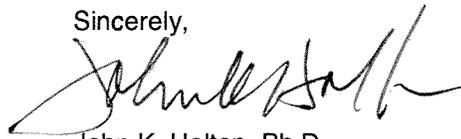
- Establishing adequate staffing levels and funding
- Establishing basic and specialized education and training for persons when responsibilities make it likely they will come into contact with persons with AD and related dementias and their caregivers
- Facilitate planning, treatment and research
- Provide assistance to unpaid caregivers of persons with AD
- Determine an effective system to collect data

We must continue to examine our current capability to meet the Alzheimer's crisis and propose action to prepare for and respond to these challenges which include the development of a standardized caregiver assessment; establishment of the ADRC service delivery model; continue collaborative efforts of the Lifespan Respite Program; continue to incorporate consumer directed care service models through the

National Family Caregiver Support Program; continue to collaborate with the Alzheimer's Association in Illinois; utilize Area Agencies on Aging and service providers to disseminate information and provide culturally sensitive training and materials to providers and caregivers; assist families and individuals in planning for future needs and provide updates to families, caregivers and providers regarding the latest clinical guidelines and information on how to work with people with AD; examine the capacity of public safety and law enforcement to respond to person's with Alzheimer's; examination of trends in the Alzheimer's population and needs, including assistance to persons with early stage and early on-set Alzheimer's and persons with Alzheimer's and developmental disabilities.

The Illinois Department on Aging and the Aging Network is committed to continue to respond in the most appropriate and effective way to this growing health problem and meet the challenge of providing service to Alzheimer's patients, their families and caregivers. The proposed National Plan is sensitive to local efforts to support caregivers and direct-care workers and offers viable proposals to support, educate and train the direct-care workforce and state aging workforces. Thank you for this opportunity to provide comments.

Sincerely,

A handwritten signature in black ink, appearing to read "John K. Holton". The signature is fluid and cursive, with a long horizontal stroke at the end.

John K. Holton, Ph.D.
Director

- 1) 2009 National Alliance for Caregiving/AARP Study
- 2) National Alliance for Caregiving