

2017 National Plan Update and Non-Federal Recommendations

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Main Points

- ▶ Expected Release in August 2017
- ▶ Updated Implementation Milestones
- ▶ Officially a NATIONAL Plan, with items from members of the Council and other national partners
- ▶ Recommendations from the Advisory Council and formal response from Federal agencies included in an appendix

Highlights

- ▶ Over 100 new items
- ▶ 5 states provided new items or ongoing work: Georgia, Minnesota, Oregon, West Virginia, and New York
- ▶ 5 non-federal organizations have contributed items about their work over the past year, including partnerships conducted with the federal government.
 - Would like to encourage more to contribute

Updated Implementation Milestones

- ▶ Completed items have been removed and are now archived on the website
- ▶ New items (projects, papers, initiatives, etc) have been added under the Goals and Strategies
 - New target actions and completion dates
- ▶ Next steps in completed items have been added

2017 Recommendations and Federal Response (Appendix 2)

Recommendation 1


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 (AD/ADRD) by 2025.

- A roadmap for accomplishing the primary goal of the Plan should include input from experts in the field through research summits on AD/ADRD including a research summit on care and services
- Recommendations from these summits and the research community should be re-evaluated each year and translated into milestones.
- Include specific research milestones to:
 - Reduce racial/ethnic/socioeconomic disparities in AD/ADRD
 - 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, African Americans)
 - Increased attention should be paid to person- and family-centered outcomes with respect to research planning and the delivery of care and services

NIH Response


NIH will continue to engage a broad range of stakeholders, including academia, industry, non-governmental organizations (NGOs), and individuals directly affected by AD/ADRD, in advancing the goals of the National Plan. This Plan focuses on identifying effective interventions and improving care and services, and its future updates will build upon research advances and emerging opportunities, and will be informed by additional research summits as well as feedback from the broader community. Upcoming summits that will provide guidance regarding future implementation of the Plan's goals include a summit focused on AD/ADRD care and services research in October 2017, and large AD and ADRD summits in 2018 and 2019, respectively.

NIH leadership and staff continues to update its specific research plans and cost estimates annually, as outlined in each year's *Bypass Budget for Alzheimer's Disease and Related Dementias*. Part of this process involves regularly updating, implementing, and tracking a broad set of specific AD/ADRD research milestones. To enable federal agencies and other organizations to track progress in reaching these milestones, NIH has made a searchable database available to the public. The Advisory Council's recommendations regarding specific research milestones will greatly contribute to these NIH planning processes.



CMS Response

CMS has supported work led by HHS Office of the Assistant Secretary for Planning and Evaluation to engage in efforts to plan research summits on ADRD, including a fall 2017 summit on care and services. Through the "Connected Care" campaign, CMS, working with HRSA, is raising awareness of the benefits of Medicare's Chronic Care Management (CCM) service for beneficiaries with multiple chronic conditions including ADRD, and furnishing resources for implementation across all diverse populations. CMS is driving efforts to empower beneficiaries and their providers to make decisions, take ownership of their care, and make certain they have the information they need to make informed choices.



Recommendation 2

A top priority remains the urgent need to continue to increase annual federal research funding sufficient to meet the 2025 goal.

- At present, the US spends less than 0.5% of its annual care costs for ADRD on research, therefore investments in research should be increased to achieve the primary goal of the National Plan
- Initial estimates suggested that \$2 billion or more per year is needed and more accurate estimates can be generated by the Professional Judgment Budget.
- 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.
- This investment would be applied to Alzheimer's disease and related disorders research initiatives spanning basic, translational, clinical, care and services research

NIH Response

As a component of the Department of Health Human Services under the Executive Branch of the United States government, NIH cannot comment on targets for -- or algorithms that could be used to estimate -- the total research funds needed for AD/ADRD research, beyond the President's Budget and the estimate that NIH submits as part of the *Bypass Budget for Alzheimer's Disease and Related Dementias*.

Recommendation 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.

- Enhance methodologies to effectively engage persons with dementia and families in research on care decision making and planning
- Develop and implement quality care measures across all settings that include person-and family-centered outcomes
- Identify and evaluate (non-drug) care strategies that reduce disease burden and delay disease progression and evaluate their costs and downstream effects
- Study comprehensive dementia care from time of diagnosis to end of life and associated costs
- 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 neuropsychiatric symptoms and functional decline.
- 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.
- Convene a conference of key stakeholders to identify a meaningful pathway or pipeline for developing and testing nonpharmacological treatments, and scaling up and implementing effective approaches.

NIH Response

Research on provision of care and services for individuals with AD/ADRD and their families is an important research priority at NIH; the NIA has played a key role in developing the 2017 National Research Summit on Care, Services and Supports for Persons with Dementia and their Caregivers. The NIA looks forward to integrating recommendations from the 2017 summit into its future planning and FOA development, following the meeting.

CMS Response

CMS, through its work to implement the National Quality Strategy and the CMS Quality Strategy, seeks to ensure person- and family-centered care across the healthcare landscape in partnership with beneficiaries, families, and caregivers. As one example, CMS regularly solicits nominations for technical expert panel (TEP) members for CMS measure development and maintenance contractors to provide input to the contractor on the development, selection, and maintenance of measures for which CMS measure contractors are responsible. Convening a TEP is one important step in the measure development or reevaluation process that CMS uses to ensure transparency, and provides an opportunity to include multi-stakeholders early in the process. CMS, through its Medicaid Testing Experience and Functional Tools grants, is developing and testing electronic long-term services and supports plans, personal health record systems, and Functional Assessment Standardized Items to use technology to better link beneficiaries, providers, and caregivers.

Recommendation 4

Emphasis should be given to the standardization of terminology in dealing with cognitive and dementing disorders.

- 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.
- 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

NIH Response

NIH supports the effort to standardize language in this area of research, and devoted a special session to this topic at the recent Alzheimer's Disease-Related Dementias 2016 Summit, specifically to discuss issues and challenges regarding nomenclature and to gather suggestions on how to move forward. One of that Summit's draft recommendations proposed that a working group be organized to include all stakeholders and convene a workshop to develop a coherent nomenclature for all dementias. Once the NAPA Advisory Council establishes this working group, it will develop a plan for taking next steps and gathering public input on the issue. NIH recognizes that standardization is critical, but standards developed and applied for different types of stakeholders (e.g., research vs. public) may need to be interoperable rather than identical.

One of the ADRD 2016 Summit's recommendations, now formalized as one of the ADRD Prioritized Research Milestones (Topic 2 Focus Area 2), is to organize a working group of all dementia stakeholders and convene a meeting to develop a consistent nomenclature in dementia research and care. At the National Research Summit on Care, Services, and Supports for Persons with Dementia and their Caregivers in October 2017, there will be another session on nomenclature to discuss challenges associated with dementia nomenclature such as stigma and limited access to care and services.

Recommendation 5

As recommended in the National Plan the US government should support global efforts to address issues of research, care and services.

- US public and private entities should acknowledge and scrutinize the work of the World Dementia Council and the World Health Organization
- Continued collaborations on international research efforts should be promoted

NIH Response

NIH communicates regularly on global efforts in a variety of forums with government representatives and many other stakeholders in the international dementia community. Staff welcome these discussions and resulting opportunities for collaborations. The United States welcomes additional participation in this database by governmental organizations or NGOs. IADRP currently captures more than 7,000 unique projects conducted by more than 4,000 researchers across more than 1,000 institutions – supported by 35 public, private and international funding organizations in 11 countries – reflecting more than \$5.7 billion in research funding worldwide

In addition, NIA continues to co-host quarterly international funders conference calls with the Alzheimer's Association -- which offers an opportunity for NIH and other organizations to discuss research priorities and initiatives.

As a third example, foreign institutions are eligible to apply for funding to support research solicited in both of the FOAs for Research on Informal and Formal Caregiving for Alzheimer's Disease, which specifically encouraged both national and cross-national population-based research, and in the Health Disparities and Alzheimer's Disease FOA..

Recommendation 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 major challenge in the development of effective therapies for AD/ADRD has been the inefficient recruitment of participants in clinical trials
- Emphasis should be placed on the enhancement of diversity and inclusiveness in these efforts
- The documentation of recruitment goals should be required in applications for randomized controlled trials and incentives should be in place for meeting those goals

NIH Response

With substantial community and stakeholder involvement, NIA is leading efforts to provide practical approaches to help study sites and researchers overcome the challenges and barriers in recruiting and retaining the right volunteers, at the right times, in the right studies. With facilitation by the Alzheimer's Association and in collaboration with a wide group of government, private, and academic stakeholders, NIA is developing a National Strategy for Recruitment and Participation in Alzheimer's Disease Clinical Research. In 2017, NIA convened a workshop for experts from academia, communications, advocacy, and clinical care and research to identify the best strategies for engaging a range of audiences, including minority and underrepresented groups, in the clinical research enterprise. When the strategy is finalized, attention will turn to its implementation, not only for actions that can be considered by the federal government, but by stakeholders in government, academia, advocacy, medicine and the public with an interest in progress in Alzheimer's research.

Recommendation 7

The National Plan should continue to promote early detection and diagnosis of Alzheimer's Disease and related dementias (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.

- 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 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.
- 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 Annual Wellness Visit in a primary care setting. Alzheimer's & Dementia.

CMS Response

Dementia: Cognitive Assessment (Percentage of patients, regardless of age, with a diagnosis of dementia for whom an assessment of cognition is performed and the results reviewed at least once within a 12 month period, is available as an applicable measure in the new Quality Payment Program for Merit-Based Incentive Payment System physicians and groups. CMS develops and tests an array of measures for many of its quality programs that could impact beneficiaries with dementia, and continues its work as a measure developer to develop and implement performance measures for use in multiple programs across care settings. CMS has worked on developing two electronic clinical quality measures to address quality of care for patients 1) at risk of or who have cognitive impairment Cognitive Impairment Assessment Among Older Adults (75 years and older) – CI Assessment and 2) Documentation of a Health Care Partner for Patients with Dementia or Mild Cognitive Impairment – Health Care Partner. Next steps during the pre-rulemaking process would be inclusion in the annual CMS Measures Under Consideration List.

IHS Response


The IHS will continue to develop workforce training and community education strategies to enhance recognition of cognitive impairment and effective diagnosis.



NIH Response

Given that treatments are very likely to be most effective the earlier they are instituted, NIH released a new funding opportunity announcement in 2017 to increase early detection of cognitive impairment, including dementia, when a patient or a caregiver voices a concern in primary care and other everyday clinical settings. The goal is to create a research consortium to develop and test clinical paradigms that utilize cognitive assessment tools (new or existing) that are simple to use, standardized, and can be quickly administered in a primary care setting.

With respect to education on early detection and diagnoses, several NIA resources are already available to support clinicians in assessing and managing patients with cognitive impairment; see the "Assessing Cognitive Impairment," "Managing Cognitive Impairment," and the "Patient Checklist" sections of the Alzheimer's and Dementia Resources for Professionals web page. Moreover, clinicians can use the "Talking with Your Patients About Cognitive Problems" chapter of NIA's new *Talking with Your Older Patient* resource to initiate conversations about these and other related issues. NIH strongly supports moving forward with an educational outreach campaign to clinicians.



Recommendation 8

CMS should annually report data by state/region and by diagnosis regarding the use of the new G0505 billing code.

- 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.

CMS Response

Because it is a new service, CMS does not have information on utilization for code G0505 at present. CMS may monitor utilization data in the future.

Recommendation 9

Federal agencies should offer and support educational efforts that improve healthcare 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 working group of health professional associations should be convened to develop competencies in delivering evidenced-based dementia care across care settings.
- Training related to quality dementia care should be included in curricula and continuing education sessions for health professionals.
- Specifically, training should enhance healthcare provider awareness and understanding of the Medicare Annual Wellness Visit, 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

CMS Response

CMS continues its work with the HHS Office on Women's Health and HRSA to promote current policies and practices that improve the ability of caregivers for persons living with ADRD to manage or sustain their own health, and is helping its partners package training "modules" to educate and support caregivers. CMS continues to address (e.g. Medicare Learning Network, National Partnership to Address Dementia Care in Nursing Homes, the Long-Term Care Final Rule, and other policy issuances) dementia care training for health providers.

NIH Response

With respect to education on early detection and diagnoses, several NIA resources are already available to support clinicians in assessing and managing patients with cognitive impairment; see the "Assessing Cognitive Impairment," "Managing Cognitive Impairment," and the "Patient Checklist" sections of the Alzheimer's and Dementia Resources for Professionals web page. Moreover, clinicians can use the "Talking with Your Patients About Cognitive Problems" chapter of NIA's new *Talking with Your Older Patient* resource to initiate conversations about these and other related issues. NIH strongly supports moving forward with an educational outreach campaign to clinicians.

Recommendation 10

The Advisory Council on Alzheimer’s Research, Care and Services should devote one meeting to advancing the work the HHS’s Office of the Assistant Secretary for Planning and Evaluation has conducted with RTI International on defining best practices for comprehensive dementia care.

- 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; 3) non-federal reporting from health systems and/or payers of exemplar population health solutions for dementia care; and 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.

ASPE Response

The “Examining Models of Dementia Care” Report is published and available on the ASPE website. As was discussed during the April 2017 NAPA Advisory Council meeting, there are a number of different directions in which to pursue future research, and ASPE would welcome the opportunity to discuss these opportunities in greater detail with the Council at large, or with one or more of the relevant NAPA subcommittees.

Recommendation 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.

- 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 Program of All-Inclusive Care for the Elderly (PACE).
- 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.
- 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.

CMS Response

CMS periodically offers opportunities for states and other entities to apply for demonstrations, waivers, and models and other special initiatives through the Medicaid program, and its Innovation Center. States and accountable entities (such as Medicare Accountable Care Organizations), when applying for/implementing such opportunities, have some discretion in choosing what topics to address (e.g., AD/ADRD) within these. The CMS Innovation Center is focused on testing new payment and service delivery models, and evaluating and sharing the results. Occasionally, there may be a path to wider adoption in a CMS program, should a model meet statutory and other criteria. Such adoption would be subject to a formal rulemaking process including opportunities for public comment. Public and private payers such as state Medicaid agencies, state and local government, managed care plans, private insurers, and other entities are encouraged to review the results of CMS model testing and demonstration results, and adopt best practices. CMS will keep stakeholders apprised of future opportunities to provide input as models, including those that address AD/ADRD and/or behavioral health, are developed.

IHS Response

The CPC+ model in testing in 18 regions by CMMI and partnering payers offers a monthly risk adjusted care management fee and includes persons with dementia in the highest risk category. This could be seen as at least a partial test of this approach within primary care.

Recommendation 12

Changes to national healthcare must ensure continuation of support that is critical to people living with dementia and their caregivers including Medicare annual wellness visits that include cognitive assessment, protection for pre-existing conditions, funding for person- and family-centered* research on dementia, and support for innovative models of care.

CMS Response

CMS is driving efforts to empower beneficiaries, consumers, and their providers to make decisions, take ownership of their care, and make certain they have the information they need to make informed choices.

Recommendation 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

Combined Federal Response

The member agencies of the NAPA Council are committed to research that improves the lives of individuals with dementia and their caregivers. We will identify any and all recommendations from the Summit, and consider them as we develop and update our research milestones.

Recommendation 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 intellectual/developmental disabilities, 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 healthcare providers to provide care planning with family caregivers; increase support for respite care; and address the financial burden to family caregivers. To accomplish this:

- Increase federal funding by at least 50% for ACL dementia-specific funding that supports state, tribal, and community dementia interventions by 2020.
- Use results of October 2017 Research Summit to build and fund a research and translation strategy to address clinical care, and long-term services and supports.
- 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.
- Amend the Older Americans Act to allow additional OAA services to be provided to younger adults with dementia.
- Double funding for the National Family Caregiver Support Program, including funding for Tribes under the Older Americans Act Title VI, by 2020.
- 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.

Recommendation 14, Continued

- 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.
- Expand Medicare benefits to ensure individuals with AD/ABRD and their families receive information, care coordination, caregiver supports, and home and community-based services.
- Expand innovative paid and volunteer respite programs.
- Promote state expansion of respite care through Medicaid waiver programs or state-funded respite services.
- Establish tax and Social Security credits for family caregivers by 2020.
- 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.
- Expand the Family Medical Leave Act (FMLA) and state laws to expand paid family leave for family caregivers
- 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.
- 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.

ACL Response

ACL continues to make federal funding available dementia-specific programs that support state, tribal, and community dementia interventions. Funded programs promote development of new dementia-capable service systems across the country, expansion of existing systems, as well as caregiver education and support. Other recommendations in this section would require changes to federal law or appropriations.

CMS Response

CMS beneficiaries may have a representative of their choosing (including an emergency contact) with access to information and participates in health care discussions with their knowledge and consent, as well as a legal representative such as an individual who has a power of attorney for health care, a guardian, or health care surrogate or proxy appointed in accordance with state law act on their behalf, if they are unable to make their own decisions. CMS regularly works with its HRSA partners, and provides education and information through a variety of venues on an array of topics (e.g. Open Door forums, Medicare Learning Network, "Grand Rounds," etc.) CMS is ushering in a new era for the federal-state Medicaid partnership where states have even more freedom to design programs that meet the spectrum of diverse needs of their Medicaid population, and is empowering states to advance the next wave of innovative solutions to Medicaid's challenges through solutions that focus on improving quality, accessibility, and outcomes in the most cost-effective manner. States, as administrators of the Medicaid program, are in the best position to assess the unique needs of their respective Medicaid-eligible citizens and to drive reforms that result in better health outcomes. CMS will continue to provide technical assistance to states that want to provide self-directed service delivery mode options and paid family caregiver options in their Medicaid home and community-based services programs.

IHS Response

The IHS will review the findings of the October 2017 Research Summit to inform priorities in support of spread of evidence-based services in Tribal Communities. Additionally, IHS continues efforts to expand caregiver support services through the REACH intervention in Tribal Communities.

NIH Response

The NIH recognizes the importance of research to understand and address caregiver needs. The Resources for Enhancing Alzheimer's Caregiver Health (REACH) intervention, supported by the NIH, developed the first intensive caregiver support intervention to be proven effective, through rigorous testing, in an ethnically diverse population. The REACH intervention is currently being translated more broadly through the VA, with participating centers in fifteen states. The VA is also partnering with the Administration for Community Living (ACL), the Indian Health Service, and a private foundation to adapt and implement REACH in Tribal communities. In addition, NIH is currently supporting the design, development, implementation and dissemination of numerous other ADRD-related interventions, as well as evidence-based tools and training materials to help support the many and various needs of caregivers for example, The NYU Caregiver Intervention.


Recommendation 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.

- 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.
- 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.
- Identify existing information from federal agencies including ACL, CMS, HUD, Dept. of Transportation or others, on the prevalence and housing situation for individuals who may have dementia and live alone.
- Identify best practices for housing and transportation services that can meet the needs of individuals with cognitive impairment or dementia who live alone.

CMS Response

CMS established the Medicaid Innovation Accelerator Program (IAP) with the goal of improving health and health care for Medicaid beneficiaries by supporting states' ongoing efforts related to payment and delivery system reforms through the provision of technical assistance, tools development and cross-state and national learning opportunities. In 2017, IAP launched the second "track" of the State Medicaid-Housing Agency Partnerships. The goals of the State Medicaid-Housing Agency Partnerships are to develop public and private partnerships between Medicaid and housing systems and to support states in the creation of detailed action plans that foster additional community living opportunities for Medicaid beneficiaries. Consistent with statute, CMS does not provide funds for room and board. Program support begins this fall and runs for nine months. It will offer intensive, hands-on technical support to move state Medicaid agencies towards building sustained collaborations with housing partners, and those from other service agencies.




NIH Response

The NIH supports research to identify people with dementia who live alone. In a recent study supported by the NIA, it was estimated that of people with dementia living in the community, 14.3% live by themselves. The identification of the needs of persons living alone with dementia can lead to continued health-focused research on this vulnerable population. NIA values this population and recognizes that more research is needed in this area.

ACL Response

ACL continues to make federal funding available dementia-specific programs that support state, tribal, and community dementia interventions. ACL's funded programs promote development of new initiatives designed to identify and provide supportive services to at-risk and/or under-served populations, including individuals who live-alone. Other recommendations in this section would require changes to federal law or appropriations.



Recommendation 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.

- Incorporate AD/ADRD standards, including standards for effective ways to address behavioral symptoms, into all relevant clinical and LTSS quality measures by 2022.
- Increase by at least 50% dementia funding for training and scaling of evidence-based behavioral symptom management interventions for persons with AD/ADRD.
- Double HRSA funding for geriatric workforce training that includes increased dementia training to address challenging behavioral symptoms.

ACL Response

ACL continues to make federal funding available dementia-specific programs that support state, tribal, and community dementia interventions. ACL's funded programs promote development of new and/or expanded efforts to address behavioral symptoms attributable to AD/ADRD. All ACL AD/ADRD grant programs require inclusion of evidence-based and evidence informed interventions in support of individuals living with AD/ADRD and their caregivers. Other recommendations in this section would require changes to federal law or appropriations.

CMS Response

Last year CMS, with the assistance of ACL, released a set of "FAQs" that discuss strategies to ensure the health and safety of Medicaid beneficiaries at risk of wandering, including people with AD/ADRD. These focus on how person-centered planning can be used to identify any appropriate restrictions while facilitating individualized services and community integration. CMS also furnished guidance to states on suggested approaches to strengthen and stabilize the Medicaid home care workforce.

IHS Response

The IHS will be exploring the use of Project ECHO to provide both clinical consultation and training in the diagnosis and management of dementia in Tribal communities. The IHS and ACL partner in training the Tribal Aging Network in the recognition and management of ADRD in Tribal communities.

Recommendation 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 intellectual and developmental disabilities.

- Increase and coordinate federal agency, state, and national organization funding for innovative outreach and messages, in order to reach diverse populations.
- Increase information developed for children and youth using video and social media, and provided through school curriculum and youth-serving organizations.
- Develop expanded partnerships to support outreach through groups such as unions, community colleges/adult education, community and faith organizations, and first responders.
- Increase engagement of national health-related organizations (e.g. Down Syndrome, Heart, and Diabetes) in providing information and resources addressing dementia.
- Study ways these websites may be used to further expand outreach to diverse racial/ethnic and socioeconomic groups.

ACL Response

ACL continues to make federal funding available dementia-specific programs that support state, tribal, and community dementia interventions. ACL's funded programs promote outreach to and services for diverse and underserved populations, including dementia friendly community education efforts. Other recommendations in this section would require changes to federal law or appropriations

IHS Response

The IHS is working with the Alzheimer's Association and the National Indian Council on Aging to increase understanding and awareness of ADRD in Tribal communities.

NIH Response

Beyond research-specific efforts, NIH is also committed to continuing to enhance and provide evidence-based information, resources, and referrals through the ADEAR Center to specific populations of people with AD/ADRD and their caregivers including younger people, non-traditional families, people with IDD, such as Down syndrome, and racial and ethnic minorities who are at increased risk of acquiring AD/ADRD. The NIA plans to convene a meeting of federal communicators at agencies involved in Alzheimer's and related dementias research, care and services to enhance collaboration outreach generally and in the upgrading and promotion of alzheimers.gov and brainhealth.gov for an increasingly diverse public audience.

July 28, 2017 -- Advisory Council Meeting #25

The meeting was held on Friday, July 28, 2017, in Washington, DC. The Advisory Council spent the morning discussing information gaps across the three areas of research, clinical care, and long-term services and supports. There was also a presentation on the recently released National Academy of Sciences, Engineering, and Medicine (NASEM) report on preventing cognitive decline. Additional presentations included a presentation on planning and progress towards the October Care and Services Summit and federal workgroup updates. Material available from this meeting is listed below and is also available at <https://aspe.hhs.gov/advisory-council-alzheimers-research-care-and-services-meetings#Jul2017>.

Comments and questions, or alerts to broken links, should be sent to napa@hhs.gov.

General Information

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Presentation Slides

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CommunityRx for Community-Residing People with Dementia and Their Caregivers	[HTML Version] [PDF Version]
Dementia Caregiving in the U.S.	[HTML Version] [PDF Version]
Development of the FY 19 NIH Bypass Budget for Alzheimer's Disease and Related Dementias	[HTML Version] [PDF Version]
Implications of a Biologically Based Definition of Alzheimer's Disease	[HTML Version] [PDF Version]
Increasing Opportunities for Choice and Control for Persons with Dementia	[HTML Version] [PDF Version]
Interventions to Prevent or Slow Cognitive Decline, MCI and Dementia in Individuals without Dementia	[HTML Version] [PDF Version]
Living Alone With Dementia	[HTML Version] [PDF Version]

Long-Term Services and Supports Committee Update	[HTML Version] [PDF Version]
Managing Chronic Conditions in People Living with Dementia	[HTML Version] [PDF Version]
Preventing Cognitive Decline and Dementia	[HTML Version] [PDF Version]
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Videos

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