Clinical Care Subcommittee Recommendations
July 29, 2019

Clinical Care Themes:

- Advancement of themes and results of the National Research Summit on Dementia Care.

- Public education about early detection and diagnosis.

- Workforce development.

- Attention to best practices in AD/ADRD.

- Encouragement of health system models that align performance, care quality and payment.

- Encouragement of additional use of metrics to assess progress of the National Plan.

RECOMMENDATION 1: Advance the themes and recommendations of the 2017 and 2020 National Research Summits on Care, Services and Supports for Persons with Dementia and their Caregivers.

The research findings presented at the 2017 and 2020 National Research Summits on Care, Services and Supports for Persons with Dementia and their Caregivers and the final sets of research themes and recommendations should be considered for federal agencies' and others' current plans to improve care for AD/ADRD; gaps in evidence should be addressed by appropriate funders; and, the 2019 National Plan should be updated based on current data and Summits' themes and findings.

a. Federal agencies and others should review research findings such as those presented at the Research Summits on Dementia Care and, when possible, enact evidence-based care delivery models which have demonstrated efficacy and effectiveness at improving care for AD/ADRD, including advancing a public health approach to promote the health and well- being of persons living with AD/ADRD and their caregivers. (https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers-final-report#FinalRpt).

b. Additional investments are needed to federal agencies in addition to NIH to address research recommendations, including those identified at the Research Summits on Dementia Care. New legislation or modification to existing legislation may be required to identify funding needed by other federal agencies to reach the 2025 goals.

c. Federal agencies and non-governmental organizations should allocate funding and issue requests for applications to address research recommendations stemming from the National Research Summits.

d. The Office of the Assistant Secretary for Planning and Evaluation (ASPE) and other entities contributing to the writing of the National Plan should review research findings such as those presented at the Research Summits on Dementia Care to determine if anything should be added to the Goals of the National Plan or to milestones for goals.

e. ASPE or the National Institute on Aging (NIA) should solicit information from agencies about their review of Research Summits on Dementia Care, including any agency plans to act now or in the future on Summit themes, research findings, and recommendations for new research. ASPE or NIA should synthesize this information and present it to the Advisory Council.

RECOMMENDATION 2: Educate the public about early detection and diagnosis of AD/ADRD, person-centered care planning, and the importance of and ways to enter into research.

Education about the availability of early detection and diagnosis of AD/ADRD is important because people living with cognitive symptoms are better able to participate in person- centered planning when symptoms are in an early stage. General education and information about local/regional resources, including resources and information on recruiting and enrolling persons with cognitive impairment or dementia into research, should be easily accessible and should support the decision-making of persons at-risk for and living with AD/ADRD and their caregivers. Further research on the predictions of early diagnostic testing in terms of prognosis is a critical need.

a. Federal, state, tribal, and community agencies should increase the education of the public by enhancing linkages of national information centers to materials made available at the state and local level.

   - Promotion of educational materials, such as those available through the NIA (https://www.nia.nih.gov/health/alzheimers), should continue including increased linkage of this information to educational resources maintained by advocacy groups and state/local healthcare systems.

   - States and community-based providers should be encouraged to advance coordinated materials for practical use by persons at risk for and living with AD/ADRD and their caregivers through single entry points ("No Wrong Door" https://nwd.acl.gov/) such as Area Agencies on Aging, Aging and Disability Resource Centers, and Community Independent Living Programs.

   - States and community-based providers should be encouraged to use new educational information about care planning for persons living with AD/ADRD, such as materials available through the National Center on Advancing Person-Centered Practices and Systems (NCAPPS) https://ncapps.acl.gov/about-ncapps.html.

b. The HHS operating divisions, the VA, and the Department of Defense should educate the public at the national, state and community levels about the benefits of early detection and diagnosis of AD/ADRD, including early assessment and the importance of care planning, to improve the health and well-being of older adults and their caregivers. Examples of resources include:

   - CDC's Healthy Brain Initiative Road Map for Public Health and other resources (https://www.cdc.gov/aging/index.html).

- ACL's issue brief Dementia-capable States and Communities: the Basics and other National Alzheimer's and Dementia Resource Center (NADRC) resources (https://nadrc.acl.gov).

- ACL's Brain Health: You Can Make a Difference! resources (https://www.acl.gov/index.php/node/293).

- HRSA training materials that include early detection and diagnosis of AD/ADRD. (https://bhw.hrsa.gov/grants/geriatrics).

- NIA's What is Brain Health initiative (https://brainhealth.nia.nih.gov/).

c. The U.S. Preventive Services Task Force's should inform the public about recommendations from the research plan for Cognitive Impairment in Older Adults: Screening (https://www.uspreventiveservicestaskforce.org/Page/Document/final-research-plan/cognitive-impairment-in-older-adults-screening1).

d. NIA at NIH, CDC, and ACL should continue efforts such as the Recruiting Older Adults into Research (ROAR) project to encourage older adults and their families and caregivers, including underrepresented populations, to consider participating in research. NIA, CDC, ACL and state/local entities should tailor recruitment materials like the ROAR Toolkit (https://www.nia.nih.gov/health/recruiting-older-adults-research-roar-toolkit) to include local information to meet the needs of communities.

RECOMMENDATION 3: Enhance the current and future workforce though education to better address the needs of persons living with AD/ADRD and their caregivers.

Federal agencies and others should continue to offer and support current and future workforce education to improve workforce members' abilities to work with persons living with AD/ADRD, including recognizing early signs and symptoms, addressing early detection and diagnosis, offering and providing counselling to persons living with AD/ADRD and their family members and caregivers, and connecting them to local services and resources.

   a. Federal agencies and others should develop specific new training models to advance workforce readiness nationally in the areas of:

   - Disaster Preparedness -- to train health care workers, first-responders and individuals to recognize and better protect the health and safety of persons living with AD/ADRD and their family members and caregivers who experience a disaster or hazard.

   - Acute Care -- to train individuals, first-responders and health care workers caring for persons living with AD/ADRD in urgent care, emergency room and hospital settings to recognize and better identify and address needs of persons living with AD/ADRD.

   - Behavioral Health -- to train health care workers, first-responders and individuals to recognize and better address needs of persons living with AD/ADRD and other mental health disorders such as substance use disorder, and mood disorders including depression or suicidal ideation.

   - Comorbid Medical and Mental Health Conditions -- to train health care workers to recognize and better identify, distinguish, and appropriately manage symptoms of AD/ADRD when they occur concurrently with signs and symptoms of acute and chronic medical conditions and multifactorial conditions such as pain and reduced communication abilities.

   - Recruitment into Research -- to train health care workers and individuals on the importance of and options for recruiting persons with AD/ADRD into research. 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.

   - Continuing Education Modules for Health Professionals about Brain Health based -- to train health professionals on: the importance of early detection; the importance of risk reduction; and, culturally appropriate content and

materials.

- Available resources to address this recommendation include:
    - https://www.nia.nih.gov/health/now-what-next-steps-after-alzheimers-diagnosis
    - https://www.nia.nih.gov/health/managing-older-patients-cognitive-impairment
    - https://www.nia.nih.gov/health/talking-older-patients-about-cognitive-problems
    - https://www.nia.nih.gov/health/assessing-cognitive-impairment-older-patients

b. One or more working group(s) of health professional associations should be convened to define skills needed by persons delivering evidence-based AD/ADRD care across care settings, and determine strategies for incorporation of the needed skills into educational materials and training in clinical and other practices.

- The working groups should address how to train workforce members on the benefits and risks of pharmacotherapy, including the integration of medication use and "deprescribing" into comprehensive non-pharmacological approaches to care.

- The working groups should address measures of success including how to assess that trained workforce members are incorporating learning into current practice.

c. Federal agencies and others should align current training related to AD/ADRD care with evidence based guidelines (including new dementia practice care recommendations) and should consider them in curricula and continuing education for health professionals, first responders and other individuals. Examples of such recommendations include:

- The Alzheimer's Association's 2018 Dementia Care Practice Recommendations (https://www.alz.org/professionals/professional-providers/dementia_care_practice_recommendations)

- HRSA Alzheimer's Disease and Related Dementias Core curriculum and the HRSA Caregiving Curriculum (https://bhw.hrsa.gov/grants/geriatrics/alzheimers-curriculum)

- Brain health education about AD/ADRD and caregiving in curricula for students of public health available through CDC and the Alzheimer's Association (https://www.cdc.gov/aging/aginginfo/alzheimers.htm#Curriculum)

- Recommendations from the National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers (https://aspe.hhs.gov/basic-report/research-summit-dementia-care-main-summit-recommendations)

- Guidance on Inappropriate Use of Antipsychotics: Older Adults with Intellectual and Developmental Disabilities in Community Settings (https://store.samhsa.gov/product/Inappropriate%20Use%20of%20Antipsychotics%20Brief%20Guidance%3A%20Older%20Adults%20and%20People%20Living%20with%20Intellectual%20Disabilities%20in%20Community%20Settings/PEP19-INAPPUSE-BR)

d. Federal programs and others with such capabilities should report on the number of workforce members trained per year, and this reporting should be considered in updates to the National Plan.

RECOMMENDATION 4: Determine a process for reaching consensus on definitions of best practices for comprehensive care of AD/ADRD at all disease stages.

There should be current best practices for comprehensive care of AD/ADRD at all disease stages, informed by evidence, so that persons living with AD/ADRD, caregivers, health systems and payers have similar understanding regarding diagnosis, treatment and/or services and supports; and the Advisory Council should identify an approach for outlining practices for such comprehensive care.

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

- Involve comprehensive stakeholder input including from people living with cognitive symptoms, care partners and other stakeholders.

- Consider public health approaches, data for action, and training opportunities for health professionals.

- Consider ACL guidance on person-directed Services and Supports during Serious Illness: https://acl.gov/sites/default/files/Aging%20and%20Disability%20in%20America/Serious%20Illness%20Principles%208-30-17%20508%20compliant.pdf

b. The work group should consider factors such as the following:

- Elements of care and services that are based on level of function.

- Health disparities and cultural competencies to advance best practices.

- Financial concerns and options counselling for health insurance coverage and other benefits

- Data elements to be potentially included in a person-centered care plan for AD/ADRD and best practices for care plan facilitation and use.

- Use of electronic health records to enhance person-centered planning.

- Development and evaluation of technologies to link persons living with AD/ADRD and family members (defined broadly to include fictive kin, neighbors, friends, non-blood relatives), and other caregivers to care providers, share information more efficiently, deliver care interventions, monitor health and symptom status, and promote health and safety.

- Risks related to quality of life that are either perceived or actual in response to disclosure of a diagnosis of a cognitive disorder; including, for example, loss of employment or insurance in response to knowledge of a diagnosis.

- The potential of person-centered planning to function continuously over time and to transcend setting; specifically, best practices for use of a person-centered plan that can function well 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.

- Definitions of "dementia capability" in a health system or community, including adaptability of the processes based on a person's level of function and the setting in which the person lives.

- Alignment of services with the principles of "age friendly" health systems (https://www.johnahartford.org/grants-strategy/current-strategies/age-friendly-hospitals/) and community activities (http://www.who.int/ageing/age-friendly-world/en/)

- Pros and cons, barriers and supports, bioethics of various advances

c. The work group should consider ethical factors and make recommendations to the Advisory Council regarding the goals of the National Plan and best practices for comprehensive care.

d. The work group should incorporate knowledge gained from activities the National Center on Advancing Person-Centered Practices and Systems (NCAPPS); and the Administration for Community Living (ACL), the Centers for Medicare and Medicaid Services (CMS) and the Human Services Research Institute (HSRI) 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 incorporate the results of the National Quality Forum's initiative on Person Centered Planning and Practice (http://www.qualityforum.org/Person_Centered_Planning_and_Practice.aspx), including the use of quality measures for person centered planning that can be used among other AD/ADRD quality measures and metrics for assessing the implementation of best practices for comprehensive care of AD/ADRD.

RECOMMENDATION 5: Encourage further development, evaluation and use of healthcare models for AD/ADRD that align performance measures, the experience of care by persons living with AD/ADRD and their caregivers, and payment.

Federal agencies (CMS, VA, HHS), states and non-governmental payers for health care services should increase the use of value-based care[1] for persons living with AD/ADRD to pay for health care services in a manner that directly links health services payments to performance on cost, quality, and resource use metrics; this alignment will better support comprehensive person-centered care leading to improved health outcomes and quality of life for persons living with AD/ADRD.

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

    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:

- Cognitive Impairment and Assessment Care Planning Codes.

- Quality Payment Program measures relevant to AD/ADRD.

- 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 (PBPM) payment to provide care and services to eligible persons living with AD/ADRD as described in Recommendation 11 of the 2017 National Plan.

    e. States and other payers (Medicare, Medicaid) should increase attention to cost-effective home and community-based services (HCBS), which support person-centered care and self-determination for persons living with AD/ADRD and their caregivers.

---

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

RECOMMENDATION 6: Encourage further use of metrics to assess progress of the National Plan to Address AD/ADRD.

The Office of the Assistant Secretary for Planning and Evaluation (ASPE) should apply relevant metrics to the key drivers in the logic model (driver diagram) as a means of assessing progress and should use those metrics to report annually on the progress towards the goals of the National Plan.

    a. ASPE should request information from federal agencies and others regarding metrics to assess progress.

    b. ASPE, in collaboration with the Advisory Council, should identify and select key drivers that can be followed by one or more metrics.

    c. ASPE, in collaboration with the Advisory Council, should regularly review all available metrics in order to identify metrics which will aid in summarizing progress of the National Plan.

    d. ASPE should determine how data from the selected metrics can be reported, and best strategies to incorporate the reporting of those metrics into the driver diagram for the National Plan.

    e. ASPE should include metric reporting in annual updates of the National Plan.