

PUBLIC MEMBERS OF THE ADVISORY COUNCIL ON ALZHEIMER'S RESEARCH, CARE AND SERVICES: 2018 Recommendations

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.
- 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 National Research Summit on Care, Services and Supports for Persons with Dementia and their Caregivers.

The research findings presented at the 2017 National Research Summit on Care, Services and Supports for Persons with Dementia and their Caregivers and the final set of research recommendations should be incorporated into federal agencies' and others' current plans to improve care for AD/ADRD; gaps in evidence should be addressed by appropriate funders; and, the 2019 National Plan should be updated based on Summit themes and findings.

- a. Federal agencies and others should review the research findings presented at the Care Summit and 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 to federal agencies in addition to NIH to address research recommendations of the Care and Services Summit. 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 Summit on Care and Services.
- d. ASPE should integrate the 12 themes derived from the Care Summit into their meeting planning and deliberations and consider how they may inform the goals and strategies of the National Plan.

- e. ASPE and NIA should build upon the research recommendations of the first National Research Summit on Care and Services in planning for the March 24-25, 2020 Research Summit on Dementia Care.

RECOMMENDATION 2: Educate the public about early detection and diagnosis of AD/ADRD and the importance of and ways to enter into research.

Education about 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.

- a. Federal, state, and community agencies should increase the education of the public by enhancing linkages of national information centers to materials made available at the state and local level.
 - 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 healthcare systems.
 - 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 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.
- b. The HHS operating divisions, the VA, and the Department of Defense 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:
 - CDC’s Healthy Brain Initiative Road Map for Public Health and other resources (<https://www.cdc.gov/aging/index.html>).
 - ACL’s issue brief Dementia-capable States and Communities: the Basics and other National Alzheimer’s and Dementia Resource Center (NADRC) resources (<https://nadrc.acl.gov>).
 - ACL’s Brain Health: You Can Make a Difference! resources (<https://www.acl.gov/index.php/node/293>).
 - HRSA training materials that include early detection and diagnosis of AD/ADRD. (<https://bhw.hrsa.gov/grants/geriatrics>).
 - NIA’s What is Brain Health initiative (<https://brainhealth.nia.nih.gov/>).
- c. The U.S. Preventive Services Task Force’s should inform the public about recommendations from the research plan for Cognitive Impairment in Older Adults: Screening

<https://www.uspreventiveservicestaskforce.org/Page/Document/final-research-plan/cognitive-impairment-in-older-adults-screening1>).

- d. 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.

RECOMMENDATION 3: 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, including recognizing early signs and symptoms, 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 specific new training models to advance workforce readiness nationally in the areas of:
 - 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.
 - 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.
 - Behavioral Health -- to train health care workers, first-responders and individuals to recognize and better address needs of persons living with AD/ADRD live with mental health disorders such as substance use disorder, and mood disorders including depression or suicidal thoughts.
 - 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 and mental health syndromes such as pain and reduced communication abilities.
 - Recruitment into Research -- to train health care workers and individuals on the importance of and options for recruiting persons with AD/ADRD into research.
 - Continuing Education Modules for Health Professionals about Brain Health based -- to train health professionals on: the importance of early detection;

the importance of risk reduction; and, culturally 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.
- c. Federal agencies and others should align current training related to AD/ADRD care with evidence based guidelines (including new 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:

- The Alzheimer's Association's 2018 Dementia Care Practice Recommendations (https://www.alz.org/professionals/professional-providers/dementia_care_practice_recommendations)
- HRSA Alzheimer's Disease and Related Dementias Core curriculum and the HRSA Caregiving Curriculum (<https://bhw.hrsa.gov/grants/geriatrics/alzheimers-curriculum>)
- 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>)
- 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>)

RECOMMENDATION 4: Determine a process for reaching consensus on national definitions of best practices 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 so that persons living with AD/ADRD, caregivers, health systems and payers have similar understanding regarding diagnosis, treatment and/or services and supports; and the Advisory Council should identify an approach for outlining practices for such comprehensive care.

- a. A federally-organized work group of thought leaders should be established to review practice guidelines for AD/ADRD. This work group should:
 - Involve comprehensive stakeholder input including from people living with cognitive symptoms, care partners and other stakeholders.
 - Consider public health approaches, data for action, and training opportunities for health professionals.
 - Consider ACL guidance on person-center dementia care (<https://www.acl.gov/news-and-events/acl-blog/person-centered-planning-and-self-direction-hhs-issues-new-guidance>)
- b. The work group should consider factors such as the following:
 - Elements of care and services that are based on level of function.
 - Health disparities and cultural competencies to advance best practices.
 - Financial concerns and options counselling for health insurance coverage
 - Data elements included in a person-centered care plan for AD/ADRD and best practices for care plan use.
 - Use of electronic health records to enhance person-centered planning.
 - 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 safety.
 - 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.
 - The potential of person-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 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.
 - 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.
 - Alignment of services with the principles of “age friendly” health systems (<https://www.johnhartford.org/grants-strategy/current-strategies/age-friendly-hospitals/>) and community activities (<http://www.who.int/ageing/age-friendly-world/en/>)
 - Pros and cons, barriers and supports, 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.

RECOMMENDATION 5: Encourage further development, evaluation and use of healthcare 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 care¹ 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 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 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:
 - Cognitive Impairment and Assessment Care Planning Codes.
 - Quality Payment Program measures relevant to AD/ADRD.
 - Use of Medicare’s Annual Wellness Visit.
- c. Congress and/or federal agencies should authorize and/or designate funding to conduct large-scale 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.
- d. States and other payers (Medicare, Medicaid) should increase attention to cost-effective home and community-based services (HCBS), which support person-centered care for persons living with AD/ADRD and their caregivers.

¹ Value-Based Healthcare: “a healthcare delivery model in which providers, including hospitals and physicians, are paid based on patient health outcomes” (<https://catalyst.nejm.org/what-is-value-based-healthcare>) .

Long-Term Services and Supports (LTSS) Subcommittee

LTSS Themes:

- Decrease disparities in access to long-term services and supports (LTSS), including HCBS.
- Build more effective integration between clinical care and HCBS.
- Improve family/friend caregiver identification, assessment, support, and engagement by health care systems.
- Provide high quality, person and family-centered LTSS, including HCBS programs.
- Address behavioral symptoms of AD/ABRD across the full range of care settings.

RECOMMENDATION 1: Improve access to LTSS including nursing home care and HCBS² among persons at-risk for and living with AD/ABRD and their caregivers.

The number and diversity of people living with AD/ABRD is growing, with the greatest burden for care falling upon family caregivers.³ There is a need for additional LTSS to assist this group. Federal programs that provide HCBS to eligible individuals, their families and caregivers, such as those through ACL, the VA and CMS, must be brought to scale and should tailor programs to address the needs of an increasingly heterogeneous⁴ population.

- a. Congress should increase funding for the ACL Alzheimer's Program Initiative (ADPI) from \$23.5 million to \$50 million by 2025 to increase the number of individuals benefitting from tailored education and supports.
- b. Congress should increase funding for the Older Americans Act National Family Caregiver Support Program (NFCSP) from \$180 million to \$360 million by 2025.
- c. Congress' funding should be sufficient to underwrite evaluation of the reach and benefits of these two ACL programs.
- d. The ACL and its National Alzheimer's and Dementia Resource Center should coordinate validation of the Dementia Capability Assessment Tool to make available a valid and reliable tool for federal, state and local HCBS providers, including those delivering the NFCSP.
- e. ACL should conduct an evaluation of the reach/impact of programing and have funding allocated specifically for evaluation of NFCSP and ADPI.
- f. The HHS Office of Minority Health should prioritize both AD/ABRD and dementia support programs that demonstrate cultural competency and language

² HCBS are types of person-centered care delivered in the home and community. They are often designed to enable people to stay in their homes, rather than moving to a facility for care. HCBS programs generally fall into two categories: health services and human services

³ Caregiver is defined in the broadest terms as including fictive kin, neighbors, friends, and non-blood relatives.

⁴ Heterogeneous includes but is not limited to people of color, diverse ethnic groups, people with intellectual or developmental disabilities and AD/ABRD, people with related dementias, those with young onset, those who live alone, people who are economically disadvantaged, and those with limited English-speaking and literacy skills.

accessibility, to better address appropriate education and outreach to diverse communities that are disproportionately impacted by AD/ADRD.

- g. Operating divisions within HHS charged with serving people living with AD/ADRD, such as CMS, ACL, CDC and HRSA, and the VA, should tailor programs to address the HCBS needs of a heterogeneous population living with AD/ADRD and their families and caregivers.

RECOMMENDATION 2: Build more effective integration between clinical care services and HCBS across the disease trajectory.

Caregivers are the backbone of the nation’s community-based supports for people living with AD/ADRD. They also provide necessary care management, from medical follow-up, to medication monitoring, and personal care. To assure that health care systems support people with AD/ADRD and their caregivers, the HHS should ensure people living with AD/ADRD and their caregivers receive ongoing disease information, care planning and coordination, caregiver assessment and supports, and improved connections to HCBS/tailored to their needs.

- a. CMS should issue an Informational Bulletin(s) or other policy guidance on AD/ADRD and dementia care to states, insurers, medical and HCBS providers, emphasizing the scope of the issue (demographics, costs and quality challenges), the critical roles played by caregivers in the delivery of dementia care, challenges to engagement of caregivers, and the importance of person and caregiver identification, assessment, support, and connection to HCBS. CMS and the states should develop and implement follow-up strategies to encourage adoption of recommendations in the guidance.
- b. CMS and ONC should jointly develop standards, policies and programs that leverage health IT to: (i) designate the caregiver in the care recipient’s, and; (ii) in the caregiver’s medical records, and; (iii) encourage providers to connect people living with AD/ADRD and caregivers to disease education and LTSS services, including HCBS.
- c. 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 caregivers to people living with AD/ADRD served by the health care system. Then establish baselines and monitor change overtime in satisfaction: (i) with caregiver engagement, and; (ii) with the referral process to HCBS LTSS.
- d. HHS should address HIPAA issues through federal AD/ADRD education outlets to assure that HIPAA does not create a barrier to the provision of care by caregivers.

RECOMMENDATION 3: Identify and address behavioral symptoms across the disease trajectory and in all care settings.

Behavioral symptoms of AD/ADRD are an integral part of dementia that increase morbidity and burden, affect quality of life and impact cost of care. To more effectively address these issues across the full span of care settings, it is recommended that federal, state and community organizations increase provider and caregiver knowledge about person and family-centered care through training and dissemination of evidence-based and evidence-informed interventions.

- a. Federal, state and community organizations should support development of training/education programs and materials reflecting best evidence on assessing and addressing behavioral and psychological symptoms and their dissemination and implementation in all care settings (home, community and residential) in multiple languages and at varying literacy levels.
- b. HRSA, ACL, CMS, and CDC, and VA should increase the number of grant programs offering education for paid and unpaid caregivers that support use of evidence-based or informed strategies for behavioral management.
- c. CMS (and others) should identify, catalogue and disseminate promising practices for reducing anti-psychotic use in nursing homes and explore further dissemination for use with Medicare-funded home health settings and to states for use in other Medicaid-funded LTSS settings.

Research Subcommittee

Research Themes:

- Robust biomedical and holistic strategy.
- Sufficient resources.
- Silos minimized.
- Optimal infrastructure and research climate.
- An inclusive role for the dementia community.
- Global leadership role.
- Broad dissemination.
- Commitment to quality.
- Continuous and objective process improvement.

RECOMMENDATION 1: The 2018 National Plan should continue to provide 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.

- 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.
 - 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.
- 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 all the 2025 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 goals of the plan.
 - 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.
- 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: As recommended in the National Plan the United States government (HHS, NIH, CDC) 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.

- a. United States public and private entities should collaborate in the work of international organizations focused on reducing the burden of AD/ADRD.
- b. Continued collaborations on international research efforts should be promoted.

RECOMMENDATION 5: 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.
- b. NIH should advance innovative recruitment efforts to increase recruitment and retention in randomized controlled clinical trials. (see recommendation on 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 6: Federal agencies should develop a strategy and infrastructure to increase ethical and open sharing of, access to, and utilization of research data, with a continued emphasis on ethics, in collaboration with

academia, biotech and information system industries. This strategy should accelerate the pace of scientific discovery in AD/ADR research by addressing a comprehensive range of issues including cross-sector data sharing practices and policies, data harmonization and interoperability, and the training of data scientists in AD/ADR 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.

RECOMMENDATION 7: All federal and non-governmental agencies funding AD/ADR research, along with PCORI, academia and industry, should establish the engagement of the AD/ADR community as a standard practice in both participating in setting national research priorities for AD/ADR and throughout all stages of clinical research and care, and services and support 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/ADR and their care partners, leveraging international expertise as needed.
- b. NIH should establish funding methods to support participant/caregiver engagement in all AD/ADR 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/ADR by disease etiology.
- d. Enhance methodologies to effectively engage persons living with AD/ADR, 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.