

# Clinical Care Subcommittee Recommendations

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Chair, Advisory Council and Clinical Care Subcommittee

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## Clinical Care Subcommittee Members

### Non-Federal Members

- Randall Bateman
- Deke Cateau
- Fawn Cothran
- Roberta J. Cruz
- Susan DeMarois
- Helen B. Medsger
- Adrienne Mims (Chair)
- John-Richard Pagan
- Yakeel T. Quiroz-Gaviria

### Federal Members

- Arlene Bierman - AHRQ
- Ellen Blackwell - CMS
- Teresa Buracchio - FDA
- Bruce Finke - IHS
- Melinda Kelley - NIA
- Walter Koroshetz - NINDS
- Helen Lamont - ASPE
- Shari Ling - CMS
- Erin Long - ACL
- Lisa McGuire - CDC
- Maria-Theresa Okafor - ASPE
- Courtney Wallin - NIH
- Joan Weiss - HRSA

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### Recommendation 1:

Reauthorization of and budget appropriations for the National Alzheimer's Disease Project Act (NAPA) - Congress should reauthorize NAPA for another 10 years. Congress and the Department of Health and Human Services (HHS) should fund NAPA organizers, including the Office of the Assistant Secretary for Planning and Evaluation (ASPE), to have increased resources and authority to accomplish the following:

- A. For fiscal year (FY)2025, fund and appoint at least 1 full time employee (FTE) for federal coordinator(s) with the authority to prioritize, organize, implement, and follow up on cross-stakeholder recommendations, through NAPA reauthorization.
- B. Track the progress and milestones of prior NAPA recommendations with a goal to prioritize those recommendations with the largest potential impact.
- C. Assist NAPA Council and its Chair in determining the level of appropriate resources (e.g., financial, personnel effort, and authority) for NAPA to track and convey recommendations optimally.

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### Recommendation 2:

(EDUCATION) Increase resources to educate the public and inform health care providers about the importance of Alzheimer's disease and Alzheimer's disease related dementias (AD/ADRD), clinical care, risk reduction, early detection, screening, differential diagnosis, person-centered care models, disease-modifying therapies, clinical research participation, and available educational and community resources for persons living with dementia (PLWD) and their family/caregivers.

- A. Congress should increase appropriations to the Health Resources and Services Administration (HRSA), National Institute on Aging (NIA), Centers for Disease Control (CDC), and National Institute for Neurological Diseases and Stroke (NINDS) for the continued development and modification of AD/ADRD educational tools and materials.
- B. These educational tools and materials should be inclusive of and address the unique needs of persons with life-long neuroatypical conditions, younger-onset dementia, persons with Intellectual and Developmental Disabilities (IDD), those who are not primary English speakers, have varying literacy levels, Veterans, and/or come from cultural or ethnic groups with differing norms and beliefs.
- C. Promote the development, use and updating of evidence-based guidelines, strategies for continuous quality assessment and improvement, efforts addressing access to care for all, and advancing health equity.

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## Recommendation 2 (continued):

Increase resources to educate the public and health care differential diagnosis about the importance of AD/ADRD, clinical care, risk reduction, early detection, screening, differential diagnosis, person-centered care models, disease-modifying therapies, clinical research participation, and available educational and community resources for PLWD and their family/caregivers.

- D. Dementia-specific clinician training should include:
  1. Proficiency in discussing all types of clinical treatment options.
  2. The ability to understand, interpret, and explain differences between and significance of clinical and diagnostic tools for AD/ADRD.
  3. Competence in identifying and managing adverse treatment reactions.
  4. Enhanced clinical skills for managing complex patient/client scenarios.
  5. Tailoring treatments to suit individual needs.
- E. Healthcare professional training programs should implement minimum education standards for dementia care.
- F. Promote comprehensive dementia-focused training to community health workers (CHWs), caregivers, paid and unpaid.
- G. Promote active engagement and empowerment of PLWD and their caregivers. Encourage self-management strategies, development of person-centered care plans, and shared decision making.
- H. CMS should encourage Quality Improvement Organizations to work with health care systems and practices to provide high quality, culturally competent dementia.

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## Recommendation 3:

(SYSTEMS) Develop systems of clinical care to support the provision of services to promote healthier cognitive aging, dementia risk reduction, early detection, differential diagnosis, early intervention, ongoing care planning and management of AD/ADRD

- A. Congress should increase funding for Tribal and Urban Indian health programs to further develop systems of care for those living with dementia and their caregivers.
- B. CMS should encourage hospitals and health care providers to put in place procedures to:
  1. Create Age Friendly Health Systems
  2. Influence the quality of the patient/client and caregiver experience.
  3. Identify cognitive decline and integrate management of cognitive impairment into the care plan.
  4. CMS should encourage dementia training for care navigators and CHWs reimbursed by Medicare/Medicaid.
  5. Work towards an integrated system of care including home and community-based services (HCBS) resources, all with access to and ability to update the person-centered care plan.
- C. CMS should encourage accountable care payment programs to implement population-based payment at the level of primary care.
- D. Federal rulemaking should increase payment for primary care to ensure equitable access to care and services.
- E. Congress should pass laws to eliminate state Medicaid rules that require estate recovery of funds after the death for enrollees who receive Medicaid sponsored HCBS.

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### Recommendation 3 (continued):

Develop Systems of clinical care to support the provision of services to promote healthier cognitive aging, dementia risk reduction, early detection, differential diagnosis, early intervention, ongoing care planning and management of AD/ADRD.

- F. Agency for Healthcare Research and Quality (AHRQ) should promote the use of e-care plans by all treating practitioners, non-clinical providers, the patient, and their caregiver.
- G. HRSA and AHRQ should fund the development of a curriculum for anticipatory guidance for people diagnosed with dementia that can be used by the entire care team, PLWD and caregivers.
- H. Health systems should leverage technology, data platforms, electronic health records (EHRs), telehealth and artificial intelligence to enhance dementia care delivery, training, and education.
- I. Administration for Community Living (ACL) should provide sufficient funding to facilitate dissemination of coordinated dementia care to every state.
- J. HRSA, in collaboration with AHRQ (with supported funding), health care organizations and academic institutions, should lead the development, testing, and implementation of integrated person-centered models of care for PLWD, with focus on primary care settings.
- K. Congress should appropriate funding to foster connections between the healthcare system and community support programs, with a focus on rural and minority health, and patients whose primary language is not English.
- L. Congress should amend the Older Americans Act (OAA) to support and mandate state health departments to maintain information on existing dementia diagnostic resources, including staffing, case management, and social worker assistance through Area Agencies on Aging for information and referral.

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### Recommendation 4:

#### (WORKFORCE)

Implement solutions to address the geriatric and gerontology workforce crisis through training, continuing education, recommended standards, and improved pay to better address the needs of PLWD and their families/caregivers.

- A. Increase efforts and implement systems solutions at the federal level to address the workforce crisis for those who provide care to older adults.
  1. Congress should appropriate funds to HRSA or the National Academies of Sciences, Engineering, and Medicine to evaluate incentives to increase recruitment into the primary care workforce and assure that they have competencies in care of older adults.
  2. Employer and tax incentives.
  3. Congress should increase HRSA funding for training of primary care health professionals who care for older adults and loan repayment for health professionals.
  4. Congress should increase HRSA funding to specifically educate and train dementia care navigators, interdisciplinary teams and home and community-based workers.
  5. HRSA should increase the number of slots that cover health care school tuition for people who will care for older adults in primary care after residency.
  6. Congress should provide pathways for immigrants who commit to work within clinical dementia care systems, particularly for those in workforce shortage areas or in cultural/ethnic diverse communities in which they identify with.

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## Recommendation 5:

### (PARTICIPATION IN THE CLINICAL CARE TEAM)

Encourage PLWD and their unpaid caregivers (as appropriate) to be integral parts of the clinical care team and foster coordination of comprehensive, person-centered dementia care with HCBS.

- A. Promoting PLWD and their unpaid caregiver to participate in the coordination of clinical care with HCBS. Health care providers such as hospitals, health plans, health systems, federally qualified health centers, mobile clinics, and primary care practices serving PLWD should implement evidence-based procedures and tools for:
1. Identifying and documenting unpaid caregivers and/or legal representatives, where appropriate, to participate in care planning and effective goal implementation.
  2. Designing person-centered care plans. These plans should be revisited annually or sooner as necessary.
  3. Assisting PLWD and their unpaid caregivers in finding resources, services, and support needed for optimal disease management.
  4. Assessing the needs of both the PLWD and their unpaid caregiver (as appropriate), providing access to disease-specific education and training on symptom management for both the PLWD and the caregiver.

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## Recommendation 6:

### (YOUNG ONSET)

Eliminate barriers to the receipt and payment of clinical care services and long-term services and support for adults living with dementia who are under age 65.

- A. Congress should appropriate funding to address barriers to clinical care and community-based long-term services for younger individuals living with dementia or mild cognitive impairment:
1. Amend the OAA to extend services to all persons diagnosed with AD/ADRD regardless of age and increase funding to support the added populations.
  2. Eliminate the two-year waiting period for Medicare in younger individuals living with dementia or mild cognitive impairment who qualify for SSDI.
  3. Quantify the number of PLWD among those who are diagnosed under the age of 65 by type of dementia.
  4. Measure and improve the quality of care. Ensure timely diagnosis, differential diagnosis, care planning and referral to needed services and supports.

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## Recommendation 6 (continued):

Eliminate barriers to the receipt and payment of clinical care services and long-term services and support for adults living with dementia who are under age 65.

- B. Raise awareness, promote early detection, implement risk reduction strategies, and support caregivers for individuals with Down syndrome/IDD at risk of AD/ADRD and their families/caregivers.
1. Education and Awareness Campaigns: Federal and non-federal entities should partner in coordinating public/private education and awareness campaigns about the increased risk of AD/ADRD.
  2. Early Detection and Diagnosis: State developmental disabilities agencies, Area Agencies on Aging, and state-based associations for healthcare professionals should promote early detection and diagnosis of AD/ADRD in individuals with Down syndrome/IDD by ensuring interventions are tested in special populations and providing training and resources to healthcare professionals on recognizing and assessing cognitive changes associated with dementias in individuals with IDD.
  3. Risk Reduction Strategies: Public health agencies should develop and disseminate evidence-based risk reduction strategies tailored to individuals with Down syndrome/IDD to help mitigate the possibility of dementia.