

Long Term Services and Supports Subcommittee Recommendations 2016

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LTSS Recommendations - process

- Building on past recommendations
 - Maintained same three areas
 - Added responsible leads, grouped by immediate/longer-term, and added funding where available
- Review of other national guidelines and recommendations
- Collaboration with Clinical Services Subcommittee

LTSS Recommendations – 3 areas

1. **Dementia-Capable LTSS:** States, HHS, and Tribes assure robust, dementia capable LTSS systems to meet the growing impact of Alzheimer’s disease and related dementias.
2. **Caregiver Support:** HHS, states, Tribes, healthcare, and aging services providers assure that family/unpaid caregiver health and well-being is regularly assessed and addressed.
3. **LTSS Research and Evaluation:** Federal agencies in partnership with national organizations and states, support research to identify model standards and best practices to improve quality of life and LTSS for individuals and families impacted by dementia.

1. Dementia-Capable LTSS

Immediate

- a. Increase the number of states with an **identified state lead entity for Alzheimer's disease** to coordinate activity across state agencies and programs, and to work with state, local and private sector partners to implement strategies in concert with the National Plan. [States] *(since 2011, 18 states have identified a lead as part of ADSSP dementia-capable grant funding)*
- b. National partners should work with HHS and states to **assure engagement of state Governors and legislatures** in state efforts to address dementia capable LTSS, expand use of evidence-based and best practices, and advocate for adequate funding for LTSS.
- c. **Double current funding for the Alzheimer’s Disease Supportive Services Program (ADSSP) and Alzheimer’s Disease Initiative – Specialized Supportive Services (ADI-SSS) program** to increase state and communities’ use of evidence-based and evidence-informed strategies, programs, and dementia-capable systems. [Congress] *(Current status: 18 ADSSP states, anticipate 5 new states funded with \$4.8 mil in FY16; 21 ADI-SSS projects, anticipate 10 new projects funded with \$10.5 mil in FY16)*

1. Dementia-Capable LTSS

Longer-Term

- d. Provide **adequate funding to support state lead entities** to plan and coordinate public and private activities to assure states are able to address the growing impact of dementia and assure dementia-capable health and LTSS systems. [Congress] (*est. \$80 million*)
- e. **Increase state and local public health role** in supporting brain health, prevention, surveillance, and community policies to support cognitive health, implementation of CDC's Healthy Brain Initiative: Public Health Road Map, and incorporation of brain health and dementia into other existing public health efforts. [States, and CDC in collaboration with ACL & NIA]
- f. **Amend Older Americans Act and expand funding to support making Title III services available to people under age 60 with younger-onset dementia.** [Congress]
- g. **Adopt common metrics** that states, Tribes, and communities can use to measure and track progress in developing dementia-capable LTSS. [HHS, National Organizations, States]

2. Caregiver Support

Immediate

- a. Assure that health and related systems funded with federal resources provide **chronic disease management and related services for people with Alzheimer's disease, as well as family caregivers.** [HHS]
- b. Educate and **clarify for healthcare providers and health systems how Medicare care planning and other covered benefits can be provided to a beneficiary with dementia in compliance with HIPAA,** when a family caregiver is present and the individual with the disease is not. [CMS; National Healthcare and Aging Partners]
- c. Provide **full funding for the National Family Caregiver Support Program,** including funding to ensure regular evaluation of the impact of the program on family caregivers for people with dementia. [Congress] (*FY16 funding: \$150.6 mil*)

2. Caregiver Support

Longer-term

- d. The **process of diagnosis should include engaging individuals and families in care planning** and referrals to appropriate community resources to support this planning. Care planning should address health, LTSS, caregiving resources, legal, estate planning, and finances. [HRSA, CMS, Provider Organizations, States]
- e. Provide **care planning with an unpaid/family caregiver as a covered benefit** under Medicare and Medicaid. [CMS, States]
- f. **Identify family/unpaid caregivers in electronic health records** of individuals with dementia, as well as in the caregiver's own medical records. [CMS, States, Health and LTSS Systems]
- g. Expand **pilot payment programs in Medicare and Medicaid models that include caregiver support** for patients with dementia, many of whom have complex care needs.. [CMS]
- h. Identify and advocate for **employment practices and policies** that allow employers to balance paid employment with unpaid care. [States, Businesses, Congress]
- i. Support the **expansion to scale of evidence-based and evidence-informed caregiver support programs** and their cultural adaptations. [CMS, HHS, States]

3. LTSS Research and Evaluation

Immediate

- a. Convene a **national dementia care and services research summit**, building on existing work, to identify research priorities to provide care and services to persons with dementia and family caregivers, and to provide recommendations as to best practices and priorities. [HHS, National Organizations]
- b. Provide **training for paid/paraprofessional caregivers** in every care setting to address cultural and dementia competence. HHS should **identify model state standards of care and policies** that promote fair and reasonable compensation and appropriate dementia care training. [HHS and States]
- c. Assess and **share findings on the impact of CMS's 2014 home and community-based settings rule** (CMS 2249-F; CMS 2296-F) on individuals with dementia and their caregivers. [HHS]
- d. Assess and **share findings on the impact of states' managed LTSS systems** on individuals with dementia and their caregivers. [HHS]