

# **PUBLIC MEMBERS OF THE ADVISORY COUNCIL ON ALZHEIMER'S RESEARCH, CARE AND SERVICES: 2023 Recommendations**

The Advisory Council on Alzheimer's Research, Care, and Services was established by the National Alzheimer's Project Act (NAPA) to advise the Secretary of the U.S. Department of Health and Human Services (HHS) and Congress on priority actions to accelerate efforts to treat or prevent the condition, as well as actions to improve care for people with Alzheimer's disease and related dementias (AD/ADRD), and expand support for their caregivers. Each year the public (non-federal) members of the Advisory Council develop recommendations via four subcommittees: Clinical Care, Long-Term Services and Supports (LTSS), Research, and Risk Reduction. These subcommittees identify areas of focus, specific recommendations, and details about each recommendation. The following Recommendations inform the annual update to the National Plan to Address Alzheimer's Disease, as well as congressional legislation and appropriations.

## Clinical Care Subcommittee

**RECOMMENDATION 1: Increase resources to educate the public (including patients, families/caregivers, health care administrators, clinicians, and community members) and increase awareness about the importance of Alzheimer’s disease and related dementia clinical care, including risk reduction, early detection, accurate diagnosis, person-centered care models, disease-modifying therapies, clinical research participation, and available resources for persons living with Alzheimer’s disease and related dementia and family/caregivers.**

Raising awareness about the disease and enhancing understanding within communities is a crucial first step in getting individuals to seek out clinical care for cognitive concerns. Awareness strategies should focus on reducing stigma within diverse communities, how to access resources and clinical care, and how to engage in supportive decision-making.

- A. Congress should increase allocation of funds to the National Institutes of Health (NIH) for the continued development and modification of educational tools and materials for assessing, diagnosing, and treating adults with suspected AD/ADRD and encouraging clinical research participation. These educational tools and materials should:
  1. Address unique needs of persons with life-long neuroatypical conditions and those who are not primary English speakers, have varying literacy levels, and/or come from cultural or ethnic groups with differing norms and beliefs.
  2. Continue to be readily available for distribution to clinicians, health care systems, state and county health departments, and other professional medical organizations.
  3. Be widely promoted to ensure better visibility and usage of these resources across national, federal, state, and local agencies.
  4. Be updated frequently to reflect feedback and changing knowledge.
  
- B. The HHS operating divisions, the U.S. Department of Veterans Affairs (VA), the U.S. Department of Defense and health systems should continue to educate the public at the national, state, and community levels about the benefits of risk reduction, early detection and diagnosis of AD/ADRD, treatment of AD/ADRD, and the importance of care planning, to improve the health and well-being of all individuals diagnosed with AD/ADRD, younger-onset, older adults, all persons with Intellectual and Developmental Disabilities (IDD) and their caregivers. Examples of resources include:
  1. The Centers for Disease Control and Prevention (CDC) Healthy Brain Initiative (HBI) Road Map for Public Health and other resources. [\[https://www.cdc.gov/aging/index.html\]](https://www.cdc.gov/aging/index.html)
  2. The Administration for Community Living (ACL) issue brief Dementia-capable States and Communities: The Basics and other National

Alzheimer's and Dementia Resource Center (NADRC) resources.

[\[https://nadrc.acl.gov\]](https://nadrc.acl.gov)

3. ACL's Brain Health: You Can Make a Difference! resources.  
[\[https://www.acl.gov/index.php/node/293\]](https://www.acl.gov/index.php/node/293)
4. The Health Resources and Services Administration (HRSA) training materials that include early detection and diagnosis of AD/ADRD.  
[\[https://bh.w.hrsa.gov/grants/geriatrics\]](https://bh.w.hrsa.gov/grants/geriatrics)
5. National Institute on Aging's What is Brain Health Initiative.  
[\[https://brainhealth.nia.nih.gov/\]](https://brainhealth.nia.nih.gov/)
6. American College of Preventive Medicine's (ACPM) Brain Health Continuing Education Course and Resource Website, and Healthy Brain Resource Center. [\[https://www.cdc.gov/aging/healthy-brain-resource-center/index.html\]](https://www.cdc.gov/aging/healthy-brain-resource-center/index.html)
7. An article by the CDC/ACPM, Cognitive Decline and Dementia Risk Reduction: Promoting Healthy Lifestyles and Blood Pressure Control.  
[\[https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8656338/\]](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8656338/)
8. CDC/National Association of Chronic Disease Directors customizable Rack Cards (Spanish and English) that are designed to educate patients about risk reduction practices related to AD/ADRD, including the importance of blood pressure control, physical activity, healthy diet, blood sugar management, and smoking cessation.  
[\[https://www.cdc.gov/aging/partnership/nacdd-partner-resources/index.html\]](https://www.cdc.gov/aging/partnership/nacdd-partner-resources/index.html)
9. Association of State and Territorial Health Officials/CDC Healthy Heart, Healthy Brain campaign to support American Indian and Alaska Native nations and Tribal-serving organizations. The materials for use by health care providers and public health professionals include steps patients can take to promote heart, brain, and overall health.  
[\[https://www.astho.org/topic/population-health-prevention/chronic-disease/healthy-aging-brain-health/healthy-heart-healthy-brain/\]](https://www.astho.org/topic/population-health-prevention/chronic-disease/healthy-aging-brain-health/healthy-heart-healthy-brain/)

C. ACL and CDC should continue to foster collaborative relationships with state units on aging (SUAs) and Area Agencies on Aging (AAAs) to promote the dissemination of information on risk reduction and the importance of early detection and accurate diagnosis of AD/ADRD. SUAs should:

1. Work in collaboration with their respective state's disability authority and Aging and Disability Resource Centers (ADRCs) to compile listings of providers with expertise in assessing and diagnosing AD/ADRD in persons with IDD, including those with sensory impairments and lifelong neurodevelopmental conditions.
2. Identify and promote clinicians who are proficient in the main non-English languages prevalent in their communities. These clinicians should also be knowledgeable about the cultural variances and values of these diverse populations and their perceptions of cognitive impairment.

D. NIH, CDC, and ACL should continue efforts such as the Recruiting Older Adults into Research (ROAR) project to encourage older adults and their families and

caregivers to consider participating in AD/ADRD research. These efforts should include attention to underrepresented populations, individuals with younger-onset AD/ADRD, and persons with IDD. Clinicians, health care systems, and state and other local entities should tailor recruitment materials like the ROAR Toolkit to include local information to meet the needs of communities.

[\[https://www.nia.nih.gov/health/recruiting-older-adults-research-roar-toolkit\]](https://www.nia.nih.gov/health/recruiting-older-adults-research-roar-toolkit)

**RECOMMENDATION 2: Accelerate efforts in clinical care to promote healthy cognitive aging, dementia risk reduction, early detection, accurate diagnosis, and early intervention and management of Alzheimer’s disease and related dementia, including co-morbid health conditions of people living with dementia.**

Translating evidence-based recommendations into clinical practice should be the focus of clinicians and workforce members who care for persons of all ages living with or at risk for AD/ADRD, in collaboration with the community, state, and federal agencies. The implementation of recommendations in clinical practice will require better person-centered communication, involving families/caregiver in care, education, care coordination, and workforce training, including all health care providers (physicians, nurses, nurse practitioners, physician assistants, pharmacists, and other clinical staff) and non-clinical staff (employees who interact with patients but are not involved in direct clinical care, such as receptionists, administrative personnel, transport staff, etc.). Additional requirements include effective dissemination of evidence-based guidelines, strategies for continuous quality assessment and improvement, efforts addressing access to care for all, and advancing health equity.

- A. Hospitals and health care provider practices serving people living with AD/ADRD or older adults at risk for AD/ADRD should put in place procedures to:
  1. Expand system dementia-capability by including dementia education in the employee annual training requirements. Such training should be supported by health care leadership, human resources departments, managers and supervisors and should reach not only all health care providers, but also non-clinic staff, as they play a significant role in creating a dementia-friendly environment and can greatly influence the quality of the patient and caregiver experience.
  2. Identify cognitive decline and integrate management of cognitive impairment into the care plan. This should include:
    - a. Promotion of education that increases familiarity with cultural differences and with presentations by adults with neuroatypical conditions to help improve early recognition of dementia symptoms.
    - b. Development of a quality metric to be used in primary care (such as those proposed by John A. Hartford Foundation Age-Friendly Health Care Initiative Mentation measure for primary care practices) that can track the proportion of patients aged 65 and over screened for cognitive impairment and, if identified, the integration and

- implementation of management of cognitive impairment into the care plan.
- c. Identification and integration of risk reduction strategies into the clinical care plan, focusing on those six risk factors identified in the NAPA Risk Reduction Subcommittee that are thought to have greatest potential for impact: hypertension, obesity, physical activity, smoking, depression, and hearing loss.
  - d. Addressing the impact of cognitive impairment on management of the individual's other health conditions (e.g., hypertension, diabetes, etc.).
3. Increase capacity of primary care practices to diagnose and manage AD/ADRD in the context of managing other primary care conditions. This can be achieved by facilitating continuous education for health care providers, integrating cognitive screening into routine checkups, and adopting an interdisciplinary, person-centered care approach. Promising strategies identified in the HHS Action Plan to Strengthen Primary Care that reflect these principles should be adopted into health care systems.
  4. Prioritize the provision of accurate and timely AD/ADRD diagnoses by developing streamlined care pathways that integrate cognitive testing, neuroimaging, biomarkers, and other diagnostic tools and that optimize use of primary care and specialty providers' time within each health care system. Appropriate dementia care professional development opportunities should be identified and guidance on appropriate billing codes should be provided to clinicians.
  5. Participate in innovative dementia care models, such as collaborative care models and integrated care pathways that include alignment of payment models. These models offer comprehensive and personalized care plans, integrate health and social care services, and focus on improving the quality of life for people living with dementia (PLWD) and their caregivers. Examples of such models include the Alzheimer's Disease Coordinated Care for San Diego Seniors and the Resources for Advancing Alzheimer's Caregiver Health.
  6. Promote active engagement and empowerment of patients and their caregivers. Encourage self-management strategies, the development of personalized care plans, and the use of decision aids to support informed decision-making about care and treatment options. This is in line with the person-centered approach endorsed by the World Health Organization's Global Action Plan on the Public Health Response to Dementia 2017-2025.
  7. Work towards an integrated system of care, connecting primary, secondary, and tertiary services, and including home and community-based resources. This ensures a smooth transition of care, prevents unnecessary hospitalizations, and allows for more holistic and effective care provision. Telehealth and digital health technologies can play a significant role in facilitating this connectivity and continuity of care. Encourage integration of early detection and screening into social and community settings, such as senior/community centers and adult day care programs. These initiatives should be linked directly to clinical care settings for follow-up, diagnosis, and

treatment, thereby providing a seamless care pathway. Primary care settings should remain the frontline for early detection of cognitive impairment, AD/ADRD.

- B. Congress should appropriate funding to explore measures to incentivize primary care settings and community health centers to establish outreach programs for early detection of AD/ADRD, particularly targeting underserved communities. This initiative should include developing care pathways post-diagnosis and fostering connections to community support programs, with a particular focus on rural health, minority health, and addressing social determinants of health (SDoH).
- C. NIH, AD/ADRD health organizations, and professional medical societies should work together to identify protocols and instruments as well as issue guidelines for the screening, assessment, and diagnosis of adults with cultural, language, and disability backgrounds differing from the general population where commonly used protocols and instruments may not easily apply or lead to misdiagnosis. Such populations include primary non-English speakers and adults with IDD and/or traumatic brain injury (TBI), among others.
- D. Clinicians should be encouraged to:
  - 1. Participate in dementia-specific continuing education, including Project ECHO trainings, to address dementia risk reduction, brain health, early detection and diagnosis of dementia, delivery of diagnosis, and dementia across the disease trajectory including early intervention, management, and medication management, including training on advances in dementia medications.
  - 2. Increase hearing testing, to support access to hearing aids for individuals with hearing loss.
  - 3. Disseminate dementia risk reduction strategies on co-occurring chronic conditions and dementias.
  - 4. Inform their patients of the dementia risks connected to behavioral health conditions, including depression, other mental illnesses, and substance use disorders (SUD). These materials should be updated on a regular basis, as research provides more insights and information, to help clinicians understand the impact of SUD on their patients and families/caregivers. Available toolkits include:
    - a. Substance Abuse and Mental Health Services Administration (SAMHSA) Treatment of Depression in Older Adults Evidence-Based Practices toolkit.
    - b. SAMHSA's guide for practitioners on Psychosocial Interventions for Older Adults with Serious Mental Illness.
    - c. Get Connected: Linking Older Adults with Resources on Medication, Alcohol, and Mental Health toolkit.
    - d. *Growing Older: Providing Integrated Care for an Aging Population.*

- e. Agency for Healthcare Research and Quality (AHRQ)'s Academy for Integrating Behavioral Health and Primary Care. The AHRQ Academy offers numerous resources, such as toolkits, webinars, and literature, to support the integration of behavioral health and primary care services.
  - 5. Build awareness and utilize evidence-based interventions to support caregivers in managing challenging behaviors. SAMHSA, the Centers for Medicare & Medicaid Services (CMS), HRSA, and ACL collaborated to publish *Guidance on Inappropriate Use of Antipsychotics: Older Adults and People with IDD in Community Settings*. The Guidance reviews non-pharmacologic behavioral approaches and strategies to avoid and reduce prescribing of antipsychotics whenever possible for older adults with dementia and people with IDD.
- E. As hearing loss has been identified as a target for dementia risk reduction, the Food and Drug Administration (FDA) should continue its implementation of the new regulatory category for over-the-counter (OTC) hearing aids and make related amendments to update the regulatory framework for hearing aids. The Proposed Rule aims to foster innovation in hearing aid technology and improve access to hearing aids, as OTC options would likely be easier to obtain and less expensive.
- F. State health departments, rather than state aging agencies, should maintain directories of health care providers and settings offering early detection and diagnostic services. Emphasis should be given to those providers and settings capable of serving diverse language groups and adults with neuroatypical conditions.
- G. Congress should amend the Older Americans Act (OAA) or consider other legislative measures to mandate that state health departments maintain information on existing dementia diagnostic resources, particularly emphasizing health care providers with the competency to diagnose and treat diverse populations.

**RECOMMENDATION 3: Implement solutions to address the geriatric and gerontology workforce crisis through training, continuing education, mandated standards, and improved pay to better address the needs of persons living with Alzheimer’s disease and related dementia and their families/caregivers.**

The shortage of health professionals specializing in geriatrics and gerontology, particularly in the context of dementia care, creates a pressing need for an expanded and more dementia-capable workforce. The identified "dementia neurology deserts in 20 U.S. states," by the Alzheimer’s Association, emphasize the geographic disparities in health and clinical/social care access and the urgent need for targeted efforts to address these gaps.

- A. Increase efforts and implement systems solutions at the federal level to address the workforce crisis.
  - 1. Congress should allocate funds to HRSA to establish and support Geriatric Workforce Development Centers of Excellence in each state.
  - 2. The 10% enhanced federal matching funds offered by the American Rescue Plan Act (ARPA) should be extended beyond 2024 and repurposed for focused efforts on improving the geriatric care workforce.
  - 3. HRSA should provide incentives and resources to health systems to hire and train more providers and care navigators to support people with dementia, their families and caregivers.
  
- B. Provide incentives for people to enter the geriatric care workforce.
  - 1. Congress should allocate funds to HRSA and other federal agencies to provide grants to clinics, hospitals, and other health care providers for the purposes of loan repayment, sign-on bonuses, education/training, and certification costs for geriatric care clinicians.
  - 2. Congress should enact legislation to provide affordable health insurance, free or low-cost child care, paid sick, family and medical leave, and retirement savings options for people who enter the geriatric care workforce.
  - 3. Congress should appropriate funds to HRSA for a public education campaign that improves the public's understanding and value of dementia care, and conduct a large-scale, national recruitment campaign that encourages more people to enter the geriatrics workforce.
  - 4. Congress should consider immigration reforms to attract and retain immigrants within the clinical direct care workforce.
  - 5. Congress should provide pathways to citizenship for immigrants who commit to work within clinical dementia care systems, particularly for those who work in areas of the country devoid of workforce resources or in ethnic communities in which they are members.
  - 6. State medical societies should be encouraged to offer continuing education programs focusing on the early detection and diagnosis of cognitive impairment in older people as part of licensing requirements. State licensure boards should mandate training on dementia as a prerequisite for license renewal.
  - 7. As advances are made in diagnostics, including biomarker-based tests, efforts should be coordinated among federal agencies, state health departments, private health systems, and medical societies to ensure relevant information reaches health care providers and patients. This includes novel technologies, discoveries, and innovations related to diagnostics and interventions for AD/ABCD. Although community organizations may not directly engage in biomarker-based diagnostics, they play a crucial role in disseminating information, facilitating access to services, and supporting patients and caregivers in navigating care pathways.



- C. Increase availability and improve training and supervisory support for people providing clinical care to PLWD.
1. Subject to Congressional appropriation, HRSA, through its Geriatric Workforce Enhancement Program (GWEP), should expand the development and dissemination of dementia care training curricula that use approaches shown to change clinician practice. These curricula should promote using a “whole-person” approach to brain and behavioral health in the context of co-occurring conditions and health related social needs and how to best integrate cognitive assessments into the Medicare Annual Wellness Visit.
  2. Congress should appropriate funds to HRSA to work with high schools, community colleges, colleges, universities, professional societies, and non-governmental organizations to develop and provide on and off-campus programs for training clinical care workers and increase internship and supervision support for the clinical care workforce.
  3. HRSA should continue to allocate a portion of GWEP funding, not less than \$200,000 per grantee, uniquely toward workforce training in dementia and encourage training participation by students and trainees of color, those with needed language skills, and those representing diverse ethnic communities.
  4. Congress should consider legislation to incentivize health care systems to provide dementia care and dementia care training that is culturally competent to clinicians who provide clinical care to people living with AD/ADRD, especially in our nation’s highly populated diverse areas.
  5. Health systems should leverage technology, data platforms, electronic health records (EHRs), and artificial intelligence to enhance dementia care delivery, training and education. They should build capacity to use telehealth to improve access to care for PLWD, particularly in rural and other underserved areas. Additionally, assistive, therapeutic, and remote monitoring technologies can be employed to supplement the role of the dementia care workforce, improve quality of life for PLWD, and provide support to caregivers. This includes devices for safety monitoring, cognitive aids, and technologies to support daily activities and social engagement.
  6. Given the FDA approval of new disease-modifying treatments (DMTs) for AD, health systems should develop the necessary infrastructure and workflow to identify and safely treat persons likely to benefit and to monitor for adverse effects. Clinicians should also receive training to develop the following skills:
    - a. Proficiency in administering and interpreting cognitive tests to identify potential candidates for DMTs.
    - b. The ability to understand, interpret, and explain the significance of key biomarkers associated with AD/ADRD.
    - c. Competence in identifying and managing adverse reactions associated with DMTs, which may include interpreting imaging abnormalities.
    - d. Enhanced clinical skills for managing complex patient scenarios, including multiple pathologies and unusual presentations of AD/ADRD.

- e. Tailoring treatments to suit individual patient needs, including those with atypical presentations or co-existing conditions.
  - f. Providing culturally competent care, with the ability to apply these skills across diverse populations and adults with neuroatypical conditions.
- D. Federal agencies, states, professional societies, health care systems and others should continue to offer and support current and future workforce education to improve workforce members' abilities to work with persons of all ages living with AD/ADRD and their family/caregivers, including those in diverse communities. Workforce education programs should include recognizing and addressing risk factors, early signs and symptoms, early detection, diagnosis, treatment, plan of care, counseling, and connecting persons living with AD/ADRD and their family members and caregivers to local services and resources for continuity of care at all stages.
1. **Primary Care** -- to train the primary care workforce about dementia and promote interprofessional teamwork in the care of persons living with AD/ADRD and integrate family/caregivers in the plan of care.
  2. **Dementia Care Management** -- to train dementia care managers (e.g., nurses and social workers) within health care organizations to effectively support all PLWD and family/caregivers.
  3. **Disaster Preparedness** -- train health care workers, first-responders, and individuals to recognize and better protect the health and safety of persons living with AD/ADRD and their family/caregivers who experience a disaster or hazard.
  4. **Acute Care** -- to train individuals, first-responders, and health care workers providing care to persons living with AD/ADRD in urgent care, emergency department, and hospital settings to recognize and better identify and address needs of persons living with AD/ADRD.
  5. **Behavioral Health** -- to train health care workers, first-responders, and individuals to recognize and better address needs of persons living with AD/ADRD, including those living with IDD and mental health disorders and their family/caregivers.
  6. **Co-morbid Medical and Mental Health Conditions** -- to train health care workers to recognize and better identify, distinguish, and appropriately manage symptoms of AD/ADRD when they occur concurrently with signs and symptoms of acute and chronic medical conditions, multi-factorial conditions such as pain and reduced communication abilities, IDD, and mental health disorders and to manage these conditions in the context of dementia. Knowledge of presentation of adults with neuroatypical conditions should be included.
  7. **Pre-Existing Cognitive Conditions** -- to train workers to distinguish between a person's typical level of function, given their pre-existing cognitive or psychiatric disabilities, and new or increasing difficulties that might suggest the onset or progression of mild cognitive impairment (MCI) or dementia.

8. **Recruitment into Research** -- to train health care workers and individuals on the importance of and options for recruiting persons with AD/ADRD into research, focusing on persons from diverse populations and those most affected by SDoH.
  9. **Train Health Professionals** -- the importance of early detection; risk reduction; and culturally and literacy appropriate content and materials. Available resources to address this recommendation include:
    - a. [<https://www.nia.nih.gov/health/now-what-next-steps-after-alzheimers-diagnosis>]
    - b. [<https://www.nia.nih.gov/health/managing-older-patients-cognitive-impairment>]
    - c. [<https://www.nia.nih.gov/health/talking-older-patients-about-cognitive-problems>]
    - d. [<https://www.nia.nih.gov/health/assessing-cognitive-impairment-older-patients>]
- E. Policymaker discussions should continue to engage stakeholders and seek their input regarding the evolution of payment models. These models should be informed by emerging clinical care recommendations, research findings, and real-world experiences in the field. While organizations such as CMS do have systems in place for soliciting stakeholder input, it is important to emphasize the ongoing need for this collaboration in order to enhance services and supports for PLWD and their caregivers.
- F. Enhance the process for stakeholder input into policymaker discussions, especially regarding payment models that directly affect the care of persons living with AD/ADRD. The aim is to ensure that these models are informed by the latest clinical care recommendations and research findings.
- G. HRSA and AHRQ, in collaboration with health care organizations and academic institutions, should lead the development, testing, and implementation of integrated person-centered models of care for PLWD, with a particular focus on primary care settings.
- H. Professional health care associations should convene working groups to define the skills needed by persons delivering evidence-based AD/ADRD care across care settings. These groups should:
1. Address workforce training on the benefits and risks of pharmacotherapy, including the integration of medication use and "deprescribing" into comprehensive, person-centered, culturally appropriate non-pharmacological approaches to care.
  2. Develop strategies to assess the implementation of acquired knowledge and skills into clinical practice and the impact on health outcomes in PLWD, which would serve as measures of success.

- I. Federal agencies, academic institutions, and professional associations should collaborate to ensure that existing and future training related to AD/ADRD care aligns with evidence-based guidelines and is incorporated into curricula and continuing education for health professionals, first-responders, and other relevant personnel. This includes but is not limited to the recommendations and guidelines provided by:
  1. The Alzheimer's Association's 2018 Dementia Care Practice Recommendations.
  2. HRSA AD/ADRD Core curriculum and the HRSA Caregiving curriculum.
  3. Brain health education about AD/ADRD and caregiving in curricula for students of public health available through CDC and the Alzheimer's Association.
  4. Recommendations from the National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers.
  5. *Guidance on Inappropriate Use of Antipsychotics: Older Adults with IDD in Community Settings*.
  
- J. Federal programs and relevant stakeholders that provide AD/ADRD care training should continue to report the number of workforce members trained per year. This data should be considered in updates to the National Plan. Further, these entities should explore ways to improve their reporting capabilities for more granular and accurate tracking of the trained workforce.

**RECOMMENDATION 4: Encourage people living with Alzheimer’s disease and related dementia and their designated care partners to be integral parts of the clinical care team and foster coordination of comprehensive, person-centered dementia care with home and community-based services.**

People living with AD/ADRD and their designated care partners should be encouraged to be integral parts of the clinical care team. Their involvement in the decision-making process and care planning fosters person-centered care, considering unique needs, preferences, and goals. By actively engaging individuals with AD/ADRD and their care partners, health care professionals can gather valuable insights into the patients' experiences, challenges, and strengths, leading to more effective and personalized care, improved outcomes, and enhanced quality of life.

Further, promoting coordination of clinical care with home and community-based services (HCBS) enhances overall care experience and outcomes for individuals with AD/ADRD. HCBS offer a variety of supportive services that complement clinical interventions and allow individuals to remain in their preferred living environments for as long as possible. This coordination ensures a comprehensive approach, addressing both medical and non-medical needs, and promotes continuity of care across different settings.

- A. The Clinical Care Subcommittee recommends that a variety of health care providers such as hospitals, health plans, health systems, federally qualified health centers, mobile clinics, and primary care practices serving PLWD should develop procedures and tools for:
1. Identifying and documenting designated care partners, where appropriate, to participate in care planning and effective goal implementation.
  2. Designing person-centered care plans, incorporating both the person living with dementia and the designated care partner's inputs. These plans should be revisited annually or whenever necessary for updates.
  3. Assisting persons living with dementia and their caregivers in finding resources, services, and supports needed for optimal disease management.
  4. Assessing the needs of both the person living with dementia and their designated care partner, providing them with disease education, caregiver skill development training, and HCBS.
  5. Monitoring quality measures to encourage the implementation of these recommendations, including existing measurement strategies and the development of new measures for feedback on factors such as the number of patients with identified caregivers, how their needs were assessed, and the impact of their receiving disease education and community-based support.

**RECOMMENDATION 5: Promote the implementation of evidence-based, non-pharmacological interventions to address behavioral and psychological symptoms of dementia.**

Behavioral and psychological symptoms of dementia (BPSD) may appear in up to 90% of persons living with dementia. Implementing evidence-based non-pharmacological interventions, delivered in a person-centered manner in a supportive environment, is essential for comprehensive clinical care.

- A. Health care systems, clinicians, and community-based staff should encourage the following three key considerations be addressed:
1. **Environment** -- The physical and social environments of the patient should be conducive for intervention. An ideal environment should be safe, comfortable, clear of clutter and hazards, well-lit, and ventilated. It should also offer opportunities for social interaction, be supportive, and encouraging.
  2. **Care Efficacy** -- Continuous education and training in non-pharmacological interventions should be provided to caregivers, both non-professional (including family) or professional, to help them manage BPSD symptoms effectively. Skills such as recognizing BPSD symptoms, effective communication with patients with dementia, and providing emotional support should be imparted.
  3. **Patient-Centeredness** -- The individual needs and preferences of the patient should be at the heart of any intervention. Autonomy should be

respected, and patients should be encouraged to participate in meaningful activities. Interventions should be tailored considering the patient's personality, interests, and abilities.

- B. Federal agencies (HRSA, ACL, CDC, VA, Indian Health Service [IHS], National Institute of Nursing Research [NINR], NIH) and other organizations should:
1. **Fund Research** -- Support research into the effectiveness of non-pharmacological interventions for BPSD. This can help identify best practices and develop improved interventions. Increased funding for dementia-specific research, training opportunities focusing on BPSD, and grants to small businesses for developing innovative assistive technologies should be considered.
  2. **Provide Training** -- Offer comprehensive training to caregivers, both non-professional (including family) and professional, on implementing non-pharmacological interventions for BPSD. Expand existing training programs to include more information on non-pharmacological interventions. Encourage health care providers to incorporate evidence-informed non-pharmacological interventions, such as cognitive stimulation therapy, music therapy, art therapy, and physical activity programs into their practice.
  3. **Create Policies** -- Formulate policies that endorse the use of non-pharmacological interventions for BPSD. These policies could involve insurance coverage for non-pharmacological interventions and financial assistance to caregivers implementing these interventions.

**RECOMMENDATION 6: Initiate a comprehensive dialogue involving a broad cross-section of experts to discuss implementation processes related to Alzheimer’s disease-modifying treatments in the context of high quality, person-centered care.**

A comprehensive dialogue involving diverse experts is crucial to discuss both the opportunities and challenges associated with the implementation of FDA approved AD modifying treatments (DMTs), and other potentially beneficial strategies. Key topics would include raising awareness of these therapies, addressing the variance in state drug formulary prescribing criteria, defining the hiring and training requirements for DMT experts and patient navigators, identifying how health systems will effectively administer, monitor, and integrate these DMTs with other interventions, and addressing the unique access needs of urban, suburban, rural communities, and underserved populations, including persons with neuroatypical conditions.

Federal funding should be allocated to support meetings that specifically address the complex issues surrounding equitable access to new DMTs. Such meetings should include federal partners, non-federal NAPA members, health care systems and EHR companies, clinicians, patients, families, and community-based stakeholders.

- A. Federal funding should support efforts in health services research and implementation science to study how to best develop and implement DMT programs that optimize patient access and prioritize patient safety. This research and program development should include discussion on infrastructure needs (e.g., DMT experts, neuroimaging access, infusion sites, staffing, etc.), use of EHR tools, and unique access needs of urban, suburban, rural communities, and underserved populations.
- B. Initiatives should be discussed that secure appropriate reimbursements for DMTs and related services to ensure equitable access to these treatments and interventions.

**RECOMMENDATION 7: Promote the further development, evaluation, and practical implementation of effective person-centered health care models for Alzheimer’s disease and related dementia that integrate performance measures and payment models.**

The approach in this recommendation acknowledges the importance of understanding and addressing real-world practice challenges in implementing these models. Federal agencies (CMS, VA), states, and non-governmental payers for health care services should enhance the utilization of value-based care for persons living with AD/ADRD, including linking payments to performance on cost, quality, and resource use. Such alignment would support comprehensive person-centered care, leading to improved health outcomes and quality of life for persons living with AD/ADRD and their families/caregivers.

- A. Initiatives delivering value-based programs should adhere to definitions of value outlined by CMS and other relevant entities.  
[\[https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Value-Based-Programs/Value-Based-Programs.html\]](https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Value-Based-Programs/Value-Based-Programs.html)
- B. Initiatives assessing value should be evidence-informed, and further research should be conducted to study how care models improve health outcomes, including effective management of co-morbidities.
- C. Initiatives assessing value should employ a framework such as the CMS Meaningful Measures initiative and adapt it specifically for persons living with known AD/ADRD or cognitive impairment, their family members, and caregivers. This could be coupled with other reporting metrics of health care use and performance, such as:
  - 1. Cognitive Impairment and Assessment Care Planning Codes.
  - 2. Quality Payment Program measures relevant to AD/ADRD.
  - 3. Use of Medicare's Annual Wellness Visit.

- D. Congress and/or federal agencies should prioritize the evaluation of comprehensive models that include a per-beneficiary-per-month payment to provide care and services to eligible persons living with AD/ADRD, as described in Recommendation 11 of the 2017 National Plan.  
[\[https://aspe.hhs.gov/report/national-plan-address-alzheimers-disease-2017-update\]](https://aspe.hhs.gov/report/national-plan-address-alzheimers-disease-2017-update)
- E. States and other payers (Medicare, Medicaid) should amplify their focus on HCBS, which support person-centered care and self-determination for persons living with AD/ADRD and their caregivers. Considerations should also be given to develop mechanisms for reimbursing these providers for their services to patients. Further clarification is required to ascertain the specific means for reimbursement under consideration.

**RECOMMENDATION 8: Promote health equity and eliminate barriers to the receipt and payment of clinical care services and long-term services and supports for adults living with dementia who are under age 65.**

Younger adults living with dementia can face eligibility restrictions for certain dementia-specific services due to age-related statutory barriers. First, the OAA typically requires recipients to be age 60 or older to receive covered services. Secondly, Medicare has a two-year waiting period for younger individuals living with AD/ADRD who qualify for Social Security Disability Insurance (SSDI). To address these barriers and assure health equity, legislative actions and a thorough understanding of their impact on beneficiaries with dementia and the health care system are required.

The Clinical Care Subcommittee encourages consideration of these issues within the scope of the National Plan and suggests that federal partners gather and provide data to inform future policy proposals. To enhance the understanding of these issues, they could potentially be the focus of a dedicated NAPA meeting.

- A. The Clinical Care Subcommittee recommends that the National Plan address the following barriers to clinical care and community-based long-term services for younger individuals living with AD/ADRD:
  - 1. The OAA requires recipients to be age 60 or older to receive covered services. The Clinical Care Subcommittee suggests that Congress amend the OAA to extend services to persons under age 60 diagnosed with AD/ADRD.
  - 2. The two-year waiting period for younger individuals living with AD/ADRD who qualify for SSDI to have access to Medicare poses a barrier to clinical care. The Clinical Care Subcommittee recommends that Congress consider eliminating this waiting period to enhance access to crucial health care services.



## Long-Term Services and Supports (LTSS) Subcommittee

### **RECOMMENDATION 1: Improve access to long-term services and supports for people with dementia and their caregivers.**

Quality of life experienced by people with dementia is often dependent upon the ability to access quality services and supports. Yet millions of Americans with dementia and those who provide care are faced with daily challenges in accessing services.

This set of recommendations focus on five issues that the committee sees as some of the most significant gaps in accessing LTSS: (1) availability of culturally and linguistically tailored dementia care for marginalized and disproportionately affected populations of people with dementia; (2) diminishing availability of services that are important to people with dementia and their caregivers; (3) the unaddressed impacts of social isolation and loneliness on health outcomes, safety and quality of life; (4) assisting people with dementia who are homeless in transitioning to stable housing and support services; and (5) addressing issues generated after the COVID-19 pandemic.

To assist in filling these gaps, the Committee offers the following recommendations:

- A. Expand the availability of culturally and linguistically tailored LTSS to ensure access for populations that are marginalized, historically underserved, and disproportionately affected by dementia.
  1. Congress should allocate funding to ACL to provide state grants for the purpose of expanding community health workers (CHWs) within the aging network. This network plays a significant role in helping people access dementia services and enrolling in LTSS programs, therefore, it is crucial to have people in the aging network who are dedicated to serve as community advocates and connectors to culturally responsive dementia supports for members of underserved communities.
  2. Federal agencies should encourage collaboration amongst CHWs that are employed by community health clinics, managed care plans, public health, and community-based organizations to provide holistic and system-integrated services to populations that are disproportionately impacted by dementia.
  3. Congress should authorize Medicare to reimburse CHWs employed outside of health care settings.
  4. Office of the Assistant Secretary for Planning and Evaluation (ASPE) should conduct and publish a study on the impact and return on investment that CHWs can have on LTSS for underserved communities, as a potential means of supporting growth of the model across the country.
  5. Congress should allocate \$10m to ACL to pilot community-based Dementia Care Specialist/Navigator programs within the nationwide aging network. Congress should also allocate funding to IHS to support a Tribal Dementia

Care Specialist/Navigator program within tribes. States are encouraged to sustain successful pilot programs through state legislation and funding.

6. HRSA should provide training to Federally Qualified Health Centers that can assist immigrant, rural and low-income populations in accessing LTSS.
  7. Congress should provide financial incentives for diverse business owners and not-for-profit organizations to become dementia-capable LTSS service providers.
  8. Congress should increase funding for ADRCs/No Wrong Door systems to address unmet community needs, gaps in provider networks and improve access to public and private LTSS for PLWD and their unpaid caregivers, regardless of payor or income. Limited and dwindling funding at the state and federal level puts these essential services at risk and at a minimum, has made it difficult for states to create quality ADRCs across the country.
- B. Expand the availability of dementia-capable HCBS available to people with dementia and their unpaid caregivers.
1. Adult day and adult day health centers provide socialization, recreation, and health services for people with dementia and others, and are also a valuable source of respite for caregivers. There has been a significant loss of adult day service providers across the country. ASPE should conduct a study on the causes of this issue and provide recommendations to entities who can have an impact on expanding and ensuring that adult day services are available to meet the needs of people with dementia.
  2. Respite care options are essential for giving unpaid caregivers a break, which can have an impact on their caregiving longevity and capacity to care.
    - a. States should make at-home and community-based day and overnight respite services available to dementia caregivers through various LTSS programs.
    - b. HRSA should study the impact that direct care workforce recruitment, sustenance, and education challenges have had on respite care options and make recommendations for addressing the issues identified in the study.
    - c. ACL should provide resources to expand the availability of innovative dementia-specific respite programs and evaluate, document and disseminate successful interventions or models.
    - d. Congress should allocate additional funding to the Lifespan Respite Care Program and the Lifespan Respite Care Enhanced Grants Program. These programs allow states to plan, establish, and expand respite systems, including new and planned emergency respite services, training and recruiting respite workers and volunteers and assisting caregivers with gaining access to needed services.
- C. Implement strategies to reach people living alone with dementia and strategies that address the impacts of social isolation and loneliness on health outcomes, safety, and quality of life.

1. ACL and CDC should continue to collaboratively promote and fund the expansion of dementia-friendly communities' efforts, including dementia-friendly employers and caregiver-friendly workplace policies, accessible and inclusive public spaces, memory cafés, accessible transportation, housing, technology and broadband Internet access, and other strategies that are helpful for addressing the negative consequences of social isolation and loneliness. ACL and CDC should encourage inclusion of such efforts in SUA plans and State Health Improvement Plans. [<https://www.dfamerica.org/>]
  2. ACL should encourage collaboration between its Administration on Aging (AoA) and the Administration on Disabilities (AoD) to create cross-cutting strategies and plan for identifying and assisting older adults with disabilities living alone and at risk for dementia. AoA and AoD should encourage their respective state entities (SUAs and State Developmental Disabilities Planning Councils) to do the same.
  3. ACL should provide technical assistance to SUAs on ways to identify isolated adults with possible cognitive decline, and approaches that work, like home visitor programs, "home share pairing" and home risk and safety assessments for possible inclusion in state aging plans. ACL should advance awareness of best practices in service and support offerings and in outreach efforts by senior centers and nutrition programs to draw in isolated adults.
  4. ACL should provide technical assistance to SUAs and AAAs to support clinical assessment of loneliness and isolation in older adults and to make referrals to diagnostic services.
  5. Congress should allocate funding to the National Endowment for the Arts to create a grant program that promotes the use of creative programming to reduce social isolation and loneliness amongst PLWD and their unpaid caregivers.
  6. States should implement practices and utilize tools provided by ACL (through the NADRC) to train emergency services, first-responders, community governments and police department personnel to identify, engage and refer people living alone with dementia, including those with lifelong significant disabilities living alone, to services and supports.
  7. NIH should allocate funding to research to better understand how to address the impact of social isolation and loneliness on people with dementia and their unpaid caregivers.
  8. ACL should develop and disseminate education and training for LTSS service providers on the impact that social isolation has had on older Americans, especially those with dementia, and ways to address those impacts.
- D. Implement strategies to improve outreach, housing, and supportive services to better address the needs of older adults experiencing homelessness, including those with dementia.

Adults aged 65 years and older make up the fastest growing population of people experiencing homelessness. Those adults experiencing homelessness aged 50 and older currently compose nearly half of the homeless population in the United States. This rapid increase is expected to continue, with populations of older adults experiencing homelessness tripling by 2030 in hard-hit areas like Boston, New York City, and Los Angeles County. Older adults who are homeless develop health conditions, including memory loss, cognitive and functional impairments, falls, and difficulty performing ADLs, 20 years earlier than older adults with housing; these conditions occur at higher rates and with greater severity among older adults experiencing homelessness. They also have significantly shorter lifespans when compared to their housed counterparts. Given the growing population of older adults with AD/ABD, it is likely that many older adults experiencing homelessness may have or develop a form of dementia; however, there is insufficient understanding of dementia among older adults experiencing homelessness.

1. The U.S. Interagency Council on Homelessness should convene a summit or workgroup to explore possible actions to address homelessness amongst this group, including those with dementia, and develop strategies to improve the response to homelessness among older adults as part of the Council's federal response and strategic plan. Utilizing existing data, this plan should include strategies to train and encourage collaboration between outreach teams, Continuums of Care, local governments, shelters, and other homelessness and housing providers on the unique challenges faced by older adults experiencing homelessness, including dementia. These strategies should include development of training opportunities, webinars, and written guidance. Topics could include communicating with someone showing cognitive impairment or the impacts of trauma, TBI, and lack of sleep on dementia risk and on aging.
2. The VA should carry out an evaluation of older adults currently housed through the United States Housing and Urban Development-Veterans Affairs Supportive Housing (HUD-VASH) program to identify the unique and developing needs of older and aging participants, particularly in relation to MCI and dementia. The VA should identify both challenges and opportunities for serving this population and meeting their housing, behavioral health, and health needs and develop guidance on best practices for other housing providers.
3. HUD and HHS should provide grants to local housing and homelessness providers to develop new and/or adapt existing programs, including shelters, to better meet the needs of older adults experiencing homelessness, including those with dementia. For example, improving accessibility and safety of physical spaces by widening walkthroughs or installing grab bars in supportive housing. Grants could also focus on the hiring and training of a workforce that is able to meet ADL needs of older adults experiencing homelessness as they transition into permanent supportive housing.

- E. Implement strategies to address the new and unique issues generated from the COVID-19 pandemic.
1. ASPE should conduct an assessment on the impact that the COVID-19 pandemic has had on the LTSS system, particularly on people with dementia and their caregivers, and make recommendations for ways in which the Federal Government, states and community-based organizations can respond to future pandemics, disasters, and emergencies.
  2. Federal agencies should develop a workgroup to explore possible actions to address the results of the assessment.
  3. The CDC and state and local public health should collect, analyze, and share with the public as appropriate, surveillance data regarding older adults with long-COVID and abnormal cognitive decline or noted impairment that appears to result from COVID-19.
  4. HHS should ensure dementia programming and support systems are connected or integrated into other HHS work that is underway related to recovery and systemic issues generated by the pandemic.
  5. The Federal Government should develop and fund solutions for ensuring broadband access across the country for the provision of telehealth, medical evaluation, LTSS and for socialization and access to support networks.

**RECOMMENDATION 2: Implement strategies that create the conditions for high quality, person-centered and strengths-based long-term services and supports throughout the course of the disease.**

Dementia care that is personal and not just professional, that keeps people with dementia and caregivers at the center is a key driver in high quality dementia care. Person-centered, culturally competent care must extend through all stages of the disease, including care for people with advanced dementia and within the delivery of end-of-life care.

The benefits of palliative care are significant for people with dementia and their caregivers. Palliative care can help improve symptom management, reduce unnecessary hospitalizations, improve satisfaction with care, and decrease prolonged grief and stress among family members and caregivers. Palliative care can be appropriate at any stage and at any age and can be done by many types of health professionals and volunteers. Yet, palliative care is largely misunderstood by people with dementia, their care partners and amongst health care and LTSS providers. It is underutilized or used too late, access is disparate, and cultural considerations in end-of-life are inadequately addressed in the delivery of services.

To assist in addressing these issues, the LTSS committee provides the following recommendations that focus on four areas: (1) improvements in person-centered, strengths-based and culturally competent LTSS; (2) reduction in the use or over-use of psychotropic medications in LTSS settings; (3) continued increase in the use of

evidence-based interventions in LTSS settings; and (4) advancements in care provided to people with advanced dementia.

A. Improve the quality of care and safety provided to people with dementia across LTSS settings.

1. Federal agencies and other public and private organizations should disseminate culturally responsive, person-centered, and strengths-based care planning models.
2. Institutional and HCBS providers, community-based organizations and managed care plans should utilize training and guidance from CMS and ACL regarding methods for creating care plans for people with dementia that:
3. Ensure person-centered, strength-based, and culturally competent care across the care continuum.
4. Encourage use of shared and self-directed decision-making processes, in partnership with individuals living with AD/ADRD, to develop person-centered care plans that are culturally inclusive and understandable by the consumer.
5. Are provided in a way that promotes health equity, cultural humility/competency, personal authenticity, and addresses sources of discrimination or segregation.
6. Integrate solutions for addressing individual barriers related to SDoH.
7. Enable individuals and their caregivers (as appropriate) to navigate, coordinate, and manage care appropriately and effectively.
8. Help PLWD find the resources, services, and supports needed to help them live their best life as the disease progresses.

B. Reduce inappropriate use or over-use of psychotropic medications in LTSS settings.

1. BPSD are a common component of dementia that can increase the burden on the family, affect quality of life, impact cost of care and increase morbidity. Recognizing that antipsychotic medications are frequently used off-label to control these symptoms and that such use can lead to excess morbidity and even mortality, the standard of care across all settings should encourage use of person-centered care and promising non-pharmacological approaches first, before using antipsychotics.
2. Federal agencies (HRSA, ACL, CDC, VA, IHS, NINR) and other organizations should continue to build the capacity of the workforce (paid and unpaid) to deliver person-centered care and/or evidence-based, non-pharmacological interventions to address BPSD.
3. 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 to unpaid caregivers, to increase adoption.
4. Disseminate the findings from the various non-pharmacological intervention outcomes stemming from the ACL's Alzheimer's Disease Programs Initiative (ADPI) funded dementia care program projects.

5. NIH, NINR, and other federal entities should fund research assessing the effectiveness of non-pharmacological interventions for BPSD and disseminate findings to LTSS providers of care.
- C. Increase the availability and use of evidence-based dementia and caregiving interventions within the LTSS system.
1. Federal agencies and other public and private organizations should disseminate information to LTSS providers about evidence-based dementia interventions, including those for use with diverse groups and those developed for emergency situations.
  2. Federal and other funders of research should direct some of those funds to support the creation of robust tools and resources such as replication guides, facilitator guides, and participant materials to assist with implementation in LTSS settings.
  3. Federal, state, and private entities that fund LTSS should pay for interventions that have demonstrated positive outcomes for people living with AD/ABD or caregivers. Federal payors should create care and payment models that allow for the use of evidence-based interventions for people living with AD/ABD and caregivers, as well as for person-centered care planning.
- D. Increase availability, utilization, and quality of care for people with advanced dementia.
1. Congress should pass legislation to create a palliative care benefit under Medicare for people with serious illness, including people with dementia.
  2. HHS and other federal agencies should take action to ensure access to high quality and culturally competent palliative care for people with dementia and their families across LTSS settings.
    - a. HHS and other federal agencies should leverage existing policy mechanisms (such as payment, regulatory and public reporting) to ensure access to high quality care for people with advanced dementia and their caregivers.
    - b. HHS and other federal agencies should develop strategies for addressing the significant disparities in access, use and inconsistent or inequitable approaches to palliative care.
    - c. HHS should develop a strategy for broadening the public's awareness of the benefits of palliative care, including education about the opportunities to access this type of care much sooner in the disease process than when hospice or end-of-life care is needed.
  3. HHS should continue to develop and enhance distribution of information that can be shared with the public regarding the importance of advance planning, financial and health care decision-making options, the spectrum of care settings and services, and where people can turn for assistance with these topics. HHS should utilize its authority to define the role that health care and LTSS providers could play in distributing this information and supporting this planning early in the dementia-journey.

4. HHS should support quality metrics that ensure transparency and accountability for the care of people with advanced dementia across settings and payors, and:
  - a. Develop incentives for HCBS providers to identify, document, and track the level of functional and cognitive status to identify people with advanced dementia early.
  - b. Develop mechanisms for sharing and integrating documentation across settings to support care transitions and coordination among systems.
5. Congress should allocate funds to support research, evaluation, and dissemination of models of care that meet the needs of people with advanced dementia and their caregivers across care settings and payors.

**RECOMMENDATION 3: Implement solutions to address the long-term services and supports workforce crisis.**

Numerous studies have documented shortages of personnel to manage, supervise and provide LTSS. Shortages in a well-trained, well-compensated and adequate workforce can leave residents of long-term care facilities particularly vulnerable, especially during public health and other emergencies.

Congress, federal agencies, states, and other organizations should recognize that workforce compensation, recruitment, retention, and training are challenges that must be addressed. Therefore, the NAPA Committee provides the following recommendations:

- A. Increase efforts and implement systems solutions at the federal level to address the workforce crisis.
  1. HHS should create a Direct Care Workforce Task Force, drawing from the RAISE Family Caregiving Council, the NAPA Council and other Advisory Committees, to serve as a federal advisory committee that will make recommendations and develop a national strategy for addressing the LTSS workforce crisis.
  2. The U.S. Department of Labor (DoL) should award specific funding for long-term care workforce development, including the dementia care workforce, and for the establishment of Direct Care Workforce Development Centers of Excellence, one per state.
  3. Congress should fund the ARPA 10% enhanced federal matching funds to states, beyond the current timeframe, with focused efforts on improving the LTSS workforce.
- B. Establish a national caregiver career pathway to create consistent, transferable, and broadly available career advancement opportunities.
  1. HRSA should establish a national pathway to a variety of health professions. They should commission the development of national



standards for direct care workers and certification offerings for use by community colleges, training institutions and in-service programs, as well as for use by states to create career ladders and set compensation targets. The standards should apply in general to direct care and include provisions for dementia care.

2. States that create career pathways should consider regulatory parity and certification portability across settings including home care, long-term care facilities, and other settings where people with dementia reside.

C. Provide incentives for people to enter the workforce.

1. Congress should allocate funds to HRSA to provide grants to representative payees and clinics, hospitals, private duty nursing organizations, home health, disability providers, and other clinical providers for the purposes of loan repayment, sign-on bonuses, training, and certification costs for direct care staff.
2. The Federal Government should authorize legislation and appropriate funds to DoL to establish a program that provides affordable health insurance, free or low-cost child care, paid sick leave, paid family and medical leave, and retirement savings options for people who enter the direct care workforce.
3. LTSS payors (such as state Medicaid agencies and managed care plans) should provide a minimum base rate to employers that adequately cover wages, benefits, and other workforce investments.
4. The Federal Government should fund public education campaigns that improve the public's understanding of the direct care workforce, the rewarding nature of serving aging populations, and conduct a large-scale, national recruitment campaign that encourages more people to enter the workforce.
5. Immigrants and the immigration system can contribute to the effort to increase the number of people in the United States available to provide direct care. One out of four direct care workers are immigrants and 38% of current home health aides are foreign born. Congress should consider ways in which laws can be changed to attract and retain immigrants within the direct care workforce.
6. Congress should provide pathways to citizenship for immigrants who commit to work within LTSS systems, particularly for those who work in areas of the country short on workforce resources or in communities for which they are members.

D. Increase availability and improve training and supervisory support for people providing direct care to people with dementia.

1. States and the Federal Government should encourage high schools, community colleges, colleges, universities, professional societies, and non-governmental organizations to develop and provide on and off-campus programs for training direct care workers and increase internship and supervision support for the direct care workforce.

2. HRSA should continue to allocate a portion of GWEP funding, not less than \$100,000 per grantee, uniquely toward workforce training in dementia, encourage participation in training by students and trainees of color, with needed language skills, and those representing diverse communities.
3. States should explore ways to require or incentivize LTSS systems to provide dementia and dementia care training that is culturally competent to all staff who interact with people living with AD/ADRD including, but not limited to, customer service, food service, billing, janitorial, security, and transportation staff as well as those providing clinical care.
4. Federal and state agencies and LTSS industry associations should explore options for making no-cost training available to nursing homes, assisted living facilities, home care and other LTSS providers with guidance on dementia and dementia care training requirements for enhancing the competency of the workforce.

**RECOMMENDATION 4: Ensure that family and unpaid caregivers of people with dementia have the support they need.**

As stated in the RAISE Family Caregiving Council report [[https://acl.gov/sites/default/files/RAISE-InitialReportToCongress2021\\_Final.pdf](https://acl.gov/sites/default/files/RAISE-InitialReportToCongress2021_Final.pdf)]: Family caregivers have long been the backbone of America’s caregiving infrastructure. Each year, more than 53 million people provide a broad range of assistance to support the health, quality of life, and independence of someone close to them. Millions of older adults and people with disabilities would not be able to live in the community without that support, and replacing it with paid services would cost an estimated \$470 billion each year.

Providing that support is rewarding, but it can be challenging. When family caregivers do not have training, support, and opportunities for rest and self-care, their own health, well-being, and quality of life suffer. Their financial future can also be put at risk -- lost income due to family caregiving is estimated to be a staggering \$522 billion each year.

The recommendations of the RAISE Family Caregiving Council align with caregiver concerns of the NAPA Council and provides a solid framework for addressing the needs of caregivers. To help assure that family and unpaid caregivers of people with dementia have the support they need, the NAPA Advisory Council recommends:

- A. Leverage implementation of the National Caregiving Strategy to align with NAPA goals and ensure dementia caregivers are considered in implementation.
  1. Congress should appropriate funds to all appropriate federal agencies to support and act on the national strategy developed by the RAISE Family Caregiving Council that focuses on the priority areas of: (1) Increased awareness of family caregiving; (2) Increased emphasis on integrating the caregiver into processes and systems from which they have been traditionally excluded; (3) Increased access to services and supports to

- assist family caregivers; (4) Increased financial and workplace protections for caregivers; (5) Better and more consistent research and data collection.
2. ACL should support SUAs in aligning NAPA recommendations related to dementia caregivers with their efforts to implement the National Caregiver Strategy in their state plans.
- B. Increase access to and quality of information that can assist unpaid caregivers in their caregiving role.
1. ACL or HRSA should evaluate the degree which current training registries (that serve as a clearinghouse of training programs for family and caregivers), meet caregiver training needs and whether their educational content is easy to access and broadly available. Develop a strategy for filling any gaps that are identified.
  2. Federal agencies 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.
  3. ACL should encourage SUAs and AAAs to use their network of senior centers and other community-based providers to undertake efforts to improve digital literacy amongst the older adult population, provide access to the Internet, and aid caregivers with using Internet resources to enhance care and for on-line supports. ACL should put in place programs which increase access to technology and offer caregivers the opportunity to learn how to use various devices. All federal agencies should advocate for broadband expansion across the country.
  4. AHRQ should work on the development and implementation of technology applications to support people with dementia and their unpaid caregivers, including the use of e-care plans, patient generated health data, patient reported outcomes and caregiver support. Research should be conducted on the effectiveness of these applications and strategies for implementation.
- C. Increase caregiver strategies to reduce the financial burden and provide protections for working caregivers.
1. Congress and states should create an individual income tax credit for expenses (such as adult day programs, home health services and caregiver training) incurred by a caregiver who is assisting a qualified family member as has been done for people with other dependents.
  2. Family Medical Leave Act (FMLA) should become paid leave to facilitate the feasibility of caregiving.
    - a. Congress should pass legislation to expand the FMLA and should make paid family leave more available and responsive to the needs of different types of caregivers.
    - b. Expand the FMLA to include siblings, grandchildren, other kin, and others taking on caregiving responsibilities.
    - c. Expand the FMLA to apply to adult chronic conditions and to caregiving responsibilities.

- d. Expand the definition of leave to include attendance at trainings and education on caregiving duties and responsibilities, discharge planning meetings, and care planning meetings.

**RECOMMENDATION 5: Implement new payment models to make long-term services and supports more affordable and eliminate gaps in coverage among government programs that support people with dementia.**

HCBS and supports are largely paid for using personal and family resources. For many individuals and caregivers, out-of-pocket costs drain their personal savings. This “spenddown” has become more rapid as LTSS costs continue to increase, coupled with lost savings and stagnant or declining wages. People will either forgo needed services or rely on underfunded, costly, and limited public programs to support their needs.

The publicly funded system is overly complex, inadequate, and not well understood by America’s older adults and unpaid/family caregivers. Medicare does not cover HCBS. Medicaid does cover HCBS costs for low-income beneficiaries who qualify and when a state elects to furnish the services to a particular group. For people who meet functional and financial criteria to qualify, Medicaid will cover nursing home costs as an entitlement, but community-based services are not an entitlement in most states resulting in waiting lists, even though most people prefer to receive care in the community.

Older American’s Act (OAA) funding is available without a means test, to provide supports and services such as access to nutritious food, caregiver support, transportation and other supportive services, however the OAA is a discretionary program (not an entitlement) and federal funding has not kept pace with the need. There is often a waitlist for these services as well.

New payment models are needed to address the many issues that result in people with dementia not being able to access and pay for services they need.

- A. Explore and implement new social insurance programs that make long-term care more affordable and prevent financial insecurity of older adults and people with dementia of all ages.
  1. ASPE should commission a study and develop a report to Congress on new social insurance programs that would make LTSS affordable to older adults, people with dementia of all ages, and people with disabilities, regardless of income.
  2. Congress should pass legislation to strengthen and create pathways for long-term care insurance to be more affordable and more aligned with the long-term care services that people want and need, such as covering home-based care and dementia-specialized services nationwide.

3. Congress should take steps to ensure consumer protections, including transparency regarding insurance limits, waiting periods, abbreviated coverage with duration and/or spending caps.
  4. States should expand voluntary long-term care savings accounts and other strategies that enable individuals to save funds to pay for LTSS.
- B. Strengthen the OAA and other Aging Network programs to meet increased needs and integrate PLWD.
1. The OAA should be amended by Congress, upon re-authorization in 2025, to include dementia as a condition experienced by a significant share of the older adult population and expand provisions under Title IV of the Act into other OAA areas, such as Title III.
  2. The OAA re-authorization should expand the age of eligibility for services below the age of 60 for individuals diagnosed with younger-onset AD/ADRD.
  3. Congress should increase funding for Title III programs within the OAA to increase the number of individuals living with dementia and caregivers benefitting from supportive services, nutrition services, family caregiver support and health promotion. Targeting criteria should be expanded to include PLWD and their caregivers, with expanded efforts to meet the needs of populations of older Americans that are marginalized, historically underserved, and disproportionately affected by dementia.
  4. The OAA should be amended to include AD/ADRD programming in Title IV and create Dementia Care Specialist services as a program within the aging network. The amendment should be accompanied by adequate funding for states to start up programs.
  5. Congress should increase funding under Title VI of the OAA which funds Native American programs. These programs help address caregiver support, nutrition and other dementia risk factors for Tribal members.
  6. Congress should increase funding to \$50 million for the ACL ADPI. Eliminate or reduce the state match requirement which creates a barrier for applicants to apply. Continue to ensure the programs are available to tribes as well as states and community-based organizations.
  7. The Federal Government and states should utilize the Behavioral Risk Factor Surveillance Survey and other data sets to better identify and document the population experiencing dementia for purposes of targeting OAA funds. ACL should encourage states to leverage this data in their next state plans to ensure support for this population.
  8. The Federal Government should provide adequate funding for the 2025 White House Conference on Aging to support the collective building of a national aging policy agenda for the next decade. Unlike 2015, funding must be adequate to support an effective event, with broad participation by state delegates, populations of older adults, including those living with or representing people with dementia. Dementia should be more visible and included in any resulting policy recommendations.

- C. Eliminate gaps and increase coverage for LTSS under Medicare and Medicaid that meet the needs of PLWD and their unpaid caregivers.
1. The Federal Government should conduct a study on the costs that result from gaps in coverage and from the lack of a national, integrated Medicare and Medicaid long-term care benefit for people who are dually eligible.
  2. Congress should consider adding LTSS benefits to Medicare Part B to address the health care needs of people living with AD/DRD more fully (such as respite care, adult day services, transportation for community inclusion and physical activity, supportive home care and personal care services).
  3. Congress should consider legislation that exempts people with younger-onset dementia from the 24-month “Medicare Waiting Period” which requires people with disabilities to first receive SSDI for 24 months before they receive Medicare benefits.
  4. The Federal Government should sustain the increased percentage of matching funds for the Medicaid program beyond 2024 (ARPA 10% enhanced match) so that states can reinvest GPR in the LTSS system.
  5. CMS should continue to support efforts to rebalance the Medicaid system (through programs such as Money Follows the Person) and states should pass legislation and appropriate funds to make HCBS Medicaid an entitlement across the country.
  6. Congress and states should explore ways for improving Medicaid reimbursement to increase the percentage of facilities who accept Medicaid participants with dementia and to improve the quality of care at these facilities.

**RECOMMENDATION 6: Implement strategies that support coordination, integration, and dementia-capability.**

Dementia-capability and system collaboration is essential for people to remain in the community. In addition to the LTSS systems that provide community and institutional care, people with dementia and their unpaid caregivers often encounter other systems throughout their dementia experience; systems such as the health care system, the elder justice and adult protection system, the crisis and criminal justice systems and the public health system. In most states and within local communities, these systems are fragmented and lack knowledge of how to serve people with dementia. These various systems often do not understand the other systems, how they intersect with each other and the unique roles they can play in providing care to people with dementia and their unpaid caregivers.

- A. Implement strategies that support broad systems improvements and make current crisis and adult protective services (APS) systems dementia-capable and able to provide abuse and neglect prevention, crisis response and stabilization and LTSS for PLWD.

1. Many people with dementia are vulnerable to financial exploitation, self-neglect, physical, mental, and other forms of abuse. Like the child protective services system, Congress should take responsibility for adequately funding the adult protection system and for developing national regulations and improved data collection.
    - a. Congress should increase funding for Title VII of the OAA and fund the Elder Justice Act which supports ombudsman programs, programs for the prevention of elder abuse, neglect and exploitation, legal assistance and to ensure a comprehensive elder rights system for older adults, including those with dementia, irrespective of where they reside.
    - b. Congress should invest in the development of dementia-focused crisis response and stabilization. Congress should allocate funding to ACL and CMS to establish and fund dementia crisis innovation grants within states to support promising practices and cross-sector collaboration that can help stabilize people in place.
  2. People living alone with dementia are often discovered through interactions with law enforcement and the APS and crisis systems. The Federal Government should lead an initiative that brings together partners from these systems to better clarify roles and responsibilities for providing intervention and assistance and to form cross-system solutions.
  3. Self-neglect can be an outcome of living alone with dementia. Self-neglect accounts for 50-75% of the nation's APS cases, many of which are people with dementia. The Federal Government should begin an initiative, supported with funding, to assist APS systems across the country in gaining greater access to clinical experts, to self-neglect assessment tools and more streamlined connections to community supports for cases of self-neglect.
  4. ACL should develop or provide funding to states to develop training for APS workers, including training on interviewing for decisional abilities, to help identify early signs of dementia, memory issues and engage in services earlier.
  5. Congress should allocate funding to ACL to provide grants to states, allowing them to develop programs and staff positions that specifically focus on the prevention of abuse, neglect and exploitation of PLWD.
- B. Implement strategies that improve coordination of LTSS with the behavioral health system.
1. BPSD are a common component of dementia. Some people with dementia exhibit self-injurious, aggressive or violent behaviors towards themselves and others that can be a symptom of the dementia or of a co-occurring mental health issue. The appropriate response to an individual with dementia alone is likely to be different from the response needed for people who have dementia in addition to mental illness or SUD, thereby making appropriate diagnosis, treatment, and coordination between the LTSS and

behavioral health system paramount for this population. Federal agencies should develop strategies, in partnership with states to:

- a. Increase access to behavioral health services for co-occurring conditions.
  - b. Increase availability of geriatric psychiatry and coordination with other health care and LTSS providers.
  - c. Provide tools to physicians, mental health providers and LTSS providers to assist in delineating when a behavior is tied to a mental health condition or to dementia, thereby setting the course of care and treatment (e.g., medications and/or non-pharmacological interventions), stabilization and crisis response.
2. Congress should allocate funds and/or the CDC should use existing funds to increase research and interventions to help prevent suicide and suicidal behavior in older adults and people with dementia.
- a. Congress should fund research on the prevalence of suicide among people with dementia and caregivers, as well as interventions for addressing the risk factors and increasing protective factors in this population.
  - b. HHS should identify ways to increase and fund depression-screening and suicide-screening within the LTSS system and disseminate information about emergent and long-term interventions that can be employed across settings.
  - c. SAMHSA, HHS and state government should develop and widely distribute public information related to firearm safety amongst households where a person with dementia resides. Information about firearm safety and ways to reduce access to other common lethal means should be included in advance planning materials.
  - d. Assessments that are performed within the LTSS system should include questions related to a person's history of depression and other mental illnesses, substance use, current/prior history of adverse childhood experiences, violence victimization and/or perpetration, family history of suicide, current/prior conflictual or violent relationships, presence of social isolation, community violence, historical trauma, and discrimination to ensure that risk factors for suicide are considered and addressed in plans of care.
3. States should identify ways to braid LTSS funding with behavioral health funding to target and serve this unique dementia population. States should consider people with dementia when planning for use of new federal funding made available in 2023.

C. Implement strategies to enhance alignment and integration of the health care and HCBS systems.

1. The Federal Government should advance models that integrate health care with LTSS, especially for people who are dually eligible for Medicare and Medicaid. The Federal Government should provide incentives to states and



providers that encourage collaboration between the health care system and the HCBS system.

2. Dementia education should be required to be integrated into curricula for medical schools and other health and social service professions and should be required in continuing education for licensed medical and health professionals. The dementia training should include information about the HCBS system and referrals that can be made to community-based organizations.

## Research Subcommittee

### **RECOMMENDATION 1: Increase federal research funds to meet NAPA aims.**

In order to build on the momentum of recent scientific breakthroughs, a top priority remains the urgent need for Congress to increase annual federal research and implementation science funding (based on professional judgment budgets by NIH and other agencies) to meet NAPA goals across biomedical, clinical, LTSS, and public health settings. High priority areas of research include:

- A. Fundamental biological processes and basic disease mechanisms of AD/ADRD (e.g., younger and late-onset sporadic AD/ADRD, familial AD/ADRD, individuals with IDD including Down syndrome).
- B. Dementias with clinical diagnoses other than AD and mixed/multiple etiology dementias, as identifying specific biomarkers for these conditions could improve diagnostic capabilities and provide increased therapeutic options.
- C. Early detection of cognitive decline and precursors of dementia at an individual level, identification of pathology(s), and development and use of person-centered treatment(s).
- D. Research into recently developed amyloid therapies including determining optimal duration of treatment, characteristics of patients and groups who benefit, and medical system delivery to optimize benefit and minimize risk.
- E. Models of dementia care and support and the testing of innovative payment models (potentially funded by the CMS Center for Medicare and Medicaid Innovation (CMMI), private foundations, etc.) and encourage uptake efforts through state public health and aging services departments.
- F. Research into workforce and systems capacity needs in clinical care and research staffing needs.
- G. Translational technologies for diagnostics and therapeutics.
- H. Research into methods of improving prevention and risk reduction of cognitive decline and dementia, as discussed in more detail by the risk reduction subcommittee.
- I. Research into neurological effects of COVID-19 in older adults and people with AD/ADRD, and causes, relationships, and risk reduction of delirium.

- J. Research from the newly created Advanced Research Projects Agency for Health should play a major role in the translation and demonstration of scientific breakthroughs in the diagnosis, treatment, and management of dementias.

**RECOMMENDATION 2: Address critical scientific and clinical questions in the implementation of the first generation of disease-modifying treatments.**

Research is needed to determine:

- A. How best to identify persons who would benefit from anti-amyloid therapy and ensure equitable access for all patients who could benefit from treatment.
- B. Which persons with cognitive decline and evidence of amyloid deposition in brain, but who did not fit criteria of the successful clinical trials, may also benefit from anti-amyloid therapy.
- C. What infrastructure is needed to appropriately identify, treat, and monitor persons treated with anti-amyloid therapy.
- D. The cause of side effects and adverse reactions in persons treated with anti-amyloid therapy and how to best monitor and manage these.
- E. Diagnostic testing options in identifying persons who may benefit from anti-amyloid therapy.
- F. Whether anti-amyloid treatment of cognitively normal persons identified as high risk for AD based on blood or PET biomarkers can help prevent or delay cognitive decline.
- G. How to manage persons treated with anti-amyloid therapy over longer time periods including patients who progress in clinical dementia, the effects of multiple co-morbidities and medications, and optimal duration of treatment.

**RECOMMENDATION 3: Implement research of active dementia care models to compare effectiveness.**

- A. Diagnostic strategy implementation from primary care through specialty centers should be studied. Research is needed in how to provide timely and accurate diagnostic and prognostic information for people with AD/ABR using recent scientific developments in biomarkers. Access should include all communities.
- B. Interventions such as medication management, care support for caregivers providing care for patients, clinical care team management, exercise, diet, and activity should continue to be studied.

- C. Research in how to integrate medical interventions (e.g., DMTs, within medical systems).

**RECOMMENDATION 4: To address health equity and representation in research, representation and diversity in Alzheimer’s disease and related dementia clinical trials should be increased.**

- A. Potential strategies include leveraging models of community-based recruitment and primary care, scaling up of funding to enable research to develop and grow the necessary infrastructures, targeted Request for Applications, government requirements for trial and observational study enrollment, and including patient and public involvement of PLWD and unpaid caregivers representative of diverse populations.
- B. Prioritize inclusion and representation in public/private clinical trials, fund research into recruitment science, and set milestones for engagement and inclusion of diverse populations with a focus on diagnostic and treatment related trials.
- C. An understudied area that should be prioritized is the impact of stigma related to dementia on health-seeking behaviors to improve access to health services.
- D. Current work has focused on stigma attached to race/ethnicity, sex and gender, and socioeconomic status. A greater understanding of these and other factors, including the stigma on dementia itself, is needed to understand and resolve patient, family, caregiver, provider, and societal effects of stigma on access to care, diagnosis and treatment, and support systems.

**RECOMMENDATION 5: Improve translation from scientific discovery to health impact.**

In order to meet the scientific recommendation goals of NAPA, independent annual funding for NAPA goals and management are needed to increase synergies among all stakeholders, including community, state, delivery systems, advocacy groups, industry, and federal agencies involved in the National Plan, to accelerate translation of evidence-based advancements into clinical practice and approved diagnostic, treatment, and care paradigms to improve outcomes for people with dementia. This approach to fast translation is to cover the entire continuum from research studies through regulatory review and approval, and delivery and impact on diagnosis and care.

- A. NAPA organizers, including ASPE, should have increased resources (e.g., financial and personnel support) and authority to accomplish the following:

1. By June 2024, appoint a federal coordinator with the authority to prioritize, organize, implement, and follow up on cross-stakeholder recommendations, possibly through NAPA re-authorization.
  2. Track the progress and milestones of prior NAPA recommendations with a goal to prioritize those recommendations with the largest potential impact.
  3. 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.
- B. In order to meet the scientific recommendation goals of NAPA, independent annual funding for NAPA goals and management (i.e., not dependent on other groups voluntarily providing it) are needed to accomplish the NAPA aims. This should include funding to support:
1. Management of the top-level roadmap that describes to stakeholders and the public the status and progress of NAPA aims and goals.
  2. Implementation and support for meetings to accomplish NAPA aims and goals, including travel costs and time and effort of required attendees.
  3. Staff to provide support for NAPA leadership to accomplish aims, including program and project managers, etc.
  4. Provide mechanisms to engage multiple stakeholders beyond federal agencies including health systems, research organizations, treatment developers, etc.

**RECOMMENDATION 6: Implement scientific and evidence-based evaluations of factors for decision-making.**

- A. Implementation science research should be performed to determine information on safety, utilization, and outcomes from ongoing treatments while accounting for any potential added burden on patients, caregivers, and health care systems that would impact health of patients with AD/ADRD.
- B. NAPA federal agencies should ***investigate successful models for increasing involvement of people with AD/ADRD in clinical research studies, including trials***. This may include evaluating successful models from other disease areas, incentivization of research participation, evidence-based models of implementation, and payer evaluation of successful advancements based on evidence.
- C. The impact of anti-amyloid therapies on research efforts should be studied, specifically how access to disease-modifying drugs affect research participation in clinical trials, clinical trial design, review and approval of drug use, payment, coverage, and implementation of treatments.

## Risk Reduction Subcommittee

### **RECOMMENDATION 1: Identify priorities for and track progress toward addressing cognitive decline and dementia risk factors across the lifespan.**

- A. In prioritizing efforts to address risk for cognitive decline and dementia as part of Goal 6 of the National Plan, HHS should focus on the following six risk factors that we believe show the greatest potential for impact: midlife hypertension, midlife obesity, physical activity, smoking, depression, and hearing loss.
- B. To begin measuring progress on Goal 6, HHS should track the prevalence of the above-mentioned risk factors by overall population, by race/ethnicity, and among those with neuroatypical conditions. In addition, HHS should track efforts to address the above-mentioned risk factors, including interventions undertaken and other appropriate means of controlling the risk factors. HHS should establish a monitoring and evaluation workgroup to make recommendations no later than May 2024 for specific indicators and related data sources to be used, consistent, where appropriate, with Healthy People 2030 and the HBI Road Map.
- C. No less than once every five years, HHS should convene an AD/DRD risk reduction summit, with CDC as the lead agency. These summits should focus on translating the latest state of the evidence on modifiable risk factors for, and SDoH related to, cognitive decline and dementia into public health action -- and should engage diverse stakeholders. Specific actions by public and private entities should be identified, including actions by public and private partners that focus on the targeted risk factors, and actions that would address specific barriers/challenges for historically underserved communities.
- D. HHS and all relevant federal agencies should build upon existing activities that address risk factors for cognitive decline and dementia -- and should identify, coordinate, and implement additional strategies within their current authorities on the focus areas identified by HHS under Goal 6.
  - 1. Relevant federal agencies should expand reach by partnering with non-governmental organizations that are currently working on risk factors for cognitive decline and dementia, and should work to synergize agency work with existing non-governmental strategies.
  - 2. In addition to reporting annually on their activities undertaken toward Goal 6, relevant federal agencies should annually report on significant actions and progress at the state, local, and Tribal level; and should identify gaps that need to be addressed.
- E. HHS should issue a public report on the current level of spending at the federal and state levels on activities that address the risk factors for cognitive decline and dementia. Each year, in the annual Administration budget, the Office of Management and Budget should identify the amounts proposed in the budget

request for addressing risk factors for cognitive decline and dementia across all relevant federal agencies

- F. CDC should periodically update the list of key risk factors that are the focus of efforts to achieve Goal 6 of the National Plan, based on the strength of scientific evidence, ripeness for public health action, and potential for impact -- and considering the needs of and potential benefits to at-risk communities.

**RECOMMENDATION 2: Accelerate public health and aging network action on addressing the risk factors with the strongest evidence of beneficial impact on dementia prevalence, particularly for communities or target groups at greatest risk.**

- A. The Federal Government should sustain and strengthen the public health and aging network infrastructure to address risk factors for cognitive decline and dementia at the federal, state, local, and Tribal levels through expanded community outreach and education on dementia risk factors, brain health, and related evidence-informed interventions.
  - 1. Congress should provide at least \$35 million in fiscal year 2024 funding for the CDC to implement the BOLD Infrastructure for Alzheimer’s Act.
  - 2. Congress should fully fund the OAA as specified in the Supporting Older Americans Act of 2020 and, particularly, increase funding for ACL to incorporate dementia risk reduction education and interventions in relevant OAA programs, such as Nutrition Quality, Chronic Disease Management, and Falls Prevention.
  - 3. Congress should enhance appropriations of relevant existing federal programs -- and fund additional new programs -- that promote cognitive decline and dementia risk reduction.
  - 4. CDC, ACL, CMS, HRSA, SAMHSA and IHS should expand efforts to target resources toward education and outreach of the public health and aging network on dementia risk factors.
- B. In partnership with state, local, and Tribal governments, payers, community-based organizations, and relevant private sector entities, the Federal Government should develop and implement specific strategies to address SDoH that affect risk and produce adverse health outcomes related to dementia.
- C. Strategies and interventions to address dementia risk factors should include historically underserved communities experiencing the highest prevalence of priority risk factors, low longevity rates, and the highest prevalence of AD/ADRD with explicit attention to mitigating adverse SDoH and strategies and interventions that promote brain healthy behavior.
- D. While the aim of risk reduction efforts should mainly focus on primary prevention, activities should also include encouraging individuals diagnosed with dementia to

engage (or continue to engage) in healthy behaviors, especially those behaviors that research indicates may slow progression of dementia and/or help maximize functionality by persons with dementia.

- E. As the responsibilities of dementia caregiving often result in lack of physical activity and sleep, and increased depression, among other outcomes (such as increased exhaustion and stress), dementia caregivers may be at increased risk for dementia themselves and should be a target for risk reduction efforts.
  - 1. The BOLD Center on Dementia Caregiving and BOLD Center on Dementia Risk Reduction should analyze data on dementia risk factors among dementia caregivers and develop tools for public health agencies to address dementia risk among caregivers.
  - 2. The CDC's HBI Collaborative should disseminate new tools for public health, identify opportunities for collaboration, and promote action by state public health, aging, disability, and other relevant agencies that would address and help mitigate dementia risk factors among caregivers.
  
- F. Actions included in the National Plan should be aligned with those identified in CDC's *Healthy Brain Initiative: State and Local Road Map for Public Health, 2023-2027* and *Road Map for Indian Country, Healthy People 2030*, and the Million Hearts campaign.

**RECOMMENDATION 3: Identify and accelerate efforts to reduce risk and intervene early in clinical care.**

- A. Public and private payers, health systems, and provider networks should identify and implement a comprehensive set of actions that assess risk factors for cognitive decline and dementia, ensuring equitable reach and impact of interventions for historically underserved populations. This should include:
  - 1. Conducting health risk assessments, such as that included as part of the Medicare Annual Wellness Visit.
  - 2. Identifying opportunities to address possible risk for cognitive decline and dementia by addressing known risk factors, including patient and provider education; offering reimbursement incentives to providers to promote brain health; providing payments for prevention and care delivery models that incorporate brain health as part of care and treatment of other conditions that may increase dementia risk; and developing and implementing quality measures specifically related to brain health.
  - 3. Identifying existing benefits related to factors that can potentially help reduce dementia risk, and identifying coverage gaps and inequities that, if addressed, could improve brain health. (Examples include: nutrition support; physical activity prescriptions; diabetes management and treatment; audiology assessments and screenings, hearing rehabilitation, appropriate hearing technology; and screening and treatment for depression and alcohol abuse.)



4. Educating and training the primary care workforce (including CHWs and nurse practitioners), within the context of the Age-Friendly Health Systems Framework and dementia-capable communities, to address dementia risk reduction and brain health.
  5. Increasing clinical identification of persons (including adults with lifelong neurocognitive or neuro-affect disabilities), who may, as a result of the presence of risk factors, be at greatest risk for dementia, and identifying those factors that could be addressed to potentially mitigate that risk.
- B. HHS should identify and accelerate strategies to improve access to primary care, team-based care, home and community-based care, and preventive care, including better utilization of existing benefits such as Medicare’s Annual Wellness and Care Planning Visits.
- C. CMMI should pilot AD/ADRD risk reduction interventions. For example, CMMI could pilot a “Dementia Prevention Program” modeled on the National Diabetes Prevention Program, with special attention on optimal implementation including payment, training, delivery, and uptake.
- D. Congress should address coverage gaps in Medicare, Medicaid, IHS, and the VA that would improve interventions for identified AD/ADRD risk factors (e.g., expansion of Medicare coverage to include hearing aids and related hearing care rehabilitation services).

**RECOMMENDATION 4: Initiate and fund research to strengthen the strategies for addressing the potential risk factors for dementia.**

- A. HHS, including NIH, CDC, AHRQ, and other agencies should utilize fundamental principles of diversity, equity, and inclusion while developing and supporting research on factors for dementia risk reduction to address biases in eligibility criteria, proportional representation, oversampling, data stratification, systemic racism, historical context, and structural factors that disproportionately affect the health of historically underserved populations.
- B. The Federal Government should increase scientific research to:
1. Increase understanding of the causal pathway for dementia.
  2. Identify and understand the SDoH that may elevate the risk of developing dementia and the SDoH that may act as barriers to addressing modifiable risk factors for dementia, such as for cardiovascular health.
  3. Examine less-understood areas of potential risk, such as environmental influences, microbiome, and the exposome.
  4. Identify what modifiable factors may decrease risk for developing dementia and identify factors related to co-morbidities that may aggravate or mitigate risk for developing dementia among those with IDD.

5. Identify trajectories of decline in select high risk populations to determine when in the lifespan to best target mitigation and prevention strategies and interventions.
- C. The Federal Government should support translational research that:
    1. Evaluates efforts to implement the uptake of evidence on risk factor reduction in clinical practice and identifies key barriers that impede uptake.
    2. Develops, implements, and evaluates models of care to increase the uptake of evidence on risk reduction in primary and ambulatory care.
    3. Develops, implements, and evaluates models to align public health and health care interventions to reduce population risk.
  - D. The Federal Government should monitor the outcomes and implications of COVID-19 post-recovery with respect to the risk for cognitive decline and dementia, including long-COVID. Particular attention should be paid to psychological and behavioral issues, such as depression, stress and 'brain-fog', as well as potential mediating factors.

**RECOMMENDATION 5: Appropriate non-federal governmental entities and private sector organizations should work to improve brain health.**

- A. State health departments, state developmental disabilities authorities, and state agencies and Tribal authorities tasked with aging and mental health should undertake cooperative efforts to address dementia risk factors.
- B. Foundations and charitable organizations that promote healthy outcomes should invest in projects and initiatives in support of brain health, including through training and deployment of CHWs and community pharmacists.
- C. Medical associations and health systems should promote physical health as a means to address brain health.
- D. National, state, and local/community-based provider organizations working with select special segments of the population (e.g., those with IDD and adults at elevated risk) should undertake efforts to improve brain health.
- E. Community organizations (including civic organizations and business clubs) should facilitate local efforts to improve brain health in their communities.

**RECOMMENDATION 6: Establish a set of dementia risk reduction policies at the federal, state, and local level that will address risk factors, including the social determinants of health, for cognitive decline and dementia.**

- A. Federal, state, and local governmental agencies should select and/or recommend policies and systems changes that would:
  1. Improve food quality and affordability.
  2. Increase access to safe and inexpensive opportunities to engage in physical activity.
  3. Decrease access to commercial tobacco products and ultra-processed foods.
  4. Improve the ability of individuals to control and normalize blood pressure.
  5. Expand hearing testing and use of hearing aids.
  6. Increase access to preventive care and mental health services.
  
- B. National public health organizations, non-profits, and medical associations should collaborate on creating and advancing a policy agenda to increase access to healthy foods, safe spaces to exercise, hearing aids, means of controlling blood pressure, and preventive and mental health care.