# National Plan to Address Alzheimer's Disease: 2016 Update

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# National Plan to Address Alzheimer's Disease: 2015 Update

U.S. Department of Health and Human Services

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# Introduction

## Vision Statement

For millions of Americans, the heartbreak of watching a loved one struggle with Alzheimer's disease is a pain they know all too well. Alzheimer's disease burdens an increasing number of our Nation's elders and their families, and it is essential that we confront the challenge it poses to our public health.

-- President Barack Obama

## National Alzheimer's Project Act

On January 4, 2011, President Barack Obama signed into law the National Alzheimer's Project Act (NAPA) (Public Law 111-375), requiring 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 ethnic and racial minority populations that are at higher risk for Alzheimer's disease.
- 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 Alzheimer's disease and related dementias (ADRD).

NAPA offers a historic opportunity to address the many challenges facing people with Alzheimer's disease 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 ADRD and their family members, 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 5.1 million Americans.[1] 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).[2] 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 (amyloidal plaques) and tangled bundles of fibers (neurofibrillary tangles). Brain plaques and tangles, in addition to the loss of connections between neurons, are the main features of AD.[3]

In addition to Alzheimer's disease, this National Plan addresses related dementias, consistent with the approach Congress used in NAPA. Related dementias include frontotemporal dementia (FTD), Lewy body, mixed, and vascular dementias. It is often difficult to distinguish between ADRD in terms of clinical presentation and diagnosis. Some of the basic neurodegenerative processes have common pathways.

People with dementia and their families face similar challenges in finding appropriate and necessary medical and supportive care. As such, many of the actions described in this plan are designed to address these conditions collectively.

The first symptom of Alzheimer's disease, and sometimes ADRD, is often memory impairment. However, in ADRD, behavioral, visual, 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 and ADRD are completely reliant on others for assistance with even the most basic ADLs, such as eating.[4,5]

In more than 90% of people with ADRD, symptoms do not appear until after age 60, and the incidence of the disease increases with age. The causes of ADRD are not completely understood, but researchers believe they include a combination of genetic, environmental, and lifestyle factors.[6] The importance of any one of these factors in increasing or decreasing the risk of developing Alzheimer's disease may differ from person to person. In rare cases, known as early or younger-onset AD, people develop symptoms of AD 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.

ADRD is a major public health issue and will increasingly affect the health and well-being of the population. Unless the disease can be effectively treated or prevented, the number of Americans with Alzheimer's disease will increase significantly in the next two decades. The number of people age 65 and older in the United States is expected to grow from an estimated 47.8 million in 2015 to 74.1 million in 2030. The prevalence of people with ADRD doubles for every 5-year interval beyond age 65. Without a preventative treatment or cure, the significant growth in the population over age 85 that is estimated to occur between 2015 and 2030 (from 6.3 million to 9.1 million) suggests a substantial increase in the number of people with AD.

The disease places enormous emotional, physical, and financial stress on individuals who have it and their family members. Unpaid caregivers, such as family members and friends, provide the majority of care for people with ADRD in the community. Unpaid caregivers often do not identify themselves as such; they are a wife, daughter, husband, parent, son, or friend helping a person whom they care about. However, the intensive support required for a person with 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.[7]

Dementia care costs are significant and often a burden to families providing unpaid care. Recent estimates from one nationally representative study found that paid and unpaid care costs of caring 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 community care, and the 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 $41,000 to $56,000 depending on how unpaid care costs were estimated. These national dementia care costs are comparable to, if not greater than, those for heart disease and cancer.[8]

Caring for people with the disease also strains health and long-term care systems. Individuals with ADRD use a disproportionate amount of health care resources; for instance, they are hospitalized 2-3 times as often as people the same age who do not have the disease.[9] Similarly, while people living in nursing homes are a small percentage of the older population, nearly half (48%) of nursing home residents have ADRD.[10] As the number of people with ADRD grows over the next two decades, this disease will place a major strain on these care systems as well as on Medicare and Medicaid, the major funders of this care. Although Medicaid, a program for eligible low income Americans, covers long-term care services (custodial care), Medicare does not.

## The Challenges

This National Plan is designed to address the major challenges presented by Alzheimer's disease:

1. While research on ADRD has made steady progress, there are no pharmacological or other interventions to definitively prevent, treat, or cure the disease.

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 -- 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 ADRD, need services and support. The majority of people with ADRD 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.[11,12]

4. Stigmas and misconceptions associated with ADRD are widespread and profoundly impact the care provided to and the isolation felt by people with ADRD and their families.

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 ADRD are limited.

## Framework and Guiding Principles

The enactment of NAPA creates an opportunity to focus the Nation's attention on the challenges of ADRD. 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 ADRD.

Central to and guiding the National Plan are the people most intimately impacted by ADRD -- those who have the disease and their families and other caregivers. Individuals with ADRD and their caregivers receive assistance from both the clinical health care system and long-term care including home and community-based services (HCBS), legal services, and other social services. Both the clinical care and community/support environments need better tools to serve people with ADRD and their unpaid caregivers. Ongoing and future research seeks to identify interventions to assist clinicians, supportive service providers, HCBS providers, persons with ADRD, and caregivers. All of these efforts must occur in the context of improved awareness of the disease 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 is also 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 Alzheimer's disease. 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 ADRD. The activities included in the inventory comprise ongoing work and new opportunities created by the Affordable Care Act. 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 care. [The inventory is available at http://aspe.hhs.gov/daltcp/napa/NatlPlan.shtml#append3.]

2. ***Support Public-Private Partnerships***. The scope of the problem of ADRD is so great that partnerships with a multitude of public and private stakeholders will be essential to making progress. This National Plan begins the partnership process by identifying areas of need and opportunity. The plan relies on the Advisory Council in particular to identify key areas where public-private partnerships can improve outcomes.

3. ***Transform the Way We Approach ADRD***. The National Plan recognizes that this undertaking that will require 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 is committing to through this plan, HHS and its federal partners seek to take the first of many transformative actions that will be needed to address this disease. Through an ongoing dialogue with the Advisory Council, the Federal Government is identifying the most promising areas for progress and marshalling 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 ADRD starts with concrete goals. Below are the five that form the foundation of this National Plan:

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

## 2015 Update

This is the 2015 Update to the National Plan. In order to create a more focused and accessible document, agencies have provided narrative descriptions of those activities that were completed in 2014, as well as some which are ongoing and have important updates. This is an attempt to provide a clear report of progress that was made since the last plan update in April 2014. For more information about ongoing or previously completed projects, please consult Appendix 2: Implementation Milestones.

The activities outlined in this National Plan vary in scope and impact, and include: (1) immediate actions that the Federal Government has taken and will take; (2) actions toward the goals that can be initiated by the Federal Government or its public and private partners in the near term; and (3) longer-range activities that will require numerous actions to achieve. This is a national plan and not a federal plan. Active engagement of public and private sector stakeholders is needed to achieve these national goals. In the case of many of the long-range activities, the path forward will be contingent upon resources, scientific progress, and focused collaborations across many partners. Over time, HHS will work with the Advisory Council and stakeholders to incorporate and update additional transformative actions.

# Goal 1: Prevent and Effectively Treat Alzheimer's Disease by 2025

Research continues to expand our understanding of the causes of, treatments for, and prevention of Alzheimer's disease. 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, 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 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.

In 2014/2015, Goal 1 of the National Plan moved forward with expanded and innovative research initiatives, with a focus on intensified translational studies in target identification and drug discovery, and the start of major new trials to test therapies as early as possible in the disease process. Investigator-initiated research remains the mainstay of National Institutes of Health (NIH)-funded efforts to learn more about ADRD, including studies to uncover their molecular, cellular and genetic causes.

At the same time, the national conversation to regularly re-examine and update research priorities included more diverse voices, beyond the research community and advocates to directly engaging people with ADRD and clinicians. All these efforts were supported with enhanced collaboration among governments and with the private sector to leverage research opportunities and further accelerate the pace of progress.

The NIH is supporting research across many diverse topics in ADRD. The section below offers several examples of recent progress; however the NIH will continue to invest in high-priority research areas, as identified through the 2012 and 2015 Alzheimer's Disease Research Summits, the 2013 Alzheimer's Disease-Related Dementias, and the 2013 Advancing Treatment for Alzheimer's Disease in Individuals with Down Syndrome, among other strategic planning efforts.

These efforts, as well as other research plans and activities in ADRD, will be considered as the NIH develops an annual bypass budget estimate for the President and Congress, as mandated in Section 230, Division G of the Consolidated and Further Continuing Appropriations Act, 2015. Per the Act's language, the Secretary of HHS, as well as the Advisory Council, may review and comment on, but not alter, the NIH bypass budget submission. Each annual bypass budget will be estimated based on the NIH components of the most recent update to the National Plan. This process will include activities relevant to Goal 1, as well as other Goals outlined in the National Plan. **The National Institute on Aging (NIA) published the Summit recommendations on May 1, 2015, at**: http://www.nia.nih.gov/research/recommendations-nih-ad-research-summit-2015. **The first Alzheimer's disease bypass budget, for FY2017, is anticipated to be released in the summer of 2015**.

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

***2015 Alzheimer's Disease Research Summit Advances Research Agenda***. The *Alzheimer's Disease Research Summit 2012: Path to Treatment and Prevention*, held in May 2012, produced recommendations that influenced the direction of research for several years. Building on those advances and seeking the best strategies toward meeting the research goals of the National Plan, NIH convened the *Alzheimer's Disease Research Summit 2015: Path to Treatment and Prevention* on February 9-10, 2015. More than 1,000 leading national and international researchers and clinicians, advocates and caregivers attended in person or via webcast. Among the recommendations -- developing new research models and public-private collaborations aimed at identifying and speeding up the delivery of promising therapeutic targets and inclusion of people with ADRD in the leadership of research, particularly in the design and conduct of clinical trials. The recommendations will also include health disparities as an important area of focus. NIA published the Summit recommendations in May 2015. [See

http://www.nia.nih.gov/about/events/2012/alzheimers-disease-research-summit-2012-path-treatment-and-prevention for recommendations; videocast available http://www.nia.nih.gov/about/events/2014/alzheimers-disease-research-summit-2015.]

***Research Conferences on Alzheimer's Disease and Related Dementias***. On May 1-2, 2013, the National Institute of Neurological Disorders and Stroke (NINDS), along with NIA, held the *Alzheimer's Disease-Related Dementias: Research Challenges and Opportunities (ADRD 2013) Summit*, bringing together an international group of experts and members of the public to develop research priorities for accelerating the development of therapies for FTD, Lewy body, mixed and vascular dementias. NINDS will convene the second ADRD Summit on March 29-30, 2016 to assess progress and revise and update the ADRD 2013 recommendations, which will be posted on the NAPA website later this year. In 2014, NINDS held two additional workshops that addressed topics related to the priorities identified at the ADRD 2013 Summit. At the Small Blood Vessels, Big Health Problems workshop, an interdisciplinary group of researchers addressed issues related to small blood vessels in the brain and other organ systems, which will inform research on the underlying causes of the vascular contribution to dementia. The *Advances in ALS (Amyotrophic Lateral Sclerosis) and FTD (Frontotemporal Dementia) Genetics* workshop brought together researchers and clinicians to facilitate collaboration and advance genetic research on these diseases. [See http://www.ninds.nih.gov/ADRD2013, https://meetings.ninds.nih.gov/Home/Index/8225, and https://meetings.ninds.nih.gov/Home/Index/9159.]

***New Recommendations Move Down Syndrome Research Forward***. Alzheimer's disease is quite common in people with Down syndrome, occurring 3-5 times more often than in the general population. To better understand why, in 2013 NIH supported the *Advancing Treatments for Alzheimer's Disease in Individuals with Down Syndrome* workshop. Research recommendations from the workshop included developing animal models of Down syndrome and AD to better predict response to therapies, sharing existing data, and developing new data sets that follow study participants with Down syndrome as they age; these objectives are included in the *2014 NIH Down Syndrome Research Plan*. Many of the workshop participants will join other subject experts at a May 2015 meeting to further this research agenda. Additionally in 2014, NIH issued a Request for Applications (RFA) to better understand the risk factors and biomarkers associated with development of AD in adults with Down syndrome; these awards will be announced in the summer of 2015. [See https://www.nichd.nih.gov/publications/pubs/Documents/DSResearchPlan_2014.pdf, and http://grants.nih.gov/grants/guide/rfa-files/RFA-AG-15-011.html.]

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

***Research Advances Enabled by Additional Funding***. Alzheimer's disease research in the United States has benefited from the provision of additional funds over the past several years. In FY2012, as part of a Presidential initiative, Dr. Francis Collins, Director of NIH, redirected $50 million to expand AD research, and in FY2013, he provided $40 million for this purpose from unallocated funds in the NIH budget. Additional increases in annual federal appropriations to NIH of $100 million in FY2014 and $25 million in FY2015 were provided with the expectation that a significant portion of these increases would be directed towards AD research. Spending at the NIH on AD research increased 25% from FY2011 through FY2014. Those funds contributed significantly to the initiatives and studies undertaken during those years to meet the goals of the National Plan, including several cited in this 2015 National Plan Update.

***Expanding Basic Understanding of Alzheimer's Disease***. Investigator-initiated research reported in 2014 offered new insights into the complex molecular, biological and genetic factors that influence disease onset and progression.

Abnormal tau can travel across synapses from one neuron to another, but why neurons release toxic tau was unclear. An NIA-funded animal *study* showed that neurons release tau when they become overactive. This discovery provides further insight into how tau pathology propagates through the brain, and could help in the development of therapies targeting abnormal tau. [See http://www.ncbi.nlm.nih.gov/pubmed/24534188.]

One of the first studies to link epigenomic changes -- the chemical modifications on our DNA that turn gene activity on and off -- to Alzheimer's disease found DNA methylation changes may play a role in disease onset. The finding advances understanding of how a person's life experience, diet, and other environmental influences may interact with their DNA to influence risk of AD. [See http://www.ncbi.nlm.nih.gov/pubmed/25129075.]

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***Collaborating on Drug Targets***. *Accelerating Medicines Partnership - Alzheimer's Disease (AMP-AD)* is part of the Accelerating Medicines Partnership (AMP), a bold new venture among the NIH, ten biopharmaceutical companies, and several non-profit organizations aiming to identify and validate the most promising biological targets of disease for new diagnostic and drug development. In early 2015, the *AMP-AD Target Discovery and Preclinical Validation Project* launched a data portal with innovative analytical tools to the wider research community to shorten the time between the discovery of potential drug targets and the development of new drugs. [See http://www.nia.nih.gov/alzheimers/amp-ad, and http://www.nia.nih.gov/alzheimers/amp-ad-target-discovery-and-preclinical-validation-project.]

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***Identifying Genetic Risk and Prevention Factors***. NIH funds cutting-edge research into the genetic underpinnings of ADRD, analyzing how genome sequences -- the order of nucleotides in a cell's DNA -- may contribute to increased risk or protect against the disease. The ultimate goal is to find new pathways for treatments and prevention.

In 2014, NIH awarded an estimated $24 million over 4 years to investigators using innovative new technologies and computational methods to analyze the genome sequencing data generated during the first phase of the *Alzheimer's Disease Sequencing Project (ADSP)*. The first phase of ADSP determined the order of all 3 billion nucleotides in the individual genomes of 580 participants. It also generated whole exome sequencing data (focused on the proteins influencing the disorder) of an additional 11,000 volunteers -- 6,000 with AD compared to 5,000 controls. [See https://www.niagads.org/adsp/content/home.]

As part of an international collaboration to understand the genetic causes of ADRDs, NIH intramural researchers are using whole exome sequencing of 1,500 people with FTD and 1,300 people with dementia with Lewy bodies to characterize regions of DNA that are associated with a risk of developing these diseases.

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***Promising Drugs to Treat or Prevent Alzheimer's Disease***. Currently more than 40 NIA-supported clinical trials for AD treatment and prevention are underway. In addition, NIH supports over 70 projects aiming to discover and develop new therapeutics for AD. For example, the *Study of Nasal Insulin to Fight Forgetfulness (SNIFF)* trial is evaluating whether a type of insulin, when administered as a nasal spray, improves memory in adults with mild memory impairment or AD. [See http://adcs.org/Studies/SNIFF.aspx.]

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***Testing Therapies at Earliest Stages of Alzheimer's Disease***. Several NIA-supported clinical trials are testing new paradigms about when the disease starts and if intervening in symptom-free but at-risk people in the earliest stages of the disease might forestall symptoms and delay progression. In 2014, recruitment began for the *Anti-Amyloid Treatment in Asymptomatic Alzheimer's (A4)* trial, which is testing

the drug solanezumab in 1,000 cognitively normal volunteers, age 65-85, who through imaging have been shown to have enough of the amyloid protein in the brain to put them at-risk for developing AD, but do not show clinical symptoms of the disease. [See http://adcs.org/Studies/A4.aspx.]

***Exercise and Alzheimer's Disease Prevention***. NIH is studying whether lifestyle interventions, such as diet, exercise, and cognitive enrichment, may be preventive interventions for cognitive decline and AD. For example, one clinical trial is currently testing the impact of a 52-week aerobic exercise program on levels of amyloid in the brains of volunteers, and how this is associated with brain atrophy and cognitive decline. The goal is to see if exercise can prevent AD-related changes in brain function and structure. [See http://projectreporter.nih.gov/project_info_description.cfm?aid=8600741&icde=18372319&ddparam=&ddvalue=&ddsub=&cr=1&csb=default&cs=ASC.]

***Discovering the Molecular, Cellular, and Genetic Causes of Alzheimer's Disease and Related Dementias***. NIH funds a broad range of research to understand the underlying causes of dementia, which is an important first step for developing new treatments and prevention strategies. For example, NIH-funded researchers are conducting studies to understand the complex interactions between amyloid, tau, and blood vessels and how these interactions contribute to dementia, investigating the mechanisms by which mutations in genes linked to FTD cause disease, and using sophisticated brain imaging to determine whether there are structural differences in the brains of people with Parkinson's disease dementia (a form of Lewy body dementia). NIA and NINDS are also collaborating on an initiative soliciting interdisciplinary research on the mechanisms by which vascular factors contribute to dementia. [See http://grants.nih.gov/grants/guide/rfa-files/RFA-AG-15-010.html.]

***Networking to Promote Recruitment***. NIH/NIA-funded *Resource Centers for Minority Aging Research* and *Alzheimer's Disease Research Centers* held a joint meeting on outreach and education at the Gerontological Society of America (GSA) annual scientific meeting in 2014 that focused on ways to improve recruitment and retention methods used to encourage volunteers from diverse racial and ethnic groups to participate in AD research studies. [See http://www.rcmar.ucla.edu/, and http://www.nia.nih.gov/alzheimers/alzheimers-disease-research-centers.]

***ROAR Supports Recruitment***. Research cannot be conducted without the volunteers and their caregivers who make clinical trials possible. It is estimated that some 70,000 volunteers with Alzheimer's disease, mild cognitive impairment (MCI), or normal cognition are needed for clinical trials and studies; researchers will need to screen at least half a million potential volunteers to reach this goal. To address this need, the NIA, Administration for Community Living (ACL) and the Centers for Disease Control and Prevention (CDC) collaborate on Recruiting Older Adults into Research (ROAR), a program to promote older adult research participation through outreach and messaging at the national, state, and local levels.

In 2014, the ROAR team developed, tested, and refined a toolkit of customizable materials for aging services and public health professionals to use in community settings and social media to spread a message about healthy aging and research participation. A key strategy is to offer easy, actionable opportunities for volunteering through existing research matching services and registries, including NIH's ResearchMatch, the Alzheimer's Association's TrialMatch, and the Alzheimer's Prevention Registry. ROAR activities also have resulted in a number of new collaborations at the local and state levels. [See http://www.nia.nih.gov/health/publication/roar-toolkit.]

## Strategy 1.C: Accelerate Efforts to Identify Early and Presymptomatic Stages of Alzheimer's Disease

***Collaborating on Biomarker Research***. One of the primary goals of the previously-noted *AMP* is to identify and characterize biomarkers and targets for intervention. The *AMP-AD Biomarkers Project* is a consortium of three NIA-supported Phase II/III secondary prevention trials testing several anti-amyloid therapies. Imaging and fluid biomarker panels already included in these trials will be supplemented with tau PET imaging and novel fluid biomarkers. [See http://www.nih.gov/science/amp/index.htm, and http://www.nia.nih.gov/alzheimers/amp-ad-biomarkers-project.]

***Tracking Biomarker Trajectories Over Time***. NIH-supported researchers continue to develop and refine biomarkers -- brain imaging and tests of blood and other body fluids -- as well as non-invasive measures to detect the onset and progression of Alzheimer's disease. In 2014, a *study* of volunteers with the rare, familial early-onset form of AD participating in the NIA-supported Dominantly Inherited Alzheimer's Network (DIAN) showed how cerebrospinal fluid (CSF) biomarkers changed as the disease progressed. The results suggest that neuronal death slows down during the later stages of AD, and that the use of neuronal death markers should be used with caution in tracking disease progression in clinical trials. [See http://www.ncbi.nlm.nih.gov/pubmed/24598588.]

***Discovering Biomarkers for Alzheimer's Disease and Related Dementias***. NINDS-funded researchers are creating a biomarker-based tool for predicting significant cognitive decline in people with Parkinson's disease, and are working to enhance brain imaging techniques to make it possible to detect the earliest changes in the blood brain barrier, which may be an early sign of cognitive impairment and dementia. NIH is funding several large, collaborative projects on FTD that seek to improve diagnosis, identify preventive strategies and provide new insights into the genetics underlying this complex disorder. One component of these projects is to identify biomarkers that signal the onset and progression of FTD. [See http://www.ninds.nih.gov/research/parkinsonsweb/udall_centers/centers/upenn_new.htm, http://www.ncbi.nlm.nih.gov/pubmed/25611508, and http://www.ninds.nih.gov/news_and_events/news_articles/pressrelease_FTD_grant_10232014.htm.]

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

***Planning Efforts Expand Reach***. The *International Alzheimer's Disease Research Portfolio (IADRP)* -- a free, searchable database providing a global overview of AD research and funding -- is an invaluable tool for assessing and planning AD 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. [See http://www.nia.nih.gov/research/dn/international-alzheimers-disease-research-portfolio.]

Since its 2012 launch by NIA, in collaboration with the Alzheimer's Association, IADRP has amassed data on more than 5,800 unique projects from 2008 through 2014, reflecting more than $3.8 billion in research funding worldwide. The number of contributors is growing, too. During the past 3 years, 31 funding organizations have joined the IADRP effort. The Alzheimer's Association and NIA co-hosted a funders meeting at the Alzheimer's Association International Conference in July 2014, as well as convened representatives of several funding organizations around the world for regular teleconferences, to invite contributions to IADRP and to further ties among international research funders.

***World Dementia Research Leaders Hosted by NIH***. The NIA convened a research-specific meeting of 50 dementia leaders February 11, 2015 at NIH in Bethesda. National health experts, including NIH Director Dr. Francis Collins, from the G7 countries -- the United States, Canada, United Kingdom, France, Germany, Italy, and Japan -- shared their recent progress in dementia research and care, and discussed research spending, clinical research strategies, and critical areas for future collaborations.

***Efforts Intensify to Establish Global Goals for Dementia Research and Care***. The HHS Deputy Assistant Secretary for Planning and Evaluation Dr. Linda Elam and NIA Director Dr. Richard J. Hodes joined health ministers, leading scientists, and advocates from around the world March 16-17, 2015 in Geneva, Switzerland, to advance planning on dementia research and care on a global scale. The agenda at the *Ministerial Conference on Global Action Against Dementia*, hosted by the World Health Organization (WHO), reflected shared goals that are gaining momentum worldwide: to raise awareness of dementia's socioeconomic impact, and discuss ways to advance scientific research, foster the availability of new treatments and improved care, and finding ways to reduce the risk of neurodegenerative disorders. [See http://www.who.int/mental_health/neurology/dementia/en/.]

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

***Reporting Research Findings***. NIA's *Alzheimer's Disease Education and Referral (ADEAR)* Center, the primary Federal Government resource for information about ADRD, research, and caregiving, develops materials for health and long-term care providers and the public based on the latest research findings. The ADEAR Center regularly publishes *Connections*, an update focused on research advances and new practices in caring for people with AD. [See http://www.nia.nih.gov/alzheimers.]

***Resources for the Aging, Disability, Public Health, and Research Networks***. ACL continues its collaboration with NIA and CDC on educating these networks about the latest brain health and dementia research findings and resources available. These networks use the Brain Health Resource they developed jointly to educate the public. Periodically, this Resource is updated and enhanced. [See http://www.acl.gov/Get_Help/BrainHealth/Index.aspx.]

***Resources for Clinicians***. In 2014, the NIA ADEAR Center, in collaboration with clinicians at Alzheimer's Disease Centers (ADCs), developed and is disseminating a brief for clinicians: *Assessing Cognitive Impairment in Older Patients: A Quick Guide for Primary Care Physicians*, summarizing current guidelines and recommendations for clinical practice. [See http://www.nia.nih.gov/alzheimers/publication/assessing-cognitive-impairment-older-patients, and http://www.nia.nih.gov/alzheimers/announcements/2014/11/nia-guide-primary-care-doctors-assessing-cognitive-impairment.]

***Resources for the Dementia Services Community***. Since 2012, the NIA and ACL have co-hosted an annual webinar series on ADRD to educate professionals and improve coordination of federal resources between the research and aging services communities. In 2014, CDC joined as a sponsor and continuing education credits were made available for participants. In 2014, a key focus of the series was how to forge successful community collaborations serving people with ADRD, as well as updates on resources and research. Free continuing education is available through 2016 to professionals who need it when they view recorded webinars. [See http://www.aoa.acl.gov/AoA_Programs/HPW/Alz_Grants/index.aspx#resources.]

***U.S. Department of Defense (DoD) Work on Alzheimer's Disease***. Since 2011, the DoD Peer Reviewed Alzheimer's Research Program (PRARP) has been devoted to understanding the association between Traumatic Brain Injury (TBI) and AD. Equally important, the program also focuses on reducing the burden on caregivers and individuals living with the common symptoms of TBI and AD, especially in the military community. Funding of $12 million was executed by September 30, 2014. For FY2013, 37 pre-proposals were received for the *Convergence Science Research Awards* and *Military Risk Factor Awards*. A total of eight awards were made, bringing the number of funded projects to 29. Using the Common Alzheimer's Disease Research Ontology (CADRO) criteria, FY2013 funding was distributed among the following categories:

- **Category A**: Molecular Pathogenesis and Pathophysiology of Alzheimer's Disease (4 Projects).
- **Category B**: Diagnosis, Assessment and Disease Monitoring (3 Projects).
- **Category D**: Epidemiology (1 Projects).

In the period from October 1, 2014 to March 12, 2015, three Program Announcements were released to fund research in basic and translational sciences. FY2015 funding was $12 million. The announcements asked scientists to address one of five overarching research challenges (Paucity of Research Resources; Paucity of Clinical Studies; Need for Diagnostic Technologies, Tests, Interventions, or Devices; Quality of Life; or Caregiver Burden). Awards will be made by no later than September 30, 2015.

During the April 31, 2014 to March 1, 2015 annual reporting period, one patent was applied for and 14 publications were produced. The PRARP continues partnerships across the DoD, U.S. Department of Veterans Affairs (VA), and other governmental agencies by having their staff provide guidance to the PRARP as participants at the program's regular meetings.

# Goal 2: Enhance Care Quality and Efficiency

Providing all people with 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 HCBS providers, 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. Person-centered quality should be measured accurately and inter-operably across all settings of care, coupled with quality improvement tools. Further, care should address the complex care needs that persons with 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

***Person-Centered Counseling Training Program***. HHS has shown a strong interest in person-centered planning and self-direction, where people receiving HCBS are empowered to have more control and direction over the HCBS they receive. ACL continues its development of a six-course training program for person-centered planning and counseling. The program addresses cognitive disabilities and dementia in each of the following courses:

1. Introduction to the "No Wrong Door" System.
2. Introduction to Person-Centered Planning.
3. Person-Centered Planning and Implementation.
4. Introduction to the Long-Term Services and Supports System.
5. Who We Serve.
6. Protection and Advocacy.

Each of these courses will train front line Person-Centered Counseling Professionals (PCCP) in the skills necessary to assist older adults who need supports and people with disabilities in reaching their goals for community living in a respectful and dignified manner. Each course teaches the learner how to use specific tools to interact with each person in a way that gives him or her control over the goal-setting process, and helps foster the development of meaningful and trusting relationships. The training program will be tested and ready for states to use in early 2016. [See http://www.acl.gov/Programs/CDAP/OIP/docs/2402-a-Guidance.pdf.]

***Dementia-Specific Guidelines and Curricula***. The Health Resources and Services Administration (HRSA) has created and will disseminate a repository of dementia curricula and practice guidelines for providers across the care continuum, including physicians, nurses, social workers, psychologists, other health care professionals, direct care workers, and informal caregivers. The repository will be hosted on a publicly-available website and updated regularly. HHS will seek expert input from public and private entities to develop the repository to ensure that its content incorporates existing evidence-based guidelines. The web links for these curricula are currently in development and will be available soon.

***Provider Education About Federal Programs to Address Alzheimer's Disease***. Monthly conference calls to HRSA geriatrics grantees included agency specific presentations on ADRD. Each conference call had between 70 and 90 participants. Participants were informed of federal ADRD activities by dementia expert staff from the Office of the Assistant Secretary for Planning and Evaluation (ASPE), ACL, Agency for Healthcare Research and Quality (AHRQ), CDC, Indian Health Service (IHS), HRSA, NIA, and VA.

***Healthy Brain Initiative (HBI)***. CDC's HBI continues to support the actions of *The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013-2018* (referred to as the HBI Road Map) and the nation's Healthy People 2020 topic and objectives for *Dementia, Including Alzheimer's Disease*. [See http://www.cdc.gov/aging/pdf/2013-healthy-brain-initiative.pdf.]

***Implemented Road Map Actions in States***. CDC supported a successful collaboration with the Alzheimer's Association in September 2010-September 2015. In FY2014, CDC provided supplemental funds to support caregiver surveillance through the Behavioral Risk Factor Surveillance System (BRFSS) in states. CDC also supported the Association of State and Territorial Health Officials and the National Association of Chronic Disease Directors to implement priority action items from the Road Map of particular significance to their constituencies in select states across the United States. A major focus of CDC's efforts to support the actions of the *HBI Road Map* and the Healthy People 2020 objectives related to dementia is to "educate and empower the nation." To meet that challenge, CDC initiated a number of special interest projects within the CDC Prevention Research Centers (PRCs) program.

***Public Health and Economic Costs***. CDC funded a project designed to promote public health understanding regarding the economic costs associated with ADRD by examining different economic models to estimate community and inpatient care, as well as the societal costs associated with losses of productivity and quality of life by persons living with Alzheimer's disease and their caregivers. The University of Washington PRC began conducting a review of the literature and will examine de-identified data from the Group Health Cooperative to calculate costs and make recommendations for improvement to allow states and localities to better forecast dementia care costs.

***Educate Health Care Providers***. In 2012, HHS began a comprehensive effort to educate health care providers such as physicians, nurses, direct care workers and other professionals about Alzheimer's disease. The initiative is funded by HRSA through its Geriatric Education Center (GEC). During the first 2 years of this initiative, 45 GEC grantees partnered with 719 community stakeholders to provide 1,468 inter-professional education offerings to over 81,400 health professionals on topics such as tools to identify dementia, signs and symptoms of dementia, caregiver needs, managing dementia in the context of other chronic diseases, accessing long-term services in the community, managing care transitions, participation in clinical trials, and effective behavior management for persons with ADRD. Trainings also address the unique needs of medically underserved and special populations including racial and ethnic minorities and individuals with intellectual disabilities. Some grantees have translated materials into other languages such as Spanish, Chinese, Vietnamese, and Arabic.

In 2014, this effort continued to ensure that providers receive training on the latest dementia clinical guidelines and research findings in order to provide high-quality, culturally-competent care for older adults and their caregivers. In September 2013, HRSA released a continuing education course entitled *Case Challenges in Early Alzheimer's Disease*, aimed at educating primary care physicians, nurse practitioners, and nurses on how to utilize evidence-based strategies to diagnose, monitor, and treat individuals with ADRD and improve early detection in primary care and outpatient settings. As a result of the success of the training, it was extended for 1 year. To date, 59,283 health care professionals have participated in this training. In 2014, HRSA expanded these efforts by extending its training to direct care workers and lay/family caregivers, in addition to its ongoing efforts to provide continuing education to health care professionals. GEC grantees will be collaborating with local, state, regional, national, and federal partners to maximize their outreach for all three of these trainee groups. Trainee data will be available in fall of 2015. HRSA also began the process to develop short-term and long-term targets, strategies and milestones to help ensure a dementia-capable primary and specialty care workforce in both the number of professionals needed and ensuring basic competence among health care professionals in care for persons with ADRD and their caregivers.

***Educate All Providers to Deliver Quality Health Care to Older Adults, Including Dementia Education and Training***. In 2015, HRSA announced a new Geriatrics Workforce Enhancement Program (GWEP) that combined elements of the previous four programs (GECs; Geriatric Training for Physicians, Dentists, and Behavioral and Mental Health Professionals; Geriatric Academic Career Awards; and the Comprehensive Geriatric Education Programs [CGEPs]) into one program to provide greater flexibility to awardees by allowing them to develop programs that are responsive to specific inter-professional geriatrics education and training needs of their communities. The purpose of this cooperative agreement program is to develop a health care workforce that maximizes individual and family engagement and improves health outcomes for older adults by integrating geriatrics with primary care. Special emphasis is on providing the primary care workforce with the knowledge and skills to care for older adults and on collaborating with community partners to address gaps in health care for older adults through individual, system, community, and population level changes. Focus areas include: (1) transforming clinical training environments to integrated geriatrics and primary care delivery systems to help ensure trainees are well prepared to practice in and lead these kinds of systems; (2) developing providers who can assess and address the needs of older adults and their families/caregivers at the individual, community, and population levels; (3) creating and delivering community-based programs that will provide individuals, families and caregivers with the knowledge and skills to improve health outcomes and the quality of care for the older adult(s); and (4) applicants may also choose to address providing ADRD education to families, caregivers, direct care workers, and health professions students, faculty, and providers.

***Develop and Disseminate a Uniform Curriculum for Primary Alzheimer's Disease and Related Dementias Care***. HRSA is working with federal partners at ACL, CDC, the Centers for Medicare and Medicaid Services (CMS), IHS, and VA on a contract to develop a Uniform ADRD Curriculum to build a workforce with the skills to provide high-quality care, ensure timely and accurate detection and diagnosis of AD, and identify high-quality dementia care guidelines and measures across care settings. Specifically, 15-20 modules will be developed and pilot tested. These modules build upon the *ACT on Alzheimer's Preparing Minnesota Communities* training materials and address various high-priority issues related to the detection, management, and treatment of ADRD. [See http://www.actonalz.org/dementia-curriculum.]

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

***Linking the Public to Diagnostic and Clinical Management Services***. In 2012 and 2013, ACL and NIA offered a webinar series with presentations by the NIA ADEAR Center, NIA-funded ADCs, National Alzheimer's Call Center, and Eldercare Locator. In 2014, CDC joined NIA and ACL in providing a series of webinars that describe resources and services related to Alzheimer's disease diagnosis and management, clinical trials, and caregiving so that Aging Network providers can share this information with the people they serve. [See http://www.aoa.acl.gov/AoA_Programs/HPW/Alz_Grants/index.aspx.]

***Geronotological Society of America Report***. A new report is available that summarizes the discussion of a workgroup convened to outline the pathway from detection to diagnosis to management using evidence-supported tools that could be integrated into clinical work flow, including the assessment opportunity created by the inclusion of cognitive impairment detection as a required element of the Medicare Annual Wellness Visit. The workgroup involved a team of experts that GSA assembled from across the public, private, and academic sectors. [See http://www.geron.org/ci.]

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

***Patient and Family Engagement Campaign (PFEC)***. The purpose of the PFEC, which concluded in 2014, was to fund fresh and original models to develop and implement innovative projects that supported HHS and CMS goals of person-centeredness and family engagement. The main goals were to involve beneficiaries and families in decisions regarding health and health care to ensure consistency with the individual's choices and priorities; and to empower them to take action for their own health care to help improve quality of life. Proposed projects targeted behaviors among beneficiaries, families, and providers for multiple topics, including among them *Care for Individuals Diagnosed with Dementia*. For dementia care, some Quality Improvement Organizations (QIOs), the entities in the states that drive Medicare improvements in an array of areas, held workshops and formed partnerships with various caregiver organizations and participated in a caregiver coalition to further disseminate and replicate information about programs related to dementia care. Teaming up with organizations, such as AARP, allowed the QIOs to reach a broader audience and allowed more caregivers to become aware of the initiatives, which enabled them to continue to seek help and resources even after the workshop series were completed. QIOs recommended that, where possible, offline social networks such as the Learning and Action Networks be tapped to encourage peer-to-peer sharing among future participants. The creation of building trust takes time, especially when asking paid and unpaid caregivers to share intimate concerns in providing care for individuals with dementia. Moving forward, CMS will share additional recommendations during upcoming work in this area.

***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 continuing an ongoing partnership with federal partners, public and private entities, and the health care provider community to identify steps to effectively educate physicians and other health care providers about support resources and services available to assist people with ADRD and their caregivers, including HCBS.

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

***National Quality Forum (NQF) Project "Priority Setting for Healthcare Performance Measurement: Addressing Performance Measure Gaps for Dementia, including Alzheimer's Disease."*** HHS contracted with NQF to conduct an environmental scan for existing dementia-specific performance measures and convene a multi-stakeholder committee to develop a conceptual measurement framework and recommend priorities for future performance measurement development focusing on people with dementia and their family caregivers. With guidance from the multi-stakeholder committee, NQF identified a total of 125 dementia-specific performance measures. A total of 60 United States measures were identified and a total of 65 international measures were identified. Of the 125 measures, 96 focused on the person with dementia, 14 focused on the family or caregiver, nine focused on both, and the remaining six were structural measures that focused on availability of services or training. This project also identified/updated 85 care guidelines. This comprises foundational work from which quality measures can be selected for implementation, and others developed to fill much needed measurement gaps. NQF has recently begun similar work to examine quality measurement for HCBS, much sought after to support people with ADRD and their families and caregivers living at home, and other populations. This project extends over a 2-year period, and will prepare the way for a nationally endorsed set of quality measures for HCBS. NQF is actively soliciting public comment to inform the HCBS multi-stakeholder committee's activities. [See http://www.qualityforum.org/Measuring_HCBS_Quality.aspx.]

***Focus Group Summary***. CMS held two focus groups on March 18, 2014 to collect individual and caregiver perspectives on two measures intended for potential use in CMS quality reporting programs for eligible professionals and related to care for individuals with, or at-risk of, cognitive impairment. The two measures are: (1) Cognitive Impairment Assessment among at-Risk Older Adults; and (2) Documentation of a Health Care Partner for Patients with Cognitive Impairment. Among the individual participants generally supported a cognitive impairment assessment as part of their annual exam. The measurement construct with numerator and denominator specifications has yet to be defined, as well as an appropriate measurement interval. The participants also supported the concept of having a health care agent -- the person they designate to make care decisions on their behalf when they cannot. There was general support for the identification of a health care agent as a quality measure topic given utility for individuals, caregivers and health care providers. An expert workgroup will be convened to consider all the feedback received and discuss refining the current measure specifications. Additionally, the workgroup will assess the feasibility of beta testing the measures using individual-level electronic health record (EHR) data and conduct implementation testing to ensure consistent implementation of the measure specifications by EHR vendors.

***Clarify and Disseminate Information on Privacy, Autonomy, and Safety Issues for Physicians***. Based on the recommendation of the Advisory Council to clarify information on privacy, HHS will continue to develop information for physicians on privacy, autonomy, and safety issues. This resource will help providers better understand these issues and the balance among them. HHS will disseminate this information through HRSA's GECs.

***Institute of Medicine (IOM) Expert Panel on Advanced Dementia***. Beginning in January 2014, in response to the Advisory Council, IOM convened experts to review current research, innovative practices, and health policy pertinent to the care of persons with advanced dementia and their families, and to make recommendations to HHS and the Advisory Council about priority initiatives to improve that care. People with advanced dementia are a vulnerable population with unique needs, gradual severe functional and cognitive impairment, with a greater reliance on surrogate decision making. Over time, many people with advanced dementia cannot live alone and therefore place greater demands on family and caregivers. The IOM's three panels invited experts to discuss three areas: research (January 2014), innovative care models (September 2014), and policy recommendations (January 2015). The members of the panel provided the Advisory Council with recommendations that focus on advanced dementia and build upon the National Plan.

## Strategy 2.E: Explore the Effectiveness of New Models of Care for People with Alzheimer's Disease

***Alzheimer's Disease Supportive Services Program (ADSSP)***. ACL continues to support its 15 current grantees and their partners who are implementing dementia-capable LTSS systems and any former grantees or partners who wish to participate in learning activities. The grantees have lead dementia agencies, in direct response to recommendations from the Advisory Council. Grantees are: (1) developing a "no wrong door" service system; (2) ensuring access to comprehensive, sustainable services for people with dementia and their family caregivers; and (3) implementing evidence-based or informed interventions as part of their programs. A limited number of ADSSP grantees are in the final stages of implementing and evaluating the translation of evidence-based interventions in support of individuals with ADRD and their unpaid caregivers. ACL plans to award new grants to six new states that do not already have grants to implement dementia-capable systems and to develop public-private partnerships to promote dementia-friendly communities to the extent feasible. This program's focus on dementia capability is in direct response to the recommendations of the Advisory Council.

***ACL National Alzheimer's and Dementia Resource Center***. ACL continues to fund a Resource Center that supports ACL grantees, their partners, and the larger Aging and Disability Networks in developing and implementing dementia-capable programs, dementia-friendly communities, specialized supportive services, and evidence-based programs. In addition to providing technical assistance to ACL, Alzheimer's disease grantees, their partners, and former grantees, the Resource Center manages an annual webinar series that is open to the general public, writes issue briefs on program-related topics, and evaluates and summarizes program results. The Resource Center staff also manages and facilitates grantee learning collaboratives that result in resources that are beneficial to program activities and also made available to the general public.

***Supported Decision Making Resource Center***. ACL has for years been aware of the great work being done in the field of supported decision making, and this work's potential to provide a significant improvement to current guardianship arrangements for older adults and people with disabilities who need support. However, the supported decision making model has faced obstacles to adoption, including a lack of formal evaluation and awareness. To address these challenges, ACL in 2014 awarded a cooperative agreement to build a national training, technical assistance, and resource center to explore and develop supported decision making as an alternative to guardianship. The Resource Center will gather and disseminate data on the various ways in which supported decision making is being implemented and generate research in the area. The goal is that the information collected during the cooperative agreement will lead to a model that will help states as they consider alternatives to guardianship. This is a 5-year cooperative agreement awarded through FY2019. [See http://www.supporteddecisionmaking.org.]

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

***Preventable Hospitalizations***. CDC worked with partners to conduct a review of interventions related to dementia and decreasing preventable hospitalizations. The findings from this review will help to inform the current state of evidence-based strategies and interventions related to the Healthy People topic area "Dementias, including Alzheimer's disease" and its objective "To reduce the proportion of preventable hospitalizations in persons with diagnosed Alzheimer's disease and other dementias." A publication that described the results is available. [See http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4310672.]

## Strategy 2.G: Advance Coordinated and Integrated Health and Long-Term Services and Supports for Individuals Living with Alzheimer's Disease

***Evaluate Evidence on Care Integration***. HHS continued to explore how service delivery models that integrate acute care and LTSS add value beyond that of the traditional, fragmented care system. The project will have a special focus on integrated care functions for people with disabilities and cognitive impairment, and will describe payment policies that promote integrated care. This information will help HHS compare and evaluate existing integrated care interventions and support their growth. Information from the project will facilitate the expansion of promising integrated care models to improve care for Medicare and Medicaid beneficiaries with Alzheimer's disease.

***Assess Health Information Technology (HIT) Standards Capacity to Support the Needs of Individuals with Alzheimer's Disease and Related Dementias***. ASPE continued work with HHS's Office of the National Coordinator for Health Information Technology (ONC) and partners in exploring the feasibility and timing of activities to assess, identify, and fill gaps in accepted HIT standards for the

representation of care plans to represent the health concerns, goals, interventions, and other information identified by individuals, caregivers and family members in caring for individuals receiving LTSS, including those with ADRD.

## Strategy 2.H: Improve Care for Populations Disproportionately Affected by Alzheimer's Disease and for Populations Facing Care Challenges

***Alzheimer's Disease Initiative - Specialized Supportive Services (ADI-SSS)***. ACL continues to support its ten ADI-SSS grantees and their partners, which are located across the country and in Puerto Rico. The grantees are operating within dementia-capable systems and implementing new programs designed to provide more effective services to: (1) individuals living alone in the community with dementia; (2) individuals with intellectual disabilities 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. One of the aims of the behavioral symptom management effort is to reduce use of anti-psychotics in home and community settings as called for in the 2015 General Accountability Office (GAO) report on this topic. ACL intends to fund ten new dementia-capable states or other entities in 2015 to implement new programs in these three areas and possibly others. In addition, ACL plans to develop public-private partnerships to promote "dementia-friendly communities" to the extent feasible. The focus on people with intellectual disabilities and fostering of dementia-friendly communities is in direct response to recommendations of the Advisory Council. [See http://www.gao.gov/products/GAO-15-211.]

***Veterans-Directed Long-Term Services and Supports***. ACL and the Veterans Health Administration (VHA) continue to partner in supporting states' efforts to develop and better coordinate no wrong door systems of access to services. Together they lead the national expansion of Veteran-Directed Home and Community-Based Services (VD-HCBS) with the goal of assuring that veterans of all ages receive the care they need in their homes and communities, and are provided appropriate supports that allow them to remain there. In many cases, veterans in VD-HCBS hire individuals they are most comfortable with including family, friends and neighbors, to provide the services and supports they require. Veterans with dementia who reside in VA and community nursing facilities have been successfully transitioned back into the community with the support of VD-HCBS.

# Goal 3: Expand Supports for People with Alzheimer's Disease and Their Families

People with Alzheimer's disease 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 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 families and caregivers.

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

***National Alzheimer's Call Center***. Through the National Alzheimer's Call Center, ACL funds the operation of a national information and counseling service for individuals with Alzheimer's disease, their family members and unpaid caregivers. The National Alzheimer's Call Center is available at all times, every day to people across United States and territories. It provides expert advice, care consultation and information and referrals nationwide, at the national and local levels, regarding AD in over 100 languages. The grantee is currently in the second year of a 5-year funding period which will end July 31, 2018.

***Indian Country Aging Programs***. Indian Country programs involve educational efforts and implementation of a proven caregiver support program. Education involves: consumer fact sheets on dementia in Indian Country, conference presentations, training programs, and webinars. ACL is also participating in the Banner Institute's Conference for Native Americans and developing relationships between state Alzheimer's Councils and tribes. [See http://www.cms.gov/Outreach-and-Education/American-Indian-Alaska-Native/AIAN/LongTermCare.html.]

***Training Resources for IHS Staff***. IHS completed a review of training resources for IHS nursing staff. Articles in the IHS Primary Care Provider highlighted person-centered goals and strategies for improving care for persons with dementia. IHS collaborated with HRSA to engage the HRSA-funded GECs in strategies to improve recognition and diagnosis of dementia.

***Outreach and Training in Indian Country***. IHS provided training at the *National Meeting of the Title VI Directors* (the ACL-funded Aging Network) on ADRD and outreach and education at the National Indian Council on Aging Biennial Meeting. The IHS, CMS, and ACL provide technical assistance in the development of LTSS through the jointly sponsored LTSS Technical Assistance website, and shared tribal models of LTSS in the monthly webinar series. [See http://www.cms.gov/Outreach-and-Education/American-Indian-Alaska-Native/AIAN/LTSS-Technical-Assistance-Center/Overview.html.]

***Language to Assist with the Indian Health Care Improvement Act***. IHS developed sample language to assist tribes to make use of new authorities under the Indian Health Care Improvement Act to provide LTSS.

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

***Identify Unmet Service Needs***. In spring 2014, ASPE released a set of three reports describing disability and care needs of the older population using baseline (2011) measures from the National Health and Aging Trends Study (NHATS), a new longitudinal study designed to support understanding of both trends and trajectories in health and disability in later life. The three volumes examine: (1) the impact of functional disability and the extent of activity limitations; (2) the care needs of those with dementia; and (3) the role and experiences of unpaid caregivers for the older population, using a special supplement to NHATS -- the National Survey of Caregiving. The reports describe the substantial role dementia plays in late-life disability and caregiving for older people. Those with probable dementia account for almost one out of three older persons not residing in nursing homes who receive help with self-care, mobility, or household activities for health reasons. Persons with probable dementia also account for almost half of the nearly 3 million older adults receiving help with three or more self-care or mobility activities. Although the population with dementia makes up about 10% of the non-nursing home population with long-term care needs, 32% of unpaid caregivers (5.8 million) are caring for older people with dementia. Caregivers to people with dementia report more negative effects of caregiving compared with caregivers to people without dementia. [See http://aspe.hhs.gov/daltcp/reports/2014/NHATS.cfm.]

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***REACH into Indian Country***. REACH (Resources for Enhancing Alzheimer's Caregivers' Health) into Indian Country is a 3-year project of the University of Tennessee Health Sciences Center REACH Training Center, which the Rx Foundation funds. The project will make the REACH intervention available to caregivers of elders with dementia, providing them with the tools and skills to manage challenges that arise in the course of caregiving. REACH is based on NIA-funded research, adapted and further evaluated by the VA system as REACH-VA. REACH-VA found that caregivers provided with this support experience significant decreases in burden, depression, anxiety, caregiving frustrations, and stress symptoms. In 2014, the REACH-VA intervention was piloted in three tribal communities. Continued coordination between ACL, IHS, and VA and funding by the Rx Foundation provides an opportunity and plan for implementation of the REACH intervention through IHS and tribal health programs and the Tribal Aging Network (NACSP) supported by ACL.

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***Lifespan Respite***. ACL continues to support the expansion and enhancement of State Lifespan Respite Care programs which are coordinated systems of accessible, community-based respite care services for family caregivers of children and adults of all ages with special needs, to give them a break from the demands of caregiving. These programs are designed to reduce duplication of effort and assist in the development of respite care infrastructures at the state and local levels. Lifespan Respite Care programs work to improve the delivery and quality of respite services available to families across the age and disability spectrum, including those with dementia. Lifespan Respite Care programs advance the following objectives:

1. Expand and enhance respite services in the states.
2. Improve coordination and dissemination of respite services.
3. Streamline access to programs.
4. Fill gaps in service where necessary.
5. Improve the overall quality of the respite services currently available.

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***Adult Day Care and Residential Care State Policy Compendia***. ASPE recently updated two policy compendia examining state approaches to regulation of long-term care settings. The first compendium examines state regulation around adult day services (ADS) -- a non-residential service that provides services outside of an individual's home for less than a full day to older adults and younger adults with physical disabilities. These services also meet unpaid caregivers' need for respite in order to work, fulfill other obligations, and recover from the demands of continuous caregiving. Many caregivers who use

ADS are providing care to family members with dementia who need constant supervision to ensure their safety. The second compendium (to be released fall 2015) examines state approaches to residential care, including assisted living. Residential care provides 24 hour supervision, meals, and assistance with ADLs. States vary in their approaches to licensure for residential care facilities. [See http://aspe.hhs.gov/daltcp/reports/2014/adultday14.cfm.]

***Effect of Dementia on Hospitalization and Emergency Department Use in Residential Care Facilities***. ASPE recently released a report examining the experiences of individuals living in residential care facilities (including assisted living) who have dementia. Understanding the availability and adequacy of these services is critical to understanding the range of options available to individuals with functional and cognitive limitations. These papers examine dementia care in residential care facilities based on analysis from the National Center for Health Statistics (NCHS)-ASPE National Survey of Residential Care Facilities (NSRCF). The analysis finds that:

- Half of residential care facility residents aged 65+ had severe cognitive impairment.
- Nearly one-quarter of all residential care facility residents had at least one hospitalization and more than one-third had at least one emergency department visit in the past 12 months.
- Among residential care facility residents, living in a special care unit for dementia or a facility that only serves individuals with Alzheimer's disease decreased the risk of hospitalization.

[See http://aspe.hhs.gov/daltcp/reports/2014/RCFdementia.cfm.]

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

***Long-Term Care Awareness Survey***. ASPE is working to better understand why middle-aged adults do or do not plan for long-term care needs. ASPE conducted a national survey to examine attitudes toward long-term care. The survey had two distinct components. First, it contained general survey items, including long-term care knowledge and experience, attitudes and concerns, preferences on public policy options for long-term care financing, and core socio-demographic characteristics. The second part of the survey was a discrete choice experiment (DCE) involving choice of long-term care insurance policies with different features and prices. The survey sample was a nationally representative sample of non-institutionalized adults between 40-70 years old residing in the United States. Participation in the panel was by invitation only. The results are in the process of being compiled and will be shared, along with relevant data, in the fall of 2015.

## Strategy 3.D: Maintain the Dignity, Safety and Rights of People with Alzheimer's Disease

***Long-Term Care Ombudsman (LTCO) Regulations***. ACL promulgated regulations to support person-centered complaint investigation and resolution, including for individuals living with dementia. Staff is working to promote their implementation. The regulations were published in February 2015, with implementation by grantees required by July 2016. These federal regulations clarify implementation of the parts of the Older Americans Act governing grants to states for operation of LTCO programs. They provide guidance on complaint processing, including when a nursing home resident, due to dementia or other impairment, is unable to communicate informed consent, and has no resident representative to communicate on their behalf. Complaint processing guidance describes person-centered principles and approaches to resolve complaints. This is especially critical when addressing complaints about behaviors such as agitation or aggression. These principles include understanding the person, their background and preferences, and determining what might be causing the behavior. Once the cause of the behavior is understood, facility staff, family and the Ombudsman can develop solutions that address unmet needs. Problem solving strategies may include such actions as treating any medical conditions,

evaluating any facility practices that negatively affect a resident's health, safety or quality of life, training of facility staff on person-centered approaches, including non-pharmacological approaches which may prevent the unnecessary use of anti-psychotics. ACL staff and the National Ombudsman Resource Center (NORC) are providing training and technical assistance on new LTCO regulations regarding person-centered complaint processes, including for individuals living with dementia, building upon past National Plan-related training activities.

***Emergency Preparedness and Response -- Model Policies and Procedures for State LTCO Programs***. Although LTCO programs are not first responders, they can play an important role in emergencies and disasters by advocating for long-term care facility residents, about half of whom have dementia or cognitive disabilities. ACL is developing model policies and procedures to: (1) clarify appropriate functions and limitations of the Ombudsman program in relation to emergencies affecting long-term care facility residents; (2) assist Ombudsman programs in developing related program policies; and (3) assist state agencies on aging and Area Agencies on Aging to incorporate the functions of Ombudsman programs into their emergency preparedness planning. ACL staff is finalizing model policies and procedures, and will introduce them to states in coordination with the NORC. The NORC will assist with implementation by: (1) soliciting proposals from up to five states for targeted technical support related to incorporating the model policies and procedures; and (2) providing targeted support to two states' Ombudsman and elder rights teams. Support will help states develop a coordinated model for emergency response when long-term care facility residents are affected by an emergency or disaster situation.

***Elder Abuse Prevention***. ACL's National Center on Elder Abuse (NCEA) is dedicated to protecting all from the many forms of elder abuse, particularly vulnerable older adults, including those with dementia. Currently the NCEA is rebranding and updating all of its fact sheets, research briefs and training materials. Many of these materials are adaptable to assist families in crisis especially when their family member has lost the capacity to make their own decisions and maybe especially susceptible to harm by others. A new research brief on dementia is available. NCEA also consults with Alzheimer's Association chapters on elder abuse issues. [See http://www.ncea.aoa.gov/Resources/Publication/docs/NCEA_Dementia_ResearchBrief_2013.pdf.]

***National Partnership to Improve Dementia Care in Nursing Homes***. The focus of the National Partnership to Improve Dementia Care in Nursing Homes continues to be on the improvement of comprehensive dementia care in nursing homes across the country. In September 2014, the National Partnership, a public-private coalition, established a new national goal of reducing the use of anti-psychotic medications in long-stay nursing home residents by 25% by the end of 2015, and 30% by the end of 2016. In addition, this effort has the potential to expand its outreach and educational impact to care settings beyond the nursing home, and was included as a recommendation in a recent GAO report. Importantly, it should be emphasized that the Partnership's larger mission is to enhance person-centered dementia care that includes non-pharmacologic best practices. Information pertaining to non-pharmacologic approaches and person-centered care are disseminated through presentations to groups around the country, direct education and outreach to provider organizations, maintenance of a resource repository dedicated to the partnership through the Advancing Excellence website, as well as the completion of a Focused Dementia Care Survey Pilot in 2014. The pilot consisted of five states, with five surveys completed per state. The purpose of the survey was to optimize survey efficiency and effectiveness, examine the process for prescribing anti-psychotic medication, as well as other dementia care practices in nursing homes and gain new insights about surveyor knowledge, skills, and attitudes. Most state surveyors stated that they were able to cite deficient practices related to dementia care and unnecessary drugs. In fact, some focused dementia teams found deficient practices just a few

weeks after a standard survey team had been in the facility and had not cited deficiencies. Discussions with survey teams revealed that some surveyors struggle with linking anti-psychotic medication use with actual harm outcomes in people with dementia, particularly psychosocial harm. Continued focused dementia care surveys are planned for 2015 in volunteer states starting with nursing facilities in Texas.

***The Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule and Alzheimer's and Related Dementias: A Resource List***. With input from the non-federal members of the Advisory Council, as well as other experts, ASPE worked with colleagues in the Office of Civil Rights (OCR) to develop a resource list for providers regarding consent, capacity, and decision making when treating individuals with dementia. Although the resource list does not specifically address dementia, due to constraints on OCR's ability to create guidance on specific diseases, it does provide links to material that would be relevant to providers when helping individuals and their families. There will be further refinement of this document, and it will be posted in its final form on the NAPA website.

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

***Explore Affordable Housing Models, A Picture of Health and Housing: Medicare and Medicaid Use among Older Adults in HUD-Assisted Housing***. The U.S. Department of Housing and Urban Development (HUD) and HHS released a report in June 2014 examining the health care utilization and chronic conditions of older adults receiving HUD assistance. This was a pilot project to create a new data set linking HUD tenant and Medicare/Medicaid claims data in 12 jurisdictions across the country. The results show that older adults receiving HUD assistance have higher Medicare and Medicaid utilization than individuals in the community not receiving HUD assistance. When comparing Medicare and Medicaid enrollees (i.e., dual eligibles), those receiving HUD assistance also used more health care services than dual eligibles not receiving HUD assistance. Dual eligibles receiving HUD assistance use significantly more Medicaid HCBS than those not receiving HUD assistance. For example, dual eligibles receiving HUD assistance used over 100% more personal care services than individuals not receiving HUD assistance. These findings indicate that older adults receiving HUD assistance may benefit from health and supportive services interventions to address many complex health needs. [See http://aspe.hhs.gov/daltcp/reports/2014/HUDpic.shtml.]

***First Annual Report for the Support and Services at Home (SASH) Evaluation***. HHS and HUD have been evaluating an innovative model of housing with services -- *SASH Demonstration in Vermont*. It is part of a larger state Medicare demonstration -- the Multipayer Advanced Primary Care Practice (MAPCP) Demonstration. In December 2014, the first annual evaluation memorandum with interim findings was released. Early findings show a promising model of coordinated health and supportive services within affordable housing settings. The impact estimates in this report are preliminary because they only include the first year of SASH implementation. Future analyses will explore, in more detail, the costs of administering the SASH program relative to benefits that accrue to its participants, and the impact on their Medicare and Medicaid expenditures. [See http://aspe.hhs.gov/daltcp/reports/2014/SASH1.cfm.]

# Goal 4: Enhance Public Awareness and Engagement

Most of the public is aware of Alzheimer's disease; more than 85% of people surveyed can identify the disease and its symptoms. AD is also one of the most feared health conditions. Yet there are widespread and significant public misperceptions about diagnosis and clinical management. These issues can 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 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 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

***Cognitive Health Awareness***. HHS is developing a campaign to change the way consumers aged 60-70 think about their brains and brain health. Additionally the campaign will encourage those experiencing MCI to seek medical attention. During 2015, messages will be developed and tested with the participation of a number of governmental and non-governmental stakeholders. Late in 2015, the campaign will be launched and carry-over into 2016. The campaign will focus on two market areas but will have some national elements. Also during 2015, planning will begin on a campaign designed for a Hispanic audience. Development of this campaign will require additional development and testing with an entirely new set of stakeholders. Beyond 2016, the campaign plans to address different populations such as African-Americans and people with intellectual and developmental disabilities.

***Alzheimer's Disease Information***. NIA operates the ADEAR Center, the primary Federal Government resource for information about ADRD, research, and caregiving. The ADEAR Center educates the public about the latest research findings and clinical trial participation via free, evidence-based information available online and in print. [See http://www.nia.nih.gov/alzheimers.]

***Alzheimers.gov***. HHS launched the website http://alzheimers.gov in 2012 and it now needs to be refreshed. Two sets of analyses are underway to guide this process. The first analyzes website use to understand how many people are using the site and what information they find most useful. The second assessment involves a scan of other websites providing information on ADRD. The result of these analyses will help determine how the website can best provide valuable information while not duplicating information already available from other sources.

***Public Health Research Network***. CDC created a new Healthy Brain Research Network. The Network's activities build on the mission of CDC's HBI to better understand attitudes and perceived changes in cognitive functioning over time through public health surveillance, build a strong evidence base for communication (e.g., messaging) and programmatic interventions to improve or maintain cognitive function, and help to translate that evidence base into effective public health programs and practices in states and communities. The PRCs include the University of Washington Health Promotion Research Center (Coordinating Center), Oregon Health and Science University Center for Healthy Communities; University of Arizona Prevention Center; University of Pennsylvania PRC; and the University of South Carolina PRC.

***Message Development and Testing***. CDC funded year 1 of a 2-year project to develop and disseminate science-based, culturally-relevant messages and strategies that promote awareness about cognition and cognitive impairment, including Alzheimer's disease, which will lead to increased detection of this type of impairment. The University of Pennsylvania PRC will assess perceptions about cognitive health and impairment among non-Hispanic White and African-American adults aged 50 or older living in the Philadelphia area. This work will inform the development, pilot testing, and dissemination of timely public health messages for this population and examine the potential scaling of these findings to other populations.

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

***REACH into Indian Country***. IHS and ACL are partnering with the REACH-VA training team at the University of Tennessee Health Sciences Center in REACH into Indian Country, a project funded by the Rx Foundation to implement the REACH intervention in at least 50 tribal communities over the next 3 years.

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

***World Dementia Research Leaders***. NIA convened a research-specific meeting of 50 dementia leaders February 11, 2015 at NIH in Bethesda. National health experts, including NIH Director Dr. Francis Collins, from the G7 countries -- the United States, Canada, United Kingdom, France, Germany, Italy, and Japan -- shared their recent progress in dementia research and care, and discussed research spending, clinical research strategies, and critical areas for future collaborations.

***Efforts Intensify to Establish Global Goals for Dementia Research and Care***. The HHS Deputy Assistant Secretary for Planning and Evaluation Dr. Linda Elam and NIA Director Dr. Richard J. Hodes joined health ministers, leading scientists, and advocates from around the world March 16-17, 2015 in Geneva, Switzerland, to advance planning on dementia research and care on a global scale. The agenda at the *Ministerial Conference on Global Action Against Dementia*, hosted by WHO, reflected shared goals that are gaining momentum worldwide: to raise awareness of dementia's socioeconomic impact, and discuss ways to advance scientific research, foster the availability of new treatments and improved care, and finding ways to reduce the risk of neurodegenerative disorders. [See http://www.who.int/mental_health/neurology/dementia/en/.]

# Goal 5: Improve Data to Track Progress

The Federal Government is committed to better understanding ADRD and its impact on individuals, families, the health and long-term care systems, and society as a whole. Data and surveillance efforts are paramount to tracking the burden of Alzheimer's disease on individual and population health, and will be used to identify and monitor trends in risk factors associated with ADRD, and assist with understanding health disparities among populations such as racial and ethnic 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

***CDC Data Reports and Publications***. CDC released two publications using surveillance data from the 2011-2012 BRFSS about increased confusion or memory loss. These findings highlight that individuals or others within their household may notice changes in memory and confusion over time. This is important because a diagnosis for ADRD, is often missed or delayed. Talking with a health care provider about such changes is important to begin determining the reason why the person is experiencing increased confusion or memory loss. These findings also expand what we know about the general public's perceptions about increased confusion or memory loss and its relationship to other physical and mental health issues. [See http://www.cdc.gov/pcd/issues/2015/14_0429.htm, and http://www.cdc.gov/pcd/issues/2015/14_0430.htm.]

***2015 Behavioral Risk Factor Surveillance Survey Data***. CDC worked with partners and revised the BRFSS Cognitive Decline and Caregiving Optimal Modules, which were approved as official modules in 2015. In January 2015, 35 states began collecting data using the Cognitive Decline Module and 24 states began collecting data using the Caregiving Module.

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

***Healthy People 2020***. CDC, in collaboration with NIH, released the first baseline data for the Healthy People 2020 topic areas, *Dementias Including Alzheimer's Disease*. Additionally, CDC, NIH, ACL, and CMS participated in the Healthy People 2020 *Progress Review on Older Adults, and Dementias, Including Alzheimer's Disease*. [See http://www.healthypeople.gov/2020/topics-objectives/topic/dementias-including-alzheimers-disease/objectives, and http://www.cdc.gov/nchs/healthy_people/hp2020/hp2020_OA_DIA_progress_review.htm.]

# Appendix 1: List of Participating Departments and Agencies

Administration for Children and Families
Administration for Community Living
Administration on Aging
Administration on Intellectual and Developmental Disabilities
Agency for Healthcare Research and Quality
Association of State and Territorial Health Officials

Centers for Disease Control and Prevention
Centers for Medicare and Medicaid Services
Consumer Finance Protection Bureau
Corporation for National and Community Services

Department of Defense
Department of Education
Department of Health and Human Services
Department of Housing and Urban Development
Department of Justice
Department of Labor
Department of Veterans Affairs

Food and Drug Administration

General Accountability Office

Health Resources and Services Administration

Indian Health Service
Institute of Medicine

National Association of Chronic Disease Directors
National Center on Elder Abuse
National Human Genome Research Institute
National Indian Council on Aging
National Institute on Minority Health and Health Disparities
National Institute of Neurological Disorders and Stroke

National Institute on Aging
National Institutes of Health
National Quality Forum
National Science Foundation

Office of Civil Rights
Office of Global Affairs
Office of Intergovernmental and External Affairs
Office of the Assistant Secretary for Planning and Evaluation
Office of the Assistant Secretary for Preparedness and Response
Office of the Assistant Secretary for Public Affairs
Office of the Assistant Secretary for Health
Office of the National Coordinator of Health Information Technology
Office of the Surgeon General
Office on Disability

Social Security Administration
Substance Abuse and Mental Health Services Administration

Veterans Health Administration

# Appendix 2: Implementation Milestones

| Action Number | Action Description (from Plan) | Method of Action | Lead Agency | Partner(s) | Project Completion Date/Status | Activities in 2014 and 2015 |
|---|---|---|---|---|---|---|
| ***Goal 1: Prevent and Effectively Treat Alzheimer's Disease by 2025*** | | | | | | |
| **Strategy 1.A: Identify Research Priorities and Milestones** | | | | | | |
| 1.A.1 | Regularly convene an AD Research Summit to update priorities. | Convene second Summit in 2015. | NIH/NIA | Research Subgroup, academia, industry, professional, advocacy groups | First Summit May 2012<br><br>Second Summit February 2015 | 2012 Summit http://www.nia.nih.gov/about/events/2012/alzheimers-disease-research-summit-2012-path-treatment-and-prevention<br><br>2015 Summit http://www.nia.nih.gov/about/events/2014/alzheimers-disease-research-summit-2015 |
| 1.A.2 | Solicit public-private input on AD research priorities. | RFI inviting public-private input on funded research addressing ADRD. | NIH/NIA | Alzheimer's Association | Ongoing | Funder meeting was held in July 2012 at the Alzheimer's Association International Conference to encourage input. IADRFC teleconferences & meetings are ongoing. The CEOi held in October 2013 provided additional recommendations. http://www.ceoalzheimersinitiative.org/ |
| 1.A.3 | Regularly update the National Plan & refine Goal 1 strategies & action items based on feedback & input. | Update Goal 1 elements of the National Plan to reflect new insights & input from the community. | ASPE | Advisory Council, NIH/NIA, Research Subgroup | Ongoing | |
| 1.A.4 | Convene a scientific workshop on other dementias in 2013. | Hold a workshop to solicit input on special research priorities & timelines for addressing related dementias. | NIH/NINDS | Other federal funders of dementia research, national & international experts, public-private stakeholders, Advisory Council | Completed | Final Report of the ADRD Summit http://www.ninds.nih.gov/ADRD2013 |
| 1.A.5 | Update research priorities & milestones. | Updated research priorities & milestones. | ASPE | Advisory Council, NIH/NIA, Research Subgroup | Ongoing | |
| 1.A.6 | Create a timeline with milestones for achieving Goal 1. | Create & update milestone document. | NIH/NIA | | Ongoing | The milestones will continue to be updated with the 2015 summit recommendations. http://aspe.hhs.gov/daltcp/napa/milestones/index.shtml |
| 1.A.7 | Create milestones for research goals based on the recommendations from the 2013 ADRD conference. | Create milestone document. | NIH/NINDS | | Completed | Recommendations will be posted to the NAPA website in fall 2015. |

| Action Number | Action Description (from Plan) | Method of Action | Lead Agency | Partner(s) | Project Completion Date/Status | Activities in 2014 and 2015 |
|---|---|---|---|---|---|---|
| 1.A.8 | Regularly convene an ADRD Summit to review progress on ADRD research recommendations & refine & add new recommendations as appropriate, based on recent scientific discoveries. | Convene second summit in 2016. | NIH/NINDS | Research Subgroup, academia, industry, professional, advocacy groups | March 29-30, 2016 | |
| 1.A.9 | Convene a workshop focused on the research needs related to Down syndrome & AD. | Hold a workshop to solicit input on special research priorities & timelines AD among people with Down syndrome. | NIH/NIA, NIH/NICHD | DSRTF, RDS | Completed | More information including executive summary available at http://downsyndrome.nih.gov/meetings/Pages/041713.aspx. |
| **Strategy 1.B: Expand Research Aimed at Preventing and Treating Alzheimer's Disease** | | | | | | |
| 1.B.1 | Expand research to identify the molecular & cellular mechanisms underlying AD, & translate this information into potential targets for intervention. | Develop an integrated interdisciplinary basic science research agenda to enable the identification & selection of therapeutic targets. | NIH/NIA | Potential research partners in the public-private sectors | Ongoing | NIH RFA: Interdisciplinary Approach to Identification & Validation of Novel Targets for AD (RFA-AG-13-013) led to funding research on promising prevention drugs. http://grants.nih.gov/grants/guide/rfa-files/RFA-AG-13-013.html<br><br>AMP-AD & R34 Translational Center Planning Grant RFA also available. |
| 1.B.2 | Expand genetic epidemiologic research to identify risk & protective factors for AD. | Conduct whole genome sequencing to identify areas of genetic variation that correspond to risk factors of AD. | NIH/NIA | Potential research partners in the public-private sectors | Ongoing | ADSP sequenced the whole genomes of more than 580 volunteers & made the data freely accessible to researchers. https://www.niagads.org/ |

| Action Number | Action Description (from Plan) | Method of Action | Lead Agency | Partner(s) | Project Completion Date/Status | Activities in 2014 and 2015 |
|---|---|---|---|---|---|---|
| 1.B.3 | Increase enrollment in clinical trials & other clinical research through community, national, & international outreach. | Identify approaches & coordination points for these efforts; develop an action plan that incorporates these ideas; collaborate to increase awareness among health & social service providers. | NIH/NIA, ACL, CDC, VA | FDA, VA, CDC, HRSA, CMS, in partnership with the private sector | Ongoing | Several HHS agencies (NIA, ACL, CDC) collaborated on the ROAR project to promote research participation by connecting researchers with the aging & public health networks. In 2014, developed & piloted a customizable toolkit of materials.<br><br>ROAR Toolkit<br>http://www.nia.nih.gov/health/publication/roar-toolkit<br><br>Alzheimer's Prevention Registry was launched in October 2012 by the Banner Alzheimer's Institute (1 of 27 NIA-funded AD research centers).<br>http://www.endalznow.org/<br><br>An NIA RFI sought ideas on how to increase participation in AD clinical trials.<br>http://grants.nih.gov/grants/guide/notice-files/NOT-AG-12-017.html<br><br>Ongoing webinars<br>http://www.aoa.gov/AoARoot/AoA_Programs/HPW/ALz_Grants/index.aspx |
| 1.B.4 | Monitor & identify strategies to increase enrollment of racial & ethnic minorities in AD studies. | Track enrollment in NIH AD studies; identify & implement next steps for engaging & enhancing research participation by racial & ethnic minorities; raise awareness of need for participation. | NIH/NIA, NIH/NIMHD | ACL | Ongoing | NIH/NIA-funded Resource Centers for Minority Aging Research & AD Research Centers held a joint meeting on outreach & education at the GSA annual scientific meeting in 2014 that focused on ways to improve recruitment & retention methods used to encourage diverse volunteers to participate in AD research studies.<br>http://www.nia.nih.gov/alzheimers/alzheimers-disease-research-centers<br><br>http://www.rcmar.ucla.edu/<br><br>http://www.rcmar.ucla.edu/gsa14/overview.php |

| Action Number | Action Description (from Plan) | Method of Action | Lead Agency | Partner(s) | Project Completion Date/Status | Activities in 2014 and 2015 |
|---|---|---|---|---|---|---|
| 1.B.5 | Conduct clinical trials on the most promising pharmacologic interventions. | Identify partnerships with private sector participants to voluntary share information about new & ongoing clinical trials. Develop partnerships to better coordinate federal & private sector review of the status & progress of the trials & emerging opportunities. Review the status & progress of clinical trials annually. | NIH/NIA | VA | Ongoing | NIA's ADCS was renewed in 2013 with additional funding to advance studies of interventions that might not otherwise be tested by industry. http://adcs.org/<br><br>AD Prevention Trials (RFA-AG-13-015) led to funding of 3 new trials to test amyloid clearing treatments. http://grants.nih.gov/grants/guide/rfa-files/RFA-AG-13-015.html<br><br>AD Phase I Clinical Trials (RFA-AG-13-016) led to funding of 1 new trial to evaluate the safety & tolerability of a natural brain steroid. http://grants.nih.gov/grants/guide/rfa-files/RFA-AG-13-016.html<br><br>AMP-AD (Project A) http://www.nia.nih.gov/alzheimers/amp-ad |
| 1.B.6 | Continue clinical trials on the most promising lifestyle interventions. | Conduct annual reviews of the status & progress of clinical trials. | NIH/NIA | VA | Ongoing | Plasticity & Mechanisms of Cognitive Remediation in Older Adults (RFA-AG-14-016) studies will test interventions for remediating age-related cognitive decline. http://grants.nih.gov/grants/guide/rfa-files/RFA-AG-14-016.html |
| **Strategy 1.C: Accelerate Efforts to Identify Early and Presymptomatic Stages of Alzheimer's Disease** | | | | | | |
| 1.C.1 | Identify imaging & biomarkers to monitor disease progression. | Conduct annual reviews of ADNI to identify & monitor disease progression. | NIH/NIA | ADNI Partners | Ongoing | AMP http://www.nih.gov/science/amp/index.htm<br><br>AMP-AD (Project A) http://www.nia.nih.gov/alzheimers/amp-ad |
| 1.C.2 | Maximize collaboration among federal agencies & the private sector. | Identify additional partnership opportunities with the private sector & facilitate collaborative efforts to enhance identification of risk factors & early biomarkers. | NIH/NIA | FDA, CMS | Ongoing | AMP http://www.nih.gov/science/amp/index.htm<br><br>AMP-AD (Projects A & B) http://www.nia.nih.gov/alzheimers/amp-ad |

| Action Number | Action Description (from Plan) | Method of Action | Lead Agency | Partner(s) | Project Completion Date/Status | Activities in 2014 and 2015 |
|---|---|---|---|---|---|---|
| **Strategy 1.D: Coordinate Research with International Public and Private Entities** | | | | | | |
| 1.D.1 | Inventory AD research investments. | Compile portfolios of domestic & international funders of ADRD research & make the information available to public through searchable online database. | NIH/NIA | Alzheimer's Association, other private sector partners | Ongoing | http://iadrp.nia.nih.gov/cadro-web/ |
| 1.D.2 | Expand international outreach to enhance collaboration. | Invite international colleagues to meet & discuss ADRD research priorities & collaboration through regular meetings in person & via teleconference. | NIH/NIA | Alzheimer's Association | Ongoing | IADRFC<br><br>Alzheimer's Association International Conference http://www.alz.org/aaic/overview.asp<br><br>European Union Joint Programming Initiative on Neurodegenerative Diseases Research http://www.neurodegenerationresearch.eu/<br><br>New York Academy http://www.nyas.org/Events/Detail.aspx?cid=a643a4ab-37b7-42f3-b0c9-c5e88909c9b4 |
| **Strategy 1.E: Facilitate Translation of Findings into Medical Practice and Public Health Programs** | | | | | | |
| 1.E.1 | Identify ways to compress the time between target identification & release of pharmacological treatments. | Examine current average time & identify places where the timeline could be shortened. Release report. | ASPE, NIH/NIA | FDA | January 2015 | |
| 1.E.2 | Leverage public-private collaborations to facilitate dissemination, translation, & implementation of research findings. | Disseminate research findings through various media & in partnership with organizations, particularly those involving interventions in treatment & care. | NIH/NIA | FDA, ACL, CDC, partner organizations | Ongoing | Assessing Cognitive Impairment in Older Patients: A Quick Guide for Primary Care Physicians http://www.nia.nih.gov/alzheimers/publication/assessing-cognitive-impairment-older-patients |
| 1.E.3 | Continue to promote use of ADEAR to educate the public about the latest research findings. | Prepare & disseminate regular reports on ADRD research findings. | NIH/NIA | NIH/NIA ADEAR, ACL, CDC, FDA, CMS, HRSA, VA, partner organizations | Ongoing | ADEAR Center http://www.nia.nih.gov/alzheimers |

| Action Number | Action Description (from Plan) | Method of Action | Lead Agency | Partner(s) | Project Completion Date/Status | Activities in 2014 and 2015 |
|---|---|---|---|---|---|---|
| 1.E.4 | Issue guidance about drugs for early stage AD. | Issue recommendations about standards for evaluating the effectiveness of treatments for early stage AD. | FDA | | Ongoing | Draft Guidance for Industry: AD: Developing Drugs for the Treatment of Early Stage Disease http://www.fda.gov/Training/GuidanceWebinars/ucm345077.htm |
| 1.E.5 | Expand & disseminate research on co-occurring conditions & dementias. | Literature review to be disseminated through CDC's public health network, ACL/AoA's Aging Network, & NIA research network. | CDC | ACL/AoA, NIH/NIA | December 2015 | |
| 1.E.6 | Provide information to the public on brain health. | Develop & disseminate a brain health resource to aging, disability, & public health professionals. | ACL/AoA, NIH/NIA, CDC | CMS, HRSA, VA, private partners | Ongoing | Brain Health resource http://www.acl.gov/Get_Help/BrainHealth/Index.aspx |
| 1.E.7 | Synthesize evidence on non-pharmacologic interventions to manage behavioral symptoms in people with dementia. | Review existing evidence; publish report on findings. | AHRQ, NIH/NIA | | Ongoing; Research protocol completed 2014 | Research protocol http://effectivehealthcare.ahrq.gov/search-for-guides-reviews-and-reports/?pageaction=displayproduct&productid=1999 |
| 1.E.8 | Leverage research in areas related to neurodegeneration. | Initiate series of joint meetings. | DoD | VA | Ongoing | |
| ***Goal 2: Enhance Care Quality and Efficiency*** | | | | | | |
| **Strategy 2.A: Build a Workforce with the Skills to Provide High-Quality Care** | | | | | | |
| 2.A.1 | Educate health care providers. | Educate providers through HRSA's Geriatrics Centers about how to: (1) work with people with the disease, & their families; (2) link people to support services in the community, identify signs of caregiver burden & depression; & (3) detect cognitive impairment & assess/diagnose ADRD. | HRSA | CMS-NIH/NIA-CDC collaboration | Ongoing | NIA produced & disseminated Assessing Cognitive Impairment in Older Patients: A Quick Guide for Primary Care Physicians. http://www.nia.nih.gov/alzheimers/publication/assessing-cognitive-impairment-older-patients |

| Action Number | Action Description (from Plan) | Method of Action | Lead Agency | Partner(s) | Project Completion Date/Status | Activities in 2014 and 2015 |
|---|---|---|---|---|---|---|
| 2.A.2 | Encourage providers to pursue careers in geriatric specialties. | Educate providers about opportunities through: (1) the CGEP; (2) the Geriatric Academic Career Awards Program; & (3) training projects that provide fellowships for individuals studying to be geriatricians, geriatric dentists, or geriatric psychiatrists. | HRSA | | Ongoing | |
| 2.A.3 | Collect & disseminate dementia-specific guidelines & curricula for provider groups across the care spectrum. | Convene meeting with public-private partners. Develop voluntary dementia-specific guidelines & curricula. Develop website with appropriate links & contact information. | HRSA | VA, CMS, NIH, IHS | Completed | Links are in the process of being developed & will be posted later in 2015. |
| 2.A.4 | Strengthen the direct care workforce. | Release training for the nursing home direct care workforce. | CMS | AHRQ | Completed | |
| 2.A.5 | Strengthen state aging, public health, & intellectual & developmental disability workforces. | Educate the workforces through various means including online training, webinars, fact sheets & other tools. | HRSA | ACL/AoA | Ongoing | |
| 2.A.6 | Support state & local AD strategies. | Share best practices with states. | ACL/AoA | ASPE, CDC, HRSA | Completed | |
| 2.A.7 | Develop & disseminate a voluntary unified primary care AD curriculum. | Develop a voluntary curriculum for primary care practitioners. | HRSA | CMS, NIH/NIA, VA | September 2016 | |

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| 2.A.8 | Ensure aging & public health network providers have access to research-based up-to-date information on AD. | Webinars with representatives from the Aging Network, ADCs, ADEAR, the National Alzheimer's Call Center & Elder Locator, Alzheimers.gov & other federal partners to ensure aging & public health workforces receive recent, updated & culturally-competent information. | ACL/AoA, NIH/NIA | CDC | Ongoing | Free continuing education is available to professionals who need it when they view recorded webinars. This continuing education is available through 2016. http://www.aoa.acl.gov/AoA_Programs/HPW/Alz_Grants/index.aspx#resources |
| 2.A.9 | Engage the public health workforce on brain health. | Conduct briefings with federal, state, & local public-private partners regarding The HBI: The Public Health Road Map for State & National Partnerships, 2013-2018. | CDC | ACL, NIH/NIA | Completed | HBI: The Public Health Road Map for State & National Partnership, 2013-2018. http://www.cdc.gov/aging/pdf/2013-healthy-brain-initiative.pdf |
| 2.A.10 | Educate providers about federal programs to address AD. | Hold a series of webinars to teach Geriatrics Program grantees about existing federal programs & opportunities to partner & collaborate with grantees in other federal agencies. | HRSA | ACL, AHRQ, CDC, CMS, IHS, NIH/NIA, SAMHSA, VA | Completed | |
| 2.A.11 | Strengthen the ability of primary care teams in Indian Country to meet the needs of people with AD & their caregivers. | Incorporate training for AD into the online continuing education curriculum for IHS/tribal/urban program nursing. | IHS | | Ongoing | |
| 2.A.12 | Enhance the ability of LTCO to support people with AD. | Train LTCO as "Hand-in-Hand" trainers. | ACL/AoA | CMS | Completed | |

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| 2.A.13 | Strengthen states' ability to provide & sustain dementia-capable HCBS. | Grants to states & technical assistance on high-quality person-centered dementia care. Develop learning collaboration & tool to evaluate dementia capability. | ACL/AoA | CMS | Ongoing | |
| 2.A.14 | Fill service gaps in dementia-capable systems by expanding the availability of specialized services & supports to target previously underserved populations. | Grants to states & localities. | ACL/AoA | CMS | Ongoing | |
| 2.A.15 | Strengthen the long-term care workforce. | Provide technical assistance to states. | DoL, CMS | HHS | Technical assistance ongoing | Final Rule issued October 2013. |
| 2.A.16 | Improve home & community-based LTSS provided through state Medicaid waivers. | Hold webinars, national calls, & provide information to key stakeholders. | CMS | | Ongoing | |
| **Strategy 2.B: Ensure Timely and Accurate Diagnosis** | | | | | | |
| 2.B.1 | Link the public to diagnostic & clinical management services. | Educate the public-providers about the latest evidence on the signs, symptoms, & current methods of diagnosing AD. | ACL, NIH/NIA | | Completed | Webinars http://www.aoa.acl.gov/AoA_Programs/HPW/Alz_Grants/index.aspx |
| 2.B.2 | Identify & disseminate a variety of appropriate assessment tools. | Identify a variety of appropriate assessment tools that can be used in a variety of outpatient settings, including the Medicare Annual Wellness Visit, to assess cognition. Complete the development of the "toolbox" of cognitive assessment tools. Disseminate recommended tools to practitioners. | CMS, NIH/NIA | CDC | Ongoing | Searchable database of assessment tools http://www.nia.nih.gov/research/cognitive-instrument<br><br>Updated fact sheet on Annual Wellness Visit to FFS Medicare providers http://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/Downloads/AWV_Chart_ICN905706.pdf |

| Action Number | Action Description (from Plan) | Method of Action | Lead Agency | Partner(s) | Project Completion Date/Status | Activities in 2014 and 2015 |
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| 2.B.3 | Educate family members of & service providers for persons with intellectual disabilities about changes that may indicate the onset of dementia. | Develop fact sheets & tools to aid in identifying the onset of dementia. | ACL/AIDD | National Task Group on Intellectual Disabilities & Dementia Practice | Ongoing | |
| **Strategy 2.C: Educate and Support People with Alzheimer's Disease and Their Families upon Diagnosis** | | | | | | |
| 2.C.1 | Educate physicians & other health care providers about accessing LTSS. | Increase knowledge of available resources among doctors, nurses, & hospitals. | HRSA | CMS, VA, ACL | Ongoing | |
| 2.C.2 | Enhance assistance for people with AD & their caregivers to prepare for care needs. | Strengthen the ability of existing LTSS systems, including the Aging Network, to increase awareness of available family caregiver assessment tools, resource materials from across the government, & support programs designed to educate caregivers & persons with the disease & support programs designed to educate caregivers & persons with the disease. | ACL/AoA | AHRQ, VA, ASPE, NIH/NIA ADEAR | Completed | |
| 2.C.3 | Connect American Indians & Alaska Natives to AD resources. | As new resources become available, they will be distributed through a variety of venues to Indian Country. | IHS | ACL/AoA, NIH/NIA | Ongoing | |

| Action Number | Action Description (from Plan) | Method of Action | Lead Agency | Partner(s) | Project Completion Date/Status | Activities in 2014 and 2015 |
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| **Strategy 2.D: Identify High-Quality Dementia Care Guidelines and Measures Across Care Settings** | | | | | | |
| 2.D.1 | Explore dementia care guidelines measures. | Convene meetings with public-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 & clinical stakeholders, as well as quality measure developers. | CMS | ASPE, AHRQ | Ongoing | |
| 2.D.2 | Identify & review measures of high-quality dementia care. | Develop conceptual framework for measurement of dementia care quality & identify concepts that can be translated into performance measures. | CMS | ASPE, VA, ACL, AHRQ, CDC, FDA, IHS, HRSA, NIH/NIA | Completed | Priority Setting for Healthcare Performance Measurement - AD http://www.qualityforum.org/priority_setting_for_healthcare_performance_measurement_alzheimers_disease.aspx |
| 2.D.3 | Convene an expert panel on advanced dementia. | Convene panel & report on discussion. | HHS/ASPE | IOM, outside experts | Completed | Meetings held in January 2014, September 2014, & January 2015. |
| 2.D.4 | Solicit stakeholder input on meaningful outcomes to drive quality measurement. | Convene listening sessions with relevant stakeholders. | CMS | ASPE | Completed | |
| 2.D.5 | Clarify & disseminate information on privacy, autonomy, & safety issues to physicians. | Develop information & disseminate. | HHS/ASPE, HRSA | | December 2015 | |
| **Strategy 2.E: Explore the Effectiveness of New Models of Care for People with Alzheimer's Disease** | | | | | | |
| 2.E.1 | Evaluate the effectiveness of relevant Innovation Center models for people with AD. | Examine changes in care quality & care coordination among people with AD. | CMS/ Innovation Center | NIH/NIA | Ongoing | |
| 2.E.2 | Evaluate the effectiveness of the Independence at Home Demonstration. | Examine whether health & functional status outcomes are improved among people with AD in this demonstration. | CMS/ Innovation Center | | Ongoing | |

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| 2.E.3 | Share results & lessons learned about new models in the VHA system with federal partners. | Share summary report of completed non-institutional long-term care pilot programs with dementia components. | VA | ASPE, ACL, CMS, HRSA | December 2015 | |
| **Strategy 2.F: Ensure that People with Alzheimer's Disease Experience Safe and Effective Transitions between Care Settings and Systems** | | | | | | |
| 2.F.1 | Identify & promote safer hospital care for persons with AD. | Perform subgroup analysis of Innovation Center models. | CMS/ Innovation Center | | July 2015 | More information is available at http://innovation.cms.gov/initiatives/partnership-for-patients/. |
| 2.F.2 | Implement & evaluate new care models to support effective care transitions for people with AD. | Evaluate care transition demonstration programs. | CMS | ACL/AoA | Ongoing | |
| 2.F.3 | Enhance understanding of avoidable hospitalizations & emergency department use among people with AD. | Release report. | ASPE | | Completed | Hospital & Emergency Department Use by People with ADRD: Final Report http://aspe.hhs.gov/daltcp/reports/2013/adrdhed.shtml |
| 2.F.4 | Identify & disseminate information on interventions to reduce preventable hospitalizations. | Review of interventions that are effective in decreasing preventable hospitalizations & release report. | CDC | NIA, CMS | Completed | |
| 2.F.5 | Assess the adequacy of HIT standards to support the exchange of information at times of referrals & transitions in care for persons with ADRD. | Convene partners to explore feasibility & timing. | ASPE | ONC, CMS | Ongoing | |
| **Strategy 2.G: Advance Coordinated and Integrated Health and Long-Term Services and Supports for Individuals Living with Alzheimer's Disease** | | | | | | |
| 2.G.1 | Review evidence on care coordination models for people with AD. | Convene meeting to review existing research on care coordination models; ask workgroups to define the health & psychosocial outcomes on which the interventions will be evaluated. | ASPE | | Completed | Care Coordination for People with ADRD: Literature Review http://aspe.hhs.gov/daltcp/reports/2013/alzcc.shtml |
| 2.G.2 | Implement & evaluate care coordination models. | Implement & evaluate care coordination models. | CMS/ Innovation Center | | Ongoing | More information available at http://www.integratedcareresourcecenter.com/. |

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| 2.G.3 | Evaluate evidence on care integration. | Issue report on findings. | ASPE | | Ongoing | |
| 2.G.4 | Assess the adequacy of HIT standards for care plans to support the needs of persons with ADRD. | Convene partners to explore feasibility & timing. | ASPE | ONC | Ongoing | |
| **Strategy 2.H: Improve Care for Populations Disproportionally Affected by Alzheimer's Disease and for Populations Facing Care Challenges** | | | | | | |
| 2.H.1 | Create a task force to improve care for these specific populations. | Convene a task force; develop a strategic plan with action steps. | ASPE, ACL/AIDD | ACL, NIH, OD, NIMH | Completed | Improving Care for Populations Disproportionately Affected by ADRD: Report from the Task Force on Specific Populations http://aspe.hhs.gov/daltcp/reports/2013/AlzSpPop.shtml |
| 2.H.2 | Identify steps to ensure access to LTSS for younger people with AD. | Coordinate activities to identify barriers to these supports & make recommendations to the Advisory Council & HHS on ways to address these barriers. | ACL/AoA | ASPE | Completed | Improving Care for Populations Disproportionately Affected by ADRD: Report from the Task Force on Specific Populations http://aspe.hhs.gov/daltcp/reports/2013/AlzSpPop.shtml |
| 2.H.3 | Create an opportunity for providers to discuss services for persons with younger-onset dementia. | Focus webinar for dementia care service providers on care for people with younger-onset dementia. | ACL/AoA | | Completed | More information on webinars available at http://www.aoa.gov/AoARoot/AoA_Programs/HPW/Alz_Grants/index.aspx. |
| 2.H.4 | Enhance understanding of models of family support for people with intellectual disabilities as they age. | Explore promising models, release report. | ASPE | | December 2015 | |
| ***Goal 3: Expand Supports for People with Alzheimer's Disease and Their Families*** | | | | | | |
| **Strategy 3.A: Ensure Receipt of Culturally Sensitive Education, Training, and Support Materials** | | | | | | |
| 3.A.1 | Distribute materials to caregivers. | Distribute training & education materials through federal agencies & state & local networks. | ACL | NIH/NIA, ADEAR | Completed | Information available at http://www.alzheimers.gov.<br><br>Fact sheets http://www.eldercare.gov/eldercare.NET/Public/REsources/Advanced_Care/Index.aspx |
| 3.A.2 | Distribute materials to caregivers. | Distribute training & education materials through federal agencies & state & local networks. | ACL | NIH/NIA, ADEAR | Ongoing | |

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|---|---|---|---|---|---|---|
| 3.A.3 | Utilize HIT for caregivers & persons with AD. | Identify tools, evaluate, & disseminate findings | AHRQ | | July 2016 | Grant awarded (#1P50 HS 019917) & used to create Elder Tree, a suite of electronic services to support older adults & their caregivers. The Elder Tree tool is being evaluated. Results will be available in 2016. |
| **Strategy 3.B: Enable Family Caregivers to Continue to Provide Care while Maintaining Their Own Health and Well-Being** | | | | | | |
| 3.B.1 | Identify unmet service needs. | Release report summarizing analysis of NHATS data. | ASPE | | Completed | Reports available at http://aspe.hhs.gov/daltcp/reports/2014/NHATS.cfm. |
| 3.B.2 | Identify & disseminate best practices for caregiver assessment & referral through the LTSS system. | AoA will explore a public-private partnership to identify best practices in caregiver assessment & referral. This effort will examine caregiver assessment tools used in states. | ACL/AoA | Private partners | Completed | http://caregiver.org/caregiver/jsp/content/pdfs/SelCGAssmtMeas_ResInv_FINAL_12.10.12.pdf |
| 3.B.3 | Review the state of the art of evidence-based interventions that can be delivered by community-based organizations. | Identify measures used to evaluate the evidence-based interventions. | ACL/AoA | Private partners, NIH/NIA, CDC | Completed | http://www.aoa.gov/AoARoot/AoA_Programs/HPW?Alz_Grants/index.aspx |
| 3.B.4 | Develop & disseminate evidence-based interventions for people with AD & 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/AoA | Ongoing | Several new NIA Roybal Centers are developing tools to support caregivers. http://www.nia.nih.gov/research/dbsr/edward-r-roybal-centers-translation-research-behavioral-and-social-sciences-aging<br><br>NIA commissioned papers identified research needs related to AD caregiving. http://www.nia.nih.gov/sites/default/files/gerald-summary_11-21-14_0.pdf<br><br>Support new research to identify vulnerable caregivers & support their needs, including NSOC survey. http://www.nhats.org/scripts/NSOCOverview.htm<br><br>http://projectreporter.nih.gov/project_info_description.cfm?aid=8502945&icde=24005725 |

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| 3.B.5 | Provide effective caregiver interventions through AD-capable systems. | Work with states to identify caregiver interventions for dissemination. | ACL/AoA | | Ongoing | |
| 3.B.6 | Share lessons learned through VA caregiver support strategies with federal partners. | 2 informational meetings. | VA | Federal partners | Completed | |
| 3.B.7 | Support caregivers in crisis & emergency situations. | Webinars with representatives from the Aging Network, ADCs, & other federal partners. | ACL/AoA | NIH/NIA | Completed | Webinars http://www.aoa.gov/AoARoot/AoA_Programs/HPW/Alz_Grants/index.aspx |
| 3.B.8 | Provide education on respite for caregivers of people with AD. | Develop & disseminate information on respite care for individuals with dementia. | ACL | ARCH National Respite Network | Completed | http://www.archrespite.org/productspublications.arch-fact-sheets |
| 3.B.9 | Collaborate to share information on LTSS with tribal providers. | Various dissemination mechanisms such as webinars & sharing materials with relevant networks. | ACL/AoA | IHS, CMS | Ongoing | |
| 3.B.10 | Share information on caregiver support services between the Aging Network & VA. | Webinars & trainings. | ACL/AoA | VA | Completed | Materials available http://www.adrc-tae.acl.gov/tiki-index.php?page=vdhcbskey&filter=all.%20Search%20for%20Administration%20for%20Community%20Living%20Presentation%20to%20the%20VA%20Network%20and%20VA%20Presentation%20to%20the%20Aging%20&%20Disability%20Services%20Network. |
| 3.B.11 | Pilot evidence-based interventions for caregivers in Indian Country. | Pilot the REACH-VA Family Caregiver intervention in a small number of tribes & disseminate intervention in Indian Country. | IHS, ACL/AoA | VA | Completed | Pilot programs in progress & will be assessed over 2014. |
| 3.B.12 | Continue to promote use of the National Alzheimer's Call Center to provide information, advice, & support to people with dementia or their caregivers. | ACL/AoA will continue to contribute funding to this public-private effort. | ACL/AoA | Alzheimer's Association | Ongoing | |

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| 3.B.13 | Make behavioral symptom management education & training available to caregivers. | Award grants. | ACL/AoA | CMS | September 2014 | |
| 3.B.14 | Develop resources to encourage collaboration between VHA and State Lifespan Respite programs. | Develop & disseminate resources. | ACL/AoA | ACL/AoA, ARCH National Respite Network, VA | August 2015 | |
| 3.B.15 | Educate family caregivers about how to engage in disaster preparedness planning. | Webinar & related print materials will be developed & disseminated to the aging & disability networks to assist family caregivers in developing emergency plans. | ASPR | ACL | April 2014 | |
| 3.B.16 | Enhance understanding of state regulations on residential care & adult day health services. | Develop compendiums on state residential care policies & ADS regulations. | ASPE | CMS | Completed | Regulatory Review of ADS: Final Report http://aspe.hhs.gov/daltcp/reports/2014/adultday14.cfm<br><br>Compendium of Residential Care & Assisted Living Regulations & Policy available fall 2015. |
| 3.B.17 | Examine technological solutions to support family caregivers. | Grant awarded--awaiting results. | AHRQ | | December 2019 | |
| **Strategy 3.C: Assist Families in Planning for Future Care Needs** | | | | | | |
| 3.C.1 | Examine awareness of long-term care needs & barriers to planning for these needs. | Finalize Long-Term Care Awareness Survey; Conduct survey; analyze results; release final report. | ASPE | | Fall 2015 | Survey has been completed, & results are being analyzed. Colloquium to be held in early summer 2015 to release data & results. |
| 3.C.2 | Expand long-term care awareness efforts. | Develop campaign materials. Select states. Implement campaign. | ACL | | Completed | http://www.longtermcare.gov |
| **Strategy 3.D: Maintain the Dignity, Safety and Rights of People with Alzheimer's Disease** | | | | | | |
| 3.D.1 | Educate legal professionals about working with people with AD. | Develop training materials. Conduct training webinars. Provide summary reports of the training webinars. | ACL/AoA | NLRC | Completed | Training materials http://www.aoa.gov/AoARoot/AoA_Programs/HPW/Alz_Grants/index.aspx |

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| 3.D.2 | Monitor, report & reduce inappropriate use of anti-psychotics in nursing homes. | National Partnership to Improve Dementia Care. | CMS | ACL/AoA, NORC | Ongoing | Information for Ombudsman Program http://www.theconsumervoice.org/advocate/antipsychotic-drugs<br><br>http://www.theconsumervoice.org/advocate/antipsychotic-drugs#education<br><br>Other information https://www.nhqualitycampaign.org/star_index.aspx?controls=welcome |
| 3.D.3 | Enhance training to prevent abuse in long-term care setting. | Updated trainings for LTCO. | ACL/AoA | NORC | Completed | |
| 3.D.4 | Incorporate elder abuse awareness into Aging Network activities. | Eldercare Locator & other Aging Network & prevention programs providers to recognize warning signs of abuse. | ACL/AoA | Private partner/grantees | Ongoing | |
| 3.D.5 | Translate & disseminate information on abuse of people with dementia. | Create & disseminate research briefs, fact sheets & webinars. | ACL/AoA | NIH/NIA, DoJ, private partners | Ongoing | |
| 3.D.6 | Improve the ability of legal services to address the needs of people with AD. | Award, monitor, & report on demonstration grants. Revise NLRC website. | ACL/AoA | Legal assistance developers, NLRC | Ongoing | Grants were awarded in July 2013. National LTCO program held a webinar on legal issues related to nursing facility discharge. http://www.ltcombudsman.org/issues/transfer-discharge |
| 3.D.7 | Educate fiduciaries about managing the finances of people with AD. | Release lay fiduciary guide. | CFPB | ACL/AoA | Completed | Lay fiduciary guides http://www.consumerfinance.gov/blog/managing-someone-elses-money/ |
| 3.D.8 | Develop public-private partnerships to combat abuse & exploitation of Social Security beneficiaries. | An interagency, public-private partnership program to address abuse & exploitation of individuals who are incapable of managing their finances. | SSA | ACL/AoA, CNCS, CFPB | Ongoing | |
| 3.D.9 | Educate law enforcement about interacting with AD. | Educate law enforcement & public safety professionals about how to interact appropriately with missing persons with AD. | DoJ | | Ongoing | |

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| 3.D.10 | Work with communities to develop best practices for protecting people with AD. | A guide to educate law enforcement & inform communities, families & caregivers about best practices for protecting persons with AD & preventing them from wandering & becoming lost. | DoJ | | Ongoing | |
| **Strategy 3.E: Assess and Address the Housing Needs of People with Alzheimer's Disease** | | | | | | |
| 3.E.1 | Explore affordable housing models. | Examine housing sites that link health & LTSS. Link HUD & HHS data to understand the older adult population in HUD housing. | ASPE, HUD | ACL | Completed | The Value Added of Linking Publicly Assisted Housing for Low-Income Older Adults with Enhanced Services: A Literature Syntheses & Environmental Scan http://aspe.hhs.gov/daltcp/reports/2012/ValueAdd.shtml<br><br>SASH Evaluation: First Annual Report http://aspe.hhs.gov/daltcp/reports/2014/SASH1.cfm |
| 3.E.2 | Examine patterns of housing & services. | Study where people with AD live & availability of services in those settings. | ASPE, CDC/NCHS | ACL | Completed | Data brief http://www.cdc.gov/nchs/data/databriefs/db134.htm |
| ***Goal 4: Enhance Public Awareness and Engagement*** | | | | | | |
| **Strategy 4.A: Educate the Public about Alzheimer's Disease** | | | | | | |
| 4.A.1 | Design & conduct a national education & outreach initiative. | Design a national education & outreach initiative & implement with states, local governments, & NGOs. | ACL/AoA | CDC, CMS, HRSA, IHS NIH/NIA, ASPE, VA | Ongoing | |
| 4.A.2 | Enhance public outreach about AD. | Update website & ADEAR site/publications & disseminate information through social media. | ACL/AoA NIH/NIA | | Ongoing | http://www.eldercare.gov<br><br>NIH/NIA ADEAR http://www.nia.nih.gov/alzheimers |

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| **Strategy 4.B: Work with State, Tribal, and Local Governments to Improve Coordination and Identify Model Initiatives to Advance Alzheimer's Disease Awareness and Readiness across the Government** | | | | | | |
| 4.B.1 | Convene leaders from state, tribal, & local governments. | Convene to identify steps for raising AD awareness & readiness. Develop an agenda for supporting these efforts. | IEA | ASPE, ASPA, ACL/AoA | Completed | |
| 4.B.2 | Continue to convene federal partners. | Convene to share research findings, innovative or best practices, & information about new or upcoming initiatives. | ASPE | CDC, NIH/NIA, ACL/AoA, CMS, HRSA, AHRQ, IHS, SAMHSA, OASH, VA, NSF, DoD | Ongoing | |
| 4.B.3 | Build upon lessons learned to improve the dementia-capability of state & local service systems. | Expand Dementia Capability Toolkit to include educational materials on identifying persons with cognitive impairment, direct links to tools, & examples of best practices in other states. | ACL/AoA | CMS | Ongoing | ADSSP learning collaborative results http://www.aoa.gov/AoARoot/AoA_Programs/HPW/Alz_Grants/index.aspx |
| 4.B.4 | Get tribal input on AD. | Convene tribal leaders. | IHS | ASPE, ACL/AoA | Ongoing | |
| 4.B.5 | Support improved coordination between IHS, tribal, & urban Indian Health programs & the Tribal Aging Network around 4 person-centered goals. | Improve coordination between IHS, tribal, & urban Indian health programs & the Tribal Aging Network around 4 person-centered goals. | IHS | ASPE, ACL/AoA | Ongoing | |

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| | | IHS & ACL will adapt the VA approach to dementia warning signs & pilot-test it in clinical & community-based settings. IHS & ACL will partner with AD advocacy organizations to link state & local chapters with Tribal Senior Centers & IHS, tribal, & urban Indian Health Programs. | IHS, ACL/AoA | VA | Ongoing | |
| **Strategy 4.C: Coordinate United States Efforts with Those of the Global Community** | | | | | | |
| 4.C.1 | Work with global partners to enhance collaboration. | Convene global partners in collaboration with G8 Dementia Summit. | ASPE | | Ongoing | US participated in legacy meetings throughout 2014. US hosted the final legacy meeting in February 2015, & was represented at the WHO dementia meeting in Geneva in March 2015. |
| ***Goal 5: Improve Data to Track Progress*** | | | | | | |
| **Strategy 5.A: Enhance the Federal Government's Ability to Track Progress** | | | | | | |
| 5.A.1 | Identify major policy research needs. | Convene federal partners to identify current & future policy & research questions. Identify gaps in data. | ASPE | CMS, CDC, NIH/NIA, ACL/AoA, VA, IHS | Ongoing | |
| 5.A.2 | Identify needed changes or additions to data. | Work with federal partners & researchers. | ASPE | CMS, CDC, NIH/NIA, ACL/AoA, VA, IHS | Ongoing | |
| 5.A.3 | Make needed improvements to data. | Develop questions to be fielded for data collection. Add to surveys. | ASPE | CDC/NCHS, NIH/NIA | Ongoing | |
| 5.A.4 | Summarize data on cognitive impairment across states. | Report on 2012 BRFSS data on perceptions about increased confusion & memory loss. | CDC | | Completed | |
| 5.A.5 | Develop & disseminate measures of awareness of AD. | Release report on validated survey questions. | CDC | | October 2015 | |
| 5.A.6 | Summarize existing data on people with AD & their caregivers. | Develop & release chartbook. | ASPE | CDC/NCHS, NIH/NIA, ACL/AoA | Ongoing | |

| Action Number | Action Description (from Plan) | Method of Action | Lead Agency | Partner(s) | Project Completion Date/Status | Activities in 2014 and 2015 |
|---|---|---|---|---|---|---|
| 5.A.7 | Develop a consistent set of ICD-9/ICD-10 codes for AD & dementia for federal agencies to use in analyses of administrative data. | Convene interagency group to reach consensus. Crosswalk to ICD-10 codes. | ASPE | CMS, VA, NIH, IHS | Ongoing | |
| **Strategy 5.B: Monitor Progress on the National Plan** | | | | | | |
| 5.B.1 | Designate responsibility for action implementation. | Designate office. | ASPE | | Completed | |
| 5.B.2 | Track plan progress. | Track progress on the plan, & incorporate measures into other efforts to monitor population health such as Healthy People 2020. | ASPE | | Ongoing | |
| 5.B.3 | Update the National Plan annually. | Release updated National Plan. | ASPE | | Ongoing | |

# 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. 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

| | |
|---|---|
| A4 | Anti-Amyloid Treatment in Asymptomatic Alzheimer's |
| ACL | Administration for Community Living |
| AD | Alzheimer's Disease |
| ADC | Alzheimer's Disease Center |
| ADCS | Alzheimer's Disease Cooperative Study |
| 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 |
| ADRD | Alzheimer's Disease-Related Dementias |
| ADS | Adult Day Services |
| ADSP | Alzheimer's Disease Sequencing Project |
| ADSSP | Alzheimer's Disease Supportive Services Program |
| AHRQ | Agency for Healthcare Research and Quality |
| AIDD | Administration on Intellectual and Developmental Disabilities |
| ALS | Amyotrophic Lateral Sclerosis |
| AMP | Accelerating Medicines Partnership |
| AMP-AD | Accelerating Medicines Partnership - Alzheimer's Disease |
| AoA | Administration on Aging |
| ASPA | Office of the Assistant Secretary for Public Affairs |
| ASPE | Office of the Assistant Secretary for Planning and Evaluation |
| ASPR | Office of the Assistant Secretary for Preparedness and Response |
| BRFSS | Behavioral Risk Factor Surveillance System |
| CADRO | Common Alzheimer's Disease Research Ontology |
| CDC | Centers for Disease Control and Prevention |
| CEOi | Global CEO Initiative on Alzheimer's Disease |
| CFPB | Consumer Finance Protection Bureau |
| CGEP | Comprehensive Geriatric Education Program |
| CMS | Centers for Medicare and Medicaid Services |
| CNCS | Corporation for National and Community Service |
| CSF | Cerebrospinal Fluid |
| DCE | Discrete Choice Experiment |
| DIAN | Dominantly Inherit Alzheimer's Network |
| DNA | Deoxyribonucleic Acid |
| DoD | U.S. Department of Defense |
| DoJ | U.S. Department of Justice |
| DoL | U.S. Department of Labor |
| DSRTF | Down Syndrome Research and Treatment Foundation |
| EHR | Electronic Health Record |
| FDA | Food and Drug Administration |
| FTD | Frontotemporal Dementia |
| FY | Fiscal Year |
| GAO | General Accountability Office |
| GEC | Geriatric Education Center |
| GSA | Gerontological Society of America |
| GWEP | Geriatrics Workforce Enhancement Program |

| | |
|---|---|
| HBI | Healthy Brain Initiative |
| HCBS | Home and Community-Based Services |
| HHS | U.S. Department of Health and Human Services |
| HIPAA | Health Insurance Portability and Accountability Act |
| HIT | Health Information Technology |
| HRSA | Health Resources and Services Administration |
| HUD | U.S. Department of Housing and Urban Development |
| IADRFC | International Alzheimer's Disease Research Funder Consortium |
| IADRP | International Alzheimer's Disease Research Portfolio |
| ICD-9 | International Classification of Diseases, 9th revision |
| ICD-10 | International Classification of Diseases, 10th revision |
| IHS | Indian Health Service |
| IOM | Institute of Medicine |
| LTCO | Long-Term Care Ombudsman |
| LTSS | Long-Term Services and Supports |
| MAPCP | Multipayer Advanced Primary Care Practice |
| MCI | Mild Cognitive Impairment |
| NACSP | National Association for State Community Services Programs |
| NAPA | National Alzheimer's Project Act |
| NCEA | National Center on Elder Abuse |
| NCHS | National Center for Health Statistics |
| NGO | Non-Governmental Organization |
| NHATS | National Health and Aging Trends Study |
| NIA | National Institute on Aging |
| NIH | National Institutes of Health |
| NIMH | National Institute of Mental Health |
| NIMHD | National Institute of Minority Health and Health Disparities |
| NINDS | National Institute of Neurological Disorders and Stroke |
| NLRC | National Legal Resource Center |
| NORC | National Ombudsman Resource Center |
| NQF | National Quality Forum |
| NSF | National Science Foundation |
| NSRCF | National Survey of Residential Care Facilities |
| OASH | Office of the Assistant Secretary for Health |
| OCR | Office of Civil Rights |
| OD | Office on Disability |
| ONC | Office of the National Coordinator for Health Information Technology |
| PCCP | Person-Centered Counseling Professionals |
| PET | Positron Emission Tomography |
| PFEC | Patient and Family Engagement Campaign |
| PRARP | Peer Reviewed Alzheimer's Research Program |
| PRC | Prevention Research Center |
| QIO | Quality Improvement Organization |

| | |
|---|---|
| RDS | Research Down Syndrome |
| REACH | Resources for Enhancing Alzheimer's Caregivers' Health |
| REACH-VA | Resources for Enhancing Alzheimer's Caregivers' Health - VA |
| RFA | Request for Application |
| RFI | Request for Information |
| ROAR | Recruiting Older Adults into Research |
| SAMHSA | Substance Abuse and Mental Health Services Administration |
| SASH | Support and Services at Home |
| SNIFF | Study of Nasal Insulin to Fight Forgetfulness |
| SSA | U.S. Social Security Administration |
| TBI | Traumatic Brain Injury |
| US | United States |
| VA | U.S. Department of Veterans Affairs |
| VD-HCBS | Veteran-Directed Home and Community-Based Services |
| VHA | Veterans Health Administration |
| WHO | World Health Organization |

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