

Clinical Care Subcommittee Recommendations 2018

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Clinical Care Themes

- Advancement of themes and results of the National Research Summit on Dementia Care
- Public education about early detection and diagnosis
- Workforce development
- Attention to best practices in AD/ADRD
- Encouragement of health system models that align performance, care quality and payment

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

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

- a. Federal agencies and others should review the research findings presented at the Care Summit and enact evidence-based care delivery models which have demonstrated efficacy and effectiveness at improving care for AD/ADRD, including advancing a public health approach to promote the health and well-being of persons living with AD/ADRD and their caregivers. (available here: <https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers-final-report#FinalRpt>).
- b. Additional investments are needed for federal agencies in addition to NIH to implement milestones out of the Care and Services Summit. New legislation or modification to existing legislation may be required to identify funding needed by other federal agencies to reach the 2025 goals.
- c. Federal agencies should issue requests for applications to address research recommendations.
- d. Non-governmental organizations should allocate funding and issue requests for applications to address research recommendations.
- e. ASPE should integrate the 12 themes from the Care Summit into the goals and strategies of the National Plan, and identify a steering committee and associated infrastructure to prepare for the March 24 – 25, 2020 Research Summit on Dementia Care.

RECOMMENDATION 2: Educate the public about early detection and diagnosis of AD/ADRD.

Education about early detection and diagnosis of AD/ADRD is important because people living with cognitive symptoms are better able to participate in person-centered planning when symptoms are in an early stage. General education and information about local/regional resources should be easily accessible and should support the decision-making of persons at-risk for and living with AD/ADRD and their caregivers.

- a. Federal and state 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 National Institute on Aging (<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.
 - Opportunities should be encouraged for local No Wrong Door (NWD; information available here: <https://nwd.acl.gov/>) entities to advance coordinated educational materials for practical use by persons at-risk for and living with AD/ADRD and their caregivers.

- b. The U.S. Department of Health and Human Services operating divisions 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>)

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

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

- a. Federal agencies and others should prepare specific new training modules and implement them nationally to advance workforce readiness regarding:
- Disaster Preparedness – to train health care workers, first-responders and individuals to better protect the health and safety of persons living with AD/ADRD and their family members and caregivers who experience a disaster.
 - 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 better address needs of persons living with AD/ADRD.
 - Behavioral Health – to train health care workers, first-responders and individuals to 1) better address needs of persons living with AD/ADRD who experience mental health concerns such as substance abuse, depression or suicidal thoughts; and, 2) identify, distinguish, and appropriately manage symptoms of AD/ADRD when they occur concurrently with signs and symptoms of other conditions such as pain, reduced communication abilities, and reduced mobility.
 - Continuing Education modules for health professionals about brain health based on evolving science, including: the importance of early detection; the importance of risk reduction; and, culturally appropriate content and materials.

- b. One or more working group(s) of health professional associations should be convened to define skills needed by persons delivering evidence-based AD/ADRD care across care settings, and determine strategies for incorporation of the needed skills into educational materials and training in clinical and other practices.
- c. Federal agencies and others should align current training related to AD/ADRD care with new evidence-based guidelines and should include the evidence-based guidelines in curricula and continuing education for health professionals, first responders and other individuals. Examples of such guidelines 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 which can be found at <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>)
 - To be discussed with Debra and LTSS about location of dementia capability link and recommendation

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

It is important to define best practices for comprehensive care of AD/ADRD at all disease stages so that persons living with AD/ADRD, caregivers, health systems and payers have similar understanding of the targets for clinical care services; and, it is necessary to re-define best practices in response to new evidence regarding diagnosis, treatment and/or services and supports. Therefore, the Advisory Council on Alzheimer's Research, Care and Services should identify an approach for addressing best practices for comprehensive care of AD/ADRD at all disease stages.

- a. A federally-organized work group of thought leaders should be established to review practice guidelines for AD/ADRD. This work group should:
 - Involve comprehensive stakeholder input including from people living with cognitive symptoms, care partners and other stakeholders.
 - Consider public health approaches, data for action, and training opportunities for health professionals.
 - Consider federal guidance regarding person-centered care such as the guidance issued by the ACL on implementation of Section 2402(a) of the Affordable Care Act (<https://www.acl.gov/news-and-events/acl-blog/person-centered-planning-and-self-direction-hhs-issues-new-guidance>)

- b. The work group should consider factors such as the following:
- Elements of care and services that are based on level of function.
 - Health disparities and cultural competencies to advance best practices.
 - Data elements included in a person-centered care plan for AD/ADRD and best practices for care plan use.
 - Use of electronic health records to enhance person-centered planning.
 - The development and evaluation of technologies to link persons living with AD/ADRD and family members to care providers, share information more efficiently, deliver care interventions, monitor health and symptom status, and promote safety.
 - Risks related to quality of life that are either perceived or actual in response to disclosure of a diagnosis of a cognitive disorder; including, for example, loss of employment or insurance in response to knowledge of a diagnosis.
 - The ability of person-centered planning to function continuously over time and to transcend setting; specifically, best practices for use of a person-centered plan that can function well when a person with AD/ADRD lives alone, does or does not have an identified family member or caregiver, and/or transitions to a hospital or residential care setting.
 - Definitions of “dementia capability” in a health system or community, including adaptability of the processes based on a person’s level of function and the setting in which the person lives.
 - Alignment of services with the principles of “age friendly” health systems (<https://www.johnahartford.org/grants-strategy/current-strategies/age-friendly-hospitals/>) and community activities (<http://www.who.int/ageing/age-friendly-world/en/>)
- c. The work group should make recommendations to the Advisory Council regarding the goals of the National Plan related to best practices for comprehensive care.

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

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

* 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/>

- a. Initiatives delivering value-based programs should rely on definitions of value outlined by CMS and others.
 - <https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Value-Based-Programs/Value-Based-Programs.html>
- b. Initiatives to assess value should rely on a framework such as the CMS Meaningful Measures initiative; and then 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 the Annual Wellness Visit
- c. Congress and/or federal agencies should authorize and/or designate funding to conduct large-scale evaluation of comprehensive models which include a per-beneficiary-per-month (PBPM) payment to provide care and services to eligible persons living with AD/ADRD as described in Recommendation 11 of the 2017 National Plan.
- d. States and other payers (Medicare, Medicaid) should increase attention to cost-effective home and community-based services (HCBS), which support person-centered care for persons living with AD/ADRD and their caregivers.