

PUBLIC MEMBERS OF THE ADVISORY COUNCIL ON ALZHEIMER'S RESEARCH, CARE AND SERVICES: 2016 Recommendations

Since 2012, the National Plan and its accompanying recommendations have catalyzed progress in the field of AD/ADRD.

The 2016 Recommendations from the public members of the Advisory Council are presented below. Fulfilling the recommendations is contingent on limitations on legislative authority, resources, and data among the Federal Government. Appendix 2 of the National Plan 2016 Update gives federal responses to make clear which of these recommendations have been addressed and which would require congressional authority or additional resources.

- 1. The 2016 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 AD/ADRD by 2025.**
 - a. A roadmap for accomplishing the primary goal of the Plan should include input from experts in the field through research summits on AD/ADRD dementias 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/ADRD.
 - Make significant improvements in research recruitment rates and outreach among diverse populations.
 - Re-evaluate research priorities among AD/ADRD 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/ADRD (e.g., people with Down syndrome).
 - 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. Initial estimates of that level are \$2 billion per year but may be more. This investment would be applied to AD/ADRD research initiatives spanning basic, translational, clinical, care and services research.
 - b. The annual research funding target should be dynamically modified to approximately 1% of the cost of caring for persons with AD/ADRD.
 - c. The annual professional judgment budget recommended by the Alzheimer's Accountability Act and prepared by NIH should reflect the science-driven funding needs for the budget year to enable investigators to reach the 2025 goal of the plan.

- 3. The 2016 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, disease etiologies and disease trajectories to address key clinical features including NPS and functional decline.
 - f. 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. An integrated conference should be convened 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 reach a consensus 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 WDC.
 - b. Continued collaborations on international research efforts should be promoted.

- 6. The 2016 National Plan should increase early detection and diagnosis of AD/ADRD by encouraging and promoting cognitive assessment; and confirm measurement strategies to track progress within 2 years.**
 - a. Encourage clinicians to implement GSA's Workgroup on Cognitive Impairment Detection and Earlier Diagnosis' four-step process. The steps include: (1) "Kickstart the cognition conversation;" (2) "Assess if symptomatic;" (3) "Evaluate with full diagnostic workup if cognitive impairment detected;" and (4) "Refer to community resources and clinical trials, depending on the diagnosis."
 - b. Promote early detection and diagnosis: support continuing education efforts that improve health care providers' ability to recognize early signs of dementia, including AD/ADRD, and to offer counseling to individuals and their care partners. Sessions should enhance health care provider awareness and understanding of the Medicare AWW and knowledge of validated cognitive assessment tools, through local and state conferences.
 - c. Determine if and how the Medicare AWW can be used to measure the rate of screening for cognitive impairment. Also, determine if and how other measures, such as items within the Physician Quality Reporting System (PQRS), could be used to track progress regarding the rate of screening for cognitive impairment.
 - d. Measure and publicly report data on AD/ADRD diagnostic levels nationally and by state, released within 6 months of year end.

- e. Expand Diagnosis Disclosure, Improve Assessment and Care Planning, and Enhance Care Coordination. Develop and implement educational campaigns directed towards: (a) persons at risk for dementia and their family and caregivers; and (b) clinicians capable of conducting cognitive screening assessments. For the education of clinicians, include information about best practices for how to conduct the cognition conversation such that the diagnosis is understood, how to conduct conversations about care planning, and how to enhance care coordination through referrals to community resources. For the education of persons at risk for dementia and their family and caregivers, include information about what to expect after cognitive screening.

7. The 2016 National Plan should enhance care planning and care coordination by increasing the use of person-centered and caregiver goals, and improving measurement within 3 years.

- a. Identify standards of care that reflects delivery of a comprehensive assessment to establish the diagnosis of dementia, identification of contributing factors, identification of support needs, and formulation of a care plan.
- b. Develop and implement a plan to improve measurement capability so that the perspectives and goals of persons with AD/ADRD, their families and caregivers are known.
- c. Incorporate best practices from the CMS Financial Alignment Initiative, including guidance provided in "three-way contracts" between CMS, states and health plans to improve care coordination for dementia. One example is the Dementia Cal MediConnect program which implemented care manager training and technical assistance in response to California's three-way contract specifying that each health plan must have a dementia care specialist.

8. The 2016 National Plan should increase the number of communities working to become dementia-friendly by 50% within 1 year.

- a. Encourage efforts to foster Dementia-Friendly Communities. As an example, tools and resources used in Minnesota have been replicated through a privately-funded collaboration called *Dementia Friendly America*; under this initiative all United States communities have access through a website (<http://www.dfamerica.org>) to free tools, resources, best practices and technical assistance to support them in working to become dementia-friendly. Incorporate examples such as this into an update of the November 2011 Dementia-Capability Toolkit and the September 2014 report,

Dementia-Capable States and Communities: the Basics; and/or promote expanded use of the Toolkit and report.

- b. Promote the Dementia-Friendly Community approach as an organizing vehicle to implement state AD/ADRDR plans. A public-private collaborative approach should provide funding that is designed to specifically support communities and/or states with seed money to foster the coordination of community efforts and support technical assistance through a centralized hub and/or state lead entity. In 2016, this collaborative should fund at least 20 communities (via an Request for Proposal process) and a technical assistance hub. The communities chosen should reflect differences in cultural groups and size of community, as well as rural and urban locales.

9. The 2016 National Plan should convene a national dementia care and services research summit.

- a. Build on existing work to identify research priorities related to improving early detection and diagnosis of AD/ADRDR, providing care and services to persons with dementia and family caregivers, and providing recommendations as to standards of care, best practices and priorities.

10. States, HHS, and Tribes must assure robust dementia-capable LTSS systems to meet the growing impact of AD/ADRDR.

- a. Increase the number of states with an identified state lead entity for AD/ADRDR to coordinate activity across state agencies and programs, and to work with state, local and private sector partners to implement strategies in concert with the National Plan.
- b. National partners should work with HHS and states to assure engagement of state governors and legislatures in state efforts to address dementia-capable LTSS, expand use of evidence-based and best practices, and advocate for adequate funding for LTSS.
- c. Double current funding for the ADSSP and ADI-SSS program to increase state and communities' use of evidence-based and evidence-informed strategies, programs, and dementia-capable systems.
- d. Provide adequate funding to support state lead entities to plan and coordinate public and private activities to assure states are able to address the growing impact of AD/ADRDR and assure dementia-capable health and LTSS systems.
- e. Increase state and local public health role in supporting brain health, prevention, surveillance, and community policies to support cognitive health, implementation of CDC's *Healthy Brain Initiative: Public Health Road Map*,

and incorporation of brain health and AD/ADRD into other existing public health efforts.

- f. Amend Older Americans Act and expand funding to support making Title III services available to people under age 60 with younger-onset dementia.
- g. Adopt common metrics that states, Tribes, and communities can use to measure and track progress in developing dementia-capable LTSS.

11. HHS, states, Tribes, and health care and aging services must assure that family or unpaid caregiver health and well-being is addressed.

- a. Assure that health and related systems funded with federal resources provide chronic disease management and related services for people with AD/ADRD, as well as family caregivers.
- b. Educate and clarify for health care providers and health systems how Medicare care planning and other covered benefits can be provided to a beneficiary with AD/ADRD in compliance with HIPAA, when a family caregiver is present and the individual with the disease is not.
- c. Provide full funding for the National Family Caregiver Support Program, including funding to ensure regular evaluation of the impact of the program on family caregivers for people with AD/ADRD.
- d. The process of diagnosis should include engaging individuals and families in care planning and referrals to appropriate community resources to support this planning. Care planning should address health, LTSS, caregiving resources, legal, estate planning, and finances.
- e. Provide care planning with an unpaid/family caregiver as a covered benefit under Medicare and Medicaid.
- f. Identify family/unpaid caregivers in EHRs of individuals with AD/ADRD, as well as in the caregiver's own medical records.
- g. Expand pilot payment programs in Medicare and Medicaid models that include caregiver support for patients with AD/ADRD, many of whom have complex care needs.
- h. Identify and advocate for employment practices and policies that allow employers to balance paid employment with unpaid care.
- i. Support the expansion to scale of evidence-based and evidence-informed caregiver support programs and their cultural adaptations.

- 12. Federal agencies in partnership with national organizations and states, support research to identify standards and best practices to improve quality of life and LTSS for individuals and families affected by AD/ADRD.**
- a. Provide training for paid/paraprofessional caregivers in every care setting to address cultural and dementia competence. HHS should identify model state standards of care and policies that promote fair and reasonable compensation and appropriate dementia care training.
 - b. Assess and share findings on the impact of CMS's 2014 HCBS settings rule on individuals with AD/ADRD and their caregivers.
 - c. Assess and share findings on the impact of states' managed LTSS systems on individuals with AD/ADRD and their caregivers.