2021 Research Recommendations

July 19, 2021

Themes

Robust biomedical and holistic strategy.

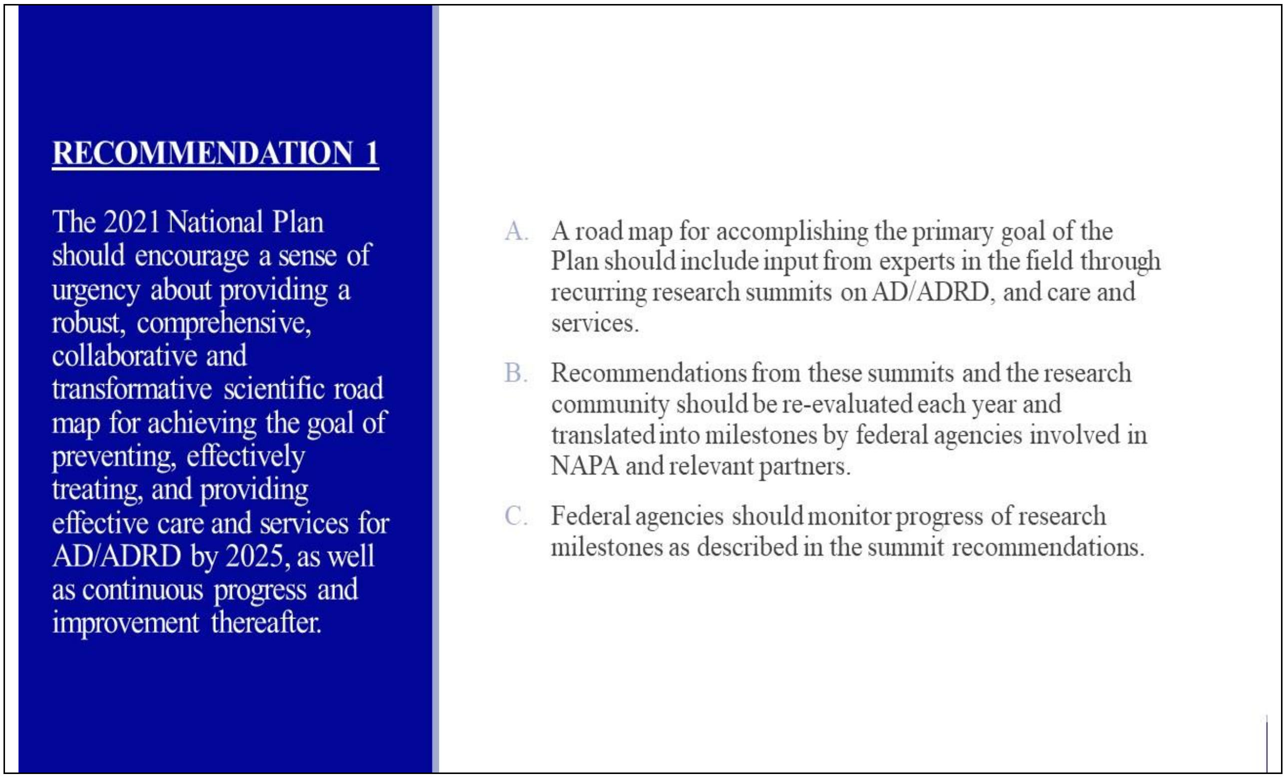
Sufficient resources.

Consistent terminology

Recruitment of people with highest risk for research

Ethical data sharing

An inclusive role for the dementia community.



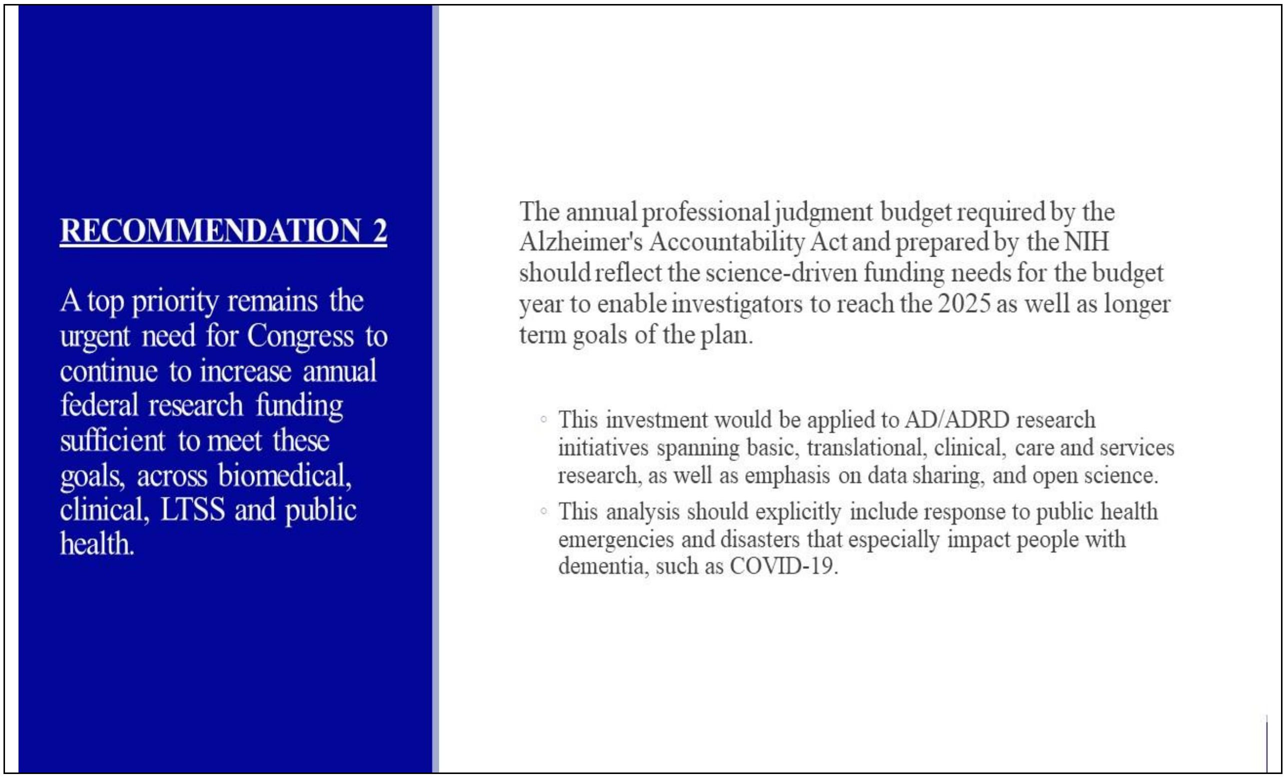
RECOMMENDATION 1

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.

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.

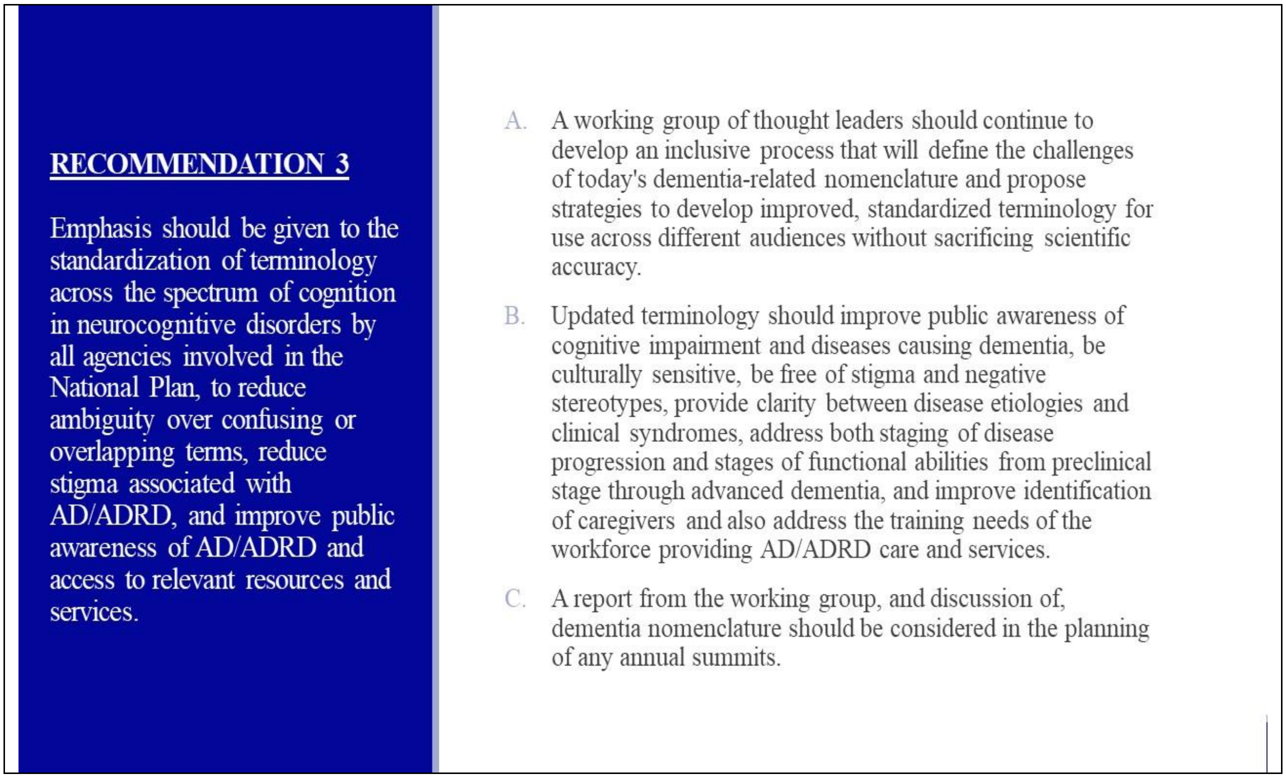


RECOMMENDATION 2

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.

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.

- 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.
- This analysis should explicitly include response to public health emergencies and disasters that especially impact people with dementia, such as COVID-19.



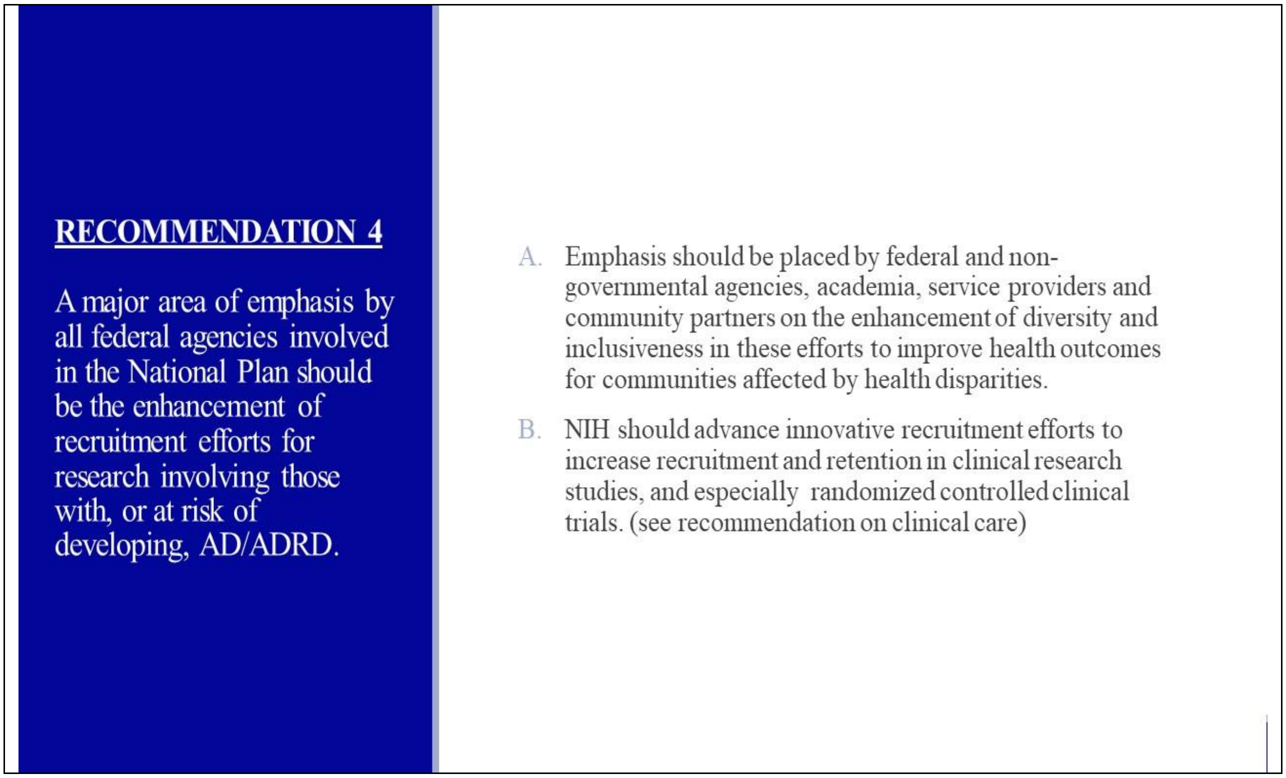
RECOMMENDATION 3

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.

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, and 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 is needed on methods for early recognition and progression of disease using cutting edge technologies, e.g. 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.

Research Subcommittee Membership

- **Non-federal partners**
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  - Rob Egge
  - Brad Hyman (Chair)
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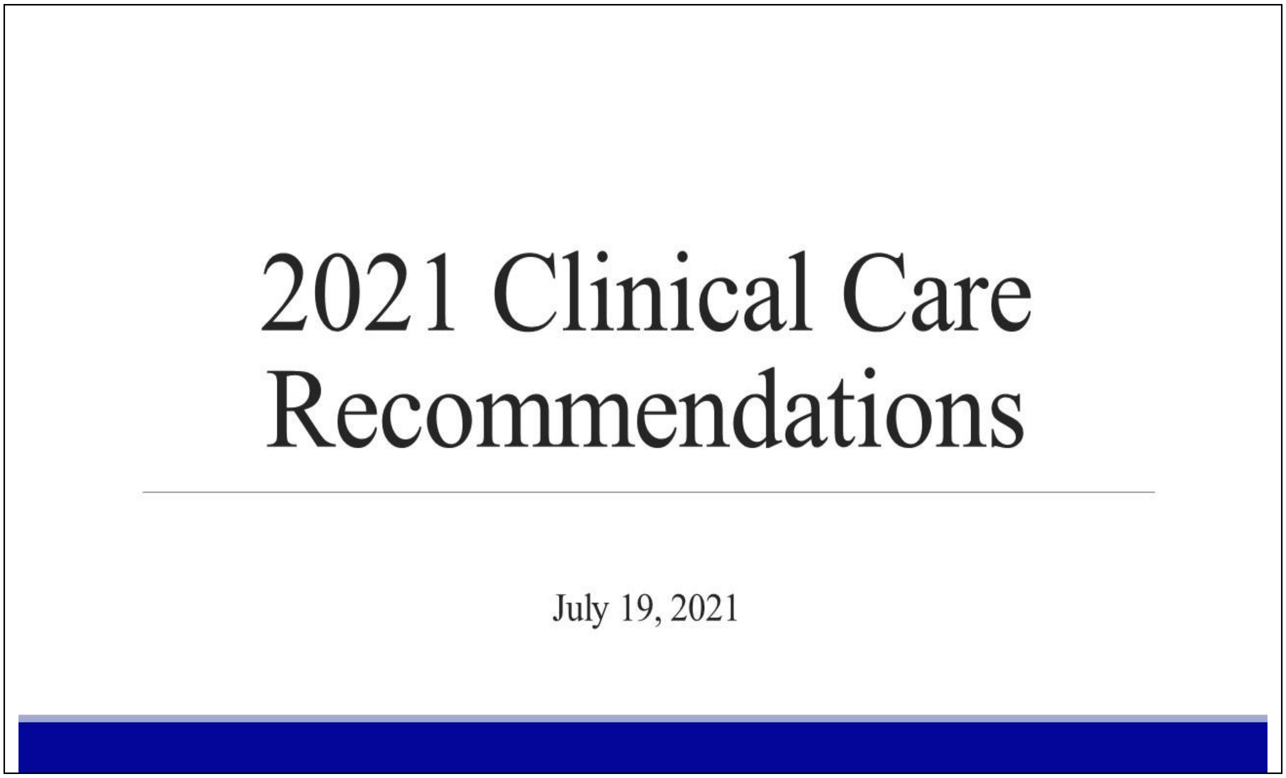
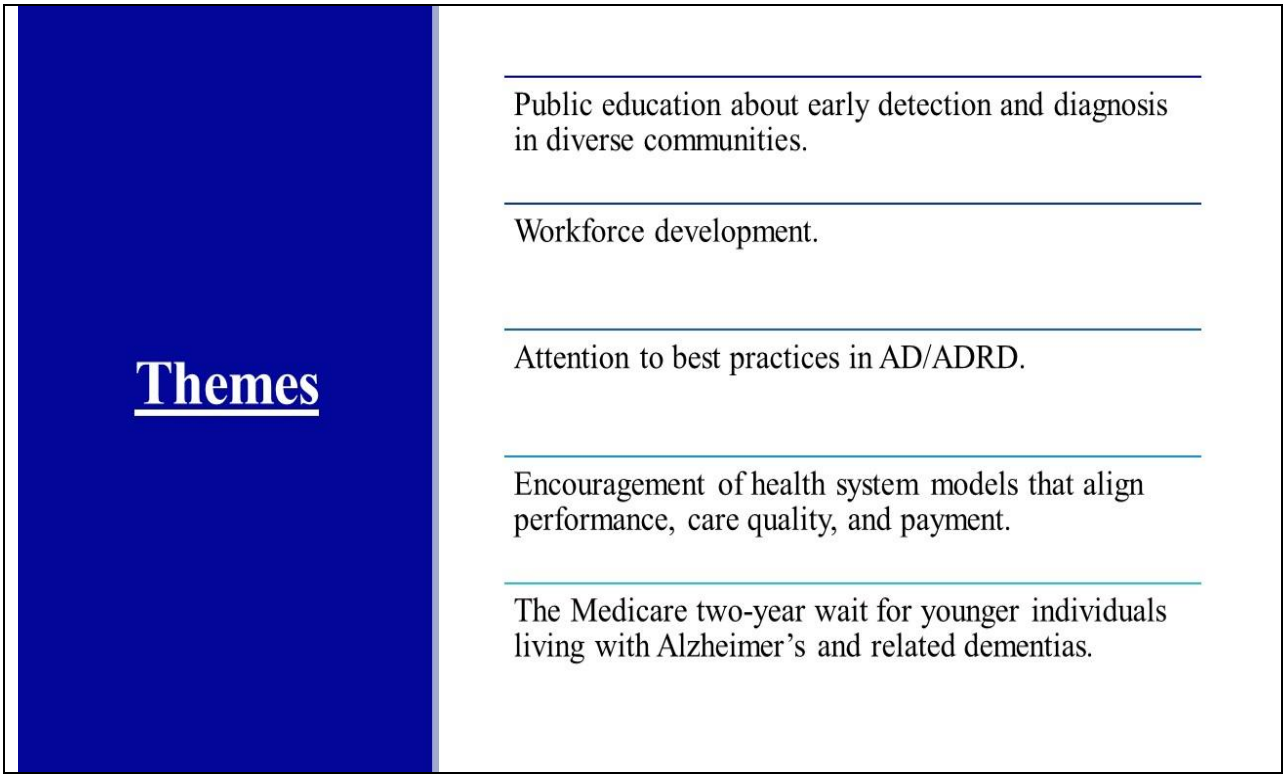


2021 Clinical Care Recommendations

July 19, 2021



Themes

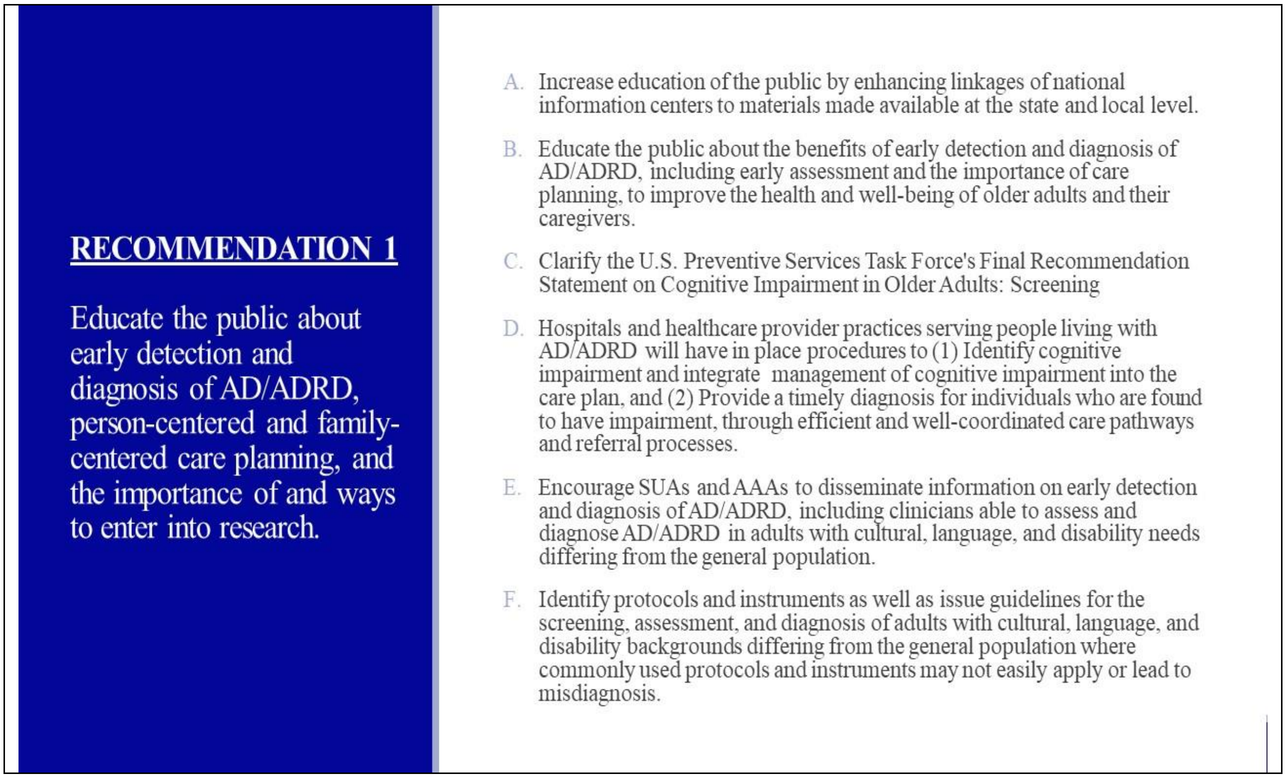
Public education about early detection and diagnosis in diverse communities.

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.

A. Increase education of the public by enhancing linkages of national information centers to materials made available at the state and local level.

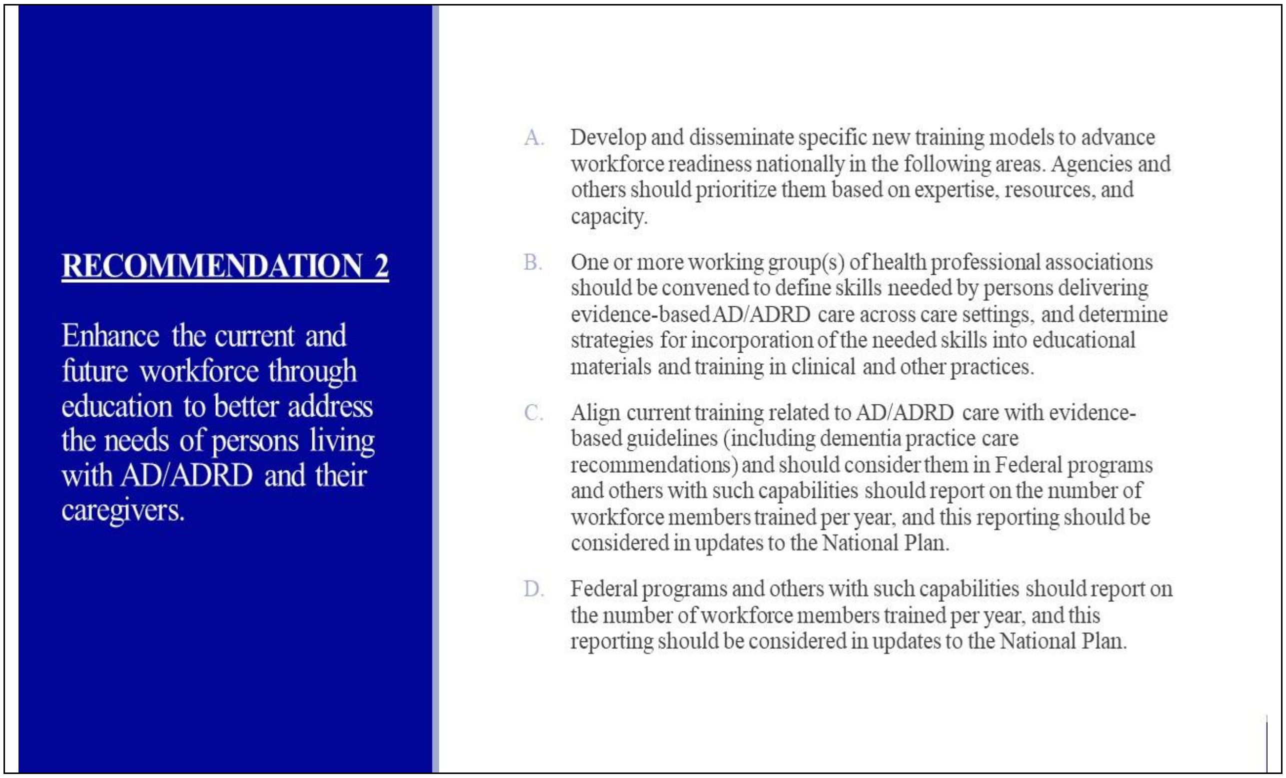
B. Educate the public about the benefits of early detection and diagnosis of AD/ADRD, including early assessment and the importance of care planning, to improve the health and well-being of older adults and their caregivers.

C. Clarify the U.S. Preventive Services Task Force's Final Recommendation Statement on Cognitive Impairment in Older Adults: Screening

D. 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, and (2) Provide a timely diagnosis for individuals who are found to have impairment, through efficient and well-coordinated care pathways and referral processes.

E. Encourage SUAs and AAAs 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.

F. 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.



RECOMMENDATION 2

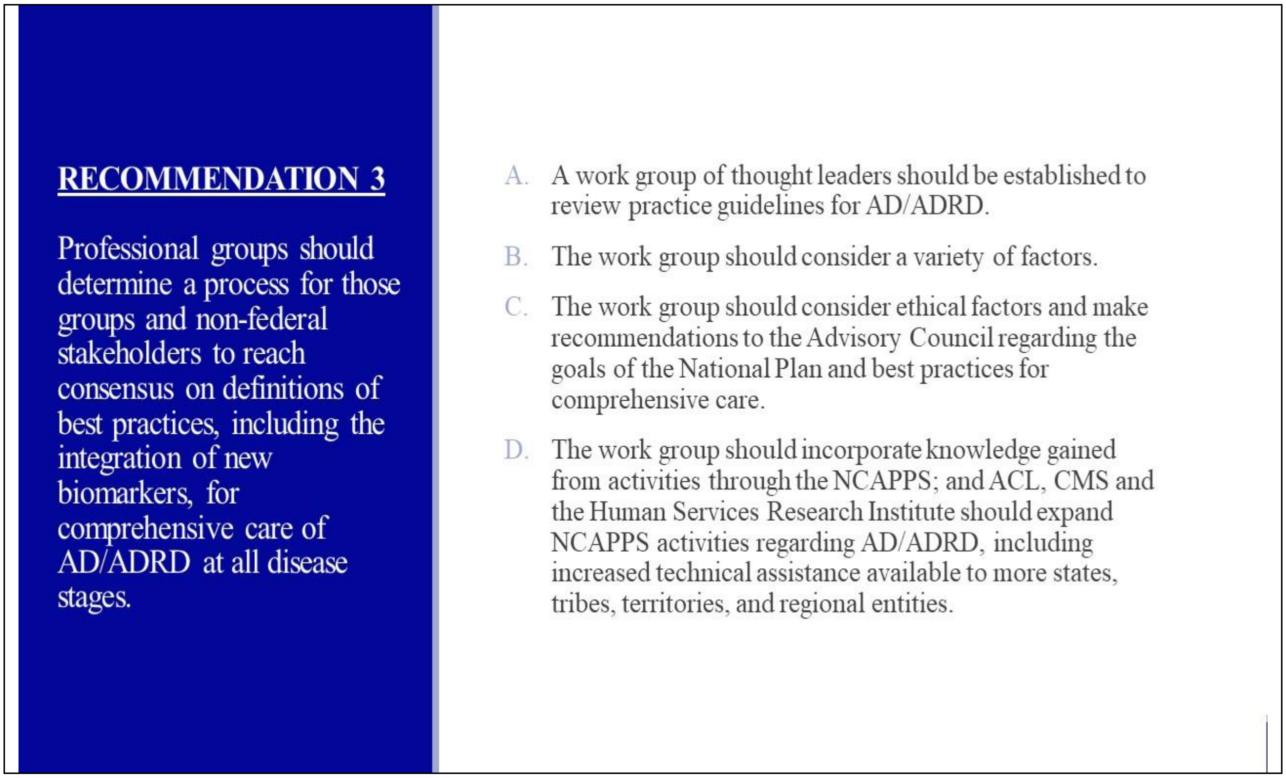
Enhance the current and future workforce through education to better address the needs of persons living with AD/ADRD and their caregivers.

A. 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.

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. Align current training related to AD/ADRD care with evidence-based guidelines (including dementia practice care recommendations) and should consider them in 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.

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

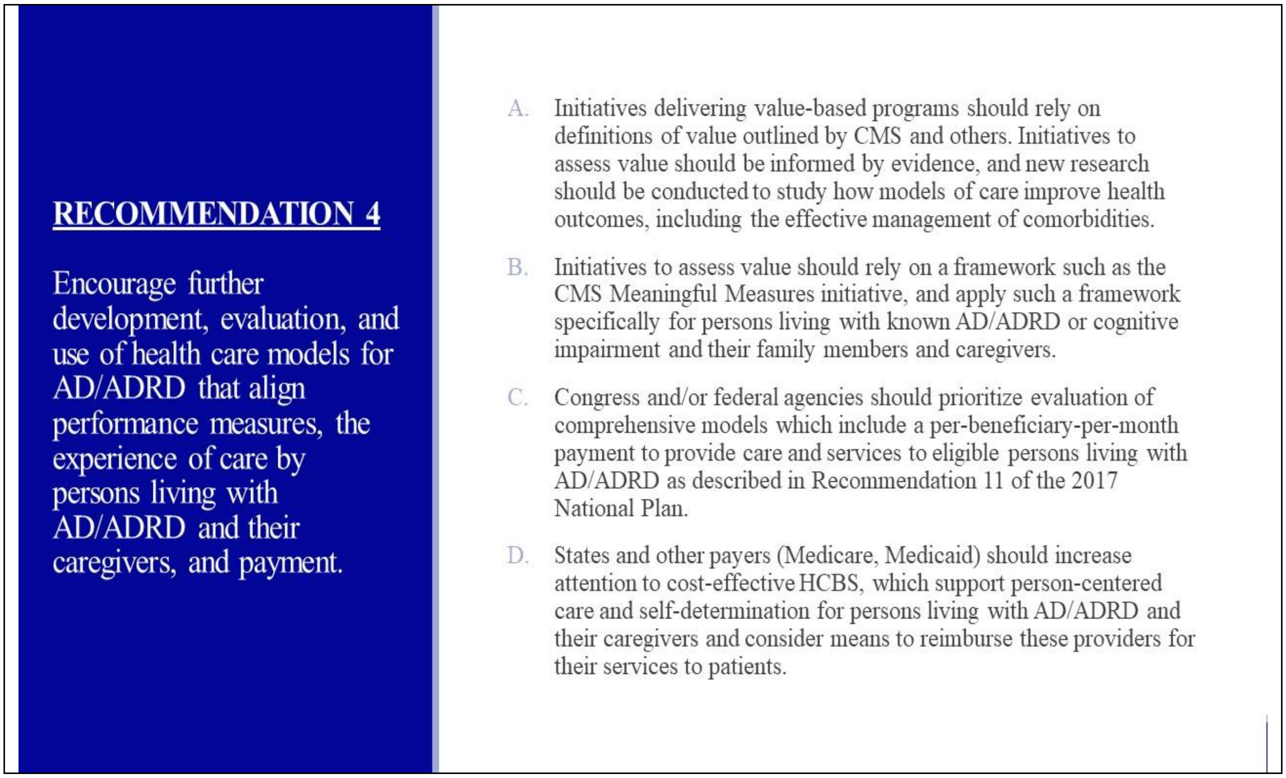
Professional groups should determine a process for those groups and non-federal stakeholders to reach consensus on definitions of best practices, including the integration of new biomarkers, for comprehensive care of AD/ADRD at all disease stages.

A. A work group of thought leaders should be established to review practice guidelines for AD/ADRD.

B. The work group should consider a variety of factors.

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.



RECOMMENDATION 4

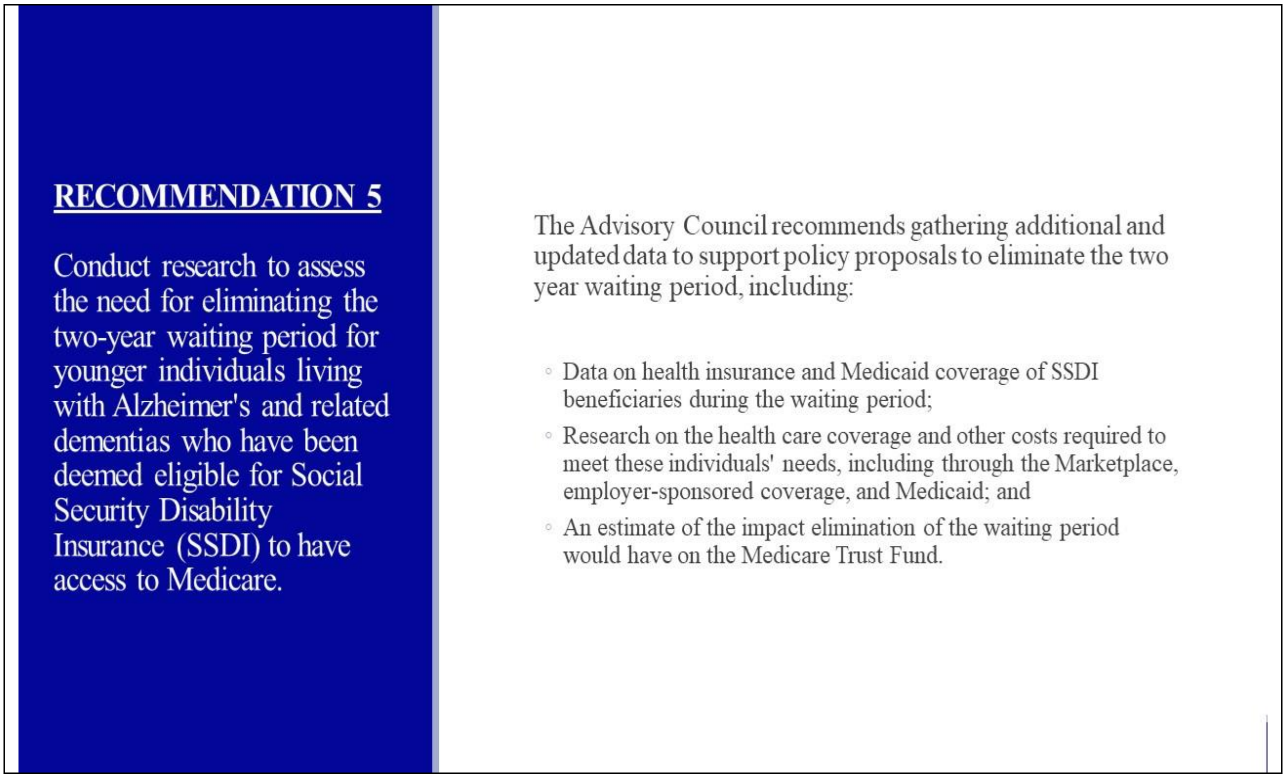
Encourage further development, evaluation, and use of health care models for AD/ADRD that align performance measures, the experience of care by persons living with AD/ADRD and their caregivers, and payment.

A. Initiatives delivering value-based programs should rely on definitions of value outlined by CMS and others. 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.

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.

C. 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.

D. 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.

The Advisory Council recommends gathering additional and updated data to support policy proposals to eliminate the two year waiting period, including:

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

Clinical Care Subcommittee Membership

Non-federal partners

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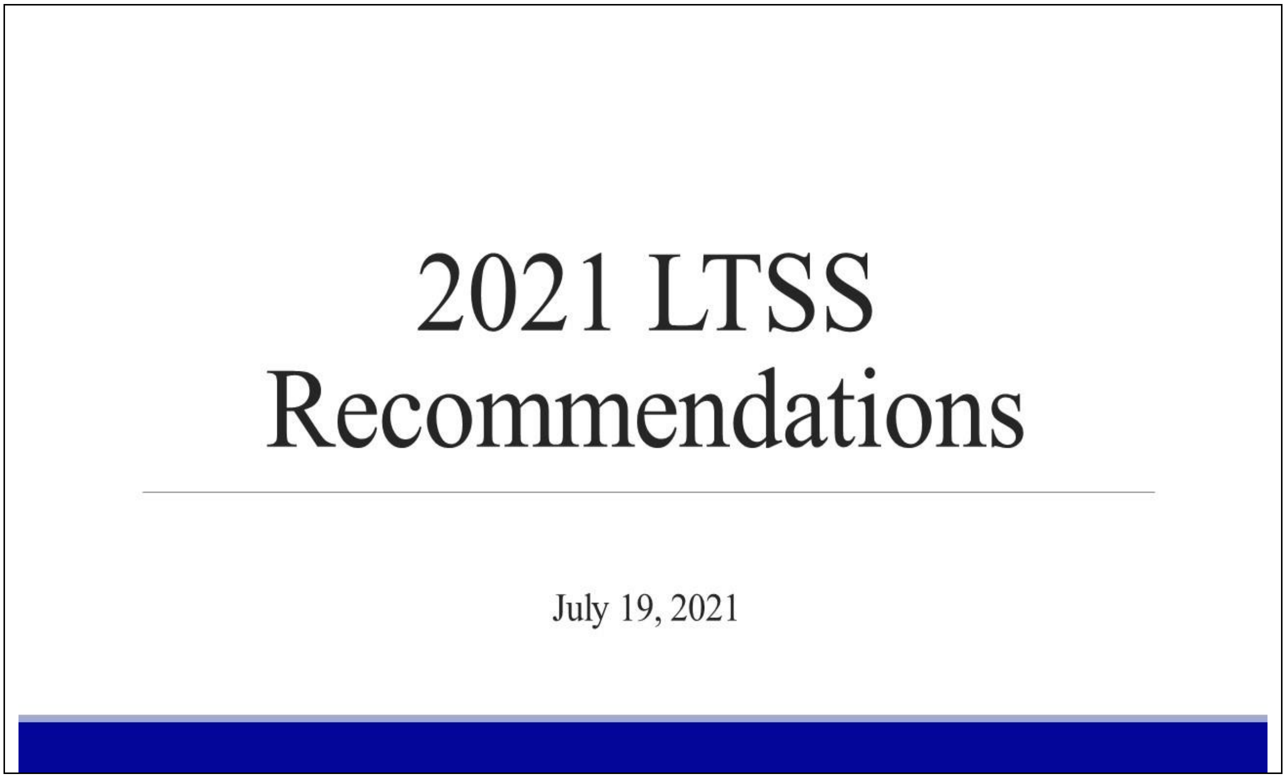
- Erin Long, ACL
- Lisa McGuire, CDC
- Joan Weiss, HRSA



2021 LTSS Recommendations

July 19, 2021

Themes

- Decrease disparities, increase equity and expand access to an utilization of LTSS
- Improve coordination of clinical care with HCBS
- Provide high quality, person and family-centered LTSS
- Develop a dementia-capable workforce
- Address behavioral & psychological symptoms of ADRD across care settings
- Improve and expand LTSS emergency preparedness

RECOMMENDATION 1

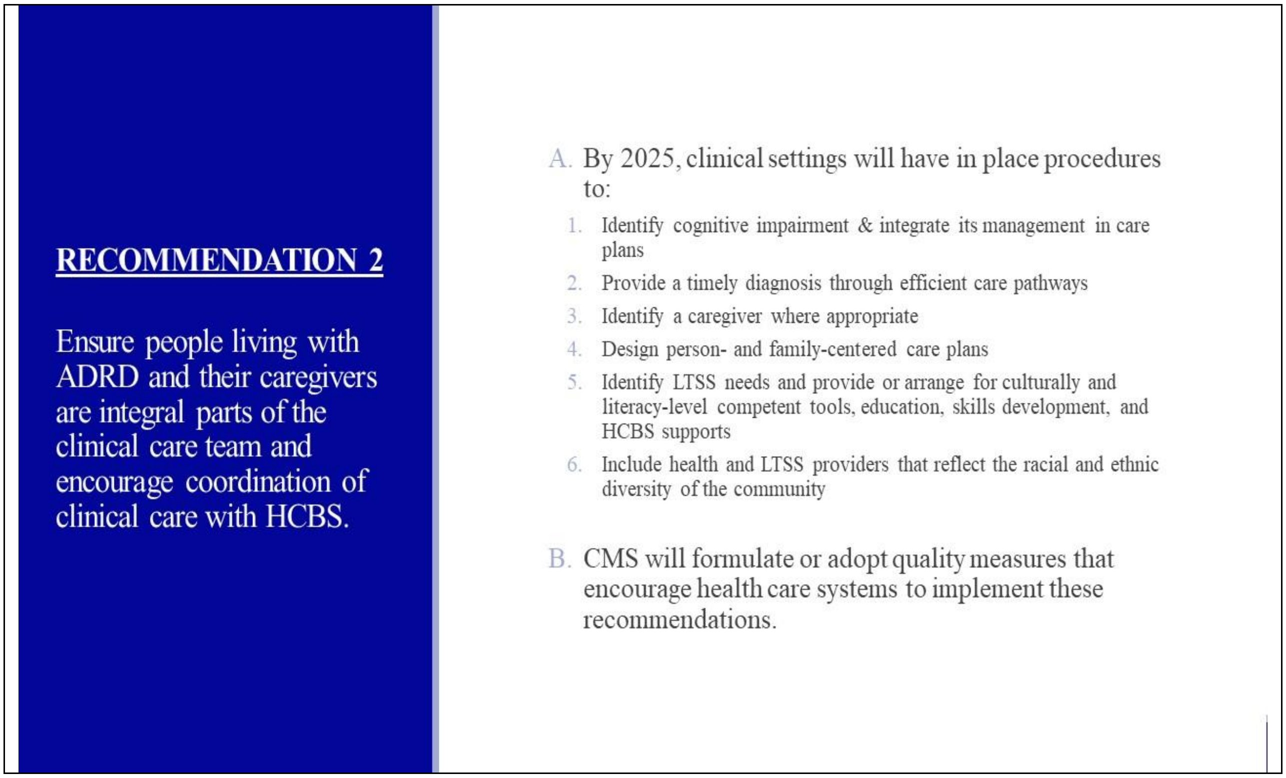
Expand access to and utilization of affordable HCBS, particularly for people living with ADRD who are marginalized, historically underserved, or disproportionately affected by dementia.

A. Expand access through Medicaid

B. Expand access through Medicare

C. Expand, fully fund, and promote LTSS programs beyond Medicaid

D. Protect the financial security of people living with ADRD and their caregivers

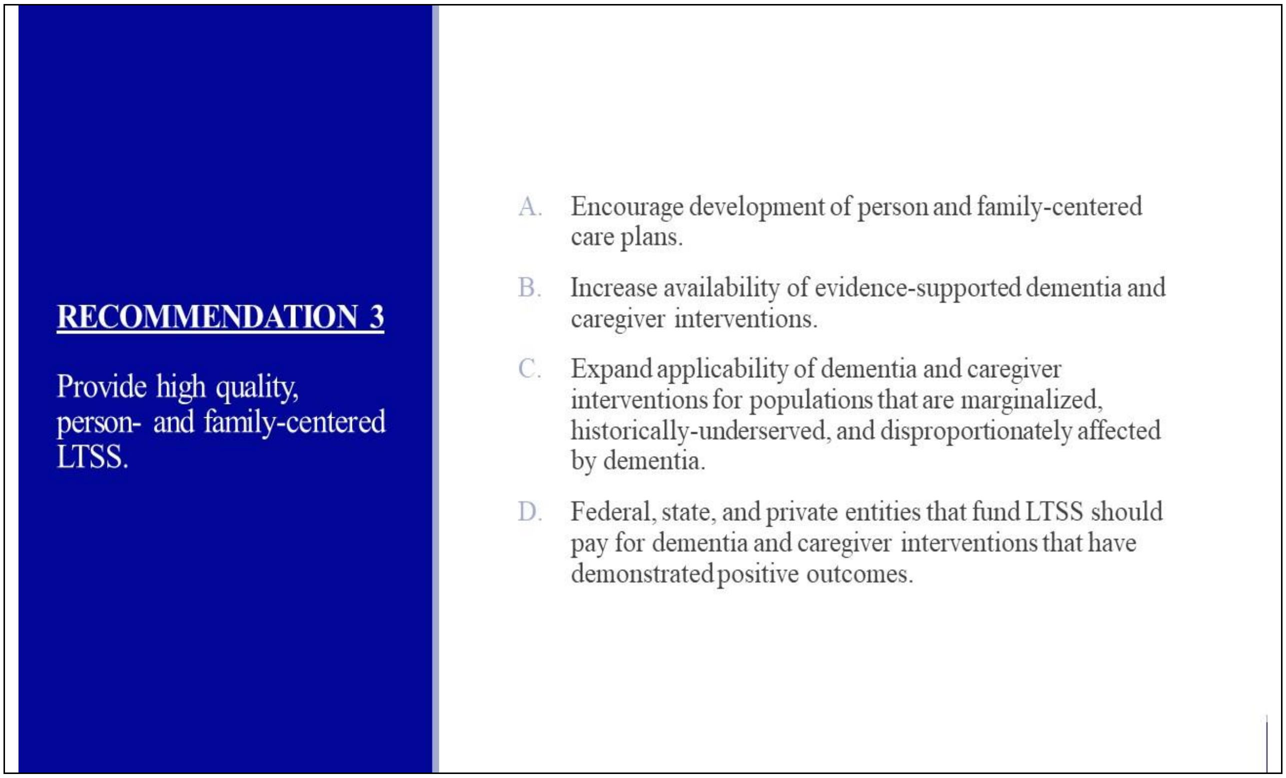


RECOMMENDATION 2

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

A. By 2025, clinical settings will have in place procedures to:
   1. Identify cognitive impairment & integrate its management in care plans
   2. Provide a timely diagnosis through efficient care pathways
   3. Identify a caregiver where appropriate
   4. Design person- and family-centered care plans
   5. Identify LTSS needs and provide or arrange for culturally and literacy-level competent tools, education, skills development, and HCBS supports
   6. Include health and LTSS providers that reflect the racial and ethnic diversity of the community

B. CMS will formulate or adopt quality measures that encourage health care systems to implement these recommendations.



RECOMMENDATION 3

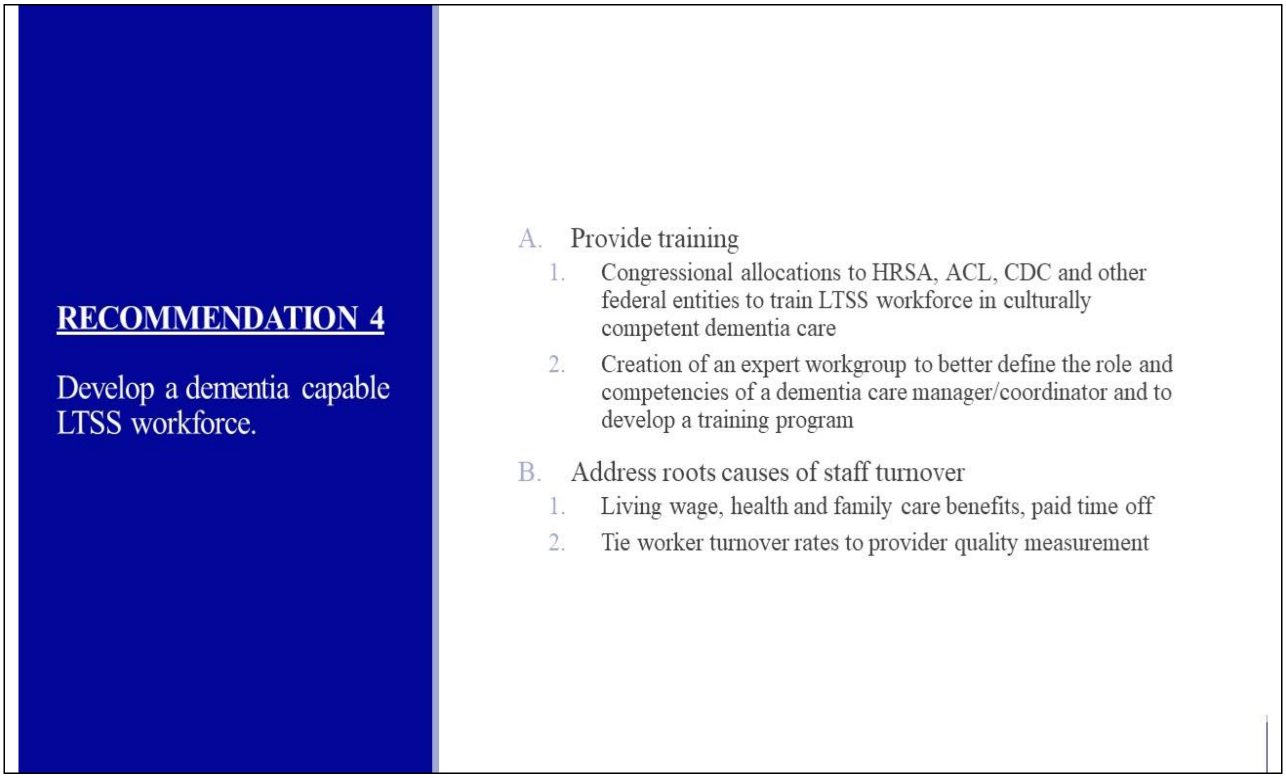
Provide high quality, person- and family-centered LTSS.

A. Encourage development of person and family-centered care plans.

B. Increase availability of evidence-supported dementia and caregiver interventions.

C. Expand applicability of dementia and caregiver interventions for populations that are marginalized, historically-underserved, and disproportionately affected by dementia.

D. Federal, state, and private entities that fund LTSS should pay for dementia and caregiver interventions that have demonstrated positive outcomes.

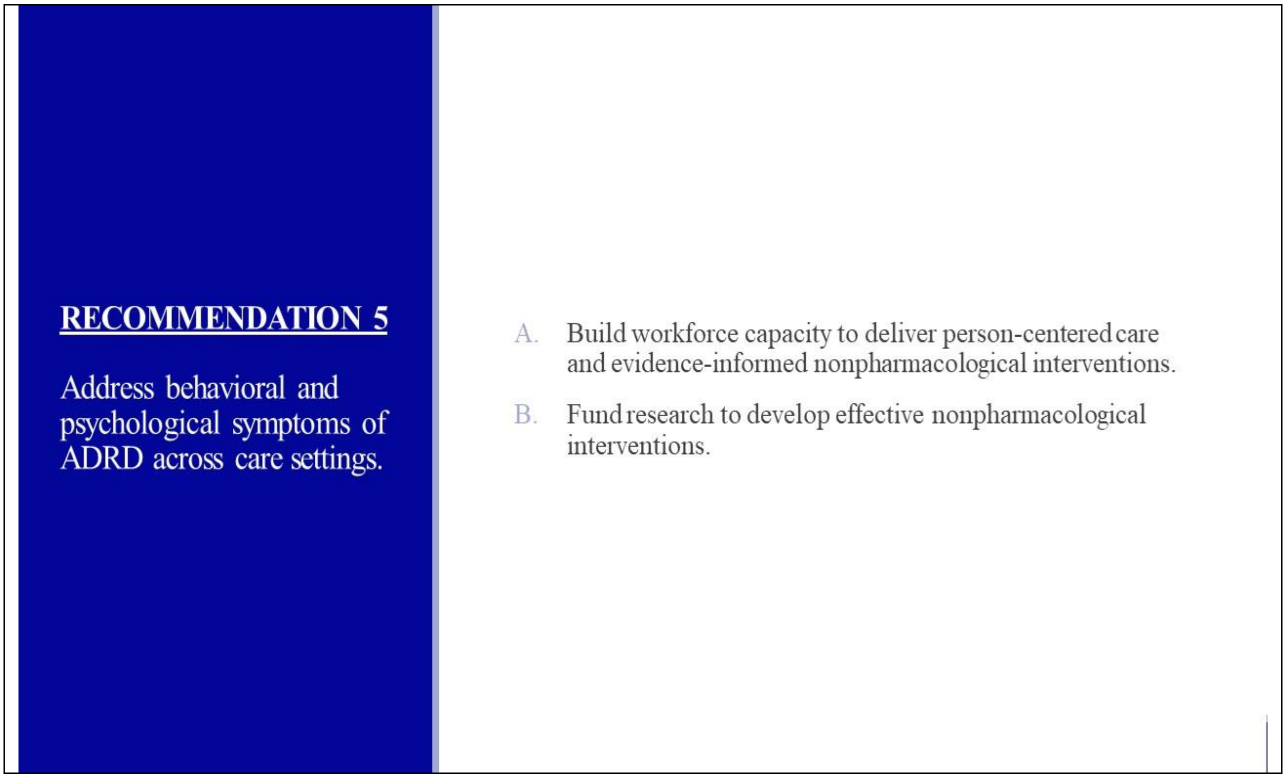


RECOMMENDATION 4

Develop a dementia capable LTSS workforce.

A. Provide training
   1. Congressional allocations to HRSA, ACL, CDC and other federal entities to train LTSS workforce in culturally competent dementia care
   2. Creation of an expert workgroup to better define the role and competencies of a dementia care manager/coordinator and to develop a training program

B. Address roots causes of staff turnover
   1. Living wage, health and family care benefits, paid time off
   2. Tie worker turnover rates to provider quality measurement

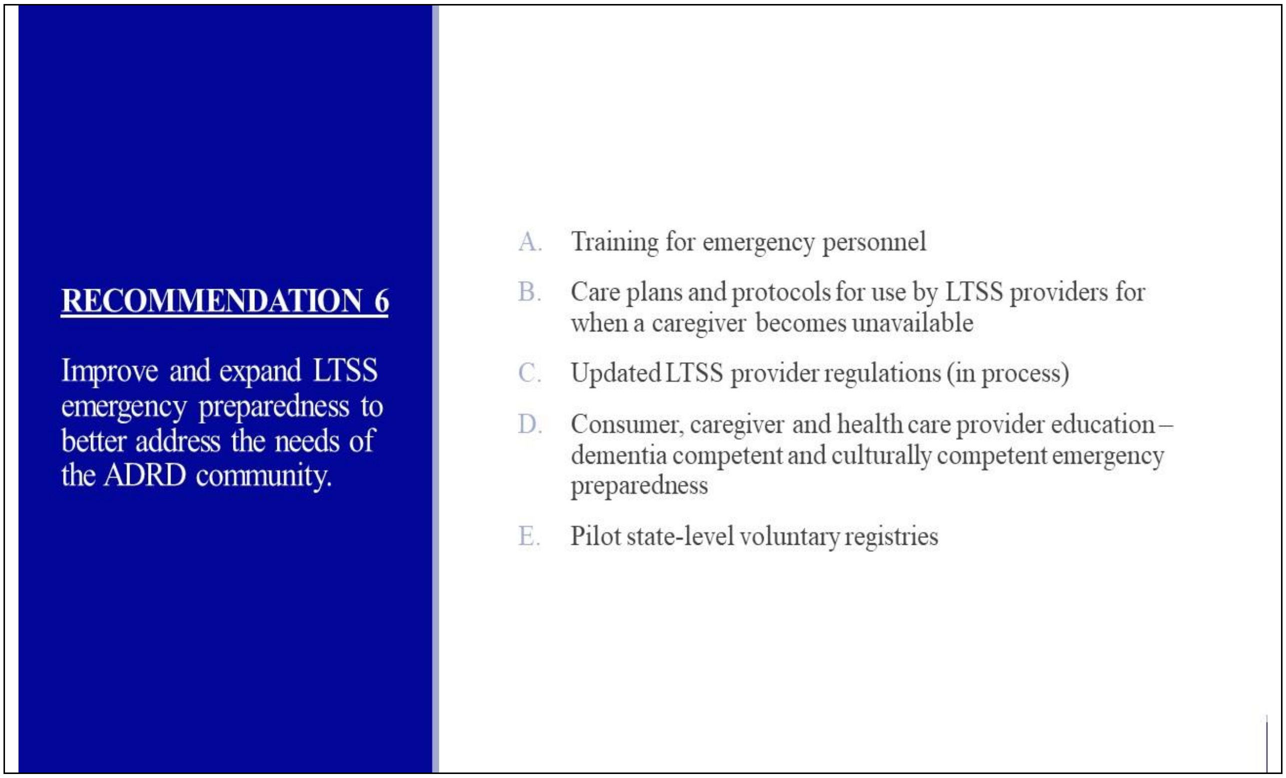


RECOMMENDATION 5

Address behavioral and psychological symptoms of ADRD across care settings.

A. Build workforce capacity to deliver person-centered care and evidence-informed nonpharmacological interventions.

B. Fund research to develop effective nonpharmacological interventions.



RECOMMENDATION 6

Improve and expand LTSS emergency preparedness to better address the needs of the ADRD community.

A. Training for emergency personnel
B. Care plans and protocols for use by LTSS providers for when a caregiver becomes unavailable
C. Updated LTSS provider regulations (in process)
D. Consumer, caregiver and health care provider education – dementia competent and culturally competent emergency preparedness
E. Pilot state-level voluntary registries

LTSS Subcommittee Membership

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