

# Advisory Council on Alzheimer's Research, Care, and Services

## 2022 Draft Recommendations

### Research Subcommittee

#### Recommendations

**Recommendation 1:** Increase synergies among all federal agencies involved in the National Plan to facilitate faster and more comprehensive translation of research into clinical practice of evidence-based advancements and approved diagnostic, treatment, and care paradigms to improve outcomes for people with dementia. This approach to faster translation is to cover the entire continuum from research studies through regulatory review and approval, payer review and approval, and delivery of improved diagnosis and care. Stakeholders should design and implement pipelines for faster and more complete translation of research findings. Because access by doctors and patients to scientific advancements is dependent on several different agencies, coordination in the approach to implementation has the promise to deliver more clinically beneficial results, more quickly to patients.

- A. Federal agencies responsive to NAPA should work together to identify areas with the opportunity for translation of research to clinical practice to occur more rapidly. Examples include coordination among NIH, ARPA-H, FDA, CDC, VA, HRSA, AHRQ, NSF, CDMRP/DOD, and CMS to implement care programs along the translational research continuum that impact health of people with AD/ADRD.
  1. Translation from clinical trials to implementation, including payment support of approved treatments and tests. Strategies to improve translation of research to the clinic include:
    - i. Coordination in the review of clinical studies that demonstrate effectiveness of treatments and tests to determine the standards of clinical utility and approval for access and payment.
    - ii. Collaboration by the agencies responsible for approval for access and payment on an agreed set of measures, analytic tools, and standards of clinical benefit for functional, clinical, cognitive, patient reported, and other outcomes applicable for review is needed to guide clinical studies.
    - iii. The NAPA agencies should review the current timelines, gaps and delays, and opportunities for improving the time needed for agency approvals and implementation of research advancements.
    - iv. NAPA agencies should also evaluate opportunities to better implement research supported strategies to improve the health and care of AD/ADRD and report recommendations to NAPA and the appropriate government bodies to make needed changes to implement improvements. Some recommendations may be made intra-agency, while others may require coordination across agencies or other changes, including changes to current policies. Evaluation of

the impact of the current scope of agencies, cross-agency coordination, and other barriers and opportunities is needed.

- v. The cost of current delays or denial of diagnostic and therapeutic implementation should be studied and calculated in terms of human illness and suffering, quality of life, financial cost of disease, and impact to society. These costs should be evaluated and balanced with the costs of taking action in a risk-benefit approach. Prior precedents include the OMB tracking and managing the cost of time spent on administrative burden.
2. Examples of coordinated programs include:
    - i. Diagnostic tests for Alzheimer’s disease and other neurodegenerative diseases by CSF, PET scans or blood tests which can provide accurate diagnosis.
    - ii. Therapeutic development of drugs and interventions which can improve clinical outcomes and impact the progression or risk of the disease.
    - iii. Other disease interactions such as research into causes, relationships, and risk reduction of delirium (including Covid delirium) and dementia and transfer best practices to care through AHRQ and CMS mechanisms.
  3. Increase cross-agency interaction to plan strategic cross-agency responsiveness to relevant NIH Summit recommendations and other translational priorities for AD/ADRD, and address barriers to doing so. For example, recommendations could be shared by scientists and health implementation system groups at the next Research Summit on Care, Services, and Support in 2023, followed by a separate meeting for federal staff to discuss implementation and appropriate policy changes and activities.
- B. NAPA organizers, including ASPE, should have increased resources (e.g., financial and personnel support) and authority to accomplish the following:
1. Track the progress and milestones of prior recommendations with a goal to prioritize those recommendations with the largest potential impact. Examples of project management tracking systems to be utilized and reported at NAPA include dashboards of recommendation progress, milestone tracking, Gantt charts, etc.
  2. Appoint a federal coordinator with the authority to prioritize, organize, implement, and follow up on cross-agency recommendations.
  3. Provide appropriate resources (e.g., financial, FTE, and authority) to NAPA efforts to implement recommendations.

**Recommendation 2:** By the end of 2022, NAPA federal agencies should investigate and propose successful models for increasing involvement of people with AD/ADRD in clinical research studies, including trials. The proposal should evaluate how clinical care can be synergized with research participation to accelerate scientific advancements that can be quickly translated into clinical practice. This may include evaluating successful models from other disease areas (e.g., cancer and the NCI model for clinical trials, Covid-19 studies, etc.), incentivization of research participation, evidence-based models of implementation, and payer evaluation of successful advancements based on evidence (e.g., CMS). The goal should be for all people with AD/ADRD to be offered opportunities to participate in research.

- A. The potential impact of FDA approval of anti-amyloid therapies, including aducanumab, should be studied to understand their impact on research efforts and the goals of NAPA to implement effective treatments and prevention by 2025. Areas of study with high-impact implications include how approval and access to disease modifying drugs will impact research participation in clinical trials, clinical trial design, review and approval of drug use, payer coverage, and implementation of treatments. These areas of study could transform how AD care is provided at a national level and impact NAPA goals.
- B. The rapid pace of translating Covid-19 research findings into clinical practice highlight opportunities to improve the coordination and translation of research discoveries into care impact for people with AD/ADRD and unpaid caregivers. Increased funding and resources from Congress are needed for NAPA federal agencies to review and implement relevant Covid-19 approaches as a model for novel AD/ADRD approaches to accelerate translation of clinical trials, review and approval of demonstrated effective tests and treatments, and clinical care implementation.
- C. The newly created ARPA-H should play a major role in the translation and demonstration of scientific breakthroughs in the diagnosis, treatment, and management of dementias.

**Recommendation 3:** A top priority remains the urgent need for Congress to continue to increase annual federal research and implementation science funding (by NIH and other agencies) sufficient to meet NAPA goals across biomedical, clinical, long-term services and supports, and public health settings. 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, familial AD, individuals with Down syndrome).
- B. Dementias with clinical diagnoses other than AD and mixed/multiple etiology dementias (e.g., primary tauopathies, alpha-synuclein, TDP-43, vascular, etc.). Identifying specific biomarkers for these dementias would improve diagnostic capabilities, and continued research into interventions may provide increased therapeutic options.

- C. Early detection of cognitive decline and precursors of dementia at an individual level, identification of the pathology(s) causing a person's trouble, and development and testing of treatments targeted appropriately at the biologic underpinnings in a given individual.
- D. Models of dementia care and support and the testing of innovative payment models (potentially funded by CMS/CMMI, private foundations, etc.).
- E. Translational technologies for diagnostics and therapeutics, including diagnostic testing and CNS drug delivery.
- F. Prevention and risk reduction of cognitive decline and dementia, as discussed in more detail by the risk reduction subcommittee.

**Recommendation 4:** Representation and diversity in AD/ADRD clinical trials should continue to be increased to address health equity and representation in research.

- A. Potential strategies include leveraging models of community-based recruitment, integrating into primary care systems with recruitment of clinical patients, scaling up of funding to enable research to develop and grow the necessary infrastructures, targeted RFAs, requirements by NIH, CMS, and other funding agencies for trial and observational study enrollment, and including PPI panels inclusive of those living with dementia and unpaid caregivers representative of these diverse targets.

**Recommendation 5:** Research into implementation of dementia care to provide best care models should continue to be increased.

- A. Examples include evidence-based interventions such as medication management, care support, clinical care team management, exercise, diet, and activity. Diagnostic strategy implementation from primary care through specialty centers should also continue to be studied.
- B. Timely and accurate diagnostic and prognostic information should be provided for people with ADRD and caregivers (as appropriate) using recent scientific developments in biomarkers such as PET, CSF, and blood-based diagnostic tests. Access to diagnostic evaluations should include all communities.

**Recommendation 6:** 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.

- A. 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, medical provider, and societal effects of stigma on access to care, diagnosis and treatment, and support systems. This research may help identify why payers have not supported newer diagnostic evaluations and what is needed to provide accurate diagnosis of ADRD.

**Recommendation 7:** A cross-cutting recommendation across all NAPA subcommittees is to increase research into neurological effects of Covid-19 and development of emergency preparedness programs for the safety and wellness of older adults and people with ADRD.

- A. Encourage longitudinal study into the effects of Covid-19 on the brain, inclusive of neuroinflammation, and their long-term impact on diagnostic, treatment, and support systems. Research should have an emphasis on inclusion of diverse populations, taking into consideration race and ethnicity, rural and urban areas, and representative geographical areas across the US and globally if possible.
- B. Encourage research into the development of community-based programs designed in a proactive and preemptive manner to provide for the safety and wellness of those living with AD/ADRD and their care partners. Examples include research into effectiveness of dementia training for first responders and integration of dementia-trained professionals as part of mental health response teams.

# Clinical Care Subcommittee

## Themes

Clinical aspects of care related to dementias need strengthening and expanding in scope and breadth. The United States lacks a coordinated and integrated system of provision of screening, assessment, and diagnostic services reaching into and available to all segments of our society. Those segments include: urban, suburban, rural areas; insured or uninsured; English speaking or fluent in any other language; formal living settings or informal with families and others. No unitary legislation nor funding that exists at the national level which provides for standards of care, services, or supports, or for medical and diagnostic assessments related to clinical care. While some efforts exist in varied forms, it is not linked, joined, or coordinated in a manner that would best serve the interests of persons living with dementia or their caregivers or families. Inadequacies still exist in:

- Educating the public about risk reduction, early detection, diagnosis, access to and course of care, particularly in diverse communities.
- Ensuring adequate workforce, both with respect to education and remuneration.
- Assuring management of chronic care conditions and medical/medication and other factors that influence cognitive decline.
- Integrating the family caregiver into the whole care plan and diagnostic process.
- Utilizing guidelines for diagnosis (including best practices for delivering the diagnosis, considering culture and language), ongoing management, caregiver support, and advanced care planning - emphasizing dementia care training across clinical care specialists (emphasis on dementia capable workforce within healthcare systems, including the interprofessional aspect/team-based care).
- Increase the use of person-centered and family-centered health care models for Alzheimer's disease and related dementias (AD/ADRD) that align performance measures and payment models.
- Remove any barriers for the receipt of, and payment for, clinical and care services for adults living with dementia who are under the age of 65.
- Accelerate efforts to promote healthy aging, reduce risk factors for AD/ADRD and intervene early in clinical care.
- Integrating clinical care with research opportunities that focus on improvement of clinical care, practice, systems - care quality, care delivery.
- Utilizing research to direct best practices in diagnostics and care.
- Nomenclature consensus to ensure that clinicians, patients, caregivers, researchers, and stakeholders have common language to communicate.

## Recommendations

**Recommendation 1:** Educate the public (including clinicians, consumers, families, and community members) about the importance of risk reduction, early detection and accurate diagnosis of Alzheimer’s disease and related dementias (AD/ADRD), care models useful for person-centered and family-centered care, resource access and utilization.

Education about the availability of early detection and diagnosis of AD/ADRD is important so that people living with cognitive symptoms are provided the opportunity to participate in person-centered care and planning when symptoms are in an early stage. General education and information about local/regional resources, including information on research recruitment and enrollment of persons of all ages including those with cognitive impairment, dementia, those at risk for cognitive decline, caregivers, as well as healthy controls should be easily accessible. Such information and resources should support inclusivity and diversity in care, care coordination, patient safety, and the decision-making of persons at-risk for and living with AD/ADRD and their caregivers. Information for accessing available services and supports and how to best make use of them is also needed. Awareness of existing social stigma of people with dementia as a barrier to gain knowledge and access to education, care and supports, and how it is uniquely expressed or lived in diverse communities, should be addressed through education.

- A. NIH and CMS (and State Departments of Health) should offer guidance on assessing and diagnosing adults with suspected AD/ADRD who present with life-long neurotypical conditions, are not primary English language speakers, or come from cultural or ethnic groups with beliefs and norms at variance to the main population of a specific area.
- B. NIH and ACL should develop and distribute dementia educational materials in varied languages and within context of cultural or ethnic target groups.
- C. ACL should produce educational materials that destigmatize perceptions of AD/ADRD among cultural or ethnic groups where cognitive impairment is devalued or not regarded as acceptable.
  - 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>]
- D. 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 risk reduction, early detection and diagnosis of AD/ADRD, including early assessment and the importance of care planning, to improve the health and well-being of all individuals diagnosed with AD/ADRD, younger-onset, older adults, all persons with intellectual and developmental disabilities (IDD) 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/>]
- E. The Advisory Council should clarify the U.S. Preventative 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>]
- F. 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 at NIH, CDC, and ACL should also focus on recruitment and retention efforts on including individuals with younger-onset AD/ADRD and all persons with intellectual and developmental disabilities (IDD). 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>]
- G. 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, specifically encouraging people to make lifestyle changes associated with known risk factors such as physical inactivity, poor diet quality, smoking or unhealthy alcohol use, and by integrating risk reduction strategies for hypertension and diabetes control into clinical practice. (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.
- H. ACL should encourage state units on aging and area agencies on aging to disseminate information on risk reduction, early detection and diagnosis of AD/ADRD, including clinicians able to integrate risk reduction strategies in clinical care, 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 those 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.
- I. 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:** Expand and enhance the current and future clinical care workforce through training, continuing education, mandated standards, and remuneration to better address the needs of persons living with AD/ADRD and their families/caregivers.

- A. Federal agencies and others should continue to offer and support current and future workforce education to improve workforce members' abilities to work with persons of all

ages, living with AD/ADRD and their family caregivers, including those in diverse communities.

1. Primary Care -- to train the primary care workforce about dementia and promote interprofessional teamwork in the care of persons living with AD/ADRD and integrate family/caregivers in the plan of care.
2. Dementia Care Management - to train dementia care managers (nurses and social workers) within healthcare organizations to effectively support all people living 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 and include caregiver needs..
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 and their family/caregivers..
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. Knowledge of presentation of adults with neuroatypical conditions should be included.
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, focusing on persons from diverse populations and those most affected by social determinants of health. 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; risk reduction; and culturally and literacy appropriate content and materials. Available resources to address this recommendation include:

- i. <https://www.nia.nih.gov/health/now-what-next-steps-after-alzheimers-diagnosis>
  - ii. <https://www.nia.nih.gov/health/managing-older-patients-cognitive-impairment>
  - iii. <https://www.nia.nih.gov/health/talking-older-patients-about-cognitive-problems>
  - iv. <https://www.nia.nih.gov/health/assessing-cognitive-impairment-older-patients>
- B. Workforce education programs should include recognizing and addressing risk factors, early signs and symptoms (within a person- and family-centered cultural context), early detection, diagnosis, treatment, plan of care, offering and providing counseling to persons living with AD/ADRD and their family members and caregivers, and connecting them to local services and resources for continuity of care at all stages.
  - C. NIH and CMS (and State Departments of Health) should offer guidance on assessing and diagnosing adults with suspected AD/ADRD who present with life-long neurotypical conditions, are not primary English language speakers, or come from cultural or ethnic groups with beliefs and norms at variance to the main population of a specific area.
  - D. Policy maker discussions should include stakeholders' input about payment models based on clinical care recommendations, research, etc.
  - E. Develop, test and implement integrated person-centered and family-centered models of care for people living with dementia, especially in primary care settings.
  - F. Expansion of training across all clinical disciplines including recertification maintenance of state licensure.
  - G. 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, person-family centered, culturally appropriate 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.
  - H. Federal agencies and others should align current training related to AD/ADRD care with evidence-based guidelines (including dementia practice care recommendations) and should consider them in curricula and continuing education for health professionals, first-responders, and other individuals. Examples of such recommendations include:
    - 1. The Alzheimer's Association's 2018 Dementia Care Practice Recommendations [[https://www.alz.org/professionals/professional-providers/dementia\\_care\\_practice\\_recommendations](https://www.alz.org/professionals/professional-providers/dementia_care_practice_recommendations)]

2. HRSA AD/ADRD Core curriculum and the HRSA Caregiving Curriculum [<https://bhw.hrsa.gov/grants/geriatrics/alzheimers-curriculum>]
  3. Brain health education about AD/ADRD and caregiving in curricula for students of public health available through CDC and the Alzheimer's Association [<https://www.cdc.gov/aging/aginginfo/alzheimers.htm#Curriculum>]
  4. Recommendations from the National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers [<https://aspe.hhs.gov/basic-report/research-summit-dementia-care-main-summit-recommendations>]
  5. Guidance on Inappropriate Use of Antipsychotics: Older Adults with Intellectual and Developmental Disabilities in Community Settings [<https://store.samhsa.gov/product/Guidance-on-Inappropriate-Use-of-Antipsychotics-Older-Adults-and-People-with-Intellectual-and-Developmental-Disabilities-in-Community-Settings/PEP19-INAPPUSE-BR>]
- I. 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:** Using the best available evidence, stakeholders should reach consensus on guidance for best practices for diagnosis, management, and integration of family caregivers into the care team. For developing comprehensive multi-stage care of AD/ADRD, consideration should include the uniqueness of different populations. Specifically, the different populations include persons with young-onset and atypical AD/ADRD, Down Syndrome and other Intellectual and Developmental Disabilities [IDD]), and those from other neuroatypical conditions, racial and ethnic communities who are disproportionately affected, caregivers, health systems, and payers.

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, and research opportunities. An effort, supported by the federal government should be undertaken to identify clinical and care best practice models that can be easily documented and made available for use throughout the nation. The effort should involve a range of experts and representatives from diverse interests, professional backgrounds, and populations impacted by AD/ADRD.

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.  
[\[https://acl.gov/sites/default/files/Aging%20and%20Disability%20in%20America/Serious%20Illness%20Principles%208-30-17%20508%20compliant.pdf\]](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 and health equity.
  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 and family-centered care 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 risk reduction, 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 and family-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.johnhartford.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>]
  - E. The work group should establish and promote guidelines that provide guidance to help those diagnosed with AD/ADRD including the diagnostic pathway, where to go for support, assistance, and information, including information on how to live well with AD/ADRD, and how to engage in risk reduction strategies. Dementia specialists should fully appreciate the emotional trauma experienced when receiving an AD/ADRD diagnosis. This is particularly important for those diagnosed with younger-onset AD/ADRD and their families.

**Recommendation 4:** Encourage further development, evaluation, and implementation of person-centered and family-centered health care models for AD/ADRD that align performance measures and payment models. These models should incorporate the lived experience of care of persons living with AD/ADRD of all ages and their caregivers (considering diversity).

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. Consideration should include physical, mental, and social factors, to pay for health care services in a manner that directly links payments to performance on cost, quality, and resource use. This alignment would support comprehensive person-centered and family-centered care leading to improved health outcomes and quality of life for persons living with AD/ADRD and their families/caregivers.

- A. Initiatives delivering value-based programs should rely on definitions of value outlined by CMS and others. [<https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Value-Based-Programs/Value-Based-Programs.html>]

- B. Initiatives to assess value should be informed by evidence, and new research should be conducted to study how models of care improve health outcomes, including the effective management of comorbidities.
- C. Initiatives to assess value should rely on a framework such as the CMS Meaningful Measures initiative, and apply such a framework specifically for persons living with known AD/ADRD or cognitive impairment and their family members and caregivers. This could be combined with other reporting of metrics of health care use and performance such as:
  - 1. Cognitive Impairment and Assessment Care Planning Codes.
  - 2. Quality Payment Program measures relevant to AD/ADRD.
  - 3. Use of Medicare's Annual Wellness Visit.
- D. Congress and/or federal agencies should prioritize evaluation of comprehensive models which include a per-beneficiary-per-month 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:** To assure health equity, remove any barriers for the receipt of, and payment for, clinical and care services, and long-term services and supports, for adults living with dementia who are under the age of 65.

Adults with younger onset dementia may be ineligible for certain dementia-specific services, due to statutory barriers related to age of eligibility. First, the Older Americans Act requires recipients to be age 60 or older to receive covered services. Second, there is a barrier posed by eligibility requirements under Medicare. This barrier is a two-year waiting period for younger individuals living with AD/ADRD who have been deemed eligible for Social Security Disability Insurance (SSDI) to have access to Medicare. Eliminating this waiting period will require an act of Congress, therefore, policymakers need to understand the impact of this wait on beneficiaries with dementia and the health care system. The Advisory Council recommends raising these issues in the Plan and encouraging our federal partners provide data to support policy proposals.

- 1. The National Plan should address the following issues that are barriers to clinical care and community-based long-term services for younger individuals living with AD/ADRD.
  - 1. The Older Americans Act requires recipients to be age 60 or older to receive covered services. Congress should amend the Older Americans Act to provide services for persons under age 60 living with dementias.

2. This barrier is a two-year waiting period for younger individuals living with AD/ADRD who have been deemed eligible for Social Security Disability Insurance (SSDI) to have access to Medicare. This is a barrier to clinical care for younger people with dementia. Congress should eliminate this waiting period.

**Recommendation 6:** Accelerate efforts to promote healthy aging, reduce risk factors for Alzheimer’s Disease and Related Dementias and intervene early in clinical care.

A growing body of evidence shows that addressing certain modifiable risk factors for cognitive decline and promoting healthy lifestyle behaviors can reduce the risk of cognitive decline, possibly reduce the risk of dementia, protect cognitive health, and promote healthy aging. Modifiable risk factors for cognitive health include managing high blood pressure; eating healthy foods; being physically active; keeping your mind active; staying connected with social activities; managing stress; improving the quality of sleep; and reducing or stopping alcohol intake. In addition, hearing loss is an identified risk factor for dementia. Research demonstrates that hearing aid use is associated with reduced dementia risk.

Translating evidence-based recommendations into clinical practice should be the focus of clinicians and workforce members, who care for persons of all ages living with or at risk for AD/ADRD, in collaboration with the community, state, and federal agencies. The implementation of recommendations in clinical practice will require better person-centered and family-centered-clinician communication, education, improved care coordination, and targeted clinician (workforce) training. Additional requirements include effective dissemination of evidence-based guidelines, strategies for continuous quality assessment and improvement, efforts addressing access to care for all, and advancing health equity.

**A. FEDERAL PARTNERS:**

1. Take measures to ensure that the health care workforce understand the risk factors for dementia and promote brain health maintenance and dementia risk reduction actions in people of all ages.
  - i. HRSA, through its Geriatric Workforce Enhancement Program (GWEP)s, should expand the development and dissemination of curricula to train the health care workforce in using a “whole-person” approach that encompasses all of patient’s needs to address individuals’ brain and behavioral health. HRSA should include training on how to best use the annual wellness visit to deliver dementia capable care in their geriatric’s workforce development programs.
  - ii. FDA should implement the recently issued Proposed Rule to establish a new regulatory category for over-the-counter (OTC) hearing aids and make related amendments to update the regulatory framework for hearing aids. The Proposed Rule aims to foster innovation in hearing aid technology. It would also improve access to hearing aids, as OTC options would likely be easier to obtain and less expensive.



- iii. CMS should identify the steps needed to make hearing aids accessible to as many people as possible, through Medicare/Medicaid benefits, particularly those in diverse and under-served populations.

**B. HEALTH SYSTEMS:**

1. Health systems should implement a comprehensive set of actions to assess and reduce dementia risk, delay the onset of dementia, and improve early intervention for their patients - ensuring equitable reach and impact of interventions for historically marginalized populations. This would benefit everyone from clinicians, community health workers, and other health system staff that interact with the patients and caregivers.
2. Expand system dementia-capability by including dementia education in the employee annual training requirements.
3. Health systems should utilize CDC resources to increase health and social service providers awareness of brain health as a serious public health concern using existing and future resources, including, but not limited to:
  - i. American College of Preventive Medicine's (ACPM) Brain Health Continuing Education Course and Resource Website, and [Healthy Brain Resource Center \(cdc.gov\)](#)
  - ii. An article by the CDC/ACPM, Cognitive Decline and Dementia Risk Reduction: Promoting Healthy Lifestyles and Blood Pressure Control. For free access: <https://alz-journals.onlinelibrary.wiley.com/doi/10.1002/alz.12638>

**C. CLINICIANS:**

1. Identify opportunities to reduce the risk of mild cognitive impairment and dementia by addressing known risk factors and support early intervention on risk factors for cognitive decline and dementia. Access education for the clinical care and patients on promoting brain health. Use quality measures specifically related to dementia risk reduction.
2. Learn existing health system and home and community-based resources that can support reduction of dementia risk factors and inequities associated with AD/ADRD to support making appropriate referrals for supports and services. Examples include: nutrition support; physical activity prescriptions; falls prevention; chronic disease management and treatment; audiology assessments and screenings, hearing rehabilitation, access to hearing technology; and screening and treatment for depression and unhealthy alcohol use.
3. Participate in dementia specific continuing education, including ECHO trainings, to address dementia-risk reduction, brain health, early detection and diagnosis of dementia, delivery of diagnosis, and dementia across the disease trajectory including early intervention, management, and medication management, including training on advances in dementia medications.
4. Increase hearing testing, to support access to hearing aids for individuals with hearing loss.
5. Dissemination of dementia risk reduction practices on co-occurring chronic conditions and dementias.

- i. Expand the availability and reach of dementia education and health promotion resources in health settings. For example:
  - 1. Increase access to CDC / National Association of Chronic Disease Directors (NACDD) customizable Rack Cards (Spanish and English) that are designed to educate patients about risk reduction practices related to AD/ADRD, including the importance of blood pressure control, physical activity, healthy diet, blood sugar management, and smoking cessation.
  - 2. Expand the availability and reach of the [Healthy Heart, Healthy Brain](#) campaign to support American Indian and Alaska Native nations and tribal-serving organizations. The materials for use by health care providers and public health professionals include steps patients can take to promote heart, brain, and overall health.
- 6. Encourage treatment of co-occurring behavioral health conditions:
  - i. Clinicians should become educated in and inform their patients of the dementia risks connected to behavioral health conditions, including depression, other mental illnesses, and substance use disorders (SUD).
  - ii. Build awareness of and utilize the Substance Abuse and Mental Health Services Administration's (SAMHSA's) Treatment of Depression in Older Adults Evidence-Based Practices (EBP) toolkit in their practice. The kit offers information about an array of EBP for treatment and services to improve outcomes for older adults experiencing depression, including dysthymia. It considers planning, implementation, and maintenance. Treatment approaches for older adults with dementia or other cognitive impairments are included in the case examples.
  - iii. Build awareness of and utilize SAMHSA's guide for practitioners on Psychosocial Interventions for Older Adults with Serious Mental Illness (SMI) which provides considerations and strategies for interdisciplinary teams, peer specialists, clinicians, registered nurses, behavioral health organizations, and policy makers in understanding, selecting, and implementing evidence-based interventions that support older adults with SMI.  
For individuals in the early stage of AD/ADRD, psychosocial therapies for serious mental illness (SMI) may still be effective, although the interventions may not be appropriate if a person is in a more advanced stage of dementia.
  - iv. Build awareness and utilize evidence-based interventions to support caregivers in managing behavioral systems. SAMHSA, CMS, HRSA, and ACL collaborated to publish *Guidance on Inappropriate Use of Antipsychotics: Older Adults and People with IDD in Community Settings*. The Guidance reviews non-pharmacologic behavioral approaches and strategies to avoid and reduce prescribing of antipsychotics whenever possible for older adults with dementia and people with IDD.
  - v. Increase awareness of substance use disorder (SUD) and its impact on older adults and AD/ADRD. As we age, the body's ability to process alcohol and

other substances becomes less effective; cognitive impairment can also alter the impacts of alcohol and other substances. Clinicians should familiarize themselves with SAMSHA's developed resources including:

1. **Get Connected: Linking Older Adults with Resources on Medication, Alcohol, and Mental Health toolkit.** The toolkit is designed for organizations that provide services to older adults and offers information and materials to help understanding the issues associated with substance misuse and mental illness in older adults.
  2. ***Growing Older: Providing Integrated Care for an Aging Population.*** In partnership with HRSA, this report for clinicians explains approaches to providing integrated care to older adults living with SUD and mental illness. It highlights the importance of assessing patients for cognitive deficits and adapting behavioral interventions to help improve treatment outcomes. The report also stresses the importance of including family caregivers, when possible, in the diagnostic and treatment process.
- These materials should be updated on a regular basis, as research provides more insights and information, to help clinicians understand the impact of SUD on their patients and families.

# Long-Term Services and Supports Subcommittee

## Themes

- Access to Long-term Services and Supports
- Direct Care Workforce
- Family and Unpaid Caregivers
- Payment Models
- System Integration

## Recommendations

**Recommendation 1:** Improve access to LTSS for people with dementia and their unpaid caregivers.

Quality of life experienced by people with dementia is often dependent upon the ability to access quality services and supports. Yet millions of Americans with dementia and those who care for them are faced with daily challenges in accessing services.

This set of recommendations focus on four issues that the committee sees as some of the most significant gaps in accessing LTSS: (1) availability of culturally and linguistically tailored dementia care for populations that are marginalized, historically underserved, and disproportionately affected by dementia; (2) diminishing availability of some HCBS particularly of value to people with dementia and their unpaid caregivers; (3) people living alone with dementia and the impacts of social isolation and loneliness on health outcomes, safety and quality of life; and (4) new issues generated from the COVID-19 pandemic.

To assist in filling these gaps, the Committee offers the following recommendations:

- 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.
  1. Congress should allocate funding to ACL and the CDC for distribution to states for the purpose of creating local networks of dementia care advocates that are drawn from and serve marginalized, underserved, and culturally diverse communities.
  2. ACL should develop and fund a community health worker (CHW) program, like the CHW model within health care and public health systems, that can be deployed within States, Aging and Disability Resource Centers (ADRCs), Area Agencies on Aging (AAAs), and other organizations that serve as the state's No-Wrong-Door and Medicaid "choice counseling" entities. As these organizations play a significant role in helping people access dementia services and enroll in LTSS programs, it is crucial

- to have people dedicated to serve as community advocates and connectors to culturally responsive dementia supports for members of underserved communities.
3. HRSA should include a dementia educational component in the CHW training program that supports the expansion of culturally appropriate cognitive screening, enhances knowledge of neuroatypical conditions with elevated risk for dementia, and covers outreach and education pertaining to risk reduction, brain health, and connecting with community and clinical resources.
  4. Federal agencies should encourage collaboration between Community Health Clinics, Managed Care Plans, Public Health, and community-based organizations to create networks of CHWs to serve populations that are disproportionately impacted by dementia.
  5. Because CHWs work under the guidance of licensed professionals, CMS should allow CHW positions to be billable under Medicare for people who are 65+ or who have a disability and provide information to States on the ability to expand these provider types under Medicaid.
  6. ASPE should conduct and publish a study on the impact and return on investment that CHWs can have on the health of underserved communities and on health care and LTSS providers, as a potential means of supporting growth of the model across the country.
  7. ACL should require State Units on Aging (SUAs) to include a strategy in their state aging plans for the creation of an inclusive and coordinated caregiver support system that includes public and private agencies impacting older adults, people with disabilities, transport authorities and payor systems.
  8. Modeled after successful state programs, Congress should allocate funding to ACL to develop a community-based Dementia Care Specialist/Navigator program within the aging network, across all 50 states, Washington D.C. and U.S. territories. Congress should also allocate funding to IHS to support a Tribal Dementia Care Specialist/Navigator program within tribes.
  9. DHHS should provide training to Federally Qualified Health Centers that can assist immigrant, rural and low-income populations in accessing LTSS.
  10. DHHS should provide incentives for diverse business owners and not-for-profit organizations to become dementia-capable LTSS service providers.
  11. Congress should increase funding for Aging and Disability Resource Centers (ADRCs)/No Wrong Door systems to improve access to public and private LTSS for people living with dementia and their unpaid caregivers, and others, regardless of payor or income.
- B. Expand the availability of certain home and community-based services (HCBS) particularly of value to people with dementia and their unpaid caregivers.
1. Adult day and adult day health centers provide socialization, recreation, and health services for people with dementia and others, and are also a valuable source of respite for caregivers. There has been a significant loss of day service providers due to the COVID-19 pandemic and state abatement and payment policies across the country. ASPE should conduct a study on the causes of this issue and provide recommendations to entities who can have an impact on expanding and ensuring

- that day services are sufficiently available across the country for people with dementia in need.
2. Respite care options are essential for giving unpaid caregivers a break, which can have an impact on their caregiving longevity and capacity to care.
    - i. ACL and CMS should encourage states to make at-home and community-based day and overnight respite services available to families/unpaid caregivers through various LTSS programs. These respite services should include programs, based on evidence, including therapies, exercise programs, and socialization models.
    - ii. HRSA should study the impact that direct care workforce recruitment, sustenance, and education challenges have had on respite care options and make recommendations for addressing the issues identified in the study.
    - iii. ACL should provide resources to expand the availability of innovative dementia-specific respite programs and evaluate, document and disseminate successful interventions or models.
  3. Life Care Planning and Counseling is an important service, especially for people beginning their dementia journey and for families caring for them. ACL and CMS should encourage ADRCs, AAAs, SUAs, managed care organizations, and Medicaid-Waiver agencies to include life care planning and counseling services within their scope of available services.
- 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.
1. ACL and the CDC should continue to collaboratively promote and fund the expansion of [dementia-friendly communities](#)' efforts, and begin to promote and fund dementia-friendly employers and caregiver-friendly workplace policies, accessible and inclusive public spaces, memory café's, accessible transportation, housing, technology and broadband internet access, and any other strategies helpful for addressing the negative consequences of social isolation and loneliness. ACL should encourage inclusion of such efforts in State Units on Aging (SUA) plans and State Health Improvement Plans (SHIPs).
  2. Congress should increase funding for ACL to expand community grants that provide [evidence-informed innovative practices](#) in a variety of locations to support people living alone with dementia. Example practices include friendly visitor, gatekeeper programs, emergency response and law enforcement programs.
  3. ACL should encourage collaboration between its Administration on Aging (AoA) and the Administration on Developmental Disabilities (ADD) to create cross-cutting strategies and plan for identifying and assisting older adults with disabilities living alone and presenting with a risk for dementia. AoA and ADD should encourage their respective state agencies (SUAs and State Developmental Disabilities Planning Councils) to do the same.
  4. ACL should provide technical assistance to SUAs on ways to identify isolated adults with possible cognitive decline, and approaches that work, like home visitor programs, 'home share pairing' and home risk and safety assessments for possible

- inclusion in state aging plans. ACL should also develop ways to modify service and support offerings and expand outreach efforts by senior centers and nutrition programs to draw in isolated adults.
5. ACL should provide technical assistance to SUAs and AAAs to support clinical assessment of loneliness and isolation in older adults and to make referrals to diagnostic services. CMS should incentivize physicians to assess and diagnose isolation and loneliness and perform cognitive screening and make these assessments billable under Medicare and Medicaid.
  6. Congress should allocate funding to the National Endowment for the Arts to create a grant program that promotes the use of creative programming to reduce social isolation and loneliness amongst people living with dementia and their unpaid caregivers.
  7. ACL and DOJ should continue to provide and/or expand funding to support training of emergency services, first responders, community governments and police department personnel to identify, engage and refer people living alone with dementia, including those with lifelong significant disabilities living alone, to services and supports.
  8. NIH should allocate funding to research to better understand how to address the impact of social isolation and loneliness on people with dementia and their unpaid caregivers.
  9. ACL should develop and disseminate education and training for LTSS service providers on the impact that social isolation has had on older Americans, especially those with dementia, and ways to address those impacts.
  10. ACL should continue to support the “Commit to Connect” initiative dedicated to addressing social isolation and loneliness and integrate promising practices for addressing this issue among people with dementia and their caregivers.
- D. Implement strategies to address the new and unique issues generated from the COVID-19 pandemic.
1. ASPE should conduct an assessment on the impact that the COVID-19 pandemic has had on the LTSS system, particularly the impact on people with dementia and their caregivers and make recommendations for ways in which the federal government, states and community-based organizations can respond to future pandemics.
  2. Federal agencies should develop a workgroup to explore possible actions to address the results of the assessment.
  3. ACL, the CDC, and state and local public health should collect, analyze and share with the public as appropriate, surveillance data regarding older adults with long COVID and abnormal cognitive decline or noted impairment resulting from COVID-19.
  4. HHS should ensure dementia programming and support systems are connected or integrated into other HHS work that is underway related to recovery and systemic issues generated by the pandemic.
  5. The federal government should develop and fund solutions for ensuring broadband access across the country for the provision of telehealth, medical evaluation, LTSS and for socialization and access to support networks.

**Recommendation 2:** Implement solutions to address the LTSS workforce crisis.

Over the years, numerous studies have documented shortages of trained personnel to manage, supervise and provide LTSS. 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 contributes to compromised quality of care and safety issues for people living with dementia. 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, well-compensated and adequate workforce leaves residents of long-term care facilities particularly vulnerable, especially during public health and other emergencies.

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. Therefore, the NAPA Committee provides the following recommendations:

- A. Increase efforts and implement systems solutions at the federal level to address the workforce crisis.
  - 1. DHHS should create a statutorily established Direct Care Workforce Task Force, drawing from the RAISE Family Caregiving Council, the NAPA Council, and other Advisory Committees, to serve as a federal advisory committee that will make recommendations and develop a national strategy for addressing the LTSS workforce crisis.
  - 2. The Department of Labor (DOL) should award specific funding for long-term care workforce development, including the dementia care workforce, and for the establishment of Direct Care Workforce Development Centers of Excellence, one per state.
  - 3. Congress should continue to offer the ARPA 10% enhanced federal matching funds to States, past the initial 2024 timeframe, with focused efforts on improving the LTSS workforce.
- B. Establish a national caregiver career pathway to create a consistent, transferable, and broadly available career advancement opportunities.
  - 1. HRSA should establish a national pathway to a variety of health professions. They should commission the development of national standards for direct care workers and certification requirements for use by community colleges, training institutions



- and in-service programs, as well as for use with creating career ladders and setting compensation targets. The standards should apply in general to direct care and include provisions for specialty care populations, such as dementia care.
2. Ensure the career pathway includes regulatory parity and certification portability across states, and across settings including home care, facilities, and other settings for older adults with physical care needs and for people with neuroatypical conditions.
- C. Provide incentives for people to enter the workforce.
1. Congress should allocate funds to HRSA to provide grants to clinics, hospitals, private duty nursing organizations, home health, disability providers, and other clinical providers for the purposes of loan repayment, sign-on bonuses, training, and certification costs for direct care staff.
  2. The federal government should establish a program that provides affordable health insurance, free or low-cost childcare, paid sick leave, paid family and medical leave, and retirement savings options for people who enter the direct care workforce and attain certification.
  3. CMS should explore the feasibility of managed care plans to provide a minimum base rate to employers that adequately cover wages, benefits, and other workforce investments.
  4. The federal government should fund public education campaigns that improve the public's understanding of the direct care workforce, the rewarding nature of serving aging populations, and conduct a large-scale, national recruitment campaign that encourages more people to enter the workforce.
  5. Immigrants and the immigration system can contribute to the effort to increase the number of people in the United States available to provide direct care. One out of 4 direct care workers are immigrants and 38% of current home health aides are foreign born. Congress should consider ways in which laws can be changed to attract and retain immigrants within the direct care workforce.
  6. Congress should provide pathways to citizenship for immigrants who commit to work within LTSS care systems, particularly for those who work in areas of the country devoid of workforce resources or in communities for which they are members.
- D. Increase availability and improve training and supervisory support for people providing direct care to people with dementia.
1. HRSA should work with high schools, community colleges, colleges, universities, professional societies, and non-governmental organizations to develop and provide on- and off-campus programs for training direct care workers and increase internship and supervision support for the direct care workforce.
  2. HRSA should continue to allocate a portion of GWEP funding, not less than \$100,000 per grantee, uniquely toward workforce training in dementia, encourage participation in training by students and trainees of color, with needed language skills, and those representing diverse communities.
  3. HRSA and ACL should increase education for paid and unpaid caregivers through their grant funded programs (i.e., ADPI, NFCSP, GWEP), including funding for

- implementation of evidence-supported interventions that reflect the diversity and for person and family-centered care planning. HRSA should expand training on emergencies, including pandemics, into their existing curricula.
4. The federal government should explore ways to require or incentivize health care and LTSS systems to provide dementia and dementia care training that is culturally competent to all staff who interact with people living with AD/ADRD including, but not limited to, customer service, food service, billing, janitorial, security, and transportation staff as well as those providing clinical care.
  5. 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.
  6. Similar to the “Hand in Hand Training Series for Nursing Homes”, federal and state agencies should make training available to Assisted Living, home care and other LTSS providers with guidance on dementia and dementia care training requirements for enhancing the competency of the workforce.

**Recommendation 3:** Ensure that family and unpaid caregivers of people with dementia have the support they need.

As stated in the RAISE Family Caregiving Council [report](#): “Family caregivers have long been the backbone of America’s caregiving infrastructure. Each year, more than 53 million people provide a broad range of assistance to support the health, quality of life, and independence of someone close to them (AARP and National Alliance for Caregiving, 2020). Millions of older adults and people with disabilities would not be able to live in the community without that support, and replacing it with paid services would cost an estimated \$470 billion each year (Reinhard, Feinberg, Houser, Choula, & Evans, 2019).

Providing that support is rewarding, but it can be challenging. When family caregivers do not have training, support, and opportunities for rest and self-care, their own health, well-being, and quality of life suffer. Their financial future can also be put at risk – lost income due to family caregiving is estimated to be a staggering \$522 billion each year (Chari, Engberg, Ray, & Mehrotra, 2015).”

The recommendations of the RAISE Family Caregiving Council align with caregiver concerns of the NAPA Council and provides a solid framework for addressing the needs of caregivers. To help assure that family and unpaid caregivers of people with dementia have the support they need, the NAPA Advisory Council recommends:

- A. Implement the National Caregiving Strategy developed by the RAISE Family Caregiving Council and ensure dementia caregivers are considered.
  1. All appropriate federal agencies should support and act on the national strategy developed by the RAISE Family Caregiving Council that focuses on the priority areas of: (1) Increased awareness of family caregiving; (2) Increased emphasis on integrating the caregiver into processes and systems from which they have been

- traditionally excluded; (3) Increased access to services and supports to assist family caregivers. (4) Increased financial and workplace protections for caregivers. (5) Better and more consistent research and data collection.
2. [Agencies implementing the recommendations should ensure that the unique needs of dementia caregivers are considered and applied.](#)
- B. Increase access to and quality of information that can assist unpaid caregivers in their caregiving role.
1. ACL or HRSA should evaluate the degree which current training registries (that serve as a clearinghouse of training programs for family and informal caregivers), meet caregiver training needs and whether their educational content is easy to access and broadly available. Develop a strategy for filling any gaps that are identified.
  2. Federal agencies 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.
  3. ACL should encourage SUAs and AAAs to use their network of senior centers and other community-based providers (such as libraries and community centers) to undertake efforts to improve digital literacy amongst the older adult population, provide access to the internet, and aid caregivers with using internet resources to enhance care and for on-line supports. ACL should put in place programs which increase access to technology and offer caregivers the opportunity to learn how to use various devices. All federal agencies should advocate for broadband expansion across the country.
  4. AHRQ should work on the development and implementation of technology applications to support people with dementia and their unpaid caregivers, including the use of e-care plans, patient generated health data, patient reported outcomes and caregiver support. Research should be conducted on the effectiveness of these applications and strategies for implementation.
- C. Increase caregiver longevity and sustainability by implementing strategies to reduce the financial burden and provide protections for working caregivers.
1. Congress and states should create an individual income tax credit for expenses (such as adult day, home health services and caregiver training) incurred by a caregiver who is assisting a qualified family member as has been done for families with other dependents.
  2. Congress should expand the Family Medical Leave Act (FMLA) and should make paid family leave more available and responsive to the needs of AD/ADRD caregivers:
    - i. Expand the FMLA to include siblings, grandchildren, other kin, and others taking on caregiving responsibilities.
    - ii. Expand the FMLA to apply to adult chronic conditions and to caregiving responsibilities.
    - iii. Expand the definition of leave to include attendance at trainings and education on caregiving duties and responsibilities, discharge planning meetings, and care planning meetings.
- D. FMLA should become paid leave to facilitate the feasibility of caregiving.

**Recommendation 4:** Implement new payment models to make long-term care more affordable and eliminate gaps in coverage among government programs that support people with dementia.

Home and community-based services (HCBS) and supports are largely paid for using personal and family resources. For many individuals and families, out-of-pocket costs drain their personal savings. This “spenddown” has become more rapid as long-term care costs continue to increase, coupled with lost savings and stagnant or declining wages. People will either forgo needed services or rely on underfunded, costly, and limited public programs to support their needs.

The publicly funded system is overly complex, inadequate, and not well understood by America’s older adults and unpaid/family caregivers. Medicare does not cover HCBS. Medicaid does cover HCBS costs for low-income beneficiaries who qualify and when a state elects to furnish the services to a particular group. For people who meet functional and financial criteria to qualify, Medicaid will cover nursing home costs as an entitlement, but community-based services are not an entitlement in most states resulting in long waiting lists, even though most people prefer to receive care in the community.

Older American’s Act (OAA) funding is available without a means test, to provide supports and services such as access to nutritious food, caregiver support, transportation and other supportive services, however the OAA is a discretionary program (not an entitlement) and federal funding has not kept pace with the need. There is often a waitlist for these services as well.

New payment models are needed to address the many issues that result in people with dementia not being able to access and pay for services they need.

- 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.
  1. ASPE should commission a study and develop a report to Congress on new social insurance programs that would make LTSS affordable to older adults, people with dementia of all ages, and people with disabilities, regardless of income.
  2. The federal government should strengthen and explore ways to make LTC insurance more affordable and more aligned with the long-term care services that people want and need, such as covering home-based care and dementia-specialized services.
  3. Congress should take steps to ensure consumer protections, including transparency regarding insurance limits, waiting periods, abbreviated coverage with duration and/or spending caps.

4. States should expand voluntary long-term care savings accounts and other strategies that enable individuals to save funds to pay for LTSS.
- B. Strengthen the OAA and other Aging Network programs to meet increased needs and integrate people living with dementia.
1. The OAA should be amended by Congress, upon reauthorization in 2025, to include dementia as a condition experienced by a significant share of the older adult population and expand upon provisions under Title IV of the Act into other OAA areas.
  2. Congress should increase funding for Title III programs within the OAA to increase the number of individuals living with dementia and caregivers benefitting from supportive services, nutrition services, family caregiver support and health promotion. Targeting criteria should be expanded to include people living with dementia and their caregivers, with expanded efforts to meet the needs of populations of older Americans that are marginalized, historically underserved, and disproportionately affected by dementia.
  3. The OAA should be amended to include Alzheimer and dementia programming in Title IV and create Dementia Care Specialist services as a program within the aging network. The amendment should be accompanied by adequate funding for States to start up programs.
  4. Congress should increase funding under Title VI of the OAA which funds Native American programs. These programs help address caregiver support, nutrition and other serious dementia risk factors for tribal members.
  5. Congress should increase funding to \$50 million for the ACL Alzheimer's Disease Programs Initiative. Eliminate or reduce the state match requirement which creates a barrier for applicants to apply. Continue to ensure the programs are available to tribes as well as states and community-based organizations.
  6. Congress should sustain increased funding levels for OAA programs as allocated through various COVID relief packages in 2020 and 2021 through 2024. Sustaining this funding is essential for ensuring that states and AAAs have resources to serve the increased number, declining health status, and complexity of people seeking assistance with issues resulting from the pandemic.
  7. Increased funding should be provided to ACL's National Alzheimer's and Dementia Resource Center (NADRC) to increase capacity for the provision of technical assistance and critical support provided by this agency.
  8. The federal government should create a mechanism to better identify and document the population experiencing dementia for purposes of targeting OAA funds. ACL should encourage states to leverage this data in their next state plans to ensure support for this population.
  9. The federal government should provide adequate funding for the 2025 White House Conference on Aging (WHCOA) to support the collective building of a national aging policy agenda for the next decade. Unlike 2015, funding must be adequate to support an effective event, with broad participation by state delegates, populations of older adults, including those living with or representing people with dementia.

Dementia should be more visible and included in any resulting policy recommendations.

- 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.
1. Congress should consider adding benefits to Original Medicare that addresses the needs of people living with AD/ADRD and their unpaid caregivers and address the social determinants of health (SDoH) in this population. Specifically, access to transportation, social connectedness and community inclusion, healthy food, physical activity and patient education materials.
  2. Congress should consider legislation that exempts people with young onset dementia from the 24-month “Medicare Waiting Period” which requires people with disabilities to first receive SSDI for 24 months before they receive Medicare benefits.
  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 dementia, exploring a package of HCBS benefits that can provide reimbursement through Medicare (such as disease education, respite services, adult day health services, and other HCBS).
  4. The federal government should sustain the increased percentage of matching funds for the Medicaid program beyond 2024 (ARPA 10% enhanced match) so that states can reinvest GPR in the LTSS system.
  5. CMS should continue to support efforts to rebalance the Medicaid system and move the nation towards HCBS Medicaid entitlement.
  6. CMS should explore ways for improving Medicaid reimbursement to increase the percentage of facilities who accept Medicaid patients with dementia and to improve the quality of care at these facilities.
  7. The federal government should conduct a study on the costs that result from gaps in coverage and from the lack of a national, integrated Medicare and Medicaid long-term care benefit for people who are dually eligible.
  8. The federal government should produce a plan to create a wrap-around services system for unpaid caregivers supporting someone at home with dementia.

**Recommendation 5:** Implement strategies that support coordination, integration, and dementia capability.

Dementia-capability and system collaboration is essential for people to remain in the community. In addition to the LTSS systems that provide community- and facility-based care, people with dementia and their unpaid caregivers often encounter other systems throughout their dementia experience; systems such as the health care system, the elder justice and adult protection system, the crisis and criminal justice systems and the public health system. In most States and within local communities, these systems are fragmented and lack knowledge of how to serve people with dementia. These various systems often do not understand the other systems, how they intersect with each other and the unique roles they can play in providing care to people with dementia and their unpaid caregivers.

- 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, stabilization and LTSS for people living with dementia.
1. Many people with dementia are vulnerable to financial exploitation, self-neglect, physical, mental, and other forms of abuse. Abuse and neglect have increased over time and has been elevated by the pandemic. Like the child protective services system, the federal government should take responsibility for adequately funding the adult protection system and for developing national regulations and improved data collection.
  2. Congress should increase funding for Title VII of the OAA and fund the Elder Justice Act which supports ombudsman programs, programs for the prevention of elder abuse, neglect and exploitation, legal assistance and to ensure a comprehensive elder rights system for older adults, including those with dementia, irrespective of where they reside.
  3. People living alone with dementia are often discovered through interactions with law enforcement and the adult protective services (APS) and crisis systems. The federal government should lead an initiative that brings together partners from these systems to better clarify roles and responsibilities for providing intervention and assistance and to form cross-system solutions.
  4. Congress should invest in the development of dementia-focused crisis response and stabilization. Congress should allocate funding to ACL and CMS to establish and fund dementia crisis innovation grants within states to support promising practices and cross-sector collaboration that can help stabilize people in place.
  5. Self-neglect can be an outcome of living alone with dementia. Self-neglect accounts for 50-75% of the nation's APS cases, many of which are people with dementia. The federal government should begin an initiative, supported with funding, to assist APS systems across the country in gaining greater access to clinical experts, to self-neglect assessment tools and more streamlined connections to community supports for cases of self-neglect.
  6. ACL should develop or provide funding to states to develop training for APS workers, including training on interviewing for decisional abilities, to help identify early signs of dementia, memory issues and engage in services earlier.
  7. Congress should allocate funding to ACL to provide funding to states to develop programs and staff positions that specifically focus on the prevention of abuse, neglect and exploitation of people living with dementia.
- B. Increase engagement of public health agencies in efforts to reduce dementia risk, identify underserved communities, enhance data systems and outcomes tracking, educate the public about lifestyle and disease management, and advocate for needed LTSS in the community.
1. The CDC should better define public health's role in dementia and the ways to integrate within and between other systems.
  2. The CDC should continue to fund and enhance the Health Brain Initiative (HBI) Road Map. Enhancements should include a stronger emphasis on equity, detail on

- supporting caregiver health and wellbeing, key partners to engage, tools for implementation and evaluation, case studies of successful implementation and guidance on how to mobilize a team with limited staff capacity and knowledge of HBI.
3. The CDC should continue to allocate a portion of HBI and BOLD funding uniquely toward public health workforce training in AD/ADRD, encouraging participation by students, trainees, and workers from diverse racial and ethnic communities.
  4. The CDC should allocate a portion of HBI and BOLD funding to strengthen clinical capacities for assisting people with neuroatypical conditions.
  5. ACL and the CDC should collaborate to create incentives for public health and the aging network to collaborate. Many public health organizations are not aware of the aging network and vice versa and therefore are not working together towards healthy brain programming, prevention, health care access and community development efforts.
- C. Implement strategies to enhance alignment and integration of the health care and HCBS systems.
1. The federal government should advance models that integrate health care with LTSS, especially for people who are dually eligible for Medicare and Medicaid. The federal government should provide incentives to states and providers that encourage collaboration between the health care system and the HCBS system.
  2. The federal government should develop and distribute educational materials for primary care and specialty dementia care providers regarding HCBS options and resources that are available for people living with dementia and their unpaid caregivers.
- D. Dementia education should be required to be integrated into curricula for medical schools and other health and social service professions and should be required in continuing education for licensed medical and health professionals. The dementia training should include information about the HCBS system and referrals that can be made to community-based organizations.



# Risk Reduction Subcommittee

## Recommendations

**Recommendation 1:** Identify priorities and specific milestones that would make progress toward addressing risk factors for cognitive decline and dementia.

- A. As part of Goal 6 of the National Plan, HHS, in consultation with the Advisory Council, should identify how progress toward the goal will be measured and should establish targets for that progress. In doing so, HHS should develop an iterative method to detect (a) changes over time in the prevalence of risk factors for cognitive decline and dementia; and (b) how those changes in risk factor prevalence over time may affect the incidence of the various conditions (such as Lewy Bodies and Alzheimer's disease) that cause dementia. These data should enable an understanding of how the relationships between risk factors and future dementia are influenced by race, ethnicity, geography, and socioeconomic status.
- B. HHS should establish a process for measuring the extent to which interventions to address risk factors for cognitive decline and dementia are used.
- C. HHS should convene a bi-annual AD/ADRD summit on risk reduction, with CDC as the lead agency.
  - 1. Meetings should establish and update priorities and milestones for addressing dementia risk factors.
  - 2. Meetings should engage diverse stakeholders including historically marginalized voices and communities; other federal agencies; state and local public health departments and other relevant agencies; health providers, educators and payers; community-based organizations; and private sector partners. Specific time-bound actions by public and private entities that advance the milestones should be identified. This includes private and public partners outside the traditional AD/ADRD community who focus on the targeted risk factors including depression, diabetes, hearing loss, mid-life hypertension, physical inactivity, poor diet quality and obesity, poor sleep quality and sleep disorders, commercial tobacco use, traumatic brain injury and alcohol abuse.
  - 3. Meetings should address specific barriers/challenges and strategies to effect measurable change for marginalized communities.
- D. HHS and all relevant federal agencies should identify, coordinate, and implement strategies within their current authorities and annually report on progress within the National Plan. In their reports, relevant agencies should:
  - 1. Identify gaps.
  - 2. Monitor progress toward meeting the goal, with reporting and updating annually, considering new science, emerging challenges, and opportunities.
  - 3. In their internal budget process, for the purposes of submission of the agency budget to the Office of Personnel Management (OPM), annually estimate the federal funding that is needed to successfully reach the milestones; and OMB's

- annual Administration budget request to Congress should identify the amounts proposed in the budget request for addressing dementia risk reduction across all relevant federal agencies.
4. Highlight significant actions and progress at the state, local, and tribal level.
- E. Non-profit organizations with expertise on public health, federal and state government budgets, the risk factors for cognitive decline and dementia, and Alzheimer’s and other dementias should issue a public report on:
1. The current level of spending at the federal and state levels on activities that address the risk factors for cognitive decline and dementia.
  2. The investment necessary to:
    - i. Achieve Goal 6 of the National Plan.
    - ii. Monitor progress toward Goal 6 of the National Plan.
- 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 taking into account 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 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.
1. Congress should provide at least \$30 million in fiscal year 2023 funding for the CDC to implement the BOLD Infrastructure for Alzheimer’s Act.
  2. Congress should fully fund the Older Americans Act as specified in the Supporting Older Americans Act of 2020 and, particularly, increase funding for ACL to incorporate dementia risk reduction education and interventions in relevant Older Americans Act programs, such as Nutrition, Chronic Disease Management, and Falls Prevention.
  3. Congress should enhance appropriations of relevant existing federal programs – and fund additional new programs – that promote cognitive decline and dementia risk reduction.
  4. CDC, ACL, CMS, HRSA, SAMHSA and IHS should expand efforts to target resources toward education and outreach of the public health and aging network on dementia risk factors.
- B. In partnership with state, local, and Tribal governments, 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 health outcomes for people with dementia.

- C. Strategies and interventions to address dementia risk factors should target communities with both the highest prevalence of priority risk factors, low longevity rates, and the highest prevalence of AD/ADRD with explicit attention to the social determinants of health and strategies and interventions for historically marginalized communities.
- D. Because the burden of dementia caregiving often results 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. We encourage the CDC's Healthy Brain Initiative Collaborative to identify opportunities and promote action by state public health, aging, disability, and other relevant agencies that would address and help mitigate dementia risk factors among caregivers.
- E. Actions included in the National Plan should be aligned with those identified in CDC's *Healthy Brain Initiative State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map and Road Map for Indian Country*.

**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 to assess and reduce dementia risk, delay the onset of dementia, and improve early intervention, ensuring equitable reach and impact of interventions for historically marginalized populations. This should include:
  1. Identifying opportunities to reduce the risk of mild cognitive impairment and dementia by addressing known risk factors and support early intervention on risk factors for cognitive decline and dementia, including but not limited to patient and provider education; offering reimbursement incentives to providers to promote brain health; providing payments for prevention and care delivery models that incorporate brain health as part of care and treatment of other conditions that may increase dementia risk; and developing and implementing quality measures specifically related to dementia risk reduction.
  2. Identifying existing benefits related to factors that can potentially help reduce dementia risk, as well as coverage gaps and inequities that, if addressed, could potentially reduce known risk factors associated with AD/ADRD. Examples include: nutrition support; physical activity prescriptions; diabetes management and treatment; audiology assessments and screenings, hearing rehabilitation, appropriate hearing technology; and screening and treatment for depression and alcohol abuse.
  3. Educating and training the primary care workforce (including community health workers and nurse practitioners), within the context of the Age-Friendly Health Systems Framework and dementia capable communities, to address dementia-risk reduction and brain health.

4. Increasing clinical identification of persons who may, as a result of the presence of risk factors, be at greatest risk of a trajectory of decline so as to identify life factors that could be addressed to potentially mitigate risk.
- 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 Visit.
- 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 and the VA that would improve interventions for identified AD/ADRD risk factors – for example, expansion of Medicare coverage to include hearing aids and related hearing care rehabilitation services, and services directed to those with younger-onset dementia.

**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 the equity and inclusion framework developed by the NIA ([www.nia.nih.gov/research/osp/framework](http://www.nia.nih.gov/research/osp/framework)) when 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 impact the health of historically underserved populations.
- B. The federal government should increase scientific research to:
  1. Identify linkages to 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.
- C. The federal government should support specific research within health care that:
  1. Evaluates efforts to implement the uptake of evidence on risk factor reduction in clinical practice.
  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 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 and stress.

**Recommendation 5:** Appropriate non-federal governmental entities and private sector organizations should work to improve health in general and brain health specifically by targeting vulnerable, disadvantaged, and marginalized populations; persons compromised by lifelong conditions; and those who would benefit from special focus and orientation to healthy lifestyles and avoidance of risk across the lifespan.

- A. State health departments, state developmental disabilities authorities, and state agencies and tribal authorities tasked with mental health and public welfare, as well as legislatively-created bodies charged with promoting health wellness and improved living conditions should undertake efforts to address dementia risk factors.
- B. Foundations and charitable organizations that promote healthy outcomes should invest in projects and initiatives in support of this recommendation.
- C. Medical associations and health systems should invest in promoting physical health as a means to address dementia risk.
- D. National, state, and local/community-based provider organizations working with select special segments of our population (e.g., intellectual/developmental disabilities, psychiatric/mental health conditions, physical disabilities, early childhood development, adults at elevated risk, etc.) should initiate special projects and/or seek funding for efforts to advance this recommendation.
- E. Civic organizations and business clubs should support local efforts to create healthy communities.