

# Long-Term Services and Supports (LTSS) Subcommittee Recommendations

January 14, 2014

1. **States should assure that they have robust, dementia capable LTSS systems.**
  - Every state should identify a state lead entity for AD to coordinate activity across state agencies and programs and work with the private sector to implement strategies in concert with the National Alzheimer's Plan. The dementia capable systems should include a full array of LTSS that are culturally and linguistically competent and evidence-informed or evidenced-based. Services and supports should be available in individual and community settings. According to the National Council on Aging, evidenced-based programs come from "*a process of planning, implementing, and evaluating programs adapted from tested models or interventions.*"
  - The array of services for people with AD include -- outreach; early detection; diagnostic services; care and estate planning; treatment (medical, psychiatric, pharmacological and social/cognitive interventions; e.g., memory classes); care/treatment advocacy (e.g., medication management, benefits counseling and patient navigation); early stage support services; social support services (such as adult day services, activity of daily living supports like escorted transportation, meal preparation, home and personal care assistance, etc.) supportive housing and home safety assessment/modifications; safety services (medic-alert, safe return, GPS based programs, etc.); hospital and community based end-of-life and palliative care.
  - Services for families and caregivers include -- outreach; advocacy; disease and self-care education; caregiver assessment; psycho-social support groups; supports for long distance caregivers; caregiver centered dementia care management (such as T-Care); legal and financial (including family care tax relief policies and benefits counseling) services; a continuum of respite services; and supportive workplace family care policies.
  - The Centers for Medicare & Medicaid Services (CMS) should provide guidance to all states about how to add adult day services as a state optional service under Medicaid.
  - Public and private payments for services should reflect reasonable compensation that recognizes any special training for dementia capable service providers.

- 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.**
  - HHS should identify an appropriate office or operating division to manage funds for the program supporting the state lead entities and convene representatives of state lead entities regularly.
  - The identified office should develop standards for state lead entities that should be met as a condition of funding. Understanding that states are organized differently, standards should be flexible enough to accommodate various entities as lead, based on what is appropriate for each state.
  - Governors should be enlisted to designate the lead entity for their state, and that designation should carry authority to impact program activity across agency lines when necessary.
  - States should draft (or update) a state plan to address AD, in concert with the National Plan.
  - HHS should fully fund the costs of cognitive impairment and caregiver surveillance through the Behavioral Risk Factor Surveillance System in every state.
  
- 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.**
  - These organizations should require that paraprofessional caregivers receive sufficient training to demonstrate cultural and dementia competence from a reliable source.
  - States should enact policies that ensure that their hours and pay reflect fair and reasonable compensation because many of these workers are working multiple shifts at below subsistence wages, often with few benefits and collect necessary data to assure this occurs.
  - Compensation should reflect the completion of a prescribed training program.

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.**
  - This Medicare coverage should include care planning with a family caregiver even if the individual with the disease is not present.
  - The Health Resources and Services Administration (HRSA) and CMS should clarify and disseminate information to providers about the procedures under Health Insurance Portability and Accountability Act with regard to sharing medical information with caregivers related to dementia, prognosis, and care planning in FFY 2013.
6. **LTSS systems should refer people to a health care 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.**
  - People with AD often have other (multiple) chronic conditions. Treatment options for persons with AD are limited and prognosis is negatively affected when individuals have acute flare-ups related to their other conditions or complications, (e.g., stroke, chronic obstructive pulmonary disease, coronary heart disease). Therefore, HHS, states, and private sector plans or providers should require that care plans for people with AD should be tailored to all of their conditions, especially during recovery and rehabilitation. Professional organizations should develop tools and guidance for clinicians and social service professionals. These tools should link to the HHS Framework to Address Multiple Chronic Conditions.

**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.**
  - HHS and state lead entities should work with providers to assure that supports are tailored for caregivers/family members of specific populations with AD.
  - All guidelines and quality improvement efforts should include specific populations.
  - Congress should amend the Older Americans Act Title III to make these services available to those with younger-onset AD.
  - The Administration on Aging (AoA) should track and report use of Title III services, especially under the National Family Caregiver Support Act, by those with younger-onset AD to assure that data is readily available on related costs for future planning.
  - Services should include provisions for support for children and teenagers who provide supports for persons with 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.**
  - ADSSP supports essential evidenced-based and innovative practices that assist people with AD and their caregivers in the community.
  - HHS, state lead entities and partners can use the lessons learned from this program to spread the availability of valuable services and should develop a long-range plan to convert ADSSP from a demonstration program to a program that provides widely-available services based on the findings from the demonstrations.
  
- 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.**