

Long-Term Services and Supports Subcommittee Recommendations

January 2013

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.
 - Public and private providers should utilize innovative gap filling and financing strategies.
 - 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.
 - Services should encourage development and provide LTSS linkages to state, local; and private supportive housing resources.
 - Services should encourage development and implementation of dementia-capable transportation services.
 - 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 2013.**
 - The state lead entity will be responsible for: facilitating development of a dementia capable system, coordinating public and private resources and programs; building capacity for epidemiology; evaluating programs and improving quality; maximizing the positive impact of services for people with AD and their caregivers; reducing duplication; coordinating public awareness efforts; and assuring that evidenced-based, high quality services are available in their state.
 - 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:**
 - 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.
 - Translation of interventions for persons with dementia and their caregivers into culturally appropriate programs.
 - Translation of interventions for persons with dementia and their caregivers into community settings.

4. **State education and health agencies and others should include key information about AD in all curricula for any profession or career track affecting LTSS.**
 - State education agencies, other relevant state agencies, regional accrediting bodies, and professional organizations should require that current information about AD be included as a condition of approval of any curriculum or course of study leading to relevant provider licensure or certification.
 - Appropriate organizations should require that current information about AD be included in all relevant continuing education activity and all relevant state recertification programs.
 - State, local, and private sector first responders, health and human service personnel, and others who serve the public should receive appropriate information and training regarding AD and the early warning signs of possible cognitive impairment to assure they can effectively perform their work.

5. **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 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,.
 - Public and private sector compensation should reflect the completion of a prescribed training program.
 - Federal agencies should utilize every opportunity to help assure this recommendation is carried out, beginning in 2013.

6. **Congress and 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.**
 - Congress should pass legislation to create Medicare coverage for a package of services that covers the clinical diagnosis of AD as well as care planning for the individual and their caregivers.
 - This Medicare coverage should include care planning with a family caregiver even if the individual with the disease is not present.
 - In exchange for Medicare reimbursement for this package of services, physicians and other healthcare providers should be required to document the AD diagnosis and any associated services provided in the individual's medical record.
 - 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.

7. **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.**
 - The state lead entity should assure that this recommendation is included in any assessment for eligibility for LTSS.
8. **Providers engaged in diagnosis should consider the National Institute on Aging's 2011 guidelines for diagnosis of Alzheimer's disease and rule out and treat any conditions that may mimic this disease.**
 - Whenever a person exhibits symptoms of cognitive decline, providers should consider a diagnosis using the 2011 guidelines.
 - Federal agencies should assure that appropriate training resources are available to health care providers on the use of the guidelines.
9. **The process of diagnosis should include engaging individual and family in advance care planning (health, legal, estate, and financial).**
 - Health and LTSS providers involved in diagnosis should include advance care planning in the health and LTSS care plan after discussion with the individual and family members as appropriate.
 - Health and LTSS providers should have ready access to information for referral of people diagnosed with AD and their family to community resources for financial and estate planning.
 - The state lead entity for AD should assure that an inventory of community resources is maintained through appropriate state, local, and private resources. This should be one of the activities eligible for federal funds as available.
10. **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.
 - Providers should incorporate training regarding the impact of AD on care for comorbid conditions in existing pre-service and in-service training curricula.
 - Professional organizations should develop tools and guidance for clinicians and social service professionals.

- Professional organizations should develop tools for caregivers, which help them with manage multiple chronic conditions. These tools should link to the HHS Framework to Address Multiple Chronic Conditions.
11. **HHS should develop quality measures and indicators for the comprehensive care and treatment of individuals with AD.**
 - The Agency for Healthcare Research and Quality -- in consultation with the National Quality Forum, the Institute of Medicine, and various stakeholders -- should develop quality care measures and indicators for diagnosis, treatment, and care of individuals with AD.
 - Over time, these quality measures and indicators should cover care in the full array of medical and LTSS settings; and care coordination and transitions among settings.
 - The Centers for Medicare and Medicaid Services (CMS) should implement demonstration projects to study the application of dementia quality care measures and indicators as they are developed.
 - CMS should implement policies for Medicare and Medicaid to embed the quality measures and indicators in the health and LTSS care system.
 12. **Practice recommendations for care in every setting should be embedded in CMS' federal and state surveillance and quality improvement systems.**
 - Stakeholders should develop or update consensus practice recommendations for the full array of LTSS settings.
 - These guidelines should be widely disseminated and embedded in all federal and state surveillance and quality improvement systems.
 - Practice recommendations should include the appropriate management of AD and common co-morbid physical and behavioral health conditions.
 13. **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.
 - Federal and state surveillance and quality improvement systems should all include measures of whether this communication has taken place in a meaningful way.
 14. **HHS should provide grants through CMS' Center for Medicare and Medicaid Innovation (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.**
 - Within one year, CMMI should provide grants for medical home pilot projects specifically targeted at Medicare beneficiaries with AD.

- Within one year, CMMI should provide grants for medical home pilot projects specifically targeted at dual eligible individuals (those seniors eligible for both Medicare and Medicaid) with AD.
 - CMS should incorporate those projects that prove successful into the Medicare and Medicaid programs.
15. **HHS should 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.**
16. **HHS should 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.**
- HHS, states, and the private sector should work together to develop and evaluate methods of improving hospital care, care coordination, and transitions of care for people with AD, including training approaches and proposed quality measures.
 - Within one year of formation of this partnership, CMMI should create a specific grant round focused exclusively on pilot projects and demonstrations to reduce emergency department visits, preventable hospitalizations and length of hospital stays among individuals with AD.
 - Funded projects should include at least one project that targets individuals from diverse communities.
 - The grant round should also consider funding projects aimed at reducing re-hospitalizations among those with AD by, for example, testing models of transitional care.
 - CMS should incorporate those projects that prove successful into the Medicare and Medicaid programs, as appropriate.
 - Within one year, CMS should gather findings from Community-Based Care Transitions Programs to disseminate widely and consider policy and reimbursement changes to Medicare that would make transitions safer and less common.
17. **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.

18. Recommended use of Federal Funds (\$10.5 million) currently proposed for AoA

- HHS (AoA) should use the \$10.5 million for state grants to seed the development of state action plans and state lead entities that maximize use of public and private resources to support dementia capable LTSS.
- Governors should designate the state lead entity and commit to sharing publicly a state plan with recommendations for action.
- State agencies and relevant partners should be included in the state action plan
- Legislation enacting this program should require matching funds so as to expand program impact.
- This program should be expanded in future years with additional resources.
- Additional funding available at HHS or other Operating Divisions in FFY 2013 and beyond should support this activity.
- Estimated funds necessary to fully fund all states' action plans = \$85 million.

19. Funding for the Alzheimer's Disease Supportive Services Program (ADSSP) should be restored to the FFY 2003 level of \$13.4 million.

- 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.

20. Fully fund caregiver support under AoA

- AoA currently has the National Family Caregiver Support Program, a component of which can be expanded to better meet the needs of caregivers of individuals with AD.
- These improvements may result in mitigation of other system costs.
- This program is currently dramatically underfunded and therefore unable to meet the needs of this growing population of caregivers.
- Fully funding this program can enhance other related efforts to improve quality of life for people with AD and their caregivers.
- We recommend that program funding be doubled to move toward full funding.

21. **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.**
- The health and well-being of a caregiver has a direct impact on the health and quality of life of a person with AD.
 - Whenever a caregiver accompanies a person with AD to a health care appointment; emergency department visit; or hospitalization, the attending health care provider should ask if the caregiver is well for the purpose of information and referral to services, if needed.
 - HHS should explore adding a Health Effectiveness Data and Information Set question to determine whether caregiver risk assessment is occurring.
 - Appropriate federal, state, and private sector organizations should assure that the importance of this action is incorporated into training of health and LTSS providers and incorporated into education messages for the public.
 - Caregiver needs assessments should be made an explicit, permitted use of federal funds by states under Medicare, Medicaid, and the National Family Caregiver Support Program.
22. **The Office of the National Coordinator for Health Information Technology, in partnership with the private sector, should work to assure that development of health information technology includes tools that assist caregivers of persons with AD. Tools could assist caregivers by: helping them organize the care they provide, educating them about dementia and multiple chronic conditions, and providing tools to help them maintain their own mental and physical health.**
- Caregivers should have access to reminder tools; communication methods among caregivers; home monitoring tools; and enhanced decision supports that help instill confidence and reduce isolation.
 - Caregiver health and wellbeing should be incorporated into electronic records.
23. **HHS should launch a nationwide public awareness campaign to increase awareness and to promote early detection of AD.**
- HHS should coordinate a public awareness campaign with relevant federal agencies and other stakeholders in a public-private partnership to increase awareness of AD and to promote early detection and diagnosis.
 - HRSA should partner with CDC and other HHS agencies, as well as professional groups to launch a parallel awareness campaign targeted at physicians and other health care professionals about the benefits of early detection and diagnosis of AD.
 - Both campaigns should include promotion of Medicare's Annual Wellness Visit as a vehicle for health care professionals and patients to talk about memory problems and cognitive function.

- The campaigns should include specific efforts in diverse communities and populations, including younger-onset individuals and persons with intellectual disabilities.
- The campaigns should involve appropriate state, county, and local organizations, including public health departments, and encourage them to launch public awareness and early detection campaigns of their own.