

2023 Recommendations

Research Recommendations

Research Subcommittee

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RECOMMENDATION 1

**Increase federal
research funds to meet
NAPA aims.**

High-priority areas of research include:

- A. Fundamental biological processes and basic disease mechanisms of AD/ADRD (e.g., young and late onset sporadic AD/ADRD, familial AD/ADRD, individuals with intellectual or developmental disabilities including Down syndrome).
- B. Dementias with clinical diagnoses other than AD and mixed/multiple etiology dementias, as identifying specific biomarkers for these conditions could improve diagnostic capabilities and provide increased therapeutic options.
- C. Early detection of cognitive decline and precursors of dementia at an individual level, identification of pathology(s), and development and use of person-centered treatment(s).
- D. Research into recently developed amyloid therapies including determining optimal duration of treatment, characteristics of patients and groups who benefit, and medical system delivery to optimize benefit and minimize risk.
- E. Models of dementia care and support and the testing of innovative payment models (potentially funded by CMS/CMMI, private foundations, etc.) and encourage uptake efforts through state public health and aging services departments.
- F. Research into workforce and systems capacity needs in clinical care and research staffing needs.
- G. Translational technologies for diagnostics and therapeutics.
- H. Research into methods of improving prevention and risk reduction of cognitive decline and dementia, as discussed in more detail by the risk reduction subcommittee.
- I. Research into neurological effects of Covid-19 in older adults and people with ADRD, and causes, relationships, and risk reduction of delirium.
- J. Research from the newly created Advanced Research Projects Agency for Health (ARPA-H) should play a major role in the translation and demonstration of scientific breakthroughs in the diagnosis, treatment, and management of dementias.

RECOMMENDATION 2

Address critical scientific and clinical questions in the implementation of the first generation of disease modifying treatments.

Research is needed to determine:

- A. How best to identify persons who would benefit from anti-amyloid therapy and ensure equitable access for all patients who could benefit from treatment.
- B. Which persons with cognitive decline and evidence of amyloid deposition in brain, but who did not fit criteria of the successful clinical trials, may also benefit from anti-amyloid therapy.
- C. What infrastructure is needed to appropriately identify, treat, and monitor persons treated with anti-amyloid therapy.
- D. The cause of side effects and adverse reactions in persons treated with anti-amyloid therapy and how to best monitor and manage these.
- E. Diagnostic testing options in identifying persons who may benefit from anti-amyloid therapy.
- F. Whether anti-amyloid treatment of cognitively normal persons identified as high risk for AD based on blood or PET biomarkers can help prevent or delay cognitive decline.
- G. How to manage persons treated with anti-amyloid therapy over longer time periods including patients who progress in clinical dementia, the effects of multiple co-morbidities and medications, and optimal duration of treatment.

RECOMMENDATION 3

Implement research of active dementia care models to compare effectiveness.

- A. Diagnostic strategy implementation from primary care through specialty centers should be studied. Research is needed in how to provide timely and accurate diagnostic and prognostic information for people with ADRD using recent scientific developments in biomarkers. Access should include all communities.
- B. Interventions such as medication management, care support for caregivers providing care for patients, clinical care team management, exercise, diet, and activity should continue to be studied.
- C. Research in how to integrate medical interventions, e.g., disease modifying treatments, within medical systems.

RECOMMENDATION 4

To address health equity and representation in research, representation and diversity in AD/ADRD clinical trials should be increased.

- A. Potential strategies include leveraging models of community-based recruitment and primary care, scaling up of funding to enable research to develop and grow the necessary infrastructures, targeted RFAs, government requirements for trial and observational study enrollment, and including patient and public involvement (PPI) of people living with dementia and unpaid caregivers representative of diverse populations.
- B. Prioritize inclusion and representation in public/private clinical trials, fund research into recruitment science, and set milestones for engagement and inclusion of diverse populations with a focus on diagnostic and treatment related trials.
- C. An understudied area that should be prioritized is the impact of stigma related to dementia on health-seeking behaviors to improve access to health services.
- D. Current work has focused on stigma attached to race/ethnicity, sex and gender, and socioeconomic status. A greater understanding of these and other factors, including the stigma on dementia itself, is needed to understand and resolve patient, family, caregiver, provider, and societal effects of stigma on access to care, diagnosis and treatment, and support systems.

RECOMMENDATION 5

Improve translation from scientific discovery to health impact.

- A. NAPA organizers, including ASPE, should have increased resources (e.g., financial and personnel support) and authority to accomplish the following:
 - 1. By June 2024, appoint a federal coordinator with the authority to prioritize, organize, implement, and follow up on cross-stakeholder recommendations, possibly through NAPA reauthorization.
 - 2. Track the progress and milestones of prior NAPA recommendations with a goal to prioritize those recommendations with the largest potential impact.
 - 3. Assist NAPA Council and its Chair in determining the level of appropriate resources (e.g., financial, personnel effort, and authority) for NAPA to track and convey recommendations optimally.
- B. In order to meet the scientific recommendation goals of NAPA, independent annual funding for NAPA goals and management (i.e., not dependent on other groups voluntarily providing it) are needed to accomplish the NAPA aims. This should include funding to support:
 - 1. Management of the top-level roadmap that describes to stakeholders and the public the status and progress of NAPA aims and goals.
 - 2. Implementation and support for meetings to accomplish NAPA aims and goals, including travel costs and time and effort of required attendees.
 - 3. Staff to provide support for NAPA leadership to accomplish aims, including program and project managers, etc.
 - 4. Provide mechanisms to engage multiple stakeholders beyond federal agencies including health systems, research organizations, treatment developers, etc.

RECOMMENDATION 6

Implement scientific and evidence-based evaluations of factors for decision making.

- A. Implementation science research should be performed to determine information on safety, utilization, and outcomes from ongoing treatments while accounting for any potential added burden on patients, caregivers, and health care systems that would impact health of patients with AD/ADRD.
- B. NAPA federal agencies should investigate successful models for increasing involvement of people with AD/ADRD in clinical research studies, including trials. This may include evaluating successful models from other disease areas, incentivization of research participation, evidence-based models of implementation, and payer evaluation of successful advancements based on evidence.
- C. The impact of anti-amyloid therapies on research efforts should be studied, specifically how access to disease modifying drugs affect research participation in clinical trials, clinical trial design, review and approval of drug use, payment, coverage, and implementation of treatments.

Risk Reduction Recommendations

Risk Reduction Subcommittee

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RECOMMENDATION 1:

Identify priorities for and track progress toward addressing cognitive decline and dementia risk factors across the lifespan.

- A. In prioritizing efforts to address risk for cognitive decline and dementia as part of Goal 6 of the National Plan, HHS should focus on the following six risk factors that we believe show the greatest potential for impact: midlife hypertension, midlife obesity, physical activity, smoking, depression, and hearing loss.
- B. To begin measuring progress on Goal 6, HHS should track the prevalence of the above-mentioned risk factors by overall population, by race/ethnicity, and among those with neuro-atypical conditions. In addition, HHS should track efforts to address the above-mentioned risk factors, including interventions undertaken and other appropriate means of controlling the risk factors. HHS should establish a monitoring and evaluation workgroup to make recommendations no later than May 2024 for specific indicators and related data sources to be used, consistent, where appropriate, with Healthy People 2030 and the Healthy Brain Initiative Road Map.
- C. No less than once every five years, HHS should convene an AD/ADRD risk reduction summit, with CDC as the lead agency. These summits should focus on translating the latest state of the evidence on modifiable risk factors for, and social determinants of health related to, cognitive decline and dementia into public health action – and should engage diverse stakeholders. Specific actions by public and private entities should be identified, including actions by public and private partners that focus on the targeted risk factors, and actions that would address specific barriers/challenges for historically underserved communities.
- D. HHS and all relevant federal agencies should build upon existing activities that address risk factors for cognitive decline and dementia – and should identify, coordinate, and implement additional strategies within their current authorities on the focus areas identified by HHS under Goal 6.
- E. HHS should issue a public report on the current level of spending at the federal and state levels on activities that address the risk factors for cognitive decline and dementia. Each year, in the annual Administration budget, the Office of Management and Budget (OMB) should identify the amounts proposed in the budget request for addressing risk factors for cognitive decline and dementia across all relevant federal agencies.
- F. CDC should periodically update the list of key risk factors that are the focus of efforts to achieve Goal 6 of the National Plan, based on the strength of scientific evidence, ripeness for public health action, and potential for impact – and considering the needs of and potential benefits to at-risk communities.

RECOMMENDATION 2

Accelerate public health and aging network action on addressing the risk factors with the strongest evidence of beneficial impact on dementia prevalence, particularly for communities or target groups at greatest risk.

- A. The federal government should sustain and strengthen the public health and aging network infrastructure to address risk factors for cognitive decline and dementia at the federal, state, local, and Tribal levels through expanded community outreach and education on dementia risk factors, brain health, and related evidence-informed interventions.
- B. Strategies and interventions to address dementia risk factors should include historically underserved communities experiencing the highest prevalence of priority risk factors, low longevity rates, and the highest prevalence of AD/ADRD with explicit attention to mitigating adverse social determinants of health and strategies and interventions that promote brain healthy behavior
- C. While the aim of risk reduction efforts should mainly focus on primary prevention, activities should also include encouraging individuals diagnosed with dementia to engage (or continue to engage) in healthy behaviors, especially those behaviors that research indicates may slow progression of dementia and/or help maximize functionality by persons with dementia.
- D. As the responsibilities of dementia caregiving often result in lack of physical activity and sleep, and increased depression, among other outcomes (such as increased exhaustion and stress), dementia caregivers may be at increased risk for dementia themselves and should be a target for risk reduction efforts.
- E. In partnership with state, local, and Tribal governments, payers, community-based organizations, and relevant private sector entities, the federal government should develop and implement specific strategies to address social determinants of health that affect risk and produce adverse health outcomes related to dementia.
- F. Actions included in the National Plan should be aligned with those identified in CDC's Healthy Brain Initiative: State and Local Road Map for Public Health, 2023-2027 and Road Map for Indian Country, Healthy People 2030, and the Million Hearts campaign.

RECOMMENDATION 3

Identify and accelerate efforts to reduce risk and intervene early in clinical care.

- A. Public and private payers, health systems, and provider networks should identify and implement a comprehensive set of actions that assess risk factors for cognitive decline and dementia, ensuring equitable reach and impact of interventions for historically underserved populations.
- B. HHS should identify and accelerate strategies to improve access to primary care, team-based care, home and community-based care, and preventive care, including better utilization of existing benefits such as Medicare's Annual Wellness and Care Planning Visits.
- C. The Center for Medicare and Medicaid Innovation (CMMI) should pilot AD/ADRD risk reduction interventions. For example, CMMI could pilot a "Dementia Prevention Program" modeled on the National Diabetes Prevention Program, with special attention on optimal implementation including payment, training, delivery, and uptake.
- D. Congress should address coverage gaps in Medicare, Medicaid, IHS, and the VA that would improve interventions for identified AD/ADRD risk factors (e.g., expansion of Medicare coverage to include hearing aids and related hearing care rehabilitation services).

RECOMMENDATION 4

Initiate and fund research to strengthen the strategies for addressing the potential risk factors for dementia.

- A. HHS, including NIH, CDC, AHRQ, and other agencies should utilize fundamental principles of diversity, equity, and inclusion while developing and supporting research on factors for dementia risk reduction to address biases in eligibility criteria, proportional representation, oversampling, data stratification, systemic racism, historical context, and structural factors that disproportionately affect the health of historically underserved populations.
- B. The federal government should increase scientific research to:
 1. Increase understanding of the causal pathway for dementia.
 2. Identify and understand the social determinants of health that may elevate the risk of developing dementia and the social determinants of health that may act as barriers to addressing modifiable risk factors for dementia, such as for cardiovascular health.
 3. Examine less-understood areas of potential risk, such as environmental influences, microbiome, and the exposome.
 4. Identify what modifiable factors may decrease risk for developing dementia and identify factors related to comorbidities that may aggravate or mitigate risk for developing dementia among those with intellectual and developmental disabilities.
 5. Identify trajectories of decline in select high risk populations to determine when in the lifespan to best target mitigation and prevention strategies and interventions.
- C. The federal government should support translational research that:
 1. Evaluates efforts to implement the uptake of evidence on risk factor reduction in clinical practice and identifies key barriers that impede uptake.
 2. Develops, implements, and evaluates models of care to increase the uptake of evidence on risk reduction in primary and ambulatory care.
 3. Develops, implements, and evaluates models to align public health and health care interventions to reduce population risk.
- D. The federal government should monitor the outcomes and implications of COVID-19 post-recovery with respect to the risk for cognitive decline and dementia, including long-COVID. Particular attention should be paid to psychological and behavioral issues, such as depression, stress and 'brain-fog', as well as potential mediating factors.

RECOMMENDATION 5

Appropriate non-federal governmental entities and private sector organizations should work to improve brain health.

- A. State health departments, state developmental disabilities authorities, and state agencies and tribal authorities tasked with aging and mental health should undertake cooperative efforts to address dementia risk factors.
- B. Foundations and charitable organizations that promote healthy outcomes should invest in projects and initiatives in support of brain health, including through training and deployment of community health workers and community pharmacists.
- C. Medical associations and health systems should promote physical health as a means to address brain health.
- D. National, state, and local/community-based provider organizations working with select special segments of the population (e.g., those with intellectual/developmental disabilities and adults at elevated risk) should undertake efforts to improve brain health.
- E. Community organizations (including civic organizations and business clubs) should facilitate local efforts to improve brain health in their communities.

RECOMMENDATION 6

Establish a set of dementia risk reduction policies at the federal, state, and local level that will address risk factors, including the social determinants of health, for cognitive decline and dementia.

- A. Federal, state, and local governmental agencies should select and/or recommend policies and systems changes that would:
 - 1. Improve food quality and affordability
 - 2. Increase access to safe and inexpensive opportunities to engage in physical activity
 - 3. Decrease access to commercial tobacco products and ultra-processed foods
 - 4. Improve the ability of individuals to control and normalize blood pressure
 - 5. Expand hearing testing and use of hearing aids
 - 6. Increase access to preventive care and mental health services.
- B. National public health organizations, non-profits, and medical associations should collaborate on creating and advancing a policy agenda to increase access to healthy foods, safe spaces to exercise, hearing aids, means of controlling blood pressure, and preventive and mental health care.

Clinical Care Recommendations

Clinical Care Subcommittee

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RECOMMENDATION 1

Increase resources to educate the public & increase awareness about the importance of AD/ADRD clinical care: risk reduction, early detection, accurate diagnosis, person-centered care models, disease-modifying therapies, clinical research participation & available resources.

- A. Congress should increase funds to NIH for continued development and modification of educational tools and materials for assessing, diagnosing, and treating adults with suspected AD/ADRD and encouraging clinical research participation.
- B. The U.S. DHHS operating divisions, Department of Veterans Affairs (VA), Department of Defense (DoD) & health systems should continue to educate the public about benefits of early clinical care for all individuals with AD/ADRD, younger-onset, older adults, persons with IDD and caregivers.
- C. ACL & CDC should continue to foster relationships with state units on aging and AAAs to promote dissemination of information on risk reduction and the importance of early detection & accurate diagnosis.
- D. NIH, CDC, & ACL, clinicians, healthcare systems and state and local entities should continue efforts to encourage older adults, families & caregivers to consider participating in AD/ADRD research, in particular those from underrepresented populations.

RECOMMENDATION 2

Accelerate efforts to promote healthy cognitive aging, dementia risk reduction, early detection, accurate diagnosis, and early intervention & management of AD/ADR, including co-morbid health conditions.

A. Hospitals and healthcare practices should put in place procedures to:

1. Implement dementia education in annual training for all staff, supporting a dementia-friendly environment.
2. Identify cognitive decline and integrate management of cognitive impairment into care plans.
3. Enhance primary care capacity to diagnose/manage AD/ADR alongside other conditions.
4. Streamline care pathways for accurate/timely AD/ADR diagnoses with optimal resource use.
5. Participate in innovative dementia care models such as the Alzheimer's Disease Coordinated Care for San Diego Seniors (ADCCSDS) and the Resources for Advancing Alzheimer's Caregiver Health (REACH).
6. Promote patient/caregiver engagement with self-management strategies and personalized care plans and the use of decision aids to support informed decision-making about care and treatment options.
7. Work towards an integrated system of care, connecting primary, secondary, and tertiary services, and including home and community-based resources.

RECOMMENDATION 2 (continued)

Accelerate efforts to promote healthy cognitive aging, dementia risk reduction, early detection, accurate diagnosis, and early intervention & management of AD/ADR, including co-morbid health conditions.

- B. Advocate for congressional funding to incentivize early AD/ADR detection in primary care and community centers, focusing on underserved communities.
- C. Encourage collaboration between NIH, AD/ADR health organizations, and medical societies to develop inclusive screening protocols for diverse populations, including primary non-English speakers and adults with IDD and/or traumatic brain injury, among others.
- D. Promote clinician engagement in improving dementia care.
- E. Support FDA in regulating OTC hearing aids for improved accessibility and affordability, in line with dementia risk reduction.
- F. State health departments should catalog healthcare providers offering early detection/diagnostic services for diverse groups. Emphasis should be given to those providers and settings capable of serving diverse language groups and adults with neuroatypical conditions.
- G. Congress should amend the Older Americans Act or consider other legislation to mandate that state health departments maintain information on dementia diagnostic resources, emphasizing healthcare providers with the competency to diagnose and treat diverse populations.

RECOMMENDATION 3

Implement solutions to address the geriatric & gerontology workforce crisis through training, continuing education, mandated standards & improved pay to better address needs of persons living with AD/ADRD & their families/caregivers.

- A. Enhance federal efforts to address the geriatric care workforce crisis.
- B. Incentivize entry into the geriatric care workforce.
- C. Boost availability, training, and support for people providing clinical care to PLWD.
- D. Advocate ongoing workforce education for AD/ADRD care across diverse communities.
- E. Foster stakeholder input in policymaker discussions on evolving payment models to enhance PLWD support.
- F. Improve stakeholder engagement on payment models affecting AD/ADRD care.
- G. Encourage HRSA and AHRQ collaboration on developing person-centered dementia care models with a particular focus on primary care settings.
- H. Engage professional associations in defining skills for delivering evidence-based AD/ADRD care across care settings.
- I. Facilitate federal, academic, and professional collaboration for AD/ADRD care training alignment.
- J. Federal programs and relevant stakeholders that provide AD/ADRD care training should continue to report the number of workforce members trained per year. This data should be considered in updates to the National Plan.
- K.

RECOMMENDATION 4

Encourage people living with AD/ADRD & their designated care partners to be integral parts of the clinical care team & foster coordination of comprehensive, person-centered dementia care with Home & Community-Based Services (HCBS).

- A. The Clinical Care Subcommittee recommends that a variety of health care providers such as hospitals, health plans, health systems, federally qualified health centers, mobile clinics, and primary care practices serving people living with dementia should develop strategies to:
 - 1. Identify and involve designated care partners in care planning.
 - 2. Create and regularly update person-centered care plans.
 - 3. Aid in accessing necessary resources and services for disease management.
 - 4. Provide disease education, caregiver training, and HCBS.
 - 5. Monitor quality measures for feedback on caregiver identification, needs assessment, and the effects of education and community support.

RECOMMENDATION 5

Promote the implementation of evidence-based, nonpharmacological interventions to address behavioral & psychological symptoms of dementia.

- A. Healthcare systems, clinicians, and community-based staff should encourage the following three key considerations be addressed:
 - 1. Environment
 - 2. Care Efficacy
 - 3. Patient-Centeredness
- B. Federal agencies (HRSA, ACL, CDC, VA, IHS, NINR/NIH) and other organizations should:
 - 1. Fund Research
 - 2. Provide Training
 - 3. Create Policies

RECOMMENDATION 6

Initiate a comprehensive dialogue involving a broad cross-section of experts to discuss implementation processes R/T AD modifying treatments in the context of high-quality, person-centered care.

- A. Allocate federal funds for meetings addressing equitable access to new DMTs, involving a wide range of stakeholders.
- B. Use federal funding to research and implement DMT programs focusing on optimizing patient access and safety, considering infrastructure needs and unique access needs of urban, suburban, rural communities, and underserved populations.
- C. Discuss initiatives for appropriate DMT reimbursement and related services to guarantee equitable treatment access.

RECOMMENDATION 7

Promote further development, evaluation, & practical implementation of effective person-centered health care models for AD/ADRD that integrate performance measures & payment models.

- A. Value-based initiatives should align with CMS-defined value measures.
- B. Value assessment should be evidence-based, with research on care models' impact on health outcomes, including effective management of comorbidities.
- C. Use frameworks like CMS's Meaningful Measures Initiatives for persons with AD/ADRD or cognitive impairment, their family members, and caregivers.
- D. Congress and/or federal agencies should prioritize the evaluation of comprehensive models that include a per-beneficiary-per-month payment to provide care and services to eligible persons living with AD/ADRD, as described in the 2017 National Plan.
- E. States and payers (Medicare, Medicaid) should amplify their focus on home and community-based services (HCBS), which support person-centered care and self-determination for persons living with AD/ADRD and their caregivers. Considerations should also be given to develop mechanisms for reimbursing these providers for their services to patients.

RECOMMENDATION 8

Promote health equity & eliminate barriers to the receipt and payment of clinical care services & long-term services & supports for adults living with dementia who are under age 65.

The Clinical Care Subcommittee recommends that the National Plan address the following barriers to clinical care and community-based long-term services for younger individuals living with AD/ADRD:

1. The OAA requires recipients to be age 60 or older to receive covered services. The Clinical Care Subcommittee suggests that Congress amend the OAA to extend services to persons under age 60 diagnosed with AD/ADRD.
2. The two-year waiting period for younger individuals living with AD/ADRD who qualify for SSDI to have access to Medicare poses a barrier to clinical care. The Clinical Care Subcommittee recommends that Congress consider eliminating this waiting period to enhance access to crucial healthcare services.

Long-Term Services & Supports Recommendations

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RECOMMENDATION 1

Improve access to LTSS for people with dementia and their caregivers.

- A. Expand the availability of culturally and linguistically tailored LTSS to ensure access for populations that are marginalized, historically underserved, and disproportionately affected by dementia.
- B. Expand the availability of dementia-capable home and community-based services (HCBS) available to people with dementia and their unpaid caregivers.
- C. Implement strategies to reach people living alone with dementia and strategies that address the impacts of social isolation and loneliness on health outcomes, safety, and quality of life.
- D. Implement strategies to improve outreach, housing, and supportive services to better address the needs of older adults experiencing homelessness, including those with dementia.
- E. Implement strategies to address the new and unique issues generated from the COVID-19 pandemic.

RECOMMENDATION 2

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

- A. Improve the quality of care and safety provided to people with dementia across LTSS settings.
- B. Reduce inappropriate use or over-use of psychotropic medications in LTSS settings.
- C. Increase the availability and use of evidence-based dementia and caregiving interventions within the LTSS system.
- D. Increase availability, utilization, and quality of care for people with advanced dementia.

RECOMMENDATION 3

Implement solutions to address the LTSS workforce crisis.

- A. Increase efforts and implement systems solutions at the federal level to address the workforce crisis.
- B. Establish a national caregiver career pathway to create consistent, transferable, and broadly available career advancement opportunities.
- C. Provide incentives for people to enter the workforce.
- D. Increase availability and improve training and supervisory support for people providing direct care to people with dementia.

RECOMMENDATION 4

Ensure that family and unpaid caregivers of people with dementia have the support they need.

- A. Leverage implementation of the National Caregiving Strategy to align with NAPA goals and ensure dementia caregivers are considered in implementation.
- B. Increase access to and quality of information that can assist unpaid caregivers in their caregiving role.
- C. Increase caregiver strategies to reduce the financial burden and provide protections for working caregivers.

RECOMMENDATION 5

Implement new payment models to make LTS more affordable and eliminate gaps in coverage among government programs that support people with dementia.

- A. Explore and implement new social insurance programs that make long-term care more affordable and prevent financial insecurity of older adults and people with dementia of all ages.
- B. Strengthen the OAA and other Aging Network programs to meet increased needs and integrate people living with dementia.
- C. Eliminate gaps and increase coverage for LTSS under Medicare and Medicaid that meet the needs of people living with dementia and their unpaid caregivers.

RECOMMENDATION 6

Implement strategies that support coordination, integration, and dementia capability.

- A. Implement strategies that support broad systems improvements and make current crisis and adult protective services systems dementia-capable and able to provide abuse and neglect prevention, crisis response and stabilization and LTSS for people living with dementia.
- B. Implement strategies that improve coordination of LTSS with the behavioral health system.
- C. Implement strategies to enhance alignment and integration of the health care and HCBS systems