

# Long-Term Services and Supports Subcommittee Recommendations

July 29, 2019

## Goal 3: Expand Supports for People Living with AD/ADRD and Their Caregivers<sup>1</sup>

### LTSS Themes:

- Improve access to LTSS, including home and community-based services (HCBS).
- Improve integration of clinical care with HCBS including systematic identification, assessment, support, and engagement of family/friend caregivers by health care systems.
- Provide high quality, person- and family-centered LTSS, that address behavioral and psychiatric symptoms of AD/ADRD across care settings.

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<sup>1</sup> All references to “caregivers” apply to care partners, families and friends providing assistance to people living with AD/ADRD.

## **Recommendation 1. Improve Access to Affordable LTSS**

**Background:** Impoverishment can be an issue for individuals and caregiving families who may be forced stop working or to spend down their personal savings trying to purchase or furnish care for a relative with AD/ADRD. Unpaid caregivers providing substantial HCBS may be less able to be productive members of the workforce. For the most part, LTSS are not covered by Medicare. And, while Medicaid covers some LTSS costs for low-income beneficiaries who qualify, for many individuals and families, out-of-pocket LTSS costs drain their personal savings. According to AARP's Family Caregiving Cost Study (2015), the average out-of-pocket cost caring for a person with dementia is \$10,697 annually and full-time in-home care or assisted living residential care can cost \$4,000 a month or more. This is prohibitive for most middle to lower income individuals and families. The recommendations below focus on non-means-tested programs that can expand the availability of LTSS, especially in home and community-based settings

**To help assure that people living with AD/ADRD and their families can access the LTSS they need, including HCBS, it is recommended that:**

**A. By 2025, programs beyond Medicaid that provide LTSS (e.g., OAA, state and non-profit programs) should be expanded to support individuals and families with unmet needs, including under-served, diverse populations.**

1. Congress should expand covered populations to include people under the age of 60 with a diagnosis of young onset AD/ADRD in the reauthorization of the Older Americans Act.
2. Congress should increase funding for the ACL Alzheimer's Disease Program Initiative from \$23.5M to \$50M to increase the number of individuals benefitting from tailored education and supports; target the program to under-served and high-risk populations; and evaluate the program's reach and impact.
3. Congress should increase funding for the ACL National Family Caregiver Support Program (NFCSP) from \$180M to \$360M, target the program to families of people with AD/ADRD, and evaluate the reach and dementia capability of the program.
4. Congress should establish new funding for ACL respite programs, target the funding to under-served and high-risk populations and evaluate the programs' reach and impact.
5. Operating divisions within the US Department of Health and Human Services such as CMS, ACL, CDC and HRSA, as well as the VA, should tailor programs to address the HCBS needs of a heterogeneous population living with AD/ADRD and their families and caregivers.

6. Disbursement of resources should consider communities and populations with the greatest need, using objective data sources (like U.S. Census data) for determinations.
7. State models for expanding the availability of LTSS and/or supporting unpaid caregivers through 1115 waivers and other strategies should be evaluated and, if warranted, disseminated broadly to encourage adoption by other states See the Medicaid LTSS toolkit for examples:  
[https://www.chcs.org/media/Strengthening-LTSS-Toolkit\\_032019.pdf](https://www.chcs.org/media/Strengthening-LTSS-Toolkit_032019.pdf).

**B. Federal agencies and states should build workforce capacity to provide dementia capable LTSS**

1. To address the shortage of a dementia-knowledgeable workforce:
  - a. Congress should allocate an additional \$25 million in funding for HRSA to support geriatric workforce training in AD/ADRD across the educational continuum.
  - b. HRSA should continue to allocate a portion of GWEP funding uniquely toward workforce training in AD/ADRD (Currently a minimum of \$100,000 for each of 48 grant recipients).
2. Increase education for paid and unpaid caregivers through ACL and HRSA grant funding (i.e., ADPI, NFCSP & GWEP) including funding for implementation of evidence-based or evidence-informed interventions.

**C. Health care systems should expand access to HCBS:**

1. CMS should monitor Medicare Advantage (MA) Plans for HCBS supplemental benefits aimed at people living with AD/ADRD and their caregivers.
2. HHS should provide technical assistance, informational bulletins, webinars or other guidance on LTSS needs of people living with AD/ADRD to states, insurers and medical and LTSS providers and develop plans for monitoring implementation.
3. Congress should sustain Section 2404 protections against spousal impoverishment in the Affordable Care Act (ACA), and the section 1915(i) HCBS state plan option, Community First Choice (CFC) attendant care services and supports, and individuals eligible through a medically needy spend down to HCBS waivers.

4. Federal agencies (HRSA, CMS, ACL, IHS, VA, CDC) should offer annual education to providers about HIPAA regulations and circumstances for appropriate communication about patient protected personal health information to unpaid caregivers to address the perception by health providers that HIPAA prevents such communication.
5. (Measurement: Establish a baseline and count # of trainings, # of attendees reached with this information annually. Ask for annual report outs to the Council).

## **Recommendation 2. Improve integration of clinical care with HCBS**

### **A. By 2025, 20% of hospitals and primary care practices serving people living with AD/ADRD will have in place procedures to:**

1. Identify cognitive impairment, and integrate management of cognitive impairment into the Care Plan. This should include addressing impact of that impairment on management of the individual's other health conditions. (Measurement of outcome -- JAHF Age-Friendly Health Care Initiative Mentation measure for primary care practices.)
2. Provide a timely diagnosis for individuals who are found to have impairment, through efficient and well coordinated care pathways and referral processes.
3. Identify and document a caregiver or authorized health care proxy, where applicable, to delineate and document the individual's goals of care and better assure goal implementation. (Measurement of outcome -- JAHF Age-Friendly Health Care Initiative Mentation measure for hospitals.)
4. Co-design care plans with the individual and care giver or authorized health care proxy (where appropriate), so that plans are concordant with the individuals' goals of care and can be supported in the home environment.
5. For individuals who are receiving care in a facility, discharge planning should include due consideration of the individual's cognitive status and care needs including post-discharge care teams that include the individual and a caregiver or authorized health care proxy, so as to lessen risk of re-hospitalization or other adverse events.
6. Assess the caregiver's LTSS needs, provide them with disease education and HCBS, and/or refer them to community-based services.

### **B. By 2025, CMS will have quality measures in place that will encourage health care systems (health plans) to implement these recommendations.**

1. 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 services and (ii) the experience of people living with AD/ADRD and their caregivers served by the healthcare system; then establish baselines and monitor change overtime in satisfaction with caregiver engagement and with the referral process to home and community-based LTSS.

### **Recommendation 3. Individuals with AD/ADRD will not be prescribed antipsychotics unless clinically indicated**

**Background:** Behavioral and psychiatric symptoms of AD/ADRD are a common component of the dementia syndrome that increase morbidity and burden, affect quality of life, and impact cost of care. Recognizing that anti-psychotic medications are frequently used off-label to control these symptoms and that such use can lead to excess patient morbidity and even mortality, the standard of care across all settings must promote person-centered care and promising nonpharmacological approaches and avoid the use of antipsychotic medications unless clinically indicated.

**To promote person-centered care and promising nonpharmacological treatments for behavioral and psychiatric symptoms of dementia (BPSD), it is recommended that:**

- A. Research should be funded through federal agencies (NIA, AHRQ, NINR) to delineate barriers to adoption of evidence-based interventions and to also identify bright spots where uptake is achieved.**
- B. Federal agencies and other organizations should disseminate promising evidence supported interventions.**
- C. Federal agencies (HRSA, ACL, CDC, VA, IHS, NINR) and other organizations should continue to build workforce capacity to deliver person-centered care as well as the use of promising and/or evidence-derived nonpharmacological interventions for BPSD.**
  - 1. Provide webinars and other training opportunities with this focus for the full range of care providers from direct service workers to prescribers, as well as family/friend/caregivers, and increase adoption.
  - 2. Continue to provide dementia-specific grant funding to GWEPs and ACL grantees to educate the workforce on this issue.
- D. Federal agencies should create care or payment models for use of effective evidence-based interventions.**
  - 1. By 2021, care or payment models that bridge clinical health care and with LTSS in nursing homes and in community settings will be proposed. This should include care models that integrate evidence-supported non-pharmacological interventions for BPSD.
- E. Federal agencies should encourage measure development for HCBS, including measures that address challenging behavioral symptoms.**

**F. By 2021, HHS should develop a coordinated process for measuring anti-psychotic medication use that will delineate inappropriate use, that can be applied to community as well as facility residents, and can be used to calculate prescribing trends over time. Data sources to be considered for this purpose could include:**

1. Medicare Part D -- prescriber specific data
2. State Medicaid Drug Utilization data
3. Vendor Drug Programs data
4. National Partnership Quarterly Data