

Advisory Council on Alzheimer’s Research, Care and Services
LTSS Subcommittee 2017 Recommendations

The Long-Term Services & Supports (LTSS) subcommittee notes the growing synergy among recommendations and strategies proposed as part of different national efforts over the past few years. The LTSS subcommittee’s recommendations highlight key areas of concern to our committee, but the subcommittee also strongly supports issues identified by other national groups, and notes the importance of both public and private partners to address the need for critical and sustainable efforts to address the needs of people with ADRD and their families.

NAPA Goal 3: Expand services and supports for people with Alzheimer’s disease and their families.

1. Congress, federal agencies, and states must expand efforts to address the needs of family caregivers, including caregivers from diverse populations, caregivers of younger adults and people with intellectual/developmental disabilities, and children and youth who provide care for older adults. Particular support is needed to expand and scale effective caregiver interventions for diverse populations; address reimbursement, training, and HIPAA policy and practice barriers to enable healthcare providers to provide care planning with family caregivers; increase support for respite care; and address the financial burden to family caregivers.

Measures of accomplishment or success:

- Increase federal funding by at least 50% for ACL dementia-specific funding that supports state, tribal, and community dementia interventions by 2020.
- Use results of October 2017 Research Summit to build and fund a research and translation strategy to address clinical care, and long-term services and supports.
- By 2025, at least 90% of people with ADRD and their key family and friend caregivers have access to a community-based education or support program on dementia caregiving.
- Congress must amend the Older Americans Act to allow additional OAA services to be provided to younger adults with dementia.
- Double funding for the National Family Caregiver Support Program, including funding for Tribes under the Older Americans Act Title VI, by 2020.
- By 2020, CMS, HRSA, and states should educate health care providers on HIPAA, including clarification on HIPAA implementation, ways to support person-centered plans and advance care planning, addressing HIPAA concerns, and the provision of care when the person may not be competent.
- Primary caregiver role is designated in both the caregiver’s own medical record, and in the care recipient/patient’s medical record systems by 2020.
- Expand Medicare benefits to ensure individuals with ADRD and their families receive information, care coordination, caregiver supports, and home and community-based services.
- Expand innovative paid and volunteer respite programs.
- Promote state expansion of respite care through Medicaid waiver programs or state-funded respite services.
- Congress must establish tax and Social Security credits for family caregivers by 2020.
- Increase by at least 50% funding for Medicaid’s Money Follows the Person demonstration program, self-directed HCBS programs, and caregiving options that pay friend/family caregivers.
- Expand the Family Medical Leave Act (FMLA) and state laws to expand paid family leave for family caregivers
- Identify the roles, prevalence, and impact of caregiving among young children, including children in immigrant, minority, and tribal populations, who provide care for older adults with dementia.
- Provide resources to states, tribes, and communities to provide outreach and support to families and children where children provide caregiving for older relatives with dementia.

2. Federal agencies, states, and health systems must take steps to increase identification of people with dementia who live alone, and to provide programs and services to meet the needs of this population.

Measures of accomplishment or success:

- Increase by at least 50% ACL dementia funding for community Gatekeeper programs that train community partners to identify and connect at-risk and live-alone individuals to community aging services.
- Double funding for the National Family Caregiver Support Program by 2020, including specific outreach and support to families who care for individuals who live alone.

3. Federal agencies, states, and health systems must increase efforts to assess, prevent, and manage behavioral symptoms associated with dementia through effective programs and services and improved workforce knowledge and skills.

Measures of accomplishment or success:

- ADRD standards, including standards for effective ways to address behavioral symptoms, are incorporated into all relevant clinical and LTSS quality measures by 2022.
- Increase by at least 50% dementia funding for training and scaling of evidence-based behavioral symptom management interventions for persons with ADRD.
- Double HRSA funding for geriatric workforce training that includes increased dementia training to address challenging behavioral symptoms.

NAPA Goal 4: Enhance public awareness and engagement

4. Federal agencies, states, national health and aging organizations, and community partners must continue to expand public awareness and training, reduce stigma, and help connect people to information and available resources.* Outreach should include children and youth, diverse populations, and people with intellectual and developmental disabilities.

Measures of accomplishment or success:

- Increase and coordinate federal agency, state, and national organization funding for innovative outreach and messages, in order to reach diverse populations.
- Increase information developed for children and youth using video and social media, and provided through school curriculum and youth-serving organizations.
- Develop expanded partnerships to support outreach through groups such as unions, community colleges/adult education, community and faith organizations, and first responders.
- Increase engagement of national health-related organizations (eg Down Syndrome, Heart, Diabetes) in providing information and resources addressing dementia.

* Examples of current national and state efforts to address public awareness include Minnesota's ACT on Alzheimer's, Dementia Friendly Orange County (NC), CDC's Healthy Brain Initiative, and Dementia Friendly America.

Potential measures were identified by subcommittee members, and in some cases were adopted or adapted from the Alzheimer's Association *Report on Milestones for Care & Support*, and the November 2016 LEAD recommendations to Congress.

Two additional joint recommendations in partnership with the Clinical Subcommittee:

5. **Changes to the national healthcare system must ensure continuation of support that is critical to people with dementia and their caregivers, including Medicare annual wellness visits that include cognitive assessment, protection for pre-existing conditions, funding for person- and family-centered* research on dementia, and support for innovative models of care.**

6. **Federal agencies, national health and aging organizations, states, and other industry stakeholders should identify ways to implement recommendations that result from the October 2017 National Research Summit on Care, Services and Supports for Persons with Dementia and Their Caregivers.**

* The CMS Person and Family Centered Engagement Strategy report (Nov. 2016) defines “family” broadly to include participants in a person’s health care including informal caregivers, along with the primary caregivers of persons who are in need of the support of their caregivers to make informed health care decisions.