

# **PUBLIC MEMBERS OF THE ADVISORY COUNCIL ON ALZHEIMER'S RESEARCH, CARE AND SERVICES: 2017 Recommendations**

The initial version of the National Plan to Address Alzheimer's Disease was published in 2012 and has been revised annually since. Since 2012, the National Plan and its accompanying recommendations have catalyzed progress in the field of Alzheimer's disease and related disorders. The Advisory Council on Research, Care and Services has reached a consensus and produced recommendations for the 2017 National Plan to Address Alzheimer's Disease.

## **Research**

This is an exciting time to be involved in research on Alzheimer's disease and related dementias (ADRD). While pharmacologic therapies for these disorders remain elusive, there has been enormous progress made in understanding the underlying biology of the diseases with advancements in research. At the outset of the first National Plan to Address Alzheimer's Disease in 2012, the budget for federal research was approximately \$450M. With the recent passage of the FY17 budget by Congress, the annual research funding for ADRD is now \$1.4B. This tremendous increase in funding has led to the significant advances in research regarding the mechanisms of the underlying diseases, diagnostic criteria and development of therapeutics. Through the Alzheimer's Accountability Act, the staff at the National Institutes of Health generates a Professional Judgment Budget each year designed to inform Congress on the annual funding necessary to meet the goal of the National Plan to Address Alzheimer's Disease by 2025. The field is confident that these goals can be met with the increasing support recommended by the Advisory Council for Research, Care and Services for the U.S. National Plan to Address Alzheimer's Disease.

## **Clinical Care**

The Advisory Council recognizes the importance of and the opportunities for improvement to increase early detection and diagnosis of ADRD. This year's recommendations also emphasized the importance of enhancing care planning and care coordination by increasing the use of person-centered and caregiver goals, as well as identifying measurement strategies to track this progress. The subcommittee encourages the creation of more dementia friendly communities across the country through a public-privately funded collaborative. Finally, the Advisory Council supports and calls for the National Research Summit on Care, Services and Supports for persons with dementia and their caregivers.

## **Long-Term Services and Supports**

While the Advisory Council recognizes the extensive work being done at the federal, state and community level to address long-term services and supports, the Council is still very aware of the enormous challenges that exist in meeting the needs of those with dementia and their families. Recommendations this year focus on the needs of family caregivers, people with dementia who live alone, challenges resulting from behavioral symptoms related to dementia and the need for more public awareness of dementia and available resources. A variety of the measures of accomplishment or success have been suggested for each recommendation, including ways that both public and private partners need to be involved in order to address the needs of people with ADRD and their families. The Advisory Council also looks forward to the recommendations regarding the additional needs and priorities that will emerge from the National Research Summit on Care, Services and Supports for persons with dementia and their caregivers.

## **2017 Recommendations**

The 2017 Recommendations from the public members of the Advisory Council for Research, Care and Services are presented below:

- The 2017 National Plan should continue to provide a robust, comprehensive, and transformative scientific roadmap for achieving the goal of preventing, effectively treating and providing effective care and services for Alzheimer's Disease and related dementias by 2025.
- A top priority remains the urgent need to continue to increase annual federal research funding sufficient to meet the 2025 goal.
- The 2017 National Plan should develop research goals aimed at the establishment of recommendations to improve uptake, spread and delivery of evidence-based and evidence-informed care and services.
- The National Plan should continue to promote early detection and diagnosis of Alzheimer's disease and related dementias by encouraging cognitive assessment while at the same time CMS works to confirm measurement strategies to track progress through the implementation of new quality measures.
- Federal agencies should offer and support educational efforts that improve healthcare providers' ability to recognize early signs of dementia, including Alzheimer's Disease, and to offer counseling to individuals and their caregivers, as well as connect them to local services and resources.

- CMS should use the results of evidenced-based programs combined with definitions of best practices for comprehensive dementia care to provide adequate payment and incentives for providing evidenced-based care. This could include a comprehensive risk- based payment for reimbursement of comprehensive dementia care services.
- Federal agencies, national health and aging organizations, states, and other industry stakeholders should identify ways to implement recommendations that result from the October 2017 National Research Summit on Care, Services and Supports for Persons with Dementia and their caregivers.
- Congress, federal agencies, and states must expand efforts to address the needs of family caregivers, including caregivers from diverse racial/ethnic/socioeconomic groups, caregivers of younger adults and people with intellectual/developmental disabilities, and children and youth who provide care for older adults.
- Federal agencies, states, and health systems must take steps to increase identification of people with dementia who live alone, and to provide programs and services to meet the needs of this population.
- Federal agencies, states, and health systems must increase efforts to assess, prevent, and manage behavioral symptoms associated with dementia through effective programs and services and improved workforce knowledge and skills.
- Federal agencies, states, national health and aging organizations, and community partners must continue to expand public awareness and training, reduce stigma, and help connect people to information and available resources. Outreach should include children and youth, diverse racial/ethnic/socioeconomic groups, and people with intellectual and developmental disabilities.

## Full Expanded List of 2016 Recommendations

1. **The 2017 National Plan should continue to provide a robust, comprehensive, and transformative scientific Road Map for achieving the goal of preventing, effectively treating, and providing effective care and services for AD/ADR by 2025.**
  - a. A Road Map for accomplishing the primary goal of the Plan should include input from experts in the field through research summits on AD/ADR including a research summit on care and services.
  - b. Recommendations from these summits and the research community should be re-evaluated each year and translated into milestones.
  - c. Include specific research milestones to:
    - Reduce racial/ethnic/socioeconomic disparities in AD/ADR.
    - Re-evaluate research priorities among AD/ADR across all research areas (e.g., from identifying disease modifying treatments to identifying effective care and services).
    - Include and prioritize specific milestones for populations at high risk for AD/ADR (e.g., people with Down syndrome, African Americans).
    - Increased attention should be paid to person-centered and family-centered outcomes with respect to research planning and the delivery of care and services.
2. **A top priority remains the urgent need to continue to increase annual federal research funding sufficient to meet the 2025 goal.**
  - a. At present, the United States spends less than 0.5% of its annual care costs for ADR on research, therefore investments in research should be increased to achieve the primary goal of the National Plan.
  - b. Initial estimates suggested that \$2 billion or more per year is needed and more accurate estimates can be generated by the Professional Judgment Budget.
  - c. The annual professional judgment budget recommended by the Alzheimer's Accountability Act and prepared by the NIH should reflect the science-driven funding needs for the budget year to enable investigators to reach the 2025 goal of the plan.
  - d. This investment would be applied to AD/ADR research initiatives spanning basic, translational, clinical, care and services research.
3. **The 2017 National Plan should develop research goals aimed at the establishment of recommendations to improve uptake, spread and delivery of evidence-based and evidence-informed care and services.**
  - a. Enhance methodologies to effectively engage persons with dementia and families in research on care decision making and planning.
  - b. Develop and implement quality care measures across all settings that include person-centered and family-centered outcomes.

- c. Identify and evaluate (non-drug) care strategies that reduce disease burden and delay disease progression and evaluate their costs and downstream effects.
  - d. Study comprehensive dementia care from time of diagnosis to end-of-life and associated costs.
  - e. Develop and evaluate effective care programs across diverse settings (e.g., home, nursing home, assisted living, community-based programs, primary care), disease etiologies and disease trajectories to address key clinical features including NPS and functional decline.
  - f. Develop and evaluate technologies to link families to care providers, share information more efficiently, deliver care interventions, monitor health and symptom status and promote home safety.
  - g. Convene a conference of key stakeholders to identify a meaningful pathway or pipeline for developing and testing non-pharmacological treatments, and scaling up and implementing effective approaches.
- 4. Emphasis should be given to the standardization of terminology in dealing with cognitive and dementing disorders.**
- a. A federally-led working group of thought leaders should be convened to identify existing barriers, opportunities and recommend strategies to develop consistent language for cognitive disorders among the scientists, care providers and the public.
  - b. Engage all of the stakeholders around these issues to reduce the use of confusing or conflicting terminology and propose improved terminology for the benefit of persons with dementia, their family members and caregivers and the scientific and service communities.
- 5. As recommended in the National Plan the United States government should support global efforts to address issues of research, care and services.**
- a. United States public and private entities should acknowledge and scrutinize the work of the World Dementia Council and the World Health Organization (WHO).
  - b. Continued collaborations on international research efforts should be promoted.
- 6. A major area of emphasis for the 2017 National Plan should include the enhancement of recruitment efforts for randomized controlled trials for AD/ADRD.**
- a. A major challenge in the development of effective therapies for AD/ADRD has been the inefficient recruitment of participants in clinical trials.
  - b. Emphasis should be placed on the enhancement of diversity and inclusiveness in these efforts.
  - c. The documentation of recruitment goals should be required in applications for randomized controlled trials and incentives should be in place for meeting those goals.

- 7. The National Plan should continue to promote early detection and diagnosis of AD/ADRD by encouraging cognitive assessment while at the same time CMS works to confirm measurement strategies to track progress through the implementation of new quality measures.**
  - a. Specifically, within the next year, CMS should implement the new quality measure: Cognitive Impairment Assessment Among At-Risk Older Adults. Percentage of patients age 75 years or older at the start of the measurement period with documentation in the electronic health record (EHR) at least once during the measurement period of: (1) results from a standardized cognitive impairment assessment tool; or (2) a patient or informant interview.
  - b. The cognitive assessment should be conducted per the guidance provided by the Medicare Detection of Cognitive Impairment Workgroup's Recommendations: Alzheimer's Association recommendations for operationalizing the detection of cognitive impairment during the Medicare AWW in a primary care setting. *Alzheimer's & Dementia*. March 2013; 9 (2)141-150.
- 8. CMS should annually report data by state/region and by diagnosis regarding the use of the new G0505 billing code.**
  - a. The new G0505 billing code provides for cognition and functional assessment using standardized instruments with development of recorded care plan for the patient with cognitive impairment, history obtained from patient and/or caregiver, in office or other outpatient setting or home or domiciliary or rest home.
- 9. Federal agencies should offer and support educational efforts that improve health care providers' ability to recognize early signs of dementia, including AD/ADRD, and to offer counseling to individuals and their caregivers, as well as connect them to local services and resources.**
  - a. A working group of health professional associations should be convened to develop competencies in delivering evidenced-based dementia care across care settings.
  - b. Training related to quality dementia care should be included in curricula and continuing education sessions for health professionals.
  - c. Specifically, training should enhance health care provider awareness and understanding of the Medicare AWW, knowledge of validated cognitive assessment tools, methods for reporting all dementia-related quality measures active in the Quality Payment Program, and the Cognitive Impairment Assessment and Planning Code G0505.
- 10. The Advisory Council on Alzheimer's Research, Care and Services should devote one meeting to advancing the work ASPE has conducted with RTI International on defining best practices for comprehensive dementia care.**
  - a. Specific topics should include: (1) an in-depth description of the Examining Models of Dementia Care report and appendices; (2) federal agency reporting of current innovative services for persons with dementia and their caregivers;

and (3) non-federal reporting from health systems and/or payers of exemplar population health solutions for dementia care. Advisory Council discussion of next steps to advance consensus definitions of best practice models, including measurement targets for clinical outcomes and value-based outcomes concerning cost and the care experience.

- 11. CMS should use the results of evidenced-based programs combined with definitions of best practices for comprehensive dementia care to provide adequate payment and incentives for providing evidenced-based care. This could include a comprehensive risk-based payment for reimbursement of comprehensive dementia care services.**
  - a. For example, CMS should use the results of evidenced-based programs, combined with definitions of best practices for comprehensive dementia care, to create a fixed Per Beneficiary Per Month (PBPM) payment for reimbursement of comprehensive dementia care services. The first target for the PBPM payment model should be community-dwelling persons with dementia and their caregivers who are not eligible for (or do not have access to) a PACE.
  - b. CMS should establish a system for determining that accountable entities receiving PBPM payments have the ability to supply all essential elements of comprehensive dementia care.
  - c. Congress and/or federal agencies should authorize and/or designate funding to conduct large-scale evaluation of the PBPM payment model for comprehensive dementia care; and, if the evaluations replicate the value proven by CMS dementia demonstration projects, then CMS should implement the PBPM model nationwide.
  
- 12. Changes to national health care must ensure continuation of support that is critical to people living with dementia and their caregivers including Medicare AWVs that include cognitive assessment, protection for pre-existing conditions, funding for person-centered and family-centered research on dementia, and support for innovative models of care.**
  
- 13. Federal agencies, national health and aging organizations, states, and other industry stakeholders should identify ways to implement recommendations that result from the October 2017 National Research Summit on Care, Services and Supports for Persons with Dementia and their Caregivers.**
  
- 14. Congress, federal agencies, and states must expand efforts to address the needs of family caregivers, including caregivers from diverse racial/ethnic/socioeconomic groups, caregivers of younger adults and people with IDD, and children and youth who provide care for older adults. Particular support is needed to expand and scale effective caregiver interventions for diverse racial/ethnic/socioeconomic groups; address reimbursement, training, and HIPAA policy and practice barriers to enable health care providers to provide care planning with family caregivers;**

**increase support for respite care; and address the financial burden to family caregivers. To accomplish this:**

- a. Increase federal funding by at least 50% for ACL dementia-specific funding that supports state, Tribal, and community dementia interventions by 2020.
- b. Use results of October 2017 Care Summit to build and fund a research and translation strategy to address clinical care, and LTSS.
- c. 90% of people with AD/ADRD and their key family and friend caregivers have access to a community-based education or support program on dementia caregiving by 2025.
- d. Amend the Older Americans Act (OAA) to allow additional OAA services to be provided to younger adults with dementia.
- e. Double funding for the National Family Caregiver Support Program, including funding for tribes under the OAA Title VI, by 2020.
- f. Educate health care providers on HIPAA by 2020, including clarification on HIPAA implementation, ways to support person-centered plans and advance care planning, addressing HIPAA concerns, and the provision of care when the person may not be competent. This should be accomplished by CMS, HRSA and states.
- g. Designate the primary caregiver role in both the caregiver's own medical record, and in the care recipient/patient's medical record systems by 2020.
- h. Expand Medicare benefits to ensure individuals with AD/ADRD and their families receive information, care coordination, caregiver supports, and HCBS.
- i. Expand innovative paid and volunteer respite programs.
- j. Promote state expansion of respite care through Medicaid waiver programs or state-funded respite services.
- k. Establish tax and Social Security credits for family caregivers by 2020.
- l. Increase by at least 50% funding for Medicaid's Money Follows the Person demonstration program, self-directed HCBS programs, and caregiving options that pay friend/family caregivers.
- m. Expand the Family Medical Leave Act and state laws to expand paid family leave for family caregivers.
- n. Identify the roles, prevalence, and impact of caregiving among young children, including children in immigrant, minority, and Tribal populations, who provide care for older adults with dementia.
- o. Provide resources to states, tribes, and communities to provide outreach and support to families and children where children provide caregiving for older relatives with dementia.

**15. Federal agencies, states, and health systems must take steps to increase identification of people with dementia who live alone, and to provide programs and services to meet the needs of this population.**

- a. Increase by at least 50% ACL dementia funding for community Gatekeeper programs that train community partners to identify and connect at-risk and live alone individuals to community aging services.



- b. Double funding for the National Family Caregiver Support Program by 2020, including specific outreach and support to families who care for individuals who live alone.
  - c. Identify existing information from federal agencies including ACL, CMS, HUD, Department of Transportation (DoT) or others, on the prevalence and housing situation for individuals who may have dementia and live alone.
  - d. Identify best practices for housing and transportation services that can meet the needs of individuals with cognitive impairment or dementia who live alone.
- 16. Federal agencies, states, and health systems must increase efforts to assess, prevent, and manage behavioral symptoms associated with dementia through effective programs and services and improved workforce knowledge and skills.**
- a. Incorporate AD/ADRD standards, including standards for effective ways to address behavioral symptoms, into all relevant clinical and LTSS quality measures by 2022.
  - b. Increase by at least 50% dementia funding for training and scaling of evidence-based behavioral symptom management interventions for persons with AD/ADRD.
  - c. Double HRSA funding for geriatric workforce training that includes increased dementia training to address challenging behavioral symptoms.
- 17. Federal agencies, states, national health and aging organizations, and community partners must continue to expand public awareness and training, reduce stigma, and help connect people to information and available resources. Outreach should include children and youth, diverse racial/ethnic/socioeconomic groups, and people with IDD.**
- a. Increase and coordinate federal agency, state, and national organization funding for innovative outreach and messages, in order to reach diverse populations.
  - b. Increase information developed for children and youth using video and social media, and provided through school curriculum and youth-serving organizations.
  - c. Develop expanded partnerships to support outreach through groups such as unions, community colleges/adult education, community and faith organizations, and first responders.
  - d. Increase engagement of national health-related organizations (e.g., Down syndrome, heart, and diabetes) in providing information and resources addressing dementia.
  - e. Study ways these websites may be used to further expand outreach to diverse racial/ethnic and socioeconomic groups.