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.**

    - The State Lead Entity will be responsible for: coordination of public and private resources and programs; building capacity for epidemiology; program evaluation and quality improvement; maximizing positive impact of services for people with Alzheimer's disease and their caregivers; reducing duplication; coordinating public awareness; and assure evidenced-based high quality services are available in their state. (Possible funding source -- ACA PPHF).
    - HHS should identify an appropriate Office or Operating Division to manage funds for the identification of State Lead Entities.
    - The identified Office should develop standards for State Lead Entity that should be met as a condition of funding.
    - Understanding that states are organized differently, standards should be flexible enough to accommodate various agencies 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.
    - State's should be engaged to draft (or update) a State Plan to Address Alzheimer's Disease 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 (BRFSS) in every state.

2. **Recommended use of Federal Funds ($10.5 million) currently allocated to AoA**

    - HHS (AoA) should use the $10.5 million for state grants to seed the development of state action plans that maximize use of public and private resources to support services.
    - Governor's should designate the "State Lead Entity" and commit to sharing a state plan with recommendations for action publically.
    - State agencies and relevant partners should be included.
    - Match should be required to expand impact.

- This should be expanded in future years with additional resources.
- Estimated funds necessary to fully fund all states = $85 million.

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

- This program supports evidenced-based and promising practices in supporting 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.

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.
- These improvements can result in mitigation of other system costs.
- This program is currently dramatically underfunded and therefore unable to meet the needs of this growing population.
- Fully funding this program can enhance other related efforts to improve quality of life for people with Alzheimer's disease and their caregivers.
- We recommend that program funding be doubled to move toward full funding.

5. Assure a robust, dementia capable system of Long Term Services and Supports (LTSS) is available in every state.

- Every state should identify a State Lead Entity for Alzheimer's disease to coordinate activity across state agencies and programs in concert with the National Plan.
- Services should include a full array of culturally and linguistically competent and evidence-informed (or evidenced-based -- according to the National Council on Aging, evidenced-based is *"a process of planning, implementing, and evaluating programs adapted from tested models or interventions in order to address health issues"* in individual and community settings. It focuses on populations -- like older adults -- emphasizing both prevention and treatment. It does not replicate research.), accessible long term supportive client and family caregiver services.
- Services for people with Alzheimer's disease include -- outreach, screening; diagnostic; care and estate planning; treatment (medical, psychiatric,

pharmacological and social/cognitive interventions (ex. memory classes); care/treatment advocacy (ex. Medication management, benefits counseling and patient navigation); early stage support services; social support services (such as adult day, ADL 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/Caregivers include -- outreach, advocacy; disease and self-care education; 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.
- Services should utilize innovative gap filling and financing strategies.
- CMS should provide guidance to all states on adding 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 payments for services should reflect a living wage and recognize any special training for dementia capable services.

6. States should ensure that Paraprofessional Caregivers in every venue are adequately trained and compensated.

- Mandate that Paraprofessional Caregivers receive at least 10 hours of dementia specific training from a reliable source.
- Because many of these workers are working multiple shifts at below subsistence wages, often with few benefits, states should enact policies that ensure that their hours and pay reflect a fair and living wage.
- Compensation should reflect the completion of a prescribed training program.

7. LTSS systems should refer to a healthcare provider for diagnosis whenever someone is admitted to/assessed for eligibility for LTSS and exhibits signs of cognitive impairment. Providers engaged in diagnosis should consider the 2011 Guidelines for Diagnosis.

- Whenever a person exhibits symptoms of cognitive decline, or has risk factors for Alzheimer’s disease, a diagnosis should be considered using the 2011 Guidelines.

- State Lead Entity should assure this recommendation is included in any assessment for eligibility for Long Term Care Services.
- Federal agencies should assure that appropriate training resources should be available to health care providers on the use of the Guidelines.

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

   - Health care providers involved in diagnosis should include advance care planning in the health care plan after discussion with the individual and family members as appropriate.
   - Health care providers should have ready access to information for referral of people diagnosed with Alzheimer's disease 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 and local resources. This should be one of the activities eligible for Federal funds as available.

9. **Recommendations for end-of-life/ palliative care should be incorporated into all surveillance and QI systems (specific -- CMS).**

   - Because at this time Alzheimer's disease is a terminal illness marked by diminishing capacity, use of palliative care and desires regarding end-of-life care should be discussed and documented as early as practical in the process.
   - Federal and state surveillance and quality improvement systems should all include measures assuring this communication has taken place in a meaningful way.

10. **Practice recommendations for care in every setting should be embedded in Federal and State surveillance and QI systems (specific -- CMS).**

    - Appropriate Federal agencies should engage broad groups of stakeholders in the development of "best practice" guidelines for all long term care settings (home, supportive housing, rehabilitation facilities, nursing home, hospital).
    - These guidelines should be widely disseminated.
    - These guidelines should be imbedded in all Federal and state surveillance and quality improvement systems.
    - Practice recommendations should include the appropriate management of Alzheimer's disease and common co-morbid physical and behavioral health conditions.

11. **HHS should assure that health and related systems funded with Federal resources should improve chronic disease treatment and related services for people with Alzheimer’s disease.**

    - People with Alzheimer’s disease often have other (multiple) chronic conditions. Treatment options for persons with Alzheimer’s disease are limited and prognosis is negatively affected when patients have acute flare-ups related to these conditions or complications, (e.g., stroke, COPD, CHD).
    - Care plans for people with Alzheimer’s disease should be tailored to their condition, especially during recovery and rehabilitation.
    - Incorporate training for primary care providers and specialists regarding the impact of Alzheimer’s disease on care for comorbid conditions in existing pre-service and in-service training curricula.
    - Engage professional organizations to develop tools and guidance for clinicians and social service professionals.
    - Engage professional organizations to develop tools for caregivers to assist with management of multiple chronic conditions and link to the HHS Framework to Address Multiple Chronic Conditions.

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.
    - Whenever a caregiver accompanies a person with Alzheimer’s disease 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 care if needed.
    - HHS should explore adding a HEDIS question to assess that this is occurring.
    - Appropriate Federal agencies and State Lead Entities should assure that the importance of this action is incorporated into training of healthcare 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 the National Family Caregiver Support Program.

13. **In partnership, HHS and State Lead Entities should assure access to the full array of LTSS for special and emerging populations of people with Alzheimer’s disease including younger people, people with developmental disabilities such as Downs Syndrome, and others.**

- HHS and State Lead Entities should also assure supports are tailored for caregivers/family members of special and emerging populations.
- All guidelines and quality improvement efforts should include special and emerging populations.
- Implementation efforts should be coordinated with similar efforts directed at specific populations.
- All Older Americans Title III services should be made available to those with younger-onset Alzheimer’s disease.
- The AoA should track and report use of Title III services, especially under the National Family Caregiver Support Act, by those with younger-onset Alzheimer’s disease to assure that data is readily available on related costs for future planning.

14. State Education and Health agencies and others should include key information about Alzheimer’s disease in all curricula for any profession or career track effecting long term services and supports.

- State Education Agencies, Other relevant State Agencies, Regional Accrediting bodies, and Professional Organizations should require current information about Alzheimer’s disease be included as a condition of approval of any curricular or course of study leading to licensure or certification.
- Appropriate organizations should require that current information about Alzheimer’s disease be included in all relevant continuing education activity and all relevant state recertification programs.
- First responders, state and local health and human service personnel, and others who serve the public (including staff at relevant federally-funded agencies, such as Area Agencies on Aging (AAA) and Aging and Disability Resource Centers (ADRCs)) should receive appropriate information and training regarding Alzheimer’s disease and the early warning signs of possible cognitive impairment to assure they can effectively perform their work.

15. The Office of the National Coordinator, in partnership with the private sector, should assure that development of health information technology should include tools for caregivers to assist in the care of the person with Alzheimer’s disease to address dementia and multiple chronic conditions as well as maintain their own mental and physical health.

- Caregivers should have access to reminder tools; communication between caregivers; home monitoring tools; and enhanced decision supports that help instill confidence and reduce isolation.