

Long Term Services and Supports (LTSS) Subcommittee Recommendations

January 2014

1. States should assure that they have robust, dementia capable LTSS systems.

2. HHS should provide federal funds to support a state lead entity in every state and territory. This entity will facilitate development of the state's dementia capable systems, 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. HHS should use available funds to begin this process in 2014.

3. HHS should engage all relevant federal agencies to include research on LTSS that addresses dementia capability in their research agendas. Topics needing further research include:

- Culturally and linguistically appropriate interventions across settings and translation of these interventions for persons with dementia and their caregivers.
- Interventions for persons in the early stages of dementia, including those that mitigate symptoms of the disease.
- Interventions for persons with Down syndrome and other intellectual disabilities that are at high risk of acquiring dementia as they age.
- Impact of caregiving on health and quality of life of caregivers.

4. State, local and private sector organizations should ensure that paraprofessional caregivers in every venue are adequately trained and compensated.

5. CMS should redesign Medicare coverage and physicians' and other health care providers' reimbursement to encourage appropriate diagnosis of AD and to provide care planning to diagnosed individuals and their caregivers.

6. LTSS systems should refer people to a healthcare provider for diagnosis whenever they are admitted to or assessed for eligibility for LTSS and exhibit signs of cognitive impairment.

7. Providers engaged in diagnosis should consider the most current guidelines for diagnosis of Alzheimer's disease and rule out and treat any conditions that may mimic this disease.

8. The process of diagnosis should include engaging individual and family in advance care planning (health, legal, estate, and financial).

- The state lead entity for AD should assure that an inventory of culturally and linguistically appropriate community resources is maintained through state, local, and private resources. This should be one of the activities eligible for federal funds as available.

9. HHS should assure that health and related systems funded with federal resources should improve chronic disease treatment and related services for people with AD.

10. HHS should continue development of quality measures and indicators for the comprehensive care and treatment of individuals with AD.

- The Agency for Healthcare Research and Quality, National Quality Forum and Institute of Medicine should continue to develop and implement quality care measures and indicators for diagnosis, treatment, and care of individuals with AD across care settings.

11. Recommendations for end-of-life or palliative care should be incorporated into all CMS surveillance and quality improvement systems at the earliest possible time.

- Because at this time AD is a terminal illness marked by diminishing capacity, providers should discuss and document use of palliative care and desires regarding end-of-life care as early as practical in the disease process.

12. HHS/CMS activity should include:

- Convene a blue ribbon panel of experts to recommend one or more models of palliative care for people with advanced dementia, including eligibility criteria and financing mechanisms, and provide grants through CMMI to implement and evaluate the models.
- Provide grants through CMMI for medical home pilot projects specifically targeted at improving medical and chronic condition management for individuals with AD, and coordination with family and community care providers in the full array of settings.
- Create a specific grant round of pilot projects through CMMI to implement and evaluate ways to reduce preventable emergency department visits, hospitalizations, and length of hospital stays for individuals with AD, who are living in the full array of settings.
- Convene a panel to recommend innovative means of financing long term care services and supports

13. HHS and state lead entities should partner to assure access to the full array of LTSS for specific populations of people with AD including younger people, non-traditional families, people with intellectual disabilities, such as Down syndrome, and racial and ethnic minorities who are at increased risk of acquiring AD.

14. Funding for the Alzheimer's Disease Supportive Services Program (ADSSP) should be restored to the FFY 2003 level of \$13.4 million and the National Family Caregiver Support Program should be fully funded.

15. HHS, state lead entities, and providers 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 AD.

16. The Office of the National Coordinator for Health Information Technology, in partnership with the private sector, should work to assure development of HIT includes tools for caregivers. Tools could assist caregivers by: helping organize care, educating them about dementia and multiple chronic conditions, use of home monitoring tools and decision supports and providing tools to help them maintain their own mental and physical health.