

# National Plan to Address Alzheimer's Disease: 2019 Update



U.S. Department of Health and Human Services

# National Plan to Address Alzheimer's Disease: 2019 Update



## Table of Contents

<b>Introduction</b> .....	3
National Alzheimer’s Project Act.....	3
Alzheimer’s Disease and Related Dementias.....	3
The Challenges .....	5
Framework and Guiding Principles.....	5
Goals as Building Blocks for Transformation .....	6
2019 Update.....	6
<b>Goal 1: Prevent and Effectively Treat Alzheimer’s Disease and Related Dementias by 2025</b> .....	7
Strategy 1.A: Identify Research Priorities and Milestones .....	7
Strategy 1.B: Expand Research Aimed at Preventing and Treating Alzheimer’s Disease and Related Dementias .....	10
Strategy 1.C: Accelerate Efforts to Identify Early and Presymptomatic Stages of Alzheimer’s Disease and Related Dementias.....	16
Strategy 1.D: Coordinate Research with International Public and Private Entities .....	18
Strategy 1.E: Facilitate Translation of Findings into Medical Practice and Public Health Programs .....	20
<b>Goal 2: Enhance Care Quality and Efficiency</b> .....	24
Strategy 2.A: Build a Workforce with the Skills to Provide High-Quality Care .....	24
Strategy 2.B: Ensure Timely and Accurate Diagnosis .....	30
Strategy 2.C: Educate and Support People with Alzheimer’s Disease and Related Dementias and Their Families upon Diagnosis.....	32
Strategy 2.D: Identify High-Quality Dementia Care Guidelines and Measures Across Care Settings .....	33
Strategy 2.E: Explore the Effectiveness of New Models of Care for People with Alzheimer’s Disease and Related Dementias.....	34
Strategy 2.F: Ensure that People with Alzheimer’s Disease and Related Dementias Experience Safe and Effective Transitions between Care Settings and Systems.....	35
Strategy 2.G: Advance Coordinated and Integrated Health and Long-Term Services and Supports for People Living with Alzheimer’s Disease and Related Dementias .....	36
Strategy 2.H: Improve Care for Populations Disproportionally Affected by Alzheimer’s Disease and Related Dementias, and for Populations Facing Care Challenges .....	39
<b>Goal 3: Expand Supports for People with Alzheimer’s Disease and Related Dementia and Their Families</b> .....	40
Strategy 3.A: Ensure Receipt of Culturally-Sensitive Education, Training, and Support Materials .....	40
Strategy 3.B: Enable Family Caregivers to Continue to Provide Care while Maintaining Their Own Health and Well-Being .....	42
Strategy 3.C: Assist Families in Planning for Future Care Needs.....	45
Strategy 3.D: Maintain the Dignity, Safety and Rights of People with Alzheimer’s Disease and Related Dementias .....	46
Strategy 3.E: Assess and Address the Housing Needs of People with Alzheimer’s Disease and Related Dementias .....	50
<b>Goal 4: Enhance Public Awareness and Engagement</b> .....	52
Strategy 4.A: Educate the Public about Alzheimer’s Disease and Related Dementias .....	52
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.....	53
Strategy 4.C: Coordinate United States Efforts with Those of the Global Community .....	55
<b>Goal 5: Improve Data to Track Progress</b> .....	56
Strategy 5.A: Enhance the Federal Government’s Ability to Track Progress.....	56
Strategy 5.B: Monitor Progress on the National Plan .....	58
<b>Appendix 1: List of Participating Departments and Agencies</b> .....	60

---

---

<b>Appendix 2: Implementation Milestones</b> .....	61
<b>References</b> .....	110
<b>List of Acronyms Used</b> .....	111

---

## Introduction

### National Alzheimer's Project Act

---

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

---

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 ADRD 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

---

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/ADRD 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/ADRD, symptoms do not appear until after age 60, and the incidence of the disease increases with age. The causes of AD/ADRD 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/ADRD 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/ADRD 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/ADRD will increase significantly in the next 2 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/ADRD 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/ADRD.

Significant emotional, physical, and financial stress is placed on individuals with AD/ADRD and their family members. Unpaid caregivers, such as family members and friends, provide the majority of care for people with AD/ADRD 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/ADRD 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/ADRD 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/ADRD 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/ADRD 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>

---

## The Challenges

---

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.

---

## Framework and Guiding Principles

---

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
-

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.

---

## Goals as Building Blocks for Transformation

---

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.

---

## 2019 Update

---

This is the 2019 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.

This is the seventh Update to the National Plan. To see how Actions have progressed, changed, and expanded since 2012, see the side-by-side index at <https://aspe.hhs.gov/report/national-plan-action-side-side>.

---



## 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

---

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.

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

---

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 across the AD/ADRD research community for the kinds of new resources, infrastructure, and multi-stakeholder partnerships needed to fully realize emerging research opportunities. NIH is committed to regularly updating its research priorities and planning is underway for an AD research summit in 2021.

For more information, see:

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

#### **(UPDATED) Action 1.A.2: Solicit diverse community input on Alzheimer's disease research priorities**

---

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. These milestones and the accompanying milestone database are updated annually based on this diverse input. This planning process and its systematic updates have informed the research community about NIH's interests and priorities in funding projects in AD/ADRD. As of July 2019, the milestone database now includes better tracking of progress including success criteria and specific implementation activities.

For more information, see:

- <https://aspe.hhs.gov/alzheimers-disease-related-dementias-adrd-summit-2016-prioritized-research-milestones>
- <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/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers>
- <https://www.nia.nih.gov/research/administration/recommendations-nih-ad-research-summit-2018>
- <https://www.nia.nih.gov/research/milestones>

---

**(ONGOING) Action 1.A.3: Regularly update the National Plan and refine Goal 1 strategies and action items based on feedback and input**

HHS and its federal partners will use the diverse 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 assistance of consensus advice from the Advisory Council.

---

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

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.

---

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

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, information obtained through the various research summits results 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 *Alzheimer's Disease Research Summit* in April 2018 and *Alzheimer's Disease-Related Dementias Summit* in March 2019.

For more information, see:

- <https://www.nia.nih.gov/research/milestones>
- <https://www.nia.nih.gov/sites/default/files/2018-07/fy2020-milestones-chart.pdf>

---

**(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**

The National Institute of Neurological Disorders and Stroke (NINDS) convened the third ADRD Summit on March 14-15, 2019. As in the past, researchers, clinicians, patients, caregivers, families, and advocates gathered to assess scientific progress and update and/or generate

---

research recommendations to be considered by the broad scientific community for AD/ADRD, including FTD, LBD, mixed, and vascular dementias along with broader cross-cutting areas such as dementia nomenclature and AD/ADRD health disparities. This year, there was also a new session focused on emerging scientific topics: TDP-43 pathology in common dementias and traumatic brain injury (TBI) as a risk factor for AD/ADRD. NIH continuously develops research initiatives and activities to address the research priorities identified through the ADRD Summits. Final research recommendations from ADRD Summit 2019 have recently been considered and adopted by the NINDS Advisory Council in September 2019, and will be presented to the NAPA Advisory Council for its consideration early next year.

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-2019>

---

**(ONGOING) Action 1.A.7: 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 HHS 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 for the greater scientific community. 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 information obtained from the various perspectives presented at the Summit will help inform National Institute on Aging (NIA) investments and priority setting.

The second National Research Summit on Care, Services, and Supports for Persons with Dementia is scheduled for March 24-24, 2020.

For more information, see:

- <https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers>
- <https://aspe.hhs.gov/basic-report/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers-final-summit-report>
- <https://www.nia.nih.gov/2020-dementia-care-summit>

---

**(NEW) Action 1.A.8: Create and implement a strategic plan for the Congressionally Directed Medical Research Program Peer Reviewed Alzheimer's Research Program**

The Congressionally Directed Medical Research Program (CDMRP) is a partnership between the United States Congress, the military, and the public to fund innovative and impactful research in targeted program areas. One of the CDMRP programs is the Peer Reviewed Alzheimer's Research Program (PRARP), which is specifically focused on understanding the relationship between TBI and dementia. In 2019, the PRARP will release an updated Strategic Plan that identified the high-impact research goals in the areas of TBIs and AD/ADRD. The Strategic Plan summarizes research funding and findings through the PRARP program since 2011, and identified short, medium, and long-term goals for the program.

---

For more information, see:

- <https://cdmrp.army.mil/prarp/default>
- 

**(NEW) Action 1.A.9: Develop and administer a scientific landscape survey for the Congressionally Directed Medical Research Programs Peer Reviewed Alzheimer's Research Program**

---

The CDMRP PRARP is administering a survey to the general public regarding future research directions for dementia subsequent to TBI. The survey requests input regarding future research directions for: (1) Basic and Translational science; (2) Quality of Life and Caregiving Research; and (3) Efforts regarding future pre-clinical and clinical research. Individuals or groups interested in participating in future surveys must register at eBRAP.org for updates from the PRARP. The survey response closes at the end of October 2019.

For more information, see:

- [https://cdmrp.army.mil/prarp/pdfs/PRARP%20Survey%20For%20Distro\\_FY20.pdf](https://cdmrp.army.mil/prarp/pdfs/PRARP%20Survey%20For%20Distro_FY20.pdf)
  - <https://ebrap.org/eBRAP/public/index.htm>
- 

**Strategy 1.B: Expand Research Aimed at Preventing and Treating Alzheimer's Disease and Related Dementias**

---

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**

---

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/pa-files/PAR-17-029.html>
  - <https://grants.nih.gov/grants/guide/pa-files/PAR-17-031.html>
  - <https://grants.nih.gov/grants/guide/pa-files/PAR-17-033.html>
  - <https://grants.nih.gov/grants/guide/pa-files/PAR-17-039.html>
  - <https://grants.nih.gov/grants/guide/pa-files/PAR-17-047.html>
  - <https://grants.nih.gov/grants/guide/pa-files/PAR-18-029.html>
-

- <https://grants.nih.gov/grants/guide/pa-files/PAR-18-497.html>
- <https://grants.nih.gov/grants/guide/pa-files/PAR-18-512.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-18-760.html>
- <https://grants.nih.gov/grants/guide/pa-files/PAR-19-070.html>
- <https://grants.nih.gov/grants/guide/pa-files/PAR-19-071.html>
- <https://grants.nih.gov/grants/guide/pa-files/PAR-19-167.html>
- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-19-025.html>
- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-19-026.html>
- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-20-016.html>
- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-20-025.html>
- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-20-040.html>
- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-20-041.html>
- <https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-19-013.html>
- <https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-19-015.html>
- <https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-19-026.html>
- <https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-19-027.html>
- <https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-19-030.html>
- <https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-19-039.html>

---

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

---

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. The NIA Genetics of Alzheimer’s Disease Data Storage Site (NIAGADS) serves as the ADSP Data Coordinating Center. In 2017, NIA launched the ADSP Follow-Up Study, which aims to pursue rare variants in a range of different populations (e.g., African American, Hispanic, American Indian and Alaska Native [AI/AN], Asian). In keeping with the high priority that the AD genetics community places on diversity, the ADSP has prioritized the study of ethnically diverse populations.

NIAGADS now hosts 37 human genetics datasets in addition to ADSP data, covering about 38,000 subjects and 24.5 billion genotypes. In July 2018, NIAGADS announced the release of data generated on 5,000 whole-genomes and 11,000 whole exomes from a diverse population of individuals. NIAGADS is hosting the harmonized ADSP data; NIH’s Database for Genotypes and Phenotypes hosts the data from the first phase of the project. Using data from NIAGADS and other repositories, scientists have been able to expand the number of known genetic risk factors for AD, and several others are under investigation.

In addition to ADSP, 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 cardio 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, a longitudinal cohort study to understand why Southerners and African Americans have higher rates of stroke and related diseases that affect brain health. NIH will also support the Northern Manhattan Study (NOMAS), a

---

longitudinal study of stroke risk factors in Whites, African Americans, and Hispanics living in the same community. As the emerging scientific consensus recognizes the role of midlife cardio 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:

- <http://www.regardsstudy.org>
- <https://grants.nih.gov/grants/guide/pa-files/PA-16-205.html>
- <https://grants.nih.gov/grants/guide/pa-files/PA-16-371.html>
- <https://grants.nih.gov/grants/guide/pa-files/PA-16-406.html>
- <https://grants.nih.gov/grants/guide/pa-files/PA-17-214.html>
- <https://grants.nih.gov/grants/guide/pa-files/PA-18-889.html>
- <https://grants.nih.gov/grants/guide/pa-files/PA-19-234.html>
- <https://grants.nih.gov/grants/guide/pa-files/PA-19-269.html>
- <https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-17-017.html>
- <https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-19-012.html>
- <https://northernmanhattanstudy.org/>
- <https://www.niagads.org/>
- <https://www.niagads.org/adsp/content/home>

---

### **(UPDATED) Action 1.B.3: Increase enrollment in clinical trials and other clinical research through community, national, and international outreach**

Starting in 2016, with facilitation by the Alzheimer's Association and in close collaboration with experts from government, private, and academic sectors, NIA led an effort to develop comprehensive goals and strategies to enhance recruitment into clinical research, particularly focusing on underrepresented communities. To ensure broader input, NIA gathered feedback on the recruitment strategies through the IdeaScale crowdsourcing platform. These efforts resulted in the National Strategy for Recruitment and Participation in Alzheimer's Disease and Related Dementias Clinical Research, which was presented at the NAPA Advisory Council meeting in October 2018.

In 2019, NIA launched Alzheimer's and Dementia Outreach, Recruitment, and Engagement Resources (ADORE), a searchable collection of materials designed to support recruitment and retention into clinical trials and studies. ADORE stems from the National Strategy and represents some of the materials and activities that Alzheimer's Disease Research Centers, NIA and the broader NIH, and other organizations have developed to engage people in research. In addition, NIA developed several collateral materials to include in ADORE, including a recruitment planning guide, a series of testimonial videos, and an easy-to-read booklet to promote older adult research participation.

NIA continues to promote participation in AD/ABD 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

---



federal agencies and advocacy organizations to encourage research participation among older adults. All materials are drafted in plain language formats for ease of communications.

Additionally in 2018, NIA released an 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. This FOA will be active until January 26, 2021.

In 2019, the U.S. Department of Veterans Affairs (VA) is in the process of operationalizing a pilot program to increase veterans' enrollment in five NIA-funded clinical trials, leveraging joint resources and infrastructure of the AD Research Centers of NIA and the Network of Dedicated Enrollment Sites of VA Cooperative Studies Program.

In 2019, the Health Resources and Services Administration's (HRSA) Geriatrics Workforce Enhancement Program (GWEP) Notice of Funding Opportunity included language calling for applicants to describe how they would educate and train patients, families, caregivers, direct care workers, health care providers, and health professions students, faculty, residents, and fellows on when it is appropriate to recruit older adults into research.

For more information, see:

- <https://bhw.hrsa.gov/fundingopportunities/default.aspx?id=4c8ee9ff-617a-495e-ae78-917847db86a9>
- <https://grants.nih.gov/grants/guide/pa-files/PAR-18-749.html>
- <https://www.nia.nih.gov/alzheimers/clinical-trials>
- <https://www.nia.nih.gov/health/roar-toolkit>
- <https://www.nia.nih.gov/research/adore>
- <https://www.nia.nih.gov/research/alzheimers-dementia-outreach-recruitment-engagement-resources>
- <https://www.nia.nih.gov/research/recruitment-strategy>

---

#### **(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**

---

See 1.B.3 for updates regarding the National Strategy for Recruitment and Participation in Alzheimer's Disease Clinical Research released in fall 2018. This strategy includes approaches to increase enrollment of racial and ethnic minorities in AD/ADRD studies as recommended by the National Strategy Group's Local, Diverse Working Group and outlined in the Alzheimer's Disease and Related Dementias Clinical Studies Recruitment Planning Guide.

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 to establish the community infrastructure needed to accelerate recruitment. This FOA remains active. Another active FOA encourages applications that examine mediators of disparities in AD, using diverse cohorts of subjects with a focus on strategies for recruitment and retention in clinical trials.

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 and Precision Medicine among Native People". An innovative pragmatic Randomized Controlled Trial with 4,000 AI/AN enrollees. This study will evaluate recruitment strategies for AI/ANs and proposes several specific aims: create culturally tailored materials on AD and Precision Medicine (PM) (phase 1); evaluate the clarity and acceptability of the materials and their effect on completion of the AD-PM Module in a randomized controlled trial and subsequent enrollment into an AD-PM cohort (phase 2); identify patient-level predictors of enrollment; and evaluate potential

---

differences in the effectiveness of recruitment approach by age, sex, education, cultural identity, and rurality (phase 2).

The NIA-supported Alzheimer's Clinical Trials Consortium (ACTC) also aims to develop and implement cutting-edge participant recruitment and retention strategies, especially in diverse populations, and establish a new minority outreach and recruitment team. This clinical trials network with 35 United States sites will develop, harness, and deploy the best practices and latest methods for the conduct of AD/ADRD trials.

For more information, see:

- <https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-047.html>
- <https://grants.nih.gov/grants/guide/pa-files/PA-18-749.html>
- [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=)
- <https://www.nia.nih.gov/news/new-nih-consortium-award-enhance-clinical-trials-alzheimers-disease-related-dementias>
- <https://www.nia.nih.gov/research/recruitment-strategy>
- <https://www.nia.nih.gov/sites/default/files/2019-05/ADEAR-recruitment-guide-508.pdf>

---

#### **(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 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 AD 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 200 active trials of interventions to enhance cognitive health in older adults and to prevent, treat, or manage AD/ADRD. NIH also released a number of FOAs specifically focused on clinical trials for AD/ADRD. These include pharmacologic as well as lifestyle interventions.

For more information, see:

- <https://grants.nih.gov/grants/guide/pa-files/PA-18-513.html>
- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-20-029.html>
- <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>

---

#### **(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 200 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 FOAs specifically focused on clinical trials for AD/ADRD.

---



In 2019, the VA participated in the NIH-funded SPRINT MIND trial, a substudy of Systolic Blood Pressure Intervention Trial (SPRINT) that established the benefit of aggressive blood pressure lowering on preventing cognitive impairment. The results were published.

For more information, see:

- <https://grants.nih.gov/grants/guide/pa-files/PAR-18-513.html>
- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-20-029.html>
- <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>

---

**(UPDATED) 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/ABDRD, 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 INvestigation of Co-occurring conditions across the Lifespan to Understand Down syndrome (INCLUDE) project was launched in June 2018 in support of a congressional directive. INCLUDE focuses 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.

In FY 2018, NIH spent almost \$23 million to jump-start INCLUDE via administrative supplements, including one focused on creating an AD clinical trial network for adults with Down syndrome. This network, the Alzheimer’s Clinical Trial Consortium -- Down Syndrome Network (ACTC-DSN) aims to utilize the existing depth and breadth of expertise across its ACTC infrastructure to conduct AD clinical trials in adults with Down syndrome. The overarching goal of the project is to build an efficient clinical trial network to address the critical need for treatment of AD in adults with Down syndrome.

NIA and National Institute of Child Health and Human Development (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://health.ucsd.edu/news/releases/Pages/2016-01-13-clinical-trial-alzheimers-characteristics-in-down-syndrome.aspx>
  - [https://projectreporter.nih.gov/project\\_info\\_description.cfm?aid=9749625&icde=46135063&ddparam=&ddvalue=&ddsub=&cr=1&csb=default&cs=ASC&pball=](https://projectreporter.nih.gov/project_info_description.cfm?aid=9749625&icde=46135063&ddparam=&ddvalue=&ddsub=&cr=1&csb=default&cs=ASC&pball=)
  - <https://www.nia.nih.gov/health/alzheimers-disease-people-down-syndrome>
  - <https://www.nia.nih.gov/research/abc-ds>
  - <https://www.nih.gov/include-project>
-

---

**(NEW, COMPLETED) Action 1.B.8: Convene a workshop on the association of traumatic brain injury and dementia**

---

In February 2019, NIA partnered with the VA and NINDS to hold a joint workshop to establish a program to increase veterans' participation in AD/ADRD research, leveraging joint NIH and VA resources. This workshop was convened under the Strategic Partnership to Advance Research and Knowledge (SPARK) for Dementia Research. The workshop focused on TBI as a risk factor for AD/ADRD.

---

**(NEW, COMPLETED) Action 1.B.9: Issue a joint Department of Veterans Affairs/National Institute on Aging career development award for physician scientists new to the area of dementia research**

---

In July 2019, the VA issued a new funding announcement to support early career physician-scientist mentored research in AD/ADRD. NIA issued a notice for supplemental funding to support the research proposed by the trainee. This initiative is under the SPARK for Dementia Research.

---

**(NEW) Action 1.B.10: Expand research for care and support of individuals with cognitive and behavioral symptomatology related to both traumatic brain injury and dementia**

---

The CDMRP PRARP has continued to offer two funding opportunities to support research focused on robust, patient-centered approaches to address cognitive and behavioral symptomatology common to TBI and dementia. The Innovations in Care and Support Award (InCASA) mechanism was offered for the first time for the CDMRP PRARP in 2019. The InCASA supports innovative research that improves the quality of life and care for individuals living with the common symptoms of TBI and/or AD/ADRD and/or their families and care providers. For this funding opportunity, applicants were encouraged to propose work that should challenge existing research paradigms, or exhibit high levels of creativity. The Research Partnership Award (RPA) mechanism was also offered as a multi-partnered funding opportunity. The RPA requires partners from diverse backgrounds to come together and work on a project that neither individual investigator alone could achieve. Applications to this mechanism were required to demonstrate long and short-term benefits of their projects. Applications to the RPA were also required to show how the efforts will ultimately benefit individuals affected by AD/ADRD, their caregivers, and their families.

For more information, see:

- <https://cdmrp.army.mil/funding/archive/prarparchive>

---

**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 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, FTD, 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 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 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://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-048.html>
  - <https://grants.nih.gov/grants/guide/pa-files/PAR-18-519.html>
  - <https://grants.nih.gov/grants/guide/pa-files/PAS-19-210.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-19-012.html>
  - <https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-19-014.html>
  - <https://markvcid.partners.org/>
  - <https://www.nia.nih.gov/research/amp-ad>
-

---

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

---

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 (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 Association for Frontotemporal Degeneration (AFTD), CurePSP, 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://grants.nih.gov/grants/guide/rfa-files/RFA-NS-16-023.html>
- <https://iadrp.nia.nih.gov/>
- <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4847536/>
- <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5111162/>
- <https://www.nia.nih.gov/alzheimers/amp-ad>

---

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

---

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.

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

---

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, 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>

---

#### **(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.

Additionally, NIA participated in the Alzheimer's Disease Funders' meeting held during the 2019 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.

The NIA-supported Health and Retirement Study (HRS): Harmonized Cognitive Assessment Protocol (HCAP) initiative is an innovative approach to assessing trends in cognitive function and aging in the United States and worldwide. The primary aim of the HRS, funded by NIA and the Social Security Administration, is to collect and distribute multi-disciplinary data for research on aging. To provide the research community with new and richer data to study the prevalence, predictors, and outcomes of cognitive impairment and dementia, NIH first supported HCAP during the HRS' 2016 field period, in which investigators administered a supplemental in-home, 1-hour battery of cognitive tests to about 3,200 randomly selected HRS respondents age 65 and older, along with a 20-minute informant interview. The data from that 2016 assessment have now been made publicly available to the scientific community, and analyses are underway.

HCAP is also being administered in other developed and developing countries, where HRS-like representative population surveys are conducted, including in China, England, India, Mexico, South Africa, and parts of the EU.

For more information, see:

- <http://www.neurodegenerationresearch.eu/initiatives/mapping-exercise/data-collected/>
- <https://grants.nih.gov/grants/guide/pa-files/PAS-17-028.html>
- <https://hrs.isr.umich.edu/welcome-health-and-retirement-study>
- <https://iadrp.nia.nih.gov>
- [https://projectreporter.nih.gov/project\\_info\\_description.cfm?aid=9618704&icde=42939202](https://projectreporter.nih.gov/project_info_description.cfm?aid=9618704&icde=42939202)
- <https://www.neurodegenerationresearch.eu/wp-content/uploads/2018/07/JPND-Mapping-Exercise-Report-28Final2912072018.pdf>
- <https://www.src.isr.umich.edu/projects/health-and-retirement-study-harmonized-cognitive-assessment-protocol-hrs-hcap/>

---

#### **(ONGOING) 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 Centers for Disease Control and Prevention (CDC) with state public health authorities. There are two optional

---

modules that states can include in their annual BRFSS survey on the topics of caregiving and cognitive decline. 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.

---

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

---

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**

---

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.

Additionally, the AMP-AD is a precompetitive public-private effort of government, industry, and non-profit organizations that focuses on discovering novel therapeutic targets and biomarkers for validating existing and new targets. The AMP-AD Target Discovery Project has generated a wealth of molecular data from over 3,000 human brain and plasma samples collected in several NIA-supported AD cohorts and brain banks. The project makes these datasets available to the greater research community through the AMP-AD Knowledge Portal.

In 2018, these novel target predictions, along with the data and analyses that led to their discovery, were made available via a new AMP-AD data resource, the AGORA platform. This web-based, interactive platform will enable researchers in academia and biotech and pharmaceutical communities to leverage AMP-AD analyses and results to enhance their own work and build on the AMP-AD discoveries.

For more information, see:

- <https://ampadportal.org/>
  - <https://www.nia.nih.gov/health/alzheimers-dementia-resources-for-professionals>
  - <https://www.nia.nih.gov/research/amp-ad>
- 

#### **(ONGOING) 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**

---

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.

In 2018, of the 44 HRSA-funded GWEP grantees, 14 are co-located and working with Alzheimer's Disease Centers (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.

---



For more information, see:

- <https://www.nia.nih.gov/about/bypass-budget-proposal-archive>
- <https://www.nia.nih.gov/alzheimers>

---

**(ONGOING) Action 1.E.3: Issue guidance about drugs for early-stage Alzheimer’s disease and related dementias**

In February 2013, the Food and Drug Administration (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 issued a determination that a disease-modeling tool submitted by the Coalition Against Major Diseases for trials in mild-to-moderate AD is fit for purposes, meaning it is scientifically supported and suitable for the purpose of aiding in the design of future clinical trials in these populations. Simulations relying on this model can provide support for the choice of trial design features and facilitate protocol review.

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>

---

**(ONGOING) Action 1.E.4: Expand and disseminate research on co-occurring conditions and dementias**

The third Healthy Brain Initiative Road Map for State and Local Public Health was released in late 2018 identifying 25 actions for public health professionals related to cognitive health, including cognitive impairment and caregiving for persons with cognitive impairment through 2023. In 2019, the first Road Map for Indian Country was released identifying eight priority actions for Indian Country.

In addition, NIA and NINDS jointly produce and disseminate content on AD/ADRD, including FTD, LBD, and VCID.

For more information, see:

- <https://www.cdc.gov/aging/healthybrain/Indian-country-roadmap.html>
- <https://www.cdc.gov/aging/healthybrain/roadmap.htm>
- <https://www.nia.nih.gov/health/alzheimers/related-dementias>
- <https://www.ninds.nih.gov/current-research/focus-disorders/alzheimers-related-dementias>

---

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

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 Administration for Community Living (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.

ACL’s Alzheimer’s and Dementia Programs Initiative (ADPI) grantees embed brain health education in their funded activities. Through partnerships with private non-profit educational entities grantees are bringing a broad range of brain health resources to the communities they serve. ADPI-funded activities include, but are not limited to, brain health educational opportunities as a means to introducing opportunities for AD/ADRD screening/assessments and benefits counseling.

In 2018, all of the 44 HRSA-funded GWEPs were educating and training the public on brain health including sharing resources.

For more information see:

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

---

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

CDC in collaboration with the American College of Preventive Medicine developed a Brain Health Continuing Education Course and resource page 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 was included as an elective in the “Lifestyle Medicine Core Competencies Online Program” in December 2018.

For more information see:

- <https://www.acpm.org/page/brainhealth>

---

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

CDC 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 was co-authored by experts in public health and brain health, including scientists at CDC. The 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.

Additionally, CDC has developed a series of five Issue Maps that highlight specific sets of Road Map actions related to caregiving, risk reduction, early detection of AD/ADRD, and the education of health professionals. The associated planning tool was developed to guide state and local public health professionals through quick steps in selected Road Map items and getting started with implementation in their jurisdictions. Two podcasts were also produced discussing the

---



updated Road Map. In 2019, the first Road Map for Indian Country was released identifying eight priority actions for Indian Country.

For more information see:

- <https://www.cdc.gov/aging/healthybrain/Indian-country-roadmap.html>
  - <https://www.cdc.gov/aging/healthybrain/issue-maps/data-evidence-for-action.html>
  - <https://www.cdc.gov/aging/healthybrain/issue-maps/early-detection.html>
  - <https://www.cdc.gov/aging/healthybrain/issue-maps/educating-training-professionals.html>
  - <https://www.cdc.gov/aging/healthybrain/issue-maps/risk-reduction.html>
  - <https://www.cdc.gov/aging/healthybrain/issue-maps/supporting-caregivers.html>
  - <https://www.cdc.gov/aging/healthybrain/roadmap.htm>
  - <https://www.cdc.gov/aging/publications/podcasts.htm>
-

## 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

---

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**

---

In FY 2018, the HRSA-supported 44 GWEP grants totaled approximately \$40.7 million of which \$3.7 million was specifically budgeted to provide dementia education and training. In Academic Year 2017-2018 (latest available data), GWEP grantees provided 338 AD/ADRD courses and trained 55,057 health care providers and 26,600 caregivers in AD/ADRD. In FY 2019, HRSA competed the GWEP and made 48 awards. All GWEP awardees are educating and training the workforce on how to care for persons living with dementia. Of the \$35.7 million GWEP budget, \$8.7 million was for dementia education and training activities. In FY 2019, HRSA also competed the Geriatrics Academic Career Awards (GACA) program and made 26 awards totaling \$1.9 million. GACA grant recipients are encouraged to provide dementia education to the workforce.

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 disseminates *Assessing Cognitive Impairment in Older Patients: A Quick Guide for Primary Care Physicians* and *Managing Older Patients with Cognitive Impairment*.

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.

---

ACL, through its ADPI program, continues to expand efforts to educate health care professionals on the many facets of providing care for persons living with AD/DRD and their caregivers. Program participants are developing and translating educational tools to educate and support clinicians ranging from micro-learning modules for primary care providers doctors to training programs tailored to community health workers.

For more information, see:

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

---

**(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 and training in AD/DRD.

---

**(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/DRD training to the Aging Network.

ACL through the National Alzheimer's and Dementia Resource Center (NADRC) offers an annual dementia-specific webinar series, training in excess of 10,000 persons per year. The series targets AD/DRD 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. In 2019, the NADRC published a new guide entitled Intellectual and Developmental Disabilities and Dementia: Practical Strategies for Professionals which provides background and strategies for professionals working with individuals living with IDD and dementia.

In 2017, ACL received Office of Management and Budget (OMB) authority to collect data on professionals trained through ADPI grant funding. In 2019 alone, grantees report training over 32,000 AD/DRD professionals on a broad range of topics.

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.

Cross-agency collaborations have enhanced workforce dementia training and expertise. In FY 2018, 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. In addition, 22 of the HRSA 44 GWEPs collaborated with the VA to assist with training on dementia.

---

For more information, see:

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

---

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

In 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 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. From December 2017 to August 2019, there was 131,426 page views on the Alzheimer’s curriculum page.

CMS’s Resources for Integrated Care, which partners with health plans and providers, also offers a 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://bhwa.hrsa.gov/grants/geriatrics/alzheimers-curriculum>
- <https://www.integratedcareresourcecenter.com/>

---

**(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 Science, 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.

In 2017, the interagency ROAR group (NIH, ACL, and CDC) hosted an update in the popular webinar series for professionals on AD/ABD resources and offered continuing education credit (CEC). Free continuing education was available to professionals who viewed recorded webinars from 2017 and earlier series. This continuing education was 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:

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

- <https://www.nia.nih.gov/health/alzheimers-dementia-resources-for-professionals>
  - <https://www.nia.nih.gov/news/2017-alzheimers-and-dementia-webinars-professionals>
- 

**(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 undergraduate and graduate-level students in brain health. Students engage in a variety of educational, partnership, and research activities. This program is in Year 5 of a 5-year funding cycle.

CDC, in partnership 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/ADRD. Its four modules each contain a comprehensive faculty guide and slide deck. The course is currently being updated; the revised course will be available in late 2019.

For more information, see:

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

**(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/ADRD into the online continuing education curriculum for IHS/Tribal/Urban Indian Health program nursing. A web-based course on AD/ADRD was provided in April-June 2016 at the IHS Clinical Rounds. Results were addressed at the IHS *Nursing Leadership* meeting on May 17, 2016. A clinical training on diagnosis and management of AD/ADRD for an 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/ADRD in Tribal communities.

The preconference day of the 2019 national diabetes conference focused on geriatrics, including diagnosis and management of AD/ADRD.

---

**(ONGOING) 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/ADRD. The survey has been pilot-tested at one Tribal site.

---

**(ONGOING) 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/ADRD 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.

---

---

**(ONGOING) 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).

---

**(ONGOING) 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 ten IHS and Tribal sites with a focus on dementia care. So far, 15 separate RITT Trainings have been completed for more than 18 Tribal and IHS programs. The trainings include webinars, accredited through Employee Education System (EES) and 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>
- 

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

---

ACL's ADPI program continues to make funds available to states to develop and implement dementia-capable HCBS. Through the ADPI program, states are able to pilot programs in support of persons living with AD/DRD and their caregivers in an effort to develop evidence for sustainability post-grant funding.

In 2017, ACL rolled out their 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 over time. 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>
- 

**(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**

---

In 2014, ACL began funding community programs designed to fill service gaps in existing dementia-capable systems. Funded programs are required to target program activities providing effective supportive services to persons living alone with AD/DRD, improving quality and effectiveness of services for individuals aging with IDD and AD/DRD or those at high risk, and delivery of behavioral symptom management training and expert consultations for family caregivers. In 2018, 19 state and community programs received funding, bringing the total number of programs funded since 2014 to 63.

In 2018, CMS announced that beginning in 2019 it is expanding the definition of "primarily health-related," supplemental benefits in Medicare Advantage organizations may 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.

---

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

CMS continues to hold webinars, national calls, and provide information to key stakeholders. For example, CMS is supporting state Medicaid agencies in multiple HCBS topics like electronic visit verification. CMS is also working with its partners at ACL to address person-centered planning and practice.

For more information, see:

- [http://www.qualityforum.org/Person\\_Centered\\_Planning\\_and\\_Practice.aspx](http://www.qualityforum.org/Person_Centered_Planning_and_Practice.aspx)
- <https://www.medicaid.gov/medicaid/hcbs/training/index.html>

---

**(COMPLETED) Action 2.A.15: Disseminate Centers for Medicare & Medicaid Services Hand-in-Hand dementia training materials in Department of Veterans Affairs community living centers**

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 was conducted, and a summary report is now available on the VA Geriatrics and Extended Care Internet website. The report describes the implementation and evaluation of the training. In addition to process evaluation results, the report includes two new products that were created by the workgroup for this project: (1) A staff satisfaction with learning survey, addressing specific objectives and added competency questions for each module. (2) Knowledge test questions with multiple-choice questions on each module, to evaluate employee response at Levels 1 and 2 of the Kirkpatrick educational evaluation model respectively. The training satisfaction survey and knowledge tests may be useful to others in future implementation of this training program.

For more information, see:

- [https://www.va.gov/GERIATRICALS/GEC\\_Data\\_Reports.asp](https://www.va.gov/GERIATRICALS/GEC_Data_Reports.asp)

---

**(ONGOING) Action 2.A.16: Train future public health professionals on Alzheimer’s disease and related dementias**

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/aging/aginginfo/alzheimers.htm#Curriculum>

---

**(NEW) Action 2.A.17: Understand the impact of minimum wage increases on nursing homes**

Low wages have long been identified as problematic for long-term care providers to recruit and retain employees, and potentially lead to poorer care quality and reduced access to needed services. This study utilizes publicly-available data from the Bureau of Labor Statistics, U.S.

---



Department of Labor (DoL), and CMS to examine the association between state and federal wage characteristics, and the number of hours worked among nursing staff in nursing homes. This project will also explore the financial impact of potential minimum wage increases on the nursing home industry. The study is expected to be completed at the end of 2019.

---

## **Strategy 2.B: Ensure Timely and Accurate Diagnosis**

---

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.

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

---

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.

In 2019, NIA funded two new projects with the goal of producing Apps capable of measuring cognitive status and change on mobile devices. These grants were awarded in response to a specific FOA seeking projects focused on mobile monitoring of cognitive change.

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 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://grants.nih.gov/grants/guide/rfa-files/rfa-ag-18-012.html>
  - [https://projectreporter.nih.gov/project\\_info\\_description.cfm?aid=9781454&icde=46515933&ddparam=&ddvalue=&ddsub=&cr=4&csb=default&cs=ASC&pball=](https://projectreporter.nih.gov/project_info_description.cfm?aid=9781454&icde=46515933&ddparam=&ddvalue=&ddsub=&cr=4&csb=default&cs=ASC&pball=)
  - [https://projectreporter.nih.gov/project\\_info\\_description.cfm?aid=9781463&icde=46515933&ddparam=&ddvalue=&ddsub=&cr=9&csb=default&cs=ASC&pball=](https://projectreporter.nih.gov/project_info_description.cfm?aid=9781463&icde=46515933&ddparam=&ddvalue=&ddsub=&cr=9&csb=default&cs=ASC&pball=)
  - <https://www.detectcid.org/>
  - <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>
- 

### **(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 is 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

---



through grants to states and community-based organizations. For example, through this grant program approximately 8,000 paid and unpaid caregivers were trained on IDD and dementia with funding from 2014-2017. 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.

ACL consistently offers educational opportunities/resources in support of both paid and unpaid caregivers of those living with IDD and AD/ADRD or at-risk of developing AD/ADRD. IDD and dementia is consistently included in ACL's annual webinar series, educating attendees on a broad range of topics. Webinars have focused on important topics including early screening, palliative care, family advocacy, and promising practices in care. In 2019, the NADRC published a new guide entitled *Intellectual and Developmental Disabilities and Dementia: Practical Strategies for Professionals* which provides background and strategies for professionals working with individuals living with IDD and dementia.

For more information, see:

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

---

**(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 for 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. IHS facilities provide local resources for community-based education and training.

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.

---

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

CDC worked with the American College of Preventive Medicine to develop a curriculum and resource center 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 online course has been included as an elective in the "Lifestyle Medicine Core Competencies Online Program" and can be for continuing education credit (CME/MOC).

For more information see:

- <https://www.acpm.org/page/brainhealth>
-

---

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

---

In late 2019, ASPE will release a report that examines the size and characteristics of the populations that have dementia based on self-reported diagnosis, Medicare claims and/or functional assessment. Although the population identified with dementia should be similar with all three of these methods, there were great differences. For example, of the people whose answer to functional assessment questions indicated probable dementia, only 48% reported they had been told they had dementia by a physician. Alternatively, only 40% of people with an indication of dementia in their Medicare claims reported that a doctor had diagnosed them with dementia. Further understanding the characteristics of people who are identified or missed by each method will enhance our understanding of how to improve patient awareness of diagnosis, and also improve care planning. This work will also help us understand how well indicators in Medicare claims data identify people with dementia.

---

---

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

---

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/ADRD and their families, and enhancing the ability of other networks to assist people living with AD/ADRD and their families with addressing their needs.

---

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

---

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/ADRD, 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 a 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 required referral to community resources as needed (e.g., rehabilitation services, adult day programs, support groups), and that the care plan is shared with the patient and/or caregiver with initial education and support.

ACL’s state and community ADPI program continues to fund projects that include significant focus on the provision of 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, including educating providers on the importance of dementia-capable care transitions.

---

---

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

---

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 collaborated with the CDC in the development of the *Brain Health Public Health Road Map* designed specifically for Tribal Communities. The *Road Map for Indian Country*, co-branded with the Alzheimer's Association, was released and disseminated to multiple stakeholders and Tribal nations. Additionally, CDC developed an infographic describing subjective cognitive decline and related functional limitations, as well as caregiving, in AI/AN adults in order to educate stakeholders and policy makers on brain health in Indian Country.

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. ACL's Title VI program has significantly increased the AD/ADRD educational offerings at their annual Title VI Training Conference including increasing awareness of CDC's *Road Map for Indian Country*.

For more information, see:

- <https://www.cdc.gov/aging/healthybrain/Indian-Country-resources.html>
  - <https://www.cdc.gov/aging/healthybrain/Indian-country-roadmap.html>
- 

---

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

---

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 of 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**

---

CMS has included dementia-related measures in the Merit-based Incentives Payment System (MIPS) for Medicare such as cognitive assessment, education and support of caregivers, and others that impact people with dementia. Another area of support is examining and implementing quality and outcome measures and measure concepts for HCBS programs.

For more information, see:

- <https://qpp.cms.gov/mips/quality-measures>
  - <https://www.medicaid.gov/medicaid/quality-of-care/improvement-initiatives/hcbs/index.html>
-

---

**(UPDATED) Action 2.D.2: Solicit stakeholder input on meaningful outcomes to drive quality measurement**

---

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 continues the "Patients Over Paperwork" initiative to reduce provider burden and increase efficiencies while improving the beneficiary experience.

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>
- 

**(ONGOING) 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/ADRD. 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.

---

**(ONGOING) 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 on 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, in partnership with members of the Eastern Shoshone and Northern Arapaho tribes, completed a culturally-relevant dementia training material for American Indian people on the Wind River Reservation by creating a pictorial version of the Alzheimer's Association's "Know the 10 Signs: Early Detection Matters". This will be disseminated as a national resource.

---

---

**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 early awards under the Innovation Center's Health Care Innovation Awards (HCIA) were focused on people with AD/ADRD and their caregivers.

---

For more information, see:

- <https://innovation.cms.gov/initiatives/Health-Care-Innovation-Awards/>
  - <https://innovation.cms.gov/initiatives/primary-care-first-model-options/>
- 

#### **(UPDATED) Action 2.E.2: Evaluate the effectiveness of the Independence at Home Demonstration**

---

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 HCBS. CMS has released the results from Year 4 of the demonstration.

For more information, see:

- <https://innovation.cms.gov/Files/reports/iah-yr4evalrpt.pdf>
  - <https://innovation.cms.gov/initiatives/independence-at-home/>
- 

#### **(ONGOING) Action 2.E.3: Develop a supported decision making model as an alternative to guardianship**

---

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/>
- 

#### **(ONGOING) Action 2.E.4: Understand the role of certified community behavioral health clinics in providing access to care**

---

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.

---

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

---

People with AD/DRD 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 people with AD/DRD who often have multiple chronic conditions. Transitions include moves into acute care hospitals, from hospitals to post-acute care (PAC) settings such as skilled nursing facilities or the home, or from nursing facilities to hospitals. People with AD/DRD 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.

---

**(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**

CMS’s Primary Care First is a set of voluntary Center for Medicare and Medicaid Innovation (Innovation Center) payment model options that reward value and quality by offering innovative payment model structures to support delivery of advanced primary care. One of the Primary Care First payment model options focuses on ensuring that seriously ill patients’ care is coordinated and that patients are clinically stabilized.

ACL’s state dementia system grants continue to require a care transitions component and an evaluation of the effectiveness of these programs. Numerous evidence-based, evidence-informed, innovative models of care transitions interventions are presently being implemented through ACL’s state projects. Information on promising program practices are disseminated through the NADRC.

For more information, see:

- <https://innovation.cms.gov/initiatives/primary-care-first-model-options/>
- <https://nadrc.acl.gov>
- <https://www.integratedcareresourcecenter.com/>
- <https://www.resourcesforintegratedcare.com/>

---

**(NEW) Action 2.F.2: Understand facility-initiated involuntary discharges from nursing homes**

Facility-initiated involuntary discharges (FIDs) from nursing homes can be unsafe and traumatic, and can result in higher costs of care. This study will examine patterns of discharges using available data to observe the latest trends. The research will explore the prevalence of FIDs and whether it has increased over the years: differences across all states, types of providers (e.g., for profit vs. non-profit; chain vs. non-chain), types of patients (e.g., AD/ADRD, people living with dementia, other disabilities, functional levels), payors (i.e., Medicare, Medicaid, Medicare to Medicaid, other), demographic groups, and duality (eligible for both Medicare and Medicaid). The study will be completed at the end of 2020.

---

**Strategy 2.G: Advance Coordinated and Integrated Health and Long-Term Services and Supports for People Living with Alzheimer’s Disease and Related Dementias**

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

---

**(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, including complex and transitional care management. Care coordination models can be a critical component of care in Medicare that can contribute to better health outcomes and higher beneficiary satisfaction.

---



For more information, see:

- <https://www.cms.gov/About-CMS/Agency-Information/OMH/equity-initiatives/chronic-care-management.html>
- <https://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/Downloads/ChronicCareManagement.pdf>

---

**(ONGOING) 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**

Health information technology (HIT) is an essential tool to facilitate enhanced care coordination and communication between health care and human service providers that support patients with AD/ADRD. The Office of the National Coordinator for Health Information Technology (ONC) publishes an annual *Interoperability Standards Advisory* to bring public awareness to interoperability standards and implementation specifications that can be used by industry, including standards that support care plans and transitions in care, among others.

Emerging care plan efforts include the electronic Long-Term Services and Supports (eLTSS) Initiative, a joint project between CMS and ONC focused on identifying and harmonizing electronic standards for the inter-operable exchange of person-centered service plans used by health care and HCBS providers, payers and the individuals they serve.

In September 2019, the standards development organization, Health Level 7 (HL7), published the eLTSS Fast Healthcare Interoperability Resource (FHIR) standards which are now available for adoption and implementation by HIT vendors, including those that develop dementia care technology platforms.

For more information, see:

- <http://hl7.org/fhir/us/eltss/>
- <https://oncprojectracking.healthit.gov/wiki/display/TechLabSC/eLTSS+Home>
- <https://www.healthit.gov/isa/>

---

**(UPDATED) Action 2.G.3: 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 Dual Eligible Special Needs Plans (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 2020.

---

**(COMPLETED) Action 2.G.4: Analyze pathways of eligibility for dually eligible beneficiaries**

ASPE completed a project designed 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 age 65 have AD/DRD. 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 available on the ASPE website.

For more information, see:

- <https://aspe.hhs.gov/basic-report/analysis-pathways-dual-eligible-status-final-report>

---

**(COMPLETED) Action 2.G.5: 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/DRD. 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 available on the ASPE website.

For more information, see:

- <https://aspe.hhs.gov/basic-report/loss-medicare-medicaid-dual-eligible-status-frequency-contributing-factors-and-implications>

---

**(COMPLETED) Action 2.G.6: Understand issues specific to the “triple-user” population**

ASPE has completed a project to better understand the demographics, service utilization patterns, health status and policy challenges facing the population that is simultaneously eligible for 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 TBI, a condition linked to later development of AD/DRD. 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. The report with the findings will be released in late 2019.

---



---

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

---

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**

---

In 2014, ACL’s ADRD traditional funding for state Alzheimer’s Disease Supportive Services Program(s) (ADSSP) through the Public Health Service Act were supplemented with funds from the Prevention and Public Health Fund. The additional funding allowed ACL to expand programming directly to community-based organizations. Also in 2014, ACL funded its first ADRD community-based projects, through their Alzheimer’s Disease Initiative -- Specialized Supportive Services (ADI-SSS) program. In 2018, ADSSP and ADI-SSS were combined to create the Alzheimer’s Disease Programs Initiative (ADPI) and funded 19 state and community programs. Future grants through ADPI are contingent on availability of funding.

### **(UPDATED) Action 2.H.2: Target resources towards the intellectual and developmental disability and dementia population**

---

Through its AD/ADRD grant programs and NADRC, ACL continues to target 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. Providing a broad overview of the services and support system for persons with IDD affected by dementia and their caregivers. ACL requires that 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, the NADRC has included an IDD and dementia-specific webinar in their annual webinar series, all of which can be found online.

In 2019, the NADRC published a new guide entitled *Intellectual and Developmental Disabilities and Dementia: Practical Strategies for Professionals* which provides background and strategies for professionals working with individuals living with IDD and dementia.

For more information, see:

- <https://nadrc.acl.gov/>
  - <https://nadrc.acl.gov/node/51>
  - <https://nadrc.acl.gov/node/59>
  - <https://nadrc.acl.gov/node/74>
  - <https://nadrc.acl.gov/node/101>
  - <https://nadrc.acl.gov/node/169>
-

## 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

---

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.

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

---

NIA’s ADEAR Center continues to update and 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).

ACL’s NADRC develops and makes available resources in support of both paid and unpaid caregivers. Examples of such resources includes, but is not limited to:

- *Intellectual and Developmental Disabilities and Dementia: Practical Strategies for Professionals*
- *Handbook for Helping People Living Alone with Dementia Who Have No Known Support*
- *Working Together: How Community Organizations and First Responders Can Better Serve People Living with Dementia*
- *Disaster Planning Toolkit for People Living with Dementia*

The library of NARDC and ACL grantee developed resources for persons living with AD/ADRD and their caregivers can be found online.

For more information, see:

- <https://nadrc.acl.gov/>
- <https://nadrc.acl.gov/node/151>
- <https://nadrc.acl.gov/node/155>
- <https://nadrc.acl.gov/node/157>
- <https://nadrc.acl.gov/node/169>
- <https://www.nia.nih.gov/health/alzheimers/caregiving>

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

---

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/DRD and to study the impact on ability of caregivers to manage family member with AD/DRD. 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/bringing-communities-and-technology-together-healthy-aging>

---

**(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 can be shared throughout all networks that reach and touch approximately 40 million African Americans living in the United States.

CDC is working on a training program geared towards 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 also supported the Balm in Gilead to develop and implement Memory Sunday, designated as the second Sunday in June, within congregations serving African Americans to provide 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 is 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 supports the Alzheimer's Association to develop, using BRFSS data, several fact sheets using the most current data. 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://www.cdc.gov/aging/data/index.htm>
-

---

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

---

In collaboration with the Alzheimer's Association and numerous partners, the *Road Map for Indian Country* was released and disseminated to multiple stakeholders and Tribal leaders. This *Road Map for Indian Country* has been designed specifically for public health systems serving American Indians, Alaskan Natives, and Native Hawaiians. Additionally, CDC and IHS developed infographics illustrating subjective cognitive decline and related functional limitations, as well as caregiving in AI/AN adults, in order to education stakeholders and policy makers on brain health and caregiving in Indian Country.

CDC partnered with the Association of State and Territorial Health Officials (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.

For more information, see:

- <https://www.cdc.gov/aging/data/infographic/2017/american-indian-adults-caregiving.html>
  - <https://www.cdc.gov/aging/data/infographic/2017/american-Indian-alaska-native-cognitive-decline.html>
  - <https://www.cdc.gov/aging/healthybrain/Indian-Country-resources.html>
  - <https://www.cdc.gov/aging/healthybrain/Indian-country-roadmap.html>
- 

---

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

---

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/DRD 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**

---

NIA is supporting a study of care interventions for individuals with dementia and their caregivers. The study, which is 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/DRD 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 update and offer free information in English and Spanish on AD/DRD 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 2017 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/DRD and their caregivers. A total of 58 main research recommendations resulted from nearly 700 recommendations submitted by Summit participants.

---

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

ACL's grant programs to states and communities are designed to develop and enhance dementia-capable HCBS systems. All grantees are required to include evidence-based or evidence-informed interventions in their funded programs. In 2018, 19 state and community programs received funding, bringing the total number of programs funded since 2014 to 63. Subject to appropriations, ACL anticipates continuing the program to increase the availability of evidence-based interventions across the country.

ACL's ADPI and NADRC continue to support the translation and implementation of dementia-specific evidence-based interventions in states and communities across the Nation. ACL programs have supported the implementation of 15 evidence-based interventions, preparing some to be taken to scale across the Nation. For example, NIA funded the research behind SAVVY Caregiver and ACL-funded provider pilot programs that enabled an estimated 20,000 caregivers to receive the intervention.

For more information, see:

- <http://nationalacademies.org/hmd/activities/aging/careinterventionsforindividualswithdementiaandtheircaregivers.aspx>
- <http://www.brainhealth.gov>
- <http://nadrc.acl.gov>
- <https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers>
- <https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-056.html>
- <https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-057.html>
- <https://grants.nih.gov/grants/guide/pa-files/PA-18-502.html>
- <https://grants.nih.gov/grants/guide/pa-files/PA-18-186.html>
- <https://grants.nih.gov/grants/guide/pa-files/PA-18-326.html>
- <https://grants.nih.gov/grants/guide/pa-files/PA-18-585.html>
- <https://grants.nih.gov/grants/guide/pa-files/PA-18-587.html>
- <https://grants.nih.gov/grants/guide/pa-files/PAS-17-026.html>
- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-18-030.html>
- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-20-006.html>
- <https://nadrc.acl.gov/node/110>
- <https://nadrc.acl.gov/node/140>
- <https://www.nia.nih.gov/health/alzheimers/caregiving>
- <https://www.nia.nih.gov/news/dementia-care-summit-research-recommendations-released>

---

**(UPDATED) Action 3.B.2: Provide effective caregiver interventions through Alzheimer's disease and related dementias-capable systems**

ACL's grant programs to states and communities are designed to develop and enhance dementia-capable HCBS systems. ACL programs have supported the implementation of 15 evidence-based interventions, preparing some to be taken to scale across the nation. In 2018, 19 state and community programs received funding, bringing the total number of programs funded since 2014 to 63. Subject to appropriations, ACL anticipates continuing the program to increase the availability of evidence-based interventions across the country.

For more information, see:

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

---

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

---

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 conducts 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 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.

---

**(ONGOING) 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**

---

ACL continues 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.

---

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

---

ACL continues to expand efforts to develop more dementia-capable LTSS systems designed to meet the needs of AD/ADRD caregivers. ACL requires that all ADPI community grants include behavioral symptom management and expert consultations to support caregivers in their programs.

---

**(UPDATED) Action 3.B.6: Adapt and implement Resources for Enhancing Alzheimer's Caregivers' Health in Tribal communities**

---

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 and to identify additional training for caregiver support through public health nursing.

---

**(UPDATED) Action 3.B.7: Develop and disseminate information to caregivers on Alzheimer's disease and related dementias and caregiving**

---

CDC has developed a downloadable care planning tool to assist 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.

CDC has developed a series of web features on topics including helping people with AD/ADRD and their caregivers stay physically active, care plans for older adults and their caregivers; and the truth about aging and dementia.

---



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. In addition to hosting ten webinars on a broad range of AD/ADRD topics, the NADRC has developed several resources:

- *Handbook for Helping People Living Alone with Dementia Who Have No Known Support*
- *Disaster Planning Toolkit for People Living with Dementia*
- *Working Together: How Community Organizations and First Responders Can Better Serve People Living with Dementia*

These and other resources can be found online.

For more information, see:

- <https://www.cdc.gov/aging/caregiving/pdf/Complete-Care-Plan-Form-508.pdf>
- <https://www.cdc.gov/features/caregivers-month/index.html>
- <https://nadrc.acl.gov/>

---

**(NEW) Action 3.B.8: Develop a program to support enhanced financial literacy and preparedness of family caregivers**

Family caregivers often lack adequate information and resources to properly manage the financial concerns of their loved ones. ACL introduced a new program to address the need to advance the understanding financial literacy of family caregivers. The program will address that need through development and testing new interventions, as well as identification and dissemination of best practices.

---

**Strategy 3.C: Assist Families in Planning for Future Care Needs**

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.

---

**(UPDATED) Action 3.C.1: Understand the functional trajectories of people with Alzheimer's disease and related dementias at the end of life**

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. In late 2019, ASPE will release a report and an issue brief describing the differences in functional trajectories in the last 4 years of life between PWD and people without dementia. PWD had higher levels of functional impairment throughout the 4 years before death, compared to people without dementia who experienced functional impairment closer to death. Future analyses may examine differences in health care utilization during this end-of-life period.

---

**(NEW) Action 3.C.2: Understand the use of advance care planning for people with cognitive impairment, including Alzheimer's disease and related dementias**

ASPE has a project underway evaluating the use of advance care planning (ACP) among individuals with traditional Medicare, who have cognitive impairment, including AD/ADRD. ACP is a process that includes supporting the understanding and sharing of personal values, life goals,

---

and preferences regarding future medical care. Healthcare Common Procedure Coding System code G0505 and Current Procedural Terminology code 99483, introduced in Medicare in 2017 and 2018 respectively, reimburse providers for cognitive assessment and care planning services, including the development, update, or review of an advance care plan, provided to people with cognitive impairment. This project seeks to identify characteristics of providers billing these codes, characteristics of beneficiaries receiving cognitive assessment and care planning services, as well as characteristics of visits during which these services are provided, and factors that might inhibit or encourage use of ACP.

---

**(NEW) Action 3.C.3: Understand the risks and costs of cognitive impairments**

ASPE is working on a project to understand the expected lifetime risks and costs of cognitive impairment, including estimates of the value of informal care. The possibility of becoming severely cognitively impaired is among the most consequential risks facing older adults and their families. In addition to the emotional and physical toll associated with dementia, the financial consequences can be overwhelming, as many patients require expensive paid care. Projections of future care needs and costs are difficult because the older population is changing in ways that will likely shape the course of cognitive impairment. This study uses the Dynamic Simulation of Income Model (DYNASIM) to project the risk and costs of severe cognitive impairment at older ages over the coming decades. Using multiple data sources and sophisticated econometric techniques, DYNASIM simulates the future population and its characteristics, projecting financial resources, disability status, medical conditions, cognitive status, and use of LTSS. Unlike a lot of past research, this study will show how severe cognitive impairment and associated costs vary across the population.

---

**(NEW) Action 3.C.4: Understanding the availability of caregivers for individuals with long-term services and supports needs**

ASPE is working on a project to understand widely stated concerns about an impending shortage of informal caregivers and a resulting increase in unmet needs for care as the large Baby Boom cohort enters retirement ages. The project will compile existing evidence in the literature, produce new or updated estimates of current informal caregiving for older people, including alternative arrangements when typical sources of informal care are not available (e.g., a spouse or child), and explore the implications of population aging and other changing demographic characteristics for future met and unmet care needs and reliance on Medicaid LTSS.

---

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

People with AD/DRD 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/DRD have their dignity, safety, and rights maintained.

---

---

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

---

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 also worked with the Substance Abuse and Mental Health Services Administration (SAMHSA) to issue guidance on community antipsychotic prescribing.

CMS continues the Civil Money Penalty Reinvestment Program (CMPRP), an 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 monetary penalty (CMP) funds to conduct activities that support and protect nursing home residents. This program builds 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. CMS also hosts regular Medicare Learning Network calls, some to address dementia-related issues.

For more information, see:

- [https://store.samhsa.gov/system/files/pep19-inappuse-br\\_0.pdf](https://store.samhsa.gov/system/files/pep19-inappuse-br_0.pdf)
- <https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/LTC-CMP-Reinvestment.html>
- <https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/National-Partnership-to-Improve-Dementia-Care-in-Nursing-Homes.html>
- <https://www.cms.gov/Outreach-and-Education/Outreach/NPC/National-Provider-Calls-and-Events.html>

---

**(ONGOING) Action 3.D.2: Incorporate elder abuse awareness into Aging Network activities**

---

ACL continues 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.

For more information, see:

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

---

**(UPDATED) 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.

NIA produces online and print content on Elder Abuse including a 2019 infographic *Spotting the Signs of Elder Abuse*, to educate the public and disseminate information about types of elder abuse, dealing with caregiver stress, and how to help.

---

NIA is also actively seeking research in this area with a number of active FOAs. Per NOT-AG-18-057: Notice to Specify High-Priority Research Topic for PAR-19-070 and PAR-19-071, NIA is soliciting research on risk, protective, and resilience factors related to elder mistreatment and interventions to prevent or detect elder mistreatment in informal care settings for individuals with AD/DRD. Another FOA, RFA-AG-20-00: Interpersonal Processes in Alzheimer's Disease and Related Dementias Clinical Interactions and Care Partnerships (R01 Clinical Trial Optional) states, "Even worse, they may deliberately omit important details or provide false information, with the intention of discrediting the patient and misleading the clinician to conceal signs of neglect or abuse" and among the areas of interest to NIA include research on "Interpersonal processes impacted by AD/DRD symptomology and properties of unhealthy relationships" and "Individual and dyadic-level protective factors and processes that promote resilience in AD/DRD-affected couples and families and/or modifiable risk factors for unhealthy caregiving relationships". Finally, PAR-18-544 (R01); PAR-18-538 (R21): Basic and Translational Research on Decision Making in Aging and Alzheimer's Disease invites applications for basic research to better characterize the affective, cognitive, social, and motivational parameters of impaired and intact decision making in both normal aging and AD/DRD. Research is sought that will characterize the extent to which basic behavioral and neural processes involved in decision making are differentially impacted in normal aging and AD/DRD, investigate the influence of social factors on decision making, and investigate the decision making factors that render older adults (with or without cognitive impairment) vulnerable to financial exploitation and other forms of mistreatment and abuse.

For more information, see:

- <https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-057.html>
- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-20-006.html>
- <https://grants.nih.gov/grants/guide/pa-files/par-18-544.html>
- <https://ncea.acl.gov/>
- <https://www.nia.nih.gov/health/elder-abuse>

---

**(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. The ACL National Legal Resource Center (NLRC) website includes a special section addressing advance planning and end-of-life issues, 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 persons with dementia and their caregivers. Program participants are providing dementia training to legal services providers, as well as implementing voucher programs to aide in advance planning.

ACL grants to states and communities include pilot programs designed to make dementia-capable legal services available to persons with dementia 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 2018, the NADRC partnered with the American Bar Association (ABA) Commission on Law and Aging to develop *The Handbook for Helping People Living Alone with Dementia Who Have No Known Support*. Among other things it provides practical guidance as well as tools for helping a person living alone who does not have informal supports. The Handbook includes practical strategies for identifying people who are living alone without support, assessing risk, building trust, identifying family and friends willing to help, determining decision making capacity, options

---

for helping the person maintain their independence, and the basics of guardianship or conservatorship.

For more information, see:

- <http://www.nlrc.aoa.gov/NLRC/Index.aspx>
- <https://nadrc.acl.gov/node/137>

---

**(ONGOING) Action 3.D.5: Educate law enforcement about interacting with Alzheimer’s disease and related dementias**

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 ADI-SSS community projects are training law enforcement and other first responders. One grantee created a series of well-received law enforcement training videos to address wandering, driving and encountering disoriented individuals on “house calls”.

For more information, see:

- <https://youtu.be/cQbmcq7rC7A>

---

**(ONGOING) Action 3.D.6: Work with communities to develop best practices for protecting people with Alzheimer’s disease and related dementias**

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 of well-received law enforcement training videos to address wandering, driving and encountering disoriented individuals on “house calls”.

For more information, see:

- <https://youtu.be/cQbmcq7rC7A>

---

**(UPDATED) Action 3.D.7: Expand coverage of behavioral health services via employment-based health plans and health insurance**

The Mental Health Parity and Addiction Equity Act (MHPAEA) of 2008, as amended, does not require coverage of behavioral health services (i.e., mental or substance use disorder services); instead, MHPAEA requires that such coverage, if offered, be provided at parity with coverage of medical/surgical services. That is, MHPAEA requires covered health plans and health insurance issuers in the private insurance market to ensure that financial requirements (e.g., copayments) and treatment limitations (e.g., prior authorization requirements) applicable to mental health and substance use disorder benefits are no more restrictive than the predominant requirements or limitations applied to substantially all medical/surgical benefits. Medicaid managed care

---

organizations, Medicaid alternative benefit plans, and health plans provided under the State Children's Health Insurance Program must also comply with certain MHPAEA requirements. HHS, DoL, and U.S. Department of Treasury, as well as states, are together responsible for enforcement of MHPAEA. Within HHS, implementation of MHPAEA is a collaborative effort by CMS, SAMHSA, and ASPE.

For more information, see:

- <https://www.hhs.gov/programs/topic-sites/mental-health-parity/index.html>

---

**(NEW) Action 3.D.8: Identify research and policy priorities for addressing self-neglect**

Self-neglect is the inability to perform essential self-care activities, due to physical or mental impairment or diminished capacity. It can manifest as unsanitary and/or unsafe living conditions; lack of food, medication, or health care; poor hygiene; dehydration, malnutrition, and weight loss; in addition to other negative impacts of not caring for oneself. Cognitive impairment is one of the strongest risk factors of self-neglect, in addition to depression, substance abuse, earlier trauma, and social isolation. The impact of self-neglect can be severe: It is associated with high levels of morbidity and mortality, as well as cardiovascular disease, untreated medical conditions, and functional limitations. In order to better and more proactively address self-neglect, ASPE convened a group of experts to identify research and policy priorities. Some issues the experts identified were the challenges for enhancing APS data collection (including staff buy-in, client resistance, time, and training), the need for longitudinal data collection, aligning definitions of self-neglect, and aligning service delivery and research questions. The summary of the expert meeting will be posted on the ASPE website.

---

---

**Strategy 3.E: Assess and Address the Housing Needs of People with Alzheimer's Disease and Related Dementias**

---

Stable housing is essential to helping people with AD/DRD 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/DRD. Through the actions below, HHS will assess the availability of services in the settings where people with AD/DRD live. This information will form the basis of future actions to further link housing with services for people with AD/DRD.

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

ASPE and HUD completed an evaluation of the Support And Services at Home (SASH) program for the first years of the program (2010-2016). The SASH program in Vermont is an approach to providing support services and care coordination to older adults and individuals with disabilities, using affordable housing properties as a platform for service delivery. Under contract from HHS and HUD, RTI International conducted a mixed-methods evaluation of the SASH program.

SASH appears to be a promising model of providing care coordination within housing sites with concentrations of older adults. However, health care utilization outcomes varied between different types of SASH sites (whether rural or urban; or primarily serving housing residents (i.e., site-based) or the wider community (community-based)). Growth in average annual Medicaid expenditures for long-term institutional care was \$400 slower for dually eligible SASH participants in site-based panels and in rural panels. Analysis of Medicaid claims data indicates that the SASH program had a favorable impact on Medicaid expenditures for long-term institutional care for dually eligible SASH participants over age 65. Dually eligible participants in site-based panels and in rural panels experienced statistically significant slower growth in these Medicaid

---



expenditures that averaged about \$400 per beneficiary per year. While the program as a whole did not reduce growth in Medicare spending, the SASH program had a favorable impact on the Medicare expenditures for participants in urban areas. The impact of the SASH program on the growth of Medicare expenditures varied across different types of panels. The participants in urban panels experienced growth in Medicare expenditures that were slower by \$1,400 per beneficiary per year. These impacts on total Medicare expenditures were driven by statistically significant slower growth in Medicare expenditures for hospital stays, emergency room visits, and specialist physicians, which is consistent with the SASH program goal of preventing unnecessary high-cost care.

For more information, see:

- <https://aspe.hhs.gov/pdf-report/support-and-services-home-sash-evaluation-highlights-evaluation-program-outcomes-2010-2016>
- <https://aspe.hhs.gov/pdf-report/support-and-services-home-sash-evaluation-sash-evaluation-findings-2010-2016>
- <https://www.huduser.gov/portal/periodicals/cityscape/vol20num2/ch1.pdf>

---

### **(UPDATED) Action 3.E.2: Assess utilization of home health benefits**

ASPE continues to study the growth in use of the Medicare home health benefit by community-admitted users (those individuals for whom home health episodes are not preceded by a hospitalization or PAC stay). The Medicare home health payment policy for fee-for-service 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. The Medicare Payment Advisory Commission has suggested that this might be an indication that some beneficiaries are 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 PAC noted that as the American population ages, those with chronic conditions will likely cycle between PAC and chronic care services. Our research indicates that there are many important differences between patients based on the length of their home health care use, not just based on their source of admission, and that the source of admission may be a more important differentiator among patients who use home health care for longer periods. The study also found that use of the home health care benefit is changing -- use of home health aide care has declined and use of physical therapy services has increased, even for longer periods of care. ASPE is now working on research to better understand trends in home health care use in Medicare Advantage compared to traditional Medicare.

For more information, see:

- <https://aspe.hhs.gov/pdf-report/patterns-care-and-home-health-utilization-community-admitted-medicare-patients>
-

## 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

---

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.

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

---

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.

ACL's NADRC website is an established hub for resources to support community outreach and education efforts. The website offers a broad range of resources to support the development and implementation of community-based AD/ADRD education programs.

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 disseminates 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>

---

#### **(UPDATED) Action 4.A.2: Facilitate translation of data and surveillance to inform the public**

---

CDC partnered with the Alzheimer's Association to develop, using BRFSS data, several fact sheets and infographics. CDC has also developed additional infographics co-branded with the Alzheimer's Association as well as IHS. 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. In 2019, CDC translated the national caregiving and subjective cognitive decline infographics in to Spanish and develop corresponding infographics for African American, AI/AN, and Hispanic adults.

*State of Aging and Health in America: Data Brief Series* are topic-specific documents focusing on public health issues related to older adults, developed by CDC and the National Association of Chronic Disease Directors (NACDD). These briefs provide public health professionals with the most recent data available on health and aging-related conditions, including the importance of brain health, the management of chronic conditions, and caregiving burdens, to help identify needs and mitigate the future effects of a growing older population. The briefs also provide data by important breakdowns such as by state, age, gender, and ethnicity which can be useful for states and other stakeholders in making informed decisions and policies related to these issues.

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/ADRD 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.

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)
- <https://www.cdc.gov/aging/data/index.htm>
- <https://www.cdc.gov/aging/publications/briefs.htm>

---

#### **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/ADRD and their caregivers. Nineteen states and a handful of local entities have published plans to address AD/ADRD 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.

##### **(ONGOING) 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/ADRD efforts across 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.

---

---

**(UPDATED) 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 ADPI, and the NADRC. ACL and the NADRC have developed the Dementia Capability Assessment Tool designed to measure the dementia-capability of the LTSS in various organizations and measure improvement over time.

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.

For more information, see:

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

**(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.

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 Healthy Brain Initiative *Road Map for Indian Country* work.

---

**(UPDATED) 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, the *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.

In collaboration with the Alzheimer's Association and numerous partners, the *Road Map for Indian Country* was released in 2019 and disseminated to multiple stakeholders and Tribal leaders. This *Road Map for Indian Country* has been designed specifically for public health systems serving American Indians, Alaskan Natives, and Native Hawaiians.

For more information, see:

- <https://www.cdc.gov/aging/healthybrain/Indian-Country-resources.html>
  - <https://www.cdc.gov/aging/healthybrain/Indian-country-roadmap.html>
  - <https://www.cdc.gov/aging/healthybrain/roadmap.htm>
-

---

**(UPDATED) 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 AI/AN adults. Additionally, there are several companion materials to support brain health in Tribal communities developed by CDC in partnership with ASTHO and Alzheimer's Association. CDC and the Alzheimer's Association, in collaboration with IHS, also produced infographics sharing data from the 2015-2017 BRFSS describing caregiving and subjective cognitive declines among AI/AN adults.

*State of Aging and Health in America: Data Brief Series*, developed in collaboration with NACDD and CDC are topic-specific documents focusing on public health issues related to older adults. These briefs provide public health professionals with the most recent data available on health and aging-related conditions, including the importance of brain health, the management of chronic conditions, and caregiving burdens, to help identify needs and mitigate the future effects of a growing older population. The briefs also provide data by important breakdowns such as by state, age, gender, and ethnicity which can be useful for states and other stakeholders in making informed decisions and policies related to these issues.

For more information, see:

- <https://www.cdc.gov/aging/data/index.htm>
  - <https://www.cdc.gov/aging/healthybrain/Indian-Country-resources.html>
  - <https://www.cdc.gov/aging/publications/briefs.htm>
- 

---

**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.

---

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

---

The United States participated in the World Health Organization's (WHO's) Global Dementia Observatory (GDO) in 2019. The GDO is an information exchange platform that collects information from countries on dementia policy, service delivery, and information and research. As of August 2019, 21 other countries had submitted information to the GDO.

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

---

## Goal 5: Improve Data to Track Progress

The Federal Government is committed to better understanding AD/ADRD and its impact on PWD, 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/ADRD on individual and population health and will be used to identify and monitor trends in risk factors associated with AD/ADRD, 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

---

The Federal Government needs improved data on people with AD/ADRD, 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.

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

---

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.

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

---

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**

---

CDC worked with partners and revised the BRFSS Cognitive Decline and Caregiver 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 Caregiver Module. Additional states collected data using the Cognitive Decline and Caregiver 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 the 2017 BRFSS were released in late 2018, and national infographics with aggregated 2015-2017 data were developed for both the Cognitive Decline and Caregiver Modules. Additionally, state-specific infographics with the most recent year of data for both modules was released.

*State of Aging and Health in America: Data Brief Series*, developed by CDC in collaboration with NACDD, are topic-specific documents focusing on public health issues related to older adults. These briefs provide public health professionals with the most recent data available on health and aging-related conditions, including the importance of brain health, the management of chronic conditions, and caregiving burdens, to help identify needs and mitigate the future effects of a growing older population. The briefs also provide data by important breakdowns such as by state, age, gender, and ethnicity which can be useful for states and other stakeholders in making informed decisions and policies related to these issues.

---



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 publicly available for download and analysis. These data were collected on adults 60 years and older as part of the 2011-2012 and 2013-2014 data collection cycles. The data 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. Results from these tests are due to be released by CDC in September 2019. Additionally, CDC is supporting cognitive testing using the Montreal Cognitive Assessment (MoCA) in NHANES data collection for both 2019-2020 and 2021-2022 data collection cycles.

For more information, see:

- <http://www.alz.org/publichealth/data-collection.asp>
- <http://www.cdc.gov/nhanes>
- <https://www.cdc.gov/aging/agingdata/index.html>
- <https://www.cdc.gov/aging/data/index.htm>
- <https://www.cdc.gov/aging/healthybrain/surveillance.htm>
- <https://www.cdc.gov/aging/publications/briefs.htm>
- <https://www.cdc.gov/nchs/data/nhsr/nhsr126-508.pdf>
- [https://www.cdc.gov/Nchs/Nhanes/2011-2012/CFQ\\_G.htm](https://www.cdc.gov/Nchs/Nhanes/2011-2012/CFQ_G.htm)
- [https://www.cdc.gov/Nchs/Nhanes/2013-2014/CFQ\\_H.htm](https://www.cdc.gov/Nchs/Nhanes/2013-2014/CFQ_H.htm)

---

**(UPDATED) Action 5.A.4: Develop and disseminate measures of awareness of Alzheimer's disease and related dementias**

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, using NHANES cognitive performance testing data, will be released in fall 2019 in collaboration with NCHS.

For more information, see:

- <https://www.cdc.gov/nchs/data/nhsr/nhsr126-508.pdf>

---

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

CDC's Alzheimer's Disease and Healthy Aging Data Portal, which provides access to a range of national, regional, and state data on older adults, was updated with the 2017 BRFSS data. 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. The 2015-2017 BRFSS data, includes data on cognitive decline from 49 states, Washington, D.C., and Puerto Rico and data on caregivers from 44 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.

*State of Aging and Health in America: Data Brief Series*, developed in collaboration with NACDD, are topic-specific documents focusing on public health issues related to older adults. These briefs provide public health professionals with the most recent data available on health and aging-related conditions, including the importance of brain health, the management of chronic conditions, and caregiving burdens, to help identify needs and mitigate the future effects of a growing older population. The briefs also provide data by important breakdowns such as by state,

age, gender, and ethnicity which can be useful for states and other stakeholders in making informed decisions and policies related to these issues.

For more information, see:

- <https://www.cdc.gov/aging/agingdata/index.html>
- <https://www.cdc.gov/aging/publications/briefs.htm>

---

**(NEW) Action 5.A.6: Provide analysis of Behavioral Risk Factor Surveillance System data on Alzheimer’s disease and related dementias and their caregivers in user-friendly formats**

CDC partnered with NACDD to create a series of data briefs addressing topic-specific public health issues related to older adults. Two of these data briefs include *Caregiving for Family and Friends* and *Subjective Cognitive Decline*. Each data brief includes the most recent and relevant data available, including the importance of brain health, the management of chronic conditions and other age-related conditions. Each brief concludes with action items that give specific direction on actions that can be taken to make positive change.

For more information, see:

- <https://www.cdc.gov/aging/agingdata/data-portal/state-aging-health.html>
- <https://www.cdc.gov/aging/publications/briefs.htm>

---

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

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.

**(ONGOING) Action 5.B.1: Track National Plan progress**

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 National Health and Aging Trends Survey (NHATS), Medicare Current Beneficiary Survey, 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.

---

**(ONGOING) Action 5.B.2: Update the National Plan annually**

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.

---

---

**(NEW) Action 5.B.3: Identify key indicators of progress on the National Plan**

---

ASPE will convene federal and non-federal partners to identify key indicators of progress on the National Plan to Address Alzheimer's Disease. These indicators should be meaningful for the policy makers, program staff as well as the public and enhance our understanding of the impact of the activities described within the framework of the National Plan. Indicators may be available from federal program data or other sources. As feasible, ASPE and federal partners will report on these indicators at a meeting of the Advisory Council on Alzheimer's Research, Care, and Services.

---

---

## Appendix 1: List of Participating Departments and Agencies

Administration for Children and Families (ACF)  
Administration for Community Living (ACL)  
Administration on Aging (AoA)  
Administration on Intellectual and Developmental Disabilities (ADD)  
Agency for Healthcare Research and Quality (AHRQ)

Centers for Disease Control and Prevention (CDC)  
Centers for Medicare & Medicaid Services (CMS)  
Consumer Finance Protection Bureau (CFPB)

Department of Defense (DoD)  
Department of Health and Human Services (HHS)  
Department of Housing and Urban Development (HUD)  
Department of Veterans Affairs (VA)

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

Food and Drug Administration (FDA)

Health Resources and Services Administration (HRSA)

Indian Health Service (IHS)

National Institute of Neurological Disorders and Stroke (NINDS)  
National Institute on Aging (NIA)  
National Institute on Minority Health and Health Disparities (NIMHD)  
National Institutes of Health (NIH)  
National Science Foundation (NSF)

Office of Global Affairs (OGA)  
Office of Intergovernmental and External Affairs (IEA)  
Office of the Assistant Secretary for Health (OASH)  
Office of the Assistant Secretary for Public Affairs (ASPA)  
Office of the Assistant Secretary for Planning and Evaluation (ASPE)  
Office of the National Coordinator of Health Information Technology (ONC)  
Office of the Surgeon General (OSG)  
Office on Disability (OD)

Substance Abuse and Mental Health Services Administration (SAMHSA)

---

## Appendix 2: Implementation Milestones

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2018 and 2019
<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  Past Summits: 2012, 2015, 2018  Fourth Summit TBD 2021	2018 AD Research Summit <ul style="list-style-type: none"> <li><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></li> </ul>
1.A.2	Solicit diverse community 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		Updated  Recommendations and Milestones were updated following the May 2018 Summit	2018 AD Summit Recommendations <ul style="list-style-type: none"> <li><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></li> </ul> 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 <ul style="list-style-type: none"> <li><a href="https://www.nia.nih.gov/research/milestones">https://www.nia.nih.gov/research/milestones</a></li> </ul> As of July 2019, the Milestone database now includes better tracking of progress including success criteria and specific implementation activities.
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 diverse 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	

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2018 and 2019
1.A.5	Create a timeline with milestones for achieving Goal 1.	Create and update milestone document.	NIH/NIA, NIH/NINDS		Updated	AD/ADRD Research Implementation Milestones comprehensively updated in 2019 to cover progress toward information obtained from AD, ADRD, and Care and Services Summits, including funding initiatives, research programs and resources, and research highlights.  Full set of milestones through 2025 <ul style="list-style-type: none"> <li><a href="https://www.nia.nih.gov/research/milestones">https://www.nia.nih.gov/research/milestones</a></li> </ul> 2020 Milestones <ul style="list-style-type: none"> <li><a href="https://www.nia.nih.gov/sites/default/files/2018-07/fy2020-milestones-chart.pdf">https://www.nia.nih.gov/sites/default/files/2018-07/fy2020-milestones-chart.pdf</a></li> </ul>
1.A.6	Regularly convene an ADRD Summit to review progress on research recommendations, and refine and add new recommendations as appropriate, based on recent scientific discoveries.	Convened third Summit in 2019.	NIH/NINDS	Research Subgroup, academia, industry, professional and advocacy groups	Ongoing  Past Summits: 2013, 2016, 2019	Final recommendations from the ADRD 2016 Summit became the ADRD Summit 2016 Prioritized Research Milestones <ul style="list-style-type: none"> <li><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></li> </ul> The third ADRD Summit was on March 14-15, 2019. Final research recommendations from ADRD Summit 2019 have recently been considered and adopted by the NINDS Advisory Council in September 2019, and will be presented to the NAPA Advisory Council for its consideration in early 2020.
1.A.7	Regularly convene a Research Summit on Care, Services, and Supports for PWD and their Caregivers.	Second Summit scheduled for March 24-25 2020.	ASPE, NIH	NAPA Advisory Council, academia, industry, professional and advocacy groups	Ongoing  Past Summit: 2017	The 2017 Summit final report was released in April 2018 <ul style="list-style-type: none"> <li><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></li> </ul> Following the second Summit in March 2020, research recommendations will be publicly available. <ul style="list-style-type: none"> <li><a href="https://www.nia.nih.gov/2020-dementia-care-summit">https://www.nia.nih.gov/2020-dementia-care-summit</a></li> </ul>
1.A.8	Create and implement a strategic plan for CDMRP PRARP.	Release Strategic Plan.	DoD		New	In 2019, PRARP will release an updated Strategic Plan that identifies the high-impact research goals in the areas of TBIs and AD/ADRD. The Strategic Plan summarizes research funding and findings through the PRARP program since 2011, identified short, medium, and long-term goals for the program. <ul style="list-style-type: none"> <li><a href="https://cdmrp.army.mil/prarp/default">https://cdmrp.army.mil/prarp/default</a></li> </ul>



Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2018 and 2019
1.A.9	Develop and administer a scientific landscape survey for the CDMRP PRARP.	Develop, administer, and analyze results of survey.	DoD			The CDMRP PRARP is administering a survey to the general public regarding future research directions for dementia subsequent to TBI. The survey requests input regarding future research directions for: (1) basic and translational science; (2) quality of life and caregiving research; and (3) efforts regarding future pre-clinical and clinical research. <ul style="list-style-type: none"> <li><a href="https://cdmrp.army.mil/prarp/pdfs/PRARP%20Survey%20For%20Distro_FY20.pdf">https://cdmrp.army.mil/prarp/pdfs/PRARP%20Survey%20For%20Distro_FY20.pdf</a></li> </ul>
<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	Updated	Ongoing and newly released NIH FOAs: <ul style="list-style-type: none"> <li>PAR-17-029: Dynamic Interactions between Systemic or Non-Neuronal Systems and the Brain in Aging and in AD <a href="https://grants.nih.gov/grants/guide/pa-files/PAR-17-029.html">https://grants.nih.gov/grants/guide/pa-files/PAR-17-029.html</a></li> </ul>
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	Updated	Ongoing and newly released FOAs: <ul style="list-style-type: none"> <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>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-16-205: 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-16-406: 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-18-889: Limited Competition: Renewal of, and Revisions to the AD Genetics Consortium <a href="https://grants.nih.gov/grants/guide/pa-files/PAR-18-889.html">https://grants.nih.gov/grants/guide/pa-files/PAR-18-889.html</a></li> <li>PAR-19-234: Limited Competition: Additional Sequencing for the ADSP <a href="https://grants.nih.gov/grants/guide/pa-files/PAR-19-234.html">https://grants.nih.gov/grants/guide/pa-files/PAR-19-234.html</a></li> <li>PAR-19-269: Cognitive Systems Analysis of AD Genetic and Phenotypic Data <a href="https://grants.nih.gov/grants/guide/pa-files/PAR-19-269.html">https://grants.nih.gov/grants/guide/pa-files/PAR-19-269.html</a></li> </ul>

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2018 and 2019
1.B.2 (continued)						<p>Continue to support efforts through:</p> <p>ADSP</p> <ul style="list-style-type: none"> <li>• <a href="https://www.niaqads.org/adsp/content/home">https://www.niaqads.org/adsp/content/home</a></li> </ul> <p>Genome Center for Alzheimer's Disease</p> <ul style="list-style-type: none"> <li>• <a href="http://www.adgenomics.org/">http://www.adgenomics.org/</a></li> </ul> <p>Alzheimer's Disease Genetics Consortium</p> <ul style="list-style-type: none"> <li>• <a href="https://www.niaqads.org/resources/related-projects/alzheimers-disease-genetics-consortium-adgc-collection">https://www.niaqads.org/resources/related-projects/alzheimers-disease-genetics-consortium-adgc-collection</a></li> </ul> <p>NOMAS</p> <ul style="list-style-type: none"> <li>• <a href="https://northernmanhattanstudy.org/">https://northernmanhattanstudy.org/</a></li> </ul> <p>REGARDS</p> <ul style="list-style-type: none"> <li>• <a href="http://www.regardsstudy.org/">http://www.regardsstudy.org/</a></li> </ul> <p>NIAGADS</p> <ul style="list-style-type: none"> <li>• <a href="https://www.niaqads.org/">https://www.niaqads.org/</a></li> </ul>
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, in partnership with the private sector	Updated	<p>Culminating from the efforts of expert working groups, steering committee, and crowdsourced public input, and with facilitation by the Alzheimer's Association, NIA produced the National Strategy for Recruitment and Participation in Alzheimer's Disease and Related Dementias Clinical Research, which was presented to the NAPA Advisory Council in October 2018.</p> <ul style="list-style-type: none"> <li>• <a href="https://www.nia.nih.gov/research/recruitment-strategy">https://www.nia.nih.gov/research/recruitment-strategy</a></li> </ul> <p>Recommendations of the National Strategy Group's Local, Diverse Working Group have been transformed into the <i>Alzheimer's Disease and Related Dementias Clinical Studies Recruitment Planning Guide</i></p> <ul style="list-style-type: none"> <li>• <a href="https://www.nia.nih.gov/sites/default/files/2019-05/ADEAR-recruitment-guide-508.pdf">https://www.nia.nih.gov/sites/default/files/2019-05/ADEAR-recruitment-guide-508.pdf</a></li> <li>• <a href="https://www.nia.nih.gov/research/alzheimers-dementia-outreach-recruitment-engagement-resources/recruitment-planning-guide">https://www.nia.nih.gov/research/alzheimers-dementia-outreach-recruitment-engagement-resources/recruitment-planning-guide</a></li> </ul> <p>In 2019, NIA launched ADORE, an online repository of planning tools, best practices, and materials to support researchers' recruitment and retention efforts. In addition, NIA developed several collateral materials to include in ADORE including a series of testimonial videos and an easy-to-read booklet to promote older adult research participation.</p>

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2018 and 2019
1.B.3 (continued)						<ul style="list-style-type: none"> <li>• <a href="https://www.nia.nih.gov/research/alzheimers-dementia-outreach-recruitment-engagement-resources/why-i-participate-alzheimers">https://www.nia.nih.gov/research/alzheimers-dementia-outreach-recruitment-engagement-resources/why-i-participate-alzheimers</a></li> <li>• <a href="https://order.nia.nih.gov/publication/clinical-trials-and-older-adults-easy-to-read-booklet">https://order.nia.nih.gov/publication/clinical-trials-and-older-adults-easy-to-read-booklet</a></li> <li>• <a href="https://www.nia.nih.gov/research/alzheimers-dementia-outreach-recruitment-engagement-resources">https://www.nia.nih.gov/research/alzheimers-dementia-outreach-recruitment-engagement-resources</a></li> </ul> <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 federal agencies and advocacy organizations 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>Ongoing released FOAs:</p> <ul style="list-style-type: none"> <li>• 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></li> </ul> <p>In 2019, the VA is in the process of operationalizing a pilot program to increase veterans' enrollment in 5 NIA-funded clinical trials, leveraging joint resources and infrastructure of the AD Research Centers of NIA and the Network of Dedicated Enrollment Sites of VA Cooperative Studies Program.</p> <p>The 2019 HRSA GWEP Notice of Funding Opportunity included language to educate and train patients, families, caregivers, direct care workers, health care providers, and health professions students, faculty, residents, and fellows on when it is appropriate to recruit older adults into research.</p> <ul style="list-style-type: none"> <li>• <a href="https://bhw.hrsa.gov/fundingopportunities/default.aspx?id=4c8ee9ff-617a-495e-ae78-917847db86a9">https://bhw.hrsa.gov/fundingopportunities/default.aspx?id=4c8ee9ff-617a-495e-ae78-917847db86a9</a></li> </ul>

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2018 and 2019
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	Updated	<p>See 1.B.3 for updates regarding the National Strategy for Recruitment and Participation in AD Clinical Research released in fall 2018. This strategy includes approaches to increase enrollment of racial and ethnic minorities in AD/ADRD studies outlined in recommendations of the National Strategy Group's Local, Diverse Working Group which have been transformed into the <i>AD/ADRD Clinical Studies Recruitment Planning Guide</i>.</p> <ul style="list-style-type: none"> <li><a href="https://www.nia.nih.gov/sites/default/files/2019-05/ADEAR-recruitment-guide-508.pdf">https://www.nia.nih.gov/sites/default/files/2019-05/ADEAR-recruitment-guide-508.pdf</a></li> <li><a href="https://www.nia.nih.gov/research/alzheimers-dementia-outreach-recruitment-engagement-resources/recruitment-planning-guide">https://www.nia.nih.gov/research/alzheimers-dementia-outreach-recruitment-engagement-resources/recruitment-planning-guide</a></li> </ul> <p>The 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.</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> </ul> <p>Ongoing FOAs:</p> <ul style="list-style-type: none"> <li>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></li> <li>NOT-AG-18-047: Notice to Specify High-Priority Research Topic for PAR-19-070 and PAR-19-071 Health Disparities and AD <a href="https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-047.html">https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-047.html</a></li> </ul>
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	Updated	<p>FOAs for clinical trials have been released:</p> <ul style="list-style-type: none"> <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-20-029: Pragmatic Trials of Managing Multimorbidity in AD <a href="https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-20-029.html">https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-20-029.html</a></li> </ul>

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2018 and 2019
1.B.5 (continued)						<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.</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> </ul> <p>Coordination of federal, non-federal, and international AD/ADRD research, including clinical trials, can be found in the IADRP</p> <ul style="list-style-type: none"> <li>• <a href="http://iadrp.nia.nih.gov/">http://iadrp.nia.nih.gov/</a></li> </ul>
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	Updated	<p>FOAs for clinical trials have been released:</p> <ul style="list-style-type: none"> <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-20-029: Pragmatic Trials of Managing Multimorbidity in AD <a href="https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-20-029.html">https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-20-029.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.</p> <ul style="list-style-type: none"> <li>• <a href="http://iadrp.nia.nih.gov/cadro-web/">http://iadrp.nia.nih.gov/cadro-web/</a></li> </ul> <p>In 2019, the VA participated in the SPRINT, a substudy SPRINT MIND trial. The study was completed, and the results were published.</p>

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2018 and 2019
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		Updated	<p>INCLUDE project was launched in June 2018.</p> <ul style="list-style-type: none"> <li><a href="https://www.nih.gov/include-project">https://www.nih.gov/include-project</a></li> </ul> <p>ACTC-DSN</p> <ul style="list-style-type: none"> <li><a href="https://projectreporter.nih.gov/project_info_description.cfm?aid=9749625&amp;icde=46135063&amp;ddparam=&amp;ddvalue=&amp;ddsub=&amp;cr=1&amp;csb=default&amp;cs=ASC&amp;pball=">https://projectreporter.nih.gov/project_info_description.cfm?aid=9749625&amp;icde=46135063&amp;ddparam=&amp;ddvalue=&amp;ddsub=&amp;cr=1&amp;csb=default&amp;cs=ASC&amp;pball=</a></li> </ul> <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.</p> <ul style="list-style-type: none"> <li><a href="https://www.nia.nih.gov/research/abc-ds">https://www.nia.nih.gov/research/abc-ds</a></li> </ul> <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.</p> <ul style="list-style-type: none"> <li><a href="https://projectreporter.nih.gov/project_info_description.cfm?aid=8910609&amp;icde=45614471">https://projectreporter.nih.gov/project_info_description.cfm?aid=8910609&amp;icde=45614471</a></li> </ul> <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, <i>Alzheimer's Disease in People with Down Syndrome</i>, and outreach via email and social media.</p> <ul style="list-style-type: none"> <li><a href="https://www.nia.nih.gov/health/alzheimers-disease-people-down-syndrome">https://www.nia.nih.gov/health/alzheimers-disease-people-down-syndrome</a></li> </ul>
1.B.8	Convene a workshop on the association of TBI and dementia.	Partner on joint a workshop focusing on TBI as risk factor for AD/ADRD.	NIH/NIA	VA, NIH/NINDS	New  Completed February 2019	In February 2019, NIA partnered with VA and NINDS to hold a joint workshop to establish a program to increase veterans' participation in AD/ADRD research, leveraging joint NIH and VA resources. This workshop was convened under the SPARK for Dementia Research. The workshop focused on TBI as a risk factor for AD/ADRD.
1.B.9	Issue a joint VA-NIA career development award for physician scientists new to the area of dementia research.	Collaborate with NIA on a Mentored Physician Scientist Award in Alzheimer's Disease and Related Dementias.	VA	NIH/NIA	New  Completed July 2019	In July 2019, the VA issued a new funding announcement to support early career physician-scientist mentored research in AD/ADRD. NIA issued a notice for supplemental funding to support the research proposed by the trainee. This initiative is under the SPARK for Dementia Research.



Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2018 and 2019
1.B.10	Expand research for care and support of individuals with cognitive and behavioral symptomatology related to both TBI and dementia.	Release funding announcements and award grants for research on patient-centered approaches to address cognitive and behavioral symptomatology.	DoD		New	<p>The InCASA was offered for the first time for the CDMRP PRARP in 2019. The InCASA supports innovative research that improves the quality of life and care for individuals living with the common symptoms of TBI and/or AD/ADRD and/or their families and care providers. For this funding opportunity, applicants were encouraged to propose work that should challenge existing research paradigms, or exhibit high levels of creativity. The RPA mechanism was also offered as a multi-partnered funding opportunity. The RPA requires partners from diverse backgrounds to come together and work on a project that neither individual investigator alone could achieve. Applications to this mechanism were required to demonstrate long and short-term benefits of their projects. Applications to the RPA were also required to show how the efforts will ultimately benefit individuals affected by AD/ADRD, their caregivers, and their families. Copies of the most recent PRARP Program Funding Opportunities available online.</p> <ul style="list-style-type: none"> <li>• <a href="https://cdmrp.army.mil/funding/archive/prarparchive">https://cdmrp.army.mil/funding/archive/prarparchive</a></li> </ul>
<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	Updated	<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</p> <ul style="list-style-type: none"> <li>• <a href="http://adni.loni.usc.edu/">http://adni.loni.usc.edu/</a></li> </ul> <p>AMP-AD</p> <ul style="list-style-type: none"> <li>• <a href="https://www.nia.nih.gov/alzheimers/amp-ad">https://www.nia.nih.gov/alzheimers/amp-ad</a></li> </ul> <p>Ongoing and newly released FOAs include:</p> <ul style="list-style-type: none"> <li>• PAR-18-519: Sensory and motor system changes as predictors of pre-clinical 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>• NOT-AG-18-048: Notice to Specify High-Priority Research Topics for PAR-19-070 and PAR-19-071 Novel Approaches to Characterizing and Diagnosing AD/ADRD <a href="https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-048.html">https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-048.html</a></li> </ul>

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2018 and 2019
1.C.2	Maximize collaboration among federal agencies and with 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 4 pharmaceutical industry organizations.</p> <p>AMP-AD (Projects A and B)</p> <ul style="list-style-type: none"> <li><a href="http://www.nia.nih.gov/research/amp-ad">http://www.nia.nih.gov/research/amp-ad</a></li> </ul> <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</p> <ul style="list-style-type: none"> <li><a href="http://adni.loni.usc.edu/about/funding/">http://adni.loni.usc.edu/about/funding/</a></li> </ul> <p>IADRP facilitates tracking research efforts in the public and private sector.</p> <ul style="list-style-type: none"> <li><a href="https://iadrp.nia.nih.gov/">https://iadrp.nia.nih.gov/</a></li> </ul> <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, CurePSP, and the Rainwater Charitable Foundation.</p> <ul style="list-style-type: none"> <li><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>
<b>Strategy 1.D: Coordinate Research with International Public and Private Entities</b>						
1.D.1	Inventory AD/ADRD research investments.	<p>International AD Research Database launched July 2012 and continually updated.</p> <p>It was relaunched as the International AD/ADRD Dementias Research Portfolio in July 2018 and continually updated.</p>	NIH/NIA		Ongoing	<p>IADRP now includes data from over 40 public and private funding organizations across more than 10 countries.</p> <ul style="list-style-type: none"> <li><a href="https://iadrp.nia.nih.gov/">https://iadrp.nia.nih.gov/</a></li> </ul> <p>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.</p> <ul style="list-style-type: none"> <li><a href="https://iadrp.nia.nih.gov/about/cadro">https://iadrp.nia.nih.gov/about/cadro</a></li> </ul>

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2018 and 2019
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		Updated	<p>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).</p> <ul style="list-style-type: none"> <li><a href="http://www.neurodegenerationresearch.eu/initiatives/mapping-exercise/data-collected/">http://www.neurodegenerationresearch.eu/initiatives/mapping-exercise/data-collected/</a></li> </ul> <p>The final report for the 2016 mapping exercise was published in July 2018.</p> <ul style="list-style-type: none"> <li><a href="https://www.neurodegenerationresearch.eu/wp-content/uploads/2018/07/JPND-Mapping-Exercise-Report-28Final2912072018.pdf">https://www.neurodegenerationresearch.eu/wp-content/uploads/2018/07/JPND-Mapping-Exercise-Report-28Final2912072018.pdf</a></li> </ul> <p>Alzheimer's Disease Funders' meeting held during the 2019 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.</p> <ul style="list-style-type: none"> <li><a href="https://iadrp.nia.nih.gov/">https://iadrp.nia.nih.gov/</a></li> </ul> <p>HRS: HCAP initiative is being administered in the United States and other developed and developing countries, where HRS-like representative population surveys are conducted, including in China, England, India, Mexico, South Africa, and parts of the EU.</p> <ul style="list-style-type: none"> <li><a href="https://hrs.isr.umich.edu/welcome-health-and-retirement-study">https://hrs.isr.umich.edu/welcome-health-and-retirement-study</a></li> </ul> <p><a href="https://www.src.isr.umich.edu/projects/health-and-retirement-study-harmonized-cognitive-assessment-protocol-hrs-hcap/">https://www.src.isr.umich.edu/projects/health-and-retirement-study-harmonized-cognitive-assessment-protocol-hrs-hcap/</a></p> <p><a href="https://projectreporter.nih.gov/project_info_description.cfm?aid=9618704&amp;icde=42939202">https://projectreporter.nih.gov/project_info_description.cfm?aid=9618704&amp;icde=42939202</a></p>
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	<p>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. There are 2 optional modules that states can include in their annual BRFSS survey on the topics of caregiving and cognitive decline. 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.</p>

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2018 and 2019
<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	<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.</p> <ul style="list-style-type: none"> <li>• <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></li> </ul> <p>NIA also supports the AMP-AD Target Discovery Project, which has generated a wealth of molecular data from over 3,000 human brain and plasma samples collected in several NIA-supported AD cohorts and brain banks. The project makes these datasets available to the greater research community through the AMP-AD Knowledge Portal.</p> <p>In 2018, these novel target predictions, along with the data and analyses that led to their discovery, were made available via a new AMP-AD data resource, the AGORA platform. This web-based, interactive platform will enable researchers in academia and biotech and pharmaceutical communities to leverage AMP-AD analyses and results to enhance their own work and build on the AMP-AD discoveries.</p> <ul style="list-style-type: none"> <li>• <a href="https://www.nia.nih.gov/research/amp-ad">https://www.nia.nih.gov/research/amp-ad</a></li> <li>• <a href="https://ampadportal.org/">https://ampadportal.org/</a></li> </ul>
1.E.2	Continue to promote use of the ADEAR Center to provide evidence-based information on AD/ADRD to the public and others.	Prepare and disseminate regular reports on AD/ADRD research findings.	NIH/NIA	ADEAR, ACL, CDC, FDA, CMS, HRSA, VA, partner organizations	Ongoing	<p>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).</p> <ul style="list-style-type: none"> <li>• <a href="https://www.nia.nih.gov/alzheimers">https://www.nia.nih.gov/alzheimers</a></li> </ul> <p>Progress in AD research is also reported in the annual Bypass Budget proposal.</p> <ul style="list-style-type: none"> <li>• <a href="https://www.nia.nih.gov/about/bypass-budget-proposal-archive">https://www.nia.nih.gov/about/bypass-budget-proposal-archive</a></li> </ul> <p>In 2018, 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.</p>

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2018 and 2019
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 <ul style="list-style-type: none"> <li><a href="http://www.fda.gov/Training/GuidanceWebinars/ucm345077.htm">http://www.fda.gov/Training/GuidanceWebinars/ucm345077.htm</a></li> </ul>
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	The third HBI <i>Road Map for State and Local Public Health</i> was released in late 2018 identifying 25 actions for public health professionals related to cognitive health, including cognitive impairment and caregiving for persons with a cognitive impairment, through 2023. In 2019, the first <i>Road Map for Indian Country</i> was released identifying 8 priority actions for Indian Country. <ul style="list-style-type: none"> <li><a href="https://www.cdc.gov/aging/healthybrain/roadmap.htm">https://www.cdc.gov/aging/healthybrain/roadmap.htm</a></li> <li><a href="https://www.cdc.gov/aging/healthybrain/indian-country-roadmap.html">https://www.cdc.gov/aging/healthybrain/indian-country-roadmap.html</a></li> </ul> <p>NIA and NINDS jointly produce and disseminate content on AD/ADRD, including FTD, LBD, and VCID.</p> <ul style="list-style-type: none"> <li><a href="https://www.nia.nih.gov/health/alzheimers/related-dementias">https://www.nia.nih.gov/health/alzheimers/related-dementias</a></li> </ul>
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	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. <ul style="list-style-type: none"> <li><a href="https://mindyourrisks.nih.gov/">https://mindyourrisks.nih.gov/</a></li> </ul> <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, <i>Medicine, Age, and your Brain</i>.</p> <ul style="list-style-type: none"> <li><a href="https://www.nia.nih.gov/health/brain-health-resource">https://www.nia.nih.gov/health/brain-health-resource</a></li> </ul> <p>NIA also maintains a web portal on Cognitive Health and Older Adults</p> <ul style="list-style-type: none"> <li><a href="https://www.nia.nih.gov/health/cognitive-health">https://www.nia.nih.gov/health/cognitive-health</a></li> </ul> <p>The campaign <i>What is Brain Health?</i> formerly managed by ACL was transferred to NIA in 2017.</p> <ul style="list-style-type: none"> <li><a href="https://brainhealth.nia.nih.gov/">https://brainhealth.nia.nih.gov/</a></li> </ul>

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2018 and 2019
1.E.5 (continued)						<p>In 2018, all of the 44 HRSA-funded GWEPs were educating and training the public on brain health including sharing resources.</p> <p>ACL's ADPI grantees embed brain health education in their funded activities. Through partnerships with private non-profit educational entities grantees are bringing a broad range of brain health resources to the communities they serve. ADPI-funded activities include, but are not limited to, brain health educational opportunities as a means to introducing opportunities for ADRD screening/assessments and benefits counseling.</p>
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 in collaboration with the American College of Preventive Medicine developed a Brain Health Continuing Education Course and resource page 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 was included as an elective in the Lifestyle Medicine Core Competencies Online Program in December 2018.</p> <ul style="list-style-type: none"> <li>• <a href="https://www.acpm.org/page/brainhealth">https://www.acpm.org/page/brainhealth</a></li> </ul>
1.E.7	Facilitate translation of findings into public health practice.	Develop and update a Public Health Road Map.	CDC	Public and private partners	Updated  Released in Fall 2018	<p>CDC provided funds to 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 <i>HBI State and Local Public Health Partnerships to Address Dementia, the 2018-2023 Road Map</i> was co-authored by experts in public health and brain health, including scientists at CDC. The <i>Road Map</i> 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>



Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2018 and 2019
1.E.7 (continued)						<p>Additionally, CDC has developed a series of 5 Issue Maps that highlight specific sets of Road Map actions related to caregiving, risk reduction, early detection of AD/ADRD, and the education of health professionals. The associated planning tool was developed to guide state and local public health professionals through quick steps in selected Road Map items and getting started with implementation in their jurisdictions. 2 podcasts were also produced discussing the updated Road Map. In 2019, the first <i>Road Map for Indian Country</i> was released identifying 8 priority actions for Indian Country.</p> <ul style="list-style-type: none"> <li>• <a href="https://www.cdc.gov/aging/healthybrain/roadmap.htm">https://www.cdc.gov/aging/healthybrain/roadmap.htm</a></li> <li>• <a href="https://www.cdc.gov/aging/healthybrain/issue-maps/supporting-caregivers.html">https://www.cdc.gov/aging/healthybrain/issue-maps/supporting-caregivers.html</a></li> <li>• <a href="https://www.cdc.gov/aging/healthybrain/issue-maps/risk-reduction.html">https://www.cdc.gov/aging/healthybrain/issue-maps/risk-reduction.html</a></li> <li>• <a href="https://www.cdc.gov/aging/healthybrain/issue-maps/early-detection.html">https://www.cdc.gov/aging/healthybrain/issue-maps/early-detection.html</a></li> <li>• <a href="https://www.cdc.gov/aging/healthybrain/issue-maps/data-evidence-for-action.html">https://www.cdc.gov/aging/healthybrain/issue-maps/data-evidence-for-action.html</a></li> <li>• <a href="https://www.cdc.gov/aging/healthybrain/issue-maps/educating-training-professionals.html">https://www.cdc.gov/aging/healthybrain/issue-maps/educating-training-professionals.html</a></li> <li>• <a href="https://www.cdc.gov/aging/publications/podcasts.htm">https://www.cdc.gov/aging/publications/podcasts.htm</a></li> <li>• <a href="https://www.cdc.gov/aging/healthybrain/indian-country-roadmap.html">https://www.cdc.gov/aging/healthybrain/indian-country-roadmap.html</a></li> </ul>
<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 collaboration	Updated	<p>In 2018, HRSA supported 44 GWEP grantees totaling approximately \$40.7 million of which \$3.7 million was specifically budgeted to provide dementia education and training. In Academic Year 2017-2018 (latest available data), GWEP grantees provided 338 AD/ADRD courses and trained 55,057 health care providers and 26,600 caregivers in AD/ADRD. In FY 2019, HRSA competed the GWEP and made 48 awards. All GWEP awardees are educating and training the workforce on how to care for persons living with dementia. Of the \$35.65 M GWEP budget, \$8.68 was for dementia education and training activities. In FY 2019, HRSA also competed the GACA Program and made 26 awards totaling \$1.94 M. GACA grant recipients are encouraged to provide dementia education to the workforce.</p>

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2018 and 2019
2.A.1 (continued)						<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.</p> <ul style="list-style-type: none"> <li><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></li> </ul> <p>NIA disseminates <i>Assessing Cognitive Impairment in Older Patients: A Quick Guide for Primary Care Physicians and Managing Older Patients with Cognitive Impairment</i>.</p> <ul style="list-style-type: none"> <li><a href="http://www.nia.nih.gov/health/assessing-cognitive-impairment-older-patients">http://www.nia.nih.gov/health/assessing-cognitive-impairment-older-patients</a></li> <li><a href="https://www.nia.nih.gov/health/managing-older-patients-cognitive-impairment">https://www.nia.nih.gov/health/managing-older-patients-cognitive-impairment</a></li> </ul> <p>Newly Released FOA:</p> <ul style="list-style-type: none"> <li>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></li> </ul>
2.A.2	Encourage providers to pursue careers in geriatric specialties.	Educate providers about opportunities through the HRSA GWEP.	HRSA		Updated	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.
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	Updated	<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 AD/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.</p> <ul style="list-style-type: none"> <li><a href="https://nadrc.acl.gov">https://nadrc.acl.gov</a></li> </ul>

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2018 and 2019
2.A.3 (continued)						<p>Each year, in support of paid and unpaid caregivers, 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 NADRC include, but are not limited to, advance planning, living alone, compendiums of dementia-specific interventions and outcome measures.</p> <p>In 2019, NADRC published a new guide entitled <i>IDD: Practical Strategies for Professionals: Practical Strategies for Professionals</i> which provides background and strategies for professionals working with individuals living with IDD and dementia.</p> <p>In 2017, ACL received OMB authority to collect data on professionals trained through ADPI grant funding. In 2019 alone, grantees report training over 32,000 AD/ADRD professionals on a broad range of topics.</p> <p>In 2018, the 44 HRSA GWEP grantees collaborated with 32 AAAs and 15 QIOs to strengthen state aging, public health, and IDD workforces. In addition, 22 of the HRSA 44 GWEPs collaborated with VA to assist with training on dementia.</p>
2.A.4	Develop and disseminate a unified primary care AD/ADRD curriculum.	Develop a voluntary curriculum for primary care practitioners.	HRSA	CMS, NIH/NIA, VA	Updated	<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. From December 2017 to August 2019 there was 31,426 page views on the AD curriculum page.</p> <ul style="list-style-type: none"> <li>• <a href="https://bhw.hrsa.gov/grants/geriatrics/alzheimers-curriculum">https://bhw.hrsa.gov/grants/geriatrics/alzheimers-curriculum</a></li> </ul>

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2018 and 2019
2.A.4 (continued)						<p>CMS's RIC, which partners with health plans and providers, also offers a 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>
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, 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	Updated	<p>NIH initiated a project involving 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</p> <ul style="list-style-type: none"> <li>• <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></li> </ul> <p>NASEM report</p> <ul style="list-style-type: none"> <li>• <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></li> </ul> <p><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>In 2017, the interagency ROAR group (NIH, ACL, and CDC) hosted an update in the popular webinar series for professionals on AD/ADRD resources and offered CEC.</p>

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2018 and 2019
2.A.5 (continued)						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. <ul style="list-style-type: none"> <li><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></li> </ul>
2.A.6	Engage the public health workforce on brain health.	Conduct briefings with federal, state, and local public and private partners regarding the HBI: The Public Health Road Map for State and National Partnerships, 2013-2018.	CDC	ACL, NIH/NIA	Updated	CDC in collaboration with the HBRN has developed a Scholars Program to assist in the training of undergraduate and graduate-level students in brain health. Students engage in a variety of educational, partnership, and research activities. This program is in Year 5 of a 5-year funding cycle.  CDC, in partnership 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 you are teaching a public health course at an academic institution or delivering health education at the local level, the modules explore how you can adapt this flexible resource to fit identified your needs. The course is currently being updated; the revised course will be available in late 2019. <ul style="list-style-type: none"> <li><a href="https://www.cdc.gov/aging/aginginfo/alzheimers.htm">https://www.cdc.gov/aging/aginginfo/alzheimers.htm</a></li> </ul> In December 2018, ACL hosted a webinar during which CDC introduced its newly released Road Map. The webinar included a practical example from the Washington State Department of Social and Health Services in which they described how Washington designed and is implementing a successful program aligned with CDC's HBI. <ul style="list-style-type: none"> <li><a href="https://nadrc.acl.gov/node/159">https://nadrc.acl.gov/node/159</a></li> </ul>
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 Indian Health program nursing.	IHS		Updated	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. Inclusion of ADRD content in national Diabetes Conference in 2019.

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2018 and 2019
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	Survey pilot-tested at 1 Tribal site.
2.A.9	Improve educational resources for primary care staff in Tribal communities caring for individuals with AD/ADRD and their families.	Pilot-test the HRSA curriculum for care of AD/ADRD in IHS, Tribal, and Urban Indian Health Programs.	IHS	HRSA	Ongoing	In process of adding to online nursing educational curriculum.
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	Development of templates to support AWV (with cognitive assessment) and CCM.
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	15 RITT Trainings completed.  Webinars, accredited through EES and TRAIN for VA and community clinicians: PTSD and Memory (January 24, 2018)  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>
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	Updated	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="https://nadrc.acl.gov">https://nadrc.acl.gov</a>  ACL's ADPI program continues to make funds available to states to develop and implement dementia-capable HCBS. Through the ADPI program, states are able to pilot programs in support of persons living with AD/ADRD and their caregivers in an effort to develop evidence for sustainability post-grant funding.  In 2017 ACL rolled out their 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 over time. The tool is available for non-grantees on the NADRC website. • <a href="https://nadrc.acl.gov/node/117">https://nadrc.acl.gov/node/117</a>



Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2018 and 2019
2.A.12 (continued)						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.
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	Updated	<p>In 2014, ACL began funding community programs designed to fill service gaps in existing dementia-capable systems. Funded programs are required to target program activities to providing effective supportive services to persons living alone with AD/ADRD, improving quality and effectiveness of services for individuals aging with IDD and AD/ADRD or those at high risk and delivery of behavioral symptom management training and expert consultations for family caregivers. In 2018, 19 state and community programs received funding, bringing the total number of programs funded since 2014 to 63.</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 may 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 provided through state Medicaid waivers.	Hold webinars, national calls, and provide information to key stakeholders.	CMS		Updated	<p>As one example, CMS is supporting state Medicaid agencies in multiple HCBS topics like electronic visit verification. CMS is also working with its partners at the ACL to address person-centered planning and practice.</p> <ul style="list-style-type: none"> <li>• <a href="https://www.medicaid.gov/medicaid/hcbs/training/index.html">https://www.medicaid.gov/medicaid/hcbs/training/index.html</a></li> <li>• <a href="http://www.qualityforum.org/Person_Centered_Planning_and_Practice.aspx">http://www.qualityforum.org/Person_Centered_Planning_and_Practice.aspx</a></li> </ul>

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2018 and 2019
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	Completed	<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 was conducted, and a summary report is now available on the VA Geriatrics and Extended Care Internet.</p> <ul style="list-style-type: none"> <li>• <a href="https://www.va.gov/GERIATRICS/GEC_Data_Reports.asp">https://www.va.gov/GERIATRICS/GEC_Data_Reports.asp</a></li> </ul> <p>The report describes the implementation and evaluation of the training. In addition to process evaluation results, the report includes 2 new products that were created by the workgroup for this project: (1) A staff satisfaction with learning survey, addressing specific objectives and added competency questions for each module; and (2) Knowledge test questions with multiple-choice questions on each module, to evaluate employee response at Levels 1 and 2 of the Kirkpatrick educational evaluation model respectively. The training satisfaction survey and knowledge tests may be useful to others in future implementation of this training program.</p>
2.A.16	Train future public health professionals on AD/ADRD.	Develop a public health curriculum for use in university settings.	CDC	Private partners	Ongoing	<p>The Public Health Curriculum, developed in partnership with the Alzheimer's Association and Emory University, 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.</p> <ul style="list-style-type: none"> <li>• <a href="https://www.cdc.gov/aging/aginginfo/alzheimers.htm#Curriculum">https://www.cdc.gov/aging/aginginfo/alzheimers.htm#Curriculum</a></li> </ul>
2.A.17	Understand the impacts of minimum wage increases on nursing homes.	Analyze data from DoL and CMS.	ASPE		New	Project underway. Report expected in early 2020.

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2018 and 2019
<b>Strategy 2.B: Ensure Timely and Accurate Diagnosis</b>						
2.B.1	Identify and disseminate 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	Updated	<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> <ul style="list-style-type: none"> <li>• <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></li> </ul> <p>NIA has also funded 2 new projects that seek to produce Apps capable of measuring cognitive status and change on mobile devices in response to RFA-AG-18-012 Mobile Monitoring of Cognitive Change (U2C).</p> <ul style="list-style-type: none"> <li>• <a href="https://grants.nih.gov/grants/guide/rfa-files/rfa-ag-18-012.html">https://grants.nih.gov/grants/guide/rfa-files/rfa-ag-18-012.html</a></li> <li>• <a href="https://projectreporter.nih.gov/project_info_description.cfm?aid=9781454&amp;icde=46515933&amp;ddparam=&amp;ddvalue=&amp;ddsub=&amp;cr=4&amp;csb=default&amp;cs=ASC&amp;pball=">https://projectreporter.nih.gov/project_info_description.cfm?aid=9781454&amp;icde=46515933&amp;ddparam=&amp;ddvalue=&amp;ddsub=&amp;cr=4&amp;csb=default&amp;cs=ASC&amp;pball=</a></li> <li>• <a href="https://projectreporter.nih.gov/project_info_description.cfm?aid=9781463&amp;icde=46515933&amp;ddparam=&amp;ddvalue=&amp;ddsub=&amp;cr=9&amp;csb=default&amp;cs=ASC&amp;pball=">https://projectreporter.nih.gov/project_info_description.cfm?aid=9781463&amp;icde=46515933&amp;ddparam=&amp;ddvalue=&amp;ddsub=&amp;cr=9&amp;csb=default&amp;cs=ASC&amp;pball=</a></li> </ul>
2.B.2	Educate family service providers of 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	Updated	<p>ACL, through their AD/ADRD grants to states and communities are providing dementia-capability training to paid and unpaid caregivers of PWD, including individuals living with IDD and dementia or at-risk of developing dementia. For example, in response to a spring 2018 poll of IDD program providers grantees reported training close to 8000 paid and unpaid caregivers in IDD and dementia, through their IDD-specific service gap activities since 2014. ACL collaborates closely with 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.</p> <p>ACL consistently offers educational opportunities/resources in support of both paid and unpaid caregivers of those living with IDD and AD/ADRD or at-risk of developing AD/ADRD.</p>

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2018 and 2019
2.B.2 (continued)						The Case for Palliative Care for People with IDD. In 2019, NADRC published a new guide entitled <i>IDD and Dementia: Practical Strategies for Professionals: Practical Strategies for Professionals</i> which provides background and strategies for professionals working with individuals living with IDD and dementia. <ul style="list-style-type: none"> <li>• <a href="https://nadrc.acl.gov">https://nadrc.acl.gov</a></li> <li>• <a href="http://aadmd.org/">http://aadmd.org/</a></li> </ul>
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	Updated	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 AD/ADRD in Indian Country through participating in educational opportunities including presentations to attendees of ACL's Title VI annual conference and webinars.
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	Updated	CDC worked with the American College of Preventive Medicine to develop a curriculum and resource center 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 online course has been included as an elective in the Lifestyle Medicine Core Competencies Online Program and can be for CEC (CME/MOC). <ul style="list-style-type: none"> <li>• <a href="https://www.acpm.org/page/brainhealth">https://www.acpm.org/page/brainhealth</a></li> </ul>
2.B.5	Understand the discordance between reported diagnosis, claims, and functional assessment for people with AD/ADRD.	Analyze NHATS data on reported diagnosis and cognitive functioning assessments linked to Medicare claims data	ASPE		Updated	Project ongoing. Issue brief and report will be available in early 2020.

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2018 and 2019
<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	Updated	<p>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..</p> <p>In addition, since 2017, CMS has made separate payments in Medicare for cognitive assessment and care planning services for individuals with cognitive impairment. In Medicare, a required element of these services is the creation of a care plan, including requires referral to community resources as needed (e.g., rehabilitation services, adult day programs, support groups), and that the care plan is shared with the patient and/or caregiver with initial education and support.</p> <p>ACL's state and community ADPI program continues to fund projects that include significant focus on the provision of 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, including educating providers on the importance of dementia-capable care transitions.</p>
2.C.2	Connect AI/AN to AD/ADRD resources.	As new resources become available, they will be distributed through a variety of venues to Indian Country.	IHS	ACL, CDC	Updated	<p>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 collaborated with CDC in the development of the Brain Health Public Health Road Map designed specifically for Tribal Communities. The <i>Road Map for Indian Country</i>, co-branded with the Alzheimer's Association, was released and disseminated to multiple stakeholders and Tribal nations.</p> <p>Additionally, CDC developed an infographic describing subjective cognitive decline and related functional limitations on AI/AN adults in order to educate stakeholders and policy makers on brain health in Indian Country.</p> <ul style="list-style-type: none"> <li>• <a href="https://www.cdc.gov/aging/healthybrain/Indian-country-roadmap.html">https://www.cdc.gov/aging/healthybrain/Indian-country-roadmap.html</a></li> <li>• <a href="https://www.cdc.gov/aging/healthybrain/Indian-Country-resources.html">https://www.cdc.gov/aging/healthybrain/Indian-Country-resources.html</a></li> </ul>

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2018 and 2019
2.C.2 (continued)						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. ACL's Title VI program has significantly increased the AD/ADRD educational offerings at their annual Title VI Training Conference including increasing awareness of CDC's Road Map for Indian Country.
<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	Updated	<p>CMS has included dementia-related measures in the MIPS for Medicare such as cognitive assessment, education and support of caregivers, etc.</p> <ul style="list-style-type: none"> <li><a href="https://qpp.cms.gov/mips/quality-measures">https://qpp.cms.gov/mips/quality-measures</a></li> </ul> <p>Another area of support is examining and implementing quality and outcome measures and measure concepts for HCBS programs.</p> <ul style="list-style-type: none"> <li><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></li> </ul>
2.D.2	Solicit stakeholder input on meaningful outcomes to drive quality measurement.	Convene listening sessions with relevant stakeholders.	CMS	ASPE	Updated	<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> <ul style="list-style-type: none"> <li><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></li> </ul>
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



Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2018 and 2019
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. In FY 2018, 8 HRSA GWEPs partnered with federally recognized Tribal organizations and 1 HRSA GWEP collaborated 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, in partnership with members of the Eastern Shoshone and Northern Arapaho tribes, created culturally-relevant dementia training material for AI people on the Wind River Reservation with a pictorial version of the Alzheimer's Association's <i>Know the 10 Signs: Early Detection Matters</i> . The other members of the Interest Group are discussing how/whether to adopt similar materials. This will be disseminated nationally.
<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	Updated	HCIA's Round 1 have ended. Information about the evaluation of these projects can be found at the links below. <ul style="list-style-type: none"> <li><a href="https://innovation.cms.gov/initiatives/Health-Care-Innovation-Awards/">https://innovation.cms.gov/initiatives/Health-Care-Innovation-Awards/</a></li> <li><a href="https://innovation.cms.gov/initiatives/primary-care-first-model-options/">https://innovation.cms.gov/initiatives/primary-care-first-model-options/</a></li> </ul> HCIA R2 has also ended, and CMS is in the process of completing the evaluation.
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		Updated	CMS has released the results from Year 4 of the demonstration. <ul style="list-style-type: none"> <li><a href="https://innovation.cms.gov/Files/reports/iah-yr4evalrpt.pdf">https://innovation.cms.gov/Files/reports/iah-yr4evalrpt.pdf</a></li> </ul>
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		Ongoing  Started in 2015, expected completion in 2019	<a href="http://www.supporteddecisionmaking.org">http://www.supporteddecisionmaking.org</a>
2.E.4	Understand the role of CCBHC in providing access to care.	Conduct an evaluation of CCHBC demonstration to determine improvements in accessibility, quality, and outcomes of ambulatory care.	ASPE		Ongoing	ASPE is managing a 5-year evaluation of this demonstration. Current reports include: <ul style="list-style-type: none"> <li><a href="https://aspe.hhs.gov/report/certified-community-behavioral-health-clinics-demonstration-program-report-congress-2018">https://aspe.hhs.gov/report/certified-community-behavioral-health-clinics-demonstration-program-report-congress-2018</a></li> </ul>

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2018 and 2019
<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	Updated	CMS's Primary Care First is a set of voluntary Innovation Center payment model options that reward value and quality by offering innovative payment model structures to support delivery of advanced primary care. One of the Primary Care First payment model options focuses on ensuring that seriously ill patients' care is coordinated and that patients are clinically stabilized. <ul style="list-style-type: none"> <li>• <a href="https://innovation.cms.gov/initiatives/primary-care-first-model-options/">https://innovation.cms.gov/initiatives/primary-care-first-model-options/</a></li> <li>• <a href="https://www.resourcesforintegratedcare.com/">https://www.resourcesforintegratedcare.com/</a></li> </ul>
2.F.2	Understand FIDs from nursing homes	Analyze Medicare and Medicaid data.	ASPE		New	The research will explore the prevalence of FIDs and whether it has increased over the years; and, differences across all states, types of providers (e.g., for profit vs. non-profit; chain vs. non-chain), types of patients (e.g., AD, PWD, other disabilities, functional levels), payors (i.e., Medicare, Medicaid, Medicare to Medicaid, other), demographic groups, and duality (eligible for both Medicare and Medicaid). The study will be completed at the end of 2020.
<b>Strategy 2.G: Advance Coordinated and Integrated Health and Long-Term Services and Supports for People 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		Updated	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. <ul style="list-style-type: none"> <li>• <a href="https://www.cms.gov/About-CMS/Agency-Information/OMH/equity-initiatives/chronic-care-management.html">https://www.cms.gov/About-CMS/Agency-Information/OMH/equity-initiatives/chronic-care-management.html</a></li> <li>• <a href="https://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/Downloads/ChronicCareManagement.pdf">https://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/Downloads/ChronicCareManagement.pdf</a></li> </ul>

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2018 and 2019
2.G.2	Assess the adequacy of HIT standards to support the needs of persons with AD/ADRD.	Convene partners to explore feasibility and timing.	ONC	CMS, ASPE	Ongoing	<p>ONC publishes an annual Inter-operability Standards Advisory to bring public awareness to inter-operability standards and implementation specifications that can be used by industry, including standards that support care plans and transitions in care, among others.</p> <ul style="list-style-type: none"> <li>• <a href="https://www.healthit.gov/isa/">https://www.healthit.gov/isa/</a></li> </ul> <p>Emerging care plan efforts include the eLTSS Initiative, a joint project between CMS and ONC focused on identifying and harmonizing electronic standards for the inter-operable exchange of person-centered service plans used by health care and HCBS providers, payers and the individuals they serve.</p> <ul style="list-style-type: none"> <li>• <a href="https://onctracking.healthit.gov/wiki/display/TechLabSC/eLTSS+Home">https://onctracking.healthit.gov/wiki/display/TechLabSC/eLTSS+Home</a></li> </ul> <p>In September 2019, the standards development organization, HL7, published the eLTSS FHIR standards which are now available for adoption and implementation by HIT vendors, including those that develop dementia care technology platforms.</p> <ul style="list-style-type: none"> <li>• <a href="http://hl7.org/fhir/us/eltss/">http://hl7.org/fhir/us/eltss/</a></li> </ul>
2.G.3	Study impacts of managed care on health outcomes and quality.	Examine the Medicare-Medicaid alignment programs in Tennessee.	ASPE		Updated	Project underway. Final report is expected in 2020.
2.G.4	Analyze pathways of eligibility for dually eligible beneficiaries.	<p>Determine how beneficiaries dually eligible for Medicare and Medicaid achieve this status.</p> <p>Understand effects on spending and service use patterns.</p>	ASPE		Completed	<p>A report is available on the ASPE website.</p> <ul style="list-style-type: none"> <li>• <a href="https://aspe.hhs.gov/pdf-report/analysis-pathways-dually-eligible-status-final-report">https://aspe.hhs.gov/pdf-report/analysis-pathways-dually-eligible-status-final-report</a></li> </ul>
2.G.5	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	<p>A report is available on the ASPE website.</p> <ul style="list-style-type: none"> <li>• <a href="https://aspe.hhs.gov/basic-report/loss-medicare-medicare-dual-eligible-status-frequency-contributing-factors-and-implications">https://aspe.hhs.gov/basic-report/loss-medicare-medicare-dual-eligible-status-frequency-contributing-factors-and-implications</a></li> </ul>
2.G.6	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		Completed	A report is forthcoming in December 2019.

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2018 and 2019
<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; and (3) caregivers who need behavioral symptom management training or expert consultations to help them care for family members.	ACL		Updated	In 2018, 19 state and community programs received funding, bringing the total number of programs funded since 2014 to 63. NOTE: future grants are contingent on availability of funding.
2.H.2	Target resources towards the IDD and dementia population.	<p>Develop workforces in aging, public health, and IDD that are dementia-capable and culturally-competent.</p> <p>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.</p>	ACL		Updated	<p>Through its AD/ADRD grant programs and NADRC, ACL continues to target program resources to the IDD and dementia issue. At the White House Conference on Aging in July 2015, ACL released their <i>IDD and Dementia Report</i> on the current state of services and support system for persons with IDD living with dementia. Providing a broad overview of the services and support system for persons with IDD affected by dementia and their caregivers. ACL requires that grantees 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". Each year since 2015, NADRC has included an IDD and dementia-specific webinar in their annual webinar series, all of which can be found at:</p> <ul style="list-style-type: none"> <li>• <a href="https://nadrc.acl.gov/">https://nadrc.acl.gov/</a></li> </ul> <p>In 2019, NADRC published a new guide entitled <i>IDD and Dementia: Practical Strategies for Professionals: Practical Strategies for Professionals</i> which provides background and strategies for professionals working with individuals living with IDD and dementia.</p> <ul style="list-style-type: none"> <li>• <a href="https://nadrc.acl.gov/node/169">https://nadrc.acl.gov/node/169</a></li> </ul>

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2018 and 2019
<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 federally-developed educational materials.	Distribute training and education materials through federal agencies and state and local networks.	ACL	NIH/NIA, ADEAR	Ongoing	<p>ACL’s NADRC develops and makes available resources in support of both paid and unpaid caregivers. Examples of such resources includes, but is not limited to:</p> <ul style="list-style-type: none"> <li>• <i>IDD and Dementia: Practical Strategies for Professionals</i> <a href="https://nadrc.acl.gov/node/169">https://nadrc.acl.gov/node/169</a></li> <li>• <i>Handbook for Helping People Living Alone with Dementia Who Have No Known Support</i> <a href="https://nadrc.acl.gov/node/157">https://nadrc.acl.gov/node/157</a></li> <li>• <i>Working Together: How Community Organizations and First Responders Can Better Serve People Living with Dementia</i> <a href="https://nadrc.acl.gov/node/155">https://nadrc.acl.gov/node/155</a></li> <li>• <i>Disaster Planning Toolkit for People Living with Dementia</i> <a href="https://nadrc.acl.gov/node/151">https://nadrc.acl.gov/node/151</a></li> </ul> <p>The library of NADRC and ACL grantee developed resources for persons living with AD/ADRD and their caregivers.</p> <ul style="list-style-type: none"> <li>• <a href="https://nadrc.acl.gov/">https://nadrc.acl.gov/</a></li> </ul> <p>Fact sheets</p> <ul style="list-style-type: none"> <li>• <a href="https://eldercare.acl.gov/Public/Resources/Topic/Alzheimer_Disease.aspx">https://eldercare.acl.gov/Public/Resources/Topic/Alzheimer_Disease.aspx</a></li> </ul> <p>NIA’s ADEAR Center continues to update and 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).</p> <ul style="list-style-type: none"> <li>• <a href="https://www.nia.nih.gov/health/alzheimers/caregiving">https://www.nia.nih.gov/health/alzheimers/caregiving</a></li> </ul>

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2018 and 2019
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>
3.A.3	Increase awareness of the importance of brain health in culturally-sensitive ways.	Increase awareness of brain health, specifically AD/ADRD and caregiving among African Americans.	CDC	ACL	Updated	<p>CDC supported the development of 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 3 areas of focus are brain health education, mobilization and advocacy, and networking. NBHCAA serves as an information hub on the human brain that can be shared throughout all networks that reach and touch approximately 40 million African Americans living in the United States.</p> <p>CDC is working on a training program geared towards 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.</p> <p>CDC supported the Balm in Gilead to develop and implement Memory Sunday, designated as the second Sunday in June, within congregations serving African Americans to provide education on AD/ADRD: prevention, treatment, research studies and caregiving. The purpose of Memory Sunday is to bring national and local attention to the tremendous burden that AD/ADRD is 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/ADRD; to encourage participation in research studies, and to support persons living with AD/ADRD and their caregivers.</p>

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2018 and 2019
3.A.3 (continued)						<p>CDC supports the Alzheimer's Association to develop, using BRFSS data, several fact sheets using the most current data. 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.</p> <ul style="list-style-type: none"> <li>• <a href="http://brainhealthcenterforafricanamericans.org/">http://brainhealthcenterforafricanamericans.org/</a></li> <li>• <a href="https://www.cdc.gov/aging/data/index.htm">https://www.cdc.gov/aging/data/index.htm</a></li> </ul>
3.A.4	Increase awareness of the importance of brain health for Tribal communities in culturally-sensitive ways.	Develop materials to support implementation of the Public Health Road Map in Tribal Communities.	CDC	Private partners	Updated	<p>In conjunction with the Alzheimer's Association and other partners, the <i>Road Map for Indian Country</i> was released and disseminated to multiple stakeholders and Tribal nations. This <i>Road Map for Indian Country</i> has been designed specifically for public health systems serving AI/ANs and Native Hawaiians. Additionally, CDC developed infographics illustrating subjective cognitive decline and related functional limitations in AI/AN adults in order to education stakeholders and policy makers on brain health in Indian Country.</p> <ul style="list-style-type: none"> <li>• <a href="https://www.cdc.gov/aging/healthybrain/Indian-country-roadmap.html">https://www.cdc.gov/aging/healthybrain/Indian-country-roadmap.html</a></li> </ul> <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> <ul style="list-style-type: none"> <li>• <a href="https://www.cdc.gov/aging/healthybrain/Indian-country-roadmap.html">https://www.cdc.gov/aging/healthybrain/Indian-country-roadmap.html</a></li> <li>• <a href="https://www.cdc.gov/aging/healthybrain/Indian-Country-resources.html">https://www.cdc.gov/aging/healthybrain/Indian-Country-resources.html</a></li> <li>• <a href="https://www.cdc.gov/aging/data/infographic/2017/american-indian-alaska-native-cognitive-decline.html">https://www.cdc.gov/aging/data/infographic/2017/american-indian-alaska-native-cognitive-decline.html</a></li> <li>• <a href="https://www.cdc.gov/aging/data/infographic/2017/american-indian-adults-caregiving.html">https://www.cdc.gov/aging/data/infographic/2017/american-indian-adults-caregiving.html</a></li> </ul>



Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2018 and 2019
<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	Updated	<p>NIA is supporting a study of care interventions for individuals with dementia and their caregivers.</p> <ul style="list-style-type: none"> <li><a href="http://www.nationalacademies.org/hmd/Activities/Aging/CareInterventionsforIndividualswithDementiaandTheirCaregivers.aspx">http://www.nationalacademies.org/hmd/Activities/Aging/CareInterventionsforIndividualswithDementiaandTheirCaregivers.aspx</a></li> </ul> <p>ACL's grant programs to states and communities are designed to develop and enhance dementia-capable HCBS systems. All grantees are required to include evidence-based or evidence-informed interventions in their funded programs. In 2018, 19 state and community programs received funding, bringing the total number of programs funded since 2014 to 63. Subject to appropriations, ACL anticipates continuing the program to increase the availability of evidence-based interventions across the country.</p> <p>ACL's ADPI and the NADRC continue to support the translation and implementation of dementia-specific evidence-based interventions in states and communities across the nation. ACL programs have supported the implementation of 15 evidence-based interventions, preparing some to be taken to scale across the nation. For example, NIA funded the research behind SAVVY Caregiver and ACL-funded provider pilot programs that enabled an estimated 20,000 caregivers to receive the intervention.</p> <p>Grantee-Implemented Evidence-Based and Evidence-Informed Interventions</p> <ul style="list-style-type: none"> <li><a href="https://nadrc.acl.gov/node/140">https://nadrc.acl.gov/node/140</a></li> </ul> <p>ACL-funded SPECIAL EDITION of ASA Generations: Supporting People with Dementia and Their Caregivers in the Community.</p> <ul style="list-style-type: none"> <li><a href="https://nadrc.acl.gov/node/110">https://nadrc.acl.gov/node/110</a></li> <li><a href="https://nadrc.acl.gov/">https://nadrc.acl.gov/</a></li> </ul> <p>NIA's ADEAR Center continues to update and 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).</p> <ul style="list-style-type: none"> <li><a href="https://www.nia.nih.gov/health/alzheimers/caregiving">https://www.nia.nih.gov/health/alzheimers/caregiving</a></li> </ul>

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2018 and 2019
3.B.1 <i>(continued)</i>						<p>The 2017 Dementia Care and Services Summit, sponsored by HHS and private sector organizations, developed national recommendations for research priorities on care and services for PWD and their families. A total of 58 main research recommendations resulted from nearly 700 recommendations submitted by Summit participants.</p> <ul style="list-style-type: none"> <li>• <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></li> </ul> <p>Resources for dissemination</p> <ul style="list-style-type: none"> <li>• <a href="http://www.alzheimers.gov">http://www.alzheimers.gov</a></li> </ul> <p>Ongoing and newly released FOAs:</p> <ul style="list-style-type: none"> <li>• PAS-18-030: Improving Quality of Care and Quality of Life for Persons with AD/ADRD at the End of Life <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/PAR-18-186.html">https://grants.nih.gov/grants/guide/pa-files/PAR-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/PAR-18-585.html">https://grants.nih.gov/grants/guide/pa-files/PAR-18-585.html</a></li> <li>• RFA-AG-20-006: Interpersonal Processes in AD/ADRD Clinical Interactions and Care Partnerships <a href="https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-20-006.html">https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-20-006.html</a></li> <li>• PAR-18-326: Technology to Detect, Monitor and Assess Daily Functions in Individuals with Cognitive Decline, AD and/or AD/ADRD <a href="https://grants.nih.gov/grants/guide/pa-files/PAR-18-326.html">https://grants.nih.gov/grants/guide/pa-files/PAR-18-326.html</a></li> <li>• PAS-17-026: Improving Quality of Care and Quality of Life for Persons with AD/ADRD at the End of Life <a href="https://grants.nih.gov/grants/guide/pa-files/PAS-17-026.html">https://grants.nih.gov/grants/guide/pa-files/PAS-17-026.html</a></li> <li>• PAR-18-587: Assistive Technology for Persons with AD/ADRD and Their Caregivers <a href="https://grants.nih.gov/grants/guide/pa-files/PAR-18-587.html">https://grants.nih.gov/grants/guide/pa-files/PAR-18-587.html</a></li> </ul>

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2018 and 2019
3.B.1 (continued)						<ul style="list-style-type: none"> <li>NOT-AG-18-057: Notice to Specify High-Priority Research Topic for PAR-19-070 and PAR-19-071 Behavioral and Social Science Priority Areas in Dementia Care Research <a href="https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-057.html">https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-057.html</a></li> <li>NOT-AG-18-057: Notice to Specify High-Priority Research Topic for PAR-19-070 and PAR-19-071 Behavioral and Social Science Priority Areas in Dementia Care Research: Programs and services for persons with dementia <a href="https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-056.html">https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-056.html</a></li> </ul>
3.B.2	Provide effective caregiver interventions through AD/ADRD-capable systems.	Work with states and communities to identify caregiver interventions for dissemination.	ACL		Updated	<p>ACL's grant programs to states and communities are designed to develop and enhance dementia-capable HCBS systems. ACL programs have supported the implementation of 15 evidence-based interventions, preparing some to be taken to scale across the nation. In 2018, 19 state and community programs received funding, bringing the total number of programs funded since 2014 to 63. Subject to appropriations, ACL anticipates continuing the program to increase the availability of evidence-based interventions across the country.</p> <p>Grantee-Implemented Evidence-Based and Evidence-Informed Interventions.</p> <ul style="list-style-type: none"> <li><a href="https://nadrc.acl.gov/node/140">https://nadrc.acl.gov/node/140</a></li> </ul>
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	Through its Title VI program ACL disseminates dementia-specific information to LTSS providers in Indian Country. The culturally-appropriate information is presented at meetings, webinars and written materials.
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 continues to expand efforts to develop more dementia-capable LTSS systems designed to meet the needs of AD/ADRD caregivers. ACL requires that all ADPI community grants include behavioral symptom management and expert consultations to support caregivers in their programs.

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2018 and 2019
3.B.6	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	Updated	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.
3.B.7	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		Updated	<p>CDC has developed a downloadable care planning tool to assist 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.</p> <p>CDC has developed a series of web features on topics including helping people with AD/ADRD and their caregivers stay physically active, care plans for older adults and their caregivers; and the truth about aging and dementia.</p> <ul style="list-style-type: none"> <li>• <a href="https://www.cdc.gov/aging/publications/features/index.html">https://www.cdc.gov/aging/publications/features/index.html</a></li> <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 NADRC and its grant programs, continues to develop and make available web content on issues relevant to paid and unpaid caregivers. In addition to hosting 10 webinars on a broad range of AD/ADRD topics, NADRC has developed several resources:</p> <ul style="list-style-type: none"> <li>• <i>Handbook for Helping People Living Alone with Dementia Who Have No Known Support</i></li> <li>• <i>Disaster Planning Toolkit for People Living with Dementia</i></li> <li>• <i>Working Together: How Community Organizations and First Responders Can Better Serve People Living with Dementia</i></li> </ul> <p>Available resources</p> <ul style="list-style-type: none"> <li>• <a href="https://nadrc.acl.gov/">https://nadrc.acl.gov/</a></li> </ul>

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2018 and 2019
3.B.8	Develop a program to support enhanced financial literacy and preparedness of family caregivers	The program will address that need through development and testing new interventions, as well as identification and dissemination of best practices.	ACL	Alzheimer's Association	New	Family caregivers often lack adequate information and resources to properly manage the financial concerns of their loved ones. ACL introduced a new program to address the need to advance the understanding financial literacy of family caregivers. The program will address that need through development and testing new interventions, as well as identification and dissemination of best practices.
<b>Strategy 3.C: Assist Families in Planning for Future Care Needs</b>						
3.C.1	Understand the 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		Updated	In late 2019, ASPE will release a report and issue brief describing the differences in functional trajectories in the last 4 years of life between people with dementia and people without dementia.
3.C.2	Understand the use of ACP for people with cognitive impairment, including AD/ADRD.	Understand better the characteristics of providers billing for and beneficiaries with cognitive impairment receiving ACP services.	ASPE		New	ASPE has a project underway evaluating the use of ACP among individuals with traditional Medicare, who have cognitive impairment, including AD/ADRD.
3.C.3	Understand the risks and costs of cognitive impairments.	Use micro-simulation modeling to project the risks and costs of cognitive impairment.3.C.2.	ASPE		New	Findings from this project are expected in 2020.
3.C.4	Understanding the availability of caregivers for individuals with LTSS needs.	Conduct data analyses and micro-simulation modeling to understand the future availability of caregivers.	ASPE		New	Findings from this project are expected in 2020.
<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	Updated	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). CMS also worked with SAMHSA to issue guidance on community antipsychotic prescribing.

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2018 and 2019
3.D.1 (continued)						<p>CMS continues CMPRP, an 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 builds 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. CMS also hosts regular Medicare Learning Network calls, some to address dementia-related issues.</p> <ul style="list-style-type: none"> <li>• <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></li> <li>• <a href="https://store.samhsa.gov/system/files/pep19-inappuse-br_0.pdf">https://store.samhsa.gov/system/files/pep19-inappuse-br_0.pdf</a></li> <li>• <a href="https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/LTC-CMP-Reinvestment.html">https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/LTC-CMP-Reinvestment.html</a></li> <li>• <a href="https://www.cms.gov/Outreach-and-Education/Outreach/NPC/National-Provider-Calls-and-Events.html">https://www.cms.gov/Outreach-and-Education/Outreach/NPC/National-Provider-Calls-and-Events.html</a></li> </ul>
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 partner/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> <ul style="list-style-type: none"> <li>• <a href="https://ncea.acl.gov">https://ncea.acl.gov</a></li> </ul>
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	Updated	<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.</p> <ul style="list-style-type: none"> <li>• <a href="https://ncea.acl.gov">https://ncea.acl.gov</a></li> </ul> <p>NIA produces online and print content on Elder Abuse including a new infographic to educate the public and disseminate information about types of elder abuse, dealing with caregiver stress, and how to help.</p> <ul style="list-style-type: none"> <li>• <a href="https://www.nia.nih.gov/health/elder-abuse">https://www.nia.nih.gov/health/elder-abuse</a></li> </ul>

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2018 and 2019
3.D.3 (continued)						<p>NIA is actively seeking research in this area. New and ongoing FOAs:</p> <ul style="list-style-type: none"> <li>• NOT-AG-18-057: Notice to Specify High-Priority Research Topic for PAR-19-070 and PAR-19-071 <a href="https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-057.html">https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-057.html</a></li> <li>• RFA-AG-20-00: Interpersonal Processes in AD/ADRD Clinical Interactions and Care Partnerships <a href="https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-20-006.html">https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-20-006.html</a></li> <li>• PAR-18-544 (R01); PAR-18-538 (R21): 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> </ul>
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	Legal assistance developers, NLRC	Updated	<p>ACL grants to states and communities include pilot programs designed to make dementia-capable legal services available to persons with dementia 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 2018, NADRC partnered with the ABA Commission on Law and Aging to develop the <i>Handbook for Helping People Living Alone with Dementia Who Have No Known Support</i>. Among other things it provides practical guidance as well as tools for helping a person living alone who does not have informal supports. The Handbook includes practical strategies for identifying people who are living alone without support, assessing risk, building trust, identifying family and friends willing to help, determining decision making capacity, options for helping the person maintain their independence, and the basics of guardianship or conservatorship.</p> <p>In 2017, NADRC designed and published <i>Living with Dementia: Advance Planning Guides</i> (4 guides) for <i>Persons with Dementia and Caregivers</i>.</p> <ul style="list-style-type: none"> <li>• <a href="https://nadrc.acl.gov/node/137">https://nadrc.acl.gov/node/137</a></li> </ul> <p>ACL's NADRC continues to work closely with the ABA's Commission on Law and Aging in the development of resources that support persons with dementia 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>



Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2018 and 2019
3.D.5	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 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> <ul style="list-style-type: none"> <li>• <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></li> </ul> <p>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".</p> <ul style="list-style-type: none"> <li>• <a href="https://youtu.be/cQmcq7rC7A">https://youtu.be/cQmcq7rC7A</a></li> </ul>
3.D.6	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> <ul style="list-style-type: none"> <li>• <a href="https://www.justice.gov/elderjustice/financial/faq.html">https://www.justice.gov/elderjustice/financial/faq.html</a></li> </ul>
3.D.7	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	Updated	<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> <ul style="list-style-type: none"> <li>• <a href="http://www.hhs.gov/parity">http://www.hhs.gov/parity</a></li> </ul>
3.D.8	Identify research and policy priorities for addressing self-neglect.	Review literature and convene experts.	ASPE		New	<p>A summary of the expert meeting will be posted on the ASPE website in 2020.</p>

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2018 and 2019
<b>Strategy 3.E: Assess and Address the Housing Needs of People with Alzheimer's Disease and Related Dementias</b>						
3.E.1	Evaluate the SASH program.	Analyze the SASH program model of coordinated health and supportive services within affordable housing settings.	ASPE		Updated	<p>New ASPE SASH reports:</p> <ul style="list-style-type: none"> <li><a href="https://aspe.hhs.gov/basic-report/support-and-services-home-sash-evaluation-sash-evaluation-findings-2010-2016">https://aspe.hhs.gov/basic-report/support-and-services-home-sash-evaluation-sash-evaluation-findings-2010-2016</a></li> <li><a href="https://aspe.hhs.gov/basic-report/support-and-services-home-sash-evaluation-highlights-evaluation-program-outcomes-2010-2016">https://aspe.hhs.gov/basic-report/support-and-services-home-sash-evaluation-highlights-evaluation-program-outcomes-2010-2016</a></li> </ul> <p>The HUD Cityscape paper on SASH: The Impact of the Vermont Support and Services at Home Program on Healthcare Expenditures</p> <ul style="list-style-type: none"> <li><a href="https://www.huduser.gov/portal/periodicals/cityscpe/vol20num2/ch1.pdf">https://www.huduser.gov/portal/periodicals/cityscpe/vol20num2/ch1.pdf</a></li> </ul>
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		Updated	<p>ASPE is now working on research to better understand trends in home health care use in Medicare Advantage compared to traditional Medicare.</p> <ul style="list-style-type: none"> <li><a href="https://aspe.hhs.gov/basic-report/patterns-care-and-home-health-utilization-community-admitted-medicare-patients">https://aspe.hhs.gov/basic-report/patterns-care-and-home-health-utilization-community-admitted-medicare-patients</a></li> </ul>
<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>ACL's NADRC website is an establish hub for resources to support community outreach and education efforts. The website offers a broad range of resources to support the development and implementation of community-based AD/ADRD education programs.</p>

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2018 and 2019
4.A.1 (continued)						<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 50,000 subscribers, and social media outreach to more than 10,000 followers.</p> <ul style="list-style-type: none"> <li>• <a href="http://www.Alzheimers.gov">http://www.Alzheimers.gov</a></li> </ul>
4.A.2	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	Updated	<p>CDC partnered with the Alzheimer's Association to develop, using BRFSS data, several fact sheets and infographics. CDC has also developed additional infographics co-branded with the Alzheimer's Association as well as IHS. 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. In 2019, CDC translated the national caregiving and subjective cognitive decline infographics in to Spanish and develop corresponding infographics for African American, AI/AN, and Hispanic adults.</p> <p><i>State of Aging and Health in America: Data Brief Series</i> are topic-specific documents focusing on public health issues related to older adults developed by CDC and NACDD. These briefs provide public health professionals with the most recent data available on health and aging-related conditions, including the importance of brain health, the management of chronic conditions, and caregiving burdens, to help identify needs and mitigate the future effects of a growing older population. The briefs also provide data by important breakdowns such as by state, age, gender, and ethnicity which can be useful for states and other stakeholders in making informed decisions and policies related to these issues.</p>

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2018 and 2019
4.A.2 (continued)						<p>CDC also supported the Alzheimer's Association to develop a Needs Assessment Toolkit that serves as <i>Guidance and Resources for state Public Health Agencies on Comprehensive Needs Assessments Related to AD/ADRD</i>. This document aims to increase the use of information and insights to appropriately respond to the growing public health burden associated with AD/ADRD 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.</p> <ul style="list-style-type: none"> <li>• <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></li> <li>• <a href="https://www.cdc.gov/aging/data/index.htm">https://www.cdc.gov/aging/data/index.htm</a></li> <li>• <a href="https://www.cdc.gov/aging/publications/briefs.htm">https://www.cdc.gov/aging/publications/briefs.htm</a></li> </ul>
<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.
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	Updated	HHS will improve the dementia-capability of state and community service systems through the ACL's ADPI and NADRC. ACL and NADRC have developed the Dementia Capability Assessment Tool designed to measure the dementia-capability of the LTSS in various organizations and measure improvement over time.

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2018 and 2019
4.B.2 <i>(continued)</i>						<p>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.</p> <ul style="list-style-type: none"> <li>• <a href="https://nadrc.acl.gov">https://nadrc.acl.gov</a></li> </ul>
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.	<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	Updated	<p>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.</p> <p>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 <i>Road Map for Indian Country</i> work.</p>
4.B.4	Develop and update a public health Road Map for assisting state, Tribal, and local health departments in prioritizing actions	Convene experts, identify priorities, and develop a Road Map.	CDC		Updated	<p>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 HBI <i>State and Local Public Health Partnerships to Address Dementia. The 2018-2023 Road Map</i> 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>

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2018 and 2019
4.B.4 (continued)						<p>In collaboration with the Alzheimer's Association and numerous partners, the <i>Road Map for Indian Country</i> was released in 2019 and disseminated to multiple stakeholders and Tribal leaders. This <i>Road Map for Indian Country</i> has been designed specifically for public health systems serving AI/ANs and Native Hawaiians.</p> <ul style="list-style-type: none"> <li><a href="https://www.cdc.gov/aging/healthybrain/roadmap.htm">https://www.cdc.gov/aging/healthybrain/roadmap.htm</a></li> <li><a href="https://www.cdc.gov/aging/healthybrain/Indian-country-roadmap.html">https://www.cdc.gov/aging/healthybrain/Indian-country-roadmap.html</a></li> <li><a href="https://www.cdc.gov/aging/healthybrain/Indian-Country-resources.html">https://www.cdc.gov/aging/healthybrain/Indian-Country-resources.html</a></li> </ul>
4.B.5	Facilitate translation of findings into public health practice in Tribal communities.	<p>Develop and update a <i>Public Health Road Map</i> for assisting Tribal entities in prioritizing actions.</p> <p>Develop materials to support implementation of the <i>Public Health Road Map</i> in Tribal Communities.</p>	CDC	IHS, Alzheimer's Association, private partners	Updated  Road Map released Spring 2018	<p>In conjunction with the Alzheimer's Association and other partners, CDC is developing a special edition of the <i>Public Health Road Map for Tribal Communities</i>, the <i>HBI Road Map for Indian Country</i>. The original <i>Road Map</i> focuses on issues pertinent to state and local public health agencies and their partners. A companion <i>Road Map for Indian Country</i> has been designed specifically for public health systems serving AI/AN adults. Additionally, there are several companion materials to support brain health in Tribal communities developed by CDC in partnership with ASTHO and Alzheimer's Association. CDC and Alzheimer's Association, in collaboration with IHS, also produced infographics sharing data from the 2015-2017 BRFSS describing caregiving and subjective cognitive declines among AI/AN adults.</p> <p><i>State of Aging and Health in America: Data Brief Series</i>, developed in collaboration with NACDD and CDC are topic-specific documents focusing on public health issues related to older adults. These briefs provide public health professionals with the most recent data available on health and aging-related conditions, including the importance of brain health, the management of chronic conditions, and caregiving burdens, to help identify needs and mitigate the future effects of a growing older population. The briefs also provide data by important breakdowns such as by state, age, gender, and ethnicity which can be useful for states and other stakeholders in making informed decisions and policies related to these issues.</p> <ul style="list-style-type: none"> <li><a href="https://www.cdc.gov/aging/healthybrain/Indian-Country-resources.html">https://www.cdc.gov/aging/healthybrain/Indian-Country-resources.html</a></li> <li><a href="https://www.cdc.gov/aging/data/index.htm">https://www.cdc.gov/aging/data/index.htm</a></li> <li><a href="https://www.cdc.gov/aging/publications/briefs.htm">https://www.cdc.gov/aging/publications/briefs.htm</a></li> </ul>

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2018 and 2019
<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.	Contribute to international dementia activities.	ASPE		Updated	The United States participated in the WHO's GDO in 2019. <ul style="list-style-type: none"> <li><a href="https://www.who.int/mental_health/neurology/dementia/Global_Observatory/en/">https://www.who.int/mental_health/neurology/dementia/Global_Observatory/en/</a></li> </ul>
<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.
5.A.3	Summarize data on cognitive impairment across states.	Report on BRFSS and NHANES data on cognitive decline and caregiving.	CDC		Updated	<p>CDC worked with partners and revised the BRFSS Cognitive Decline and Caregiver 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 Caregiver Module. Additional states collected data using the Cognitive Decline and Caregiver 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 the 2017 BRFSS were released in late 2018 and national infographics with aggregated 2015-2017 data were developed for both the Cognitive Decline and Caregiver Modules. Additionally, state-specific infographics with the most recent year of data for both modules was released.</p> <p><i>State of Aging and Health in America: Data Brief Series</i>, developed by CDC in collaboration with NACDD, are topic-specific documents focusing on public health issues related to older adults. These briefs provide public health professionals with the most recent data available on health and aging-related conditions, including the importance of brain health, the management of chronic conditions, and caregiving burdens, to help identify needs and mitigate the future effects of a growing older population. The briefs also provide data by important breakdowns such as by state, age, gender, and ethnicity which can be useful for states and other stakeholders in making informed decisions and policies related to these issues.</p>



Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2018 and 2019
5.A.3 (continued)						<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/publications/briefs.htm">https://www.cdc.gov/aging/publications/briefs.htm</a></li> <li>• <a href="https://www.cdc.gov/aging/data/index.htm">https://www.cdc.gov/aging/data/index.htm</a></li> <li>• <a href="https://www.cdc.gov/aging/healthybrain/surveillance.htm">https://www.cdc.gov/aging/healthybrain/surveillance.htm</a></li> <li>• <a href="https://www.cdc.gov/aging/data/index.htm">https://www.cdc.gov/aging/data/index.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. Results from these tests were released by CDC in September 2019. Additionally, CDC is supporting cognitive testing utilizing the MoCA in additional years of NHANES data collection for both 2019-2020 and 2021-2022 data collection cycles.</p> <ul style="list-style-type: none"> <li>• <a href="https://www.cdc.gov/nchs/data/nhsr/nhsr126-508.pdf">https://www.cdc.gov/nchs/data/nhsr/nhsr126-508.pdf</a></li> <li>• <a href="http://www.cdc.gov/nhanes">http://www.cdc.gov/nhanes</a></li> </ul> <p>Cognitive Functioning (CFQ_H 2013-2014)</p> <ul style="list-style-type: none"> <li>• <a href="https://www.cdc.gov/Nchs/Nhanes/2013-2014/CFQ_H.htm">https://www.cdc.gov/Nchs/Nhanes/2013-2014/CFQ_H.htm</a></li> </ul> <p>Cognitive Functioning (CFQ_G 2011-2012)</p> <ul style="list-style-type: none"> <li>• <a href="https://www.cdc.gov/Nchs/Nhanes/2011-2012/CFQ_G.htm">https://www.cdc.gov/Nchs/Nhanes/2011-2012/CFQ_G.htm</a></li> </ul>
5.A.4	Develop and disseminate measures of awareness of AD/ADRD.	Release report on validated survey questions.	CDC		Updated  Report expected late 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 in collaboration with NCHS.</p> <ul style="list-style-type: none"> <li>• <a href="https://www.cdc.gov/nchs/data/nhsr/nhsr126-508.pdf">https://www.cdc.gov/nchs/data/nhsr/nhsr126-508.pdf</a></li> </ul>

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2018 and 2019
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	Updated	<p>CDC's AD and 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.</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> </ul> <p>2015-2017 BRFSS data, includes data on cognitive decline from 49 states, D.C., and Puerto Rico and data on caregivers from 44 states, 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.</p>
5.A.6	Provide analysis of BRFSS data on AD/ADRD and their caregivers in user-friendly formats.	Data analysis and material development.	CDC	NACDD	New	<p>CDC partnered with NACDD to create a series of data briefs addressing topic-specific public health issues related to older adults. 2 of these data briefs include <i>Caregiving for Family and Friends</i> and <i>Subjective Cognitive Decline</i>. Each brief includes the most recent and relevant data available, including the importance of brain health, the management of chronic conditions and other age-related conditions. Each brief concludes with action items that give specific direction on actions that can be taken to make positive change.</p> <ul style="list-style-type: none"> <li>• <a href="https://www.cdc.gov/aging/agingdata/data-portal/state-aging-health.html">https://www.cdc.gov/aging/agingdata/data-portal/state-aging-health.html</a></li> <li>• <a href="https://www.cdc.gov/aging/agingdata/index.html">https://www.cdc.gov/aging/agingdata/index.html</a></li> <li>• <a href="https://www.cdc.gov/aging/publications/briefs.htm">https://www.cdc.gov/aging/publications/briefs.htm</a></li> </ul>
<b>Strategy 5.B: Monitor Progress on the National Plan</b>						
5.B.1	Track National 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.
5.B.3	Identify key indicators of progress on the National Plan	Convene federal and non-federal partners	ASPE		New	This work will begin in late 2019.

---

## References

1. Hebert LE, Weuve J, Scherr PA, Evans DA. "Alzheimer's Disease in the United States (2010-2050) Estimated Using the 2010 Census." *Neurol*, 2013; 80:1778-1783.
  2. Burns A, Iliffe S. "Alzheimer's Disease." *BMJ*, 2009; 338:b158.
  3. Alzheimer's Disease Education and Referral (ADEAR) Center. Alzheimer's Disease Fact Sheet. U.S. Department of Health and Human Services, National Institutes of Health. NIH Publication No. 11-6423. July 2011.
  4. National Institute on Aging. 2009 Progress Report on Alzheimer's Disease: Translating New Knowledge. U.S. Department of Health and Human Services, National Institutes of Health. NIH Publication No. 10-7500. November 2010.
  5. Alzheimer's Disease Education and Referral (ADEAR) Center. Alzheimer's Disease Fact Sheet. U.S. Department of Health and Human Services, National Institutes of Health. NIH Publication No. 11-6423. July 2011.
  6. National Institute on Aging. 2009 Progress Report on Alzheimer's Disease: Translating New Knowledge. U.S. Department of Health and Human Services, National Institutes of Health. NIH Publication No. 10-7500. November 2010.
  7. Mahoney R, Regan C, Katona C, Livingston G. "Anxiety and Depression in Family Caregivers of People with Alzheimer's Disease: The LASER-AD Study." *J Am Geriatr Soc*, 2005; 13(9):795-801.
  8. Hurd M, Martorell P, Delavande A, Mullen K, Langa K. "Monetary Costs of Dementia in the United States." *N Engl J Med*, 2013; 368:1326-1334. <http://www.nejm.org/toc/nejm/368/14/>.
  9. Maslow K. "How Many Hospital Patients Have Dementia?" In Silverstein N and Maslow K, eds. *Improving Hospital Care for People with Dementia*. New York, NY: Springer; 2006.
  10. Magaziner J, et al. "The Prevalence of Dementia in a Statewide Sample of New Nursing Home Admissions Aged 65 and Older." *Gerontol*, 2000; 43(4):514-520.
  11. Yaffe K, Fox P, Newcomer R, Sands L, Lindquist K, et al. "Patient and Caregiver Characteristics and Nursing Home Placement in Patients with Dementia." *JAMA*, 2002; 287:2090-2094.
  12. Favreault, M., Urban Institute, ASPE Report, "Long-Term Services and Supports for Older Americans: Risks and Financing Research Brief," February 2016. <https://aspe.hhs.gov/basic-report/long-term-services-and-supports-older-americans-risks-and-financing-research-brief>.
  13. Taylor DH, Ezell M, Kuchibhatia M, Ostbye T, Clipp EC. "Identifying the Trajectories of Depressive Symptoms for Women Caring for Their Husbands with Dementia." *J Am Geriatr Soc*, 2008; 56(2):322-327.
-

## List of Acronyms Used

AAA	Area Agency on Aging
AAIC	Alzheimer's Association International Conference
ABA	American Bar Association
ACL	Administration for Community Living
ACP	Advance Care Planning
ACTC	Alzheimer's Clinical Trials Consortium
ACTC-DSN	Alzheimer's Clinical Trials Consortium -- Down Syndrome Network
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
ADORE	Alzheimer's and Dementia Outreach, Recruitment, and Engagement
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
AI/AN	American Indian and Alaska Native
AMP	Accelerating Medicines Partnership
AMP-AD	Accelerating Medicines Partnership -- Alzheimer's Disease
AoA	Administration on Aging
APOE	Apolipoprotein E
APS	Adult Protective Services
ASPE	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
CDMRP	Congressionally Directed Medical Research Program
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
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
DYNASIM	DYNAmic Simulation of Income Model
EDSD	Early Detection Screen for Dementia
EES	Employee Education System
EHR	Electronic Health Record
eLTSS	Electronic Long-Term Services and Supports
EU	European Union
FDA	Food and Drug Administration
FHIR	Fast Healthcare Interoperability Resources
FID	Facility-initiated Involuntary Discharge
FOA	Funding Opportunity Announcement
FTD	Frontotemporal Dementia
FY	Fiscal Year
GACA	Geriatrics Academic Career Award
GDO	Global Dementia Observatory
GWEP	Geriatrics Workforce Enhancement Program
HBI	Healthy Brain Initiative
HBRN	Healthy Brain Research Network
HCAP	Harmonized Cognitive Assessment Protocol
HCBS	Home and Community-Based Services
HCIA	Health Care Innovation Award
HHS	U.S. Department of Health and Human Services
HIT	Health Information Technology
HL7	Health Level 7
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
IDD	Intellectual and Developmental Disability
IHS	Indian Health Service
InCASA	Innovations in Care and Support Award
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
MCI	Mild Cognitive Impairment
MHPAEA	Mental Health Parity and Addiction Equity Act
MIPS	Merit-based Incentives Payment System
MLTSS	Managed Long-Term Services and Supports
MOC	Maintenance Of Certification
MoCA	Montreal Cognitive Assessment

---

---

NACDD	National Association of Chronic Disease Directors
NADRC	National Alzheimer's and Dementia Resource Center
NAPA	National Alzheimer's Project Act
NASEM	National Academies 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
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
NICHD	National Institute of Child Health and Human Development
NIH	National Institutes of Health
NIMHD	National Institute of 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
NRC-SDM	National Resource Center for Supported Decision-Making
NTG	National Task Group on Intellectual Disabilities and Dementia Practices
OASH	Office of the Assistant Secretary for Health
OMB	Office of Management and Budget
ONC	Office of the National Coordinator for Health Information Technology
OPM	Office of Personnel Management
OWH	Office on Women's Health
PAC	Post-Acute Care
PET	Positron Emission Tomography
PM	Precision Medicine
PPS	Prospective Payment Systems
PRARP	Peer Reviewed Alzheimer's Research Program
Project ECHO	Extension for Community Healthcare Outcomes Project
PTSD	Post-Traumatic Stress Disorder
PWD	Persons With Dementia
QIO	Quality Improvement Organization
REACH	Resources for Enhancing Alzheimer's Caregivers' Health
REGARDS	Reasons for Geographic and Racial Differences in Stroke
RFA	Request For Application
RITT	Rural Interdisciplinary Team Training
ROAR	Recruiting Older Adults into Research
RPA	Research Partnership Award
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
SPRINT	Systolic Blood Pressure Intervention Trial
SPRINT-MIND	Systolic Blood Pressure Intervention Trial -- Memory and cognition IN Decreased hypertension
TBI	Traumatic Brain Injury

---

---

VA	U.S. Department of Veterans Affairs
VCID	Vascular contributions to Cognitive Impairment and Dementia
VHA	Veterans Health Administration
WHO	World Health Organization

---



