

# **PUBLIC MEMBERS OF THE ADVISORY COUNCIL ON ALZHEIMER'S RESEARCH, CARE AND SERVICES: 2024 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.

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## Clinical Care Subcommittee

**RECOMMENDATION 1: Reauthorization of and budget appropriations for the NAPA -- Congress should reauthorize NAPA for another ten years to enable further progress on NAPA goals. Congress and HHS should fund NAPA organizers, including the Office of the Assistant Secretary for Planning and Evaluation (ASPE), to have increased resources (e.g., financial and personnel support) and authority to accomplish the following:**

- A. For fiscal year (FY) 2025, fund and appoint at least one full-time employee (FTE) for federal coordinator(s) with the authority to prioritize, organize, implement, and follow up on cross-stakeholder recommendations, through NAPA reauthorization.
- B. Track the progress and milestones of prior NAPA recommendations with a goal to prioritize those recommendations with the largest potential impact.
- C. Assist the 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.

**RECOMMENDATION 2: EDUCATION -- Increase resources to educate the public (including patients/clients, families/caregivers, and community members) and inform health care providers (administrators, clinicians, allied health professionals, and all health care workforce members) about the importance of AD/ADRD, clinical care, risk reduction, early detection, screening, differential diagnosis, person-centered care models, disease-modifying therapies, clinical research participation, and available educational and community resources for persons living with dementia (PLWD) and their family/caregivers.**

- A. Congress should increase appropriations to HHS agencies -- Health Resources and Services Administration (HRSA), National Institute on Aging (NIA), Centers for Disease Control and Prevention (CDC), and National Institute for Neurological Diseases and Stroke -- for the continued development and modification of educational tools and materials that take a person-centered approach for assessing, diagnosing, and treating adults with suspected AD/ADRD, and encouraging referral to clinical research.
- B. These educational tools and materials should be inclusive of and address the unique needs of persons with life-long neuro-atypical conditions, younger-onset dementia, persons with intellectual and developmental disabilities (IDD), those who are not primary English speakers, have varying literacy levels, veterans, and/or come from cultural or ethnic groups with differing norms and beliefs. Tools should be updated frequently to reflect feedback and changing knowledge.

- C. Promote the development, use and updating of evidence-based guidelines, strategies for continuous quality assessment and improvement, efforts addressing access to care for all, and advancing health equity.
- D. Dementia-specific clinician training should include:
  - 1. Proficiency in having a comprehensive dialogue to include all types of clinical treatment options.
  - 2. The ability to understand, interpret, and explain the differences between and significance of a variety of clinical and diagnostic tools for diseases under the umbrella of AD/ADRD.
  - 3. Competence in identifying and managing adverse reactions associated with treatments.
  - 4. Enhanced clinical skills for managing complex patient/client scenarios, including multiple chronic conditions and unusual presentations of AD/ADRD (i.e., younger-onset presentation of dementia).
  - 5. Tailoring treatments to suit individual needs, including those with atypical presentations or co-occurring conditions.
- E. Health care professional training programs should implement minimum education standards for dementia care in disaster preparedness, acute care, behavioral health, management of co-occurring conditions, pre-existing cognitive conditions and participation in research.
- F. Promote comprehensive training to community health workers (CHWs), and caregivers (paid and unpaid) on disaster preparedness, management of co-occurring conditions and implementing non-pharmacological interventions for behavioral challenges and behavioral and psychological symptoms in PLWD.
- G. Promote active engagement and empowerment of PLWD and their caregivers. Encourage self-management strategies, the development of person-centered care plans, and the use of shared decision-making to support care and treatment options.
- H. The HHS Centers for Medicare & Medicaid Services (CMS) should encourage the Quality Improvement Organizations to work with health care systems and practices to provide high quality dementia care that is culturally competent by health care providers and clinicians.

**RECOMMENDATION 3: SYSTEMS -- Develop systems of clinical care to support the provision of services to promote healthier cognitive aging, dementia risk reduction, early detection, differential diagnosis, early intervention, ongoing care planning and management of AD/ADRD.**

Translating evidence-based recommendations into programs to support clinical practice should be the focus of administrators, clinicians and workforce members who furnish

care to persons of all ages living with or at risk for AD/ADRD, in collaboration with the community, state, and federal agencies.

- A. Congress should increase funding for Tribal and Urban Indian health programs to further develop systems of care for those living with dementia and their caregivers.
- B. CMS should encourage hospitals and health care providers to put in place procedures to:
  - 1. Create age-friendly health systems.
  - 2. Influence the quality of the patient/client and caregiver experience.
  - 3. Identify cognitive decline and integrate management of cognitive impairment into the care plan.
    - a. Encourage identification of co-occurring health conditions of PLWD to be documented in a person-centered care plan that is evaluated and updated at least yearly or when there are changes to health, functional status, and/or social circumstances that warrant it as needed.
    - b. Assess cognitive function as appropriate during hospital stays and schedule follow up with primary care provider (PCP) for evaluation and/or with relevant specialist or member of an interdisciplinary team; findings should be placed into the medical record and in the discharge information given to the patient/caregiver (as appropriate).
    - c. Encourage the implementation of best practices for prevention and diagnosis of delirium.
  - 4. CMS should encourage care navigators and CHWs reimbursed by Medicare/Medicaid to have dementia training.
  - 5. Work towards an integrated system of care including home and community-based services (HCBS) resources, all with access to and ability to update the person-centered care plan.
- C. CMS should encourage accountable care payment programs to implement population-based payment at the level of primary care.
- D. Federal rulemaking should increase payment for primary care to ensure equitable access to care and services.
- E. Congress should pass laws to eliminate the state Medicaid rules that require estate recovery of funds after the death for enrollees who receive Medicaid sponsored HCBS.
- F. The HHS Agency for Healthcare Research and Quality (AHRQ) should promote the use of e-care plans by all treating practitioners (PCP, specialists, case management, pharmacy, nutrition, hospital, etc.), non-clinical providers, the patient, and their caregivers.

- G. HRSA, in partnership with AHRQ, should fund the development of a curriculum for anticipatory guidance for people diagnosed with dementia that can be used by the entire care team, PLWD, and caregivers.
- H. Health systems should leverage technology, data platforms, electronic health records (EHRs), telehealth and artificial intelligence to enhance dementia care delivery, training, and education.
- I. The HHS Administration for Community Living (ACL) should provide sufficient funding to facilitate the dissemination of coordinated dementia care to every state.
- J. HRSA, in collaboration with AHRQ (with supported funding), 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.
- K. Congress should appropriate funding to foster connections between the health care system and community support programs, with a particular focus on rural health, minority health, patient who do not have English as a primary language.
- L. Congress should amend the Older Americans Act (OAA) to support and mandate that state health departments maintain information on existing dementia diagnostic resources, CHWs, dementia navigators, case management, and social worker assistance through Area Agencies on Aging for information and referral.

**RECOMMENDATION 4: WORKFORCE -- Implement solutions to address the geriatric and gerontology workforce crisis through training, continuing education, recommended standards, and improved pay to better address the needs of PLWD and their families/caregivers.**

- A. Increase efforts and implement systems solutions at the federal level to address the workforce crisis for those who provide care to older adults.
  - 1. Congress should appropriate funds to HRSA or the National Academies of Sciences, Engineering, and Medicine to evaluate the incentives to increase recruitment into the primary care workforce and assure that they have competencies in care of older adults.
  - 2. Employer and tax incentives can include:
    - a. Free supplies and equipment, food, transportation, direct connections with employers, job placement and childcare assistance, and professional development, low-cost health care.
    - b. Sign-on bonuses, education/training, and certification costs for geriatric care clinicians.

- c. Paid sick, family, and medical leave, and retirement savings options for people who enter the geriatric care workforce.
3. Congress should increase HRSA funding for training of primary care health professionals who furnish care to older adults and loan repayment for health professionals that is consistent with the average cost of a year of school training.
4. Congress should increase in HRSA funding to specifically educate and train dementia care navigators, interdisciplinary teams and home and community-based workers.
5. HRSA should increase the number of slots that cover health care school tuition for people who will care for older adults in primary care after residency.
6. Congress should provide pathways for immigrants who commit to work within clinical dementia care systems, particularly for those who work in areas of the country devoid of workforce resources or in cultural/ethnic diverse communities in which they identify with.

**RECOMMENDATION 5: PARTICIPATION IN THE CLINICAL CARE TEAM -- Encourage PLWD and their unpaid caregivers (as appropriate) to be integral parts of the clinical care team and foster coordination of comprehensive, person-centered dementia care with HCBS.**

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

**RECOMMENDATION 6: YOUNG ONSET -- Eliminate barriers to the receipt and payment of clinical care services and LTSS for adults living with dementia who are under age 65.**

- A. The Clinical Care Subcommittee recommends Congress appropriate funding to address barriers to clinical care and community-based long-term services for younger individuals living with dementia or mild cognitive impairment:
  - 1. The OAA requires recipients to be age 60 or older to receive covered services. The Clinical Care Subcommittee recommends that Congress amend the OAA to extend services to all persons diagnosed with AD/ADRD regardless of age and increase funding to support the added populations.
  - 2. The two-year waiting period for Medicare in younger individuals living with dementia or mild cognitive impairment who qualify for Social Security Disability Insurance (SSDI) poses a barrier to clinical care and should be eliminated.
  - 3. Quantify the number of PLWD among those who are diagnosed under the age of 65 by type of dementia.
  - 4. Measure and improve the quality of care. Ensure timely diagnosis, differential diagnosis, care planning and referral to needed services and supports.
  
- B. Raise awareness, promote early detection, implement risk reduction strategies, and support caregivers for individuals with Down syndrome/IDD at risk of AD/ADRD and their families/caregivers. Specific recommendations include:
  - 1. Education and Awareness Campaigns: Federal and non-federal entities should partner in the coordination of public/private education and awareness campaigns to inform individuals with Down syndrome/IDD, their families, caregivers, and health care professionals about the increased risk of AD/ADRD.
  - 2. Early Detection and Diagnosis: State developmental disabilities agencies and Area Agencies on Aging and state-based associations for health care professionals should promote early detection and diagnosis of AD/ADRD in individuals with Down syndrome/IDD by ensuring interventions are tested in special populations and by providing training and resources to health care professionals on recognizing and assessing cognitive changes associated with dementias in individuals with IDD.
  - 3. Risk Reduction Strategies: Public health agencies should develop and disseminate evidence-based risk reduction strategies tailored to individuals with Down syndrome/IDD to help mitigate the possibility of dementia. Emphasize lifestyle factors such as physical activity, healthy diet, cognitive stimulation, and social engagement, which have been shown to support brain health and reduce the risk of cognitive decline in aging individuals.

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

### **RECOMMENDATION 1: Reauthorization of and Budget Appropriations for NAPA.**

Congress should reauthorize NAPA for another ten years to enable further progress on NAPA goals. Congress and HHS should fund NAPA organizers, including ASPE, to have increased resources (e.g., financial and personnel support) and authority to accomplish the following:

- A. For FY2025, fund and appoint at least one FTE for federal coordinator(s) with the authority to prioritize, organize, implement, and follow up on cross-stakeholder recommendations, possibly through NAPA reauthorization.
- B. Track the progress and milestones of prior NAPA recommendations with a goal to prioritize those recommendations with the largest potential impact.
- C. Assist the 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.

### **RECOMMENDATION 2: Amend the OAA age eligibility requirements and increase funding to expand delivery of services in the OAA for people of all ages living with AD/ADRD and their family caregivers.**

In the upcoming reauthorization of the OAA, congressional amendments should include a change to current 60+ age eligibility requirements to include people of all ages living with AD/ADRD and their family/caregivers to OAA funded supports and services.

- A. To accommodate the expansion of eligibility to OAA funded supports and services for people of all ages living with AD/ADRD and their family caregivers, Congress should increase current appropriations for OAA services and support programs which would impact the existing program waiting lists and increase capacity to expand delivery of services. This expansion should also require the development of a system of tracking the timely utilization of services and evaluation of the impact.
- B. Congress should authorize delivery of services under the OAA for family caregivers of people of all ages living with AD/ADRD. Currently the OAA defines a “family caregiver” as: “an adult family member, or another individual, who is an informal provider of in-home and community care to an older individual or an individual of any age with AD or a related disorder with neurological and organic brain dysfunction”. Under the 2020 reauthorization of the OAA, limited access to services was granted to these caregivers for those people of any age with a diagnosis of AD/ADRD under the National Family Caregiver Support Program



(NFCSP). This should be changed to expand delivery of AD/ADRD education, training, and respite care through NFCSP under the OAA.

- C. Congress should increase funding from \$205,000,000 to \$360,000,000 to the states under NFCSP so that they can reduce existing wait lists and expand delivery of services throughout their aging networks.
- D. Congress should increase funding from \$12,000,000 to \$20,000,000 to further states' compliance with the Civil Rights Laws Applicable to Persons with Disabilities (Title VI.C) to be respective of those with AD/ADRD.

**RECOMMENDATION 3: Expand the availability of dementia-capable HCBS available to people with AD/ADRD and their unpaid caregivers.**

- A. The Government Accountability Office should be tasked to evaluate the demonstrated impact of the American Rescue Plan Act (ARPA) and other investments to further build and sustain dementia-capable initiatives that benefit PLWD, caregivers, the direct care workforce, and community-based providers.
- B. Respite care options are essential for giving unpaid caregivers a break, which can have a significant impact on their caregiving longevity and capacity to care, therefore NAPA recommends the following:
  - 1. States should make at-home and community-based day and overnight respite services available to dementia caregivers through various LTSS programs.
  - 2. 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.
  - 3. CMS should expand the caregiver training benefit in outpatient settings to include funded respite care for all caregivers comparable to that of the Guiding an Improved Dementia Experience (GUIDE) model.
  - 4. States should explore Medicaid waiver options to fund respite support (e.g., HCBS waiver program).
  - 5. Congress should increase funding from \$10,000,000 to \$20,000,000 to the Lifespan Respite Care Program and the Lifespan Respite Care Enhanced Grants Program to provide more respite opportunities for all family caregivers, including those caring for PLWD. 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.

**RECOMMENDATION 4: Define needs and expand LTSS to people living with young-onset (PLWYO) AD/ADRD and their families/caregivers.**

Although AD/ADRD mainly affects older adults, there is a growing awareness of cases that start before the age of 65 and the prevalence of PLWYO has not been well documented. This population varies substantially and is comprised of adults who are in their wage-earning years with families, people who live alone, and people with Down syndrome or IDD. Impacted in the prime of their lives, we are starting to recognize that the needs of these individuals and their families/caregivers are unique from those of older adults as they have their legal, financial, housing, long-term health care and benefits, physical, and behavioral health heavily impacted in the short-term and long-term with few options available to them to navigate these issues.

- A. Congress should authorize and fund ASPE to gather data on the number of PLWYO throughout the United States. Currently available data (which does not include those with Down syndrome/IDD) was compiled from estimates by the Alzheimer’s Association based upon a 2021 global study, along with those provided by Blue Cross/Blue Shield (BCBS) in their 2013-2017 claims analysis for commercially insured Americans between the ages of 30-64. The BCBS four-year analysis reported a 131% increase in PLWYO whereas the CDC estimates an increase over the same period as 200%. Current data and future estimates are essential to define and develop LTSS resources and programming to address the unique challenges facing these populations and their families/caregivers.
- B. NAPA acknowledges the financial burdens placed on families of PLWYO. Given the eventuality that the PLWYO will likely lose their employment in the course of their disease and potentially face the loss of employer-provided health insurance, the options are COBRA Continuation Coverage, Health Insurance Marketplace, or if the person is eligible, Medicaid. Some younger people may qualify for Medicare, however, as with Lou Gehrig's disease (ALS) in 2001, we recommend Congress approve legislation that exempts all PLWYO from the 24-month “Medicare Waiting Period” which requires people with disabilities to first receive SSDI for 24 months before they receive Medicare benefits. This legislation would help to relieve some of the financial burden and provide consistent health care coverage through to end-of-life for eligible PLWYO.
- C. Congress should appropriate funding to ACL to provide grants to LTSS providers to develop tools and programs that assist PLWYO and their caregivers to address their housing, legal, and financial concerns in the short-term and long-term.
- D. Congress should appropriate additional funding to ACL for grants to the aging and disability networks to provide comprehensive support and resources for caregivers of individuals with Down syndrome who may be at risk of or already experiencing AD. These grants would fund caregiver education programs,

support groups, and access to practical PLWYO books and resources specifically addressing the intersection of Down syndrome and AD. Recognizing that 50% or more of those with Down syndrome will develop AD pathology in their brains by the time they reach the age of 40 and within the following decade may start to exhibit the symptoms of dementia, it is vital that tailored LTSS is defined and support for caregivers is provided.

- E. The HHS Substance Abuse and Mental Health Services Administration (SAMHSA) should conduct a study to gather nationwide statistics to determine the rate of suicide in people diagnosed with dementia by age and highlight those younger than 65 within the first year after receiving a dementia diagnosis. The study should also outline the factors that contributed, which may differ from those diagnosed at an older age. One 2019 study evidenced three times higher odds of dying by suicide in this population than people diagnosed with dementia at or after age 75.
- F. A variety of barriers continue to exist that affect the ability of people with IDD to receive the LTSS required to live their fullest life in communities of their choice. To begin to break down these barriers, NAPA recommends specific interventions for each of the following barriers:
1. Medicaid wait lists for HCBS:
    - a. States should reduce or eliminate Medicaid wait lists for HCBS to meet the needs of people with IDD to access these services before and after they are diagnosed with dementia.
  2. Continuing and worsening crisis of unmet need:
    - a. A system of comprehensive HCBS must be developed to eliminate the patchwork of systems of supports and services that are complex, frequently uncoordinated, limited in scope and relevance, and are difficult to access.
    - b. States and local systems must develop programs to actively reach out to individuals with IDD and their caregivers with unmet and under-met needs to make them aware of the process for obtaining LTSS and must maintain transparency until waiting is eliminated.
    - c. Until waiting lists are eliminated, states must develop systems to prioritize delivery of services to those on the waiting list to ensure that those experiencing emergencies (loss of caregiver, imminent threat of institutionalization) receive person-centered and self-directed (if capable) LTSS immediately.
  3. LTSS workforce (in addition to topics covered in **Recommendation 7**):
    - a. Competency-based training for those with IDD and AD/ADRD must be developed and available to all LTSS providers and direct care workers that covers the essential knowledge, ethical principles and practices, and skills necessary to provide direct support.
    - b. States must utilize a nationwide system for criminal and related background checks, including a system for tracking people for whom

abuse, neglect, and exploitation charges have been substantiated, for all public and private agencies providing LTSS in the state.

4. Institutional bias:
  - a. To create continuity of care and allow individuals with IDD and AD/DRD to remain in the community of their choice, CMS should encourage the states to revise their existing Medicaid policies to allow redirection of funding from institutional care (previously mandatory) to person-centered HCBS delivered in community environments.
5. The HHS National Institutes of Health (NIH) and ACL should continue to support the development and scaling of culturally appropriate evidence-based interventions designed to support people with IDD and dementia and those at high risk.
  - a. The intervention should include tailored dementia education and training for LTSS providers on the unique needs of these populations.
  - b. Recognizing the advancing years of many of the caregivers of individuals with Down syndrome/IDD and the lifelong roles they have undertaken, the intervention should include strengths-based person-centered support for the caregivers.
  - c. To help caregivers navigate the dementia caregiving journey effectively, the interventions should include tailored education programs, support groups, and information (guidebooks and resources) specifically addressing the intersection of IDD and AD.
  - d. The interventions should promote tailored HCBS including (but not limited to) respite care, day programs, and shared living models.

**RECOMMENDATION 5: Expand the availability of culturally and linguistically tailored LTSS to high risk populations inclusive of those with the most social and economic need, including (but not limited to) rural and Tribal communities, those with limited English proficiency, and LGBTQ+ populations.**

Quality of life experienced by PLWD is often dependent upon the ability to access quality services and supports in a timely fashion, yet millions of Americans with dementia and those who provide care are faced with daily challenges in accessing and the delivery of services due to language barriers, lack of culturally competent services, and lower literacy that affects all aspects of their ability to obtain care and support. This is further compounded by a shortage of LTSS providers overall including direct care workers, and even more so by a lack of providers proficient in the languages spoken by immigrant and refugee communities.

- A. Congress should appropriate funding to ACL to provide state grants for the purpose of expanding CHWs within the aging network. This network plays a significant role in helping people access dementia services and enroll 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.

- B. 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.
- C. ASPE should conduct and publish a study on the impact and return on investment that CHWs can have on underserved communities, as a potential means of supporting growth of the model across the country.
- D. Congress should provide financial incentives for diverse business owners and non-profit organizations to become dementia-capable LTSS service providers. Incentives could be offered by providing technical assistance, paid leave for caregivers, tax breaks, small grants to businesses to train employees to be dementia capable.
- E. Congress should increase funding for the Aging and Disability Resource Centers (ADRCs)/No Wrong Door systems to create quality ADRCs across the country. The increase in funding would allow the ADRCs to infuse dementia capability into all programming and staff training and to address the unmet community needs, gaps in provider networks and improve delivery of public and private LTSS for PLWD and their unpaid caregivers, regardless of payor or income.
- F. Congress should provide funding to private and non-profit organizations for the development and implementation of innovative multi-lingual technology solutions.

**RECOMMENDATION 6: Identify adults with a diagnosis of AD/ADRD living alone and develop and implement strategies to address their LTSS needs.**

As the number of adults living alone continues to increase across the country, it is important that we be able to identify those living alone with cognitive impairment in our communities and offer tailored LTSS that is person-centered and addresses their health, safety, autonomy, and quality of life.

- A. To assess the number of individuals living alone with cognitive impairment, ACL should encourage the participation of all states and interested parties in developing and disseminating the national survey to “Identify Adults with Long-Term Services and Supports Needs” being undertaken by ASPE. Along with general categories, inclusion of a question to determine “number in household” will facilitate data gathering on the numbers and needs of those living alone with cognitive impairment will help us to develop tailored LTSS for the future.
- B. Create an interagency workgroup to build capacity to support people with cognitive impairment living alone including ACL, CDC, CMS, ASPE, HRSA, SAMHSA, U.S. Department of Housing and Urban Development, and U.S.

Department of Transportation, as well as the Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act Public Health Center of Excellence on Dementia Caregiving funded by the CDC.

- C. Develop programs to help older adults who live alone to be prepared in case they develop cognitive impairment (e.g., food, transportation, personal care, advanced care and financial planning, environmental modifications, etc.). (See **Recommendation 10.A.**)
- D. 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 State Unit on Aging and State Health Improvement Plans.
- E. CMS should increase the number of hours permitted for in-home caregivers (consumer-directed care) to compensate for the lack of family support for persons with cognitive impairment living alone without caregivers for Medicaid-covered or state-only home care benefits.
- F. CMS should encourage more states to expand eligibility to persons with cognitive impairment or dementia living alone who are low income and close to Medicaid "spend-down" limits through demonstration waivers.
- G. CMS should encourage Medicare Advantage Plans (MAPs) that provide Special Supplemental Services for the Chronically Ill to add services that specifically support persons with cognitive impairment or dementia living alone. Those MAPs with supplemental benefits that offer personal care services should target people with cognitive impairment who live alone.
- H. CMS Center for Medicare and Medicaid Innovation (CMMI) should substitute the GUIDE model respite benefit to allow people with cognitive impairment or dementia living alone and enrolled in a GUIDE model without caregivers to hire home care services as an equivalent benefit.
- I. Congress should pass legislation for tax credits (including refundable tax credits for low-income individuals who do not pay taxes) to persons with cognitive impairment or dementia living alone to defray the costs of hiring direct support workers.
- J. Congress should pass legislation to allow the Social Security Administration to permit family caregivers of persons with cognitive impairment or dementia to earn Social Security credits as part of their employment history.

**RECOMMENDATION 7: Implement solutions to address the LTSS 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 LTSS Subcommittee provides the following recommendations:

- A. Congress should allocate an additional \$25,000,000 in funding for HRSA and CDC to support geriatric workforce training in AD/ADRD across the educational continuum including the public health workforce.
  - 1. HRSA should continue to allocate a portion of Geriatric Workforce Enhancement Program funding, not less than \$230,000 per grantee, uniquely toward workforce training in AD/ADRD, encourage participation in training by students and trainees of color, with needed language skills, and those representing diverse communities.
  - 2. CDC should continue to allocate a portion of Behavioral Health Integration and BOLD funding uniquely toward public health workforce training in AD/ADRD.
  
- B. 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 Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act Advisory 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 one Direct Care Workforce Development Centers of Excellence 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.
  
- C. 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 PLWD reside.

D. Provide incentives for people to enter the workforce.

1. Congress should appropriate 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. Congress should pass legislation and appropriate funds to DoL to establish a program that provides affordable health insurance, free or low-cost childcare, 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 covers 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 in which they are members.

E. Increase availability and improve training and supervisory support for people providing direct care to PLWD.

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-campus and off-



campus programs for training direct care workers and increase internship and supervision support for the direct care workforce.

2. 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 PLWD including, but not limited to, customer service, food service, billing, janitorial, security, and transportation staff as well as those providing clinical care.
3. 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.
4. Federal and state agencies and LTSS industry associations should encourage the uptake of education and training to identify and manage AD/ADRD behaviors that are disruptive to care. The use of non-pharmacological evidenced-based, evidence-informed, and evidence-supported models should be widely adopted.

**RECOMMENDATION 8: Expand awareness and engagement in the public and private sectors about AD/ADRD.**

Since the inception of the National Plan to Address Alzheimer’s Disease we have gained measurable ground in creating mechanisms and resources to inform the public and private sectors of the need to address AD/ADRD in their communities. However, there are many areas where the uptake of this information is limited or non-existent, resulting in continued stigmatization, unfunded and under-funded LTSS programs, inconsistent public health infrastructure, and lack of delivery of existing services and supports.

- A. The Federal Government should encourage all states to secure an Executive Order or legislation to create government support for a Multisector Plan for Aging to align state and local priorities and encourage public-private partnerships.
- B. The Federal Government should strengthen its collaboration with the AD Council to expand communication around AD/ADRD through public service campaigns not just on the Internet, but through television, radio, and print media to inform all communities inclusive of our diverse, native, and rural populations.
- C. Congress should reauthorize BOLD for another five years and should appropriate a minimum of \$35m in FY2025 for the CDC to implement the goals under the Act.
- D. The Federal Government should develop crisis care/response standards that are inclusive of AD/ADRD. These standards should also be inclusive of targeted de-

escalation and positive behavioral strategies for those experiencing neuropsychiatric symptoms.

- E. The Federal Government should encourage states to develop and implement their 988 programs and include dementia awareness training for first responders (e.g., police, fire, dispatchers, hotline staff, disaster relief workers, and mobile crisis workers, etc.).

**RECOMMENDATION 9: Increase funding to implement strategies to reduce risk of homelessness among older adults living with dementia or cognitive impairment and to respond to the needs of those already experiencing it.**

- A. Congress should increase funding to the states to expand Adult Protective Services to enhance services for people at risk of homelessness including the training of specialized case workers to help older adults maintain their housing.
- B. Congress should expand funding for residential care for very low-income people most at-risk for homelessness.
- C. Congress should increase funding to develop permanent supportive housing that includes support for activities of daily living for older adults facing homelessness.

**RECOMMENDATION 10: Implement strategies that create the conditions for high quality person-centered and strengths-based LTSS throughout the course of the disease.**

- A. HHS should continue to develop and enhance distribution of information that can be shared with the public regarding the importance of advance care planning, financial and health care decision-making options, types of long-term care settings, their payment models and services, environment modifications, 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.
- B. 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.

**RECOMMENDATION 11: Develop and implement systems and programs that support PLWD while incarcerated to provide appropriate treatment from diagnosis through to end-of-life.**

- A. Convene a taskforce to develop standardized criteria for compassionate release (medical parole) for PLWD while incarcerated composed of representatives of various states' Departments of Corrections and the Federal Bureau of Prisons to provide guidance to all states to determine eligibility for release. In addition to the standardized criteria, the taskforce should consider approaches to support PLWD such as: (1) establishing a system of regular formalized AD/ADRD screenings for the incarcerated who evidence cognitive decline; (2) the development of an advocate program to assist the PLWD while incarcerated to start the process of compassionate release (if the PLWD is unable to do so); and (3) provide a legal advocate to provide representation (if necessary) throughout the hearings with the parole board so that the PLWD is not required to represent themselves as is the current rule in most jurisdictions.
- B. Encourage all prison systems to offer access to advocates trained to assist PLWD while incarcerated to apply for eligible benefits (Supplemental Security Income, U.S. Department of Veterans Affairs [VA], Medicare and/or Medicaid) prior to compassionate release. Accurate and timely filing of applications will minimize delays in receiving benefits and improve delivery of care upon discharge from the system.
- C. Utilizing available dementia awareness training for law enforcement, both Federal Bureau of Prisons and state Departments of Corrections should develop and implement mandatory dementia training for all personnel. This training should be required for members of all parole review boards to enhance understanding of AD/ADRD when determining eligibility for compassionate release.
- D. For PLWD while incarcerated deemed ineligible for compassionate release, programs should be developed and implemented within the prison systems. These should include robust peer-to-peer support models (e.g., the Gold Coats) and the creation of normalized safe spaces for end-of-life/memory care.
- E. Within all prison systems throughout the country, there should be staff case managers employed, trained, and assigned to assist PLWD while incarcerated who are granted a compassionate release to develop a post-release plan inclusive of supportive housing or LTSS.

## Research Subcommittee

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

Significant strides have been made toward the National Plan's goal to prevent and effectively treat AD/ADRD by 2025. Highly accurate diagnostic tests for Alzheimer's disease (AD), including blood biomarkers, are now potentially available for clinical use, and the first disease-modifying treatments (DMTs) for AD are being implemented in memory clinics. These successes have provided a framework to study and develop tests and treatments for related dementias. 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. As part of this process, the Alzheimer's Accountability and Investment Act, which is the professional judgement budget process for NIA leadership to recommend the necessary additional funding levels for research directly to Congress, should be reauthorized.

High priority areas of research include:

- A. Understanding fundamental biological processes and basic disease mechanisms of AD/ADRD (e.g., younger and late-onset sporadic AD/ADRD, familial AD/ADRD, individuals with Down syndrome/IDD).
- B. Studying dementias with clinical diagnoses other than AD (including vascular dementia as the second most common form of dementia and other important types) as well as mixed/multiple etiology dementias, as identifying specific biomarkers for these conditions could improve diagnostic capabilities and are necessary to guide therapeutic options. Assessments and outcomes of importance to patients and families (e.g., quality of life and function) translatable across different neurodegenerative diseases and purposes (such as clinical management, data extraction from EHRs, and clinical trials) should be explored.
- 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 treatments (precision medicine). This also provides an opportunity for risk reduction and general management of comorbid conditions.
- 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. (See also **Recommendation 2.**)
- E. Developing and evaluating implementation of models of dementia care and support and the testing of innovative payment models (beyond the GUIDE model)

by the CMMI, evaluation by other private foundations, etc.); encourage uptake efforts through state public health and aging services departments. Additionally, models of dementia care and support should be researched and implemented beyond CMS models (e.g., for those diagnosed with young-onset dementia or ineligible for CMS coverage). (See also **Recommendation 3.**)

- F. Research into workforce and systems capacity needs in clinical care and research staffing across and within diverse geographical regions of the United States. Investment in implementation, scale and spread, and integration of these models into practices and health systems is critical. Research should be responsive to disparities and needs. Funding and resources should be allocated to AHRQ for this purpose.
- G. Further development of translation for diagnostics and therapeutics and the implementation process in clinical settings.
- H. Research into evidence for and 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 Novel Coronavirus (COVID-19) in older adults and PLWD.
- J. Research into the causes, relationships, and risk reduction of delirium in PLWD. Research methods of prevention and treatment, both pharmacological and non-pharmacological, are to be integrated into the acute and long-term care residential settings.
- K. The newly created Advanced Research Projects Agency for Health should implement a dementia portfolio that enables the translation and demonstration of scientific breakthroughs in the diagnosis, treatment, and management of dementias and facilitates efficient translation of evidence to patient care.

**RECOMMENDATION 2: Address critical scientific and clinical questions in the implementation of the first generation of DMTs.**

Research is needed to determine:

- A. How best to identify persons who would benefit from anti-amyloid therapy and ensure equitable access and ability to participate in therapy for all patients who could benefit from treatment, especially those from marginalized populations. Data from trials related to subgroup analyses (e.g., based on sex, ethnicity, apolipoprotein E [APOE], comorbidities, stage of disease, etc.) should be made publicly available to understand in which populations the treatment is beneficial and the magnitude of that benefit. For proprietary data from industry-sponsored

trials, federated data approaches are recommended to enable and encourage data sharing.

- B. Given the stringent enrollment criteria in the clinical trials, it is critical to know which persons with cognitive decline and evidence of amyloid deposition in the brain, but who did not fit criteria of the successful clinical trials (e.g., those with co-pathologies and mixed dementias), may also benefit from anti-amyloid therapy.
- C. Research and identify the infrastructure needed to appropriately identify, treat, and monitor persons treated with new therapeutic agents, beginning with anti-amyloid therapy, to ensure that all patients who could benefit from treatment receive interventions to improve health outcomes and minimize functional loss.
- D. The causes of side effects and adverse reactions in persons treated with anti-amyloid therapy and how to best monitor and manage these. For example, baseline characteristics such as number of microhemorrhages and other inclusion factors could be researched. Lower burden monitoring and prediction methods are needed, in addition to quantifying the parameters of risk and benefit (e.g., number of microhemorrhages, prior stroke, etc.).
- E. Early, accurate, and minimally invasive detection of the disease followed by differential diagnosis testing options to identify persons who may benefit from receiving anti-amyloid therapy, given that DMTs have greater effect sizes in earlier stages of the disease.
- F. Whether anti-amyloid treatment of cognitively normal persons identified as high risk for future cognitive decline based on blood or PET biomarkers can help prevent or delay the onset of cognitive impairment. This research may include the development and testing of lower cost and burden treatments such as active vaccination or oral agents to prevent AD.
- G. How to manage persons treated with anti-amyloid therapy over longer time periods including patients who progress to dementia, the effects of multiple comorbidities and medications especially those in common use to prevent and treat acute stroke and heart disease, optimal treatment duration, and cessation criteria. Data from the CMS lecanemab registry and other registries may facilitate this research.
- H. Research into novel approaches for prevention and early detection of the disease, as well as the risks and benefits of DMTs, defined as therapies that reverse some form of AD pathology such as amyloid, for those with Down syndrome and other forms of AD such as autosomal dominant, early-onset AD, etc.

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

- A. The effectiveness of diagnostic strategy implementation on the continuum of primary care to specialty centers should be studied. Research is needed in how to provide timely and accurate diagnostic and prognostic information for PLWD using recent scientific developments in biomarkers, and to identify barriers to implementing dementia care models in primary care as well as strategies and approaches to support primary care and other providers in this role. Access should include all communities.
- B. Research is needed to develop, implement, and improve person-centered models of care for people with dementia and their caregivers. Interventions such as medication management, support for caregivers of PLWD, clinical care team management, risk factor modification including physical activity, exercise, diet, and substance use treatment (smoking, alcohol) should continue to be studied.
- C. Research in how to integrate medical interventions (e.g., disease-modifying therapies, also known as DMTs) within medical systems and to measure effects of such interventions on quality of life, function, and other outcomes important to patients and families.
- D. Develop and implement care models for PLWD not being adequately served by current models (e.g., those under age 65, those with IDD and dementia, those who are unhoused or incarcerated). More research is needed on the efficacy of current models (e.g., GUIDE program) in these populations, and capacity to implement these programs if shown to be effective. Funding and resources should be appropriated to AHRQ to contribute to this evidence base.

**RECOMMENDATION 4: To address health equity, underrepresentation of diverse populations in research in AD/DRD clinical trials should be increased.**

- A. Potential strategies include leveraging community engagement models to promote diverse recruitment and participation (e.g., National Academies Improving Representation and NIA Alzheimer's and Dementia Outreach, Recruitment, and Engagement), as well as 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 (e.g., NIH, Food and Drug Administration guidance, Peer Reviewed Alzheimer's Research Program [PRARP]), publication requirements, and including patient and public involvement of PLWD and unpaid caregivers representative of diverse populations.
- B. Prioritize inclusion and representation of diverse populations in public/private clinical trials, fund research into the science of recruitment and retention, and set

milestones for engagement and inclusion of underrepresented populations with a focus on diagnostic and treatment-related trials.

1. Support initiatives that promote health equity and address systemic barriers to participation in clinical trials.
2. Ensure clinical trials are accessible to diverse participants, including non-English speakers and individuals with disabilities.
3. Analyze trial outcomes by demographic variables to understand potential disparities and inform future research and clinical 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. Public health departments play a role in increasing visibility of the role stigma plays in dementia and decreasing its detrimental impact through education, media campaigns, training, and health policy. Public health evaluation efforts can contribute to understanding which interventions help overcome stigma and improve access to health services.

1. Current work has focused on stigma attached to race/ethnicity, culture, sex and gender, socioeconomic status, among others. 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, outcomes, and support systems. Particular attention should be given to the stigma faced by individuals with young-onset dementias, which is also understudied.

### **RECOMMENDATION 5: Accelerate 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, payors, and federal agencies involved in the National Plan. This coordination is necessary to accelerate translation of evidence-based advancements into clinical practice and approved diagnostic, treatment, and care paradigms to improve outcomes for PLWD. This approach to rapid translation is to cover the entire continuum from research studies through regulatory review and approval, and delivery and impact on diagnosis and care.

- A. Congress should reauthorize NAPA for another ten years to enable further progress on NAPA goals. The first goal of NAPA, to “treat or prevent Alzheimer’s disease by 2025,” should be updated to “treat and prevent Alzheimer’s disease and related dementias by 2035.”
- B. Congress should appropriate funds for NAPA organizers, including ASPE, to have increased resources (e.g., financial and personnel support) and authority to accomplish the following:



1. For FY2025, fund and appoint at least one FTE for federal coordinator(s) with the authority to prioritize, organize, implement, and follow up on cross-stakeholder recommendations, possibly through NAPA reauthorization.
  2. Track the progress and milestones of prior NAPA recommendations with a goal to prioritize those recommendations with the largest potential impact.
  3. Assist the 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.
- C. 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, payors, 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 (e.g., by AHRQ with funding and resources) 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.
1. To better inform this research, the framework of Patient and Public Involvement should be integrated throughout the research cycle. PLWD and their caregivers should be active members of the research team and high priority should be given to recruit individuals from previously underrepresented populations (e.g., racial and ethnic minorities, lower SES, higher comorbidities, IDD, young-onset, LGBTQ+).
- 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 grant application requirements, evaluating successful models from other disease areas, incentivization of research participation, evidence-based models of implementation, and payor evaluation of successful advancements based on evidence.

1. For example, the PRARP of the U.S. Department of Defense Congressionally Directed Medical Research Programs (CDMRP) requires all clinical research applications to involve people with lived experience in meaningful and equitable ways during the design, execution, and dissemination of the research. CDMRP involves people with lived experience as equal partners in peer review.
- 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. Congress should reauthorize and provide appropriations for NAPA for another ten years to enable further progress on NAPA goals.
- B. In supporting and undertaking public health, aging network, and clinical interventions and activities to address risk for cognitive decline and dementia as part of Goal 6 of the National Plan -- including integration of such activities across sectors -- HHS should identify the risk factors that will be the priority area of focus. These areas should be based on the strength of scientific evidence, ripeness for public health action, and potential for impact -- and should consider the needs of, and potential benefits to, at-risk communities. We recommend focusing on the following six risk factors that we believe show the greatest potential for impact: midlife hypertension, midlife obesity, physical inactivity, smoking, depression, and hearing loss.
- C. To begin measuring progress on Goal 6, HHS should track the prevalence of the priority risk factors for the overall United States population; by race/ethnicity, education levels, and income; and among those with neuro-atypical conditions. In addition, HHS should track efforts to address the priority risk factors, including interventions undertaken and other appropriate means of controlling the risk factors. HHS should establish a monitoring and evaluation workgroup no later than May 2025 to make recommendations for specific indicators and related data sources to be used, consistent, where appropriate, with Healthy People 2030 and the Healthy Brain Initiative Road Map.
- D. No later than 2028, HHS should convene a second AD/ADRD risk reduction summit, with CDC as the lead agency. The summit should focus on translating the latest state of the evidence on modifiable risk factors for, and social determinants of health-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 priority risk factors, and actions that would address specific barriers/challenges for historically underserved communities.
- E. 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 priority risk factors that are 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.
- F. 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 U.S. 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.
- G. Not less than every five years, HHS should update the list of key risk factors that are the priority areas of 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 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, education, and public health messaging on dementia risk factors, brain health, and related evidence-informed interventions.
1. Congress should reauthorize BOLD for another five years and should provide at least \$35 million in FY2025 funding for the CDC to implement the Act.
  2. Congress should reauthorize the OAA and should provide sufficient funding to enable ACL to incorporate dementia risk reduction education and interventions in relevant OAA programs, such as Nutrition Quality, Chronic Disease Management, Falls Prevention, and physical activity initiatives.
  3. Congress should enhance appropriations of relevant existing federal programs -- and fund additional new programs -- that promote reducing risk of cognitive decline and dementia.
  4. CDC, ACL, CMS, HRSA, SAMHSA and HHS Indian Health Services (IHS) should expand efforts to target resources toward education and outreach of the public health and aging network on dementia risk factors.
  5. Existing federal efforts to address health conditions and behaviors that are also risk factors for cognitive decline and dementia (such as Million Hearts, the National Diabetes Prevention Program, the High Obesity Program, and

anti-smoking programs of the Office on Smoking and Health) should be promoted as also beneficial to brain health.

- 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 social determinants of health 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 social determinants of health and strategies and interventions that promote brain healthy behavior.
- D. As the responsibilities of caregiving often result in certain adverse health outcomes -- such as lack of sleep, increased depression, high blood pressure, and elevated stress -- caregivers may be at increased risk for dementia and should be a target for risk reduction efforts. Based on newly analyzed data from the BOLD Center on Dementia Caregiving and the BOLD Center on Dementia Risk Reduction regarding dementia risk factors among caregivers, the CDC's Healthy Brain Initiative Collaborative should develop and 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.
- E. 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 American Indian and Alaska Native Peoples* (forthcoming late 2024), Healthy People 2030, and the Million Hearts campaign.

**RECOMMENDATION 3: Identify and accelerate efforts to reduce risk and intervene early in primary 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 in primary care by addressing known risk factors, including developing and providing patient and provider education; empowering and activating patients to control their own health; 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; integrating the relevant evidence on successful behavior change and behavioral health into clinical practice; and developing and implementing quality measures specifically related to brain health.

3. Identifying existing insurance and health plan 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; prevention and treatment of obesity; 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, including training through vehicles such as Project Extension for Community Healthcare Outcomes (Project ECHO) that provide primary care mentoring opportunities with public health or behavioral change specialists.
  5. Increasing identification of persons (including adults with lifelong neurocognitive or neuro-affect disabilities) who have one or more modifiable risk factors for dementia so as to clinically address those factors and, as a result, potentially mitigate the risk for dementia.
  6. Strengthening the capacity of primary care and health systems to address health-related social needs related to dementia risk factors.
- B. Given the abundance of scientific evidence linking hypertension and brain health, health plans should place a particular emphasis on hypertension prevention and control, including by:
1. Using EHRs to identify patients with undiagnosed or uncontrolled hypertension (e.g., those with multiple elevated blood pressure readings in their EHR but no hypertension diagnosis).
  2. Linking patients to community programs and resources to help them get and take medications consistently, manage their risks, and make healthy lifestyle changes.
  3. Including coverage for validated home blood pressure monitors.
  4. Reducing out-of-pocket costs of anti-hypertensive medications.
  5. Encouraging access to patient-preferred methods of care, including in-person, virtual, and team-based care.
  6. Providing greater weight to successful hypertension control in value-based payment contracts.
- C. HHS should identify and accelerate strategies to improve access to and strengthen 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.

- D. Congress should address coverage gaps in Medicare, Medicaid, IHS, and VA that would improve interventions for identified AD/ADR 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 relevant agencies) should utilize fundamental principles of diversity, equity, and inclusion while developing, supporting, and monitoring research on factors and effective interventions 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 social determinants of health that may:
    - a. elevate the risk of developing dementia; or
    - b. 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 microbiome and the exposome.
  - 4. Identify what modifiable factors may decrease risk for developing dementia and identify factors related to comorbidities that may aggravate or mitigate risk for developing dementia among those with IDD.
  - 5. Identify what modifiable risk factors and lifestyle interventions may slow disease progression and/or help maximize functionality among individuals who have been diagnosed with dementia.
  - 6. 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. Congress should provide sufficient funding for, and relevant agencies within HHS (including CDC, ACL, NIH, and AHRQ) should undertake:
1. Implementation science on successful clinical trials in order to develop community-based, public health interventions for dementia risk reduction, with special attention on optimal implementation, including payment, training, delivery, and uptake. (For example, studies could be designed and funded to create a “Dementia Prevention Program” modeled on the National Diabetes Prevention Program.)
  2. Research on interventions that would mitigate exposure to possible risk factors for cognitive decline and dementia. (For example, clinical trials could be conducted on sleep intervention strategies, such as ear plugs and sleep masks, and on GLP-1 therapies for the management of Type 2 diabetes and obesity.)
- E. 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. Because of the strong relationship between hypertension and cognitive decline, employers should undertake efforts to reduce the impact of hypertension as a strategy to improve both physical and brain health. Such efforts should include promoting healthy lifestyles; hosting blood pressure screenings with direct connections to health care; educating the workforce about hypertension prevention, control, and self-management; and including access to hypertension prevention and control services in employee health benefit plans, including coverage of validated blood pressure monitors, at reasonable or no out-of-pocket costs.



- E. National, state, and local/community-based provider organizations working with segments of the population at greater risk of developing dementia (e.g., those with IDD and Black and Hispanic Americans) should undertake efforts to improve brain health.
- F. 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 implement policies and environmental and health systems changes that would:
  - 1. Improve the ability of individuals to control and normalize blood pressure.
  - 2. Improve food affordability and quality, including with respect to ultra-processed foods, trans fat, and high-sodium foods.
  - 3. Increase access to safe and inexpensive opportunities to engage in physical activity.
  - 4. Decrease access to commercial tobacco products.
  - 5. Expand hearing testing and affordable access to use of hearing aids, including among Medicare beneficiaries.
  - 6. Increase access to preventive health care and mental health services.
- B. National public health organizations, aging services 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.