

Long Term Services and Supports Sub-Committee

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HHS should provide Federal Funds to support a State Lead Entity;

- ▶ HHS should provide Federal Funds to support a state lead entity in every state and territory to coordinate all available public and private LTSS. 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 depending on what is appropriate for each state
- ▶ Governor's 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

Use of Federal Funds (\$10.5mill);

- ▶ HHS (AoA) should use the \$10.5 million for state grants to seed the development of state action plans;
- ▶ 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.

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

- ▶ 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 that include:
 - For people with Alzheimer's disease – 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;
 - For Families/Caregivers – 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; financial (including family care tax relief policies and benefits counseling); a continuum of respite services; supportive workplace family care policy.
- ▶ Services should utilize innovative gap filling and financing strategies.
- ▶ CMS should add adult day services as a state optional service under Medicaid (specific strategy).
- ▶ Services should encourage development and provide LTSS linkages to state, local; and private supportive housing resources.
- ▶ Public payments for services should reflect a living wage and recognize any special training for dementia capable services.

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.

LTSS systems should utilize 2011 Guidelines for Diagnosis whenever someone is admitted to/assessed for eligibility for LTSS;

- ▶ Whenever a person exhibit's 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

The Process of diagnosis should include engaging patient and family in advance care planning (health, estate and financial);

- ▶ Health care providers involved in diagnosis should include advance care planning in the individuals 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 Alzheimer's Disease 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
- ▶

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, 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

Practice recommendations for care in every setting should be imbedded 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 mental health conditions

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.

HHS and State Lead Entities should assure that caregiver health/mental health risk is assessed and addressed regularly;

- ▶ 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

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, and others and their caregivers;

- ▶ All guidelines and quality improvement efforts should include special and emerging populations
- ▶ Implementation efforts should be coordinated with similar efforts directed at specific populations

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
- ▶ First responders, state and local health and human service personnel, and others who serve the public should receive appropriate information and training regarding Alzheimer's disease to assure they can effectively perform their work

The Office of the National Coordinator 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;

- ▶ HIT should address dementia and multiple chronic conditions as well as assist in maintenance of caregiver 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.