2016 National Plan Update
Rohini Khillan, ASPE

Main Points

- Released August 2016
- 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
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

Highlights
Minnesota

- Minnesota: Dementia–Capable State
- Minnesota Healthy Brain Initiative
- Dementia: Awareness, Screening Testing and Support of Caregivers
- Integrated Health and Long–Term Services and Supports

Minnesota–based

- Dementia–Friendly America Program

New York

- New York State Programs for Alzheimer's Disease and Other Dementias
- New York State Alzheimer's Disease Regional Caregiver Support Initiative
- New York State Coordinating Council for Services Related to Alzheimer's Disease and Other Dementias
Oregon

• Oregon Dementia Training for Alzheimer's Disease and Related Dementias Staff

• Oregon Caregiver Training

West Virginia

• West Virginia Coordinated Action, Response, Education and Support about Families Living with Dementia

Research Projects

› Translation of Care of Persons with Dementia in their Environments in a Publicly-Funded Home Care Program

› WeCareAdvisor™

› NAS Study on Family Caregiving for Older Adults

› Hospice Referral after Inpatient Psychiatric Treatment of Individuals with Advanced Dementia from a Nursing Home
International Work, Increasing Awareness, and Tracking Progress

- World Dementia Council and the work of the G7 and WHO
- Lewy Body Dementia Association: *Lewy Who? Campaign*
- Alzheimer’s Association: *Alzheimer’s Association Care and Support Milestones Journal Article*

2016 Recommendations and Federal Response (Appendix 2)
Recommendation 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.

NIH Response

NIH will continue to advance the National Plan. This Plan focuses on finding effective interventions and improving care and services. The Plan will be informed by additional research summits as well as feedback from the broader community.

NIH will also update and outline its specific research plans annually in each year’s Bypass Budget for Alzheimer’s Disease and Related Dementias. NIH recently launched a searchable database where federal agencies and other organizations can track the progress of regularly updated A/ADRD research milestone.
Recommendation 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.

NIH Response

As part of 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 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.

**NIH Response**

Two FOAs (PAR-15-348 and PAR-15-351) released in September 2015 focus on identifying, characterizing and addressing the needs of formal and informal caregivers and care recipients, including nearly all of the Advisory Council's recommendations addressed in the 2015 FOAs.
Recommendation 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.

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 this working group is established, 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.
Recommendation 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.

NIH Response

NIH communicates regularly on global efforts in the international dementia community. As one critical example, NIA and the Alzheimer's Association developed the IADRP tracking system, in order to catalog, search, and interrogate projects in this area of research.

In addition, NIA co-hosts the 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 global research.
Recommendation 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 AWV and knowledge of validated cognitive assessment tools, through local and state conferences.

Recommendation 6 cont’d

c. Determine if and how the Medicare AWV 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.
CMS Response

In Response to Recommendation 6.a. The agency is not planning, at the present time, to issue regulations or other policy guidance requiring providers to use a particular tool or tools for detection of cognitive impairment.

In Response to Recommendation 6.b. The Medicare program offers counseling or therapy from a psychiatrist, psychologist, social worker, and other provider types in an outpatient setting. Family counseling is also permitted, if the main purpose is to help with the beneficiary’s treatment.

In Response to Recommendation 6.c. CMS is currently developing electronic clinical quality measures (eCQMs) that addresses screening for cognitive impairment. These eCQMs complement Medicare's AWV not only for screening but also for family/caregiver engagement.

In Response to Recommendation 6.d. CMS has published a "Mapping Medicare Disparities" tool that allows stakeholders to access geographic information about chronic conditions, including AD/ADRD. The tool permits comparisons between subpopulations in outcomes, utilization, and spending. CMS also furnishes researchers with Medicare and Medicaid beneficiary, claims, and assessment data through the Chronic Conditions Warehouse.

In Response to Recommendation 6.e. CMS supports a person–centered approach, where the beneficiary is at the center of directing their care. The agency is striving to improve clinical care through, for example, the Comprehensive Primary Care Initiative, where primary care physicians are asked to engage in five functions: access and continuity, planned care for chronic conditions and preventive care, risk–stratified care management, beneficiary and caregiver engagement, and care coordination across the medical neighborhood.

HRSA Response

In Response to Recommendation 6.b. HRSA, through its GWEP, will continue to support transforming clinical training environments by developing a health care workforce that maximizes patient and family engagement to improve health outcomes for older adults by integrating geriatrics with primary care. GWEP grantees are continuing to educate the health care workforce on the early detection and diagnosis of AD/ADRD including the use of GSA’s four–step process and the Medicare AWV. HRSA is in the process of identifying best practices in dementia training.

NIH Response

In Response to Recommendation 6.b. 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. 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.
Recommendation 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.

CMS Response

In Response to Recommendation 7.a. In the CMS Quality Strategy, the agency actively encourages person and family engagement throughout the care continuum, including incentivizing health plans and providers to deploy effective person resources such as person–centered care plans. Person–centered care planning is a focus across CMS’s programs. CMS has also worked with the NQF on 12 endorsed quality measures for care coordination, and on the endorsed and submitted measures for person–centered and family–centered care.

In Response to Recommendation 7.b. In 2015, CMS issued guidance on Requirements for Person–Centered Plans (PCPs) for HCBS. The PCP is synonymous with a written individual plan based on the individual’s unique needs, goals and preferences. Medicaid’s Electronic Long–Term Services and Supports (eLTSS) Initiative is identifying and harmonizing electronic resources to enable the creation, exchange and reuse of interoperable person–centered records to improve the coordination of health, social services, and other services that support a beneficiary’s mental and physical health. More than 15 of CMS’s HCIAAs involve aspects of caregiving.

In Response to Recommendation 7.c. CMS established the Integrated Care Resource Center (ICRC) to help states develop integrated programs that coordinate medical, behavioral health, and LTSS for beneficiaries who are dually eligible for Medicare and Medicaid. The ICRC provides technical assistance and facilitates peer learning opportunities for states, including those participating in the Financial Alignment Initiative. CMS also makes public reports, Systems survey results, health risk assessment completion data, enrollment of Medicare–Medicaid plans (MMPs), as well as annually submits a Report to Congress that includes information on the Financial Alignment Initiative.
NIH Response

Clinical care research is a critical research priority at NIH, with investments made to improve early diagnosis of AD/ADRD, support translational and clinical research that moves us closer to preventative strategies and treatments, and identify interventions that may reduce caregiver stress and burden. Two FOAs addressing clinical research (PAR-16–364 and PAR-16–365) were issued in October 2015 to stimulate both early and late-phase clinical trials, and many promising new therapies are moving into clinical testing.

In addition, the caregiver FOAs issued by NIA and National Institute of Nursing Research in September 2015 (PAR-15–348 and PAR-15–351) solicit research that will increase understanding of the needs of individuals with AD/ADRD, and their caregivers. These FOAs also encourage research that will lead to the development of efficacious financial planning interventions aimed at anticipating costs of LTSS.

Recommendation 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.dfaamerica.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/ADRD 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.
ACL Response

ACL, through its ADI-SSS and ADSSP cooperative agreements, continues to use available federal funding to provide states and localities with opportunities to implement projects that include dementia-friendly community components.

HRSA Response

*In Response to Recommendation 8.b.* HRSA is also working with federal partners at ACL, CDC, CMS, and VA on a contract to develop a Uniform Curriculum to build a workforce with the skills to provide high-quality care, ensure timely and accurate diagnosis, and identify high-quality dementia care guidelines and measures across care settings.

Recommendation 9

The 2016 National Plan should convene a national dementia care and services research summit. Build on existing work to identify research priorities related to improving early detection and diagnosis of AD/ADRD, providing care and services to persons with dementia and family caregivers, and providing recommendations as to standards of care, best practices and priorities.
Combined Federal Response

The federal agencies are working together and with the appointed Steering Committee to support the development and implementation of a National Research Summit on Care and Services for Persons with Dementia, Family Members, and Caregivers.

Recommendation 10

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

a. Increase the number of states with an identified state lead entity for AD/ADRD 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/ADRD 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.
ACL Response

ACL continues to make federal funding available to promote new dementia-capable service systems across the country, expand existing systems, and foster evidence-based approaches to serving special populations at risk of acquiring dementia. Other recommendations in this section would require changes to federal law or appropriations.

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 the racial and ethnic minorities who are at increased risk of acquiring AD/ADRD.

CMS Response

CMS supports person-centered and family-centered care (see CMS Quality Strategy). In Medicaid, CMS permits states to electively offer self-directed services to beneficiaries who are eligible for their HCBS programs. To implement Medicaid HCBS programs, states are required to provide CMS with performance measures tailored within the HCBS quality framework. CMS, with other HHS operating divisions, is working with NOF to begin the process of understanding more about quality measurement gaps in HCBS. CMS has also issued a Notice of Proposed Rulemaking, CMS 3260-P that, among other improvements, outlines proposed requirements for cultural competence in long-term care facilities.

*In Response to Recommendation 10.a.* CMS does most of its work at the state level on LTSS including services to elderly and disabled beneficiaries, through the Medicaid program, as Medicaid covers certain institutional and HCBS to eligible beneficiaries. CMS agrees that the involvement of state Medicaid agencies is important in coordinating programs and policies that impact individuals with AD/ADRD, and its state partners design some programs by “targeting” beneficiaries with certain conditions. CMS approves aspects of the Medicaid state plan including waivers that are submitted by states.

*In Response to Recommendation 10.b.* CMS works regularly with the listed national partners and others on many issues related to LTSS in Medicare and Medicaid including HCBS, nursing facility care, quality improvement, caregiving, and other topics that impact people with AD/ADRD.
Recommendation 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.

HRSA Response

In Response to Recommendation 11.b and 11.d. HRSA is partnering with federal partners, public and private entities, the health care provider community, and community organizations that provide LTSS to effectively educate physicians and other health care providers, direct services workers, and patients, families, and caregivers about support resources and services available to assist people with AD/ADRD and their caregivers.

NIH Response

NIH considers research on caregivers to be a high priority and two FOAs (PAR–15–348 and PAR–15–351) were released in September 2015 to promote research on this topic. Both of these FOAs address many of the research recommendations noted above, by focusing on developing interventions that apply across the full care continuum; defining caregiving and assessing the impact of formal and informal care over the trajectory of AD/ADRD; addressing palliative care needs and supporting caregivers in their role as surrogate decision makers; and developing financial planning interventions aimed at anticipating costs of LTSS and palliative care.

One of these FOAs (PAR–15–351) specifically addresses the need identified in the recommendations above to expand evidence–based and evidence–informed programs, by encouraging randomized trials for comparative effectiveness research on AD/ADRD caregiver interventions, as well as partnerships with community organizations, particularly those that have potential to deliver programs at regional or national scale.
ACL Response

In Response to Recommendation 11.a. People in the early stages of dementia and family caregivers of those with the condition are able to participate in chronic disease self-management education programs under ACL grants to state agencies, non-profit organizations, universities, and others. ACL encourages program outreach to these populations.

CMS Response

In Response to Recommendation 11.a. Medicare may pay for a health care professional's assistance in preparing and monitoring a comprehensive care plan tailored to a beneficiary's needs if the person has two or more chronic conditions through the Chronic Care Management Service. In Medicaid, states may optionally establish under the state plan Health Homes for Medicaid beneficiaries with two or more chronic conditions, or those at risk for a second chronic condition.

In Response to Recommendation 11.b. Beneficiaries may have a representative of their choosing who has access to information and participates in health care discussions with their knowledge and consent, as well as a legal representative if they are unable to make their own decisions. Advance Care Planning is covered as an optional element of the Medicare AWP. The agency supports person-centered care, including independent facilitation. Contributors to the care plan are chosen by the beneficiary.

In Response to Recommendation 11.e. In both Medicare and Medicaid, the service (and the billing code) is specific to the enrolled beneficiary, not a caregiver (unless the caregiver is also a beneficiary, and he/she is eligible for a covered benefit).

CMS Response Continued

In Response to Recommendation 11.f. Medicare beneficiaries also have the option, where available, of participating in Advance Care Planning, to design an advance directive. CMS, through the Center for Medicaid and CHIP Services (CMCS), is presently working with nine states to create and test a structured, longitudinal, person-centered eLTSS plan for beneficiaries receiving HCBS. The eLTSS plan is to be exchanged electronically across multiple HCBS and institutional settings, and with beneficiaries and payers.

In Response to Recommendation 11.g. CMS periodically has opportunities for states and other entities to apply for demonstration and grant programs and other special funding mechanisms through the CMMI, and other centers. CMMI is focused on testing new payment and service delivery models, and evaluating and sharing the results. 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.
Recommendation 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/ADR and their caregivers.

c. Assess and share findings on the impact of states' managed LTSS systems on individuals with AD/ADR and their caregivers.

CMS Response

In Response to Recommendation 12.a. CMS requires that providers be qualified to render covered, medically necessary services in both Medicare and Medicaid. Medicaid will not reimburse training costs for an individual or entity to become a qualified provider. However, costs associated with continuing education and training for Medicaid providers are allowable administrative service expenses. States have some flexibility within Medicaid to approach CMS to develop such programs and rates. In long-term care facilities, the Affordable Care Act requires dementia management training as part of the 12 hours per year in-service training for nurse aides.

In Response to Recommendation 12.b. CMS is monitoring implementation of the HCBS Final Rule on states and their HCBS systems. However, CMS has no mechanism to assess and share findings on the impact of the final rule on beneficiaries with dementia, specifically, or their caregivers. CMS encourages states to apply for programs that serve beneficiaries with particular conditions, and provides technical assistance during the development process.

In Response to Recommendation 12.c. CMS issued a comprehensive Final Rule in May 2016 for Medicaid that unifies flexible requirements across managed care authorities and recognizes that managed care is key to the provision of LTSS.
HRSA Response

In Response to Recommendation 12.a. As part of HRSA’s GWEP, awardees educate and train caregivers. Since the start of the program in July 2015, approximately 13,384 caregivers have received training on a variety of topics.

NIH Response

Another separate funding opportunity (PAR-15-350) released in September 2015 also encourages LTSS research, but with a specific focus on understanding health disparities in access to and utilization of LTSS for those with dementia and caregivers.

In addition to releasing these program solicitations, NIH staff has been engaged in discussions about the best approach to take with respect to developing a research summit focused on care and services. NIH will take the Advisory Council’s recommendations regarding topics to consider for future research under advisement as it helps to plan this research summit, when it next revises its research milestones, and as it develops future Bypass Budgets for Alzheimer’s Disease and Related Dementias.