

# National Plan to Address Alzheimer's Disease: 2018 Update



U.S. Department of Health and Human Services

# National Plan to Address Alzheimer's Disease: 2018 Update



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## Introduction

### National Alzheimer's Project Act

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On January 4, 2011, the National Alzheimer's Project Act (NAPA) (Public Law 111-375) was signed into law. The Act defines "Alzheimer's" as Alzheimer's disease and related dementias (AD/ADRD) and requires the Secretary of the U.S. Department of Health and Human Services (HHS) to establish the National Alzheimer's Project to:

- Create and maintain an integrated National Plan to overcome Alzheimer's disease;
- Coordinate Alzheimer's disease research and services across all federal agencies;
- Accelerate the development of treatments that would prevent, halt, or reverse the course of Alzheimer's disease;
- Improve early diagnosis and coordination of care and treatment of Alzheimer's disease;
- Decrease disparities in Alzheimer's disease for racial and ethnic minority populations that are at higher risk for Alzheimer's disease; and,
- Coordinate with international bodies to fight Alzheimer's disease globally.

The law also establishes the Advisory Council on Alzheimer's Research, Care, and Services (Advisory Council) and requires the Secretary of HHS, in collaboration with the Advisory Council, to create and maintain a National Plan to overcome AD/ADRD.

NAPA offers a historic opportunity to address the many challenges facing people with AD/ADRD and their families. Given the great demographic shifts that will occur over the next 30 years, including the doubling of the population of older adults, the success of this effort is of great importance to people with AD/ADRD and their family members, caregivers, public policy makers, and health and social service providers.

### Alzheimer's Disease and Related Dementias

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Alzheimer's disease (AD) is an irreversible, progressive brain disease that affects as many as 5.5 million Americans.<sup>1</sup> It slowly destroys brain function, leading to cognitive decline (e.g., memory loss, language difficulty, poor executive function), behavioral and psychiatric disorders (e.g., depression, delusions, agitation), and declines in functional status (e.g., ability to engage in activities of daily living (ADLs) and self-care).<sup>2</sup> In 1906, Dr. Alois Alzheimer first documented the disease when he identified changes in the brain tissue of a woman who had memory loss, language problems, and unpredictable behavior. Her brain tissue included abnormal clumps (amyloid plaques) and tangled bundles of fibers (neurofibrillary tangles). Brain plaques and tangles, in addition to the loss of connections between neurons, are the main pathological features of AD.<sup>3</sup> However, other pathologic features occur commonly in the brain of older Americans diagnosed with AD and these are thought to also contribute to the burden of dementia in the United States.<sup>4,5</sup>

In addition to AD, this National Plan addresses Alzheimer's Disease and Related Dementias (ADRD) consistent with the approach Congress used in NAPA. ADRD include frontotemporal dementia (FTD), Lewy body dementia (LBD), vascular contributions to cognitive impairment and dementia (VCID), and mixed dementias -- especially AD mixed with cerebrovascular disease or Lewy bodies. It is often difficult to distinguish between AD and ADRDs in terms of clinical presentation and diagnosis. Some of the basic neurodegenerative processes have common pathways. People with these forms of dementia and their families and caregivers face similar challenges in finding appropriate and necessary medical care and community-based services. As such, many of the actions described in this plan are designed to address these conditions collectively.

The first symptom of AD, and sometimes ADRD, is often memory impairment. However, in ADRD, poor attention and executive function, behavioral disorders, visual disturbances, sleep disruption or motor

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symptoms can often be the presenting symptoms. As the disease progresses, memory can decline, and other functions like language skills and decision making become more difficult. Personality and behavior changes often occur. Over time, a person with the disease may no longer recognize family and friends. Eventually, persons who survive with AD/ADR are completely reliant on others for assistance with even the most basic ADLs, such as eating.<sup>6,7</sup>

In more than 90% of people with AD/ADR, symptoms do not appear until after age 60, and the incidence of the disease increases with age. The causes of AD/ADR are not completely understood, but researchers believe they include a combination of genetic, environmental, and lifestyle factors.<sup>6</sup> The importance of any one of these factors in increasing or decreasing the risk of developing AD/ADR may differ from person to person. In rare cases, known as early or younger-onset dementia, people develop symptoms in their 30s, 40s, or 50s. A significant number of people with Down syndrome develop dementia in their 50s, often placing increased burden on their families and caregivers.

AD/ADR is a major public health issue and will increasingly affect the health and well-being of the population. Unless the diseases can be effectively treated or prevented, the number of Americans with AD/ADR will increase significantly in the next two decades. The Bureau of the Census estimates that the number of people age 65 and older in the United States will almost double, to 88 million by 2050. The prevalence of people with AD/ADR doubles for every 5-year interval beyond age 65. Without a preventive treatment or cure, the significant growth in the population over age 85 that is estimated to occur between 2015 and 2050 (from 6.3 million to 19 million) suggests a substantial increase in the number of people with AD/ADR.

Significant emotional, physical, and financial stress is placed on individuals with AD/ADR and their family members. Unpaid caregivers, such as family members and friends, provide the majority of care for people with AD/ADR in the community. Unpaid caregivers often do not identify themselves as such; they may be a wife, daughter, husband, parent, son, or friend helping a person whom they care about. However, the intensive support required for a person with AD/ADR can negatively impact the caregiver's emotional and physical health and well-being, and their ability to work. Unpaid caregivers often report symptoms of depression and anxiety, and they have poorer health outcomes than their peers who do not provide such care.<sup>7</sup>

Dementia care costs are significant and often a burden to families and others providing unpaid care. Recent estimates from one nationally representative study found that paid and unpaid care costs for people older than age 70 with dementia in the United States in 2010 were between \$159 billion and \$215 billion. These figures include direct medical expenditures, costs for long-term services and supports (LTSS) including institutional and home and community-based services (HCBS), and two different estimates of the value of unpaid care provided by family members and friends. These costs could rise dramatically with the increase in the numbers of older adults in coming decades. Care costs per person with dementia in 2010 ranged from \$75,000 to \$83,000 depending on how unpaid care costs were estimated.<sup>8</sup> These national dementia care costs are comparable to, if not greater than, those for heart disease and cancer.<sup>9</sup>

Caring for people with the disease also strains health and long-term care systems. Individuals with AD/ADR use a disproportionate amount of health care resources; for instance, they are hospitalized 2-3 times as often as people of the same age who do not have the disease.<sup>10</sup> Similarly, estimates from national data show that nearly seven out of ten residents in assisted living residences have some form of cognitive impairment.<sup>11</sup> As the number of people with AD/ADR grows over the next 3 decades, these diseases will place a major strain on these care systems as well as on Medicare and Medicaid, the major funders of institutional, clinical care, and HCBS. Although Medicaid, a program for eligible low income Americans, covers long-term care such as nursing home care and HCBS, Medicare does not. Most Americans underestimate the risk of disability and the need for long-term care. More than half of older adults turning 65 today will develop a disability such as AD/ADR serious enough to require LTSS, although most will need assistance for less than 2 years. About one in seven will have a disability for more than 5 years. On average, an American turning 65 today will incur \$138,000 in future LTSS costs.

Families will pay about half of the costs themselves out-of-pocket, with the rest covered by current public programs and private insurance.<sup>12</sup>

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## The Challenges

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The National Plan was designed to address the major challenges presented by AD/ADR:

1. While research on AD/ADR has made steady progress, there are no pharmacological or other interventions to definitively prevent, treat, or cure the diseases.
2. While HHS and other groups have taken steps to develop quality measures to assess dementia care and to improve the training of the health and long-term care workforce -- for both paid and unpaid caregivers -- there is room for improvement.
3. Family members and other unpaid caregivers, who take on the responsibility of caring for a loved one with AD/ADR, also need services and supports. The majority of people with AD/ADR live in the community, where their families provide most of their care. The toll of caregiving can have major implications for caregivers and families as well as population health, with about one-third of caregivers reporting symptoms of depression.<sup>11,13</sup>
4. Stigmas and misconceptions associated with AD/ADR are widespread and profoundly impact the care provided to and the isolation felt by people with AD/ADR and their families and caregivers.
5. Public and private sector progress is significant but should be coordinated and tracked. In addition, data to track the incidence, prevalence, trajectory, and costs of AD/ADR are limited.

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## Framework and Guiding Principles

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The enactment of NAPA provided an opportunity to focus the Nation's attention on the challenges of AD/ADR. In consultation with stakeholders both inside and outside of the Federal Government, this National Plan represents the blueprint for achieving the vision of a nation free of AD/ADR.

Central to and guiding the National Plan are the people most intimately impacted by AD/ADR -- those who have the diseases and their families and other caregivers. Individuals with AD/ADR and their caregivers receive assistance from both the clinical health care system and long-term care including HCBS, legal services, and other social services. Both the clinical care and community/support environments need better tools to serve people with AD/ADR and their unpaid caregivers. Ongoing and future research seeks to identify interventions to assist clinicians, supportive service providers, HCBS providers, persons living with dementia, and caregivers. All of these efforts must occur in the context of improved awareness of the diseases and its impacts, and the opportunities for improvement. The Plan aims to address these key needs. HHS is committed to tracking and coordinating the implementation of NAPA and making improvements aimed at achieving its ambitious vision.

The National Plan continues to be guided by three principles:

1. **Optimize Existing Resources, and Improve and Coordinate Ongoing Activities.** The first step in developing the National Plan was to set up a federal interagency working group and conduct an inventory of all federal activities involving AD/ADR. In creating the Plan, HHS and its partners sought to leverage these resources and activities, improve coordination, and reduce duplication of efforts to better meet the challenges of AD/ADR. The activities included in the inventory comprise ongoing work and new opportunities created by legislation and authority. The federal working group process continues to improve coordination and awareness throughout the
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Federal Government and set in motion commitments for further collaboration. Further, this process has allowed for identification of non-AD-specific programs and resources that may be leveraged to advance AD/ADRD care and prevention.

2. **Support Public-Private Partnerships.** The scope of the problem of AD/ADRD is so great that partnerships with a multitude of public and private stakeholders are essential to making progress. The original National Plan began the partnership process by identifying areas of need and opportunity. The Plan continues to rely on the Advisory Council in particular to identify key areas where public-private partnerships can improve outcomes.
3. **Transform the Way We Approach Alzheimer's Disease and Related Dementias.** The National Plan recognizes that this undertaking will require continued, large-scale, coordinated efforts across the public and private sectors. With principles 1 and 2 above, as well as the ambitious vision that the Federal Government has committed to through this Plan, HHS and its federal partners seek to take the first of many transformative actions that will be needed to address these diseases. Through an ongoing dialogue with the Advisory Council, the Federal Government continues to identify the most promising areas for progress and marshal resources from both within and outside the government to act on these opportunities.

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## Goals as Building Blocks for Transformation

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Achieving the vision of eliminating the burden of AD/ADRD starts with concrete goals. Below are the five that form the foundation of the National Plan:

1. Prevent and Effectively Treat Alzheimer's Disease and Related Dementias by 2025.
2. Enhance Care Quality and Efficiency.
3. Expand Supports for People with Alzheimer's Disease and Related Dementias and their Families.
4. Enhance Public Awareness and Engagement.
5. Track Progress and Drive Improvement.

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## 2018 Update

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This is the 2018 Update to the National Plan. The activities outlined in this National Plan Update vary in scope and impact, and include:

- Immediate actions that the Federal Government has taken and that it should take.
- Actions toward the goals that can be initiated by the Federal Government or its public and private partners in the near term.
- Longer-range activities that would require numerous actions by federal and non-federal partners to achieve.

This is a National Plan, and active engagement of public and private sector stakeholders is needed to achieve the goals. In the case of many of the activities, the path forward will be contingent on resources, scientific progress, and focused collaborations across many partners. Over time, HHS will work with the Advisory Council and stakeholders to incorporate additional transformative actions.

Unlike the National Plan updates of the previous 2 years, this Update does not include the recommendations made in 2018 by the Advisory Council. Because the recommendations were not available in their final form at the time of publishing this Update, they will be responded to in the course of the upcoming year via Advisory Council meetings. Fulfilling the recommendations is contingent on limitations on legislative authority, resources, and data among the federal agencies and the Federal Government. The recommendations can be found on the NAPA website once they are completed.

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## Goal 1: Prevent and Effectively Treat Alzheimer’s Disease and Related Dementias by 2025

Research continues to expand our understanding of the causes of, treatments for, and prevention of AD/ADRD. This goal seeks to develop effective prevention and treatment modalities by 2025. Ongoing research and clinical inquiry can inform our ability to delay onset of AD/ADRD, minimize its symptoms, and delay its progression. Under this goal, HHS will prioritize and accelerate the pace of scientific research and ensure that as evidence-based solutions are identified they are quickly translated, put into practice, and brought to scale so that individuals with AD/ADRD can benefit from increases in scientific knowledge. HHS will identify interim milestones and set ambitious deadlines for achieving these milestones in order to meet this goal.

### Strategy 1.A: Identify Research Priorities and Milestones

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Research agencies undertake research planning processes on an ongoing basis, but a special effort is needed to identify the priorities and milestones to achieve Goal 1. The actions below will identify the priorities, establish milestones, and ensure that appropriate stakeholders are involved in the planning process aimed at minimizing AD/ADRD as a health burden by 2025. During the course of this work, National Institutes of Health (NIH) and partner agencies will develop research priorities, and a plan for implementing each phase of research in a coordinated manner.

#### **(UPDATED) Action 1.A.1: Regularly convene an Alzheimer’s disease research summit to update priorities**

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In the spring of 2018, the NIH Alzheimer’s Disease Research Summit 2018: Path to Treatment and Prevention expanded on the research agenda set in place at the first two of such summits held in 2012 and 2015. The 2018 gathering brought hundreds of experts in AD and other chronic diseases together to identify critical knowledge gaps and set priorities for the kinds of new resources, infrastructure, and multi-stakeholder partnerships needed to fully realize emerging research opportunities.

For more information, see:

- <https://www.nia.nih.gov/research/nih-ad-summit-2018-program-agenda>
- <https://www.nia.nih.gov/alzheimers/milestones>

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#### **(UPDATED) Action 1.A.2: Solicit public and private input on Alzheimer’s disease research priorities**

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National research summits (including the Alzheimer’s Disease Research Summit, Alzheimer’s Disease-Related Dementias Summit, and National Research Summit on Care, Services, and Supports for Persons with Dementia and their Caregivers, on a rotating basis) are held yearly to gather scientific input. These larger meetings take place in addition to smaller workshops, scientific gatherings, and requests for information which help gather community input. These contributions all factor into NIH’s research plan for the 2025 goal, which is outlined as a series of research implementation milestones. This planning process and its systematic updates have informed the research community about NIH’s interests and priorities in funding projects in AD/ADRD.

For more information, see:

- <https://www.nia.nih.gov/alzheimers/milestones>
  - <https://www.nia.nih.gov/research/administration/recommendations-nih-ad-research-summit-2018>
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- <https://aspe.hhs.gov/basic-report/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers-final-summit-report>
  - <https://aspe.hhs.gov/alzheimers-disease-related-dementias-adrd-summit-2016-prioritized-research-milestones>
  - <https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers>
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**(ONGOING) Action 1.A.3: Regularly update the National Plan and refine Goal 1 strategies and action items based on feedback and input**

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HHS and its federal partners will use the input received through the Research Summits on AD, ADRD, and now Care and Services to inform implementation of the National Plan. An updated Goal 1 will reflect the priorities, milestones, and timeline elements identified through these processes to accelerate research in this area. These will be incorporated into the next iteration of the National Plan and will be updated on an annual basis with the input of the Advisory Council.

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**(ONGOING) Action 1.A.4: Update research priorities and milestones**

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To ensure that the research priorities and milestones reflect the broad input of the scientific community and the public, one Advisory Council meeting per year will be focused on this area. A relevant subcommittee focused on research or Goal 1 will collect input and recommend priorities and milestones for consideration by the Advisory Council as official recommendations. As appropriate, researchers in the field will also be invited to present at these meetings.

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**(UPDATED) Action 1.A.5: Create a timeline with milestones for achieving Goal 1**

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Since the advent of the National Plan, NIH's planning process for research on AD/ADRD has expanded in inclusion and scope among NIH Institutes and Centers and stakeholders across the scientific and care communities. Hearing a diversity of expertise and opinions is critical to updating research recommendations based on an open review of scientific progress. It also ensures prioritization based on important scientific questions that must be answered to advance our understanding of these complex disorders and helps identify how federal and other public and private organizations can most effectively collaborate to address research priorities. Ultimately, the consultations and recommendations from the various research summits result in the formation and/or update of implementation research milestones that set forth activities through fiscal year (FY) 2025 to address the ultimate goals of the National Plan. The latest of these updates took place after the third Alzheimer's Disease Research Summit in April 2018.

For more information, see:

- <https://www.nia.nih.gov/alzheimers/milestones>
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**(ONGOING) Action 1.A.6: Regularly convene an Alzheimer's disease and related dementias summit to review progress on research recommendations, and refine and add new recommendations as appropriate, based on recent scientific discoveries**

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The National Institute of Neurological Disorders and Stroke (NINDS) is planning the third ADRD Summit which will be held on March 14-15, 2019. As in the past, researchers, clinicians, patients, caregivers, families, and advocates will gather to assess scientific progress and update and/or generate ADRD research recommendations. NIH continuously develops research initiatives and activities to address the research priorities identified through the previous ADRD Summits in 2013 and 2016.

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For more information see:

- <https://aspe.hhs.gov/alzheimers-disease-related-dementias-adrd-summit-2016-prioritized-research-milestones>
- <https://www.ninds.nih.gov/News-Events/Events-Proceedings/Events/Alzheimers-Disease-Related-Dementias-Summit-2016>
- <https://www.ninds.nih.gov/About-NINDS/Strategic-Plans-Evaluations/Strategic-Plans/Alzheimers-Disease-Related-Dementias>

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**(COMPLETED) Action 1.A.7: Convene a workshop to examine the special needs of people with Down syndrome, who are at high risk for developing Alzheimer’s disease and related dementias**

To better understand AD in people at risk for developing the condition, NIH supported the *Advancing Treatment for Alzheimer Disease in Individuals with Down Syndrome* workshop in April 2013 to identify research recommendations and priorities for this population. The workshop was co-sponsored by a number of agencies and organizations including The Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), the National Institute on Aging (NIA), NINDS, Down Syndrome Research and Treatment Foundation (DSRTF), and Research Down Syndrome (RDS). The workshop brought together approximately 50 stakeholders to discuss partnerships involving the AD and Down syndrome research community, efforts that have been sustained over the past 4 years. NIA and NICHD collaborated to produce and disseminate information for people with Down syndrome and their families on the interplay of these conditions and the importance of participating in research. Efforts include a fact sheet, “Alzheimer’s Disease in People with Down Syndrome”, and outreach via email and social media.

The *Alzheimer’s Biomarker Consortium -- Down Syndrome* aims to identify biomarkers that indicate AD is developing or progressing and track the AD process in people with Down syndrome. Additionally, NIA is currently funding a Phase I clinical trial to investigate the safety and tolerability of an immunotherapy vaccine for treatment of AD in adults with Down syndrome.

For more information, see:

- <https://www.nia.nih.gov/alzheimers/publication/alzheimers-disease-people-down-syndrome>
- <https://www.nia.nih.gov/alzheimers/alzheimers-biomarkers-consortium-down-syndrome-abc-ds>
- <https://health.ucsd.edu/news/releases/Pages/2016-01-13-clinical-trial-alzheimers-characteristics-in-down-syndrome.aspx>

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**(NEW) Action 1.A.8: Regularly convene a Research Summit on Care, Services, and Supports for Persons with Dementia and their Caregivers**

Driven by NAPA to expand research to support people living with dementia, the first-ever National Research Summit on Care, Services, and Supports for Persons with Dementia and their Caregivers was convened in October 2017. Hosted by NIH and led by the Office of the Assistant Secretary for Planning and Evaluation (ASPE) and the Advisory Council, the Summit aimed to set priorities for future care and caregiving research. The goal was to identify what we know and what we need to know to accelerate the development, evaluation, translation, implementation, and scaling up of comprehensive care, services, and supports for persons with dementia (PWD), families, and other caregivers. More than 1,000 people participated either in person or via videocast in the 2-day meeting. The meeting resulted in the generation of nearly 700 draft recommendations; summit leadership condensed these into 58 final recommendations. A final report, including these recommendations, was issued on April 27, 2018, and will help inform NIA investments and priority setting.

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For more information, see:

- <https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers>
  - <https://aspe.hhs.gov/pdf-report/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers-final-summit-report>
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## **Strategy 1.B: Expand Research Aimed at Preventing and Treating Alzheimer’s Disease and Related Dementias**

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HHS and its federal partners will expand clinical trials on pharmacologic and non-pharmacologic ways to prevent AD/ADRD and manage and treat its symptoms. The Federal Government will address the challenge of enrolling enough people in clinical trials who are representative of the country’s population, including racial and ethnic populations that are at higher risk for AD/ADRD, through new partnerships and outreach. These actions will build on ongoing research focused on the identification of genetic, molecular and cellular targets for interventions and build on recent advances in the field.

### **(UPDATED) Action 1.B.1: Expand research to identify the molecular and cellular mechanisms underlying Alzheimer’s disease and related dementias, and translate this information into potential targets for intervention**

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In the past year, NIA and NINDS have issued several funding opportunity announcements (FOAs) focused on research to help develop a better understanding of the growing list of genetic risk factors and molecular pathways that are involved in AD/ADRD. In response to these FOAs and investigator-initiated studies, researchers are developing a new generation of research tools to identify, explore, and validate a variety of targets with therapeutic potential. These sophisticated tools allow researchers to collect and integrate layers of biological data in novel ways -- opening the door to new insights into the origins and progression of AD/ADRD.

These new tools are also helping researchers gain a clearer picture of the complex underlying mechanisms of these devastating neurological disorders. They are leading to an understanding of the interplay among relevant molecules and systems, the relationship between amyloid and tau proteins, the role of immunity and inflammation, and the involvement of metabolic and cardiovascular pathways. This broader view of the basic biology of AD/ADRD could lead to potential breakthroughs.

For more information, see:

- <https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-001.html>
  - <https://grants.nih.gov/grants/guide/pa-files/PAR-18-029.html>
  - <https://grants.nih.gov/grants/guide/pa-files/PAR-18-413.html>
  - <https://grants.nih.gov/grants/guide/pa-files/PAR-18-497.html>
  - <https://grants.nih.gov/grants/guide/pa-files/PAR-18-516.html>
  - <https://grants.nih.gov/grants/guide/pa-files/PAR-18-519.html>
  - <https://grants.nih.gov/grants/guide/pa-files/PAR-18-544.html>
  - <https://grants.nih.gov/grants/guide/pa-files/PAR-18-545.html>
  - <https://grants.nih.gov/grants/guide/pa-files/PAR-18-661.html>
  - <https://grants.nih.gov/grants/guide/pa-files/PAR-18-760.html>
  - <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-18-013.html>
  - <https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-18-015.html>
  - <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-18-020.html>
  - <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-18-021.html>
  - <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-18-022.html>
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- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-18-023.html>
- <https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-18-024.html>
- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-18-025.html>
- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-18-026.html>
- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-18-027.html>

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**(UPDATED) Action 1.B.2: Expand genetic epidemiologic research to identify risk and protective factors for Alzheimer’s disease and related dementias**

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Another key component in the growing toolkit of precision medicine for AD/ADRD is the Alzheimer’s Disease Sequencing Project (ADSP), an international resource of genetics data from multiple centers and studies. Launched in 2012, the ADSP is designed to promote innovative collaboration among scientists to provide genetic samples for sequencing with the goal of identifying from multi-ethnic populations new genetic variants that influence risk and protection from AD/ADRD. In 2017, NIA launched the ADSP Follow-Up Study, which aims to pursue rare variants in a range of different populations, including those that have been underrepresented in sequencing studies.

Leveraging the existing infrastructure of the ADSP, the Follow-Up Study aims to generate whole-genome sequence data in African American, Hispanic, American Indian and Alaska Native, and Asian populations. In addition to the ADSP Follow-Up Study, NIA has several ongoing FOAs that call for research to enhance the ability to uncover the genetic underpinnings of AD/ADRD, furthering our understanding of rare risk and protective variants.

To improve our understanding of geographic and racial disparities in cardiovascular and cerebrovascular risk factors that lead to cognitive impairment and dementia, NIH is supporting the Reasons for Geographic and Racial Differences in Stroke (REGARDS) study and the Northern Manhattan Study (NOMAS) which are diverse longitudinal cohort studies of African American or Black, and Hispanic or Latino participants. As the emerging scientific consensus recognizes the role of midlife cardiovascular and cerebrovascular health in cognitive outcomes, the research focus of these two studies has recently been expanded to include investigation of health disparities in risk factors for dementia, and how they relate to stroke risk factors.

To advance further discovery for genetic factors and molecular pathways involved in FTD, NIH is also supporting the FTD Sequencing Consortium. This genetics consortium is composed of researchers at universities in the United States and at NIH who are utilizing whole genome sequence technology to generate sequence for 4,000 autopsy-confirmed and clinical characterized FTD cases.

For more information, see:

- <https://www.niagads.org/adsp/content/home>
  - <https://www.niagads.org/>
  - <http://www.regardsstudy.org>
  - <https://northernmanhattanstudy.org/>
  - <https://grants.nih.gov/grants/guide/pa-files/PAR-15-356.html>
  - <https://grants.nih.gov/grants/guide/pa-files/PAR-16-047.html>
  - <https://grants.nih.gov/grants/guide/pa-files/PAR-16-205.html>
  - <https://grants.nih.gov/grants/guide/pa-files/PAR-16-371.html>
  - <https://grants.nih.gov/grants/guide/pa-files/PAR-16-406.html>
  - <https://grants.nih.gov/grants/guide/pa-files/PAR-17-214.html>
  - <https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-17-017.html>
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**(UPDATED) Action 1.B.3: Increase enrollment in clinical trials and other clinical research through community, national, and international outreach**

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Since 2016, with facilitation by the Alzheimer's Association and in close collaboration with experts from government, private, and academic sectors, NIA has led an effort to develop comprehensive goals and strategies to enhance recruitment into clinical research, particularly focusing on underrepresented communities. To ensure broader input, in 2018 NIA gathered feedback on the recruitment strategies through the IdeaScale crowdsourcing platform. The culmination of these efforts will be the forthcoming National Strategy for Recruitment and Participation in Alzheimer's Disease Clinical Research.

NIA continues to promote participation in AD/ADRD clinical trials, studies, and registries through its Alzheimer's Disease Education and Referral (ADEAR) website portal; clinical trials listing and monthly e-alert to more than 50,000 subscribers; social media messages through Facebook and Twitter; infographics; presentations; and promotion of the Recruiting Older Adults into Research (ROAR) toolkit of customizable materials for aging services and public health professionals to use in community settings and social media in English, Spanish, and Chinese; and collaboration with Administration for Community Living (ACL), Centers for Disease Control and Prevention (CDC), Food and Drug Administration (FDA) and the Patient-Centered Outcomes Research Institute (PCORI)-funded Alzheimer's and Dementia Patient/Caregiver-Powered Research Network to encourage research participation among older adults. NIA is also developing an online repository of planning tools, best practices, and materials to support researchers' recruitment and retention efforts.

Additionally in 2018, NIA released a new FOA -- Examining Diversity, Recruitment and Retention in Aging Research (PAR-18-749) -- to encourage building new, collaborative teams to target gaps in recruitment and retention methods and outcomes, as well as establishing the community infrastructure needed to accelerate studies.

For more information, see:

- <https://nia-research.ideascale.com/a/ideas/recent/campaign-filter/byids/campaigns/22646/stage/unspecified>
- <https://www.nia.nih.gov/research/recruitment-strategy>
- <https://www.nia.nih.gov/alzheimers/clinical-trials>
- <https://www.nia.nih.gov/health/publication/roar-toolkit>
- <https://grants.nih.gov/grants/guide/pa-files/PAR-18-749.html>

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**(UPDATED) Action 1.B.4: Monitor and identify strategies to increase enrollment of racial and ethnic minorities in Alzheimer's disease and related dementias studies**

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See 1.B.3 for updates regarding the National Strategy for Recruitment and Participation in Alzheimer's Disease Clinical Research that is currently under development. This strategy will include approaches to increase enrollment of racial and ethnic minorities in AD/ADRD studies. In April 2018, NIA released a new FOA -- Examining Diversity, Recruitment and Retention in Aging Research (PAR-18-749) -- to encourage building new, collaborative teams to target gaps in recruitment and retention methods and outcomes, as well as establishing the community infrastructure needed to accelerate recruitment.

Additionally, the National Institute on Minority Health and Health Disparities (NIMHD) has begun a new clinical trial on Addressing the Knowledge and Recruitment Gap in Alzheimer's Disease (AD) and Precision Medicine (PM) among Native People. An innovative pragmatic Randomized Controlled Trial, with 4,000 American Indian and Alaska Native enrollees as a part of the NIH All of Us program, with study will evaluate recruitment strategies for American Indians and Alaska Natives, create culturally tailored materials on AD-PM, evaluate the clarity and acceptability of the materials, and their effect on completion of the AD-PM Module and enrollment in the AD-PM

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Cohort, identify patient-level predictors of AD-PM cohort enrollment, and evaluate potential differences in the effectiveness of recruitment approach by age, sex, education, cultural identity, and rurality.

For more information, see:

- <https://www.nia.nih.gov/research/recruitment-strategy>
- <https://grants.nih.gov/grants/guide/pa-files/PAR-18-749.html>
- <https://www.nia.nih.gov/news/new-nih-consortium-award-enhance-clinical-trials-alzheimers-disease-related-dementias>
- [https://projectreporter.nih.gov/project\\_info\\_description.cfm?aid=9570695&icde=41152371&ddparam=&ddvalue=&ddsub=&cr=2&csb=default&cs=ASC&pball](https://projectreporter.nih.gov/project_info_description.cfm?aid=9570695&icde=41152371&ddparam=&ddvalue=&ddsub=&cr=2&csb=default&cs=ASC&pball)

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#### **(UPDATED) Action 1.B.5: Conduct clinical trials on the most promising pharmacologic interventions**

Launched in 2017, a new clinical trials consortium funded by NIA is expected to accelerate and expand studies for therapies in AD/ADRD. The new NIA-funded Alzheimer's Clinical Trials Consortium (ACTC) will develop and implement cutting-edge participant recruitment and retention strategies, especially in diverse populations and establish a new minority outreach and recruitment team. ACTC is a "next-generation" infrastructure designed to harness best practices and latest methods for Alzheimer's trials.

The ACTC's design allows rapid start-up of clinical trials and provides infrastructure and support in areas such as imaging, biostatistics, data management, and recruitment. It also requires and supports sharing of data and biosamples. With the current funding announcement, NIH anticipates applications to develop and implement Phase I to Phase III clinical trials that would use ACTC coordination and management for promising pharmacological and non-pharmacological interventions.

In addition to the ACTC infrastructure, NIH currently sponsors approximately 140 active trials of interventions to enhance cognitive health in older adults and to prevent, treat, or manage AD/ADRD. NIH also released several FOAs specifically focused on clinical trials for AD/ADRD. These include pharmacologic as well as lifestyle interventions.

For more information, see:

- <https://www.nia.nih.gov/news/new-nih-consortium-award-enhance-clinical-trials-alzheimers-disease-related-dementias>
- <https://www.nia.nih.gov/research/ongoing-AD-trials>
- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-18-031.html>
- <https://grants.nih.gov/grants/guide/pa-files/PAR-18-028.html>
- <https://grants.nih.gov/grants/guide/pa-files/PAR-18-175.html>
- <https://grants.nih.gov/grants/guide/pa-files/PAR-18-513.html>

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#### **(UPDATED) Action 1.B.6: Continue clinical trials on the most promising lifestyle interventions**

See 1.B.5 for updates regarding the ACTC and ongoing clinical trials supported by NIA. Many of the approximately 140 active trials of interventions to enhance cognitive health in older adults and to prevent, treat, or manage AD/ADRD include testing lifestyle interventions such as diet and exercise. NIA has also released several FOAs specifically focused on clinical trials for AD/ADRD.

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For more information, see:

- <https://www.nia.nih.gov/news/new-nih-consortium-award-enhance-clinical-trials-alzheimers-disease-related-dementias>
- <https://www.nia.nih.gov/research/ongoing-AD-trials>
- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-18-031.html>
- <https://grants.nih.gov/grants/guide/pa-files/PAR-18-028.html>
- <https://grants.nih.gov/grants/guide/pa-files/PAR-18-175.html>
- <https://grants.nih.gov/grants/guide/pa-files/PAR-18-513.html>

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### **(NEW) Action 1.B.7: Expand research focused on needs related to the intersection of Down syndrome and Alzheimer’s disease and related dementias**

The FY 2018 omnibus appropriations report provided NIH with the opportunity to not only expand its current efforts on Down syndrome and AD/ADRD, but to build an integrated effort across NIH that will be truly transformative in this area and other commonly co-occurring conditions in individuals with Down syndrome. The INCLUDE (INvestigation of Co-occurring conditions across the Lifespan to Understand Down syndromE) project was launched in June 2018 in support of a congressional directive. INCLUDE will focus on three overall goals: (1) conducting targeted, high-risk, high-reward basic science studies on chromosome 21; (2) assembling a large study population of individuals with Down syndrome; and (3) including individuals with Down syndrome in existing clinical trials.

NIA and NICHD have been funding an Alzheimer’s Biomarker Consortium -- Down Syndrome since 2015, which aims to identify biomarkers that indicate AD is developing or progressing and track the AD process in people with Down syndrome. NIA is also funding a Phase I clinical trial to investigate the safety and tolerability of an immunotherapy vaccine for treatment of AD in adults with Down syndrome.

NIA and NICHD have also collaborated to produce and disseminate information for people with Down syndrome and their families regarding the interplay of Down syndrome and dementia, and the importance of participating in research. Efforts include a fact sheet, “Alzheimer’s Disease in People with Down Syndrome”, and outreach via email and social media.

For more information, see:

- <https://www.nih.gov/include-project>
- <https://www.nia.nih.gov/alzheimers/alzheimers-biomarkers-consortium-down-syndrome-abc-ds>
- <https://health.ucsd.edu/news/releases/Pages/2016-01-13-clinical-trial-alzheimers-characteristics-in-down-syndrome.aspx>
- <https://www.nia.nih.gov/alzheimers/publication/alzheimers-disease-people-down-syndrome>

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### **Strategy 1.C: Accelerate Efforts to Identify Early and Presymptomatic Stages of Alzheimer’s Disease and Related Dementias**

Significant advances in the use of imaging and biomarkers in brain, blood, and spinal fluid have made it possible to detect the onset of AD/ADRD and track its progression, with the hope that it will be possible to monitor the effect of treatment in people with the disease. Without these advances, these neurodegenerative processes could only be evaluated in non-living tissues. Accelerated research will improve and expand the application of biomarkers in research and practice. These advances have shown that the brain changes that lead to AD/ADRD begin up to 10 years before symptoms. Identifying

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imaging and other biomarkers in presymptomatic people will facilitate earlier diagnoses in clinical settings, as well as aid in the development of more efficient interventions to slow or delay progression.

**(UPDATED) Action 1.C.1: Identify imaging and biomarkers to monitor disease progression**

The Alzheimer's Disease Neuroimaging Initiative (ADNI) has contributed to much progress in neuroimaging and biomarker refinement. ADNI, a long-running, NIH-supported study, was designed to develop tools for clinical trials by tracking how neuroimaging and fluid biomarkers change with disease onset and progression. Launched by NIH in 2004, this landmark public-private partnership looks at how the evolution of clinical symptoms and neurocognitive testing in healthy controls, people with mild cognitive impairment (MCI), and people with mild AD correlates with changes in multiple biomarkers reflecting disease development. The biomarkers developed and validated in ADNI are being used more and more in clinical trials. ADNI has also pioneered rapid, transparent data-sharing while protecting participants' privacy. Qualified researchers across the world can access ADNI brain scan images and biomarker data through a web-based portal as soon as data are quality-controlled and added to the database. ADNI also shares the blood, cerebrospinal fluid, and DNA it has collected with other investigators who are developing novel biomarkers.

Additionally, the Accelerating Medicines Partnership-Alzheimer's Disease (AMP-AD) Biomarkers Project, a public-private partnership, is exploring the utility of tau PET imaging and novel fluid biomarkers for tracking response to treatment and/or disease progression. Under the Biomarkers Project, NIA-supported, Phase II/III secondary prevention trials are testing several anti-amyloid therapies. Through the AMP-AD partnership, imaging and fluid biomarker tests already included in these trials will be supplemented with tau PET imaging and novel fluid biomarkers. Screening and baseline data from the trials will be made broadly available through the Global Alzheimer's Association Interactive Network collaborative platform. Trial data and biological samples will also be shared after the trials are completed.

To enable better patient stratification, diagnosis, and tracking of disease progression in LBD, FTC, VCID, and dementias with mixed etiologies, NINDS has released funding opportunities to support the development of biomarkers, including imaging ligands, for ADRD. NIH continues to support a small vessel VCID Biomarkers Consortium (MarkVCID) to develop and validate candidate human biomarkers for small vessel disease in the brain that would enable more accurate identification of those at risk for long-term cognitive decline and tracking of disease progression in individuals already affected by cognitive impairment and dementia. To improve differential diagnosis of LBD, two NIH-funded research teams are leveraging existing data and biospecimens from patients with LBD that are housed in databases of large NIH-supported programs, the ADNI/National Alzheimer's Coordinating Center (NACC) and the Parkinson's Disease Biomarker Program. NIH is also continuing to support five research teams that aim to discover biomarkers that will improve the efficiency and outcome of Phase II clinical trials for LBD.

In addition to these large initiatives, NIA and NINDS have released several FOAs in the past year that call for research to further the development of imaging and biomarker research.

For more information, see:

- <http://adni.loni.usc.edu/>
- <https://markvcid.partners.org/>
- <https://www.nia.nih.gov/alzheimers/amp-ad>
- <https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-001.html>
- <https://grants.nih.gov/grants/guide/pa-files/PAR-18-519.html>
- <http://grants.nih.gov/grants/guide/pa-files/PAR-15-359.html>
- <https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-16-022.html>
- <https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-17-016.html>
- <https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-18-025.html>

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**(UPDATED) Action 1.C.2: Maximize collaboration among federal agencies and with the private sector**

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NIH engages in multiple partnership opportunities with the private sector and other federal agencies to facilitate collaborative efforts across the entire AD/ADRD research landscape. ADNI and AMP-AD, discussed above, are two large examples of these partnerships.

Another example is the Collaboration for Alzheimer's Prevention (CAP). CAP is a public-private partnership that brings together research groups to harmonize biomarker, clinical, and cognitive measures and align data-sharing and sample-sharing approaches used in certain trials so that findings can inform the entire research community. CAP includes researchers from three trials co-funded by NIH, industry, and foundations: the Alzheimer's Prevention Initiative, the Anti-Amyloid Treatment in Asymptomatic Alzheimer's Disease study, and the Dominantly Inherited Alzheimer Network Trials Unit. Collaborative efforts like CAP provide an effective platform for implementation of AD research standards and advancing AD prevention research with rigor, care, and maximal impact.

Tau Center Without Walls (CWOW) is a multi-center, interdisciplinary program that was established in FY 2016 to investigate the molecular mechanisms of tau toxicity in FTD. One of the requirements of this program is to have ongoing collaborative partnerships with non-profit non-governmental organizations and philanthropic entities, such as the Association for Frontotemporal Degeneration (AFTD), Cure PSP, and the Rainwater Charitable Foundation.

Also, the International Alzheimer's and Related Dementias Research Portfolio (IADRP) facilitates the tracking of research support in the public and private sectors, including the initiatives mentioned above.

For more information, see:

- <http://adni.loni.usc.edu/>
- <https://iadrp.nia.nih.gov/>
- <https://www.nia.nih.gov/alzheimers/amp-ad>
- <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4847536/>
- <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5111162/>
- <https://iadrp.nia.nih.gov/>

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**Strategy 1.D: Coordinate Research with International Public and Private Entities**

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In order to facilitate communication and collaboration, build synergy, and leverage resources, it is imperative that research across nations and across funders be coordinated. The actions below will formalize the coordination process beyond HHS and the Federal Government and make research available to the public for input.

**(UPDATED) Action 1.D.1: Inventory Alzheimer's disease and related dementias research investments**

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IADRP -- a free, searchable database providing a global overview of AD/ADRD research and funding -- is an invaluable tool for assessing and planning AD/ADRD research projects. Funding organizations, researchers, and advocates are discovering IADRP's merits to help them coordinate strategies, leverage resources, avoid duplication, and identify promising areas of growth. Since NIH launched the database in 2012, in collaboration with the Alzheimer's Association, IADRP has amassed data on over 9,000 unique projects from 2008 through 2018,

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reflecting more than \$7 billion in research funding worldwide. The number of contributors is growing, too. During the past 5 years, more than 40 funding organizations across greater than ten countries have joined the IADRP effort.

In 2018 the IADRP database was relaunched with several changes to the Common Alzheimer's Disease Research Ontology (CADRO), including greater specificity in the coding of FTD, LBD, and VCID. Additionally, users can now link research to related clinical trials, patents and data repositories, as well as visualize search results with dynamic charts and graphs.

For more information, see:

- <https://iadrp.nia.nih.gov>
- <https://iadrp.nia.nih.gov/about/cadro>

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#### **(UPDATED) Action 1.D.2: Expand international outreach to enhance collaboration**

In collaboration with the European Union (EU) Joint Programme -- Neurodegenerative Research (JPND), NIH is participating in the upcoming EU mapping exercise that invites 20+ countries to submit their recently funded neurodegenerative research. This exercise will serve as a platform for increased collaboration among international dementia researchers and funding organizations.

In 2017, JPND launched a call on "Multinational research projects for Pathway Analysis across Neurodegenerative Diseases". At the same time, NIA released FOA PAS-17-028, "Common Mechanisms and Interactions Among Neurodegenerative Diseases (R01)". JPND and NIA plan to support crosscutting activities such as common workshops and data exchange and harmonization among the projects funded by JPND and NIA in response to these calls for applications.

Additionally, NIA participated in the Alzheimer's Disease Funders' meeting held during the 2017 Alzheimer's Association International Conference (AAIC) as well as quarterly international funders' calls led by the Alzheimer's Association. Also, IADRP, maintained by NIA, includes data from over 40 public and private funding organizations across more than ten countries and is publicly-available for use.

For more information, see:

- <http://www.neurodegenerationresearch.eu/initiatives/mapping-exercise/data-collected/>
- <http://www.neurodegenerationresearch.eu/initiatives/annual-calls-for-proposals/closed-calls/pathways-2017/>
- <https://grants.nih.gov/grants/guide/pa-files/PAS-17-028.html>
- <https://iadrp.nia.nih.gov>

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#### **(NEW) Action 1.D.3: Identify research priorities via surveys tracking health conditions and risk factors**

The Behavioral Risk Factor Surveillance System (BRFSS) is the world's largest, ongoing telephone health survey system, tracking health conditions and risk behaviors in the United States yearly since 1984. It is conducted by all states under the direction of the CDC with state public health authorities. Two special optional modules that states can include in their annual surveys are available on the topics of caregiving and cognitive impairment. Collecting and analyzing this data allows the study of burden, impact, and trends and is used by decision makers to decide course of action for research as well as interventions.

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## Strategy 1.E: Facilitate Translation of Findings into Medical Practice and Public Health Programs

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Currently, promising research and interventions are published in the research literature and presented at scientific meetings. Additional steps are needed to highlight promising findings and to facilitate dissemination and implementation of effective interventions to the general public, medical practitioners, the pharmaceutical industry, and public health systems, quickly and accurately.

### **(UPDATED) Action 1.E.1: Leverage public and private collaborations to facilitate dissemination, translation, and implementation of research findings**

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NIA continues to expand its efforts to educate clinicians about recent research findings; clinical practice tools for assessment, diagnosis and management of cognitive impairment; training materials; a patient checklist handout in English and Spanish, and other resources, which are available online in a mini-portal of resources for professionals.

For more information, see:

- <https://www.nia.nih.gov/health/alzheimers-dementia-resources-for-professionals>
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### **(UPDATED) Action 1.E.2: Continue to promote use of the Alzheimer's Disease Education and Referral Center to provide evidence-based information on Alzheimer's disease and related dementias to the public and others**

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NIA's ADEAR Center routinely disseminates information on AD/ADRD research findings through the NIA website, regular weekly and monthly email alerts to more than 50,000 subscribers, and social media (Twitter and Facebook). Progress in AD/ADRD research is also reported in the annual NIH Bypass Budget proposal.

For more information, see:

- <https://www.nia.nih.gov/alzheimers>
  - <https://www.nia.nih.gov/about/bypass-budget-proposal-archive>
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### **(ONGOING) Action 1.E.3: Issue guidance about drugs for early-stage Alzheimer's disease and related dementias**

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In February 2013, the FDA published a *Draft Guidance for Industry: Alzheimer's disease: Developing Drugs for the Treatment of Early Stage Disease* which discusses the Administration's current views on how trials in subjects with pre-dementia AD might be designed, conducted, and analyzed. The document also discusses a potential accelerated regulatory pathway for patients with the earliest stages of the disease. FDA published a final version of that guidance in 2014 that reflects feedback received from industry, academia, advocacy groups, physicians, and patients/caregivers.

In 2013, FDA endorsed a disease-modeling tool submitted by the Coalition Against Major Diseases for trials in mild-to-moderate AD that will enable sponsors to design more efficient trials in these populations.

In 2018-2019, FDA will continue to work with outside consortia to attempt to formally qualify (via the Drug Development Tool Qualification Process) both novel clinical endpoints as well as biomarkers for trial enrichment for use in AD trials.

For more information, see:

- <http://www.fda.gov/Training/GuidanceWebinars/ucm345077.htm>
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**(UPDATED) Action 1.E.4: Expand and disseminate research on co-occurring conditions and dementias**

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In January 2016, CDC released the Progress Report of public health Road Map action item accomplishment and next steps. In 2017, the development process of the third Road Map began that will identify action items for public health professionals related to cognitive health through 2023. The third Road Map will be released in late 2018.

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**(UPDATED) Action 1.E.5: Provide information to the public on brain health**

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On February 2, 2016, NINDS launched a public health campaign on the link between hypertension and cognitive decline for integration with the HHS Million Hearts Campaign. This campaign is still active.

The Brain Health Resource, a presentation toolkit on brain health as we age, was developed by ACL with scientific review by NIH and CDC for use at senior centers and in other community settings and was updated in 2018. Written in plain language, the evidence-based resource explains what people can do to help keep their brains functioning best. In 2016, the toolkit was expanded to include materials in Spanish and a new brain health module entitled “Medicine, Age, and your Brain”.

Additionally, the campaign, “What is Brain Health?” formerly managed by ACL was transferred to NIA in 2017. NIA also maintains a web portal on Cognitive Health and Older Adults.

For more information see:

- <https://mindyourrisks.nih.gov/>
- <https://www.nia.nih.gov/health/brain-health-resource>
- <https://brainhealth.nia.nih.gov/>
- <https://www.nia.nih.gov/health/cognitive-health>

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**(NEW) Action 1.E.6: Leverage public and private collaborations to facilitate dissemination, translation, and implementation of research findings**

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CDC is working with the American College of Preventive Medicine. A Curriculum is being developed to increase physician and health care professionals’ awareness of brain health as a serious health condition and to increase the number of physicians and health care professionals acting to address, diagnose, and refer patients with brain health issues to care and community support programs. The module will be included as an elective in the Lifestyle Medicine Core Competencies Online Program.

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**(NEW) Action 1.E.7: Facilitate translation of findings into public health practice**

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CDC has provided funds to the Alzheimer’s Association to co-develop the third in a series of Healthy Brain Initiative (HBI) Road Maps to advance cognitive health as an integral component of public health. This “Healthy Brain Initiative State and Local Public Health Partnerships to Address Dementia, The 2018-2023 Road Map” project, outlines how state and local public health agencies and their partners can continue to promote cognitive health, address cognitive impairment for people living in the community, and help meet the needs of caregivers. Twenty-five specific actions are proposed in four traditional domains of public health: educate and empower, develop policies and mobilize partnerships, assure a competent workforce, and monitor and evaluate.

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## Goal 2: Enhance Care Quality and Efficiency

Providing all people with AD/ADRD with the highest-quality care in the most efficient manner requires a multi-tiered approach. High-quality care requires an adequate supply of culturally-competent professionals with appropriate skills, ranging from direct care workers to community health and social workers to primary care providers and specialists. High-quality care should be provided from the point of diagnosis onward in settings including doctor's offices, hospitals, people's homes and nursing homes. Care quality should be measured accurately and coupled with quality improvement tools. Further, care should address the complex care needs that persons with AD/ADRD have due to the physical, cognitive, emotional, and behavioral symptoms of the disease and any co-occurring chronic conditions. High-quality and efficient care depends on: (1) smooth transitions between care settings; (2) coordination among health care and LTSS providers; and (3) dementia-capable health care and LTSS.

### Strategy 2.A: Build a Workforce with the Skills to Provide High-Quality Care

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The workforce that cares for people with AD/ADRD includes health care and LTSS providers such as primary care physicians; specialists such as neurologists, geriatricians, and psychiatrists; registered nurses and advanced practice nurses; community health workers; social workers; psychologists; pharmacists; dentists; allied health professionals; and direct care workers, home health aides, and certified nursing assistants, who provide care across the care continuum. These providers need accurate information about furnishing care to a person with AD/ADRD including the benefits of early diagnosis, how to address the physical, cognitive, emotional, and behavioral symptoms of the disease, and how to assist caregivers as they cope with the physical and emotional aspects of their caregiving responsibilities. Enhanced specialist training is also needed to prepare these practitioners for the unique challenges faced by people with AD/ADRD. In addition, work is needed to expand the capacity of the primary care community to serve people with AD/ADRD. Dementia-specific capabilities within the direct care workforce need to be expanded and enhanced. The actions below will facilitate specific training for care professionals in order to strengthen a workforce that provides high-quality care to people living with AD/ADRD.

#### **(UPDATED) Action 2.A.1: Educate health care providers**

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In FY 2017, Health Resources and Services Administration (HRSA) supported 44 Geriatrics Workforce Enhancement Program (GWEP) grantees totaling approximately \$38.7 million of which \$5.9 million was specifically budgeted to provide dementia education and training. In Academic Year 2016-2017 (latest available data), GWEP grantees provided 467 AD/ADRD courses and trained 55,640 health care providers in AD/ADRD.

NIA continues to expand its efforts to educate clinicians about recent research findings; clinical practice tools for assessment, diagnosis and management of cognitive impairment; training materials; a patient checklist handout in English and Spanish, and other resources, which are available online in a mini-portal of resources for professionals. NIA also produced and disseminated "Assessing Cognitive Impairment in Older Patients: A Quick Guide for Primary Care Physicians".

Additionally, in 2018 NIA released the FOA -- Small Research Grant Program for the Next Generation of Clinical Researchers in AD/ADRD Research -- aimed at producing trained clinical investigators pursuing careers in the field of AD/ADRD research.

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For more information, see:

- <https://www.nia.nih.gov/alzheimers/alzheimers-and-dementia-resources-professionals>
- <http://www.nia.nih.gov/alzheimers/publication/assessing-cognitive-impairment-older-patients>
- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-19-002.html>

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**(UPDATED) Action 2.A.2: Encourage providers to pursue careers in geriatric specialties**

In Academic Year 2016-2017 (latest available data), GWEP awardees trained 638 individuals in geriatrics fellowships and 136 advanced education nursing students in advanced practice adult-gerontology nursing programs. As part of their training, these individuals receive education in AD/ADRD.

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**(UPDATED) Action 2.A.3: Strengthen state aging, public health, and intellectual and developmental disability workforces**

HHS will coordinate with states to develop workforces in aging, public health, and intellectual and developmental disability (IDD) that are AD-capable and culturally-competent. ACL collaborated with HRSA to provide AD/ADRD training to the Aging Network.

ACL through the National Alzheimer's and Dementia Resource Center (NADRC) offers an annual dementia-specific webinar series, attracting as many as 1,300 attendees to a single session. The series targets AD/ADRD professionals, attracting family caregivers as well, and includes information on related dementias, innovative interventions and a wide variety of caregiving topics. Continuing education units (CEUs) are available to attendees, and the webinars are archived on the resource center web page.

Each year, in support of paid and unpaid caregivers, the NADRC develops tools and issue briefs on dementia-specific topics. New materials developed are disseminated through the ACL grant programs, as well as at professional conferences and the center website. ACL is constantly adding new tools and issue briefs to its growing library. Topics of materials developed by NADRC include, but are not limited to, advance planning, living alone, compendiums of dementia-specific interventions and outcome measures.

In FY 2017, the 44 HRSA GWEP grantees collaborated with 32 Area Agencies on Aging (AAAs) and 15 Quality Improvement Organizations (QIOs) to strengthen state aging, public health, and IDD workforces.

For more information, see:

- <https://nadrc.acl.gov/>

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**(UPDATED) Action 2.A.4: Develop and disseminate a unified primary care Alzheimer's disease and related dementias curriculum**

From FY 2015-FY 2017, HRSA partnered with federal staff at ACL, CDC, Centers for Medicare & Medicaid Services (CMS), HHS Office on Women's Health (OWH), and U.S. Department of Veterans Affairs (VA) on a contract to develop a Dementia Curriculum for Health Care Professionals and Caregivers. The curriculum is designed to build a workforce with the skills to provide high-quality care, ensure timely and accurate detection and diagnosis, and identify high-quality dementia care guidelines and measures across care settings. The curriculum was first made available as of December 2017. In the first month it was available, the site had 8,000 hits. The curriculum is being updated every 6 months. HRSA is partnering with CDC to provide CEUs

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to health professionals. HRSA is also partnering with CMS to convert the caregiver modules in the Curriculum to YouTube videos.

CMS's Integrated Care Resource Center (ICRC), which partners with health plans and providers, also offered a 2017 Geriatric-Competent Care Webinar Series designed to help health professionals in all settings and disciplines expand their knowledge and skills in the unique aspects of caring for older adults and in working with their caregivers, with some focus on dementia. The webinars are intended for front line community partners and delivery staff such as care managers, member service representatives, and home care providers. Topics have included promising practices to advance care of Medicare-Medicaid enrollees with dementia, causes of dementia in older adults, diagnosis and treatment of Parkinson's disease.

For more information, see:

- <https://bhw.hrsa.gov/grants/geriatrics/alzheimers-curriculum>
- <https://www.integratedcareresourcecenter.com/>
- <https://resourcesforintegratedcare.com/target-populations/behavioral-health>

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**(UPDATED) Action 2.A.5: Ensure aging and public health network providers have access to research-based up-to-date information on Alzheimer's disease and related dementias**

NIH initiated a project involving the Agency for Healthcare Research and Quality (AHRQ), and the National Academies of Sciences, Engineering, and Medicine (NASEM), to conduct a systematic review of the evidence on prevention of clinical Alzheimer's-type dementia, MCI, and age-related cognitive decline (AHRQ), and to shape these findings into a set of recommendations for public health practice and research (NASEM). The NASEM report, detailing recommendations for public health messaging based on findings was released in June 2017.

The interagency ROAR group (NIH, ACL, and CDC) hosted an update in the popular webinar series in 2017 for professionals on AD/ABR resources that drew 500+ participants and offered continuing education credit (CEC). Free continuing education is available to professionals who need it when they view recorded webinars from 2017 and earlier series. This continuing education is available through 2018.

NIA continues to expand its efforts to educate clinicians about recent research findings; clinical practice tools for assessment, diagnosis and management of cognitive impairment; training materials; a patient checklist handout in English and Spanish, and other resources, which are available online in a mini-portal of resources for professionals.

For more information, see:

- <https://www.effectivehealthcare.ahrq.gov/search-for-guides-reviews-and-reports/?pageaction=displayproductandproductID=2417>
- <http://nationalacademies.org/hmd/reports/2017/preventing-cognitive-decline-and-dementia-a-way-forward.aspx>
- <https://www.nia.nih.gov/news/2017-alzheimers-and-dementia-webinars-professionals>
- <https://www.nia.nih.gov/health/alzheimers-dementia-resources-for-professionals>

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**(UPDATED) Action 2.A.6: Engage the public health workforce on brain health**

CDC in collaboration with the Healthy Brain Research Network (HBRN) developed a Scholars Program to assist in the training of graduate-level students in brain health. Students engage in a variety of educational, partnership, and research activities. This program is in Year 2 of a 5-year funding cycle.

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CDC in collaboration with the Alzheimer's Association developed "A Public Health Approach to Alzheimer's and Other Dementias" curriculum. This introductory curriculum describes the role of public health in addressing the epidemic of AD/ADR. Its four modules each contain a comprehensive faculty guide and slide deck.

For more information, see:

- <https://www.cdc.gov/aging/aginginfo/alzheimers.htm>

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**(UPDATED) Action 2.A.7: Strengthen the ability of primary care teams in Indian Country to meet the needs of people with Alzheimer's disease and related dementias and their caregivers**

The Indian Health Service (IHS) incorporated training for AD/ADR into the online continuing education curriculum for IHS/Tribal/Urban program nursing. A web-based course on AD/ADR was provided in April-June 2016 at the IHS Clinical Rounds. Results were addressed at IHS Nursing Leadership meeting May 17, 2016. A clinical training on diagnosis and management of AD/ADR for ACL/IHS/CMS LTSS conference was delivered in November 2016. IHS is currently developing use of Extension for Community Healthcare Outcomes project (Project ECHO) to support diagnosis and management of AD/ADR in Tribal communities.

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**(UPDATED) Action 2.A.8: Develop a baseline understanding of self-reported competence and confidence of Indian Health Service, Tribal and Urban Indian Health nursing staff in care of individuals with Alzheimer's disease and related dementias**

IHS created a survey to assess nursing in IHS, Tribal, and Urban Indian Health programs on self-reported competence, confidence, and recent training specific to care for individuals with AD/ADR. The survey has been pilot-tested at one Tribal site.

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**(UPDATED) Action 2.A.9: Improve educational resources for primary care staff in Tribal communities caring for individuals with Alzheimer's disease and related dementias and their families**

IHS, in conjunction with HRSA, worked to pilot-test the HRSA curriculum for care of AD/ADR in IHS, Tribal, and Urban Indian Health Programs. Pending completion of the brief, targeted provider-focused curriculum, IHS will be able to report on success rates and take-up of this curriculum and further implementation in other Tribal communities.

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**(UPDATED) Action 2.A.10: Provide decision support for clinicians in Tribal communities**

IHS worked to develop and pilot-test decision support tools for clinicians using the IHS electronic health records (EHRs). As of 2018, IHS has developed templates to support the Annual Wellness Visit (AWV), including cognitive assessments and chronic care management (CCM).

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**(UPDATED) Action 2.A.11: Private interdisciplinary team training in recognition, assessment, and management of Alzheimer's disease and related dementias in small rural Indian Health facilities**

IHS worked with the VA to provide the VA Rural Interdisciplinary Team Training (RITT) to 10 IHS and Tribal sites with a focus on dementia care. So far, 12 RITT Trainings have been completed. The trainings include webinars, accredited through Employee Education System (EES) and

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TRAIN for VA and community clinicians. The latest training provided was on post-traumatic stress disorder (PTSD) and Memory (January 24, 2018).

For more information, see:

- <http://www.gerischolars.org/course/view.php?id=29>

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**(UPDATED) Action 2.A.12: Strengthen states' ability to provide and sustain dementia-capable home and community-based services**

Implementation of dementia-capability assessment tool for implementation through the ACL state and community grant program. The tool assesses program partners over the course of a grant to measure the improvement in dementia-capability. The tool is available for non-grantees on the NADRC website.

CMS extended the transition period for states to demonstrate compliance with its HCBS settings to ensure compliance activities related to integrated community settings are collaborative, transparent, and timely and assure thoughtful implementation, and impose less burden on states.

For more information, see:

- <https://nadrc.acl.gov/>
- <https://www.medicaid.gov/medicaid/hcbs/guidance/hcbs-final-regulation/index.html>

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**(UPDATED) Action 2.A.13: Fill service gaps in dementia-capable systems by expanding the availability of specialized services and supports to target previously underserved populations**

This is an ongoing project assuming continuing congressional appropriations. In 2017, 11 community programs received funding, bringing the total number of programs funded since 2014 to 43.

In 2018, CMS announced that beginning in 2019 it is expanding the definition of “primarily health-related,” supplemental benefits in Medicare Advantage Organizations to consider an item or service as a supplemental benefit if it is used to diagnose, compensate for physical impairments, acts to ameliorate the functionality/psychological impact of injuries or health conditions, or reduces avoidable emergency and health care utilization. This permits the plans to offer supplemental benefits such as adult day health, environmental modifications, palliative care, etc.

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**(UPDATED) Action 2.A.14: Improve home and community-based long-term services and supports provided through state Medicaid waivers**

Work is ongoing in this space. CMS continues to hold webinars, national calls, and provide information to key stakeholders. As one example, CMS is supporting state Medicaid agencies in community integration through HCBS. One targeted area of support is helping a select number of Medicaid agencies plan and implement quality and outcome measures and measure concepts in their HCBS programs.

For more information, see:

- <https://www.medicaid.gov/state-resource-center/innovation-accelerator-program/community-integration-ltss/ci-ltss.html>
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**(UPDATED) Action 2.A.15: Disseminate Centers for Medicare & Medicaid Services Hand-in-hand dementia training materials in Department of Veterans Affairs community living centers**

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VA disseminated the CMS Hand-in-Hand Dementia Training Materials to all VA Community Living Centers (CLCs; formerly known as VA Nursing Home Care Units) in 2015-2016. Orientation calls with CLC leaders were held, and a series of implementation coaching calls were held with CLC staff. A process evaluation is underway. When evaluation activities are complete, VA will share with federal partners a summary report on its implementation and evaluation of the dissemination of these staff training materials.

Nineteen of the HRSA 44 GWEPs collaborated with VA. The GWEP grantees are prepared to assist with training in VA CLCs should they be asked to do so.

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**(NEW) Action 2.A.16: Training future public health professionals on Alzheimer's disease and related dementias**

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CDC has developed a Public Health Curriculum in partnership with the Alzheimer's Association and Emory University. The Public Health curriculum is a comprehensive course designed to educate public health students about the growing issues related to AD/ADRD and is tied to the Core Competencies for Public Health Professionals. It includes slides, teacher notes, and other elements to create a complete course for educators to use in the classroom. The curriculum is also relevant to other audiences for broader reach.

For more information, see:

- <https://www.cdc.gov/publichealth101/index.html>
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**Strategy 2.B: Ensure Timely and Accurate Diagnosis**

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Far too many people with AD/ADRD are not diagnosed until their symptoms have become severe. Timely diagnosis gives people with the condition and their families and caregivers time to plan and prepare for the future, leading to more positive outcomes for both. For some, the inability to access health care due to a lack of insurance or limited finances is a major concern. This is particularly important for individuals with younger-onset disease who may not yet be eligible for Medicare. Even with access to affordable care for individuals, the health care workforce needs tools that can help ensure timely and accurate diagnoses. Research has helped identify some assessment tools that can be used to detect cognitive impairment that may indicate the need for a comprehensive diagnostic evaluation for AD/ADRD. The actions below will facilitate appropriate assessment and give health care providers tools to make timely and accurate diagnoses.

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**(UPDATED) Action 2.B.1: Identify and disseminate appropriate assessment tools**

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NIA continues to expand its efforts to educate clinicians about recent research findings; clinical practice tools for assessment, diagnosis and management of cognitive impairment; training materials; a patient checklist handout in English and Spanish, and other resources, which are available online in a mini-portal of resources for professionals.

NINDS continues to support DetectCID, a national consortium to test and validate clinical paradigms that can be used in primary health care and other everyday clinical settings. The ultimate goal is to increase detection of cognitive impairment/dementia among high risk populations, including health disparity populations, and lessen cultural and logistic barriers that currently impede both clinical care and research efforts. Three research teams across the United

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States are focusing on utilizing assessment tools that are simple to use, standardized, and take 10 minutes or less to administer in a primary care setting.

For more information, see:

- <https://www.nia.nih.gov/health/alzheimers-dementia-resources-for-professionals>
- <https://www.ninds.nih.gov/News-Events/News-and-Press-Releases/Press-Releases/NIH-forms-new-consortium-improve-detection>
- <https://www.detectid.org/>

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**(UPDATED) Action 2.B.2: Educate family and service providers of persons with intellectual and developmental disability about changes that may indicate the onset of dementia**

ACL, through their Alzheimer's/dementia grants to states and communities are providing dementia-capability training to paid and unpaid caregivers of persons living with dementia, including individuals living with IDD and dementia or at risk of developing dementia. For example, through the ACL community grant program, 31 of 43 funded projects (in 22 states and Puerto Rico) include IDD culturally-competent ADRD education/training activities components. ACL collaborates closely with the National Task Group on Intellectual Disabilities and Dementia Practices (NTG) with many grantees participating in their education workshops, becoming affiliated trainers and further disseminating education on IDD and dementia, as well as implementation of their Early Detection Screen for Dementia (NTG-EDSD) tool.

Two webinars and an issue paper were made available in 2015. One webinar was offered in 2017 and another in 2018. All webinars are available on the NADRC's website.

For more information, see:

- <http://aadmd.org/>
- <https://nadrc.acl.gov/>

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**(UPDATED) Action 2.B.3: Increase awareness of Alzheimer's disease and related dementias in Tribal and Urban Indian communities and of the availability of services for individuals with dementia and their families**

IHS, with ACL and VA, pilot-tested AD/ADRD awareness strategies in communities in which Resources Enhancing Alzheimer's Caregivers Health (REACH) into Indian Country was successfully implemented, through both health care and aging services settings. The focus of the REACH intervention in its final year was on increasing awareness of AD/ADRD in those communities served by REACH and increasing use of REACH caregiver support services.

Regular web-based calls with REACH Caregiver Coaches aimed at increasing awareness and use of the caregiver support services in Tribal communities.

ACL continues to bring awareness to ADRD in Indian Country through participating in educational opportunities including presentations to attendees of ACL's Title VI annual conference and webinars.

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**(NEW) Action 2.B.4: Increase provider awareness of the need for early diagnosis and provide tools and resources to enable diagnosis and referral**

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CDC is working with the American College of Preventive Medicine to develop a curriculum to increase physician and health care professionals' awareness of brain health as a serious health condition and to increase the number of physicians and health care professionals acting to address, diagnose, and refer patients with brain health issues to care and community support programs.

The new module will be included as an elective in the Lifestyle Medicine Core Competencies Online Program.

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**(NEW) Action 2.B.5: Understand the discordance between reported diagnosis, claims, and functional assessment for people with Alzheimer's disease and related dementias**

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ASPE is working on a project to understand the discrepancy between patient or proxy-reported dementia diagnosis, an indication of dementia in Medicare claims data, and performance on tests of cognitive functioning. Although people with dementia should have all of these indicators and be aware of their diagnosis, that is often not the case. By examining the characteristics of people for whom there is a discrepancy, there will be better understanding of how to improve patient awareness of diagnosis and also improve care planning.

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**Strategy 2.C: Educate and Support People with Alzheimer's Disease and Related Dementias and Their Families upon Diagnosis**

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Often, even though a physician or another health care provider has identified cognitive impairment, the patient and his or her family and caregivers are not told of the diagnosis. Further, once a diagnosis is made and disclosed, as few as half of patients and families receive counseling, support, or information about next steps. This information is important, especially for early-stage individuals who experience positive outcomes when they are involved in planning and receive appropriate services. The actions below will address this gap by educating physicians and other health care providers, incentivizing discussions with people with AD/DRD and their families, and enhancing the ability of other networks to assist people living with AD/DRD and their families with addressing their needs.

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**(UPDATED) Action 2.C.1: Educate physicians and other health care providers about accessing long-term services and supports**

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One barrier to counseling and support is that health care providers are not aware of available services or how to access them. To increase knowledge of these resources among physicians, nurses, and hospitals, HRSA is working 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/DRD, as well as their caregivers. These activities will continue as part of the training in Action 2.A.1.

In addition, since 2017, CMS has made separate Medicare payment for cognitive assessment and care planning services for individuals with cognitive impairment. A required element of these services is the creation of a care plan, including referral to community resources as needed (e.g., rehabilitation services, adult day programs, support groups), and a requirement that the care plan is shared with the patient and/or caregiver with initial education and support.

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**(UPDATED) Action 2.C.2: Connect American Indian and Alaska Natives to Alzheimer's disease and related dementias resources**

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The focus on increasing support to caregivers has been through the spread of REACH into Indian Country, with the goal of offering this intervention to those with AD/ADRD and their families. IHS has begun a collaboration with the CDC in the development of the Brain Health Public Health Road Map designed specifically for Tribal Communities.

Tribal communities continue to benefit from ACL's state and community AD/ADRD grant programs, including development of culturally-competent dementia care specialists, dementia-friendly community education/awareness initiatives and translation of the Music and Memory intervention in Indian Country.

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**Strategy 2.D: Identify High-Quality Dementia Care Guidelines and Measures Across Care Settings**

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Guidelines for delivery of high-quality care and measures of quality care are needed to ensure that people with AD/ADRD receive high-quality, culturally-competent care in the many different settings where they receive services. These guidelines and measures should be tailored to the stages of the disease, address the physical, cognitive, emotional, and behavioral symptoms of AD/ADRD, and cover the myriad care settings in which care is delivered. These guidelines should also take into account how care might be modified for diverse populations and in the context of co-occurring chronic conditions in people with AD/ADRD. HHS will seek expert input from public and private entities and ensure that content builds on existing, evidence-based guidelines. Quality measures should be based on such guidelines and track whether recommended care is being provided. Guidelines and measures need to be free of conflicts of interest. The actions below will advance the development of guidelines and measures of high-quality care, as well as the ability of the provider community to improve the quality of the care they provide. In the future, to facilitate the implementation of quality care guidelines and measurement, HHS will explore development and electronic sharing of clinical decision support interventions in concert with guidelines and measures to provide physicians the information they need at the point of care and ensure continuity between measurement, evaluation, and best practice.

**(UPDATED) Action 2.D.1: Explore dementia care guidelines and measures**

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CMS has included dementia-related measures in the Merit-Based Incentives\Payment System for Medicare such as cognitive assessment, management of neuropsychiatric symptoms (NPS), and others that impact people with dementia.

CMS is also continuing its work to test and develop measures and measure concepts for HCBS.

For more information, see:

- <https://qpp.cms.gov/mips/explore-measures/quality-measures?py=2018#measures>
  - <https://www.medicare.gov/medicaid/quality-of-care/improvement-initiatives/hcbs/index.html>
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**(UPDATED) Action 2.D.2: Solicit stakeholder input on meaningful outcomes to drive quality measurement**

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CMS's initial target was met; the agency is continuing the work of reviewing literature and guidelines, and continues to support quality measure development and implementation.

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CMS's "Meaningful Measures" framework identifies the highest priorities for quality measurement and improvement. It involves only assessing those core issues that are the most critical to providing high-quality care and improving individual outcomes. The Meaningful Measure Areas serve as the connectors between CMS goals and individual measures/initiatives that demonstrate how high-quality outcomes are being achieved across settings of care. CMS also launched the "Patients Over Paperwork" initiative to reduce provider burden and increase efficiencies while improving the beneficiary experience; initial work focused on nursing home care.

For more information see:

- <https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/QualityInitiativesGenInfo/MMF/General-info-Sub-Page.html>
- <https://www.cms.gov/Outreach-and-Education/Outreach/Partnerships/PatientsOverPaperwork.html>

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**(UPDATED) Action 2.D.3: Clarify and disseminate information on privacy, autonomy, and safety issues to physicians**

HRSA worked to develop information for physicians on privacy, autonomy, and safety issues around AD/DRD. These resources are intended to help providers better understand these issues and the balance between safety, privacy, and autonomy. HRSA continues to disseminate this information through the trainings provided by the GWEP awardees.

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**(UPDATED) Action 2.D.4: Provide improved training resources to Indian Health Service staff on person-centered goals and strategies for care improvement**

IHS collaborated with HRSA to engage the HRSA-funded GWEPs in strategies to improve recognition and diagnosis of dementia. Eight HRSA GWEPs are currently partnering with federally recognized Tribal organizations and one HRSA GWEP collaborates with a non-federally recognized Tribal organization. The nine GWEPs have developed a Native Populations Interest Group in preparation for exchanging training materials. The University of Wyoming is currently pilot-testing culturally-relevant dementia training material for American Indian and Alaska Native people on the Wind River Reservation by creating a pictorial version of the Alzheimer's Association's "Know the 10 Signs: Early Detection Matters". The other members of the Interest Group are discussing how/whether to adopt similar materials.

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**(COMPLETED) Action 2.D.5: Understand trends in residential care settings for older adults**

ASPE conducted an analysis of three national surveys -- the Health and Retirement Survey (HRS), the Medicare Current Beneficiary Survey (MCBS), and the National Health and Aging Trends Survey (NHATS) -- that estimated that the number of older Americans living in community-based residential care ranges from 0.8 million (2014 HRS) to 1.9 million (2015 NHATS); the estimate from the 2013 MCBS was in the middle: 1.2 million. The proportion of older adults living in these settings increased from 2.3% in 2002 to 2.7% in 2013 in the MCBS, but a decline was observed in the HRS and NHATS, although the number of individuals increased. These differences across surveys likely reflect variation among the surveys in how residential care settings are defined, and in how samples are selected.

With a few key exceptions, the demographic characteristics of residents were similar across years and across datasets. The age distributions of older adults living in community-based residential settings were comparable to those living in nursing homes (48%-55% of residents were aged 85 and older), while those living in traditional settings were younger (approximately

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50% were ages 65-74). Marital status also varied by setting, with more than half of those living in traditional settings being married, and more than half of those in community-based residential care or nursing homes being widowed. Estimates of functional limitation varied across data sources, likely resulting from differences in definitions and approaches to data collection. The general patterns, however, were consistent. In all data sources, and at all points in time, people living in community-based residential care settings reported more impairments than did those living in traditional settings. The prevalence of AD/ADRD was lowest among those living in traditional settings, and highest among those living in nursing homes. In all settings, the proportion of people with any type of dementia increased over time. These patterns were consistent across datasets, but the prevalence rates varied, depending how data were collected. The report will be posted in late 2018.

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**(DISCONTINUED) Action 2.D.6: Study factors influencing the progression of disability in older adults**

ASPE expected to use NHATS data from 2011 to 2015 to study the progression of disability and the implications for caregiving needs. Outcomes data would be tabulated each year (death, long-stay nursing home admission, and residential care admission, continued or increased use of informal/paid care). Those who develop dementia after 2011 would be studied, but most cases would already have dementia or symptoms in 2011, and the course of their condition would be followed through 2015.

This project was discontinued, due to data limitations; however, other data may be used to explore these topics in the future.

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**Strategy 2.E: Explore the Effectiveness of New Models of Care for People with Alzheimer's Disease and Related Dementias**

Work is underway at a number of agencies to identify models that provide more effective and efficient care for people with AD/ADRD. Models that improve health and quality of life for people eligible for both Medicaid and Medicare (dual eligibles) are also of great importance to the AD/ADRD population, as approximately 19% of the dual eligible population has some form of dementia.

**(UPDATED) Action 2.E.1: Evaluate the effectiveness of relevant Innovation Center models for people with Alzheimer's disease and related dementias**

The Innovation Center has tested several models that can include testing payment and service delivery models for improving care for Medicare beneficiaries with AD/ADRD. Several awards under the Innovation Center's Health Care Innovation Awards (HCIAs) round 1 and round 2 were focused on people with AD/ADRD and their caregivers. The Innovation Center is evaluating the effectiveness of the HCIAs, including those that focus on people with AD/ADRD.

CMS is in the process of completing the evaluation of HCIA round 2. Final evaluation results for the HCIA round 2 are anticipated to be available at the end of 2019.

For more information, see:

- <https://downloads.cms.gov/files/cmml/hcia-diseasespecific-thirdannualrpt.pdf>
  - <https://downloads.cms.gov/files/cmml/hevacia-chspt-thirdannualrpt.pdf>
  - <https://downloads.cms.gov/files/cmml/hcia2-yr3evalrpt.pdf>
  - <https://innovation.cms.gov/initiatives/comprehensive-primary-care-plus>
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- <https://innovation.cms.gov/initiatives/VBID/>
  - <https://innovation.cms.gov/Files/reports/hcia-diseasespecific-thirdannrpt-addendum.pdf>
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#### **(UPDATED) Action 2.E.2: Evaluate the effectiveness of the Independence at Home Demonstration**

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The Independence at Home Demonstration is testing a payment incentive and service delivery model that uses physicians and nurse practitioners to coordinate home-based primary care with LTSS. CMS has released the results from Year 2 of the demonstration.

For more information, see:

- <https://innovation.cms.gov/initiatives/independence-at-home/>
  - <https://www.cms.gov/newsroom/fact-sheets/independence-home-demonstration-corrected-performance-year-2-results>
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#### **(UPDATED) Action 2.E.3: Develop a supported decision making model as an alternative to guardianship**

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The National Resource Center for Supported Decision-Making (NRC-SDM) builds on and extends the work of Quality Trust's Jenny Hatch Justice Project by bringing together vast and varied partners to ensure that input is obtained from all relevant stakeholder groups including older adults, people with IDD, family members, advocates, professionals and providers. The NRC-SDM partners bring nationally recognized expertise and leadership on SDM, representing the interests of and receiving input from thousands of older adults and people with IDD. They have applied SDM in groundbreaking legal cases, developed evidence-based outcome measures, successfully advocated for changes in law, policy and practice to increase self-determination and demonstrated SDM to be a valid, less-restrictive alternative to guardianship.

For more information, see:

- <http://www.supporteddecisionmaking.org/>
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#### **(COMPLETED) Action 2.E.4: Analyze new payment and service options for Medicare-Medicaid dual eligible beneficiaries**

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ASPE is currently engaged in a project to produce targeted research briefs on options for expanding the Program of All-Inclusive Care for the Elderly (PACE). PACE was established as a permanent Medicare and Medicaid benefit by the Balanced Budget Act of 1997, and it attempts to help nursing home eligible older adults avoid institutional care by providing them with an appropriate, tailored mix of coordinated acute care and HCBS. PACE is designed for the frail elderly. To be eligible, participants must be 55 or older and certified by their state of residence as being eligible for nursing home level of care. The PACE Innovation Act gives the Secretary of HHS the authority to test changes to the PACE model, such as serving individuals under the age of 55, and people who do not meet the current nursing home level of care criteria, but may be at risk of entering a nursing home. The anticipated deliverables for this project include four research briefs that address the policy implications, benefit design, and financing structure of an expanded PACE program, including a descriptive analysis of subpopulations of dual eligible beneficiaries under age 55. Nationally, nearly half (49% comp) of PACE participants have been diagnosed with dementia, therefore lessons from the PACE model may have strong applicability to the field of dementia care broadly. Reports are expected by December 2018.

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**(NEW) Action 2.E.5: Understand the role of certified community behavioral health clinics in providing access to care**

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In April 2014, the Protecting Access to Medicare Act created the Certified Community Behavioral Health Clinic (CCBHC) demonstration. The demonstration establishes a standard definition for CCBHCs and allows states to develop new prospective payment systems (PPS) that reimburse CCBHCs for the total cost of providing comprehensive services to all individuals who seek care. ASPE is managing a 5 year evaluation of this demonstration to answer research questions on how the CCBHCs improve access to care, whether they implement a full scope of services, how they improve the quality of care, whether the PPS covers the full costs of care, and how the demonstration impacts costs and utilization in Medicaid. Reports to Congress are due annually, and interim reports and a final report will be posted on ASPE's website.

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**Strategy 2.F: Ensure that People with Alzheimer's Disease and Related Dementias Experience Safe and Effective Transitions between Care Settings and Systems**

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People with AD/ADRD have higher rates of emergency room visits and hospitalizations, two settings where they are vulnerable to stress, delirium, and unnecessary complications. A transition between providers and care settings is a complex time of care delivery for all people, but especially for frail elders or other people with AD/ADRD who often have multiple chronic conditions. Transitions include moves into acute care hospitals, from hospitals to post-acute care settings such as skilled nursing facilities or the home, or from nursing facilities to hospitals. People with AD/ADRD are at high risk of adverse events due to poor communication and other care process deficiencies during transitions and need support to help them determine the best timing for transition and site of care.

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**(UPDATED) Action 2.F.1: Implement and evaluate new care models to support effective care transitions for people with Alzheimer's disease and related dementias**

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CMS's Comprehensive Primary Care Plus Model includes about 6% of beneficiaries with dementia, where providers can receive enhanced fees for care coordination and support for beneficiaries with dementia. CMS is also hosting a "National Care Transitions Week" in 2018 to gather stakeholder input.

ACL's state dementia system grants are all required to include a care transitions component and all grantees are required to evaluate the effectiveness of their programs. Numerous models of care transitions interventions are presently being implemented through ACL's community project, all of which include collection of outcome data and will include a programmatic evaluation upon completion of the grant period.

For more information, see:

- <https://innovation.cms.gov/initiatives/comprehensive-primary-care-plus>
  - <https://www.healthcarecommunities.org/>
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**Strategy 2.G: Advance Coordinated and Integrated Health and Long-Term Services and Supports for People Living with Alzheimer's Disease and Related Dementias**

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Coordinating the care received by people with AD/ADRD in different settings by different providers can help reduce duplication and errors and improve outcomes. Despite a general consensus that care coordination is important, more research is needed to determine how best to provide such care in a high-quality and cost-efficient manner. The actions under this strategy will focus on learning from the existing

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evidence regarding care coordination and using this information to implement and evaluate care coordination models for people with AD/ADRD.

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**(UPDATED) Action 2.G.1: Implement and evaluate care coordination models**

Multiple care coordination models and guidance on care coordination continue across CMS. CMS makes payment for care management and coordination services. Care coordination models can be a critical component of care in Medicare that can contribute to better health outcomes and higher beneficiary satisfaction. Starting in 2017, based on feedback from stakeholders, CMS has made separate payment in Medicare for complex care coordination models services, in addition to payment for non-complex care coordination models services that began in 2015. Beginning in 2017, CMS also has made several significant changes to requirements and payment for care coordination models services, including simplified and reduced billing and documentation rules. In 2018, CMS released an evaluation report on the diffusion and impact of care coordination models services.

CMS's Comprehensive Care Plus Model is an advanced primary care medical home model that rewards value and quality by offering an innovative payment structure to support delivery of comprehensive primary care. One of the payments under the model are prospective monthly care management fees, including a higher care management fee for patients with complex needs.

For more information, see:

- <https://www.cms.gov/About-CMS/Agency-Information/OMH/equity-initiatives/chronic-care-management.html>
- <https://innovation.cms.gov/Files/reports/chronic-care-mngmt-finalevalrpt.pdf>

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**Action 2.G.2: Assess the adequacy of health information technology standards to support the needs of persons with Alzheimer's disease and related dementias**

ASPE continues work with HHS's Office of the National Coordinator for Health Information Technology and partners in exploring the feasibility and timing of activities to assess, identify, and fill gaps in accepted health information technology (HIT) standards for the representation of care plans to represent the health concerns, goals, interventions, and other information identified by individuals, caregivers and family members in caring for individuals receiving LTSS, including people with AD/ADRD.

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**(COMPLETED) Action 2.G.3: Compare outcomes for dual eligible beneficiaries in integrated care models**

ASPE has completed a project to determine the feasibility of an analysis that compares selected health outcomes and quality measures for Medicare-Medicaid dual eligible beneficiaries participating in managed care models that align Medicare and Medicaid benefits, such as Medicare Advantage Dual Eligible Special Needs Plans (D-SNPs), Medicare Advantage Fully Integrated D-SNPs, and PACE, to outcomes for dually eligible beneficiaries who are not participating in these models. Dually eligible beneficiaries are almost three times more likely to have dementia as their Medicare-only counterparts, therefore programs that serve large numbers of dually eligible beneficiaries are likely to also serve people with dementia. This study aims to better understand whether dually eligible beneficiaries fare differently in different integration models across a number of categories including but not limited to, mortality, nursing home utilization, hospital readmissions, and chronic conditions (inclusive of AD/ADRD or Senile Dementia, as identified in CMS's Chronic Conditions Data Warehouse). Reports are forthcoming in September 2019.

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**(NEW) Action 2.G.4: Study the impacts of managed care on health outcomes and quality**

ASPE has a project underway to evaluate the impact of Medicare and Medicaid alignment for individuals eligible for both Medicare and Medicaid on beneficiary outcomes and utilization of acute care services and LTSS. Nineteen percent of all Medicare-Medicaid dual eligible beneficiaries have AD/ADRD. This project will focus on one state (Tennessee) that has implemented Medicare and Medicaid financial alignment for duals through a combination of Medicare Advantage D-SNPs contracting and Medicaid managed long-term services and supports (MLTSS). This project is testing the hypothesis that the aligned delivery of Medicare and Medicaid-funded services to full-benefit duals is associated with improved health status and increased efficiency of health care utilization (decreased emergency department utilization, decreased nursing facility utilization, and increased use of HCBS) among full-benefit duals in Tennessee, by evaluating the impact that Tennessee's financial alignment strategy (pairing D-SNPs with MLTSS) has had on beneficiary outcomes and utilization. A report is forthcoming in June 2019.

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**(NEW) Action 2.G.5: Analyze pathways of eligibility for dually eligible beneficiaries**

ASPE has a project underway to identify the frequency with which the various eligibility pathways to Medicare-Medicaid dual eligible status are utilized to understand the circumstances and characteristics of individuals surrounding their transition to dual status. Nearly one-quarter (23%) of Medicare-Medicaid dual eligible beneficiaries over the age of 65 have AD/ADRD. Individuals become dually eligible for the Medicare and Medicaid programs through multiple pathways. They can become eligible for one of the programs before the other, based on age, disability, or income; or they may simultaneously become eligible for both programs. However, current understanding of these pathways remains limited. Differences in the pathways to dual eligibility have implications for Medicare and Medicaid spending and service use patterns. Understanding these differences can inform policy efforts to support the Medicare-Medicaid dual eligible population and individuals at risk for becoming dually eligible. A report is forthcoming in December 2018.

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**(COMPLETED) Action 2.G.6: Analyze maintenance and loss of dual eligibility status**

ASPE completed a project to document the frequency of Medicaid coverage loss among newly eligible full-benefit Medicare-Medicaid dual eligible beneficiaries and identify potential causes for coverage loss. Nineteen percent of all dual eligible beneficiaries have AD/ADRD. Generally, full-benefit dual eligible beneficiaries are expected to have relatively stable Medicaid enrollment due to their low income and high health care and LTSS needs, especially among older people and people with disabilities, whose income and assets are expected to be stable. Since dual eligible beneficiaries represent a vulnerable population, gaps in insurance coverage can compromise access to care and result in increased costs and decreased quality of care, further increasing an individual's risk for adverse health outcomes. A prior ASPE study found that a substantial proportion, approximately 30%, of new, full-benefit dual eligible beneficiaries identified during 2007-2010 lost full-benefit coverage for at least 1 month in the 12 months following their transition to full-benefit dual status. The study identifies potential causes for the loss of Medicaid coverage among full-benefit dual eligible beneficiaries to better understand the relationship between states' Medicaid eligibility and enrollment policies and reasons for loss of Medicaid coverage. A report is forthcoming in December 2018.

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**(NEW) Action 2.G.7: Understand issues specific to the "triple-user" population**

ASPE has a project underway to better understand the demographics, service utilization patterns, health status and policy challenges facing the population that is simultaneously eligible for

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Medicare, Medicaid, and Veterans Health Administration (VHA) benefits. Some research estimates that as many as half of all current VHA enrollees are dually enrolled in Medicare. Additionally, nearly one in ten veterans has Medicaid as a source of health insurance coverage, some in combination with VHA and some with Medicaid as their sole source of coverage. Among veterans with Medicaid coverage 41% have Medicaid and VA, and 9% have Medicaid and Medicare. Veterans are significantly more likely than non-veterans to experience traumatic brain injury, a condition linked to later development of AD/ADRD. This project will explore the demographics and service use patterns of veterans who use multiple systems of care, with a special focus on triple-users, to better understand how these veterans compare to other populations with multiple system use (such as Medicare-Medicaid dual eligible beneficiaries), and inform the development of an analysis plan that will lay out a Road Map for future quantitative study of service utilization and outcomes in triple eligible veterans. A report is forthcoming in December 2018.

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## **Strategy 2.H: Improve Care for Populations Disproportionately Affected by Alzheimer’s Disease and Related Dementias, and for Populations Facing Care Challenges**

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Some populations are unequally burdened by AD/ADRD, including racial and ethnic minorities and people with IDD. Racial and ethnic minorities are at greater risk for developing AD/ADRD and face barriers to obtaining a diagnosis and services after onset. People with Down syndrome almost always develop AD/ADRD as they age. In addition, because AD/ADRD primarily affects older adults, the population with younger-onset AD/ADRD faces unique challenges with diagnosis, care, and stigma. HHS will undertake the actions below to better understand the unique challenges faced by these groups and create a plan for improving the care that they receive, which will be integrated into the broader efforts to improve care for all people with AD/ADRD.

### **(UPDATED) Action 2.H.1: Create funding opportunities for organizations to improve care for these specific populations**

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ACL awarded 11 community-based grants in 2017 for a total of 43 projects awarded since 2014. ACL anticipates awarding additional grants in 2018. Note that future grants are contingent on availability of funding.

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### **(COMPLETED) Action 2.H.2: Enhance understanding of models of family support for people with intellectual and developmental disability as they age**

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This report presents the findings and resources to the community of providers who primarily serve older adults. It provides a broad overview of the services and support system for persons with IDD affected by dementia and their caregivers, examples of cross-network initiatives, and resources for improving dementia care across agencies and organizations that serve this population. This white paper presents the current state of services and support system for persons with IDD who have dementia. There is recognition in the aging and IDD networks that states are in a transition period where the future of services will be more person-centered and focused on integration in the community.

For more information, see:

- <https://aspe.hhs.gov/report/idd-and-dementia>
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**(NEW) Action 2.H.3: Target resources towards the intellectual and developmental disability and dementia population**

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ACL, through its AD/ADRD grant programs and the NADRC, has targeted program resources to the IDD and dementia issue. At the White House Conference on Aging in July 2015, ACL released their IDD and Dementia Report on the current state of services and support system for persons with IDD living with dementia. The brief provides a broad overview of the services and support system for persons with IDD affected by dementia and their caregivers. Since the 2014 inception of their community grant program, ACL has required that participating grantees develop programs that include “improvement of the quality and effectiveness of program and services dedicated to individuals aging with IDD and ADRD or at high risk of developing ADRD”. Each year since 2015, NADRC has included an IDD and dementia-specific webinar in their annual webinar series.

For more information, see:

- <https://nadrc.acl.gov/node/51>
  - <https://nadrc.acl.gov/node/59>
  - <https://nadrc.acl.gov/node/74>
  - <https://nadrc.acl.gov/node/101>
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## Goal 3: Expand Supports for People with Alzheimer’s Disease and Related Dementias and Their Families

People with AD/ADRD and their families need supports that go beyond the care provided in formal settings such as doctors’ offices, hospitals, or nursing homes. Families and other informal caregivers play a central role. Supporting people with AD/ADRD and their families and caregivers requires giving them the tools that they need, helping to plan for future needs, and ensuring that safety and dignity are maintained. Under this goal, the Federal Government and partners will undertake strategies and actions that will support people with the disease and their caregivers.

### Strategy 3.A: Ensure Receipt of Culturally Sensitive Education, Training, and Support Materials

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Caregivers report that they feel unprepared for some of the challenges of caring for a person with AD/ADRD -- for example, caring for a loved one with sleep disturbances, behavioral changes, in need of physical assistance, or advanced dementia can be an enormous challenge. Giving caregivers the information and training that they need in a culturally sensitive manner helps them better prepare for these and other challenges. The actions to achieve this strategy include identifying the areas of training and educational needs, identifying and creating culturally-appropriate materials, and distributing these materials to caregivers.

#### **(UPDATED) Action 3.A.1: Distribute federally-developed educational materials**

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NIA’s ADEAR Center continues to offer free information in English and Spanish on AD/ADRD to caregivers in print and online, as well as through its information and referral helpline, a weekly email alert specifically on caregiving issues, and social media (Facebook and Twitter).

For more information, see:

- <https://www.nia.nih.gov/health/alzheimers/caregiving>

#### **(UPDATED) Action 3.A.2: Utilize health information technology for caregivers and persons with Alzheimer’s disease and related dementias**

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Reports from the National Research Council have reinforced the need for HIT applications for caregivers, as well as people with AD/ADRD and providers. Many opportunities exist for using technology to support people with AD/ADRD and their caregivers. Opportunities include assistance with reminders, communications, and monitoring. AHRQ has awarded two grants for integrating information and communication technology to facilitate aging in place.

One grant (1P50HS019917) was awarded and used to create Elder Tree, a suite of electronic services to support older adults and their caregivers. The Elder Tree tool is currently being evaluated. So far, 400 people have been recruited to use the suite, and participants were surveyed after use. An analysis is currently underway and results will be available soon.

Another grant (5R18HS027836) was awarded to evaluate use of remote sensory technology to help manage persons with AD/ADRD and to study the impact on ability of caregivers to manage family member with AD/ADRD. So far, 60 caregivers have been recruited, out of a goal of 100, and systems are in the process of being installed and caregivers trained.

For more information, see:

- <https://healthit.ahrq.gov/ahrq-funded-projects/brining-communities-and-technology-together-healthy-aging>
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**(UPDATED) Action 3.A.3: Increase awareness of the importance of brain health in culturally-sensitive ways**

CDC supported the development of the National Brain Health Center for African Americans (NBHCAA). The mission of NBHCAA is to raise awareness of the issues of cognitive health among African Americans by working through networks of faith-based institutions, and by establishing partnerships with organizations and individuals dedicated to the Center's mission. The three areas of focus are brain health education, mobilization and advocacy, and networking. The NBHCAA serves as an information hub on the human brain that must be shared throughout all networks that reach and touch approximately 40 million African Americans living in the United States.

CDC is working on a program geared towards training African American health professionals. Together with the Balm in Gilead, the CDC will train health professionals on issues affecting cognitive health among African Americans via partnerships with the National Black Nurses Association and National Medical Association.

CDC supported The Balm in Gilead to develop and implement Memory Sunday, the second Sunday in June, as a designated Sunday, within congregations serving African Americans, that provides education on AD/DRD: prevention, treatment, research studies and caregiving. The purpose of Memory Sunday is to bring national and local attention to the tremendous burden that AD/DRD are having on the African American community; to utilize the power and influence of the African American pulpit to bring awareness; to distribute the facts about AD/DRD; to encourage participation in research studies and to support persons living with AD/DRD and their caregivers.

CDC has provided funds to the Alzheimer's Association to develop, using BRFSS data, several fact sheets and infographics using the most current data, including a new infographic specifically demonstrating the effect of subjective cognitive decline on the African American population. These resources are made available on the Alzheimer's Association's website, and distributed to a national network of state Alzheimer's Association offices, public health professionals, and decision makers. These resources are updated annually, as new data becomes available. By creating easy-to-read, visually appealing materials, uptake of knowledge is facilitated.

For more information, see:

- <http://brainhealthcenterforafricanamericans.org/>
- [https://alz.org/publichealth/downloads/infographic\\_on\\_cognitive\\_decline\\_aa\\_2015\\_brfss.pdf](https://alz.org/publichealth/downloads/infographic_on_cognitive_decline_aa_2015_brfss.pdf)

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**(NEW) Action 3.A.4: Increase awareness of the importance of brain health for Tribal communities in culturally-sensitive ways**

In conjunction with the Alzheimer's Association and other partners, CDC is developing a special edition of the "Public Health Road Map for Tribal Communities: The Healthy Brain Initiative Road Map for Indian Country". The original Road Map focuses on issues pertinent to state and local public health agencies and their partners. A companion Road Map for Indian Country has been designed specifically for public health systems serving American Indians, Alaskan Natives, and Native Hawaiians.

CDC also funded the Association of State and Territorial Health Officials (ASTHO) to develop culturally sensitive materials to educate and empower tribes and Tribal populations about brain

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health and caregiving. The materials focus on cardiovascular risk factors related to brain health and caregiving issues for Tribal communities.

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### **Strategy 3.B: Enable Family Caregivers to Continue to Provide Care while Maintaining Their Own Health and Well-Being**

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Even though unpaid caregivers usually prefer to provide care to their loved ones in their home or other community settings, sometimes the round-the-clock care needs of the person with AD/ADRD may necessitate nursing home placement. While they are providing care, supports for families and caregivers can help lessen feelings of depression and stress and help delay or avert institutional care. The actions below will further support informal caregivers by identifying their support needs; developing and disseminating interventions; giving caregivers information they need, particularly in crisis situations; and assisting caregivers in maintaining their health and well-being.

#### **(UPDATED) Action 3.B.1: Develop and disseminate evidence-based interventions for people with Alzheimer's disease and related dementias and their caregivers**

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NIA is supporting a study of care interventions for individuals with dementia and their caregivers. The study, which is just getting underway, will take place in two parts. For the first stage of the study, an ad hoc NASEM committee will provide input into the design of an AHRQ systematic review of evidence on effective care-related interventions for people with AD/ADRD and their caregivers. In the proposed second part of the study, the ad hoc committee would consider the evidence found in the previous phase of the project and develop a report that informs decision making about which care interventions are supported by sufficient evidence to be widely disseminated and implemented.

NIA's ADEAR Center continues to offer free information in English and Spanish on AD/ADRD caregiving in print and online, as well as through its information and referral helpline, a weekly email alert specifically on caregiving issues, and social media (Facebook and Twitter). Additionally, the recently held National Research Summit on Care, Services, and Supports for Persons with Dementia and their Caregivers provided a platform to disseminate evidence-based interventions for people with AD/ADRD and their caregivers.

In addition to these activities, NIA has released several FOAs in the past year that call for research to improve the care of persons living with AD/ADRD and their caregivers.

For more information, see:

- <http://nationalacademies.org/hmd/activities/aging/careinterventionsforindividualswithdementiaandtheircaregivers.aspx>
  - <https://www.nia.nih.gov/health/alzheimers/caregiving>
  - <https://www.nia.nih.gov/news/dementia-care-summit-research-recommendations-released>
  - <https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-001.html>
  - <https://grants.nih.gov/grants/guide/pa-files/PA-18-502.html>
  - <http://grants.nih.gov/grants/guide/pa-files/PAR-15-348.html>
  - <https://grants.nih.gov/grants/guide/pa-files/PAS-18-030.html>
  - <https://grants.nih.gov/grants/guide/pa-files/PAR-18-186.html>
  - <https://grants.nih.gov/grants/guide/pa-files/PAR-18-585.html>
  - <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-18-030.html>
  - <https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers>
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**(UPDATED) Action 3.B.2: Provide effective caregiver interventions through Alzheimer's disease and related dementias-capable systems**

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New grants to states and communities are awarded each year as funding permits.

ACL's compendium of evidence-based and evidence-informed interventions translated through grants to states and communities is available online.

For more information, see:

- <https://nadrc.acl.gov/node/140>

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**Action 3.B.3: Collaborate to share information on long-term services and supports with Tribal providers**

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HHS will use multiple mechanisms to share information on LTSS and care of the person and family with AD/ADRD with Tribal providers. IHS, ACL, and CMS will develop a joint website on LTSS for Tribal providers. IHS will conduct presentations on LTSS for people with AD/ADRD at Indian Country conferences, including the Older Americans Act Title VI annual conference, and conferences for Tribal Health Directors and Planners (National Indian Health Board), Tribal Leaders (National Council on American Indians), and Tribal elders (National Indian Council on Aging). IHS and ACL will host joint webinars on addressing the service and supports needs of persons with AD/ADRD. Dissemination of dementia-specific information through presentations occurs at Indian Country meetings and webinars.

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**Action 3.B.4: Continue to promote use of the National Alzheimer's Call Center to provide information, advice and support to people with dementia or their caregivers**

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ACL will continue to provide funding toward and promote use of the National Alzheimer's Call Center to provide information, advice and support about AD/ADRD. The Call Center provides 24-hour access, 7 days a week via a toll free number (1-800-272-3900). Support varies from simple referrals to crisis intervention. Complex and crisis calls are handled by master's level social workers and counselors who provide reflective listening, problem solving, education, action planning, and crisis intervention. The Call Center provides assistance in over 170 languages.

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**Action 3.B.5: Make behavioral symptom management education and training available to caregivers**

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ACL will continue to expand efforts to develop more AD-capable LTSS systems designed to meet the needs of AD/ADRD caregivers. ACL requires that all community grants include behavioral symptom management activities to support caregivers in their programs.

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**(COMPLETED) Action 3.B.6: Examine technological solutions to support family caregivers**

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Non-invasive sensor-based technologies have the potential to prevent falls or wandering by monitoring daily functioning of people with AD/ADRD. AHRQ has funded a grant to examine one such technology, eNeighbor, among people with AD/ADRD and their family caregivers. The grantees will measure the impact of the intervention on caregiver efficacy, competence, and distress, as well as negative health transitions and long-term care service utilization by people with AD/ADRD.

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A new grant was awarded to evaluate use of remote sensory technology to help manage persons with AD/ADRD and study impact on ability of caregivers to manage family members with AD/ADRD. The new grant recruited 60 caregivers out of the goal of 100.

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**(UPDATED) Action 3.B.7: Adapt and implement Resources for Enhancing Alzheimer's Caregivers' Health in Tribal Communities**

IHS and VA will complete the current pilot of REACH-VA in Indian Country and plan for expanding these pilots through public health and community nursing programs. ACL and VA will offer to pilot REACH-VA in a small number of Tribal programs funded under Older Americans Act Title VI and to assess REACH-VA's fit in the Tribal Aging Network.

The initial phase was completed with 80 REACH certified caregiver support coaches in 56 Tribal communities, serving at least 55 caregivers as of February 2018. The second phase of the effort is focused on strategies to increase penetration of REACH in the communities where there are certified coaches and on building additional, sustainable options for evidence-based caregiver support services. IHS continues work developing the Project ECHO model to support Caregiver Coaches in Tribal Communities.

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**(COMPLETED) Action 3.B.8: Determine economic impacts of programs to support informal caregivers**

ASPE has completed a study on the economic impacts of programs to support informal caregivers. Informal caregiving is likely to grow in the coming decades as the "baby boomer" cohort ages. Not only will there likely be an increased need for caregiving, as disability increases with age, but the ratio of individuals potentially available for caregiving will decrease. For some caregivers of older adults and persons with disabilities, providing care may make it difficult or impossible to have paid employment, or if they do have employment, may make it difficult to advance their career. If they take time out of the labor force, they may face obstacles to returning to employment at all, or at a similar level of responsibility and pay at the level they had when they left. Both the direct costs in lost wages of not working, as well as the loss of seniority and retirement benefits may leave some caregivers economically vulnerable when they themselves age. In addition to the costs and benefits to caregivers, there are costs and benefits to the nation of informal caregiving. Inasmuch as unpaid caregiving replaces paid caregiving, unpaid caregivers may provide a net benefit to the country, reducing federal, state, and local caregiving expenditures. However, increased informal caregiving may also lead to reduced labor force participation, resulting in lower national economic growth as the number of individuals performing informal caregiving increases. Lack of support for informal caregivers may also lead to burnout and placement of the care recipient in a facility that is more costly to the government than earlier support services such as HCBS may have been. This research provides a framework for policy makers to begin estimating costs and benefits of policies and programs aimed to help caregivers, including, for example, respite care, paid family leave, and workplace flexibility policies. While researchers have established a number of relationships that can help inform government policies that impact informal caregiving, there are both gaps in knowledge, and lack of a consistent consideration of policies from an economic perspective. This project will organize existing information around caregiving to better understand the economic impacts of caregiving. A report will be posted shortly.

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**(NEW) Action 3.B.9: Develop and disseminate information to caregivers on Alzheimer's disease and related dementias and caregiving**

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CDC highlights the need for care planning for people with AD/ADRD and their caregivers. Care plans can reduce emergency room visits, hospitalizations, and improve overall medical management for people with a chronic health condition, like AD/ADRD resulting in better quality of life for all care recipients.

Features include: Helping people with AD/ADRD and their caregivers stay physically active; Care plans for older adults and their caregivers; and Brain health and heart health.

For more information, see:

- <https://www.cdc.gov/features/caregivers-month/index.html>
  - <https://www.cdc.gov/features/heart-brain-health/index.html>
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**Strategy 3.C: Assist Families in Planning for Future Care Needs**

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The vast majority of people do not think about or plan for the LTSS they will need until they experience a disability or AD/ADRD. Many Americans incorrectly believe that Medicare will cover most of the costs of these supportive long-term care services like nursing home care and HCBS. Unfortunately, by the time care is needed, it is difficult to get coverage in the private long-term care insurance market, and financing options are limited. Educating people about their potential need for LTSS and the significant advantages of planning ahead for these services encourages timely preparation. Planning ahead can help ensure that individuals with AD/ADRD receive care in the setting they prefer, preserve individual and family assets, and maintain dignity.

**(COMPLETED) Action 3.C.2: Understand the future of Medicaid long-term services and supports**

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This report examined the role of LTSS in Medicaid. It also examines how sociodemographic changes are likely to affect the demand for LTSS in the future, and as a result, Medicaid use and expenditures. The report shows: the demand for LTSS is likely to increase dramatically; LTSS is a major part of the Medicaid program, accounting for about a third of total expenditures; and Medicaid is the dominant payer of LTSS.

For more information, see:

- <https://aspe.hhs.gov/basic-report/overview-long-term-services-and-supports-and-medicaid-final-report>
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**(NEW) Action 3.C.3: Understand the functional trajectories of people with Alzheimer's disease and related dementias at the end of life**

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An expert panel on advanced dementia convened by the Institute of Medicine in 2014-2015 highlighted the need to better understand care for people with dementia near the end of life. PWD, whose prognosis is often difficult to determine, may not meet the criteria for hospice or may use hospice services for longer than the 6 months covered by Medicare. ASPE is working on a project to understand how the functional trajectories of people with dementia differ from those without dementia in the last few years of life, as well how these trajectories vary based on other characteristics such as co-morbidities, presence of a caregiver, and setting (e.g., nursing facility, assisted living, home). The project will also examine corresponding differences in health care utilization in the last few years of life to determine if there are differences between people with and without dementia.

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### **Strategy 3.D: Maintain the Dignity, Safety and Rights of People with Alzheimer’s Disease and Related Dementias**

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People with AD/ADRD are particularly vulnerable to financial exploitation, physical or emotional abuse, and neglect both at home and in care facilities. Reports of elder abuse are handled by state Adult Protective Services (APS), which investigate allegations, provide protective services, and refer cases to law enforcement when appropriate. Not all APS programs cover residents of long-term care facilities. State survey and certification agencies receive funding from CMS to survey Medicare or Medicaid-certified nursing facilities and to investigate abuse complaints in these facilities. State licensing agencies may investigate complaints of abuse in other types of facilities, such as assisted living. State Long-Term Care Ombudsman programs advocate for residents of nursing homes and other adult care facilities, and work to resolve complaints on behalf of residents, including those related to abuse, neglect, and exploitation. The actions below will help ensure that people with AD/ADRD have their dignity, safety, and rights maintained.

#### **(UPDATED) Action 3.D.1: Monitor, report and reduce inappropriate use of antipsychotics in nursing homes**

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The National Partnership to Improve Dementia Care in Nursing Homes met its goal of reducing the national prevalence of antipsychotic use in long-stay nursing home residents by 30% by the end of 2016 and recently announced a new goal of a 15% reduction by the end of 2019 for long-stay residents in those homes with currently limited reduction rates (late adopters).

CMS continues to conduct Focused Dementia Care Surveys, first initiated in 2014, to assist in determining compliance with areas such as quality dementia care, the use of non-pharmacological approaches, and utilization of antipsychotic medications. These focused reviews examine the process for prescribing antipsychotic medications and assess compliance with other federal requirements related to dementia care practices in nursing homes.

CMS has launched the Civil Money Penalty Reinvestment Program (CMPRP), a 3-year effort to drive improvements in quality of life and quality of care for nursing home residents. CMPRP is funded by the federal portion of civil money penalty (CMP) funds to conduct activities that support and protect nursing home residents. This program will build on other CMS initiatives, such as the National Partnership. A multi-pronged approach that focuses on those homes that have been identified as late adopters is being utilized. Through this effort, CMS will provide technical assistance, as well as use a Breakthrough Community collaborative model.

For more information, see:

- <https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/National-Partnership-to-Improve-Dementia-Care-in-Nursing-Homes.html>
- <https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/LTC-CMP-Reinvestment.html>

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#### **Action 3.D.2: Incorporate elder abuse awareness into Aging Network activities**

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ACL will continue to expand awareness and detection of elder abuse and neglect among the population of people with dementia. ACL will encourage the Eldercare Locator and other Aging Network and prevention program providers to become knowledgeable about warning signs of abuse. These providers will also disseminate information on elder abuse, with a particular focus on the vulnerable population of people with AD/ADRD. The National Center on Elder Abuse (NCEA) is funded by ACL and, through their programs, addresses all facets of elder abuse.

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For more information, see:

- <https://ncea.acl.gov/>

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### **Action 3.D.3: Translate and disseminate information on abuse of people with dementia**

ACL, NIH, and the U.S. Department of Justice (DoJ) have funded research to identify the factors associated with elder mistreatment. HHS will work with the private sector to translate these findings into educational materials and resources on abuse of people with dementia.

ACL continues to fund programs designed to address elder abuse. NCEA is funded by ACL and, through their programs, addresses all facets of elder abuse, including the abuse of individuals living with dementia.

In 2016, NIH published an “Age Page on Elder Abuse” to educate the public and disseminate information about types of elder abuse, dealing with caregiver stress, and how to help.

For more information, see:

- <https://ncea.acl.gov/>
- <https://www.nia.nih.gov/health/publication/elder-abuse>

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### **(UPDATED) Action 3.D.4: Improve the ability of legal services to address the needs of people with Alzheimer’s disease and related dementias**

ACL has a number of related activities underway to improve legal services for people with AD/DRD. In July 2013, ACL/Administration on Aging (AoA) awarded seven grants designed to enhance statewide legal assistance delivery systems. One aspect of these demonstration grants is the promotion of dementia-capable legal service delivery systems by involving organizations with substantial expertise and experience in serving persons, families, and communities affected by AD/DRD. Collaborations are occurring among stakeholders, including legal services providers and AD/DRD organizations. These collaborations will focus on the identification of and responses to legal problems affecting persons with AD/DRD, including issues related to abuse, neglect and financial exploitation, specifically by: Redesigning and expanding the ACL National Legal Resource Center (NLRC) website to include a special section addressing advance planning and end-of-life issues. This will be a resource for legal and aging/disability service professionals and family caregivers assisting people with AD/DRD or other causes of diminished capacity.

ACL funded state and community grants programs include pilot programs designed to make dementia-capable legal services available to PWD and their caregivers. Program participants are providing dementia training to legal services providers, as well as implementing voucher programs to aide in advance planning.

In 2017, the NADRC designed and published *Living with Dementia: Advance Planning Guides (FOUR guides) for Persons with Dementia and Caregivers*. ACL’s NADRC continues to work closely with the American Bar Association’s Commission on Law and Aging in the development of resources that support PWD and their caregivers in legal matters.

For more information, see:

- <http://www.nlrc.aoa.gov/NLRC/Index.aspx>
  - <https://nadrc.acl.gov/node/137>
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**(COMPLETED) Action 3.D.5: Develop public-private partnerships to combat abuse and exploitation of Social Security beneficiaries**

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An interagency, public-private partnership program completed work to address abuse and exploitation of individuals who are incapable of managing their finances and are participating in the Social Security Administration's (SSA's) Representative Payee Program. SSA, ACL/AoA, the Corporation for National and Community Service (CNCS), the Consumer Finance Protection Bureau and private entities are developing two pilot programs to identify and recruit suitable individuals within the communities to serve as trusted representative payees for participating SSA beneficiaries. The pilot programs will be used to develop a toolkit for recruiting and retaining trusted individuals to serve as representative payees which can be shared with entities like AoA's Aging Network and CNCS's Senior Corps.

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**(UPDATED) Action 3.D.6: Educate law enforcement about interacting with Alzheimer's disease and related dementias**

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DoJ will continue to educate law enforcement and public safety professionals about how to interact appropriately with missing persons with AD/ADRD, and provide current information and resources to help law enforcement agencies and the communities they serve. The education will include how to prevent persons with AD/ADRD from wandering and becoming lost, as well as information on locating those who do wander and become lost. The training and resources are provided through projects funded by the Office of Justice Programs' Bureau of Justice Assistance.

As part of their funded grants, several ACL Alzheimer's Disease Initiative-Specialized Supportive Services (ADI-SSS) community projects are training law enforcement and other first responders. One grantee created a series well received law enforcement training videos to address wandering, driving and encountering disoriented individuals on "house calls".

For more information, see:

- <https://www.youtube.com/watch?v=cQbmCq7rC7A&feature=youtu.be>

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**(UPDATED) Action 3.D.7: Work with communities to develop best practices for protecting people with Alzheimer's disease and related dementias**

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DoJ will produce a guide that will educate law enforcement and inform communities, families and caregivers about best practices for the development of a community-wide, "holistic" approach to protecting persons with AD/ADRD and preventing them from wandering and becoming lost. The guide will provide law enforcement agencies with resources and a toolkit for building community collaborations designed to aid in the rapid location of those persons who wander and are reported missing.

As part of their funded grants, several ACL ADI-SSS community projects are training law enforcement and other first responders. One grantee created a series well received law enforcement training videos to address wandering, driving and encountering disoriented individuals on "house calls".

For more information, see:

- <https://www.youtube.com/watch?v=cQbmCq7rC7A&feature=youtu.be>
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**(COMPLETED) Action 3.D.8: Expand access to treatment for people with mental health and substance use disorders**

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A Mental Health and Substance Use Disorder Parity Task Force was created to expand access to treatment for people with mental health and substance use disorders. The Task Force focused key federal agencies on the work of ensuring that Americans receive the coverage and treatment that they need.

The objectives of the Task Force were to:

- Increase awareness of the protections that mental health and substance use disorder parity provide.
- Improve understanding of the requirements of mental health and substance use disorder parity among key audiences including health plans, insurers and state regulators.
- Increase transparency around compliance with parity and the support, resources, and tools available to ensure coverage is in compliance with mental health and substance use disorder parity.

The Task Force issued its Final Report, which highlights the progress to date on parity implementation, summarizes comments from stakeholders and actions taken during the Task Force's tenure, and offers recommendations on how to:

- Support consumers,
- Improve parity implementation, and
- Enhance parity compliance and enforcement.

For more information, see:

- <https://www.hhs.gov/about/agencies/advisory-committees/mental-health-parity/task-force/index.html>
- <https://www.hhs.gov/about/agencies/advisory-committees/mental-health-parity/task-force/final-report/index.html>

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**(NEW) Action 3.D.9: Expand coverage of behavioral health services via employment-based health plans and health insurance**

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Congress passed the Paul Wellstone and Pete Domenici Mental Health Parity and Addiction Equity Act (MHPAEA) of 2008 with the goal of increasing coverage of behavioral health services for a growing number of Americans. MHPAEA, which applies to employment-based group health plans and health insurance issuers that insure such plans, does not require health plans to provide behavioral health care coverage -- it only requires that those issuers and plans that choose to provide mental health and substance use disorder benefits must cover it in parity with medical and surgical benefits. The Affordable Care Act extended parity to non-grandfathered individual insurance plans and small group health plans. Beginning in 2017, the requirements of MHPAEA apply to Medicaid Managed Care Organizations, Medicaid benchmark and benchmark-equivalent plans, and the Children's Health Insurance Program.

Parity applies to quantitative treatment limitations (QTLs), for example restrictions on the number of days, episodes, or treatments that are covered and financial requirements, such as copays and coinsurance. Generally, plans must ensure that the limits imposed on behavioral health benefits must be comparable to what is imposed on medical and surgical benefits. In addition, non-quantitative treatment limitations (NQTLs), such as the use of utilization review by an issuer or prior authorization requirements, cannot be more restrictive for behavioral health benefits coverage than for medical and surgical coverage, unless the standard used to develop and apply the NQTL is comparable for both types of care.

ASPE, along with representatives from CMS, Substance Abuse and Mental Health Services Administration (SAMHSA), in coordination with Department of Labor (DoL), Department of the

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Treasury, and the Office of Personnel Management (OPM), held a public listening session on parity implementation in Washington, D.C. on July 27, 2017, and accepted written comments on this issue from stakeholders and interested parties. This public comment was used to create an Action Plan for Enhanced Enforcement of Mental Health and Substance Use Disorder Coverage. The Action Plan and other patient tools can be found online.

For more information, see:

- <https://www.hhs.gov/programs/topic-sites/mental-health-parity/index.html>
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### **Strategy 3.E: Assess and Address the Housing Needs of People with Alzheimer's Disease and Related Dementias**

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Stable housing is essential to helping people with AD/ADRD remain in the community, particularly as they experience an increasing need for services and supports as the disease progresses. Housing is a crucial platform for delivering the necessary health and supportive services. Recognizing these links, HHS and the U.S. Department of Housing and Urban Development (HUD) are working together to improve health outcomes and housing stability through supportive services for vulnerable populations including people with AD/ADRD. Through the actions below, HHS will assess the availability of services in the settings where people with AD/ADRD live. This information will form the basis of future actions to further link housing with services for people with AD/ADRD.

#### **(UPDATED) Action 3.E.1: Evaluate the Support And Services at Home program**

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ASPE and HUD continue to evaluate the Support And Services at Home (SASH) program in Vermont. Early findings show a promising model of coordinated health and supportive services within affordable housing settings. Using claims data for a sample of Medicare fee-for-service (FFS) beneficiaries, the evaluation analyzed health care utilization and expenditures among SASH participants and a comparison group of Medicare beneficiaries living in affordable housing properties in Vermont. Analysis of Medicare claims data indicated that SASH participants in the early panels -- which included 40% of the site-based participants with Medicare coverage -- had lower rates of all-cause hospital admissions compared to non-participants. However, there was no evidence that the SASH program reduced the rates of emergency room visits. Medicare claims data also showed that, among the site-based SASH participants in early panels, growth in annual Medicare expenditures was slower by an estimated \$1,227 per beneficiary per year. These same beneficiaries in the early panels also had slower rates of growth for hospital and specialty physician costs. HUD has released a new article on the results, and forthcoming products will show outcomes from the first 4 years of the program.

For more information, see:

- <https://www.huduser.gov/portal/periodicals/cityscope/vol20num2/ch1.pdf>
  - <https://aspe.hhs.gov/basic-report/support-and-services-home-sash-evaluation-second-annual-report>
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#### **(NEW) Action 3.E.2: Assess utilization of home health benefits**

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ASPE continues to study the growth in use of the Medicare home health benefit by community-admitted users. The Medicare home health payment policy for FFS has undergone several changes in the past decades. There have also been overall increases in Medicare home health utilization. Growth in utilization has been particularly strong for community-admitted users (those individuals for whom home health episodes are not preceded by a hospitalization or post-acute care stay). The Medicare Payment Advisory Commission (MedPAC) has suggested that this is indicative of the fact that some beneficiaries may be using the home health benefit as a long-term

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care benefit. Several alternative explanations for the growth of the community-admitted users are plausible. Indeed, a recent Academy Health meeting on post-acute care noted that as the American population ages, those with chronic conditions will likely cycle between post-acute care and chronic care services. This research will focus on detailed beneficiary characteristics and the trajectory of care of the community-admitted users to clarify the source of the growth in the benefit for this group of beneficiaries using home health, identify possible gaps in care or inefficient use of services, and inform benefit design.

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## Goal 4: Enhance Public Awareness and Engagement

Most of the public is aware of AD/ADRD; more than 85% of people surveyed can identify the disease and its symptoms. AD/ADRD is also one of the most feared health conditions, yet there are widespread and significant public misperceptions about diagnosis and clinical management. Misperceptions lead to delayed diagnosis and to people with the disease and their caregivers feeling isolated and stigmatized. Enhancing public awareness and engagement is an essential goal because it forms the basis for advancing the subsequent goals of the National Plan. A better understanding of AD/ADRD will help engage stakeholders who can help address the challenges faced by people with the disease and their families. These stakeholders include a range of groups such as health care providers who care for people with AD/ADRD and their caregivers, employers whose employees request flexibility to care for a loved one with the disease, groups whose members are caregivers, and broader aging organizations. The strategies and actions under this Goal are designed to educate these and other groups about the disease.

### Strategy 4.A: Educate the Public about Alzheimer's Disease and Related Dementias

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Greater public awareness of AD/ADRD can encourage families to seek assessment, reduce isolation and misunderstanding felt by caregivers, and help link people in need to accurate information, resources and services.

#### **(UPDATED) Action 4.A.1: Enhance public outreach about Alzheimer's disease and related dementias**

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Through its grant and resource center programs, ACL continues to build awareness of AD/ADRD. All ACL grantees include awareness and outreach in their programs. Numerous grantee programs include dementia-friendly community activities in their projects, partnering with established AD/ADRD stakeholders, as well as training volunteer educators of community organizations including, but not limited to, faith-based organizations, business leaders and grass roots volunteer organizations like Rotary clubs.

NIA operates the ADEAR Center, the primary Federal Government resource for information about AD/ADRD, research, and caregiving. The ADEAR Center educates the public about the latest research findings and provides evidence-based information online, in print and via a call center. Information about AD/ADRD, participation in clinical trials, and caregiving is freely available. NIA promotes ADEAR's resources through outreach in the research and care communities and through media and advocacy organizations, via weekly e-alerts to more than 50,000 subscribers, and social media outreach to more than 10,000 followers.

For more information, see:

- <https://www.alzheimers.gov/>
- <https://nadrc.acl.gov/>

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#### **(COMPLETED) Action 4.A.2: Dementia Chart Book**

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ASPE completed a chart book, "Older Adults with Dementia and Their Caregivers in 2015: Key Indicators from the National Health and Aging Trends Study", which describes the population of people with dementia in the United States living in the community and their caregivers. Dementia was more prevalent among people who were over age 80, had lower educational attainment, and were non-White. Older adults with dementia were more likely than those without dementia to have multiple chronic conditions, have functional limitations, experience depressive symptoms, or to need assistance. Older adults with dementia received significantly more hours of care per

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month than those without dementia. They had more informal caregivers and received more hours of care from those caregivers. Expected release Fall 2018.

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**(NEW) Action 4.A.3: Facilitate translation of data and surveillance to inform the public**

CDC provided funds to the Alzheimer's Association to develop, using BRFSS data, several fact sheets and infographics. These resources are marketed on their website, and distributed to a national network of state Alzheimer's Association offices, public health professionals, and decision makers. These resources are updated annually, as new data becomes available. By creating easy-to-read, visually appealing materials, uptake of knowledge is facilitated.

CDC also supported the Alzheimer's Association to develop a Needs Assessment Toolkit that serves as Guidance and Resources for State Public Health Agencies on Comprehensive Needs Assessments Related to Alzheimer's and Other Dementias. This document aims to increase the use of information and insights to appropriately respond to the growing public health burden associated with Alzheimer's and other dementias through comprehensive needs assessments. These are at the core of a state's ability to effectively use information to develop, implement, and maintain state plans that are focused either exclusively on Alzheimer's and other dementias, or more broadly on the incorporation of cognitive health and impairment into other state public health plans. Public health agencies have a high level of expertise related to developing and conducting needs assessments. This toolkit has been developed to help states leverage their expertise in conducting needs assessments to enhance their ability to gather and use information specifically related to Alzheimer's and other dementias.

For more information, see:

- [https://www.alz.org/documents\\_custom/public-health/spotlight-assessment.pdf](https://www.alz.org/documents_custom/public-health/spotlight-assessment.pdf)

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**(COMPLETED) Action 4.A.4: Publish a pamphlet to provide the public with information on dementia**

NINDS and NIA have updated and published "The Dementias: Hope Through Research," a pamphlet that is meant to provide the general public with in-depth information about AD/DRD, including common symptoms, diagnosis, and available therapies.

For more information, see:

- <https://catalog.ninds.nih.gov/ninds/product/Dementias-Hope-Through-Research/17-NS-2252>

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**Strategy 4.B: Work with State, Tribal, and Local Governments to Improve Coordination and Identify Model Initiatives to Advance Alzheimer's Disease and Related Dementias Awareness and Readiness across the Government**

State, Tribal, and local governments are working to help address challenges faced by people with AD/DRD and their caregivers. Nineteen states and a handful of local entities have published plans to address AD/DRD that cover many of the same issues as the National Plan. Leveraging the available resources and programs across these levels of government will aid in the success of these efforts.

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**Action 4.B.1: Continue to convene federal partners**

The Interagency Group on Alzheimer's Disease and Related Dementias, convened on an ongoing basis since April 2011, provides a forum for discussion of AD/DRD efforts across

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federal departments and agencies. Participants in this group have gained a better understanding of the roles and responsibilities of other departments and agencies for addressing AD/ADRD. Together, the group has identified existing resources and new opportunities for collaboration, best practices, and initiatives. HHS will continue to convene federal partners to collaborate on AD/ADRD. The group will share research findings, innovative or best practices, and information about new or upcoming initiatives.

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#### **Action 4.B.2: Build upon lessons learned to improve the dementia-capacity of state and local service systems**

HHS will improve the dementia-capability of state and community service systems through the ACL's Alzheimer's Disease Programs Initiative (ADPI). ADPI grantees, partners and other collaborators will work in peer-led groups on specific activities to make state and local-level improvements related to dementia-capability. The peer-led groups will develop practical tools to promote the adoption of dementia-capable practices at the state and local-levels. HHS will help states and communities meet the needs of people with AD/ADRD through an expanded Dementia Capability Toolkit and other, related resources. Additional materials will result from similar program activities. Alzheimer's Disease Supportive Services Program (ADSSP), ADI-SSS, and ADPI grantees and their Resource Center provide new and improved resources every year.

For more information, see:

- <https://nadrc.acl.gov/>

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#### **(UPDATED) Action 4.B.3: Get Tribal input on Alzheimer's disease and related dementias and support improved coordination between Indian Health Service, Tribal, and Urban Indian Health programs and the Tribal aging network**

HHS will solicit input from Tribal leaders on the impact of AD/ADRD on Indian Country during the annual Tribal Consultation process and through broader meetings and convenings. HHS will use these opportunities to convene leaders and solicit input on the needs related to recognition, diagnosis, and support for individuals with dementia and their families.

HHS will improve coordination between IHS, Tribal, and Urban Indian health programs and the Tribal Aging Network around four person-centered goals:

1. ***I was diagnosed in a timely way*** (diagnosis and assessment). IHS and ACL will pilot-test a campaign focused on recognition of dementia warning signs, adapting a current VA approach and piloting this in clinical and community-based settings. IHS will also develop decision support for the evaluation of an individual with possible dementia for the IHS EHR.
  2. ***I know what I can do to help myself and who else can help me*** (information and referral). IHS and ACL will partner with AD/ADRD advocacy organizations to link state and local chapters with Tribal senior centers and Tribal, IHS, and Urban Indian health facilities.
  3. ***Those helping to look after me feel well supported*** (family and caregiver support). The IHS will assess the current pilot-test of REACH-VA caregiver support program for expansion through training of public health and community health nursing programs. ACL will pilot-test REACH-VA in Tribal Senior Centers receiving funding under Older Americans Act Title VI, Part C (caregiver support).
  4. ***My wishes for care are supported*** (self-directed, person-centered planning). ACL will support the use of funds awarded under Older Americans Act Title VI, Parts A and C for tools to assist PWD in communicating their wishes for care. ACL and IHS will identify
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strategies for coordination between the Tribal Aging Network and clinical services to foster self-direction and person-centered planning for persons with AD/ADRD.

The Alzheimer's Association has started meetings with the United South and Eastern Tribes and with the Northwest Portland Area Indian Health Board. There has been increased Tribal representation on the Alzheimer's Association/CDC HBI Road Map work.

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**(NEW) Action 4.B.4: Develop and update a public health Road Map for assisting state, Tribal, and local health departments in prioritizing actions**

CDC supported the Alzheimer's Association to co-develop the third in a series of HBI Road Maps to advance cognitive health as an integral component of public health. This "Healthy Brain Initiative State and Local Public Health Partnerships to Address Dementia, the 2018-2023 Road Map", outlines how state and local public health agencies and their partners can continue to promote cognitive health, address cognitive impairment for people living in the community, and help meet the needs of caregivers. Twenty-five specific actions are proposed in four traditional domains of public health: educate and empower, develop policies and mobilize partnerships, assure a competent workforce, and monitor and evaluate.

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**(NEW) Action 4.B.5: Facilitate translation of findings into public health practice in Tribal communities**

In conjunction with the Alzheimer's Association and other partners, CDC is developing a special edition of the "Public Health Road Map for Tribal Communities: The Healthy Brain Initiative Road Map for Indian Country". The original Road Map focuses on issues pertinent to state and local public health agencies and their partners. A companion Road Map for Indian Country has been designed specifically for public health systems serving American Indians and Alaskan Natives.

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**Strategy 4.C: Coordinate United States Efforts with Those of the Global Community**

Many nations have developed dementia plans of their own that involve improved care and supports for people with AD/ADRD and their caregivers, as well as enhanced research and public awareness. In implementing the actions in this Plan, HHS and its federal partners will coordinate with global partners to enhance these plans, avoid duplication of effort, and optimize existing resources.

**(ON HOLD) Action 4.C.1: Work with global partners to enhance collaboration**

United States participated in legacy meetings throughout 2014. United States hosted the final legacy meeting in February 2015, and was represented at the World Health Organization (WHO) Dementia meeting in Geneva in March 2015.

International work in the dementia space is on hold pending Administration priorities.

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## Goal 5: Improve Data to Track Progress

The Federal Government is committed to better understanding AD/DRD and its impact on people with the disease, families, the health and long-term care systems, and society as a whole. Data and surveillance efforts are paramount to tracking the burden of AD/DRD on individual and population health and will be used to identify and monitor trends in risk factors associated with AD/DRD, and assist with understanding health disparities among populations such as racial and ethnic minorities, low income populations, rural residents, and sexual and gender minorities. HHS will make efforts to expand and enhance data infrastructure and make data easily accessible to federal agencies and other researchers. This data infrastructure will help HHS in its multi-level monitoring and evaluation of progress on the National Plan.

### Strategy 5.A: Enhance the Federal Government's Ability to Track Progress

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The Federal Government needs improved data on people with AD/DRD, their caregivers, and the care and supports that they use to address policy questions and plan and evaluate new initiatives. HHS and its partners will identify the policy questions that cannot be answered with existing data, as well as questions likely to arise in the future. These questions will provide a mechanism for identifying gaps, challenges, and changes or additions to data collection.

#### **Action 5.A.1: Identify needed changes or additions to data**

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HHS will work with federal partners and researchers to identify the data and data infrastructure needed to address new policy issues. These changes or additions may include new or improved measures, new data collection efforts, or links between existing datasets.

#### **Action 5.A.2: Make needed improvements to data**

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HHS will address the identified data needs or possible improvements and develop questions to be fielded for data collection. These questions may be added to existing studies, be part of supplements to existing studies, or form the basis of a new study.

#### **(UPDATED) Action 5.A.3: Summarize data on cognitive impairment across states**

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CDC worked with partners and revised the BRFSS Cognitive Decline and Caregiving Optional Modules, which were approved as official optional modules beginning in 2015. In 2015 and 2016, 51 states and territories collected data using the Cognitive Decline Module and 40 states collected data using the Caregiving Module. Additional states are collecting data using the Cognitive Caregiving Modules in 2017. Findings from the 2015 cognitive and caregiving data are publicly available on CDC's Healthy Aging Data Portal and fact sheets and infographics were developed for each participating state. Findings from 2016 BRFSS were released late in 2017.

CDC supported the development and collection of subjective cognitive decline and cognitive functioning data from the in-person National Health and Nutrition Examination Survey (NHANES), which are publically available for download and analysis. These data were collected in adults 60 years and older as part of the 2011-2012 and 2013-2014 data collection cycles. The data included in this release include results from three tests of cognitive function: the Consortium to Establish a Registry for Alzheimer's Disease (CERAD) Word Learning subtest, a test of Animal Fluency, and the Digit Symbol Substitution Test.

For more information, see:

- <https://www.cdc.gov/aging/agingdata/index.html>
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- <http://www.alz.org/publichealth/data-collection.asp>
  - <https://www.cdc.gov/aging/healthybrain/surveillance.htm>
  - <http://www.cdc.gov/nhanes>
  - <https://www.cdc.gov/aging/healthybrain/surveillance.htm>
  - [https://wwwn.cdc.gov/Nchs/Nhanes/2013-2014/CFQ\\_H.htm](https://wwwn.cdc.gov/Nchs/Nhanes/2013-2014/CFQ_H.htm)
  - [https://wwwn.cdc.gov/Nchs/Nhanes/2011-2012/CFQ\\_G.htm](https://wwwn.cdc.gov/Nchs/Nhanes/2011-2012/CFQ_G.htm)
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**(UPDATED) Action 5.A.4: Develop and disseminate measures of awareness of Alzheimer’s disease and related dementias**

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CDC is examining the validity of subjective cognitive questions used in national surveys by comparing self-rated perceptions of cognitive functioning to functional measures. The report will be released in 2019.

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**(UPDATED) Action 5.A.5: Summarize existing data on people with Alzheimer’s disease and related dementias and their caregivers**

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CDC’s Healthy Aging Data Portal, which provides access to a range of national, regional, and state data on older adults, was updated with the *Public Data Portal on the Health of Older Adults*. This resource was developed by the National Center for Chronic Disease Prevention and Health Promotion. It allows users to examine data on key indicators of health and well-being for older Americans, such as tobacco and alcohol use, screenings and vaccinations, and mental and cognitive health. 2016 BRFSS data, includes data on cognitive decline from 49 states, Washington, D.C., and Puerto Rico and data on caregivers from 38 states, Washington, D.C., and Puerto Rico. Portal users can retrieve CDC data by indicator or by geographic area, and then use these data to develop reports and create customized maps, charts, and graphics. Public health professionals can use the data to create a snapshot of the health of older adults in their states, which can help them prioritize and evaluate public health interventions.

For more information, see:

- <https://www.cdc.gov/aging/agingdata/index.html>
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**(ONGOING) Action 5.A.6: Develop a consistent set of International Classification of Diseases codes for Alzheimer’s disease and related dementias for federal agencies to use in analyses of administrative data**

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Across the departments and agencies working to address AD/ADRDs, a number of different International Classification of Diseases, 9th revision (ICD-9) and 10th revision (ICD-10) codes are used to identify the population with AD/ADRD when analyzing administrative claims. HHS formed an interagency group to identify which codes should be used consistently across these entities so that analyses and publications are describing the same population. The workgroup has established a cross-walk of diagnostic code sets across agencies as a precursor to defining a common code set or sets. This may be seen as a harmonization exercise across multiple code sets, with the proposed use of the code set (e.g., research, clinical improvement) determining selection.

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## Strategy 5.B: Monitor Progress on the National Plan

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The National Plan is intended to be a Road Map for accomplishing its five goals. It is a document that is designed to be updated regularly. HHS is committed to tracking progress and incorporating findings into an updated National Plan.

### **Action 5.B.1: Track National Plan progress**

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HHS will monitor progress to determine whether actions are being completed as stated in the National Plan and the extent to which implemented actions contribute to the desired outcomes and changes associated with each strategy. HHS and its federal partners will identify challenges to the successful completion of strategies and actions, and make recommendations for how they can be addressed. For each *strategy*, HHS will monitor available population-based data, such as the NHATS, MCBS, or the BRFSS to assess the extent to which progress is being made. HHS will use data from both the public and private sectors, as appropriate, to track progress on the National Plan. Additionally, HHS will work to incorporate measures related to AD/ADRD into other surveillance efforts to monitor population health, such as Healthy People 2020 and Healthy People 2030 which incorporate objectives related to AD/ADRD.

For each *action*, HHS will track implementation to determine whether actions are completed in a timely and successful manner. Appendix 2 provides a timeline, method of action, and identifies lead and partner agencies for each action step in the Plan. Progress on each of these actions will be reported to the Advisory Council.

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### **Action 5.B.2: Update the National Plan annually**

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Tracking progress will help HHS and the Advisory Council monitor progress towards the goals of the National Plan and make recommendations for priority actions and updates to the National Plan. HHS will incorporate its findings and the recommendations of the Advisory Council to update the National Plan on an annual basis.

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## Appendix 1: List of Participating Departments and Agencies

ACF -- Administration for Children and Families

ACL -- Administration for Community Living

AHRQ -- Agency for Healthcare Research and Quality

AIDD -- Administration on Intellectual and Developmental Disabilities

AoA -- Administration on Aging

ASPA -- Office of the Assistant Secretary for Public Affairs

ASPE -- Office of the Assistant Secretary for Planning and Evaluation

CDC -- Centers for Disease Control and Prevention

CFPB -- Consumer Finance Protection Bureau

CMS -- Centers for Medicare & Medicaid Services

DoD -- Department of Defense

FDA -- Food and Drug Administration

HHS -- Department of Health and Human Services

HRSA -- Health Resources and Services Administration

HUD -- Department of Housing and Urban Development

IEA -- Office of Intergovernmental and External Affairs

IHS -- Indian Health Service

NIA -- National Institute on Aging

NICHD -- Eunice Kennedy Shriver National Institute of Child Health and Human Development

NIH -- National Institutes of Health

NIMHD -- National Institute on Minority Health and Health Disparities

NINDS -- National Institute of Neurological Disorders and Stroke

NSF -- National Science Foundation

OASH -- Office of the Assistant Secretary for Health

OD -- Office on Disability

OGA -- Office of Global Affairs

ONC -- Office of the National Coordinator of Health Information Technology

OSG -- Office of the Surgeon General

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SAMHSA -- Substance Abuse and Mental Health Services Administration

VA -- Office of Veterans Affairs

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## Appendix 2: Implementation Milestones

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2017 and 2018
<b>Goal 1: Prevent and Effectively Treat Alzheimer's Disease and Related Dementias by 2025</b>						
<b>Strategy 1.A: Identify Research Priorities and Milestones</b>						
1.A.1	Regularly convene an AD Research Summit to update priorities.	Summit held 2018. Summit scheduled for 2021.	NIH/NIA	National and international experts, public and private stakeholders, Research Subgroup, academia, industry, professional and advocacy groups	Ongoing  Second Summit February 2015  Third Summit March 2018  Fourth Summit TBD 2021	2018 AD Research Summit <a href="https://www.nia.nih.gov/research/nih-ad-summit-2018-program-agenda">https://www.nia.nih.gov/research/nih-ad-summit-2018-program-agenda</a>
1.A.2	Solicit public and private input on AD/ research priorities.	Developed recommendations and milestones from 2018 AD Research Summit based on feedback from external stakeholders.  Presented recommendations and milestones during IADRFC calls.	NIH/NIA		Ongoing  Recommendations and Milestones were updated following the Summit in May 2018	2018 AD Summit Recommendations <a href="https://www.nia.nih.gov/research/administration/recommendations-nih-ad-research-summit-2018">https://www.nia.nih.gov/research/administration/recommendations-nih-ad-research-summit-2018</a>  2017 National Research Summit on Care, Services and Supports for Persons with Dementia and their Caregivers. <ul style="list-style-type: none"> <li><a href="https://aspe.hhs.gov/advisory-council-october-2016-meeting-presentation-summit-care-update">https://aspe.hhs.gov/advisory-council-october-2016-meeting-presentation-summit-care-update</a></li> <li><a href="https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers">https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers</a></li> </ul> Updated AD Research Implementation Milestones <a href="https://www.nia.nih.gov/alzheimers/milestones">https://www.nia.nih.gov/alzheimers/milestones</a>
1.A.3	Regularly update the National Plan and refine Goal 1 strategies and action items based on feedback and input.	Update Goal 1 elements of the National Plan to reflect new insights and input from the community.	ASPE	Advisory Council, NIH/NIA, Research Subgroup	Ongoing	
1.A.4	Update research priorities and milestones.	Updated research priorities and milestones.	ASPE	Advisory Council, NIH/NIA, Research Subgroup	Ongoing	

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1.A.5	Create a timeline with milestones for achieving Goal 1.	Create and update milestone document.	NIH/NIA, NIH/NINDS		Ongoing	<p>Updated AD/ADRD Research Implementation Milestones</p> <p>Full set of milestones through 2025  <a href="https://www.nia.nih.gov/alzheimers/milestones">https://www.nia.nih.gov/alzheimers/milestones</a></p> <p>2018 Milestones  <a href="https://www.nia.nih.gov/sites/default/files/AD/FY2018-Alzheimers-Disease-Related-Dementias-Budget-Bypass-Milestones-508.pdf">https://www.nia.nih.gov/sites/default/files/AD/FY2018-Alzheimers-Disease-Related-Dementias-Budget-Bypass-Milestones-508.pdf</a></p> <p>2019 Milestones  <a href="https://www.nia.nih.gov/sites/default/files/2017-07/FY2019-AD-ADRD-Milestones.pdf">https://www.nia.nih.gov/sites/default/files/2017-07/FY2019-AD-ADRD-Milestones.pdf</a></p>
1.A.6	Regularly convene an ADRD Summit to review progress on ADRD research recommendations and refine and add new recommendations as appropriate, based on recent scientific discoveries.	Convene 3rd summit in 2019.	NIH/NINDS	Research Subgroup, academia, industry, professional and advocacy groups	Third Summit expected March 14-15, 2019	<p>Final recommendations from the ADRD 2016 Summit became the ADRD Summit 2016 Prioritized Research Milestones.  <a href="https://aspe.hhs.gov/alzheimers-disease-related-dementias-adrd-summit-2016-prioritized-research-milestones">https://aspe.hhs.gov/alzheimers-disease-related-dementias-adrd-summit-2016-prioritized-research-milestones</a></p> <p>The third ADRD Summit will be on March 14-15, 2019.</p>



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1.A.7	Convene a workshop focused on research needs related to Down syndrome and AD/ADRD.	Hold a workshop to solicit input on special research priorities and timelines AD/ADRD among people with Down syndrome.	NIH/NIA	DSRTF, RDS, NIH/NICHD, NIH/NINDS	Completed	<p>Input solicited on special research priorities related to Down syndrome research.</p> <p>Sponsorship of a workshop, with NICHD, NIA, NINDS, DSRTF, and RDS: "Advancing Treatments for Alzheimer's Disease in Individuals with Down Syndrome," held April 16-17, 2013. Brought together ~50 stakeholders to discuss partnerships involving the AD and Down syndrome research community, efforts that have been sustained over the past 4 years</p> <p>NIA and NICHD collaborated to produce and disseminate information for people with Down syndrome and their families on the interplay of these conditions and the importance of participating in research. Efforts include a fact sheet, "Alzheimer's Disease in People with Down Syndrome", and outreach via email and social media.  <a href="https://www.nia.nih.gov/alzheimers/publication/alzheimers-disease-people-down-syndrome">https://www.nia.nih.gov/alzheimers/publication/alzheimers-disease-people-down-syndrome</a></p> <p>Alzheimer's Biomarker Consortium--Down Syndrome aims to identify biomarkers that indicate AD is developing or progressing and track the AD process in people with Down syndrome.  <a href="https://www.nia.nih.gov/alzheimers/alzheimers-biomarkers-consortium-down-syndrome-abc-ds">https://www.nia.nih.gov/alzheimers/alzheimers-biomarkers-consortium-down-syndrome-abc-ds</a></p> <p>Additionally, NIA is currently funding a Phase I clinical trial to investigate the safety and tolerability of an immunotherapy vaccine for treatment of AD in adults with Down syndrome.  <a href="https://health.ucsd.edu/news/releases/Pages/2016-01-13-clinical-trial-alzheimers-characteristics-in-down-syndrome.aspx">https://health.ucsd.edu/news/releases/Pages/2016-01-13-clinical-trial-alzheimers-characteristics-in-down-syndrome.aspx</a></p>
1.A.8	Regularly convene a Research Summit on Care, Services, and Supports for PWD and their Caregivers	<p>First Summit held 2017.</p> <p>Second Summit scheduled for 2020.</p>	ASPE, NIH	Advisory Council, academia, industry, professional and advocacy groups	Ongoing	<p>The final Summit report from the 2017 National Research Summit on Care, Services and Supports for Persons with Dementia and their Caregivers was released in April 2018  <a href="https://aspe.hhs.gov/basic-report/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers-final-summit-report">https://aspe.hhs.gov/basic-report/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers-final-summit-report</a></p>

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<b>Strategy 1.B: Expand Research Aimed at Preventing and Treating Alzheimer's Disease and Related Dementias</b>						
1.B.1	Expand research to identify the molecular and cellular mechanisms underlying AD/ADRD, and translate this information into potential targets for intervention.	Develop an integrated interdisciplinary basic science research agenda to enable the identification and selection of therapeutic targets.	NIH/NIA, NIH/NINDS	potential research partners in the public and private sectors	Ongoing	<p>Ongoing and newly released NIH FOAs:</p> <ul style="list-style-type: none"> <li>• PAR-18-029: Clarifying the Relationship between Delirium and AD/ADRD <a href="https://grants.nih.gov/grants/guide/pa-files/PAR-18-029.html">https://grants.nih.gov/grants/guide/pa-files/PAR-18-029.html</a></li> <li>• PAR-18-413: Mechanistic Basis of Diffuse White Matter Disease and Small Vessel Pathology in VCID <a href="https://grants.nih.gov/grants/guide/pa-files/PAR-18-413.html">https://grants.nih.gov/grants/guide/pa-files/PAR-18-413.html</a></li> <li>• PAR-18-497: Sleep disorders and circadian clock disruption in AD/ADRD of aging <a href="https://grants.nih.gov/grants/guide/pa-files/PAR-18-497.html">https://grants.nih.gov/grants/guide/pa-files/PAR-18-497.html</a></li> <li>• PAR-18-516: Human Cell Biology of AD Genetic Variants <a href="https://grants.nih.gov/grants/guide/pa-files/PAR-18-516.html">https://grants.nih.gov/grants/guide/pa-files/PAR-18-516.html</a></li> <li>• PAR-18-519: Sensory and motor system changes as predictors of preclinical AD <a href="https://grants.nih.gov/grants/guide/pa-files/PAR-18-519.html">https://grants.nih.gov/grants/guide/pa-files/PAR-18-519.html</a></li> <li>• PAR-18-544: Basic and Translational Research on Decision Making in Aging and AD <a href="https://grants.nih.gov/grants/guide/pa-files/PAR-18-544.html">https://grants.nih.gov/grants/guide/pa-files/PAR-18-544.html</a></li> <li>• PA-18-545: Research on the Mechanisms and/or Behavioral Outcomes of Multisensory Processing <a href="https://grants.nih.gov/grants/guide/pa-files/PA-18-545.html">https://grants.nih.gov/grants/guide/pa-files/PA-18-545.html</a></li> <li>• PAR-18-596: In vivo Synaptic Function in AD/ADRD <a href="https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-001.html">https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-001.html</a></li> <li>• PAR-18-596: Deciphering the Glycosylation Code of AD <a href="https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-001.html">https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-001.html</a></li> <li>• PAR-18-596: Geroscience Approaches to AD: Acceleration of Phenotypes in Asymptomatic Models of AD <a href="https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-001.html">https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-001.html</a></li> <li>• PAR-18-596: Geroscience Approaches to AD: Delay of Phenotypes in Current Models of AD <a href="https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-001.html">https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-001.html</a></li> </ul>

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1.B.1 (cont.)						<ul style="list-style-type: none"> <li>• PAR-18-596: Genetic Underpinnings of Endosomal Trafficking as a Pathological Hub in AD/ABR <a href="https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-001.html">https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-001.html</a></li> <li>• PAR-18-661: Pathway and Target Identification for ADR <a href="https://grants.nih.gov/grants/guide/pa-files/PAR-18-661.html">https://grants.nih.gov/grants/guide/pa-files/PAR-18-661.html</a></li> <li>• PAR-18-760: In Vivo Synaptic Function in AD/ABR <a href="https://grants.nih.gov/grants/guide/pa-files/PAR-18-760.html">https://grants.nih.gov/grants/guide/pa-files/PAR-18-760.html</a></li> <li>• RFA-AG-18-013: Continuation of the AMP-AD Target Discovery and Preclinical Validation Consortium <a href="https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-18-013.html">https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-18-013.html</a></li> <li>• RFA-AG-18-020: Role of Peripheral Proteostasis on Brain Aging and AD <a href="https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-18-020.html">https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-18-020.html</a></li> <li>• RFA-AG-18-021: Systems Biology Approaches using Non-Mammalian Laboratory Animals to Uncover Causes of Neurodegeneration that Might Underlie AD/ABR <a href="https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-18-021.html">https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-18-021.html</a></li> <li>• RFA-AG-18-022: Understanding the Effects of ApoE2 on the Interaction between Aging and AD <a href="https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-18-022.html">https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-18-022.html</a></li> <li>• RFA-AG-18-023: Pathogenesis of Age-Related HIV Neurodegeneration <a href="https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-18-023.html">https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-18-023.html</a></li> <li>• RFA-AG-18-025: Consequences of amyloid protein polymorphisms in AD <a href="https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-18-025.html">https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-18-025.html</a></li> <li>• RFA-AG-18-026: From Association to Function in the AD Post-Genomics Era <a href="https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-18-026.html">https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-18-026.html</a></li> <li>• RFA-AG-18-027: Exosomes: From Biogenesis and Secretion to the Early Pathogenesis of AD <a href="https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-18-027.html">https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-18-027.html</a></li> </ul>

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1.B.1 (cont.)						<ul style="list-style-type: none"> <li>RFA-NS-18-015: Structural Biology of ADRD Proteinopathies <a href="https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-18-015.html">https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-18-015.html</a></li> <li>RFA-NS-18-024: LBD CWOW <a href="https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-18-024.html">https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-18-024.html</a></li> </ul> <p>AMP-AD Activities are also relevant <a href="https://www.nia.nih.gov/alzheimers/amp-ad">https://www.nia.nih.gov/alzheimers/amp-ad</a></p>
1.B.2	Expand genetic epidemiologic research to identify risk and protective factors for AD/ADRD.	Conduct whole-genome sequencing to identify areas of genetic variation that correspond to risk factors of AD/ADRD.	NIH/NIA, NIH/NINDS	potential research partners in the public and private sectors	Ongoing	<p>Ongoing and newly released FOAs:</p> <ul style="list-style-type: none"> <li>PAR-15-356: Major Opportunities for Research in Epidemiology of AD and Cognitive Resilience <a href="https://grants.nih.gov/grants/guide/pa-files/PAR-15-356.html">https://grants.nih.gov/grants/guide/pa-files/PAR-15-356.html</a></li> <li>PAR-16-047: NIA Genetics of AD Data Storage Site <a href="https://grants.nih.gov/grants/guide/pa-files/PAR-16-047.html">https://grants.nih.gov/grants/guide/pa-files/PAR-16-047.html</a></li> <li>PAR-16-205: NIA LOAD Family-Based Study <a href="https://grants.nih.gov/grants/guide/pa-files/PAR-16-205.html">https://grants.nih.gov/grants/guide/pa-files/PAR-16-205.html</a></li> <li>PAR-16-371: Phenotypic and Functional Characterization of ApoE2 to Inform Translation Strategies for Aging-Related Conditions <a href="https://grants.nih.gov/grants/guide/pa-files/PAR-16-371.html">https://grants.nih.gov/grants/guide/pa-files/PAR-16-371.html</a></li> <li>PAR-16-406: Limited Competition: Additional Sequencing for the AD Sequencing Project <a href="https://grants.nih.gov/grants/guide/pa-files/PAR-16-406.html">https://grants.nih.gov/grants/guide/pa-files/PAR-16-406.html</a></li> <li>PAR-17-214: Limited Competition: Analysis of Data from NIA's AD Sequencing Project Follow-Up Study <a href="https://grants.nih.gov/grants/guide/pa-files/PAR-17-214.html">https://grants.nih.gov/grants/guide/pa-files/PAR-17-214.html</a></li> <li>RFA-NS-17-017: FTD Sequencing Consortium <a href="https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-17-017.html">https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-17-017.html</a></li> </ul> <p>Continue to support efforts through:</p> <p>ADSP <a href="https://www.niaqads.org/adsp/content/home">https://www.niaqads.org/adsp/content/home</a></p> <p>Genome Center for Alzheimer's Disease <a href="http://www.adgenomics.org/">http://www.adgenomics.org/</a></p>

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Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2017 and 2018
1.B.2 (cont.)						Alzheimer's Disease Genetics Consortium <a href="https://www.niaads.org/resources/related-projects/alzheimers-disease-genetics-consortium-adgc-collection">https://www.niaads.org/resources/related-projects/alzheimers-disease-genetics-consortium-adgc-collection</a>  National Institute on Aging Genetics of Alzheimer's Disease Data Storage <a href="https://www.niaads.org/">https://www.niaads.org/</a>  NOMAS <a href="https://northernmanhattanstudy.org">https://northernmanhattanstudy.org</a>  REGARDS <a href="http://www.regardsstudy.org">http://www.regardsstudy.org</a>

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1.B.3	Increase enrollment in clinical trials and other clinical research through community, national, and international outreach.	Identify approaches and coordination points for these efforts; develop an action plan that incorporates these ideas; collaborate to increase awareness among health and social service providers.	NIH/NIA, ACL, CDC, VA	FDA, VA, CDC, HRSA, CMS, private sector	Ongoing	<p>In 2018, NIA gathered feedback on various recruitment strategies through the IdeaScale crowdsourcing platform. The culmination of these efforts will be the forthcoming "National Strategy for Recruitment and Participation in Alzheimer's Disease Clinical Research".  <a href="https://www.nia.nih.gov/research/recruitment-strategy">https://www.nia.nih.gov/research/recruitment-strategy</a></p> <p>NIA continues to promote participation in AD/ADRD clinical trials, studies, and registries through our ADEAR website portal; clinical trials listing and monthly e-alert to more than 35,000 subscribers; social media messages through Facebook and Twitter; promotion of the ROAR toolkit of customizable materials for aging services and public health professionals to use in community settings and social media in English, Spanish, and Chinese, and collaboration with ACL, CDC, FDA and the PCORI-funded Alzheimer's and Dementia Patient/Caregiver-Powered Research Network to encourage research participation among older adults.</p> <ul style="list-style-type: none"> <li>• <a href="https://www.nia.nih.gov/alzheimers/clinical-trials">https://www.nia.nih.gov/alzheimers/clinical-trials</a></li> <li>• <a href="https://www.nia.nih.gov/health/publication/roar-toolkit">https://www.nia.nih.gov/health/publication/roar-toolkit</a></li> </ul> <p>Newly released FOA:            PAR-18-749: Examining Diversity, Recruitment and Retention in Aging Research  <a href="https://grants.nih.gov/grants/guide/pa-files/PAR-18-749.html">https://grants.nih.gov/grants/guide/pa-files/PAR-18-749.html</a></p> <p>In 2017, VA and NIA initiated a new research partnership called SPARK--Dementia Research. Through this partnership, in 2018 plans were developed to establish a pilot program to increase veterans' enrollment in 3 NIA-funded clinical trials, leveraging joint resources and infrastructure of VA and NIA.</p> <p>In December 2017, HRSA completed its 16-module Training Curriculum: AD/ADRD and has been posted. Several of the modules encourage primary care providers to make their patients aware of the importance of clinical trials and research.  <a href="https://bhw.hrsa.gov/grants/geriatrics/alzheimers-curriculum">https://bhw.hrsa.gov/grants/geriatrics/alzheimers-curriculum</a></p>

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1.B.4	Monitor and identify strategies to increase enrollment of racial and ethnic minorities in AD/ADRD studies.	Track enrollment in NIH AD/ADRD studies; identify and implement next steps for engaging and enhancing research participation by racial and ethnic minorities; raise awareness of need for participation.	NIH/NIA, NIH/NIMHD	ACL	Ongoing	<p>See 1.B.3 for updates regarding the National Strategy for Recruitment and Participation in AD Clinical Research that is currently under development. This strategy will include approaches to increase enrollment of racial and ethnic minorities in AD/ADRD studies.</p> <p>The new NIA-funded ACTC will develop and implement cutting-edge participant recruitment and retention strategies, especially in diverse populations and establish a new minority outreach and recruitment team.  <a href="https://www.nia.nih.gov/news/new-nih-consortium-award-enhance-clinical-trials-alzheimers-disease-related-dementias">https://www.nia.nih.gov/news/new-nih-consortium-award-enhance-clinical-trials-alzheimers-disease-related-dementias</a></p> <p>Newly released FOA:            PAR-18-749: Examining Diversity, Recruitment and Retention in Aging Research  <a href="https://grants.nih.gov/grants/guide/pa-files/PAR-18-749.html">https://grants.nih.gov/grants/guide/pa-files/PAR-18-749.html</a></p>



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1.B.5	Conduct clinical trials on the most promising pharmacologic interventions.	Identify partnerships with private sector participants to voluntarily share information about new and ongoing clinical trials. Develop partnerships to better coordinate federal and private sector review of the status and progress of the trials and emerging opportunities. Review the status and progress of clinical trials annually.	NIH/NIA	VA	Ongoing	<p>FOAs for clinical trials have been released:</p> <ul style="list-style-type: none"> <li>• PAR-18-028: Phase III Clinical Trials for the Spectrum of AD and Age-related Cognitive Decline (R01 Clinical Trial Required) <a href="https://grants.nih.gov/grants/guide/pa-files/PAR-18-028.html">https://grants.nih.gov/grants/guide/pa-files/PAR-18-028.html</a></li> <li>• PAR-18-175: Pilot Clinical Trials for the Spectrum of AD and Age-related Cognitive Decline (R01 Clinical Trial Optional) <a href="https://grants.nih.gov/grants/guide/pa-files/PAR-18-175.html">https://grants.nih.gov/grants/guide/pa-files/PAR-18-175.html</a></li> <li>• PAR-18-513: ACTC Clinical Trials (R01 Clinical Trial Required) <a href="https://grants.nih.gov/grants/guide/pa-files/PAR-18-513.html">https://grants.nih.gov/grants/guide/pa-files/PAR-18-513.html</a></li> <li>• RFA-AG-18-031: Towards Implementing Novel Training Methods to Enhance Cognition in Aging (U01 Clinical Trial Required) <a href="https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-18-031.html">https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-18-031.html</a></li> <li>• RFA-AG-18-031: Towards Implementing Novel Training Methods to Enhance Cognition in Aging (U01 Clinical Trial Required) <a href="https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-18-031.html">https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-18-031.html</a></li> </ul> <p>Launched in 2017, a new clinical trials consortium funded by NIA is expected to accelerate and expand studies for therapies in AD/ADRD. ACTC is a “next-generation” infrastructure designed to harness best practices and latest methods for AD trials. <a href="https://www.nia.nih.gov/news/new-nih-consortium-award-enhance-clinical-trials-alzheimers-disease-related-dementias">https://www.nia.nih.gov/news/new-nih-consortium-award-enhance-clinical-trials-alzheimers-disease-related-dementias</a></p> <p>Coordination of federal, non-federal, and international AD/ADRD research, including clinical trials, can be found in the IADRP <a href="http://iadrp.nia.nih.gov/">http://iadrp.nia.nih.gov/</a></p>

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2017 and 2018
1.B.6	Continue clinical trials on the most promising lifestyle interventions.	Conduct annual reviews of the status and progress of clinical trials.	NIH/NIA	VA	Ongoing	<p>FOAs for clinical trials have been released:</p> <ul style="list-style-type: none"> <li>• PAR-18-028: Phase III Clinical Trials for the Spectrum of AD and Age-related Cognitive Decline (R01 Clinical Trial Required) <a href="https://grants.nih.gov/grants/guide/pa-files/PAR-18-028.html">https://grants.nih.gov/grants/guide/pa-files/PAR-18-028.html</a></li> <li>• PAR-18-175: Pilot Clinical Trials for the Spectrum of AD and Age-related Cognitive Decline (R01 Clinical Trial Optional) <a href="https://grants.nih.gov/grants/guide/pa-files/PAR-18-175.html">https://grants.nih.gov/grants/guide/pa-files/PAR-18-175.html</a></li> <li>• PAR-18-513: ACTC Clinical Trials (R01 Clinical Trial Required) <a href="https://grants.nih.gov/grants/guide/pa-files/PAR-18-513.html">https://grants.nih.gov/grants/guide/pa-files/PAR-18-513.html</a></li> <li>• RFA-AG-18-031: Towards Implementing Novel Training Methods to Enhance Cognition in Aging (U01 Clinical Trial Required) <a href="https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-18-031.html">https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-18-031.html</a></li> </ul> <p>See 1.B.5 for updates regarding ACTC and ongoing clinical trials supported by NIA. Many of the approximately 140 active trials of interventions to enhance cognitive health in older adults and to prevent, treat, or manage AD/ADRD include testing lifestyle interventions such as diet and exercise.</p> <ul style="list-style-type: none"> <li>• <a href="https://www.nia.nih.gov/news/new-nih-consortium-award-enhance-clinical-trials-alzheimers-disease-related-dementias">https://www.nia.nih.gov/news/new-nih-consortium-award-enhance-clinical-trials-alzheimers-disease-related-dementias</a></li> <li>• <a href="https://www.nia.nih.gov/research/ongoing-AD-trials">https://www.nia.nih.gov/research/ongoing-AD-trials</a></li> </ul> <p>IADRP facilitates tracking research efforts, including treatment studies. <a href="http://iadrp.nia.nih.gov/cadro-web/">http://iadrp.nia.nih.gov/cadro-web/</a></p>

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1.B.7	Expand research focused on needs related to the intersection of Down syndrome and AD/ADRD.	Develop a research agenda from basic to clinical studies that aims to better understand the interplay between Down syndrome and AD/ADRD.	NIH		Ongoing	<p>INCLUDE project was launched in June 2018. <a href="https://www.nih.gov/include-project">https://www.nih.gov/include-project</a></p> <p>AD Biomarker Consortium--Down Syndrome aims to identify biomarkers that indicate AD is developing or progressing and track the AD process in people with Down syndrome. <a href="https://www.nia.nih.gov/alzheimers/alzheimers-biomarkers-consortium-down-syndrome-abc-ds">https://www.nia.nih.gov/alzheimers/alzheimers-biomarkers-consortium-down-syndrome-abc-ds</a></p> <p>NIA is currently funding a Phase I clinical trial to investigate the safety and tolerability of an immunotherapy vaccine for treatment of AD in adults with Down syndrome. <a href="https://health.ucsd.edu/news/releases/Pages/2016-01-13-clinical-trial-alzheimers-characteristics-in-down-syndrome.aspx">https://health.ucsd.edu/news/releases/Pages/2016-01-13-clinical-trial-alzheimers-characteristics-in-down-syndrome.aspx</a></p> <p>Additionally, NIA and NICHD collaborated to produce and disseminate information for people with Down syndrome and their families on the interplay of these conditions and the importance of participating in research. Efforts include a fact sheet, "Alzheimer's Disease in People with Down Syndrome", and outreach via email and social media. <a href="https://www.nia.nih.gov/alzheimers/publication/alzheimers-disease-people-down-syndrome">https://www.nia.nih.gov/alzheimers/publication/alzheimers-disease-people-down-syndrome</a></p>

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<b>Strategy 1.C: Accelerate Efforts to Identify Early and Presymptomatic Stages of Alzheimer's Disease and Related Dementias</b>						
1.C.1	Identify imaging and biomarkers to monitor disease progression.	Conduct annual reviews of ADNI to identify and monitor disease progression.	NIH/NIA, NIH/NINDS	ADNI partners, AMP partners	Ongoing	<p>Ongoing reporting and monitoring of ADNI activities, continuing on an annual basis, along with provision of research funding on developing and testing diagnostic tools.</p> <p>ADNI's activities are and will continue to be monitored and reviewed on an annual basis  <a href="http://adni.loni.usc.edu/">http://adni.loni.usc.edu/</a></p> <p>AMP-AD  <a href="https://www.nia.nih.gov/alzheimers/amp-ad">https://www.nia.nih.gov/alzheimers/amp-ad</a></p> <p>Ongoing and newly released FOAs include:</p> <ul style="list-style-type: none"> <li>• PAR-15-359: Novel Approaches to Diagnosing AD and Predicting Progression  <a href="http://grants.nih.gov/grants/guide/pa-files/PAR-15-359.html">http://grants.nih.gov/grants/guide/pa-files/PAR-15-359.html</a></li> <li>• PAR-18-519: Sensory and motor system changes as predictors of preclinical AD  <a href="https://grants.nih.gov/grants/guide/pa-files/PAR-18-519.html">https://grants.nih.gov/grants/guide/pa-files/PAR-18-519.html</a></li> <li>• PAR-18-596: In vivo Synaptic Function in AD/ADRD  <a href="https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-001.html">https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-001.html</a></li> <li>• RFA-NS-18-025: CWOW for PET Ligand Development for ADRD  <a href="https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-18-025.html">https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-18-025.html</a></li> </ul>

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1.C.2	Maximize collaboration among federal agencies and the private sector.	Identify additional partnership opportunities with the private sector and facilitate collaborative efforts to enhance identification of risk factors and early biomarkers.	NIH/NIA, NIH/NINDS	FDA, AMP partners	Ongoing	<p>AMP-AD is an NIH-supported precompetitive partnership among government, industry, and non-profit organizations that focuses on discovering novel, clinically relevant therapeutic targets and on developing biomarkers to help validate existing therapeutic targets. The program brings together geneticists, epidemiologists, biologists, data scientists and drug discovery experts across many academic institutions and four pharmaceutical industry organizations.</p> <p>AMP-AD (Projects A and B)  <a href="http://www.nia.nih.gov/alzheimers/amp-ad">http://www.nia.nih.gov/alzheimers/amp-ad</a></p> <p>ADNI is also a public-private partnership between NIH, the Canadian government, and over 20 biopharmaceutical companies and non-profit organizations.</p> <p>ADNI is in collaboration with the ADSP  <a href="http://adni.loni.usc.edu/about/funding/">http://adni.loni.usc.edu/about/funding/</a></p> <p>IADRP facilitates tracking research efforts in the public and private sector.  <a href="https://iadrp.nia.nih.gov/">https://iadrp.nia.nih.gov/</a></p> <p>NIH-funded Tau CWOW is a multi-center, interdisciplinary program that was established in FY 2016 to investigate the molecular mechanisms of tau toxicity in FTD. One of the requirements of this program is to have ongoing collaborative partnerships with non-profit non-governmental organizations and philanthropic entities, such as AFTD, Cure PSP, and the Rainwater Charitable Foundation.</p> <ul style="list-style-type: none"> <li>• RFA-NS-16-023: CWOW for the identification and Validation of Molecular Mechanisms Contributing to Tau Pathogenesis and Associated Neurodegeneration in FTD  <a href="https://grants.nih.gov/grants/guide/rfa-files/RFA-ns-16-023.html">https://grants.nih.gov/grants/guide/rfa-files/RFA-ns-16-023.html</a></li> </ul>

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<b>Strategy 1.D: Coordinate Research with International Public and Private Entities</b>						
1.D.1	Inventory AD/ADRD research investments.	International AD Research Database launched July 2012 and continually updated.  It was relaunched as the International AD/ADRD Dementias Research Portfolio in July 2018 and continually updated.	NIH/NIA		Ongoing	IADRP now includes data from over 40 public and private funding organizations across more than 10 countries. <a href="https://iadrp.nia.nih.gov/">https://iadrp.nia.nih.gov/</a>  In 2018, the IADRP database was relaunched with a number of changes to CADRO, including greater specificity in the coding of FTD, LBD, and VCID. <a href="https://iadrp.nia.nih.gov/about/cadro">https://iadrp.nia.nih.gov/about/cadro</a>
1.D.2	Expand international outreach to enhance collaboration.	Invite international colleagues to meet and discuss AD/ADRD research priorities and collaboration through regular meetings in person and via teleconference.	NIH/NIA		Ongoing	In collaboration with the EU JPND, NIH is participating in the upcoming EU mapping exercise that invites 20+ countries to submit their recently funded neurodegenerative research (notably AD and ADRD). <a href="http://www.neurodegenerationresearch.eu/initiatives/mapping-exercise/data-collected/">http://www.neurodegenerationresearch.eu/initiatives/mapping-exercise/data-collected/</a>  In 2017, JPND launched a call on "Multinational research projects for Pathway Analysis across Neurodegenerative Diseases". At the same time, NIA released FOA PAS17-028, "Common Mechanisms and Interactions Among Neurodegenerative Diseases (R01)." JPND and NIA plan to support crosscutting activities such as common workshops, data exchange and harmonization among the projects funded by JPND and NIA in response to these calls for applications. <a href="http://www.neurodegenerationresearch.eu/initiatives/annual-calls-for-proposals/closed-calls/pathways-2017/">http://www.neurodegenerationresearch.eu/initiatives/annual-calls-for-proposals/closed-calls/pathways-2017/</a>  Alzheimer's Disease Funders' meeting held during the 2017 AAIC; quarterly funders' calls led by NIA and Alzheimer's Association. Also, IADRP which includes data from over 40 public and private funding organizations across more than 10 countries is publicly-available for use. <a href="https://iadrp.nia.nih.gov/">https://iadrp.nia.nih.gov/</a>

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1.D.3	Identify research priorities via surveys tracking health conditions and risk factors.	Use BRFSS optional modules on Subjective Cognitive Decline and Caregiving to measure burden and determine priority areas for action.	CDC		Ongoing	BRFSS is the world's largest, ongoing telephone health survey system, tracking health conditions and risk behaviors in the United States yearly since 1984. It is conducted by all states under the direction of CDC with state public health authorities. Two special optional modules that states can include in their annual surveys are available on the topics of caregiving and cognitive impairment. Collecting and analyzing this data allows the study of burden, impact, and trends and is used by decision makers to decide course of action for research as well as interventions.
<b>Strategy 1.E: Facilitate Translation of Findings into Medical Practice and Public Health Programs</b>						
1.E.1	Leverage public and private collaborations to facilitate dissemination, translation, and implementation of research findings.	Disseminate research findings through various media and in partnership with organizations, particularly those involving interventions in treatment and care.	NIH/NIA	FDA, ACL, CDC, partner organizations	Ongoing	NIA continues to expand its efforts to educate clinicians about recent research findings; clinical practice tools for assessment, diagnosis and management of cognitive impairment; training materials; a patient checklist handout in English and Spanish, and other resources, which are available online in a mini-portal of resources for professionals. <a href="https://www.nia.nih.gov/health/alzheimers-dementia-resources-for-professionals">https://www.nia.nih.gov/health/alzheimers-dementia-resources-for-professionals</a>
1.E.2	Continue to promote use of ADEAR to educate the public about the latest research findings.	Prepare and disseminate regular reports on AD/ADRD research findings.	NIH/NIA	ADEAR, ACL, CDC, FDA, CMS, HRSA, VA, partner organizations	Ongoing	NIA's ADEAR Center routinely disseminates information on AD/ADRD research findings through our website, regular weekly and monthly email alerts to more than 50,000 subscribers, and social media (Twitter and Facebook). <a href="https://www.nia.nih.gov/alzheimers">https://www.nia.nih.gov/alzheimers</a>  Progress in AD research is also reported in the annual Bypass Budget proposal. <a href="https://www.nia.nih.gov/about/bypass-budget-proposal-archive">https://www.nia.nih.gov/about/bypass-budget-proposal-archive</a>  Of the 44 HRSA-funded GWEP grantees, 14 are co-located and working with ADCs to provide resource materials to health care professionals and the public that include the latest research findings. The remaining 30 grantees are encouraged to work with nearby ADCs.
1.E.3	Issue guidance about drugs for early-stage AD/ADRD.	Issue recommendations about standards for evaluating the effectiveness of treatments for early-stage AD/ADRD.	FDA		Ongoing	Draft Guidance for Industry: AD: Developing Drugs for the Treatment of Early Stage Disease <a href="http://www.fda.gov/Training/GuidanceWebinars/ucm345077.htm">http://www.fda.gov/Training/GuidanceWebinars/ucm345077.htm</a>



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1.E.4	Expand and disseminate research on co-occurring conditions and dementias.	Literature review to be disseminated through CDC's public health network, AoA's Aging Network, and NIA research network.	CDC	ACL, NIH/NIA	Ongoing	In January 2016, CDC released the Progress Report of public health Road Map action item accomplishment and next steps. In 2017, the development process of the 3rd Road Map began that will identify action items for public health professionals related to cognitive health through 2023. The 3rd Road Map will be released in late 2018.
1.E.5	Provide information to the public on brain health.	Develop and disseminate a brain health resource to aging, disability, and public health professionals.	ACL, NIH/NIA, NIH/NINDS, CDC	CMS, HRSA, VA, private partners	Ongoing	<p>On February 2, 2016, NINDS launched a public health campaign on link between hypertension and cognitive decline for integration with the HHS Million Hearts Campaign.  <a href="https://mindyourrisks.nih.gov/">https://mindyourrisks.nih.gov/</a></p> <p>The Brain Health Resource, a presentation toolkit on brain health as we age, was developed by ACL with scientific review by NIH and CDC for use at senior centers and in other community settings and was updated in 2018. Written in plain language, the evidence-based resource explains what people can do to help keep their brains functioning best. In 2016, the toolkit was expanded to include materials in Spanish and a new brain health module entitled, Medicine, Age, and your Brain.  <a href="https://www.nia.nih.gov/health/brain-health-resource">https://www.nia.nih.gov/health/brain-health-resource</a></p> <p>NIA also maintains a web portal on Cognitive Health and Older Adults  <a href="https://www.nia.nih.gov/health/cognitive-health">https://www.nia.nih.gov/health/cognitive-health</a>.</p> <p>The campaign What is Brain Health? formerly managed by ACL was transferred to NIA in 2017.  <a href="https://brainhealth.nia.nih.gov/">https://brainhealth.nia.nih.gov/</a></p> <p>ACL updated, in 2018, the Brain Health Resource, a presentation toolkit on brain health as we age. The toolkit was developed by ACL with scientific review by NIH and CDC for use at senior centers and in other community settings.</p> <p>All of the 44 HRSA-funded GWEPs are training and educating the public on brain health including providing resources on brain health.</p>

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1.E.6	Leverage public and private collaborations to facilitate dissemination, translation, and implementation of research findings.	Develop a 1-1.5 hour(s) CME/MOC module on the benefits of blood pressure management as a potential mechanism to reduce cognitive decline and dementia.	CDC	private partners	Ongoing	<p>CDC is working with the American College of Preventive Medicine. A Curriculum is being developed to increase physician and health care professionals' awareness of brain health as a serious health condition and to increase the number of physician and health care professionals acting to address, diagnose, and refer patients with brain health issues to care and community support programs.</p> <p>Module will be included as an elective in the Lifestyle Medicine Core Competencies Online Program</p>
1.E.7	Facilitate translation of findings into public Health Practice.	Develop and update a Public Health Road Map.	CDC	multiple agencies, private partners	Expected Release Fall 2018	<p>CDC funds the Alzheimer's Association to co-develop the 3rd in a series of HBI Road Maps to advance cognitive health as an integral component of public health (see Section IV). This "Healthy Brain Initiative State and Local Public Health Partnerships to Address Dementia, The 2018-2023 Road Map", outlines how state and local public health agencies and their partners can continue to promote cognitive health, address cognitive impairment for people living in the community, and help meet the needs of caregivers. 25 specific actions are proposed in 4 traditional domains of public health: educate and empower, develop policies and mobilize partnerships, assure a competent workforce, and monitor and evaluate.</p>

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<b>Goal 2: Enhance Care Quality and Efficiency</b>						
<b>Strategy 2.A: Build a Workforce with the Skills to Provide High-Quality Care</b>						
2.A.1	Educate health care providers.	Educate providers through HRSA's GWEP about how to: (1) work with people with the disease, and their families, (2) link people to support services in the community, identify signs of caregiver burden and depression, and (3) detect cognitive impairment and assess/diagnose AD/ADRD.	HRSA	CMS, NIH/NIA, CDC	Ongoing	<p>In FY 2017, HRSA supported 44 GWEP grantees totaling approximately \$38.7 million of which \$5.9 million was specifically budgeted to provide dementia education and training. In Academic Year 2016-2017 (latest available data), GWEP grantees provided 467 ADRD courses and trained 55,640 health care providers in ADRD.</p> <p>NIA continues to expand its efforts to educate clinicians about recent research findings; clinical practice tools for assessment, diagnosis and management of cognitive impairment; training materials; a patient checklist handout in English and Spanish, and other resources, which are available online in a mini-portal of resources for professionals.  <a href="https://www.nia.nih.gov/alzheimers/alzheimers-and-dementia-resources-professionals">https://www.nia.nih.gov/alzheimers/alzheimers-and-dementia-resources-professionals</a>.</p> <p>NIA disseminated Assessing Cognitive Impairment in Older Patients: A Quick Guide for Primary Care Physicians  <a href="http://www.nia.nih.gov/alzheimers/publication/assessing-cognitive-impairment-older-patients">http://www.nia.nih.gov/alzheimers/publication/assessing-cognitive-impairment-older-patients</a></p> <p>Newly Released FOA:  RFA-AG-19-002: Small Research Grant Program for the Next Generation of Clinical Researchers in AD/ADRD Research  <a href="https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-19-002.html">https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-19-002.html</a></p>
2.A.2	Encourage providers to pursue careers in geriatric specialties.	Educate providers about opportunities through: the HRSA GWEP.	HRSA		Ongoing	In Academic Year 2016-2017 (latest available data), GWEP awardees trained 638 individuals in geriatrics fellowships and 136 advanced education nursing students in advanced practice adult-gerontology nursing programs. As part of their training, these individuals receive education in AD/ADRD.

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2.A.3	Strengthen state aging, public health, and IDD workforces.	Educate the workforces through various means including online training, webinars, fact sheets and other tools.	ACL	HRSA	Ongoing	<p>HHS will coordinate with states to develop workforces trained in aging, public health, and IDD that are AD-capable and culturally-competent. ACL collaborated with HRSA to provide AD/ADRD training to the Aging Network.</p> <p>ACL through NADRC offers an annual dementia-specific webinar series, attracting as many as 1300 attendees to a single session. The series targets ADRD professionals, attracting family caregivers as well, and includes information on related dementias, innovative interventions and a wide variety of caregiving topics. CEUs are available to attendees, and the webinars are archived on the resource center web page.  <a href="http://www.nadrc.acl.gov">http://www.nadrc.acl.gov</a></p> <p>Each year, in support of paid and unpaid caregivers, the NADRC develops tools and issue briefs on dementia-specific topics. New materials developed are disseminated through the ACL grant programs, as well as at professional conferences and the center web page. ACL is constantly adding new tools and issue briefs to its growing library. Topics of materials developed by the NADRC include, but are not limited to, advance planning, living alone, compendiums of dementia-specific interventions and outcome measures.</p> <p>In FY 2017, the 44 HRSA GWEP grantees collaborated with 32 AAAs and 15 QIOs to strengthen state aging, public health, and IDD workforces.</p>

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2.A.4	Develop and disseminate a voluntary unified primary care AD/ADRD curriculum.	Develop a voluntary curriculum for primary care practitioners.	HRSA	CMS, NIH/NIA, VA	Ongoing	<p>From FY 2015-2017, HRSA partnered with federal staff at ACL, CDC, CMS, OWH, and VA on a contract to develop a Dementia Curriculum for Health Care Professionals and Caregivers. The curriculum is designed to build a workforce with the skills to provide high-quality care, ensure timely and accurate detection and diagnosis, and identify high-quality dementia care guidelines and measures across care settings. The curriculum was first made available as of December 2017. In the first month it was available the site had 8000 hits. The curriculum is being updated every 6 months. HRSA is partnering with CDC to provide CEUs to health professionals. HRSA is also partnering with CMS to convert the caregiver modules in the Curriculum to YouTube videos.</p> <p><a href="https://bhwh.hrsa.gov/grants/geriatrics/alzheimers-curriculum">https://bhwh.hrsa.gov/grants/geriatrics/alzheimers-curriculum</a></p> <p>CMS's ICRC, which partners with health plans and providers, also offered a 2017 Geriatric-Competent Care Webinar Series designed to help health professionals in all settings and disciplines expand their knowledge and skills in the unique aspects of caring for older adults and in working with their caregivers, with some focus on dementia. The webinars are intended for front line community partners and delivery staff such as care managers, member service representatives, and home care providers. In 2017, topics included promising practices to advance care of Medicare-Medicaid enrollees with dementia, causes of dementia in older adults, diagnosis and treatment of Parkinson's disease.</p> <ul style="list-style-type: none"> <li>• <a href="https://resourcesforintegratedcare.com/GeriatricCompetentCare/2017_GCC_Webinar_Series/Series_Overview">https://resourcesforintegratedcare.com/GeriatricCompetentCare/2017_GCC_Webinar_Series/Series_Overview</a></li> <li>• <a href="https://resourcesforintegratedcare.com/target-populations/behavioral-health">https://resourcesforintegratedcare.com/target-populations/behavioral-health</a></li> </ul>

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2.A.5	Ensure aging and public health network providers have access to research-based up-to-date information on AD/ADRD.	Webinars with representatives from the Aging Network, ADCs, ADEAR, the National Alzheimer's Call Center and Elder Locator, Alzheimers.gov and other federal partners to ensure aging and public health workforces receive recent, updated and culturally-competent information.	ACL, NIH/NIA	CDC, AHRQ, NASEM	Ongoing	<p>NIH initiated a project involving the AHRQ, and NASEM, to conduct a systematic review of the evidence on prevention of clinical AD-type dementia, MCI, and age-related cognitive decline (AHRQ), and to shape these findings into a set of recommendations for public health practice and research (NASEM).</p> <p>The NASEM report, detailing recommendations for public health messaging based on findings were released in June 2017.</p> <p>AHRQ report  <a href="https://www.effectivehealthcare.ahrq.gov/search-for-guides-reviews-and-reports/?pageaction=displayproductandproductID=2417">https://www.effectivehealthcare.ahrq.gov/search-for-guides-reviews-and-reports/?pageaction=displayproductandproductID=2417</a></p> <p>NASEM report  <a href="http://nationalacademies.org/hmd/reports/2017/preventing-cognitive-decline-and-dementia-a-way-forward.aspx">http://nationalacademies.org/hmd/reports/2017/preventing-cognitive-decline-and-dementia-a-way-forward.aspx</a></p> <p>The interagency ROAR (NIH, ACL, CDC) group hosted an update in the popular webinar series in 2017 for professionals on AD/ADRD resources that drew 500+ participants and offered CEC. Free continuing education is available to professionals who need it when they view recorded webinars from 2017 and earlier series. This continuing education is available through 2018.  <a href="https://www.nia.nih.gov/news/2017-alzheimers-and-dementia-webinars-professionals">https://www.nia.nih.gov/news/2017-alzheimers-and-dementia-webinars-professionals</a></p> <p>NIA continues to expand its efforts to educate clinicians about recent research findings; clinical practice tools for assessment, diagnosis and management of cognitive impairment; training materials; a patient checklist handout in English and Spanish, and other resources, which are available online in a mini-portal of resources for professionals.  <a href="https://www.nia.nih.gov/health/alzheimers-dementia-resources-for-professionals">https://www.nia.nih.gov/health/alzheimers-dementia-resources-for-professionals</a></p>

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2.A.6	Engage the public health workforce on brain health.	Conduct briefings with federal, state, and local public and private partners regarding the Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013-2018.	CDC	ACL, NIH/NIA	Ongoing	<p>CDC in collaboration with the HBRN has developed a Scholars Program to assist in the training of graduate-level students in brain health. Students engage in a variety of educational, partnership, and research activities. This program in Year 2 of a 5-year funding cycle.</p> <p>CDC in collaboration with the Alzheimer's Association developed "A Public Health Approach to Alzheimer's and Other Dementias". This introductory curriculum describes the role of public health in addressing the epidemic of AD/ADRD. Its 4 modules each contain a comprehensive faculty guide and slide deck. Whether an entity is teaching a public health course at an academic institution or delivering health education at the local level, the modules explore how to adapt this flexible resource to fit identified needs.</p> <p><a href="https://www.cdc.gov/aging/aginginfo/alzheimers.htm">https://www.cdc.gov/aging/aginginfo/alzheimers.htm</a></p>
2.A.7	Strengthen the ability of primary care teams in Indian Country to meet the needs of people with AD/ADRD and their caregivers.	Incorporate training for AD/ADRD into the online continuing education curriculum for IHS/Tribal/Urban program nursing.	IHS		Ongoing	<p>Web-based course on AD/ADRD April-June 2016 IHS Clinical Rounds. Addressed at IHS Nursing Leadership meeting May 17, 2016. Clinical training on diagnosis and management of AD/ADRD for ACL/IHS/CMS LTSS conference, November 2016. Developing use of Project ECHO to support diagnosis and management of AD/ADRD.</p>
2.A.8	Develop a baseline understanding of self-reported competence and confidence of IHS, Tribal and Urban Indian Health nursing staff in care of individuals with AD/ADRD.	Assess nursing in IHS, Tribal, and Urban Indian Health programs on self-reported competence, confidence, and recent training specific to care for individuals with dementia.	IHS		Ongoing	<p>Survey pilot-tested at 1 Tribal site.</p>
2.A.9	Improve educational resources for primary care staff in Tribal communities caring for individuals with AD/ADRD and their family.	Pilot-test the HRSA curriculum for care of AD/ADRD in IHS, Tribal, and Urban Indian Health Programs.	IHS	HRSA	Ongoing	<p>Pending completion of the brief, targeted provider-focused curriculum.</p>
2.A.10	Provide Decision Support for Clinicians in Tribal communities.	Develop and pilot-test decision support tools for clinicians using the IHS EHR.	IHS		Ongoing	<p>Development of templates to support AWW (with cognitive assessment) and CCM.</p>
2.A.11	Provide Interdisciplinary Team Training in recognition, assessment, and management of AD/ADRD in small rural Indian Health facilities.	Provide the VA RITT to 10 IHS and Tribal sites with a focus on dementia care.	IHS	VA	Ongoing	<p>12 RITT Trainings completed.</p> <p>Webinars, accredited through EES and TRAIN for VA and community clinicians: PTSD and Memory (January 24, 2018)</p> <p>Geriatric Scholars Toolkits: Dementia  <a href="http://www.gerischolars.org/course/view.php?id=29">http://www.gerischolars.org/course/view.php?id=29</a></p>



Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2017 and 2018
2.A.12	Strengthen states' ability to provide and sustain dementia-capable HCBS.	Grants to states and technical assistance on high-quality person-centered dementia care. Develop learning collaboration and tool to evaluate dementia-capability.	ACL	CMS	Ongoing	<p>Implementation of dementia-capability assessment tool for implementation through the ACL state and community grant program. The tool assess program partners over the course of a grant to measure the improvement in dementia-capability.  <a href="http://www.nadrc.acl.gov">http://www.nadrc.acl.gov</a></p> <p>ACL funds a grant program to states and communities (ADPI) that is designed to support and promote the development and expansion of dementia-capable HCBS.  <a href="http://www.nadrc.acl.gov">http://www.nadrc.acl.gov</a></p> <p>CMS extended the transition period for states to demonstrate compliance with its HCBS settings rule criteria until 2022, an additional 3 years, to ensure compliance activities related to integrated community settings are collaborative, transparent, and timely and assure thoughtful implementation.</p>
2.A.13	Fill service gaps in dementia-capable systems by expanding the availability of specialized services and supports to target previously underserved populations.	Grants to states and localities.	ACL	CMS	Ongoing	<p>This is an ongoing project assuming continuing congressional appropriations. In 2017, 11 community programs received funding, bringing the total number of programs funded since 2014 to 43. Programs are active in 28 states and Puerto Rico.</p> <p>In 2018, CMS announced that beginning in 2019, it is expanding the definition of "primarily health-related" supplemental benefits in Medicare Advantage organizations to consider an item or service as a supplemental benefit if it is used to diagnose, compensate for physical impairments, acts to ameliorate the functionality/psychological impact of injuries or health conditions, or reduces avoidable emergency and health care utilization. This permits the plans to offer HCBS such as adult day health, environmental modifications, palliative care, etc.</p>
2.A.14	Improve HCBS LTSS provided through state Medicaid waivers.	Hold webinars, national calls, and provide information to key stakeholders.	CMS		Ongoing	<p>As one example, CMS is supporting state Medicaid agencies in community integration through HCBS. One targeted area of support is helping a select number of Medicaid agencies plan and implement quality and outcome incentives in their HCBS programs.  <a href="https://www.medicaid.gov/state-resource-center/innovation-accelerator-program/community-integration-ltss/ci-ltss.html">https://www.medicaid.gov/state-resource-center/innovation-accelerator-program/community-integration-ltss/ci-ltss.html</a></p>

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2.A.15	Disseminate CMS Hand-in-Hand dementia training materials in VA CLCs.	Share with federal partners a summary report on implementation and evaluation of VA's dissemination of CMS Hand-in-Hand dementia training materials in VA CLCs.	VA	ASPE, ACL, HRSA	Ongoing	<p>VA disseminated the CMS Hand-in-Hand Dementia Training Materials to all VA CLCs (formerly known as VA Nursing Home Care Units) in 2015-2016. Orientation calls with CLC leaders were held, and a series of implementation coaching calls were held with CLC staff. A process evaluation is underway. When evaluation activities are complete, VA will share with federal partners a summary report on its implementation and evaluation of the dissemination of these staff training materials.</p> <p>19 of the HRSA 44 GWEPs collaborated with the VA. GWEP grantees are prepared to assist with training in VA CLCs should they be asked to do so.</p>
2.A.16	Training future public health professionals on AD/ADRD.	Develop a public health curriculum for use in university settings.	CDC	private partners	2017	Public Health Curriculum in partnership with the Alzheimer's Association and Emory University. The Public Health Curriculum is a comprehensive course designed to educate public health students about the growing issues related to AD/ADRD and is tied to the Core Competencies for Public Health Professionals. It includes slides, teacher notes, and other elements to create a complete course for educators to use in the classroom. The curriculum is also relevant to other audiences for broader reach.
<b>Strategy 2.B: Ensure Timely and Accurate Diagnosis</b>						
2.B.1	Identify and disseminate a variety of appropriate assessment tools.	Identify a variety of appropriate assessment tools that can be used in a variety of outpatient settings, including the Medicare AWW, to assess cognition. Complete the development of the "toolbox" of cognitive assessment tools. Disseminate recommended tools to practitioners.	NIH/NIA	CDC	Ongoing	<p>NIA continues to expand our efforts to educate clinicians about recent research findings; clinical practice tools for assessment, diagnosis and management of cognitive impairment; training materials; a patient checklist handout in English and Spanish, and other resources, which are available online in a mini-portal of resources for professionals.</p> <p><a href="https://www.nia.nih.gov/health/alzheimers-dementia-resources-for-professionals">https://www.nia.nih.gov/health/alzheimers-dementia-resources-for-professionals</a></p>

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2.B.2	Educate family members of and service providers for persons with IDD about changes that may indicate the onset of dementia.	Develop fact sheets and tools to aid in identifying the onset of dementia.	ACL/AIDD	NTG	Ongoing	<p>ACL, through their AD/ADRD grants to states and communities are providing dementia-capability training to paid and unpaid caregivers of persons living with dementia, including individuals living with IDD and dementia or at risk of developing dementia. For example, through the ACL community grant program, 31 of 43 funded projects (in 22 states and Puerto Rico) include IDD culturally-competent AD/ADRD education/training activities components.</p> <p>ACL collaborates closely with the NTG with many grantees participating in their education workshops, becoming affiliated trainers and further disseminating education on IDD and dementia, as well as implementation of their NTG-EDSD tool. Since 2014, through ACL, AD/ADRD projects, more than 8,000 paid and unpaid caregivers of individuals living with IDD and dementia have received training.</p> <p><a href="http://aadmd.org/">http://aadmd.org/</a></p> <p>2 webinars and an issue paper were made available in 2015: Webinar: IDD and Dementia--California Webinar <a href="http://www.nadrc.acl.gov">http://www.nadrc.acl.gov</a></p>
2.B.3	Increase awareness of AD/ADRD in Tribal and Urban Indian Communities and of the availability of services for Individuals with dementia and their families.	Pilot-test AD/ADRD awareness strategies in communities in which REACH into Indian Country is implemented, through both health care and aging services settings.	IHS	ACL	Ongoing	<p>The focus of the REACH intervention in its final year was on increasing awareness of AD/ADRD in those communities served by REACH and increasing use of REACH caregiver support services.</p> <p>Regular web-based calls with REACH Caregiver Coaches aimed at increasing awareness and use of the caregiver support services in Tribal communities.</p> <p>ACL continues to bring awareness to AD/ADRD in Indian Country through participating in educational opportunities including presentations to attendees of ACL's Title VI annual conference and webinars.</p>
2.B.4	Increase Provider Awareness of the need for early diagnosis, and provide tools and resources to enable diagnosis and referral.	Develop a 1-1.5 hour(s) CME/MOC module on the benefits of blood pressure management as a potential mechanism to reduce cognitive decline and dementia.	CDC	private partners	Ongoing	<p>CDC is working with the American College of Preventive Medicine. A curriculum is being developed to increase physician and health care professionals' awareness of brain health as a serious health condition and to increase the number of physicians and health care professionals acting to address, diagnose, and refer patients with brain health issues to care and community support programs.</p> <p>Module will be included as an elective in the Lifestyle Medicine Core Competencies Online Program.</p>

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2.B.5	Understand the discordance between reported diagnosis, claims, and functional assessment for people with AD/ADRD.	Understand the discrepancies between various sources of data on dementia diagnosis.	ASPE		Ongoing	ASPE is working on a project to better understand discrepancies between patients or proxy-reported, Medicare claims data-reported, and cognitive functioning test results on dementia diagnosis numbers and reporting. The intent is to improve patient awareness of diagnosis and better standardize diagnosis numbers across various data sources.
<b>Strategy 2.C: Educate and Support People with Alzheimer's Disease and Related Dementias and Their Families upon Diagnosis</b>						
2.C.1	Educate physicians and other health care providers about accessing LTSS.	Increase knowledge of available resources among doctors, nurses, and hospitals.	HRSA	CMS, VA, ACL	Ongoing	<p>One barrier to counseling and support is that health care providers are not aware of available services or how to access them. To increase knowledge of these resources among physicians, nurses, and hospitals, 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, as well as their caregivers. These activities will continue as part of the training in Action 2.A.1.</p> <p>In addition, since 2017, CMS has created a separate payment in Medicare for cognitive assessment and care planning services for individuals with cognitive impairment. A required element of these services is the creation of a care plan, including referral to community resources as needed (e.g., rehabilitation services, adult day programs, support groups), and a requirement that the care plan is shared with the patient and/or caregiver with initial education and support.</p> <p>ACL's state and community AD/ADRD grant program continues to fund projects that include educational opportunities for physicians and other health care providers. Grantees continue to work toward developing models such as dementia-capable hospitals and federally qualified health centers.</p>

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2.C.2	Connect American Indians and Alaska Natives to AD/ADRD resources.	As new resources become available, they will be distributed through a variety of venues to Indian Country.	IHS	ACL, CDC	Ongoing	<p>The focus on increasing support to caregivers has been through spread of REACH into Indian Country, with the goal of offering this intervention to those with AD/ADRD and their families.</p> <p>Collaboration with the CDC in the development of the Brain Health public health Road Map designed specifically for Tribal Communities.</p> <p>Tribal communities continue to benefit from ACL's state and community AD/ADRD grant programs, including development of culturally-competent dementia care specialists, dementia-friendly community education/awareness initiatives and translation of the Music and Memory intervention in Indian Country.</p>
<b>Strategy 2.D: Identify High-Quality Dementia Care Guidelines and Measures Across Care Settings</b>						
2.D.1	Explore dementia care guidelines measures.	Convene meetings with public and private organizations to discuss dementia care practices; develop/identify 3-5 evidence-based guidelines of best dementia practices; include guidelines in the National Guidelines Clearinghouse; disseminate guidelines to consumer and clinical stakeholders, as well as quality measure developers.	CMS	ASPE, AHRQ	Ongoing	<p>CMS has included dementia-related measures in the Merit-Based Incentives Payment Program for Medicare such as cognitive assessment, management of NPS, etc.  <a href="https://qpp.cms.gov/mips/explore-measures/quality-measures?py=2018#measures">https://qpp.cms.gov/mips/explore-measures/quality-measures?py=2018#measures</a></p> <p>CMS is also continuing its work to test and develop measures and measure concepts for HCBS.  <a href="https://www.medicaid.gov/medicaid/quality-of-care/improvement-initiatives/hcbs/index.html">https://www.medicaid.gov/medicaid/quality-of-care/improvement-initiatives/hcbs/index.html</a></p>

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2.D.2	Solicit stakeholder input on meaningful outcomes to drive quality measurement.	Convene listening sessions with relevant stakeholders.	CMS	ASPE	Ongoing	<p>Initial target met; continuing work of reviewing literature and guidelines and continues to support quality measure development and implementation.</p> <p>CMS's "Meaningful Measures" framework is a new initiative that identifies the highest priorities for quality measurement and improvement. It involves only assessing those core issues that are the most critical to providing high-quality care and improving individual outcomes. The Meaningful Measure areas serve as the connectors between CMS goals and individual measures/initiatives that demonstrate how high-quality outcomes are being achieved across settings of care.</p> <p><a href="https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/QualityInitiativesGenInfo/MMF/General-info-Sub-Page.html">https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/QualityInitiativesGenInfo/MMF/General-info-Sub-Page.html</a></p>
2.D.3	Clarify and disseminate information on privacy, autonomy, and safety issues for physicians.	Develop information for physicians on privacy, autonomy, and safety issues. This resource will help providers better understand these issues and the balance between safety, privacy, and autonomy.	HRSA		Ongoing	HHS continues to disseminate this information through the trainings provided by the GWEP awardees
2.D.4	Provide improved training resources to IHS staff on person-centered goals and strategies for care improvement.	Review of training resources for IHS nursing staff highlighting person-centered goals and strategies for improving care for PWD.	IHS	HRSA	Ongoing	IHS collaborated with HRSA to engage the HRSA-funded GWEPs in strategies to improve recognition and diagnosis of dementia. 8 HRSA GWEPs are currently partnering with federally recognized Tribal organizations and 1 HRSA GWEP collaborates with a non-federally recognized Tribal organization. 9 GWEPs have developed a Native Populations Interest Group in preparation for exchanging training materials. The University of Wyoming is currently pilot-testing culturally-relevant dementia training material for American Indian and Alaska Native people on the Wind River Reservation by creating a pictorial version of the Alzheimer's Association's "Know the 10 Signs: Early Detection Matters". The other members of the Interest Group are discussing how/whether to adopt similar materials.

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2.D.5	Understand trends in residential care settings for older adults.	Analyze trends in residential care, using data at various points in time from several data sources, including the MCBS, the NHATS, and the NSLTCP.	ASPE		Completed	ASPE's project analyzed trends in residential care, using data at various points in time from several data sources, including the MCBS, the NHATS, and the NSLTCP. This project presented the estimates, explained why they would be expected to differ across sources, and analyzed the resulting trends. The sources also contain some information on the characteristics of facilities and residents. Report will be posted in late 2018.
2.D.6	Study factors influencing the progression of disability in older adults.	Use the NHATS data from 2011 to 2015 to study the progression of disability and the implications for caregiving needs.	ASPE		Discontinued	ASPE's project uses the NHATS data from 2011 to 2015 to study the progression of disability and the implications for caregiving needs. Outcomes data are being tabulated each year (death, long-stay nursing home admission, and residential care admission, continued or increased use of informal/paid care). Those who develop dementia after 2011 would be studied, but most cases would already have dementia or symptoms in 2011, and the course of their condition would be followed through 2015.  This project was discontinued but portions will be included in future projects to come.
<b>Strategy 2.E: Explore the Effectiveness of New Models of Care for People with Alzheimer's Disease and Related Dementias</b>						
2.E.1	Evaluate the effectiveness of relevant CMMI models for people with AD/ADRD.	Examine changes in care quality and care coordination among people with AD/ADRD.	CMS/CMMI	NIH/NIA, Johns Hopkins University	Ongoing	HCIAs Round 1 have ended. Information about the evaluation of these projects are available. <a href="https://downloads.cms.gov/files/cmmi/hcia-diseasespecific-thirdannualrpt.pdf">https://downloads.cms.gov/files/cmmi/hcia-diseasespecific-thirdannualrpt.pdf</a> <a href="https://downloads.cms.gov/files/cmmi/hcia-chspt-thirdannualrpt.pdf">https://downloads.cms.gov/files/cmmi/hcia-chspt-thirdannualrpt.pdf</a> <a href="https://innovation.cms.gov/Files/reports/hcia-diseasespecific-thirdannrpt-addendum.pdf">https://innovation.cms.gov/Files/reports/hcia-diseasespecific-thirdannrpt-addendum.pdf</a>  HCIAs Round 2 has also ended, and CMS is in the process of completing the evaluation. Latest evaluation report is available; final evaluation results are anticipated to be available at the end of 2019. <a href="https://downloads.cms.gov/files/cmmi/hcia2-yr3evalrpt.pdf">https://downloads.cms.gov/files/cmmi/hcia2-yr3evalrpt.pdf</a>
2.E.2	Evaluate the effectiveness of the Independence at Home Demonstration.	Examine whether health and functional status outcomes are improved among people with AD/ADRD in this demonstration.	CMS/CMMI		Ongoing	CMS has released the Year 2 results. <a href="https://www.cms.gov/Newsroom/MediaReleaseDatabase/Fact-sheets/2017-Fact-Sheet-items/2017-01-19.html">https://www.cms.gov/Newsroom/MediaReleaseDatabase/Fact-sheets/2017-Fact-Sheet-items/2017-01-19.html</a>
2.E.3	Develop a SDM model as an alternative to guardianship.	Support a national training, technical assistance, and resource center to explore and develop SDM as an alternative to guardianship.	ACL		Started in 2015, expected completion in 2019	<a href="http://www.supporteddecisionmaking.org">http://www.supporteddecisionmaking.org</a>



Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2017 and 2018
2.E.4	Analyze new payment and service options for Medicare-Medicaid dual eligible beneficiaries.	Produce targeted research issue briefs on options for expanding PACE.	ASPE		Report expected December 2018	ASPE created a project to produce targeted research briefs on options for expanding PACE. PACE was established as a permanent Medicare and Medicaid benefit by the Balanced Budget Act of 1997, and it attempts to help nursing home eligible older adults avoid institutional care by providing them with an appropriate, tailored mix of coordinated acute care and HCBS.  Nationally, nearly half (49% comp) of PACE participants have been diagnosed with dementia, therefore lessons from the PACE model may have strong applicability to the field of dementia care broadly. Reports are expected by December 2018.
2.E.5	Understand the role of CCBHC in providing access to care.	Conduct an evaluation of CCHBC demonstration program to determine improvements in accessibility, quality, and outcomes of ambulatory care.	ASPE		Ongoing	ASPE is managing a 5 year evaluation of this demonstration to answer research questions on how the CCBHCs improve access to care, whether they implement a full scope of services, how they improve the quality of care, whether the PPS cover the full costs of care, and how the demonstration impacts costs and utilization in Medicaid. Reports to Congress are due annually, and interim reports and a final report will be posted on ASPE's website.
<b>Strategy 2.F: Ensure that People with Alzheimer's Disease and Related Dementias Experience Safe and Effective Transitions between Care Settings and Systems</b>						
2.F.1	Implement and evaluate new care models to support effective care transitions for people with AD/ADRD.	Evaluate care transition demonstration programs.	CMS	ACL	Ongoing	CMS's Primary Care Plus Demonstration includes about 6% of beneficiaries with dementia, where providers can engage in opportunities to receive enhanced fees for care coordination and support for dementia. <a href="https://innovation.cms.gov/initiatives/comprehensive-primary-care-plus">https://innovation.cms.gov/initiatives/comprehensive-primary-care-plus</a>  ACL's state dementia system grants are all required to include a care transitions component and all grantees are required to evaluate the effectiveness of their programs. Numerous models of care transitions interventions are presently being implemented through ACL's community project, all of which include collection of outcome data and will include a programmatic evaluation upon completion of the grant period.

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<b>Strategy 2.G: Advance Coordinated and Integrated Health and Long-Term Services and Supports for Individuals Living with Alzheimer's Disease and Related Dementias</b>						
2.G.1	Implement and evaluate care coordination models.	Implement and evaluate care coordination models.	CMS		Ongoing	Multiple care coordination models and guidance on care coordination continue across CMS. Care coordination models are a critical component of care in Medicare that contributes to better health outcomes and higher beneficiary satisfaction. Starting in 2017, based on feedback from stakeholders, CMS has made several significant changes to requirements and payment for care coordination models services, including simplified and reduced billing and documentation rules.
2.G.2	Assess the adequacy of HIT standards for care plans to support the needs of persons with AD/ADRD.	Convene partners to explore feasibility and timing.	ASPE	ONC	Ongoing	ASPE continues work with ONC and partners in exploring the feasibility and timing of activities to assess, identify, and fill gaps in accepted HIT standards for the representation of care plans to represent the health concerns, goals, interventions, and other information identified by individuals, caregivers and family members in caring for individuals receiving LTSS, including those with AD/ADRD.
2.G.3	Compare outcomes for dual eligible beneficiaries in integrated care models.	Determine the feasibility of an analysis that compares selected health outcomes and quality measures for Medicare-Medicaid dual eligible beneficiaries participating in managed care models.	ASPE		Completed	ASPE conducted a project to determine the feasibility of an analysis that compares selected health outcomes and quality measures for Medicare-Medicaid dual eligible beneficiaries participating in managed care models that align Medicare and Medicaid benefits, such as Medicare Advantage D-SNPs, Medicare Advantage Fully Integrated D-SNPs, and PACE, to outcomes for dually eligible beneficiaries who are not participating in these models. Reports are forthcoming in September 2019.
2.G.4	Study impacts of managed care on health outcomes and quality.	Study the impact of Medicare-Medicaid payment alignment for dually eligible individuals on outcomes and utilization of acute care services and LTSS.	ASPE		Ongoing	ASPE has a project underway to evaluate the impact of Medicare and Medicaid alignment for individuals eligible for both Medicare and Medicaid on beneficiary outcomes and utilization of acute care services and LTSS. This project is testing the hypothesis that the aligned delivery of Medicare and Medicaid-funded services to full-benefit duals is associated with improved health status and increased efficiency of health care utilization. A report is forthcoming in June 2019.
2.G.5	Analyze pathways of eligibility for dually eligible beneficiaries.	Determine how beneficiaries dually eligible for Medicare and Medicaid achieve this status.  Understand effects on spending and service use patterns.	ASPE		Ongoing	ASPE has a project underway to identify the frequency with which the various eligibility pathways to Medicare-Medicaid dual eligible status are utilized and to understand the circumstances and characteristics of individuals surrounding their transition to dual status. A report is forthcoming in December 2018.

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2017 and 2018
2.G.6	Analyze maintenance and loss of dual eligibility status.	Document frequency of Medicaid coverage loss among those dually eligible for both Medicare and Medicaid and implications for state policy.	ASPE		Completed	ASPE completed a project to document the frequency of Medicaid coverage loss among newly eligible full-benefit Medicare-Medicaid dual eligible beneficiaries and identify potential causes for coverage loss. This policy brief aimed to identify potential causes for the loss of Medicaid coverage among full-benefit dual eligible beneficiaries and better understand the relationship between states' Medicaid eligibility and enrollment policies and reasons for loss of Medicaid coverage. A report is forthcoming in December 2018.
2.G.7	Understand issues specific to the "triple-user" population.	Study policy issues and implications specific to those individuals eligible for Medicare, Medicaid, and Veterans Health Benefits.	ASPE		Ongoing	ASPE has a project underway to better understand the demographics, service utilization patterns, health status and policy challenges facing the population that is simultaneously eligible for Medicare, Medicaid, and VHA benefits. This project will explore the demographics and service use patterns of veterans who use multiple systems of care, with a special focus on triple-users, to better understand how these veterans compare to other populations with multiple system use. A report is forthcoming in December 2018.
<b>Strategy 2.H: Improve Care for Populations Disproportionally Affected by Alzheimer's Disease and Related Dementias and for Populations Facing Care Challenges</b>						
2.H.1	Create funding opportunities for organizations to improve care for these specific populations.	Fund dementia-capable systems to implement new programs designed to provide more effective services to: (1) individuals living alone in the community with dementia; (2) individuals with IDD who have or are at risk of developing dementia; (3) caregivers who need behavioral symptom management training or expert consultations to help them care for family members.	ACL		Ongoing	ACL awarded 11 community-based grants in 2017 for a total of 43 projects in 28 states and Puerto Rico awarded since 2014. ACL anticipates awarding additional grants in 2018. Note that future grants are contingent on availability of funding.

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2017 and 2018
2.H.2	Enhance understanding of models of family support for people with IDD as they age.	Explore promising models, release report.	ACL		Completed	This report presents the findings and resources to the community of providers who primarily serve older adults. It provides a broad overview of the services and support system for persons with IDD affected by dementia and their caregivers, examples of cross-network initiatives, and resources for improving dementia care across agencies and organizations that serve this population. This paper presents the current state of services and support system for persons with IDD who have dementia. There is recognition in the aging and IDD networks that states are in a transition period where the future of services will be more person-centered and focused on integration in the community. <a href="https://aspe.hhs.gov/report/idd-and-dementia">https://aspe.hhs.gov/report/idd-and-dementia</a>
2.H.3	Target resources towards the IDD and dementia population.	Develop workforces in aging, public health, and IDD that are dementia-capable and culturally-competent.  Develop programs that include improvement of the quality and effectiveness of program and services dedicated to individuals aging with IDD and AD/ADRD or at high risk of developing AD/ADRD.	ACL		Ongoing	ACL, through its AD/ADRD grant programs and NADRC, has targeted program resources to the IDD and dementia issue. At the White House Conference on Aging in July 2015, ACL released their IDD and Dementia Report on the current state of services and support system for persons with IDD living with dementia. The brief provides a broad overview of the services and support system for persons with IDD affected by dementia and their caregivers. Since the 2014 inception of their community grant program, ACL has required that participating grantees develop programs that include "improvement of the quality and effectiveness of program and services dedicated to individuals aging with IDD and ARD or at high risk of developing ARD". Each year since 2015, the NADRC has included an IDD and dementia-specific webinar in their annual webinar series. <ul style="list-style-type: none"> <li>• IDD and Dementia Issue Brief <a href="https://nadrc.acl.gov/node/74">https://nadrc.acl.gov/node/74</a></li> <li>• 2015 NADRC Webinar (February 26, 2015) IDD and Dementia--Experiences of a Family Advocate and Promising Practices <a href="https://nadrc.acl.gov/node/59">https://nadrc.acl.gov/node/59</a></li> <li>• 2016 NADRC Webinar: IDD and Dementia--Webinar conducted as part of NADRC technical assistance for California grantee <a href="https://nadrc.acl.gov/node/51">https://nadrc.acl.gov/node/51</a></li> <li>• 2017 NADRC Webinar: Methods and Techniques for Early Dementia Screening for People with IDD <a href="https://nadrc.acl.gov/node/101">https://nadrc.acl.gov/node/101</a></li> <li>• 2018 NADRC Webinar: The Case for Palliative Care for People with IDD and Dementia</li> </ul>

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2017 and 2018
<b>Goal 3: Expand Supports for People with Alzheimer's Disease and Related Dementias and Their Families</b>						
<b>Strategy 3.A: Ensure Receipt of Culturally Sensitive Education, Training, and Support Materials</b>						
3.A.1	Distribute materials to caregivers.	Distribute training and education materials through federal agencies and state and local networks.	ACL	NIH/NIA, ADEAR	Ongoing	<p>Networks serving caregivers have frequent opportunities for webinars, consultation, and grants to better serve caregivers.</p> <p>NADRC  <a href="http://www.nadrc.acl.gov">http://www.nadrc.acl.gov</a>  <a href="http://www.alzheimers.gov">http://www.alzheimers.gov</a></p> <p>Fact sheets  <a href="https://eldercare.acl.gov/Public/Resources/Topic/Alzheimer_Disease.aspx">https://eldercare.acl.gov/Public/Resources/Topic/Alzheimer_Disease.aspx</a></p> <p>NIA's ADEAR Center continues to offer free information in English and Spanish on AD/ADRD caregiving in print and online, as well as through our information and referral helpline, a weekly email alert specifically on caregiving issues, and social media (Facebook and Twitter).  <a href="https://www.nia.nih.gov/health/alzheimers/caregiving">https://www.nia.nih.gov/health/alzheimers/caregiving</a></p>
3.A.2	Utilize HIT for caregivers and persons with AD/ADRD.	Identify tools, evaluate, and disseminate findings.	AHRQ		Ongoing, completion expected 2019	<p>Grant awarded (1P50 HS 019917) and used to create Elder Tree, a suite of electronic services to support older adults and their caregivers. The Elder Tree tool is being evaluated. Recruited 400 people who have used the suite, participants were surveyed. Analysis underway and results will be available by July 2016.</p> <p>Grant awarded (5R18HS027836) to evaluate use of remote sensory technology to help manage persons with AD/ADRD and study impact on ability of caregivers to manage family member with AD/ADRD. Recruited 60 caregivers, systems installed and caregivers trained. The recruitment goal is 100.</p>

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2017 and 2018
3.A.3	Increase awareness of the importance of brain health in culturally sensitive ways.	Increase awareness of brain health, specifically AD/ABRD and caregiving among African Americans.	CDC	ACL	Ongoing	<p>CDC supported the development of NBHCAA. The mission of the Brain Health Center is to raise awareness of the issues of cognitive health among African Americans by working through networks of faith-based institutions and by establishing partnerships with organizations and individuals dedicated to the Center's mission. The three areas of focus are brain health education, mobilization and advocacy, and networking. The Brain Health Center serves as an information hub on the human brain that must be shared throughout all networks that reach and touch approximately 40 million African Americans living in the United States. <a href="http://brainhealthcenterforafricanamericans.org/">http://brainhealthcenterforafricanamericans.org/</a></p> <p>CDC supported The Balm in Gilead to develop and implement Memory Sunday, the second Sunday in June, as a designated Sunday, within congregations serving African Americans, that provides education on AD: prevention, treatment, research studies and caregiving. The purpose of Memory Sunday is to bring national and local attention to the tremendous burden that AD/ABRD are having on the African American community; to utilize the power and influence of the African American pulpit to bring awareness; to distribute the facts about AD; to encourage participation in research studies and to support persons living with AD and their caregivers.</p> <p>CDC supported the Alzheimer's Association to develop, using BRFSS data, several fact sheets and infographics using the most current data, including a new infographic specifically demonstrating the effect of subjective cognitive decline on the African American population. These resources are made available on the Alzheimer's Association website, and distributed to a national network of state Alzheimer's Association offices, public health professionals, and decision makers. These resources are updated annually, as new data becomes available. By creating easy-to-read, visually appealing materials, uptake of knowledge is facilitated. <a href="https://alz.org/publichealth/downloads/infographic_on_cognitive_decline_aa_2015_brfss.pdf">https://alz.org/publichealth/downloads/infographic_on_cognitive_decline_aa_2015_brfss.pdf</a></p>

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2017 and 2018
3.A.3 (cont.)						<p>In 2018, ACL's updated its Brain Health Resource, a presentation toolkit on brain health as we age. The resource was developed by ACL with scientific review by NIH and CDC for use at senior centers and in other community settings. Written in plain language, the evidence-based resource explains what people can do to help keep their brains functioning best.</p>
3.A.4	<p>Increase awareness of the importance of brain health for Tribal communities in culturally sensitive ways.</p>	<p>Develop materials to support implementation of the Public Health Road Map in Tribal Communities.</p>	<p>CDC</p>	<p>private partners</p>	<p>Ongoing</p>	<p>In conjunction with the Alzheimer's Association and other partners, CDC is developing a special edition of the "Public Health Road Map for Tribal Communities: The Healthy Brain Initiative Road Map for Indian Country". The original Road Map focuses on issues pertinent to state and local public health agencies and their partners. A companion Road Map for Indian Country has been designed specifically for public health systems serving American Indians, Alaskan Natives, and Native Hawaiians.</p> <p>CDC supported ASTHO to develop culturally-sensitive materials to educate and empower tribes and Tribal populations about brain health and caregiving. The materials focus on cardiovascular risk factors related to brain health and caregiving issues for Tribal communities.</p>



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<b>Strategy 3.B: Enable Family Caregivers to Continue to Provide Care while Maintaining Their Own Health and Well-Being</b>						
3.B.1	Develop and disseminate evidence-based interventions for people with AD/ADRD and their caregivers.	Identify specific evidence-based interventions that can be developed into training materials or new programs; develop training materials and/or design intervention programs based on NIH/NIA research.	NIH/NIA	AHRQ, CMS, CDC, ACL	Ongoing	<p>ACL's NADRC continues to develop resources designed to support the translation and implementation of evidence based interventions in states and communities.</p> <p>ACL's grant programs to states and communities are designed to develop and enhance dementia-capable HCBS systems. These dementia-specific grants include the translation of evidence-based interventions into grantee communities.</p> <p>ACL compendium of evidence-based and evidence-informed interventions translated through grants to states and communities  <a href="https://nadrc.acl.gov/node/140">https://nadrc.acl.gov/node/140</a></p> <p>ACL-funded SPECIAL EDITION of ASA Generations: Supporting People with Dementia and Their Caregivers in the Community  <a href="https://nadrc.acl.gov/node/110">https://nadrc.acl.gov/node/110</a></p> <p>NADRC  <a href="http://www.nadrc.acl.gov">http://www.nadrc.acl.gov</a>  <a href="http://www.brainhealth.gov">http://www.brainhealth.gov</a></p> <p>NIA's ADEAR Center continues to offer free information in English and Spanish on AD/ADRD caregiving in print and online, as well as through our information and referral helpline, a weekly email alert specifically on caregiving issues, and social media (Facebook and Twitter).  <a href="https://www.nia.nih.gov/health/alzheimers/caregiving">https://www.nia.nih.gov/health/alzheimers/caregiving</a></p> <p>Dementia Care Summit  <a href="https://www.nia.nih.gov/news/dementia-care-summit-research-recommendations-released">https://www.nia.nih.gov/news/dementia-care-summit-research-recommendations-released</a></p> <p>Resources for dissemination  <a href="http://www.alzheimers.gov">http://www.alzheimers.gov</a></p>

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3.B.1 (cont.)						<p>Ongoing and newly released FOAs:</p> <ul style="list-style-type: none"> <li>• PAR-15-348: Research on Informal and Formal Caregiving for AD <a href="http://grants.nih.gov/grants/guide/pa-files/PA-15-348.html">http://grants.nih.gov/grants/guide/pa-files/PA-15-348.html</a></li> <li>• PAS-18-030: Related Dementias at the End of Life (R01 Clinical Trial Optional) <a href="https://grants.nih.gov/grants/guide/pa-files/PAS-18-030.html">https://grants.nih.gov/grants/guide/pa-files/PAS-18-030.html</a></li> <li>• PAR-18-186: Development of socially-assistive robots to Engage Persons with AD/ADRD, and their Caregivers <a href="https://grants.nih.gov/grants/guide/pa-files/PA-18-186.html">https://grants.nih.gov/grants/guide/pa-files/PA-18-186.html</a></li> <li>• PA-18-502: Advancing the Science of Geriatric Palliative Care <a href="https://grants.nih.gov/grants/guide/pa-files/PA-18-502.html">https://grants.nih.gov/grants/guide/pa-files/PA-18-502.html</a></li> <li>• PAR-18-585: Pragmatic Trials for Dementia Care in LTSS Settings <a href="https://grants.nih.gov/grants/guide/pa-files/PA-18-585.html">https://grants.nih.gov/grants/guide/pa-files/PA-18-585.html</a></li> <li>• PAR-18-596: Improving the Lives of PWD: Impacts on PWD, Families, and Communities <a href="https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-001.html">https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-001.html</a></li> <li>• RFA-AG-18-030: Dementia Care and Caregiver Support Interventions (R01 - Clinical Trial Required) <a href="https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-18-030.html">https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-18-030.html</a></li> </ul>
3.B.2	Provide effective caregiver interventions through AD-capable systems.	Work with states to identify caregiver interventions for dissemination.	ACL		Ongoing	<p>New grants to states and communities are awarded each year as funding permits.</p> <p>ACL compendium of evidence-based and evidence-informed interventions translated through grants to states and communities <a href="https://nadrc.acl.gov/node/140">https://nadrc.acl.gov/node/140</a></p>
3.B.3	Collaborate to share information on LTSS with Tribal providers.	Various dissemination mechanisms such as webinars and sharing materials with relevant networks.	ACL	IHS, CMS	Ongoing	Dissemination of dementia-specific information through presentations occur at Indian Country meetings and webinars.
3.B.4	Continue to promote use of the National Alzheimer's Call Center to provide information, advice, and support to people with dementia or their caregivers.	ACL will continue to contribute funding to this public-private effort.	ACL	Alzheimer's Association	Ongoing	ACL continues to contribute funding to this public-private effort.
3.B.5	Make behavioral symptom management education and training available to caregivers.	Award grants.	ACL	CMS	Ongoing	ACL requires that all community grants include behavioral symptom management activities to support caregivers in their programs.

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3.B.6	Examine technological solutions to support family caregivers.	Grant awarded--awaiting results.	AHRQ		December 2019	Grant awarded (5R18HS027836) to evaluate use of remote sensory technology to help manage persons with AD/ADRD and study impact on ability of caregivers to manage family member with AD/ADRD. Recruited 60 caregivers, systems installed and caregivers trained. The recruitment goal is 100.
3.B.7	Adapt and implement REACH in Tribal Communities.	Working in partnership with ACL the University of Tennessee Health Sciences Center, and the Rx Foundation implement the REACH intervention as REACH into Indian Country.	IHS	ACL, VA, University of Tennessee Health Sciences Center	Ongoing	Initial phase completed with 80 REACH certified caregiver support coaches in 56 Tribal communities, serving at least 55 caregivers as of February 2018. Second phase of the effort is focused on strategies to increase penetration of REACH in the communities where there are certified coaches and on building additional, sustainable options for evidence-based caregiver support services. Developing Project ECHO model to support Caregiver Coaches in Tribal Communities.
3.B.8	Determine economic impacts of programs to support informal caregivers.	Provide a framework for policy makers to begin to estimate costs and benefits of policies and programs aimed to help caregivers.	ASPE		Completed	ASPE completed a study on the economic impacts of programs to support informal caregivers. This research aims to provide a framework for policy makers to begin estimating costs and benefits of policies and programs aimed to help caregivers, including, for example, respite care, paid family leave, and workplace flexibility policies. A report will be posted shortly.

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2017 and 2018
3.B.9	Develop and disseminate information to caregivers on AD/ADRD and caregiving.	Develop up-to-date, relevant web content on a variety of issues to support caregivers in their role and to stay healthy.	CDC		Ongoing	<p>CDC highlights the need for care planning for those with AD and their caregivers. Care plans can reduce emergency room visits, hospitalizations, and improve overall medical management for people with a chronic health condition, like AD resulting in better quality of life for all care recipients.</p> <ul style="list-style-type: none"> <li>• <a href="https://www.cdc.gov/features/alzheimers-and-exercise/index.html">https://www.cdc.gov/features/alzheimers-and-exercise/index.html</a></li> <li>• <a href="https://www.cdc.gov/features/caregivers-month/index.html">https://www.cdc.gov/features/caregivers-month/index.html</a></li> <li>• <a href="https://www.cdc.gov/features/heart-brain-health/index.html">https://www.cdc.gov/features/heart-brain-health/index.html</a></li> </ul> <p>Annually ACL, through the NADRC and its grant programs, continues to develop and make available web content on issues relevant to paid and unpaid caregivers.</p> <p>2018 tools for caregivers include a handbook for caregivers helping people living alone with no known supports, a toolkit to aide caregivers and PWD in preparing for disasters, as well as a toolkit for first responders working with PWD.</p> <p>Guide for Professionals on Practical Strategies for Persons with Dementia Living Alone <a href="https://nadrc.acl.gov/node/136">https://nadrc.acl.gov/node/136</a></p>
<b>Strategy 3.C: Assist Families in Planning for Future Care Needs</b>						
3.C.1	Understand the future of Medicaid LTSS.	Examine the role of LTSS in Medicaid and the impacts of sociodemographic changes on Medicaid.	ASPE		Completed	<p>This report examines the role of LTSS in Medicaid. It also examines how sociodemographic changes are likely to affect the demand for LTSS in the future, and as a result, Medicaid use and expenditures. The report shows: the demand for LTSS is likely to increase dramatically; LTSS is a major part of the Medicaid program, accounting for about a 3rd of total expenditures, and Medicaid is the dominant payer of LTSS.</p> <p><a href="https://aspe.hhs.gov/basic-report/overview-long-term-services-and-supports-and-medicaid-final-report">https://aspe.hhs.gov/basic-report/overview-long-term-services-and-supports-and-medicaid-final-report</a></p>
3.C.2	Understand functional trajectories of people with AD/ADRD at the end of life.	Understand better the trajectory of people with AD/ADRD, who tend to cycle in and out of hospice care at the end of life, and how numerous variables affect the trajectory.	ASPE		Ongoing	<p>This project is a follow-on the Institute of Medicine's work on advanced dementia in 2015-2016. ASPE is working on a project to understanding how the functional trajectories of people with dementia differ from those without dementia in the last few years of life, as well how these trajectories vary based on other characteristics. The project will also examine corresponding differences in health care utilization in the last few years of life to determine if there are differences between people with and without dementia.</p>

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<b>Strategy 3.D: Maintain the Dignity, Safety and Rights of People with Alzheimer's Disease and Related Dementias</b>						
3.D.1	Monitor, report, and reduce inappropriate use of antipsychotics in nursing homes.	National Partnership to Improve Dementia Care.	CMS	ACL, NORC	Ongoing	<p>The Partnership met its goal of reducing the national prevalence of antipsychotic use in long-stay nursing home residents by 30% by the end of 2016 and recently announced a new goal of a 15% reduction by the end of 2019 for long-stay residents in those homes with currently limited reduction rates (late adopters).</p> <p>CMS continues to conduct Focused Dementia Care Surveys, first initiated in 2014, to assist in determining compliance with areas such as quality dementia care, the use of non-pharmacological approaches, and utilization of antipsychotic medications. These focused reviews examine the process for prescribing antipsychotic medications and assess compliance with other federal requirements related to dementia care practices in nursing homes.</p> <p>CMS has launched CMPRP, a 3-year effort to drive improvements in quality of life and quality of care for nursing home residents. CMPRP is funded by the federal portion of CMP funds to conduct activities that support and protect nursing home residents. This program will build on other CMS initiatives, such as the National Partnership. A multi-pronged approach, that focuses on those homes that have been identified as late adopters, is being utilized. Through this effort, CMS will provide technical assistance, as well as use a Breakthrough Community collaborative model.</p> <p><a href="https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/National-Partnership-to-Improve-Dementia-Care-in-Nursing-Homes.html">https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/National-Partnership-to-Improve-Dementia-Care-in-Nursing-Homes.html</a></p>
3.D.2	Incorporate elder abuse awareness into Aging Network activities.	Eldercare Locator and other Aging Network and prevention programs providers to recognize warning signs of abuse.	ACL	private partners, grantees	Ongoing	<p>ACL continues to fund programs designed to address elder abuse. NCEA is funded by ACL and, through their programs, addresses all facets of elder abuse.</p> <p><a href="http://www.ncea.acl.gov">http://www.ncea.acl.gov</a></p>

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2017 and 2018
3.D.3	Translate and disseminate information on abuse of people with dementia.	Create and disseminate research briefs, fact sheets and webinars.	ACL	NIH/NIA, DoJ, private partners	Ongoing	<p>ACL continues to fund programs designed to address elder abuse. NCEA is funded by ACL and, through their programs, addresses all facets of elder abuse, including the abuse of individuals living with dementia.  <a href="http://www.ncea.acl.gov">http://www.ncea.acl.gov</a></p> <p>In 2016, NIH published an Age Page on Elder Abuse to educate the public and disseminate information about types of elder abuse, dealing with caregiver stress, and how to help.  <a href="https://www.nia.nih.gov/health/publication/elder-abuse">https://www.nia.nih.gov/health/publication/elder-abuse</a></p>
3.D.4	Improve the ability of legal services to address the needs of people with AD/ADRD.	Award, monitor, and report on demonstration grants. Revise NLRC website.	ACL	NLRC, legal assistance developers	Ongoing	<p>ACL grants to states and communities include pilot programs designed to make dementia-capable legal services available to PWD and their caregivers. Program participants are providing dementia training to legal services providers, as well as implementing voucher programs to aide in advance planning.</p> <p>In 2017, NADRC designed and published Living with Dementia: Advance Planning Guides (4 guides) for Persons with Dementia and Caregivers  <a href="https://nadrc.acl.gov/node/137">https://nadrc.acl.gov/node/137</a></p> <p>ACL's NADRC continues to work closely with the American Bar Association's Commission on Law and Aging in the development of resources that support PWD and their caregivers in legal matters.</p> <p>ACL funds the National Center on Law and Elder Rights and grants under the Model Approaches program.</p>
3.D.5	Develop public-private partnerships to combat abuse and exploitation of Social Security beneficiaries.	An interagency, public-private partnership program to address abuse and exploitation of individuals who are incapable of managing their finances.	SSA	ACL, CNCS, CFPB, SSA	Completed	<p>Volunteer Representative Payee Pilot Program results include the development and testing of protocols and materials to assist in the identification and training of individuals to serve as volunteer representative payees. SSA conducted a media campaign to build awareness of the pilot's results.  <a href="https://www.ssa.gov/payee/probonopilot.htm">https://www.ssa.gov/payee/probonopilot.htm</a></p>

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3.D.6	Educate law enforcement about interacting with AD/ADRD.	Educate law enforcement and public safety professionals about how to interact appropriately with missing persons with AD/ADRD.	DoJ		Ongoing	<p>March 2016: Launch of 10 regional Elder Justice Task Forces. These teams will bring together federal, state and local prosecutors, law enforcement, and agencies that provide services to the elderly, to coordinate and enhance efforts to pursue nursing homes that provide grossly substandard care to their residents.</p> <p><a href="https://www.justice.gov/opa/pr/department-justice-launches-10-regional-elder-justice-task-forces">https://www.justice.gov/opa/pr/department-justice-launches-10-regional-elder-justice-task-forces</a></p> <p>As part of their funded grants, several ACL ADI-SSS community projects are training law enforcement and other first responders. 1 grantee created a series well received law enforcement training videos to address wandering, driving and encountering disoriented individuals on "house calls".</p> <p><a href="https://youtu.be/cQbmcq7rC7A">https://youtu.be/cQbmcq7rC7A</a></p>
3.D.7	Work with communities to develop best practices for protecting people with AD/ADRD.	A guide to educate law enforcement and inform communities, families and caregivers about best practices for protecting persons with AD/ADRD and preventing them from wandering and becoming lost.	DoJ		Ongoing	<p>DoJ Elder Abuse Information</p> <p><a href="https://www.justice.gov/elderjustice/financial/faq.html">https://www.justice.gov/elderjustice/financial/faq.html</a></p>
3.D.8	Expand access to treatment for people with mental health and substance use disorders.	Maintain the Mental Health and Substance Use Disorder Parity Task Force. The Task Force will focus key federal agencies on the work of ensuring that Americans receive the coverage and treatment that they need.	ASPE, SAMHSA	DoT, DoD, DoJ, DoL, VA, OPM, ONDCP	Completed	<p>Mental Health and Substance Use Disorder Parity Task Force</p> <p><a href="https://www.hhs.gov/about/agencies/advisory-committees/mental-health-parity/task-force/index.html">https://www.hhs.gov/about/agencies/advisory-committees/mental-health-parity/task-force/index.html</a></p> <p>Mental Health and Substance Use Disorder Parity Task Force--Final Report</p> <p><a href="https://www.hhs.gov/about/agencies/advisory-committees/mental-health-parity/task-force/final-report/index.html">https://www.hhs.gov/about/agencies/advisory-committees/mental-health-parity/task-force/final-report/index.html</a></p> <p>Work will continue on this issue will continue under numerous other agencies referenced in the Final Report</p>
3.D.9	Expand coverage of behavioral health services via employment-based health plans and health insurance.	Follow-up on implementation of the MHPAEA.	ASPE	CMS, SAMHSA, Treasury, DoL, OPM	Ongoing	<p>ASPE, along with representatives from CMS, SAMHSA, DoL, Treasury, and OPM held a series of public listening sessions on parity implementation in order to develop an Action Plan for Enhanced Enforcement of Mental Health and Substance Use Disorder Coverage.</p> <p><a href="http://www.hhs.gov/parity">http://www.hhs.gov/parity</a></p>

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2017 and 2018
<b>Strategy 3.E: Assess and Address the Housing Needs of People with Alzheimer's Disease and Related Dementias</b>						
3.E.1	Evaluate SASH program.	Analyze the SASH program model of coordinated health and supportive services within affordable housing settings.	ASPE		Ongoing	<p>ASPE and HUD continue to evaluate the SASH program in Vermont. Early findings show a promising model of coordinated health and supportive services within affordable housing settings.</p> <p>Latest report  <a href="https://aspe.hhs.gov/basic-report/support-and-services-home-sash-evaluation-second-annual-report">https://aspe.hhs.gov/basic-report/support-and-services-home-sash-evaluation-second-annual-report</a></p> <p>HUD Article  <a href="https://www.huduser.gov/portal/periodicals/cityscape/vol20num2/ch1.pdf">https://www.huduser.gov/portal/periodicals/cityscape/vol20num2/ch1.pdf</a></p>
3.E.2	Assess utilization of home health benefits.	Using data from Medicare Advantage plans to better evaluate utilization and benefits of home health care.	ASPE		Ongoing	<p>ASPE continues to study the growth in use of the Medicare home health benefit by community-admitted users. The Medicare home health payment policy for FFS has undergone several changes in the past decades. There have also been overall increases in Medicare home health utilization. Growth in utilization has been particularly strong for community-admitted users (those individuals for whom home health episodes are not preceded by a hospitalization or post-acute care. MedPAC has suggested that this is indicative of the fact that some beneficiaries may be using the home health benefit as a long-term care benefit. Several alternative explanations for the growth of the community-admitted users are plausible. Indeed, a recent Academy Health meeting on post-acute care noted that as the American population ages, those with chronic conditions will likely cycle between post-acute care and chronic care services. This research will focus on detailed beneficiary characteristics and the trajectory of care of the community-admitted users to clarify the source of the growth in the benefit for this group of beneficiaries using home health, identify possible gaps in care or inefficient use of services, and inform benefit design.</p>



Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2017 and 2018
<b>Goal 4: Enhance Public Awareness and Engagement</b>						
<b>Strategy 4.A: Educate the Public about Alzheimer's Disease and Related Dementias</b>						
4.A.1	Enhance public outreach about AD/ADRD.	Update website and ADEAR site/publications and disseminate information through social media.	ACL, NIH/NIA		Ongoing	<p>Through its grant and resource center programs, ACL continues to build awareness of AD/ADRD. All ACL grantees include awareness and outreach in their programs. Numerous grantee programs include dementia-friendly community activities in their projects, partnering with established AD/ADRD stakeholders, as well as training volunteer educators of community organizations including, but not limited to, faith-based organizations, business leaders and grass roots volunteer organizations like Rotary clubs.</p> <p>NIA operates the ADEAR Center, the primary Federal Government resource for information about AD/ADRD, research, and caregiving. The ADEAR Center educates the public about the latest research findings and provides evidence-based information online, in print and via a call center. Information about AD/ADRD, participation in clinical trials, and caregiving is freely available. NIA promotes ADEAR's resources through outreach in the research and care communities and through media and advocacy organizations, via weekly e-alerts to more than 50000 subscribers, and social media outreach to more than 10000 followers.</p> <p><a href="http://www.Alzheimers.gov">http://www.Alzheimers.gov</a></p>
4.A.2	Dementia Chart Book.	Complete a chart book with important information on the population of community-dwelling people with dementia in the United States and their caregivers.	ASPE		Release in Fall 2018	ASPE completed a chart book, "Older Adults with Dementia and Their Caregivers in 2015: Key Indicators from the National Health and Aging Trends Study", which describes the population of community-dwelling people with dementia in the United States and their caregivers. Dementia was more prevalent among people who were over age 80, had lower educational attainment, and were not non-Hispanic White.

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2017 and 2018
4.A.3	Facilitate translation of data and surveillance to inform the public.	Develop and disseminate scientific information to public health professionals in a concise and accurate manner.	CDC	private partners	Ongoing	<p>CDC supports the Alzheimer's Association to develop, using BRFSS data, several fact sheets and infographics using the most current data. These resources are made available on the Alzheimer's Association website, and distributed to a national network of state Alzheimer's Association offices, public health professionals, and decision makers. These resources are updated annually, as new data becomes available. By creating easy-to-read, visually appealing materials, uptake of knowledge is facilitated.</p> <p>CDC also supported the Alzheimer's Association to develop a Needs Assessment Toolkit that serves as Guidance and Resources for state Public Health Agencies on Comprehensive Needs Assessments Related to Alzheimer's and Other Dementias. This document aims to increase the use of information and insights to appropriately respond to the growing public health burden associated with AD and other dementias through comprehensive needs assessments. These are at the core of a state's ability to effectively use information to develop, implement, and maintain state plans that are focused either exclusively on AD/ADRD, or more broadly on the incorporation of cognitive health and impairment into other state public health plans. Public health agencies have a high level of expertise related to developing and conducting needs assessments. This toolkit has been developed to help states leverage their expertise in conducting needs assessments to enhance their ability to gather and use information specifically related to AD/ADRD.  <a href="https://www.alz.org/documents_custom/public-health/spotlight-assessment.pdf">https://www.alz.org/documents_custom/public-health/spotlight-assessment.pdf</a></p>
4.A.4	Publish a pamphlet to provide the public with information on dementia.	Create and publish a pamphlet that is meant to provide the general public with in-depth information about AD/ADRD.	NIH/NIA, NIH/NINDS		Completed	<p>NINDS and NIA have updated and published "The Dementias: Hope Through Research," a pamphlet that is meant to provide the general public with in-depth information about AD/ADRD, including common symptoms, diagnosis, and available therapies.  <a href="https://catalog.ninds.nih.gov/ninds/product/Dementias-Hope-Through-Research/17-NS-2252">https://catalog.ninds.nih.gov/ninds/product/Dementias-Hope-Through-Research/17-NS-2252</a></p>
<b>Strategy 4.B: Work with State, Tribal, and Local Governments to Improve Coordination and Identify Model Initiatives to Advance Alzheimer's Disease and Related Dementias Awareness and Readiness across the Government</b>						
4.B.1	Continue to convene federal partners.	Convene to share research findings, innovative or best practices, and information about new or upcoming initiatives.	ASPE	CDC, NIH/NIA, ACL, CMS, HRSA, AHRQ, IHS, SAMHSA, OASH, VA, NSF, DoD	Ongoing	This work will continue throughout the duration of the NAPA legislation and beyond.

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2017 and 2018
4.B.2	Build upon lessons learned to improve the dementia-capability of state and local service systems.	Expand Dementia-Capability Toolkit to include educational materials on identifying persons with cognitive impairment, direct links to tools, and examples of best practices in other states.	ACL	CMS	Ongoing	ACL's grants to states and communities (ADSSP, ADI-SS and ADPI) and the NADRC provide new and improved resources every year. <a href="http://www.nadrc.acl.gov">http://www.nadrc.acl.gov</a>
4.B.3	Get Tribal input on AD/ADRD, and support improved coordination between IHS, Tribal, and Urban Indian Health programs and the Tribal Aging Network around 4 person-centered goals.	<p>Convene Tribal leaders.</p> <p>Improve coordination between IHS, Tribal, and Urban Indian Health programs and the Tribal Aging Network around 4 person-centered goals.</p> <p>IHS and ACL will adapt the VA approach to dementia warning signs and pilot-test it in clinical and community-based settings. IHS and ACL will partner with AD/ADRD advocacy organizations to link state and local chapters with Tribal Senior Centers and IHS, Tribal, and Urban Indian Health Programs.</p>	IHS, ACL	ASPE, VA	Ongoing	Alzheimer's Association meetings with the United South and Eastern Tribes and with the Northwest Portland Area Indian Health Board. Tribal representation on the Alzheimer's Association/CDC Health Brain Initiatives Road Map.
4.B.4	Facilitate translation of data and surveillance into public health practice and the public.	Develop and disseminate scientific information to public health professionals in a concise and accurate manner.	CDC	private partners	Ongoing	CDC supports the Alzheimer's Association to develop, using BRFSS data, several fact sheets and infographics using the most current data. These resources are made available on the Alzheimer's Association website, and distributed to a national network of state Alzheimer's Association offices, public health professionals, and decision makers. These resources are updated annually, as new data becomes available. By creating easy-to-read, visually appealing materials, uptake of knowledge is facilitated.

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2017 and 2018
4.B.5	Facilitate translation of findings into public Health Practice for State and Local Health departments and their partners.	Develop and update a Public Health Road Map for assisting state, Tribal and local health departments in prioritizing actions.	CDC	multiple agencies, private partners	Expected Release Fall 2018	CDC supports the Alzheimer's Association to co-develop the 3rd in a series of HBI Road Maps to advance cognitive health as an integral component of public health. This "Healthy Brain Initiative State and Local Public Health Partnerships to Address Dementia, The 2018-2023 Road Map", outlines how state and local public health agencies and their partners can continue to promote cognitive health, address cognitive impairment for people living in the community, and help meet the needs of caregivers. 25 specific actions are proposed in 4 traditional domains of public health: educate and empower, develop policies and mobilize partnerships, assure a competent workforce, and monitor and evaluate.
4.B.6	Facilitate translation of findings into public Health Practice in Tribal Communities.	Develop materials to support implementation of the Public Health Road Map in Tribal Communities.	CDC	private partners	Expected Release Fall 2018	In conjunction with the Alzheimer's Association and other partners, CDC is developing a special edition of the "Public Health Road Map for Tribal Communities: The Healthy Brain Initiative Road Map for Indian Country". The original Road Map focuses on issues pertinent to state and local public health agencies and their partners. A companion Road Map for Indian Country has been designed specifically for public health systems serving American Indians and Alaskan Natives.
<b>Strategy 4.C: Coordinate United States Efforts with Those of the Global Community</b>						
4.C.1	Work with global partners to enhance collaboration.	Convene global partners in collaboration with G8 Dementia Summit.	ASPE		On hold	United States participated in legacy meetings throughout 2014. United States hosted the final legacy meeting in February 2015, and was represented at the WHO Dementia meeting in Geneva in March 2015.  International work in the dementia space is on hold pending administration priorities.
<b>Goal 5: Improve Data to Track Progress</b>						
<b>Strategy 5.A: Enhance the Federal Government's Ability to Track Progress</b>						
5.A.1	Identify needed changes or additions to data.	Work with federal partners and researchers.	ASPE	CMS, CDC, NIH/NIA, ACL, VA, IHS	Ongoing	This work will continue throughout the duration of the NAPA legislation and beyond.
5.A.2	Make needed improvements to data.	Develop questions to be fielded for data collection. Add to surveys.	ASPE	CDC/NCHS, NIH/NIA	Ongoing	This work will continue throughout the duration of the NAPA legislation and beyond.

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2017 and 2018
5.A.3	Summarize data on cognitive impairment and caregiving across states.	Report on BRFSS and NHANES data on cognitive decline and caregiving.	CDC		Ongoing	<p>CDC worked with partners and revised the BRFSS Cognitive Decline and Caregiving Optional Modules, which were approved as official optional modules beginning in 2015. In 2015 and 2016, 51 states and territories collected data using the Cognitive Decline Module and 40 states collected data using the Caregiving Module. Additional states are collecting data using the Cognitive Caregiving Modules in 2017. Findings from the 2015 cognitive and caregiving data are publically available on CDC's Healthy Aging Data Portal and fact sheets and infographics were developed for each participating states. Findings from 2016 BRFSS will be released late in 2017</p> <ul style="list-style-type: none"> <li>• <a href="https://www.cdc.gov/aging/agingdata/index.html">https://www.cdc.gov/aging/agingdata/index.html</a></li> <li>• <a href="http://www.alz.org/publichealth/data-collection.asp">http://www.alz.org/publichealth/data-collection.asp</a></li> <li>• <a href="https://www.cdc.gov/aging/healthybrain/surveillance.htm">https://www.cdc.gov/aging/healthybrain/surveillance.htm</a></li> </ul> <p>CDC supported the development and collection of subjective cognitive decline and cognitive functioning data from the in-person NHANES, which are publically available for download and analysis. These data were collected in adults 60 years and older as part of the 2011-2012 and 2013-2014 data collection cycles. The data included in this release include results from 3 tests of cognitive function: the CERAD Word Learning subtest, a test of Animal Fluency, and the Digit Symbol Substitution Test. <a href="http://www.cdc.gov/nhanes">http://www.cdc.gov/nhanes</a></p> <p>Cognitive Functioning (CFQ_H 2013-2014) <a href="https://wwwn.cdc.gov/Nchs/Nhanes/2013-2014/CFQ_H.htm">https://wwwn.cdc.gov/Nchs/Nhanes/2013-2014/CFQ_H.htm</a></p> <p>Cognitive Functioning (CFQ_G 2011-2012) <a href="https://wwwn.cdc.gov/Nchs/Nhanes/2011-2012/CFQ_G.htm">https://wwwn.cdc.gov/Nchs/Nhanes/2011-2012/CFQ_G.htm</a></p>
5.A.4	Develop and disseminate measures of awareness of AD.	Release report on validated survey questions.	CDC		Report expected 2019	<p>CDC is examining the validity of subjective cognitive questions used in national surveys by comparing self-rated perceptions of cognitive functioning to functional measures. The report will be released in 2019.</p>

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2017 and 2018
5.A.5	Summarize existing data on people with AD/ADRD and their caregivers.	Develop and release data portal.	CDC	ASPE, NCHS, NIH/NIA, ACL	Ongoing	<p>CDC's Healthy Aging Data Portal, which provides access to a range of national, regional, and state data on older adults, was updated with the <i>Public Data Portal on the Health of Older Adults</i>. This resource was developed by the National Center for Chronic Disease Prevention and Health Promotion. It allows users to examine data on key indicators of health and well-being for older Americans, such as tobacco and alcohol use, screenings and vaccinations, and mental and cognitive health. <a href="https://www.cdc.gov/aging/agingdata/index.html">https://www.cdc.gov/aging/agingdata/index.html</a></p> <p>2016 BRFSS data, including data on cognitive decline from 49 states, DC and Puerto Rico and data on caregivers from 38 states, DC and Puerto Rico is now available. Portal users can retrieve CDC data by indicator or by geographic area, and then use these data to develop reports and create customized maps, charts, and graphics. Public health professionals can use the data to create a snapshot of the health of older adults in their states, which can help them prioritize and evaluate public health interventions.</p>
5.A.6	Develop a consistent set of ICD-9/ICD-10 codes for AD/ADRD for federal agencies to use in analyses of administrative data.	Convene interagency group to reach consensus. Crosswalk to ICD-10 codes.	CMS	ASPE, VA, NIH, IHS	Completed	The workgroup has established a cross-walk of diagnostic code sets across agencies as a precursor to defining common code set or sets. This may be seen as a harmonization exercise across multiple code sets, with the proposed use of the code set (e.g., research, clinical improvement) determining selection.
<b>Strategy 5.B: Monitor Progress on the National Plan</b>						
5.B.1	Track plan progress.	Track progress on the Plan, and incorporate measures into other efforts to monitor population health such as Healthy People 2020.	ASPE		Ongoing	This work will continue throughout the duration of the NAPA legislation and beyond
5.B.2	Update the National Plan annually.	Release updated National Plan.	ASPE		Ongoing	This work will continue throughout the duration of the NAPA legislation and beyond

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## List of Acronyms Used

AAA	Area Agency on Aging
AAIC	Alzheimer's Association International Conference
ACL	Administration for Community Living
ACTC	Alzheimer's Clinical Trials Consortium
AD	Alzheimer's Disease
AD-PM	Alzheimer's Disease and Precision Medicine
ADC	Alzheimer's Disease Center
ADEAR	Alzheimer's Disease Education and Referral
ADI-SSS	Alzheimer's Disease Initiative-Specialized Supportive Services
ADL	Activity of Daily Living
ADNI	Alzheimer's Disease Neuroimaging Initiative
ADPI	Alzheimer's Disease Programs Initiative
ADRD	Alzheimer's Disease and Related Dementias
ADSP	Alzheimer's Disease Sequencing Project
ADSSP	Alzheimer's Disease Supportive Services Program
AFTD	Association for Frontotemporal Degeneration
AHRQ	Agency for Healthcare Research and Quality
AIDD	Administration on Intellectual and Developmental Disabilities
AMP-AD	Accelerating Medicines Partnership-Alzheimer's Disease
AoA	Administration on Aging
ApoE	Apolipoprotein E
APS	Adult Protective Services
ASPE	HHS Office of the Assistant Secretary for Planning and Evaluation
ASTHO	Association of State and Territorial Health Officials
AWV	Annual Wellness Visit
BRFSS	Behavioral Risk Factor Surveillance System
CADRO	Common Alzheimer's Disease Research Ontology
CAP	Collaboration for Alzheimer's Prevention
CCBHC	Certified Community Behavioral Health Clinic
CCM	Chronic Care Management
CDC	Centers for Disease Control and Prevention
CEC	Continuing Education Credit
CERAD	Consortium to Establish a Registry for Alzheimer's Disease
CEU	Continuing Education Unit
CLC	Community Living Center
CME	Continuing Medical Education
CMMI	Center for Medicare and Medicaid Innovation
CMP	Civil Monetary Penalty
CMPRP	Civil Money Penalty Reinvestment Program
CMS	Centers for Medicare & Medicaid Services
CNCS	Corporation for National and Community Service
CWOW	Center Without Walls
D-SNP	Dual Eligible Special Needs Plan
DNA	Deoxyribonucleic acid
DoD	U.S. Department of Defense
DoJ	U.S. Department of Justice
DoL	U.S. Department of Labor
DoT	U.S. Department of Transportation
DSRTF	Down Syndrome Research and Treatment Foundation

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EDSD	Early Detection Screen for Dementia
EES	Employee Education System
EHR	Electronic Health Record
EU	European Union
FDA	Food and Drug Administration
FFS	Fee-For-Service
FOA	Funding Opportunity Announcement
FTD	Frontotemporal Dementia
FY	Fiscal Year
GAP	Global Alzheimer's Platform
GWEP	Geriatrics Workforce Enhancement Program
HBI	Healthy Brain Initiative
HBRN	Healthy Brain Research Network
HCBS	Home and Community-Based Services
HCIA	Health Care Innovation Award
HHS	U.S. Department of Health and Human Services
HIT	Health Information Technology
HIV	Human Immunodeficiency Virus
HRS	Health and Retirement Survey
HRSA	Health Resources and Services Administration
HUD	U.S. Department of Housing and Urban Development
IADRFC	International Alzheimer's Disease Research Funder Consortium
IADRP	International Alzheimer's Disease Research Portfolio
ICD-9	International Classification of Diseases, 9th revision
ICRC	Integrated Care Resource Center
IDD	Intellectual and Developmental Disability
IHS	Indian Health Service
INCLUDE	INvestigation of Co-occurring conditions across the Lifespan to Understand Down syndromE
JPND	Joint Programme -- Neurodegenerative Research
LBD	Lewy Body Dementia
LOAD	Late-Onset Alzheimer's Disease
LTSS	Long-Term Services and Supports
MCBS	Medicare Current Beneficiary Survey
MCI	Mild Cognitive Impairment
MedPAC	Medicare Payment Advisory Commission
MHPAEA	Mental Health Parity and Addiction Equity Act
MLTSS	Managed Long-Term Services and Supports
MOC	Maintenance of Certification
NADRC	National Alzheimer's and Dementia Resource Center
NAPA	National Alzheimer's Project Act
NASEM	National Academics of Science, Engineering and Medicine
NBHCAA	National Brain Health Center for African Americans
NCEA	National Center on Elder Abuse
NCHS	National Center for Health Statistics
NHANES	National Health and Nutrition Examination Survey

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NHATS	National Health and Aging Trends Survey
NIA	National Institute on Aging
NIAGADS	National Institute on Aging Genetics of Alzheimer's Disease Data Storage Site
NICHHD	National Institute of Child Health and Human Development
NIH	National Institutes of Health
NIMHD	National Institute on Minority Health and Disparities
NINDS	National Institute of Neurological Disorders and Stroke
NLRC	National Legal Resource Center
NOMAS	Northern Manhattan Study
NORC	National Ombudsman Resource Center
NPS	Neuropsychiatric Symptoms
NQTL	Non-Quantitative Treatment Limitation
NRC-SDM	National Resource Center for Supported Decision-Making
NSLTCP	National Study of Long-Term Care Places
NTG	National Task Group on Intellectual Disabilities and Dementia Practices
OASH	HHS Office of the Assistant Secretary for Health
ONDCP	White House Office of National Drug Control Policy
OPM	U.S. Office of Personnel Management
OWH	HHS Office on Women's Health
PACE	Program of All-inclusive Care for the Elderly
PCORI	Patient-Centered Outcomes Research Institute
PET	Positron Emission Tomography
PPS	Prospective Payment Systems
Project ECHO	Extension for Community Healthcare Outcomes project
PTSD	Post-Traumatic Stress Disorder
PWD	Persons With Dementia
QIO	Quality Improvement Organization
QTL	Quantitative Treatment Limitation
RDS	Research Down Syndrome
REACH	Resources for Enhancing Alzheimer's Caregivers Health
REACH-VA	Resources for Enhancing Alzheimer's Caregivers Health-VA
REGARDS	Reasons for Geographic and Racial Differences in Stroke
RFA	Request for Application
RITT	Rural Interdisciplinary Team Training
ROAR	Recruiting Older Adults into Research
SAMHSA	Substance Abuse and Mental Health Services Administration
SASH	Support And Services at Home
SDM	Supported Decision Making
SPARK	Strategic Partnership to Advance Research and Knowledge
SSA	Social Security Administration
VA	U.S. Department of Veterans Affairs
VCID	Vascular contributions to Cognitive Impairment and Dementia
VHA	Veterans Health Administration
WHO	World Health Organization

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