

# LTSS Subcommittee Recommendations 2018

July 30, 2018  
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## LTSS Sub-Committee

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**Themes:**

Decrease disparities in access to LTSS, including home and community-based services (HCBS)

Build more effective integration between clinical care and HCBS

Improve family/friend caregiver identification, assessment, support, and engagement by health care systems

Provide high quality, person- and family-centered LTSS, including HCBS programs

Address behavioral symptoms of AD/ABRD across the full range of care settings

**Recommendation 1: Decrease disparities in access to home and community-based long-term services and supports (LTSS).**

The number and diversity of people living with AD/ABRD is growing, with the greatest burden for care falling upon families. There is a need for home and community-based long-term services and supports to assist this population. Federal programs offering home and community-based supports for people with AD/ABRD and family caregivers\* such as ACL, the VA and CMS, must be brought to scale and should tailor programs to address the needs of an increasingly heterogeneous\*\* population.

\* All references to “caregivers” apply to care partners, families and friends providing assistance to people living with AD/ABRD.

\*\* Heterogeneous includes but isn’t limited to people of color, diverse ethnic groups, people with intellectual or developmental disabilities and AD, people with related dementias, those with young onset, those who live alone, people who are economically disadvantaged, and those with limited English-speaking and literacy skills.

### **Recommendation 1 continued:**

- Congress should increase funding for the ACL Alzheimer’s Program Initiative (ADPI) from \$23.5 million to \$50 million by 2025 to increase the number of individuals benefitting from tailored education and supports.
- Congress should increase funding for the Older Americans Act National Family Caregiver Support Program (NFCSP) from \$180 million to \$360 million by 2025.
- ACL and its National Alzheimer’s and Dementia Resource Center should coordinate validation of the Dementia Capability Assessment Tool to make available a valid and reliable tool for federal, state and local HCBS providers, including those delivering the NFCSP.
- The Office of Minority Health should prioritize both dementia and dementia support programs that demonstrate cultural competency and language accessibility, to address the lack of appropriate education and outreach to diverse communities that are disproportionately impacted by dementia.
- All divisions within the U.S. Department of Health and Human Services charged with serving people living with dementia, such as CMS, ACL, CDC and HRSA, and the VA, should tailor programs to address the HCBS LTSS needs of a heterogeneous population living with AD/ADRD and their caregivers.

### **Recommendation 2: Build more effective integration between clinical care and home and community based long-term services and supports.**

Family caregivers are the backbone of our home and community-based long-term services and supports system for people living with AD/ADRD. They also provide necessary medical follow-up, from medication monitoring to wound care. To assure that healthcare systems support people with AD/ADRD and their caregivers, the U.S. Department of Health and Human Services should ensure that people living with AD/ADRD and their caregivers receive disease information, care planning and coordination, caregiver assessment and supports, and connection to home and community-based long-term services and supports.

### **Recommendation 2 continued:**

- CMS should issue Informational Bulletin(s) on AD/ADRD and Dementia Care to states, insurers, medical and LTSS providers, emphasizing the scope of the issue (demographics, costs and quality challenges), the critical roles played by caregivers in the delivery of dementia care, challenges to engagement of caregivers, and the importance of person and caregiver identification, assessment, support, and connection to home and community-based LTSS. CMS and the states should develop and implement follow-up strategies to encourage adoption of recommendations in the Bulletin(s).
- CMS and the Office of the National Coordinator for Health Information Technology (ONC) should jointly develop standards, policies and programs that leverage health IT to:  
(i) designate the primary caregiver in the care recipient's and (ii) in the caregiver's medical records, and (iii) encourage providers to connect people living with AD/ADRD and caregivers to disease education and LTSS services, including home and community-based services.

### **Recommendation 2 continued:**

- AHRQ and CMS should use existing measurement strategies and consider developing new measures to obtain feedback on (i) the seamlessness of integration between clinical care and home and community-based LTSS and (ii) the experience of caregivers to people living with AD/ADRD served by the healthcare system and then establish baselines for satisfaction with (i) caregiver engagement and (ii) with the referral process to home and community-based LTSS and monitor change over time.
- U.S. Department of Health and Human Services should address HIPAA issues through federal dementia education outlets to assure that HIPAA does not create a barrier to the provision of care by caregivers.

### **Recommendation 3: Address behavioral symptoms across the full range of care settings**

Behavioral symptoms of AD/ADRD are an integral part of the dementia syndrome that increase morbidity and burden, affect quality of life and impact cost of care. To more effectively address these symptoms across the full span of care settings, it is recommended that HRSA, ACL, VA, CDC, NIH and CMS increase provider and caregiver knowledge about person and family-centered care through training and dissemination of evidence-based and evidence-informed interventions.

### **Recommendation 3 continued:**

- HRSA, ACL, NIH, CMS CDC, and the VA should create training programs and materials to help disseminate evidence-based and -informed interventions for behavioral symptoms to all care settings (home, community and residential) in multiple languages and at varying literacy levels.
- HRSA, ACL, CMS, and CDC should increase the number of grant programs offering education for paid and unpaid caregivers that support use of evidence-based or -informed strategies for behavioral symptom management.
- CMS should identify, catalogue and disseminate promising practices for reducing anti-psychotic use in nursing homes and explore further dissemination for use with Medicare-funded home health settings and to states for use in other Medicaid-funded service settings.