

# **PUBLIC MEMBERS OF THE ADVISORY COUNCIL ON ALZHEIMER'S RESEARCH, CARE AND SERVICES: 2020 Recommendations**

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## **Cross-Cutting**

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## **Clinical Care**

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## **Long-Term Services and Supports**

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## **Research**

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## Cross-Cutting Recommendations

### Themes:

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### **RECOMMENDATION 1: The U.S. Department for Health and Human Services (HHS) and federal partners should improve and expand emergency preparedness, response, and recovery with specific consideration of the needs of individuals living with Alzheimer’s disease and related dementias (AD/ADRD) and their caregivers.**

People living with AD/ADRD may be at especially high-risk during disasters and other emergencies.<sup>1</sup> Those living in long-term care facilities, roughly 50% of whom have AD/ADRD, and those living in the community without robust supports may be especially vulnerable during emergency events such as “Acts of Nature” (e.g., wildfires, earthquakes, hurricanes, floods, tornadoes) and infectious disease outbreaks. While emergency preparedness currently exists, there is opportunity to expand plans and protocols to include response and recovery for sustained emergencies that factor in the impact of prolonged social isolation in combination with disruptions in care and support. Disasters and emergency situations have the potential to create unique challenges and heightened demands for services in the areas of long-term services and supports (LTSS), clinical care, and research operations. Emergency preparedness and response and recovery plans would be incomplete without special attention to risk factors, vulnerabilities, and special needs of individuals living with AD/ADRD and their caregivers.

The current COVID-19 pandemic highlights how individuals living with AD/ADRD and their caregivers are especially vulnerable. In 2020, we have seen the devastating effects of COVID-19 on our AD/ADRD community. While the pandemic has particularly impacted residents of nursing homes and other congregate settings (e.g., group quarters for people with intellectual disability), it is also affecting people with AD/ADRD and their caregivers who live in the community in a multitude of ways that impact their physical and mental health, safety, and quality of life. People with AD/ADRD may not be aware of or understand the need to follow safety protocols established by health officials, creating elevated risk for themselves and others and adding additional strain to health care services. Due to closures of adult day centers, restrictions on in-home respite, reluctance to accept in-home services associated with risk of exposure, and social distancing requirements, informal caregivers are at greater risk for increased stress and may be less able to manage caregiving. The disruption of these and other essential community-based supports creates an increased risk for loneliness and

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<sup>1</sup> For this recommendation, the NAPA Advisory Committee is using the term “emergency” as it is commonly used and not limited to those situations in which an emergency declaration is authorized by the Stafford Act. The Stafford Act authorizes the U.S. President to declare a “major disaster” or “emergency” in response to an incident or threatened incident that overwhelms the response capability of state or local governments. A presidential declaration under the Stafford Act enables access to disaster relief assistance and funds as appropriated by Congress.

isolation resulting in anxiety and depression for both individuals living with AD/ADRD and their caregivers. The cumulative effect of disruption of routines and access to essential care and support services are compounded by increased stress and social isolation.

In recognition of the vulnerabilities of individuals living with AD/ADRD and their caregivers and the potential impact that disasters and emergencies may have on LTSS, clinical care, and research, the Advisory Council recommends the following:

- The NAPA Advisory Council subcommittees should examine how emergency preparedness, response, and recovery must be tailored to support the domains of research, care and services, and public services for individuals living with AD/ADRD and their caregivers over the next year.
- The subcommittee recommendations should integrate broad input from experts in research, care, and services as well as individuals at risk for or with symptomatic AD/ADRD and caregivers.
- The subcommittees should develop recommendations with specific goals for implementation of emergency preparedness, response and recovery plans that reflect unique needs in the areas of LTSS, clinical care and research.

Federal agencies should identify actions being taken relative to emergency preparedness and people with AD/ADRD and report periodically on these activities.

Specifically:

- A. Enhanced Training for Essential Emergency Personnel/First-Responders:
  1. Federal Emergency Management Agency (FEMA), in coordination with HHS and U.S. Department of Justice, should disseminate and develop additional specialized training on responding to individuals living with AD/ADRD, including the role of formal and informal caregivers, made available for first-responders and other emergency personnel at federal, state, and local levels.
- B. Developing Care Plans When Primary Caregivers are Unavailable:
  1. HHS Assistant Secretary for Preparedness and Response (ASPR) should develop recommended protocols for emergency planning and response for individuals living with AD/ADRD, including developing alternative plans of care for situations when a formal or informal caregiver becomes unavailable. ASPR shall convene partner agencies, including but not limited to, Administration for Community Living (ACL), Centers for Disease Control and Prevention (CDC), Centers for Medicare & Medicaid Services (CMS), Health Resources and Services Administration (HRSA), Veterans Health Administration (VHA) and FEMA, and consult with recipients of LTSS services, to assure that the protocols are relevant to a wide variety of LTSS recipients, providers, workers, settings and services, are distributed to stakeholders and providers, and are designed to be integrated into relevant

regulations, training and/or guidance, where applicable. Protocols should include provisions that can be utilized by certified Medicare and Medicaid providers, state Medicaid agencies, state units on aging, area agencies on aging, state agencies responsible for dementia planning and services, veterans' health and social services providers, and state emergency management agencies.

2. ASPR should prepare and distribute an emergency preparedness packet and training on understanding dementia and aiding people with dementia for first-responders and other public workers drawn to aid in emergencies.

C. Updated LTSS Provider Regulations:

1. CMS should update its nursing facility, home health, and hospice regulations, considering lessons learned during the COVID-19 pandemic, to ensure:

- Assure that meaningful standards for the necessary staff, training, and equipment to care for residents under emergency circumstances are available.
- Ensure that nursing facility residents have the right to move in with family during emergencies, without losing their ability to return to the facility, if desired.
- Provide for reasonable accommodations for visitations by family, friends, caregivers, or paid staff to nursing home residents, while maintaining necessary safety and health precautions, including accommodation of virtual visits when necessary.

2. Additional nursing facility/residential care communities resident protections:

- CMS should authorize states to provide temporary access to Medicaid home and community-based services (HCBS) for those Medicaid-eligible nursing facility residents who move in with family temporarily during emergencies.
- States should be prepared to activate national guard and redirect public health personnel in emergency situations where needed to preserve lives and support operations for caring for people living with AD/ADRD in nursing facilities and residential care communities.

D. Consumer/Caregiver/Health Care Provider Education:

1. ACL should develop education materials for individuals living with AD/ADRD and their caregivers, as well as training and guidance for the Aging Network and the Protection and Advocacy Network, that supports dementia-competent emergency preparedness planning for individuals living with AD/ADRD in community settings. These materials should take into consideration cultural context, language differences, and a person-centered approach.

2. CDC should develop a National Center of Public Health Excellence on Dementia Caregiving to support states, political subdivisions of states, tribes and tribal organizations to translate, disseminate, and implement evidence-informed caregiving information through public health infrastructure.
  3. HRSA, in partnership with federal agencies, should educate and train the health care workforce to prepare for, respond to, and recover from emergencies and disasters, with a particular focus on aiding persons living with AD/ADRD and their caregivers.
- E. Flexible Research Infrastructure:
1. Congress should provide additional funding and enable extensions of timelines to extend research projects that have been delayed or halted due to the impact of COVID-19.
  2. National Institutes of Health (NIH) and other federal agencies that fund AD/ADRD research should support innovation in research protocols such as the conversion from paper and pencil to digital surveys and assessments, telephone and video-based interviews and the use of flexible scheduling to accommodate increased caregiver burden.
- F. Clinical Care Expansion: Access to expert care for diagnosis, symptom management, and care of AD/ADRD is essential to help individuals living with AD/ADRD and their caregivers to live the highest quality of life possible and prepare for care decisions ahead. Continuation of clinical care for routine medical care, specialist services and management of chronic health conditions is essential to maintain cognitive resilience and support quality of life of people with AD/ADRD.
1. CMS and private health insurance companies should provide reimbursement to ensure continuation and expansion of telehealth services in order to close the gap on access to care.
  2. Federal and private payors should promote innovate clinical care applications that include the utilization of multidisciplinary teams and unconventional clinic visits that incorporate opportunities for home visits for community-based individuals; innovative technology applications such as internet-based consultations, assessments, and reviews; and site visits to memory care and skilled nursing facilities when possible.

**RECOMMENDATION 2: The Advisory Council and federal partners should develop a national goal to reduce the burden of risk factors to prevent or delay onset of AD/ADRD.**

Since the inception of the National Plan, with its aspirational goal to “to prevent and effectively treat Alzheimer’s Disease by 2025,” research progress has dramatically

improved our understanding of AD/ADRD. Research has made it clear that there is a decades-long presymptomatic phase during which numerous risk factors influence the accumulation of multiple brain pathologies and determine trajectories of symptom progression across the spectrum of AD/ADRD. Accumulating evidence suggests the potential to mitigate cognitive decline by addressing modifiable risk factors throughout the lifespan (including for example, hypertension, as demonstrated in the SPRINT MIND study). In recognition of these advances in understanding risk factors, the long preclinical stages of disease, and the heterogeneity of pathologies that cause dementias, the Advisory Council recommends the following:

- A. The Advisory Council should establish a subcommittee to address risk factor reduction to mitigate the public health burden of AD/ADRD. Over the next year, the subcommittee should determine specific goals, metrics, and timelines and provide updates at the quarterly Advisory Council meetings.
- B. HHS should review existing data on risk reduction and explore setting metrics for monitoring public health impact using a rigorous, open, transparent process.
- C. The Advisory Council's subcommittees for research, clinical care, and LTSS should coordinate and seek broad input from experts and individuals at risk for or with symptomatic AD/ADRD to inform the subcommittee recommendations.
- D. The subcommittees should identify opportunities for facilitating risk reduction across the spectrum of AD/ADRD research, clinical care, and LTSS.
- E. CDC should develop a National Center of Public Health Excellence on Risk Reduction to support states, political subdivisions of states, tribes and tribal organizations to translate, disseminate, and implement evidence-informed risk reduction interventions through public health infrastructure.

**RECOMMENDATION 3: Advance health equity by addressing racial and ethnic disparities in AD/ADRD.**

People of color experience significant disparities in prevalence and incidence of AD/ADRD, mortality, participation in research, medication and intervention efficacy, quality of care, caregiving experiences and in the use of LTSS. Numerous dynamics contribute to these disparities, including social determinants of health, cultural and linguistic differences, lack of diversity among service providers and researchers, and systemic racism.

Even though these disparities are well known, insufficient investments have been made to address their underlying causes. Further, investments focusing chiefly on improving individual health behaviors and access to health care ignore 50% of the factors that

contribute to health, specifically, those that are socially determined.<sup>2</sup> In addition, systemic racism has largely been ignored as a public health crisis, resulting in continued disparities in dementia research, services and programs, and funding.

Historically, people of color have been mistreated and neglected by the medical research community (e.g., U.S. Public Health Service Study at Tuskegee), which has led to mistrust and underrepresentation of people of color in clinical trials and other research studies. Because of this and the complexity of systemic racism, there is scant highest-level evidence for strategies that will influence the problem of underrepresentation of people of color in research. Supporting evidence-informed solutions or emerging best practices, rather than limiting policy or funding opportunities to those with the highest-levels of evidence, are necessary for addressing disparities and fostering innovation.

This recommendation seeks to broadly prepare the nation to address root causes of racial and ethnic disparities and the social determinants of dementia. An overarching principle of this recommendation is to transform the way in which research, clinical care, and long-term care services and supports are provided and to shift to a model that distributes power over decision-making and policy development.

A. National Infrastructure:

1. The Secretary of HHS should provide a special report to the Advisory Council by April 1, 2021, on initiatives taken pursuant to the National Alzheimer's Project Act requirement to: "Ensure the inclusion of ethnic and racial populations at higher risk for Alzheimer's or least likely to receive care, in clinical, research, and service efforts with the purpose of decreasing health disparities in Alzheimer's." The report should describe these initiatives, the results, and further steps that will be taken to ensure additional progress. The report should include significant input by people of color.
2. The Advisory Council should incorporate expert presentations and content in Council meetings that address health equity and social determinants of health to ensure that recommendations incorporate the needs of all individuals living with AD/ABRD and caregivers.
3. All government entities should take a "Health in All Policies" approach and embed health equity considerations into ongoing government processes and decision-making.
4. Congress should appropriate funding to ACL to expand dementia grants specifically targeting public and private community organizations that directly serve and/or are led by people of color or of diverse ethnic groups.

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<sup>2</sup> Source: <https://www.countyhealthrankings.org/explore-health-rankings/measures-data-sources/county-health-rankings-model>.

5. ACL should require the National Alzheimer's and Dementia Resource Center (NADRC) to expand its scope to include technical assistance on health equity and dementia and target areas where there is demonstrated exclusion or omission of people of color or diverse ethnic groups.
  6. CDC's Healthy Brain Initiative (HBI), BOLD National Center of Public Health Excellence, and BOLD Public Health Programs should support increasing public health capacity for dementia by focusing on disparate and underserved populations.
  7. Congress should appropriate funding through Indian Health Service (IHS) that will be used to enhance care provided to tribal elders, including, improvement in early diagnosis, assessment, care, and in efforts to encourage early recognition in Tribal communities and support for family caregivers.
- B. LTSS Programs and Services:
1. HHS should conduct an analysis of LTSS programs and policies across federal agencies to identify policies, practices and program requirements that may impede inclusiveness or the ability of public and private service providers to serve communities of color.
  2. HHS should tailor and incentivize the use of national Culturally and Linguistically Appropriate Services (CLAS) standards to advance health equity at every point of contact in the LTSS system.
  3. CMS should allow states (or create a pilot) to expand program services and supports to caregivers of persons with dementia who are eligible for LTSS. In addition to caregiver support, eligible services may include diagnostic assistance, employment support, nutrition services, housing, and transportation access.
  4. The Office of Minority Health, CMS, HRSA, and other relevant federal agencies should develop and fund strategies for addressing access to and overall quality of long-term care, facility and community-based, whereby people of color only have access to poorer quality services.
  5. CMS should develop and fund strategies for increasing diversity among long-term care service providers that would allow for increased matching of clients with staff according to ethnicity and language preferences.
  6. HHS should encourage the incorporation of cultural humility practices among long-term care and health care professionals.



C. Research:

1. NIH should fund community-based participatory research that involves people of color in the development, recruitment of participants, implementation, and evaluation of studies. Congress should then appropriate funding for new approaches, interventions and services that address the social and medical determinants of chronic conditions in people of color that emerge through community-based research.
2. NIH should increase funding for research into how the social determinants of health, including persistent or life-long adverse exposure of people of color to economic, environmental and social adversity, influence prevalence and incidence of dementia in communities of color and identify strategies that can effectively respond to and prevent similar adverse exposure in future generations.
3. Congress should appropriate funding for research focusing on people with AD/ADRD and their family caregivers and the presence and impact of racial and ethnic group membership related discrimination by long-term care and health care providers.
4. It is critical to increase the pool of research investigators from diverse racial and ethnic backgrounds. Congress should appropriate funds for National Institute on Aging (NIA) to expand Resource Centers for Minority Aging Research (RCMAR).

D. Outreach:

1. ACL and CDC should identify and expand effective AD/ADRD outreach strategies to underserved populations.
2. HHS should ensure that grantees or contracted providers tailor outreach materials and strategies to underserved populations, including the availability of such strategies/materials in multiple languages and with pictures/photos that are reflective of the people they serve.

E. Workforce Development:

1. HRSA should continue to include a requirement in its Geriatrics Workforce Enhancement Program (GWEP) to educate and train the health care workforce on how to care for older adults within the context of social determinants of health, cultural competence, health literacy, and health equity.
2. HRSA should continue to partner with federal agencies, academic institutions, primary care sites/delivery systems, and community-based organizations to accomplish this requirement.

- F. HHS should identify other efforts and agencies already engaged in health-promoting work that addresses racial and ethnic disparities where dementia-specific strategies can be added or where there is potential for synergy.

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## Clinical Care Subcommittee

### Clinical Care Themes:

- Advancement of themes and results of the National Research Summit on Dementia Care.
- Public education about early detection and diagnosis in diverse communities.
- Workforce development.
- Attention to best practices in AD/ADRD.
- Encouragement of health system models that align performance, care quality, and payment.

### **RECOMMENDATION 1: Advance the themes and recommendations of the 2017 and 2020 National Research Summits on Care, Services and Supports for Persons with Dementia and their Caregivers.**

The research findings presented at the 2017 and 2020 National Research Summits on Care, Services, and Supports for Persons with Dementia and their Caregivers and the final sets of research themes and recommendations should be considered for federal agencies' and others' current plans to improve care for AD/ADRD; gaps in evidence should be addressed by appropriate funders; and, the 2020 National Plan should be updated based on current data and Summits' themes and findings.

- A. Federal agencies and others should review research findings such as those presented at the Research Summits on Dementia Care and, when possible, enact evidence-based care delivery models which have demonstrated efficacy and effectiveness at improving care for AD/ADRD, including advancing a public health approach to promote the health and well-being of persons living with AD/ADRD and their caregivers. (<https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers-final-report#FinalRpt>).
- B. Additional investments are needed in federal agencies in addition to NIH to address research recommendations, including those identified at the Research Summits on Dementia Care. New legislation or modification to existing legislation may be required to identify funding needed by other federal agencies to reach the 2025 goals.
- C. Federal agencies and non-governmental organizations should allocate funding and issue requests for applications to address research recommendations stemming from the National Research Summits on Care, Services, and Supports for Persons with Dementia and their Caregivers as well as the NIH Alzheimer's Research Summit hosted by NIA and the AD/ADRD Summit hosted by National Institute of Neurological Disorders and Stroke (NINDS) to the extent that recommendations address clinical care.

- D. The HHS Office of the Assistant Secretary for Planning and Evaluation (ASPE) and other entities contributing to the writing of the National Plan should review research findings such as those presented at the Research Summits on Dementia Care to determine if anything should be added to the Goals of the National Plan or to milestones for goals.
- E. ASPE or NIA should solicit information from agencies about their review of Research Summits on Dementia Care, including any agency plans to act now or in the future on Summit themes, research findings, and recommendations for new research. ASPE or NIA should synthesize this information and present it to the Advisory Council.

**RECOMMENDATION 2: Educate the public about early detection and diagnosis of AD/ADRD, person-centered and family-centered care planning, and the importance of and ways to enter into research.**

Education about the availability of early detection and diagnosis of AD/ADRD is important because people living with cognitive symptoms are better able to participate in person-centered planning when symptoms are in an early stage. General education and information about local/regional resources, including resources and information on recruiting and enrolling persons with cognitive impairment or dementia into research, should be easily accessible and should support the decision-making of persons at-risk for and living with AD/ADRD and their caregivers. Further research on the predictions of early diagnostic testing in terms of prognosis is a critical need. Any and all information should be updated to reflect the most recent science as the field of detection and diagnosis may evolve rapidly in the coming months and years.

- A. Federal, state, tribal, and community agencies should increase the education of the public, including disproportionately impacted populations, by enhancing linkages of national information centers to materials made available at the state and local level.
  - 1. Promotion of educational materials, such as those available through the NIA (<https://www.nia.nih.gov/health/alzheimers>), should continue including increased linkage of this information to educational resources maintained by advocacy groups and state/local health care systems.
  - 2. States and community-based providers should be encouraged to advance coordinated materials for practical use by persons at risk for and living with AD/ADRD, including those with intellectual and developmental disabilities, and their caregivers through single entry points ("No Wrong Door" <https://nwd.acl.gov/>) such as Area Agencies on Aging, Aging and Disability Resource Centers, and Community Independent Living Programs.
  - 3. States and community-based providers should be encouraged to use new educational information about care planning for persons living with

AD/ADRD, such as materials available through the National Center on Advancing Person-Centered Practices and Systems (NCAPPS) (<https://ncapps.acl.gov/about-ncapps.html>).

- B. The HHS operating divisions, the U.S. Department of Veterans Affairs (VA), and the U.S. Department of Defense (DOD) should educate the public at the national, state, and community levels about the benefits of early detection and diagnosis of AD/ADRD, including early assessment and the importance of care planning, to improve the health and well-being of older adults and their caregivers. Examples of resources include:
1. CDC's HBI Road Map for Public Health and other resources (<https://www.cdc.gov/aging/index.html>).
  2. ACL's issue brief Dementia-capable States and Communities: the Basics and other NADRC resources (<https://nadrc.acl.gov>).
  3. ACL's Brain Health: You Can Make a Difference! resources (<https://www.acl.gov/index.php/node/293>).
  4. HRSA training materials that include early detection and diagnosis of AD/ADRD. (<https://bhw.hrsa.gov/grants/geriatrics>).
  5. NIA's What is Brain Health initiative (<https://brainhealth.nia.nih.gov/>).
- C. The Advisory Council should clarify the U.S. Preventive Services Task Force's Final Recommendation Statement on Cognitive Impairment in Older Adults: Screening, explaining that while more clinical evidence is needed to assess the benefits and harms of screening in asymptomatic adults, there are important reasons to assess and diagnose early symptoms of cognitive impairment. (<https://www.uspreventiveservicestaskforce.org/uspstf/recommendation/cognitive-impairment-in-older-adults-screening>). NIA at 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, including underrepresented populations, to consider participating in research. NIA, CDC, ACL, and state/local entities should tailor recruitment materials like the ROAR Toolkit (<https://www.nia.nih.gov/health/recruiting-older-adults-research-roar-toolkit>) to include local information to meet the needs of communities.
- D. By 2025, hospitals and physician practices serving people living with AD/ADRD will have in place procedures to:
1. Identify cognitive impairment, and integrate management of cognitive impairment into the care plan. This should include addressing impact of that impairment on management of the individual's other health conditions. (Example of measurement of outcome -- John A. Hartford Foundation (JAHF) Age-Friendly Health Care Initiative Mentation measure for primary care practices.)

2. Provide a timely diagnosis for individuals who are found to have impairment, through efficient and well-coordinated care pathways and referral processes.
- E. The Administration on Community Living should encourage state units on aging and area agencies on aging to disseminate information on early detection and diagnosis of AD/ADR, including clinicians able to assess and diagnose AD/ADR in adults with cultural, language, and disability needs differing from the general population.

State units on aging should collaborate with the state's disability authority and aging and disability resource centers to compile listings of providers:

1. Who have expertise in assessing and diagnosing AD/ADR in persons with intellectual and developmental disabilities, including persons with sensory impairments and lifelong neurodevelopmental conditions.
2. Who are proficient in the main non-English languages in their communities and who are familiar with the cultural differences and values of those diverse populations and their various perceptions of cognitive impairment.

**RECOMMENDATION 3: Enhance the current and future workforce through education to better address the needs of persons living with AD/ADR and their caregivers.**

Federal agencies and others should continue to offer and support current and future workforce education to improve workforce members' abilities to work with persons living with AD/ADR, particularly diverse communities. This includes recognizing early signs and symptoms, addressing early detection and diagnosis, offering and providing counselling to persons living with AD/ADR and their family members and caregivers, and connecting them to local services and resources.

- A. Federal agencies and others should develop and disseminate specific new training models to advance workforce readiness nationally in the following areas. Agencies and others should prioritize them based on expertise, resources, and capacity.
1. Primary Care -- to train the primary care workforce about dementia and promote interprofessional teamwork in the care of persons living with dementia.
  2. Disaster Preparedness -- to train health care workers, first-responders, and individuals to recognize and better protect the health and safety of persons living with AD/ADR and their family members and caregivers who experience a disaster or hazard.

3. Acute Care -- to train individuals, first-responders, and health care workers caring for persons living with AD/ADRD in urgent care, emergency room, and hospital settings to recognize and better identify and address needs of persons living with AD/ADRD.
  4. 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 intellectual and developmental disabilities and mental health disorders.
  5. Comorbid 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, multifactorial conditions such as pain and reduced communication abilities, intellectual and developmental disabilities, and mental health disorders.
  6. Recruitment into Research -- to train health care workers and individuals on the importance of and options for recruiting persons with AD/ADRD into research. Recruiting participants into research from typical care settings is important because new research is needed on models of care that meet the needs of people living with AD/ADRD, including how to best manage complex medical and mental health conditions.
  7. Continuing Education Modules for Health Professionals about Brain Health -- to train health professionals on: the importance of early detection; the importance of risk reduction; and culturally and literacy appropriate content and materials. Available resources to address this recommendation include:
    - <https://www.nia.nih.gov/health/now-what-next-steps-after-alzheimers-diagnosis>.
    - <https://www.nia.nih.gov/health/managing-older-patients-cognitive-impairment>.
    - <https://www.nia.nih.gov/health/talking-older-patients-about-cognitive-problems>.
    - <https://www.nia.nih.gov/health/assessing-cognitive-impairment-older-patients>.
- B. One or more working group(s) of health professional associations should be convened to define skills needed by persons delivering evidence-based AD/ADRD care across care settings, and determine strategies for incorporation of the needed skills into educational materials and training in clinical and other practices.
1. The working groups should address how to train workforce members on the benefits and risks of pharmacotherapy, including the integration of medication use and "deprescribing" into comprehensive non-pharmacological approaches to care.

2. The working groups should address measures of success including how to assess that trained workforce members are incorporating learning into current practice.
- C. Federal agencies and others should align current training related to AD/ADRD care with evidence-based guidelines (including dementia practice care recommendations) and should consider them in curricula and continuing education for health professionals, first-responders, and other individuals. Examples of such recommendations include:
1. The Alzheimer's Association's 2018 Dementia Care Practice Recommendations ([https://www.alz.org/professionals/professional-providers/dementia\\_care\\_practice\\_recommendations](https://www.alz.org/professionals/professional-providers/dementia_care_practice_recommendations)).
  2. HRSA AD/ADRD Core curriculum and the HRSA Caregiving Curriculum (<https://bhw.hrsa.gov/grants/geriatrics/alzheimers-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 (<https://www.cdc.gov/aging/aginginfo/alzheimers.htm#Curriculum>).
  4. Recommendations from the National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers (<https://aspe.hhs.gov/basic-report/research-summit-dementia-care-main-summit-recommendations>).
  5. Guidance on Inappropriate Use of Antipsychotics: Older Adults with Intellectual and Developmental Disabilities in Community Settings (<https://store.samhsa.gov/product/Inappropriate%20Use%20of%20Antipsychotics%20Brief%20Guidance%3A%20Older%20Adults%20and%20People%20Living%20with%20Intellectual%20Disabilities%20in%20Community%20Settings/PEP19-INAPPUSE-BR>).
- D. Federal programs and others with such capabilities should report on the number of workforce members trained per year, and this reporting should be considered in updates to the National Plan.

**RECOMMENDATION 4: Professional groups should determine a process for those groups and non-federal stakeholders to reach consensus on definitions of best practices, including the integration of new biomarkers, for comprehensive care of AD/ADRD at all disease stages.**

There should be current best practices for comprehensive care of AD/ADRD at all disease stages, informed by evidence, so that persons living with AD/ADRD (including



racial and ethnic communities that are disproportionately affected), caregivers, health systems, and payers have similar understanding regarding diagnosis, treatment, and/or services and supports. The Advisory Council should identify an approach for outlining practices for such comprehensive care.

- A. A work group of thought leaders should be established to review practice guidelines for AD/DRD. This work group should:
  1. Involve comprehensive stakeholder input including from people living with cognitive symptoms, care partners, and other stakeholders.
  2. Consider public health approaches, data for action, and training opportunities for health professionals.
  3. Consider ACL guidance on Person-directed Services and Supports during Serious Illness:  
<https://acl.gov/sites/default/files/Aging%20and%20Disability%20in%20America/Serious%20Illness%20Principles%208-30-17%20508%20compliant.pdf>.
- B. The work group should consider factors such as the following:
  1. Elements of care and services that are based on level of function.
  2. Health disparities and cultural competencies to advance best practices.
  3. Financial concerns and options counselling for health insurance coverage and other benefits.
  4. Data elements to be potentially included in a person-centered and family-centered care plan for AD/DRD and best practices for care plan facilitation and use.
  5. Use of electronic health records to enhance person-centered planning.
  6. Development and evaluation of technologies to link persons living with AD/DRD and family members (defined broadly to include fictive kin, neighbors, friends, non-blood relatives), and other caregivers to care providers, share information more efficiently, deliver care interventions, monitor health and symptom status, and promote health and safety.
  7. Risks related to quality of life that are either perceived or actual in response to disclosure of a diagnosis of a cognitive disorder; including, for example, loss of employment or insurance in response to knowledge of a diagnosis.
  8. The potential of person-centered and family-centered planning to function continuously over time and to transcend setting; specifically, best practices for use of a person-centered plan that can function well under a range of circumstances, for example when a person with AD/DRD lives alone, does

or does not have an identified family member or caregiver, and/or transitions to a hospital or residential care setting.

9. Definitions of "dementia capability" in a health system or community, including adaptability of the processes based on a person's level of function and the setting in which the person lives.
  10. Alignment of services with the principles of "age-friendly" health systems (<https://www.johnahartford.org/grants-strategy/current-strategies/age-friendly-hospitals/>) and community activities (<http://www.who.int/ageing/age-friendly-world/en/>).
  11. Pros and cons, barriers and supports, and bioethics of various advances.
- C. The work group should consider ethical factors and make recommendations to the Advisory Council regarding the goals of the National Plan and best practices for comprehensive care.
  - D. The work group should incorporate knowledge gained from NCAPPS activities; and ACL, CMS and the Human Services Research Institute (HSRI) should expand NCAPPS activities regarding AD/ADRD, including increased technical assistance available to more states, tribes, territories, and regional entities (<https://ncapps.acl.gov/about-ncapps.html>).

**RECOMMENDATION 5: Encourage further development, evaluation, and use of health care models for AD/ADRD that align performance measures, the experience of care by persons living with AD/ADRD and their caregivers, and payment.**

Federal agencies (CMS, VA, HHS), states, and non-governmental payers for health care services should increase the use of value-based care<sup>[1]</sup> for persons living with AD/ADRD to pay for health care services in a manner that directly links health services payments to performance on cost, quality, and resource use metrics; this alignment will better support comprehensive person-centered care leading to improved health outcomes and quality of life for persons living with AD/ADRD.

- A. Initiatives delivering value-based programs should rely on definitions of value outlined by CMS and others (<https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Value-Based-Programs/Value-Based-Programs.html>).
- B. Initiatives to assess value should be informed by evidence, and new research should be conducted to study how models of care improve health outcomes, including the effective management of comorbidities.

- C. Initiatives to assess value should rely on a framework such as the CMS Meaningful Measures initiative, and apply such a framework specifically for persons living with known AD/ADRD or cognitive impairment and their family members and caregivers. This could be combined with other reporting of 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 evaluation of comprehensive models which include a per-beneficiary-per-month (PBPM) 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>).
- E. States and other payers (Medicare, Medicaid) should increase attention to cost-effective HCBS, which support person-centered care and self-determination for persons living with AD/ADRD and their caregivers.

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

### ***Goal 3: Expand Supports for People Living with AD/DRD and their Caregivers<sup>3</sup>***

#### **LTSS Themes:**

- Decrease disparities and expand access to LTSS, including HCBS.
- Improve integration of clinical care with HCBS including systematic identification, assessment, support, referral and engagement of persons living with AD/DRD and their caregivers by health care systems.
- Provide high quality, person-centered and family-centered LTSS.
- Address behavioral and psychological symptoms of AD/DRD across care settings.
- Prepare the nation to reduce risk factors thought to lead to AD/DRD.

#### **RECOMMENDATION 1: Decrease Disparities and Expand Access to Affordable LTSS, including HCBS.**

Impoverishment can be an issue for individuals and caregiving families who may be forced to stop working or to spend down their personal savings trying to purchase or furnish care for a relative with AD/DRD. Unpaid caregivers providing substantial HCBS may be less able to be productive members of the workforce. For the most part, LTSS are not covered by Medicare. And, while Medicaid covers some LTSS costs for low-income beneficiaries who qualify, for many individuals and families, out-of-pocket LTSS costs drain their personal savings. According to AARP and the National Alliance for Caregiving's report "Caregiving in the U.S." (2020), caregivers experience significant financial strains because of this role. As an example, almost one in ten say these strains have led to periods of food insecurity. Some financial strain was found to be caused by loss of work or reduction in work hours, but the cost of care itself was identified as having significant impact on financial security. The recommendations below focus on non-means-tested programs that can expand the availability of LTSS, especially in home and community-based settings.

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

- A. By 2025, programs beyond Medicaid that provide LTSS (e.g., Older Americans Act [OAA], state and non-profit programs) should be expanded to support

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<sup>3</sup> All references to "caregivers" apply to care partners, families, friends, and others with a significant relationship providing assistance to people living with AD/DRD

individuals and their caregivers with unmet needs, including diverse, underserved, and high-risk populations living with AD/ADR. <sup>4</sup>

1. Congress should increase funding for the ACL Alzheimer's Disease Program Initiative from \$23.5M to \$50M to increase the number of individuals benefitting from tailored education and supports; target the program to diverse, underserved and high-risk populations; and evaluate the program's reach and impact.
2. Congress should increase funding for the ACL National Family Caregiver Support Program (NFCSP) from \$180M to \$360M, target the program to people living with AD/ADR and their caregivers, and evaluate the reach and dementia capability of the program.
3. Congress should increase funding for the Aging and Disability Resource Centers, specifically to improve their capacity to serve people living with AD/ADR and their caregivers.
4. Congress should establish new funding for ACL respite programs, target the funding to diverse, underserved, and high-risk populations living with AD/ADR and evaluate the program's reach and impact.
5. Operating divisions within HHS such as CMS, ACL, CDC and HRSA, as well as the VA, should tailor programs to address the HCBS needs of diverse, underserved and high-risk populations living with AD/ADR and their caregivers. Disbursement of resources should consider communities and populations with the greatest need, using objective data sources (like U.S. Census data) for determinations.
6. State models for expanding the availability of LTSS and/or supporting unpaid caregivers through 1115 waivers and other strategies should be evaluated by ASPE and, if warranted, disseminated broadly to encourage adoption by other states. See the LTSS toolkit for examples: [https://www.chcs.org/media/Strengthening-LTSS-Toolkit\\_032019.pdf](https://www.chcs.org/media/Strengthening-LTSS-Toolkit_032019.pdf).
7. To protect the financial security of caregivers
  - Congress should expand the Family Medical Leave Act (FMLA) and states should expand supports for paid leave for caregivers.
  - States should expand voluntary long-term care savings accounts.
  - Congress and states should expand tax credits for caregivers.

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<sup>4</sup> Diverse, underserved and high-risk populations living with AD/ADR include but are not limited to people from minority ethnic groups or races; American Indians and Alaska Natives; lower income and lower health literacy groups; people living alone with AD/ADR; people with intellectual and developmental disabilities; people with behavioral or psychological symptoms; and people with related dementias like frontotemporal dementia, dementia with Lewy bodies, vascular dementia, etc.

- B. Expand access to HCBS through health care providers and systems:
1. An entity should be identified to monitor Medicare Advantage (MA) Health Plans determining if they are offering HCBS supplemental benefits supporting people living with AD/ADRD and caregivers and to assess utilization of these benefits.
  2. HHS should provide guidance and informational bulletins to states, payers and providers to encourage them to address the LTSS needs of people living with AD/ADRD.
  3. Congress should sustain Section 2404 protections against spousal impoverishment in the Affordable Care Act (ACA), and the section 1915(i) HCBS state plan option, Community First Choice (CFC) attendant care services and supports, and individuals eligible through a medically needy spend down to HCBS waivers.
  4. Federal agencies (Office of Civil Rights [OCR], HRSA, CMS, ACL, IHS, VA, CDC) should offer annual education to providers about Health Insurance Portability and Accountability Act (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.<sup>5</sup>

## **RECOMMENDATION 2: Improve integration of clinical care with HCBS.**

Care transitions can be especially challenging for people living with AD/ADRD. Frequently, the clinical provider (hospital, primary care provider, nursing home) does not arrange for adequate HCBS follow-up when an individual with AD/ADRD is discharged from a hospital or moves across health care settings. Often unpaid caregivers provide necessary medical follow-up, from medication monitoring to wound care. They are also the backbone of community-based supports for people living with AD/ADRD. To assure that health care systems support people living with AD/ADRD and their caregivers, HHS, states and other funders should ensure that both receive disease information (e.g. progression, symptoms, etc.) and participate in care planning as appropriate. When caregivers are identified, their needs should be assessed. While HCBS should be offered that are tailored to the person with AD/ADRD's needs, they should also take the caregiver's needs into account. HCBS services can include respite care, disease education, caregiver training, support groups, adult day services, and other home and community-based supports.

- A. By 2025, hospitals and health care provider practices serving people living with AD/ADRD will have in place procedures to:

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<sup>5</sup> Measurement: Establish a baseline and count # of trainings, # of attendees reached with this information annually. Ask for annual report outs to the Council.

1. Identify cognitive impairment, and integrate management of cognitive impairment into the Care Plan. This should include addressing impact of that impairment on management of the individual's other health conditions. (Example of measurement of outcome -- JAHF Age-Friendly Health Care Initiative Mentation measure for primary care practices.)
  2. Provide a timely diagnosis for individuals who are found to have impairment, through efficient and well-coordinated care pathways and referral processes.
  3. Identify and document a caregiver or authorized health care proxy, where appropriate, to participate in care planning and better assure goal implementation. (Example of measurement of outcomes -- JAHF Age-Friendly Health Care Initiative Mentation measure for hospitals/ AARP for study of implementation of the CARE Act.)
  4. Co-design person-centered and family-centered care plans with the individual and caregiver or authorized health care proxy (where appropriate), so that plans are concordant with the individual's goals of care and can be supported in the community or other long-term care setting.
  5. Provide training on dementia and its care to all staff who interact with people living with AD/DRD and their caregivers including customer service, food service, billing, janitorial and transportation staff as well as those providing clinical care.
  6. When undertaking discharge planning from a facility, the individual living with AD/DRD and a caregiver or authorized health care proxy, should be involved so as to lessen risk of re-hospitalization or other adverse events.
  7. Assess the person living with AD/DRD and the caregiver's LTSS needs, provide them with disease education, caregiver training and HCBS, and/or refer them to community-based services. This should include information about costs and coverages for these services.
- B. By 2025, CMS will have quality measures in place that will encourage health care systems to implement these recommendations. AHRQ and CMS should use existing measurement strategies and consider developing new measures to obtain feedback on: (i) the seamlessness of integration between clinical care and HCBS; and (ii) the experience of people living with AD/DRD and their caregivers served by the health care system, and measure satisfaction with HCBS.

### **RECOMMENDATION 3: Provide high quality, person-centered and family-centered LTSS.**

According to the National Quality Forum, the extent to which patients and their families are involved in making decisions and feel prepared to manage their conditions is critical to improving quality and reducing cost. Commonwealth Fund research has shown that person-centered and family-centered care that incorporates shared decision-making can reap potential health care savings of \$9 billion over 10 years. Accordingly, the National Quality Forum seeks to **ensure person-centered and family-centered care** across the health care landscape, and has outlined several goals to achieve this aim:

1. Improve individual, family, and caregiver experience of care related to quality, safety, and access across settings.
2. In partnership with individuals living with AD/ABRD and their caregivers -- and using a shared decision-making process -- develop person-centered and family-centered care plans that are culturally competent and understandable by the consumer.
3. Enable individuals and their caregivers to navigate, coordinate, and manage the care appropriately and effectively.

NAPA supports this approach and the need for high quality, person-centered and family-centered care planning that extends to LTSS.

In addition, there is a growing body of evidence-supported dementia and caregiving interventions, that have demonstrated impact upon a variety of outcomes meaningful to people living with AD/ABRD and caregivers. Yet these interventions are not widely available.

To provide high quality, person-centered and family-centered LTSS across care settings, it is recommended that:

- A. Research should be funded through federal agencies and other public and private funders to study the implementation of evidence-supported dementia and caregiving interventions. It should be required that developers of the interventions to be implemented have available robust tools and resources to assist with implementation of these programs. These tools may include replication guides, facilitator guides and participant materials.
- B. Federal agencies and other public and private organizations should disseminate evidence-supported interventions and person-centered and family-centered care planning models.
- C. Federal agencies and other organizations should convene representatives from professional societies (American Academy of Neurology [AAN], American



Psychological Association [APA], American Association for Geriatric Psychiatry [AAGP], American Geriatrics Society [AGS], National Association of Social Workers [NASW], etc.) in an effort to develop and harmonize practice guidelines as pertains to care planning, caregiver support and HCBS recommendations across the evidence.

- D. To expand the applicability of evidence-supported interventions for people living with AD/ADRD and for caregivers from diverse, underserved, and high-risk populations living with dementia, NIH should:
1. Establish a repository of assessment and outcome tools and instruments that have been validated for use with culturally and linguistically disparate populations.
  2. Include in the repository Electronic Health Record compatible tools that are in the public domain.
  3. Fund efforts to translate, culturally adapt and validate evidence-supported caregivers and patient interventions for diverse, underserved, and high-risk populations living with AD/ADRD.
- E. Federal agencies, states and other organizations should build workforce capacity to provide dementia capable LTSS including training on person-centered and family-centered care planning and evidence-supported interventions for people living with AD/ADRD and caregivers.
1. To address the shortage of a dementia-knowledgeable workforce:
    - Congress should allocate an additional \$25 million in funding for HRSA and CDC to support geriatric workforce training in AD/ADRD across the educational continuum including the public health workforce.
    - HRSA should continue to allocate a portion of GWEP funding uniquely toward workforce training in AD/ADRD (Currently a minimum of \$100,000 for each of 48 grant recipients).
    - CDC should continue to allocate a portion of HBI and BOLD funding uniquely toward public health workforce training in AD/ADRD.
  2. HRSA and ACL should increase education for paid and unpaid caregivers through their grant funding programs (i.e., Alzheimer's Disease Program Initiative [ADPI], NFCSP, GWEP), including funding for implementation of evidence-supported interventions and for person-centered and family-centered care planning.
  3. Federal agencies, states and other organizations should educate professionals and caregivers about evidence-supported interventions that have been adapted for diverse populations.

- F. CMS and other federal payors should create care and payment models for use of effective evidence-supported interventions for people living with AD/ADRD and caregivers, as well as for person-centered and family-centered care planning.

**RECOMMENDATION 4: Address behavioral and psychological symptoms of AD/ADRD across care settings.**

Behavioral and psychological symptoms of dementia (BPSD) are a common component of the dementia syndrome that increase morbidity and burden, affect quality of life, and impact cost of care. Recognizing that antipsychotic medications are frequently used off-label to control these symptoms and that such use can lead to excess patient morbidity and even mortality, the standard of care across all settings should encourage use of person-centered and family-centered care and promising non-pharmacological approaches first, before using antipsychotics.

To promote development of a broader range of more effective treatments for BPSD, including person-centered and family-centered care, promising non-pharmacological treatments (behavioral and lifestyle), new pharmacological treatments and neuromodulation, it is recommended that:

- A. Federal agencies (HRSA, ACL, CDC, VA, IHS, National Institute of Nursing Research [NINR]) and other organizations should continue to build workforce capacity to deliver person-centered and family-centered care as well as the use of promising and/or evidence-informed, non-pharmacological interventions for BPSD.
  1. Provide webinars and other training opportunities with this focus for the full range of care providers from direct service workers to prescribers, as well as unpaid caregivers, and increase adoption.
  2. Continue to provide dementia-specific grant funding to GWEPs and ACL grantees to educate the workforce on this issue.

**RECOMMENDATION 5: Advance Brain Health through Development and Enhancement of the Public Health and Health Care Workforces.**

Maintaining cognitive health and avoiding preventable decline is important to people living AD/ADRD, their caregivers and the general population. There is also growing awareness among legislators and public entities of the significant health, social, and economic burdens associated with cognitive decline. While there have been scientific advancements in knowledge about behaviors that may increase risk of cognitive decline, this information is not yet fully reaching the public, people living with AD/ADRD, caregivers, or the workforce.

To help reduce the prevalence of AD/ADRD, it is recommended that federal agencies (CDC, ACL, HRSA, VA, IHS, NIH, NINR, NIA) and other organizations should educate the general public, people living with AD/ADRD, their caregivers, and the workforce about evidence-informed strategies for potentially reducing risk for cognitive impairment.

- A. Increase awareness of the general public about brain health.
  1. Congress should appropriate funding to HRSA and the CDC for dissemination of evidence-informed materials and content (public service announcements, websites, social media, etc.) on brain health, risk reduction for memory loss, and the importance of decreasing stigma around AD/ADRD.
  2. The U.S. Department of Education, States and Boards of Education should develop, curricula, textbook content, and testing requirements on brain health for K-12 and college-level education; and financially support its use. Provide funding to evaluate the impact of dementia-friendly communities and age-friendly communities.
- B. Educate workforces about ways to reduce risk for cognitive impairment.
  1. Congress should appropriate \$3 million to the CDC and HRSA to educate and train workforces about:
    - State-of-the-science materials, consistent with the HBI Road Map, about maintaining brain health, recognizing signs and symptoms of cognitive impairment and AD/ADRD, and diagnosing AD/ADRD and sharing these findings with persons living with dementia and their caregivers.
    - The relationship between chronic diseases such as hypertension and diabetes, their management, and brain health.
  2. Congress should appropriate \$2 million to ACL evaluate the impact of dementia-friendly communities and age-friendly communities.

## Research Subcommittee

### Research Themes:

- Robust biomedical and holistic strategy.
- Sufficient resources.
- Consistent terminology
- Ethical data sharing
- An inclusive role for the dementia community.

**RECOMMENDATION 1: The 2020 National Plan should encourage a sense of urgency about providing a robust, comprehensive, collaborative and transformative scientific road map for achieving the goal of preventing, effectively treating, and providing effective care and services for AD/ADRD by 2025, as well as continuous progress and improvement thereafter.**

- A. A road map for accomplishing the primary goal of the National Plan should include input from experts in the field through recurring research summits on AD/ADRD, and care and services.
  1. Cross-agency collaboration between federal agencies on the annual summits is essential to advance progress. Representatives of all federal agencies involved in the National Plan should attend the summits and coordinate efforts.
  2. Federal agencies should support global efforts to address issues of research, care and services, and workforce development in order to facilitate international collaboration and minimize silos of knowledge.
  3. Emphasis on prevention and mitigation of both underlying AD/ADRD pathology and clinical symptoms and burden of illness for affected persons and their caregivers should continue and be enhanced by planning processes leading to research programs directed to these goals.
- B. Recommendations from these summits and the research community should be re-evaluated each year and translated into milestones by federal agencies involved in NAPA and relevant partners.
- C. Federal agencies should monitor progress of research milestones as described in the summit recommendations.

**RECOMMENDATION 2: A top priority remains the urgent need for Congress to continue to increase annual federal research funding sufficient to meet these goals, across biomedical, clinical, LTSS and public health.**

- A. The annual professional judgment budget required by the Alzheimer's Accountability Act and prepared by the NIH should reflect the science-driven funding needs for the budget year to enable investigators to reach the 2025 as well as longer term goals of the National Plan.
  - 1. This investment would be applied to AD/ADRD research initiatives spanning basic, translational, clinical, care and services research.
- B. All federal agencies should submit AD/ADRD research funding awards and amounts annually to the NIH International Alzheimer's Disease Research Portfolio (IADRP).

**RECOMMENDATION 3: Emphasis should be given to the standardization of terminology across the spectrum of cognition in neurocognitive disorders by all agencies involved in the National Plan, to reduce ambiguity over confusing or overlapping terms, reduce stigma associated with AD/ADRD, and improve public awareness of AD/ADRD and access to relevant resources and services.**

- A. Convene a working group of thought leaders to develop an inclusive process that will define the challenges of today's dementia-related nomenclature and propose strategies to develop improved, standardized terminology for use across different audiences without sacrificing scientific accuracy.
  - 1. As any change to dementia nomenclature can have wide-ranging impact across research, regulatory issues, clinical care, reimbursement issues and public health efforts, dementia stakeholder organizations should assist this initiative through administrative and meeting planning support and funding.
- B. Updated terminology should improve public awareness of cognitive impairment and diseases causing dementia, be culturally sensitive, be free of stigma and negative stereotypes, provide clarity between disease etiologies and clinical syndromes, address both staging of disease progression and stages of functional abilities from preclinical stage through advanced dementia, and improve identification of caregivers and also address the training needs of the workforce providing AD/ADRD care and services.
- C. The issue of dementia nomenclature should be considered in the planning of any annual summits.

**RECOMMENDATION 4: A major area of emphasis by all federal agencies involved in the National Plan should be the enhancement of recruitment efforts for research involving those with, or at-risk of developing, AD/ADRD.**

- A. Emphasis should be placed by federal and non-governmental agencies, academia, service providers and community partners on the enhancement of diversity and inclusiveness in these efforts to improve health outcomes for communities affected by health disparities.
- B. NIH should advance innovative recruitment efforts to increase recruitment and retention in randomized controlled clinical trials. (See Recommendation 2 in clinical care.)
- C. All federal and non-federal agencies funding AD/ADRD research should require documentation of recruitment goals in applications for clinical research; incentives should also be in place for meeting those goals.

**RECOMMENDATION 5: Federal agencies should develop a strategy and infrastructure to increase ethical and open sharing of, access to, and utilization of research data and samples. There should be a continued emphasis on ethics, in collaboration with academia, the pharmaceutical industry, biotech and information system industries. This strategy should accelerate the pace of scientific discovery in AD/ADRD science by addressing a comprehensive range of issues including cross-sector data and biosample sharing practices and policies, data harmonization and interoperability, and the training of data scientists and biobanking experts in AD/ADRD research.**

- A. Special emphasis is needed on data sharing of completed biomarker studies and drug and non-drug clinical trials, including industry-sponsored trials. Patient advocacy and regulatory changes may be required.
- B. Emphasis is needed on methods for early recognition and progression of disease using cutting edge technologies, and establishment of biobanks of cells and biofluids from well phenotyped, diverse individuals reflective of the heterogeneity of AD/ADRD.
- C. To expand access to brain tissue needed for AD/ADRD research purposes, NIH should explore gaps in tissue availability for research, and review and refine the current infrastructure at NIH supported tissue repositories, including the NeuroBioBank and Alzheimer's Disease Research Centers (ADRCs), to fill these gaps. Continuing attention should be placed on consent issues, harmonizing protocols, and data sharing practices.

**RECOMMENDATION 6: All federal and non-governmental agencies funding AD/ADRD research, along with the Patient-Centered Outcomes Research Institute (PCORI), academia and industry, should establish the engagement of the AD/ADRD community as a standard practice in both participating in setting national research priorities for AD/ADRD and throughout all stages of clinical research and care, and LTSS research.**

- A. NIH, federal agencies involved in NAPA, and PCORI should develop evidence-base for optimal methods, assessment and impact of engaging persons with AD/ADRD and their care partners, leveraging international expertise as needed.
- B. NIH should establish funding methods to support participant/caregiver engagement in all AD/ADRD clinical research, including leveraging ongoing guidance to the field on methods of research engagement from PCORI, through its reauthorization by Congress.
- C. Through participant/caregiver engagement, NIH, other federal agencies, and PCORI should identify meaningful person and caregiver-centered outcomes and validated measures for AD/ADRD by disease etiology.
- D. Enhance methodologies to effectively engage persons living with AD/ADRD, families and caregivers in research on decision-making and care planning.
- E. NIH, other agencies involved in NAPA, and PCORI should establish methods for researchers and other stakeholders to identify how research stakeholder engagement is integrated into study planning, conduct and reporting, as well as dissemination and implementation.