

# 2021 PROPOSED PUBLIC MEMBER RECOMMENDATIONS

## Clinical Care Subcommittee

### Clinical Care Themes:

- 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.
- The Medicare two-year wait for younger individuals living with Alzheimer's and related dementias.

### **RECOMMENDATION 1: 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 as well as those at risk for cognitive decline into research, should be easily accessible. Such information and resources should support care coordination, patient safety, and 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, should continue including increased linkage of this information to educational resources maintained by advocacy groups and state/local health care systems. [<https://www.nia.nih.gov/health/alzheimers>]
  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 (IDD), and their caregivers through single entry points ("No Wrong Door") such as Area Agencies on Aging, Aging and Disability Resource Centers, and Community Independent Living Programs. [<https://nwd.acl.gov/>]

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 to include local information to meet the needs of communities.  
[<https://www.nia.nih.gov/health/recruiting-older-adults-research-roar-toolkit>]
- D. By 2025, hospitals and healthcare provider 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 the 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. ACL should encourage state units on aging and area agencies on aging to disseminate information on early detection and diagnosis of AD/ADRD, including clinicians able to assess and diagnose AD/ADRD 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/ADRD in persons with *IDD*, 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.
- F. The NIA should identify protocols and instruments as well as issue guidelines for the screening, assessment, and diagnosis of adults with cultural, language, and disability backgrounds differing from the general population where commonly used protocols and instruments may not easily apply or lead to misdiagnosis.
  1. Such guidelines should include a listing of major language translations of commonly used instrument for use with non-English primary speakers
  2. Such guidelines should include a listing of instruments appropriate to be used with disability groups with varying cognitive functioning levels, such as adults with IDD and TBI.

**RECOMMENDATION 2: Enhance the current and future workforce through education to better address the needs of persons living with AD/ADRD 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/ADRD, particularly diverse communities. This includes recognizing early signs and symptoms (within a cultural context), addressing early detection and diagnosis, offering and providing counselling to persons living with AD/ADRD 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. Dementia Care Management -- to train dementia care managers (nurses and social workers) within healthcare organizations to effectively support people with dementia and family caregivers.
3. 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/ADRD and their family members and caregivers who experience a disaster or hazard.
4. 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.
5. Behavioral Health -- to train health care workers, first-responders, and individuals to recognize and better address needs of persons living with AD/ADRD including those living with IDD and mental health disorders.
6. 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, IDD, and mental health disorders.
7. Pre-Existing Cognitive Conditions -- to train workers to recognize differences in behavior and function among individuals with pre-existing cognitive and psychiatric disabilities so as to be able to distinguish signs and symptoms of MCI or dementia from personal typical areas of function.
8. Recruitment into Research -- to train health care workers and individuals on the importance of and options for recruiting persons with AD/ADRD into research. 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.
9. 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:

- a. [<https://www.nia.nih.gov/health/now-what-next-steps-after-alzheimers-diagnosis>]
  - b. [<https://www.nia.nih.gov/health/managing-older-patients-cognitive-impairment>]
  - c. [<https://www.nia.nih.gov/health/talking-older-patients-about-cognitive-problems>]
  - d. [<https://www.nia.nih.gov/health/assessing-cognitive-impairment-older-patients>]
- 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>]
  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/Guidance-on-Inappropriate-Use-of-Antipsychotics-Older-Adults-and-People-with-Intellectual-and-Developmental-Disabilities-in-Community-Settings/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 3: 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/ADRD. This work group should:

1. Involve comprehensive stakeholder input including from people living with cognitive symptoms, care partners, and other stakeholders.
2. Include experts from fields of intellectual and developmental disabilities, brain injury and PTSD, psychiatry and from cultural groups knowledgeable about these fields.
3. Consider public health approaches, data for action, and training opportunities for health professionals.
4. 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/ADRD 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/ADRD 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/ADRD 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/>] 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 activities through the NCAPPS; and ACL, CMS and the Human Services Research Institute should expand NCAPPS activities regarding AD/ADRD, including increased technical assistance available to more states, tribes, territories, and regional entities.  
[\[https://ncapps.acl.gov/about-ncapps.html\]](https://ncapps.acl.gov/about-ncapps.html)

**RECOMMENDATION 4: 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 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. [\[https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Value-Based-Programs/Value-Based-Programs.html\]](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 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 and consider means to reimburse these providers for their services to patients.

**RECOMMENDATION 5: Conduct research to assess the need for eliminating the two-year waiting period for younger individuals living with Alzheimer's and related dementias who have been deemed eligible for Social Security Disability Insurance (SSDI) to have access to Medicare.**

Access to Medicare is critical to individuals living with Alzheimer's and related dementias, and the two-year waiting period for younger individuals who have been deemed eligible for Social Security Disability Insurance (SSDI) is a major barrier to care and services.

Because eliminating this waiting period will require an act of Congress, however, these policymakers need to better understand the impact of this wait on beneficiaries with dementia and the health care system. Therefore, the Advisory Council recommends gathering additional and updated data to support policy proposals, including:

- A. Data on health insurance and Medicaid coverage of SSDI beneficiaries during the waiting period.
- B. Research on the health care coverage and other costs required to meet these individuals' needs, including through the Marketplace, employer-sponsored coverage, and Medicaid.
- C. An estimate of the impact elimination of the waiting period would have on the Medicare Trust Fund.

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

### **LTSS Themes:**

- Decrease disparities, increase equity, and expand access to and utilization of long-term services and supports (LTSS), including home and community-based services (HCBS).
- Improve integration of clinical care with HCBS including systematic identification, assessment, support, referral, and engagement of persons living with ADRD and their caregivers by health care systems.
- Provide high quality, person and family-centered LTSS.
- Develop a dementia capable LTSS work force.
- Address behavioral and psychological symptoms of ADRD across care settings.
- Improve and expand LTSS emergency preparedness.

### **RECOMMENDATION 1: Expand access to and utilization of affordable home and community-based services (HCBS), particularly for people living with ADRD who are marginalized, historically underserved, or disproportionately affected by dementia.<sup>1</sup>**

HCBS supports and services are provided in the home or community to people with disabilities or to their caregivers.<sup>2</sup> These can include personal care, homemaker services, respite care, caregiver training, support groups, adult day services, and other supports. For the most part, while HCBS services are not covered by Medicare, Medicaid does cover some HCBS costs for low-income beneficiaries who qualify. For many individuals and families, out-of-pocket costs drain their personal savings. For people who meet functional and financial criteria, Medicaid will cover nursing home costs as an entitlement, but often will not cover the same needed services in the community -- even though most people prefer to receive care in the community.

In addition, 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 (which may result in mal- or undernutrition). 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 programs that can expand the availability of LTSS, especially in home and community-based settings. They respond to social determinants

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<sup>1</sup> Populations that are marginalized, historically underserved, and disproportionately affected by dementia include but are not limited to: people from minority ethnic groups or races; American Indians, Alaskan Natives and Native Hawaiians; immigrants; lower income and lower health literate groups; people living alone with ADRD; members of the LGBTQ+ community, people with intellectual, developmental or physical disabilities; people with behavioral or psychological symptoms of dementia (BPSD); and people with other dementias such as frontotemporal dementia, dementia with Lewy bodies, early-onset from various causes, and vascular dementia.

<sup>2</sup> All references to "caregivers" apply to care partners, families, friends, authorized proxies, and others with a significant relationship, who are assisting people living with ADRD.

of health (SDOH) such as caregiver availability, food insecurity, and access to transportation, and recognize the need to address root causes of inequities, such as structural racism and discrimination that can influence access to and availability of care.

To help assure that all people living with ADRD, and their families can access the LTSS they need, including HCBS, the Advisory Council recommends that:

- A. By 2025, expand access to HCBS offered through Medicaid.
  1. Congress should make HCBS an entitlement under Medicaid by passing appropriate legislation and rebalancing Medicaid funding to support beneficiaries in home and community-based settings. CMS should continue to monitor states' efforts to rebalance.
  2. Congress and states should recognize the role played by caregivers in the delivery of HCBS and assure availability of culturally appropriate services and supports for caregivers. This includes offering voluntary family caregiver assessments and tailored supportive services to address needs and SDOH identified in the assessments.
  3. Congress should require states to include the option for consumer (or surrogate) direction in all Medicaid HCBS programs.
  4. HHS should provide guidance and information to states, payers, and providers about historical trauma, structural racism, and mental, emotional and spiritual health, and require them to develop strategies and initiatives to address the SDOH needs of people living with ADRD.
  5. Congress should appropriate funding to the Department of Health and Human Services' Office of Minority Health and Health Equity (OMHHE) to provide leadership and support to states in:
    - a. The development and delivery of HCBS for marginalized and historically underserved people living with ADRD; and
    - b. In improving access for people living with ADRD and their caregivers who have low health literacy or speak English as a second language.
  6. Congress should require state HCBS programs to implement strategies for addressing the way marginalized and historically underserved people with dementia and their caregivers experience disproportionate barriers to care.
  7. Congress should increase funding to the Indian Health Service (IHS) to support Tribal development and delivery of dementia -- specific HCBS for American Indians, Alaskan Natives and Native Hawaiians.
  8. The HHS Office of the Assistant Secretary for Planning and Evaluation should evaluate state models for expanding the availability of LTSS and/or supporting unpaid caregivers through 1115 waivers and other strategies. The results of these evaluations should be disseminated broadly to encourage adoption by other states.
- B. By 2025, expand access to HCBS through Medicare, addressing social determinants of health (SDOH).

1. CMS should monitor Medicare Advantage (MA) Health Plans encouraging inclusion of benefits that address the needs of people living with ADRD and their caregivers and address SDOH in this population.
  2. Congress should consider legislation that provides a ‘compassionate allowance’,<sup>3</sup> accelerating Medicare coverage for people with young onset ADRD by eliminating the 24-month waiting period from diagnosis to eligibility.
  3. Congress should authorize and CMS should implement successful models from the CMS Innovation Center and the Department of Veterans Affairs (VA) for adults living with ADRD, exploring a package of HCBS benefits that can provide reimbursement through Medicare (such as disease education, respite services, adult day services, and patient supports).
- C. By 2025, expand, fully fund, and promote LTSS programs beyond Medicaid that support individuals living with ADRD and their caregivers, including populations that are marginalized, historically underserved, and disproportionately affected by dementia.
  1. Congress should increase funding to \$50M for the Administration on Community Living (ACL) Alzheimer’s Disease Programs Initiative.
  2. Congress should double funding for the Older Americans Act (OAA) to increase the number of individuals living with ADRD and caregivers benefitting from its services and supports. A portion of the funds for each OAA program should be required to be used for people living with dementia and their caregivers, with targeted efforts to meet the needs of populations of older Americans that are marginalized, historically-underserved, and disproportionately affected by dementia.
  3. Congress should increase funding for Aging and Disability Resource Centers (ADRCs)/No Wrong Door systems by \$100M to improve access to public and private LTSS for people living with dementia and their caregivers, regardless of payor or income.
  4. Increased funding should be provided to ACL’s Office for American Indians, Alaskan Natives and Native Hawaiians, specifically for work supporting people living with ADRD and caregivers, and to ACL’s National Alzheimer’s and Dementia Resource Center to provide technical assistance and other support to improve the delivery of OAA programs for these populations.
- D. To protect the financial security of people living with ADRD and their caregivers, by 2025:
  1. Building upon past efforts and actuarial data, Congress should pass legislation to create a system to sufficiently finance long-term services and supports that shield families impacted by ADRD from impoverishment.
  2. Congress should expand the Family Medical Leave Act (FMLA) and States should make paid family leave more available and responsive to the needs of ADRD caregivers.

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<sup>3</sup> Compassionate allowances are a way to quickly identify diseases and other medical conditions that, by definition, meet Social Security's standards for disability benefits.

- a. Expand the FMLA to include siblings, grandchildren, other kin, and others taking on caregiving responsibilities.
- b. Expand the FMLA to apply to adult chronic conditions and to caregiving responsibilities.
- c. Expand the definition of leave to include attending training and education on caregiving duties and responsibilities, discharge planning meetings, and care planning meetings.
- 3. Congress and States should make tax credits available for caregivers of people living with ADRD as has been done for families with other dependents.
- 4. States should expand voluntary long-term care savings accounts and other strategies that enable families to save funds to pay for long term care.
- 5. Congress should strengthen private long-term care insurance opportunities and ensure consumer protections.
- 6. Congress should allocate funding to the administering agencies (of the programs identified in this section) to increase financial literacy and make information about these opportunities available in plain language and via translations in multiple languages.

**RECOMMENDATION 2: Ensure people living with ADRD and their caregivers are integral parts of the clinical care team and encourage coordination of clinical care with HCBS.**

To assure that healthcare systems support people living with ADRD and their caregivers, the U.S. Department of Health and Human Services (HHS), states, and other funders should ensure that both caregivers and care recipients receive disease information (e.g., progression, symptoms, etc.), and participate in care planning as appropriate. Caregivers of people with moderate to severe dementia should be proactively identified, their needs should be assessed, and resources should be provided to address these needs, including addressing SDOH. While HCBS should be tailored to the person with ADRD's needs, they should also take the caregiver's needs into account.

- A. By 2025, hospitals, health plans, federally qualified health centers, mobile clinics, and physician practices serving people living with ADRD will have in place procedures to:
  - 1. Identify cognitive impairment, and integrate management of cognitive impairment into the individual's care plan. This should include addressing impact of that impairment on management of the individual's other health conditions.
  - 2. Provide a timely diagnosis that is trauma-informed and led with cultural humility for individuals who are found to have impairment, through efficient and well coordinated care pathways and referral processes.
  - 3. Identify and document a caregiver(s), where appropriate, to participate in care planning and more effective goal implementation.

4. Design person and family-centered care plans with the individual and caregiver, where appropriate, so that plans are concordant with the individual's goals of care and can be supported in the home, community or other long-term care settings. Plans should include emergency preparedness that is trauma-informed and utilizes community care or crisis services prior to relying upon law enforcement personnel.
  5. Identify the person living with ADRD and the caregiver's LTSS needs using culturally and literacy-level competent tools, provide them both with disease and condition education, caregiver skill development training and HCBS supports, and/or refer them to appropriate community-based services. This should include information about costs and coverages for these services.
  6. Hire, train, and promote the inclusion of health and long-term care providers that reflect the racial and ethnic diversity of the community.
- B. By 2025, CMS will formulate or adopt quality measures that 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:
1. The impact of home and community-based services on health outcomes.
  2. The number of patients with moderate to severe ADRD who have a caregiver identified in their medical records.
  3. The number of identified caregivers whose needs have been assessed using a validated tool.
  4. The experience of diverse people living with ADRD, and their caregivers receiving disease education and referral to home and community-based supports from health care providers.

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

According to the National Quality Forum, the extent to which patients and their families are involved in making decisions and are feeling prepared to manage their conditions is critical for improving quality and reducing cost. Commonwealth Fund research has shown that person and family-centered care that incorporates shared decision-making can reap potential healthcare savings of \$9 billion over 10 years.

- A. To improve individual and caregiver experience of care related to quality and safety across settings:
1. HHS should provide training and guidance to create care plans that:
    - a. Ensure person and family-centered care across the care continuum.
    - b. Encourage use of shared decision-making processes, in partnership with individuals living with ADRD and their caregivers (as appropriate), to develop person and family-centered care plans that are culturally conscious and understandable by the consumer.
    - c. Are provided in a way that promotes health equity, personal authenticity, and addresses sources of discrimination or segregation.

- d. Integrate solutions for addressing individual barriers related to SDOH.
    - e. Enable individuals and their caregivers to navigate, coordinate, and manage care appropriately and effectively.
  - 2. Federal agencies and other public and private organizations should disseminate culturally responsive, person and family-centered care planning models, including those for use in emergency situations.
- B. There is a growing body of evidence-supported dementia and caregiving interventions with demonstrated impact upon a variety of outcomes that are meaningful to people living with ADRD and to their caregivers. Yet these interventions are not widely available. To improve the quality and availability of education and supports for people living with ADRD and their caregivers, the Advisory Council recommends:
- 1. Federal agencies and other funders should support research on dementia and caregiver assistance models and interventions, focusing specifically on interventions developed for marginalized and historically underserved populations.
  - 2. Federal and other funders of research on interventions should require developers to create robust tools and resources to assist with implementation such as replication guides, facilitator guides, and participant materials.
  - 3. Federal agencies and other public and private organizations should disseminate information about evidence-supported dementia interventions, including those for use with diverse groups and those developed for emergency situations.
- C. To expand the applicability of evidence-supported interventions for people living with ADRD and for caregivers, including those from populations that are marginalized, historically-underserved, and disproportionately affected by dementia:
- 1. Congress should provide funding to NIH to establish a repository of assessment and outcome tools and instruments that have been validated for use with culturally and linguistically diverse populations. Include Electronic Health Record-compatible tools that are in the public domain in the repository.
  - 2. Congress and other entities should fund efforts through NIH, ACL, VA, HRSA, Department of Justice (DoJ), and non-federal organizations to translate, culturally adapt, and validate evidence-supported caregiver and patient interventions for populations that are marginalized, historically underserved, and disproportionately affected by dementia and their caregivers.
  - 3. Congress and other entities should fund efforts through NIH, ACL, VA, and other federal and non-federal organizations to develop and test new interventions for populations that are marginalized, historically underserved, and disproportionately affected by dementia and their caregivers.
- D. Federal, state, and private entities that fund LTSS should pay for interventions that have demonstrated positive outcomes for people living with ADRD or caregivers. Federal payors should create care and payment models for use of effective

evidence-supported interventions for people living with ADRD and caregivers, as well as for person and family-centered care planning.

#### **RECOMMENDATION 4: Develop a dementia capable LTSS workforce.**

Over the years, numerous studies and reports have documented shortages of competent personnel to manage, supervise and provide LTC services in facility-based and home care settings. These shortages have been attributed to high staff turnover and difficulty attracting new providers, which in turn have ascribed to high workload demands, low levels of compensation, lack of training and career advancement opportunities, and to high injury rates. This inadequately supported and trained workforce contributes to compromised quality of care and safety issues for people living with ADRD. It also impacts quality of life for both care recipients and their care providers. As noted by Leading Age, an industry association, “As a result of growing demand from aging baby boomers and a shrinking of the traditional caregiver labor pool, the future will be immeasurably worse without decisive action by both the public and private sectors.”

Shortages in a well-trained and adequate workforce leaves residents of long-term care facilities particularly vulnerable, especially during public health and other emergencies. This has been evident during the Covid-19 pandemic where ill-preparation, inadequate staffing, and minimal training contributed in part to the devastating death tolls among residents.

To better prepare for our aging population and to avoid the catastrophic impact of future 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.

- A. Federal agencies, states, and other organizations should build workforce capacity to provide dementia capable LTSS, including training on person and family-centered care planning, and education about evidence-supported interventions for people living with ADRD and their caregivers. To address the shortage of a dementia-capable workforce:
  1. Congress should allocate an additional \$25 million in funding for HRSA and CDC to support geriatric workforce training in ADRD care across the educational continuum and include the public health workforce. The training content and processes and the presenters should reflect the needs of diverse communities.
  2. Congress should allocate \$10 million to HRSA to convene an expert workgroup to:
    - a. Define and develop roles and responsibilities within a profession/discipline/job that encompasses oversight, management, and coordination of referrals to LTSS for persons living with ADRD.

- b. Create and set milestones and core competencies for these scopes of practice/work.
    - c. Identify and/or develop educational programming to train individuals to become qualified to perform these roles and responsibilities.
  - 3. HRSA should continue to allocate a portion of GWEP funding, not less than \$100,000 per grantee, uniquely toward workforce training in ADRD, encourage participation in training by students and trainees of color and those representing marginalized communities.
  - 4. Federal agencies (OCR, HRSA, CMS, ACL, IHS, VA, CDC) should offer annual education to providers about HIPAA regulations and circumstances for appropriate communication about patient protected personal health information to unpaid caregivers to address the perception by health providers that HIPAA prevents such communication.
  - 5. CDC should continue to allocate a portion of Healthy Brain Initiative and BOLD funding uniquely toward public health workforce training in ADRD, encouraging participation by students, trainees, and workers from diverse racial and ethnic communities.
  - 6. HRSA and ACL should increase education for paid and unpaid caregivers through their grant funding programs (i.e., ADPI, NFCSP & GWEP), including funding for implementation of evidence-supported interventions that reflect the diversity of our communities and for person and family-centered care planning. HRSA and ACL should expand training on emergencies, including pandemics, into their existing curricula.
  - 7. HRSA, ACL, healthcare and LTSS systems should provide dementia and dementia care training that is culturally competent to all staff who interact with people living with ADRD and their caregivers including, but not limited to, customer service, food service, billing, janitorial, security, and transportation staff as well as those providing clinical care.
  - 8. Federal agencies, states and other organizations should educate professionals and caregivers about evidence-supported interventions including those that have been adapted and developed for use with diverse populations.
  - 9. Federal and state agencies should provide LTSS providers with guidance on dementia and dementia care training requirements for enhancing the competency of this workforce.
- B. Given the importance of the direct care workforce for the delivery of quality LTSS:
- 1. Federal, state, and other public and private organizations should assure that the direct care workforce is paid a living wage, receives health and family care benefits, and has paid time off.
  - 2. Federal, state, and other public and private organizations should promote transparency and share data about worker turnover rates and/or incorporate turnover rates into quality or star-ratings.

## **RECOMMENDATION 5: Address behavioral and psychological symptoms of 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. Morbidity and burden are higher among Black, indigenous, people of color, and other marginalized communities, including those living in deprivation. While some BPSD behaviors are the result of frustration, stress, and being overwhelmed, some are organic and related to underlying psychiatric factors, including psychotic reactions. Recognizing that anti-psychotic 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 care and promising nonpharmacological approaches first, before using antipsychotics.

To promote development of a broader range of more effective treatments for BPSD, including person-centered care, promising nonpharmacological interventions (behavioral and lifestyle), the Advisory Council recommends the following.

- A. Federal agencies (HRSA, ACL, CDC, VA, IHS, NINR) and other organizations should continue to build the capacity of the workforce (paid and unpaid) to deliver person-centered care and/or evidence-informed, nonpharmacological interventions to address 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 to unpaid caregivers, to increase adoption.
  2. Continue to provide dementia-specific grant funding to GWEPS and ACL grantees to educate the workforce on the issues of dementia-capable and culturally competent care.
  3. Disseminate the findings from the various nonpharmacological intervention outcomes stemming from the ACL's ADPI funded dementia care program projects.
- B. NIH, NINR, and other federal entities should fund research assessing the effectiveness of nonpharmacological interventions for BPSD.

## **RECOMMENDATION 6: Improve and expand LTSS emergency preparedness to better address the needs of the ADRD community.**

The experience of the COVID-19 pandemic has highlighted the vulnerability of individuals living with ADRD and their caregivers, especially those living in congregate settings, in socially and financially deprived conditions, and those in some marginalized groups or cultures. Older adults living in long-term care facilities (roughly 50% of whom have 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.

For example, people with 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 potentially 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 due to fear of exposure, and social distancing requirements, informal caregivers are often 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 isolation for both individuals living with ADRD and their caregivers, often resulting in anxiety, depression, and poor health outcomes. The cumulative effect of disruption of routines and reduced access to essential care and support services are compounded by increased stress and social isolation. These combined stressors call upon the mobilization of current resources and the development of new protocols to meet these urgent needs.

The 2013 Pandemic and All-Hazards Preparedness Reauthorization Act<sup>4</sup> defines at-risk individuals as “children, older adults, pregnant women, and individuals who may need additional response assistance.” Examples of these populations may include but are not limited to individuals with disabilities, individuals who live in institutional settings, individuals from marginalized cultures, individuals who have limited English proficiency or are non-English speaking, individuals who are transportation disadvantaged, individuals experiencing homelessness, individuals who have chronic medical disorders, and individuals who have pharmacological dependency. This includes the ADRD community.

Drawing upon recommendations in this act and the FEMA Addendum: Delivering Personal Assistance Services in Congregate and Non-Congregate Sheltering, to address the specific needs of individuals living with ADRD, their family caregivers and professional caregivers, the Advisory Council recommends:

- A. Enhancing training for essential emergency personnel and first responders. Federal Emergency Management Agency (FEMA), in coordination with HHS and the DOJ, should develop and disseminate additional specialized training for these personnel at federal, state, and local levels, and to non-governmental agencies (such as community crisis response) on responding to individuals living with ADRD, including the role of formal and informal caregivers.
- B. Developing care plans for when primary caregivers are unavailable. HHS Office of the Assistant Secretary for Preparedness and Response (ASPR) should develop recommended protocols for emergency planning and response for individuals living with ADRD, including developing alternative plans of care for situations when a caregiver becomes unavailable.

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<sup>4</sup> US HHS Public Health Emergency 8 Mar 2021.  
<https://www.phe.gov/Preparedness/planning/abc/Pages/atrisk.aspx>.

1. ASPR should convene partner agencies, including but not limited to ACL, CDC, CMS, HRSA, VA, and FEMA, and consult with recipients of LTSS to assure that protocols are:
    - a. Relevant to a wide variety of LTSS recipients, providers, workers, settings, and services.
    - b. Distributed to stakeholders and providers.
    - c. Designed to be integrated into relevant regulations, trainings and/or guidance, where applicable.
  2. The 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.
  3. 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. Updating LTSS provider regulations.
  1. CMS should update its nursing facility, home health, and hospice regulations with consideration to lessons-learned during the COVID-19 pandemic to:
    - a. Assure that meaningful standards are in place for the necessary staff, training, and equipment to care for residents under emergency circumstances.
    - b. 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.
    - c. 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. CMS should authorize states to provide temporary access to Medicaid and HCBS for those Medicaid-eligible nursing facility residents who move in with family temporarily during emergencies.
    - a. 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. Providing education to consumers, caregivers, and health care providers.
  1. ACL, in partnership with ASPR, 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 be culturally conscious, offered in multiple languages, and include a person-centered approach.

2. 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.
3. States, in partnership with FEMA should be encouraged to fund the creation of state-level, voluntary registries for local emergency response, starting by piloting and assessing the impact of such a model in disaster-prone states.

## **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 2021 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 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 NAPA 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.
  4. Continued support of innovative clinical trials, new target validation, and transformative programs should be encouraged by NIH and other federal agencies.
  5. Continued and renewed emphasis on disparities in risk for dementia in accord with the Presidential Executive Order on advancing racial equity and support for underserved communities related to racial, ethnic, environmental, social, and sex disparities.
  6. Increased emphasis on how to make a difference in the “real world” with support of implementation science and outcomes research, especially in the fields of dementia care and caregiving.
- 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 plan.
  - 1. This investment would be applied to AD/ADRD research initiatives spanning basic, translational, clinical, care and services research, as well as emphasis on data sharing, and open science.
  - 2. This analysis should explicitly include response to public health emergencies and disasters that especially impact people with dementia, such as COVID-19.
- 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. A working group of thought leaders should continue 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. A report from the working group, and discussion 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 clinical research studies, especially randomized controlled clinical trials (see recommendation on clinical care).

**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.
- B. Continued support and emphasis are needed on methods for early recognition and progression of disease using cutting edge technologies, for example the 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, and on workforce development.

**RECOMMENDATION 6: All AD/ADRD research 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, services and support research.**

- A. Enhance methodologies to effectively engage persons living with AD/ADRD, families and caregivers in research on decision making and care planning.
- B. 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.