National Plan to Address Alzheimer's Disease: 2014 Update

U.S. Department of Health and Human Services

National Plan to Address Alzheimer's Disease

The National Plan to Address Alzheimer's Disease is updated yearly by the Advisory Council on Alzheimer's Research, Care and Services. Below is a list of the current versions available online.

Other National Plan information, as well as an interactive index list of Goals and Strategies, is also available online at https://aspe.hhs.gov/national-plans-address-alzheimers-disease.

National Plan to Address Alzheimer's Disease: 2017 Update

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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 for ethnic and racial minority populations that are at higher risk for Alzheimer's disease.
- Coordinate with international bodies to fight Alzheimer's 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 (AD).

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 AD and their family members, public policy makers, and health and social service providers.

Progress in the Fight Against Alzheimer's Disease and Related Dementias

The first National Plan to Address Alzheimer's Disease was released on May 15, 2012, following the Obama Administration's investment in Alzheimer's research, provider education, and awareness in February 2012. The 2013 Update to the National Plan was released on June 14, 2013. Highlights of some initiatives and scientific findings since the 2013 Update are described below.

Research and Scientific Discovery

The National Institutes of Health (NIH) reports annually on progress in Alzheimer's disease research. The Alzheimer's Disease Progress Report, available online and updated each spring along with this Plan, describes how the NIH research portfolio is both informed by and supportive of the Plan. It provides a comprehensive outline of what we know about Alzheimer's disease and how NIH-supported research is targeting the Plan's research goal. [See the 2012-2013 report at http://www.nia.nih.gov/alzheimers/publication/2012-2013-alzheimers-disease-progress-report.]

Understanding cognitive health can increase our ability to prevent its decline as people age. In late 2013, NIH partnered with the AARP and the McKnight Brain Research Foundation in supporting a new Institute of Medicine study on the Public Health Dimensions of Cognitive Aging and Health. This committee will make recommendations focused on the public health aspects of cognitive aging with an emphasis on definitions and terminology; epidemiology and surveillance, prevention and intervention opportunities; education of health professionals; and public awareness and education. In the meantime, following up with participants in the Advanced Cognitive Training for Independent and Vital Elderly (ACTIVE), a randomized clinical trial supported by NIH, researchers showed that training to improve reasoning and speed of processing in older people lasted to some degree 10 years after the training program was completed demonstrating that particular types of cognitive training can provide a lasting benefit and suggesting that cognitive training as an intervention that might help maintain the mental abilities of older people so that they may remain independent and in the community.[1]

NIH, ten biopharmaceutical companies, and several non-profit organizations have designed an unprecedented new partnership. The Accelerating Medicines Partnership (AMP) brings high-level government, industry, and non-profit organization partners together to identify and validate the most promising biological targets of disease for new diagnostic and drug development. The partners have designed a bold milestone-driven research plan to tackle this challenge for Alzheimer's disease with data and analyses made publicly available to the broad biomedical community. AMP proposes to: (a) identify markers of the disease (biomarkers) that can predict clinical outcomes by incorporating selected biomarkers into four NIH-funded clinical trials, which include industry support, designed to delay or prevent disease onset; and (b) conduct a large-scale analysis of human AD patient brain tissue samples, that have been donated with appropriate consent, to validate biological targets previously shown to play key roles in disease progression and, more significantly, to increase our understanding of the molecular pathways involved in the disease to identify new potential therapeutic targets. While past studies have demonstrated the promise of several AD biomarkers, AMP aims to establish an expanded set of biomarkers that can be embedded in therapeutic trials as well as identify new biological targets for drug development.

NIH is supporting a large intramural research project in which researchers will perform whole exome sequencing of DNA samples from over 1,500 people with Frontotemporal Dementia (FTD) and 1,300 people with Dementia with Lewy Bodies (DLB) to characterize chromosomal regions that are associated with a risk of developing these diseases. This project is part of a large international collaboration to understand the genetic causes of these AD-related dementias.

An NIH-funded consortium of investigators will be developing induced pluripotent stem cells (iPSCs) as a model system for FTD. The iPSCs developed by this consortium will allow scientists to study the effects of disease-causing human mutations on brain cells and test new therapies, all in a culture dish.

Meanwhile, ongoing research has led to exciting discoveries. For example, a number of risk-conferring genes for late-onset Alzheimer's disease, the most common form of the disorder, have been confirmed. Most recently, two international teams of scientists, with NIH support, identified a rare variation of the TREM2 gene as a moderate risk factor for late-onset Alzheimer's. A causative relationship was also demonstrated between homozygous TREM2 mutations and FTD. Because TREM2 is involved in inflammation and immune response, this finding may offer a target for interventions.[2]

In addition, NIH-supported researchers working as part of the International Genomic Alzheimer's Project (IGAP) have identified 11 new genes that offer important new insights into the disease pathways involved in Alzheimer's disease. The highly collaborative effort involved scanning the DNA of over 74,000 volunteers -- the largest genetic analysis yet conducted in Alzheimer's research -- to discover new genetic risk factors linked to late-onset Alzheimer's disease, the most common form of the disorder. By confirming or suggesting new processes that may influence Alzheimer's disease development such as inflammation and synaptic function, the findings point to possible targets for the development of drugs aimed directly at prevention or delaying disease progression.[3] [For a review of recent research on the

Genetics of Alzheimer's Disease, go to http://www.nia.nih.gov/alzheimers/publication/2012-2013-alzheimers-disease-progress-report/genetics-alzheimers-disease.]

NIH-supported research by two groups of scientists showed that tau spreads from one brain region to the next by moving across synapses. The researchers used mouse models that express tau protein, a hallmark of the disease. As the mice aged, the mutant tau gradually spread across the connected brain regions. These findings demonstrate one mechanism by which Alzheimer's pathology can spread and offer new targets for therapies.[4]

More studies indicate that vascular disease contributes to the development and progression of AD. In a recent study, researchers used transgenic mice to study how beta-amyloid, a molecule that accumulates in the brains of people with AD, interacts with pericytes, cells that are important for controlling the movement of molecules into and out of blood vessels in the brain. Their results suggest that beta-amyloid deposition impairs the function of pericytes, decreasing their ability to remove beta-amyloid from the brain and causing further accumulation. These findings suggest that pericytes and other blood-brain barrier cells may be new therapeutic targets for treating Alzheimer's disease.[5]

A mutation in the C9orf72 gene is the most common cause of the familial form of FTD. In a recent study, NIH-supported researchers showed that the C9orf72 mutation alters the three-dimensional shape of DNA and interferes with RNA transcription, resulting in short, misfolded RNA transcripts. Using iPSCs, the researchers identified a molecular mechanism by which these misfolded transcripts interfere with normal cell function and may contribute to neuronal degeneration. This study demonstrates the power of using iPSCs to understand the mechanisms underlying brain diseases and identifies a potential molecular target for new therapies.[6]

One function of sleep may be to allow the brain to rid itself of toxic molecules, including beta-amyloid. Using mice, researchers showed that the fluid-filled space between brain cells increases during sleep, allowing the cerebrospinal fluid to flush out toxins that build up during waking hours. The researchers then showed that radiolabeled beta-amyloid injected into the brains of mice disappeared faster when the mice were asleep, suggesting sleep clears toxic molecules from the brain.[7]

Lastly, NIH-funded researchers have also tested interventions to alleviate psychiatric conditions and symptoms, such as agitation, that distress people with AD and their caregivers. In February 2014, researchers published the results of a trial showing that the antidepressant citalopram led to significant improvement in agitation symptoms in 49% of those treated, compared to 26% of participants receiving a placebo. Citalopram volunteers also showed some decline in cognition and heart function. However, in light of the even greater heart health risks associated with antipsychotic treatments, the researchers concluded that citalopram, especially in lower doses, may be a more effective and safer alternative to treating agitation in Alzheimer's patients.[8]

Improving Care and Supports

The Health Resources and Services Administration (HRSA) continued its work to educate health care providers about Alzheimer's disease. In the first 6 months of FY 2013, the Geriatric Education Centers (GECs) trained an additional 23,000 people. 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 patients with Alzheimer's disease and improve early detection in primary care and outpatient settings.

The trainings created by the GECs through this program are appropriate for interprofessional audiences, and are available in a variety of educational modalities, from face-to-face conferences and workshops to on-demand websites that house videos and copies of other enduring educational materials. The Gateway GEC of Missouri and Illinois was able to take some of the AD curricula that was created for a new annual regional AD conference and reuse it for an international nursing home conference that was sponsored by the World Health Organization, thus giving the AD curricula an international audience. The Arizona GEC has created three Elder Care provider sheets that address dementia, which are posted on multiple websites including Alzheimer's Disease Education and Referral (ADEAR) Center [http://www.nia.nih.gov/alzheimers], Portal of Geriatric Online Education [http://www.pogoe.org/] and MedEdPORTAL [http://www.mededportal.org/]. Two of the provider sheets were published in a special Alzheimer's disease update in the *Arizona Geriatric Society Journal* in 2013 [http://www.arizonageriatrics.org/assets/2013/2013FallJournal/azgsjournal%20web%2010-17-13.pdf] and disseminated to an estimated 1,500 health care providers in Arizona. The State of Wisconsin developed a discussion group that introduces a "Most Difficult Dementia Case" once a month, which is discussed by telephone by clinicians throughout the states. This program allows providers to problem solve together about how to resolve real-life medical, social and financial issues that arise in individual AD cases. In addition, grantees have created materials in a variety of languages including Spanish, Chinese, Vietnamese, and Arabic in order to better address the needs of their local communities.

As a result of the Comprehensive Geriatric Education Program (CGEP), a program to support students pursuing advanced degrees in geriatric nursing, long-term services and supports (LTSS), and gero-psychiatric nursing, schools of nursing are actively integrating evidence-based content into their graduate and undergraduate curricula on Alzheimer's disease. The CGEP grantees are a major resource for nurses and unlicensed personnel who provide care to individuals with dementia. Mary Hitchcock Memorial Hospital is one such grantee, and has offered continuing education courses on palliation, difficult decisions, and sexuality among individuals with AD. The New York Institute of Technology CGEP project staff are teaching first responders about Alzheimer's disease, and how to work with individuals in emergent situations. CGEP grantees have reached several thousand health care providers in the last year alone.

In addition, HRSA continues to support training projects that provide fellowships for individuals studying to be geriatricians, geriatric dentists, or geriatric psychiatrists which are designed to prepare professionals to address the needs of people with Alzheimer's disease. The program currently includes 26 geriatric medicine fellows, 15 geriatric psychiatry fellows, and 17 geriatric dentistry fellows who are learning how to evaluate individuals for dementia and to manage their care needs. The fellows then teach medical and dental students basic health care management for persons with dementia. Fellows at Mount Sinai Medical School, for example, also do presentations to community groups on how to recognize and cope with Alzheimer's disease and other dementias. Oral health among individuals with dementia has been generally neglected, and the geriatric dental fellows are working to reverse that practice. Not only are they providing dental care to persons with dementia, they are teaching long-term care staff how to manage oral health needs, and how to identify the need for dental care.

The National Partnership to Improve Dementia Care in Nursing Homes, a multifaceted public-private partnership to improve person-centered care, has led to improvements in the inappropriate use of antipsychotics. The results are promising. In less than 2 years, this effort led to over a 15% reduction in the rate of antipsychotic use by long-stay nursing home residents. [More information is available at https://www.nhqualitycampaign.org/star_index.aspx?controls=dementiaCare.]

The Administration for Community Living's (ACL's) Administration on Aging (AoA) released a report analyzing the results of 6 years of grants under the Alzheimer's Disease Supportive Services Program (ADSSP). The grant projects that have ended generally achieved results similar to those of the original, evidence-based interventions. The report also describes a number of innovations, including one of the first states to require dementia training for certain home and community-based services (HCBS) staff statewide. [http://www.aoa.gov/AoARoot/AoA_Programs/HPW/Alz_Grants/index.aspx]

ACL/AoA funded three learning collaboratives for ADSSP grantees designed to promote dementia capable HCBS systems. The collaboratives produced reports on assessment of cognitive impairment, dementia care training, and quality assurance measures. These reports describe grantee experiences and consensus so as to help states wishing to develop dementia capable systems. [http://www.aoa.gov/AoARoot/AoA_Programs/HPW/Alz_Grants/index.aspx]

To continue to support the ADSSP work, ACL/AoA awarded five new grants to enable states to develop dementia capable HCBS systems, under the leadership of a lead state agency for dementia. States that received these grants are Arizona, California, Illinois, Maine, and Oregon and they have 3 years to develop their systems.

Interagency Collaborations

In 2013, the National Institute on Aging (NIA) and ACL joined forces to create "Connecting to Combat Alzheimer's," a series of free webinars and presentations that connected the research and aging services communities [http://www.aoa.gov/AoARoot/AoA_Programs/HPW/Alz_Grants/index.aspx#resources]. Sparked by the goals set forth by NAPA, the highly successful effort involved the ACL/AoA Aging Services Network, which annually reaches over 10 million older people and family caregivers, and researchers at the NIH-funded network of Alzheimer's Disease Centers (ADCs).

As follow-on to this project, NIA and ACL, joined by the Centers for Disease Control and Prevention (CDC), launched the Recruiting Older Adults into Research (ROAR) project. This project connects ACL and CDC's networks of state and community-based health and social service providers, as well as existing research registries (ResearchMatch, the Alzheimer's Association's TrialMatch, and the Alzheimer's Prevention Registry) with researchers and private organizations to encourage older adults to participate in research. The effort focuses on raising awareness, enhancing knowledge and connecting gatekeepers and older adults with easy, actionable opportunities for research participation, starting with Alzheimer's disease research. The goal of the ROAR project is to address the barriers to research participation such as lack of awareness about clinical trials and how to find research opportunities and significantly increase older adult enrollment in research registries, which provide researchers with a larger sample of people to enroll in current and future research studies.

HHS is committed to tracking the progress of the National Plan. A detailed timeline with steps for each of the actions is available in Appendix 2.

2014 Update

This is the 2014 Update to the National Plan. Like the original, this update includes recommendations for priority actions. The activities outlined in this plan vary in scope and impact and include: (1) immediate actions that the Federal Government 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 are needed to achieve the goals. In the case of many of the long-range activities, the path forward will be contingent on resources, scientific progress, and focused collaborations across many partners. Over time, HHS will work with the Advisory Council and stakeholders to incorporate additional transformative actions.

Alzheimer's Disease and Related Dementias

Alzheimer's disease is an irreversible, progressive brain disease that affects as many as 5.1 million Americans.[9] 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 and self-care).[10] 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 Alzheimer's disease.[11]

In addition to Alzheimer's disease, this plan addresses Alzheimer's disease-related dementias, consistent with the approach Congress used in NAPA. Related dementias include frontotemporal, Lewy body, mixed, and vascular dementias. It is often difficult to distinguish between Alzheimer's disease and other dementias 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 National Plan are designed to address these conditions collectively.

The first symptom of AD is often memory impairment. As the disease progresses, memory continues to decline, and other functions like language skills and decision making become more difficult. Personality and behavior changes may also occur. Over time, a person with the disease may no longer recognize family and friends. Eventually, the person who survives with Alzheimer's disease is completely reliant on others for assistance with even the most basic activities of daily living, such as eating.[12,13]

In more than 90% of people with Alzheimer's disease, symptoms do not appear until after age 60, and the incidence of the disease increases with age. The causes of AD are not completely understood, but researchers believe they include a combination of genetic, environmental, and lifestyle factors.[14] The importance of any one of these factors in increasing or decreasing the risk of developing AD 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.

AD 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 AD 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 40 million in 2010 to 72.1 million in 2030. The prevalence of people with AD 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 2010 and 2030 (from 5.5 million to 8.7 million) suggests a substantial increase in the number of people with AD.

Alzheimer's disease places enormous emotional, physical, and financial stress on individuals who have it and their family members. Informal caregivers, such as family members and friends, provide the majority of care for people with AD in the community. Informal caregivers often do not identify themselves as such; they are simply a wife, daughter, husband, son, or friend helping a person whom they care about. However, the intensive support required for a person with AD can negatively impact the caregiver's emotional and physical health and well-being. Informal caregivers often report symptoms of depression and anxiety, and have poorer health outcomes than their peers who do not provide such care.[15]

Dementia care costs are significant and often a burden to families providing unpaid care. Recent estimates from one nationally representative study found that formal and informal 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 LTSS, and the two different estimates of the value of informal, 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 informal care costs were estimated. These national dementia care costs are comparable to, if not greater than, those for heart disease and cancer.[16]

Caring for people with Alzheimer's disease also strains health and long-term care systems. Individuals with Alzheimer's disease 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.[17] Similarly, while people living in nursing homes are a small percentage of the older population, nearly half (48%) of nursing home residents have Alzheimer's disease.[18] As the number of people with AD 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.

The Challenges

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

1. While research on AD 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 Alzheimer's care and to improve the training of the health and long-term care workforce, there is room for improvement.

3. Family members and other informal caregivers, who take on the responsibility of caring for a loved one with AD, need support. The majority of people with AD 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.[19,20]

4. Stigmas and misconceptions associated with AD are widespread and profoundly impact the care provided to and the isolation felt by people with AD 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 AD are limited.

Framework and Guiding Principles

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

Central to and guiding the National Plan are the people most intimately impacted by Alzheimer's disease -- those who have the disease and their families and other caregivers. Individuals with AD and their caregivers receive assistance from both the clinical health care system and support systems such as long-term care, home care, legal services, and other social services. Both the clinical care and support environments need better tools to serve people with Alzheimer's disease and their caregivers. Ongoing and future research seeks to identify interventions to assist clinicians, supportive service providers, persons with AD, 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 National 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 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 AD. 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 Alzheimer's disease. The activities included in the inventory comprise ongoing work and new opportunities created by the Affordable Care Act. The federal working group process has already led to improved 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 Alzheimer's disease is so great that partnerships with a multitude of 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 Alzheimer's disease***. The National Plan represents a first step in an 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 National 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 will identify the most promising areas for progress and marshal resources from both within and outside the government to act on these opportunities.

Goals as Building Blocks for Transformation

Achieving the vision of eliminating the burden of Alzheimer's disease 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.

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 Alzheimer's disease, 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 Alzheimer's disease can benefit from increases in scientific knowledge. HHS will identify interim milestones and set ambitious deadlines for achieving these milestones in order to meet this goal.

Strategy 1.A: Identify Research Priorities and Milestones

Research agencies undertake research planning processes on an ongoing basis, but a special effort is needed to identify the priorities and milestones to achieve Goal 1. The actions below will identify the priorities, establish milestones, and ensure that appropriate stakeholders are involved in the planning process aimed at minimizing Alzheimer's disease as a health burden by 2025. During the course of this work, NIH will develop research priorities, and a plan for implementing each phase of research in a coordinated manner. Coordination will occur across NIH institutes and other federal research agencies and with the private sector, as appropriate.

(Updated) Action 1.A.1: Regularly convene an Alzheimer's Disease Research Summit to update priorities

The first *Alzheimer's Disease Research Summit* was held in May 2012. Recommendations, the transcript, and a list of public comments are posted on the Summit website. HHS will convene a second international *Alzheimer's Disease Research Summit* in February 2015 to revisit priorities, milestones, and a timeline. Following the 2015 Summit, NIA will release a report summarizing the recommendations and update the National Plan as appropriate. The 2015 Summit will include national and international experts, research funders, public and private stakeholders, and members of the Advisory Council. Summit proceedings will be open to the public. [http://www.nia.nih.gov/about/events/2012/alzheimers-disease-research-summit-2012-path-treatment-and-prevention]

(Updated) Action 1.A.2: Solicit public and private input on Alzheimer's disease research priorities

A Request for Information (RFI) on Alzheimer's disease research priorities was published in May 2012 and information was collected. Webinars were held with funders, and a funders meeting was held in July 2012 at the *Alzheimer's Association International Conference* to encourage input. Periodic teleconferences of the International Alzheimer's Disease Research Funder Consortium (IADRFC) coordinated by the Alzheimer's Association working with NIA facilitate continuing dialogue among funders about research priorities. Public input through the NIH *Alzheimer's Disease Research Summits* and similar conferences supported by efforts such as the Global CEO Initiative on Alzheimer's Disease (CEOi) continue to provide input to inform research priorities. [http://www.ceoalzheimersinitiative.org/]

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

HHS and its federal partners will use the input received through the *Alzheimer's Disease Research Summit*, the CEOi, and the RFI to inform implementation of the National Plan. An updated Goal 1 will reflect the priorities, milestones, and timeline elements identified through these processes to accelerate research in this area. These will be incorporated into the next iteration of the National Plan and will be updated on an annual basis with the input of the Advisory Council.

(Completed) Action 1.A.4: Convene a scientific workshop on other dementias in 2013

National Institute of Neurological Disorders and Stroke (NINDS), in collaboration with NIA, convened a research workshop on *Alzheimer's Disease-Related Dementias* (ADRD), May 1-2, 2013 to solicit input on special research priorities and timelines for addressing dementias related to Alzheimer's disease. Participants included national and international experts, federal funders of research, public and private stakeholders, and members of the Advisory Council. The final report, which includes recommendations for research priorities, can be found at http://www.ninds.nih.gov/ADRD2013. The prioritized recommendations will be used to update the National Plan as appropriate.

Action 1.A.5: Update research priorities and milestones

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

(Updated) Action 1.A.6: Create a timeline with milestones for achieving Goal 1

A number of immediate, medium, and long-term actions are needed to achieve Goal 1. NIH has identified these steps and linked them with research priorities and current projects at NIH. This document will be updated regularly to reflect progress and to incorporate recommendations from recent efforts such as the CEOi. [http://aspe.hhs.gov/daltcp/napa/milestones/index.shtml]

(New) Action 1.A.7: Create milestones for research goals based on the recommendations from the 2013 ADRD workshop

Using the research priorities recommended by the ADRD 2013 workshop as a guide, NIH will develop short, medium, and long-term milestones that are needed to achieve progress toward preventing or effectively treating dementias related to Alzheimer's disease. Federal roles and responsibilities and the roles of other sectors in achieving such milestones will be included. The National Plan will be updated regularly to reflect progress.

(New) Action 1.A.8: Regularly convene an Alzheimer's Disease-Related Dementias (ADRD) Summit to review progress on ADRD research recommendations, and refine and add new recommendations as appropriate, based on recent scientific discoveries

As a follow-up to the *Alzheimer's Disease-Related Dementias* in May 2013 (see Action 1.A.4) to solicit input on special research priorities and timelines for addressing ADRDs, NINDS will convene a second *Alzheimer's Disease-Related Dementias Research Summit* in 2016 to review progress in research on ADRDs, report progress on the ADRD 2013 milestones, and revise the research recommendations as appropriate. The Summit will be open to the public and will include national and international experts, research funders, public and private stakeholders, and members of the Advisory Council. Following the 2016 Summit, NINDS will release a report summarizing the recommendations.

(New) Action 1.A.9: Convene a workshop to examine the special needs of people with Down syndrome, who are at high risk for developing Alzheimer's disease

To better understand Alzheimer's disease in people at risk for developing the condition, NIH supported the *Advancing Treatment for Alzheimer Disease in Individuals with Down Syndrome* workshop in April 2013 to identify research recommendations and priorities for this population. The meeting was co-hosted by NIA, the Eunice Kennedy Shriver National Institute of Child Health and Human Development, and NINDS, as well as the Down Syndrome Research and Treatment Foundation (DSRTF) and Research Down Syndrome (RDS). The meeting resulted in a set of recommendations including short-term goals such as sharing existing data and development of new data sets that follow study participants with Down syndrome as they age as well as longer-term goals such as the development of a Down Syndrome-Alzheimer's Disease consortium. [http://downsyndrome.nih.gov/meetings/Pages/041713.aspx]

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

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

(Updated) Action 1.B.1: Expand research to identify the molecular and cellular mechanisms underlying Alzheimer's disease, and translate this information into potential targets for intervention

Incomplete understanding of the disease mechanisms that lead to AD is a major barrier to the discovery of effective therapies. An integrated interdisciplinary basic science research agenda will continue to advance our understanding of the molecular, cellular, and tissue level mechanisms and networks involved in the AD process to enable the identification and selection of therapeutic targets. Three new studies funded under RFA-AG-13-013, Interdisciplinary Approach to Identification and Validation of Novel Targets for AD, will focus on testing promising drugs aimed at preventing Alzheimer's and identifying and validating biological targets for novel therapies. [http://grants.nih.gov/grants/guide/rfa-files/RFA-AG-13-013.html]

Action 1.B.2: Expand genetic epidemiologic research to identify risk and protective factors for Alzheimer's disease

In 2012, NIH Director Dr. Francis Collins asked NIA and the National Human Genome Research Institute (NHGRI) to collaborate to conduct whole genome sequencing to identify areas of genetic variation that correspond to increased risk (risk factors) or decreased risk (protective factors) of AD. By December 2013, the Alzheimer's Disease Sequencing Project, had sequenced the whole genomes of more than 580 volunteers and, with donor consent, made the data freely accessible to researchers on the NIA Genetics of Alzheimer's Disease Data Storage Site [https://www.niagads.org/].This ongoing effort seeks to yield novel targets for drug development, provide improved diagnostics for screening and disease monitoring, and ultimately help define strategies for disease prevention.

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

Increased enrollment in clinical trials is crucial for the development of better treatments and ultimately a cure for AD. Participating in clinical trials and other research enables volunteers to access the latest experimental approaches available and provides them with care by clinical research staff. HHS is working to increase clinical trial enrollment by expanding awareness of clinical trial opportunities among health and long-term care providers so that they may inform interested people about these opportunities. In 2012 and 2013, webinars were held on these topics. NIA, ACL, and CDC, working together on the ROAR project, created a draft action plan to support clinical trial enrollment by connecting researchers at NIA-funded ADCs, the ACL-funded Aging Network, and the CDC's public health network. Through ROAR, HHS, in partnership with existing research registries (ResearchMatch, the Alzheimer's Association's TrialMatch, and the Alzheimer's Prevention Registry), will refine strategies and work with networks and external organizations to implement the action plan as resources permit. [http://www.aoa.gov/AoARoot/AoA_Programs/HPW/Alz_Grants/index.aspx]

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

NIH will monitor enrollment of racial and ethnic minorities in NIH Alzheimer's disease studies and work with other research funders to do the same. NIH will use this information to identify next steps for engaging and enhancing research participation by racial and ethnic minorities.

HHS is working with service providers to encourage enrollment of more racial and ethnic minorities in Alzheimer's disease research studies. One of the webinars co-hosted by NIA and ACL focused on raising awareness of the need for participation of racial and ethnic minorities in Alzheimer's disease studies. NIH will continue to solicit input in a variety of forums on how to most effectively recruit and include minorities in research on Alzheimer's disease and other dementias and incorporate strategies into the action plan to be implemented through the continuing ROAR project collaboration described in Action 1.B.3. [http://www.nia.nih.gov/newsroom/announcements/2013/05/2013-webinar-series-alzheimers-disease-and-resources]

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

HHS and the U.S. Department of Veterans Affairs (VA) will continue to develop and conduct clinical trials on the most promising pharmaceuticals for the prevention and treatment of Alzheimer's disease. Clinical trials will continue to advance the development of interventions and evaluate their effectiveness. Renewed funding from NIA for the Alzheimer's Disease Cooperative Study (ADCS) will support four new trials. [Read more about the ADCS and these trials at http://www.nia.nih.gov/newsroom/2013/01/nih-supported-alzheimers-studies-focus-innovative-treatments.] HHS will increase the pace of work under its cooperative agreement with VA and other federal agencies to advance the progress of clinical trials. HHS will coordinate these efforts with those occurring in the private sector, as appropriate, by pursuing appropriate planning and research partnerships. Some of the studies funded through this work include a trial testing an insulin nasal spray among people with mild cognitive impairment and a trial to test an amyloid-clearing drug among people with a rare, familial form of early-onset Alzheimer's disease. Three new NIA-funded clinical trials will test amyloid-clearing treatments in symptom-free volunteers at risk for the disease or in the very earliest stages, and one phase I trial will evaluate the safety and tolerability of a natural brain steroid. These are funded through two 2013 initiatives: AD Prevention Trials (RFA-AG-13-015) [http://grants.nih.gov/grants/guide/rfa-files/RFA-AG-13-015.html] and AD Phase I Clinical Trials (RFA-AG-13-016) [http://grants.nih.gov/grants/guide/rfa-files/RFA-AG-13-016.html].

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

HHS and its federal partners will continue to conduct clinical trials to test the effectiveness of lifestyle interventions and risk factor reduction in the prevention of AD, conduct peer review of new grant applications, perform annual reviews of ongoing studies, and work to identify emerging opportunities for the development of new interventions. In FY 2014, NIA is soliciting applications for 1-2 large scale trials designed to elucidate the mechanisms by which interventions, potentially including lifestyle interventions, could remediate age-related cognitive decline. (RFA-AG-14-016: Plasticity and Mechanisms of Cognitive Remediation in Older Adults; 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

Significant advances in the use of imaging and biomarkers in brain, blood, and spinal fluid have made it possible to detect the onset of Alzheimer's disease and track its progression, with the hope that it will be possible to monitor the effect of treatment in people with the disease. Without these advances, these neurodegenerative processes could only be evaluated in non-living tissues. Accelerated research will improve and expand the application of biomarkers in research and practice. These advances have shown that the brain changes that lead to Alzheimer's disease begin up to 10 years before symptoms.[21] Identifying imaging and other biomarkers in presymptomatic people will facilitate earlier diagnoses in clinical settings, as well as aid in the development of more efficient interventions to slow or delay progression.

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

HHS will expand its work to identify imaging and biomarkers through the public-private Alzheimer's Disease Neuroimaging Initiative (ADNI). This partnership will help identify and monitor disease progression, even in the early stages before individuals show symptoms of the disease.

AMP will enhance this effort through a government, industry, and non-profit organization partnership focused on identifying and validating the most promising biological targets of Alzheimer's disease. AMP proposes to identify biomarkers that can predict clinical outcomes by incorporating selected biomarkers into four NIH-funded clinical trials. AMP will then support a large-scale analysis of AD patient brain tissue samples that were donated with appropriate consent to validate biological targets previously shown to play key roles in disease progression and to improve understanding of the molecular pathways involved in the disease to identify new potential therapeutic targets. [http://www.nih.gov/science/amp/index.htm]

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

HHS will maximize the effectiveness of research findings in neuroimaging and biomarkers through partnerships, meetings, and conferences with the private sector, the Food and Drug Administration (FDA), and other federal agencies. These collaborations will focus on how to translate findings into treatments and clinical practice, as well as help identify promising new areas of exploration.

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

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

(Updated) Action 1.D.1: Inventory Alzheimer's disease research investments

The International Alzheimer's Disease Research Portfolio (IADRP) is a publicly-available database to capture the full spectrum of Alzheimer's disease research investments and resources, both in the United States and internationally. Developed by NIA in collaboration with the Alzheimer's Association, the IADRP enables public and private funders of Alzheimer's research to coordinate research planning, leverage resources, avoid duplication of funding efforts, and identify new opportunities in promising areas of growth. Along with NIA, over 20 NIH institutes and centers, a number of other federal agencies, and private sector organizations contribute to the database. As of April 2014, project data from 13 major Alzheimer's disease research funders in the United States, Europe, Canada, and Australia are available on the website, and several other funders use the database. NIH will expand IADRP to include research investments in dementias related to Alzheimer's disease. [http://iadrp.nia.nih.gov/cadro-web]

(Updated) Action 1.D.2: Expand international outreach to enhance collaboration

The Alzheimer's Association and NIA co-hosted a funders meeting at the *Alzheimer's Association International Conference* in July 2012 and July 2013. The Alzheimer's Association and NIA also convene representatives of several funding organizations around the world for regular teleconferences. NIA is exploring collaboration with the European Union Joint Programming

Initiative on Neurodegenerative Diseases Research [http://www.neurodegenerationresearch.eu/], and the HHS Office of Global Affairs is exploring opportunities to collaborate on international initiatives focused on Alzheimer's disease.

The New York Academy of Sciences and the CEOi, in collaboration with NIA, held the *Alzheimer's Disease Summit: The Path to 2025* in November 2013. Leading industry, academic, and government stakeholders discussed ways to coordinate efforts to build research resources, reengineer current drug development and evaluation systems, and identify innovative technologies and financing models. [http://www.nyas.org/Events/Detail.aspx?cid=a643a4ab-37b7-42f3-b0c9-c5e88909c9b4]

HHS will host the G8 final legacy meeting in February 2015 in conjunction with this U.S. *Alzheimer's Disease Research Summit*. International partners will be invited to participate in both the Research Summit and the legacy meeting to discuss a shared research agenda and steps to move forward globally to fight Alzheimer's disease. [http://www.hhs.gov/asl/testify/2014/01/t20140115a.html]

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

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

Action 1.E.1: Identify ways to compress the time between target identification and release of pharmacological treatments

HHS will convene a group to examine ways to speed up the processes for bringing pharmacological treatments to market, including: identifying and validating therapeutic targets; developing new interventions; testing efficacy and safety; and regulatory approval. The group will look at the current average time and will identify places where the timeline could be shortened. The group will include representatives from the FDA, the Office of the Assistant Secretary for Planning and Evaluation (ASPE), and NIH who will consult with academic researchers and representatives from the private sector.

Action 1.E.2: Leverage public and private collaborations to facilitate dissemination, translation, and implementation of research findings

HHS will expand its work to disseminate research findings. NIH will partner with other federal agencies to disseminate research findings to networks of providers and researchers. FDA will work with the pharmaceutical and medical device industries to clarify the types and characteristics of data needed for approval and clinical implementation. Other HHS and federal partners will form collaborations to promote the translation of evidence-based findings to community and practice settings. For example, ACL/AoA and NIH will continue their collaboration on translational research focused on helping older adults maintain their health and independence in the community. Additionally, ACL/AoA and CDC will build upon current collaborative efforts between public health and aging services networks to disseminate these findings. HHS will explore partnerships with stakeholder groups to facilitate further dissemination. For example, ACL's Administration on Intellectual and Developmental Disabilities (AIDD) will disseminate relevant research findings and information through networks focused on assisting persons with intellectual and developmental disabilities and through private partners. CDC will disseminate findings through the Healthy Brain Initiative Network, a thematic network within the CDC Prevention Research Centers Program.

(Updated) Action 1.E.3: Continue to promote use of the Alzheimer's Disease Education and Referral Center to provide evidence-based information on Alzheimer's disease to the public and others

The NIA's ADEAR Center will continue to work with other federal agencies to expand their outreach efforts to more effectively educate the public about Alzheimer's with a focus on evidence-based information about the pharmacological and non-pharmacological management of physical, cognitive, emotional, and behavioral symptoms and participation in clinical trials. Specifically, the ADEAR Center will work with ACL and CDC to provide findings of studies that center on community and public health interventions. [http://www.nia.nih.gov/alzheimers]

(Updated) Action 1.E.4: Issue guidance about drugs for early stage Alzheimer's disease

In February 2013, the FDA published a *Draft Guidance for Industry: Alzheimer's disease: Developing Drugs for the Treatment of Early Stage Disease* which discusses the agency's current views on how trials in subjects with pre-dementia AD might be designed, conducted, and analyzed. The document also discusses a potential accelerated regulatory pathway for patients with the earliest stages of the disease. The FDA will publish a final version of that guidance in 2014 that reflects feedback received from industry, academia, advocacy groups, physicians, and patients/caregivers. [http://www.fda.gov/Training/GuidanceWebinars/ucm345077.htm]

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

In 2014, the FDA will continue to work with outside consortia to attempt to formally qualify (via the Drug-Development Tool Qualification Process) both novel clinical endpoints as well as biomarkers for trial enrichment for use in AD trials.

(Updated) Action 1.E.5: Expand and disseminate research on co-occurring conditions and dementias

A CDC-funded project examines the effects of dementia, co-occurring chronic conditions, and geriatric syndromes on health outcomes such as functioning, quality of life, and mortality. Phase one of this project included a comprehensive review of the published literature on multiple chronic conditions, which identified issues in managing dementia and chronic conditions and identified research gaps. In phases two and three, researchers will identify data sources and information to fill the research gaps, and create a data resource catalog. The findings of the literature review and the database information will be disseminated through CDC's Healthy Aging Program, Prevention Research Centers Program, and the Healthy Brain Initiative Network.

(New) Action 1.E.6: Provide information to the public on brain health

ACL, NIA, and CDC will educate the public about brain health by providing educational materials for professionals in the aging, disability, and public health networks. These professionals can use the materials to educate those who touch their services. HRSA, VA, and Centers for Medicare and Medicaid Services (CMS) will assist in dissemination of the brain health resource. Private organizations with an interest in brain health may do likewise.

Action 1.E.7: Synthesize evidence on non-pharmacologic interventions to manage behavioral symptoms in dementia patients

Agency for Healthcare Research and Quality (AHRQ) will review and evaluate the effectiveness of a wide variety of non-pharmacological interventions used to manage behavioral symptoms in dementia patients. AHRQ will synthesize evidence on general and targeted interventions specifically for agitated and aggressive behaviors. This would inform guidance on non-pharmacologic approaches effective in managing agitation and aggression and would potentially assist in reducing the use of antipsychotics; reducing the frequency and severity of aggressive and agitated behaviors and distress; improving functioning; and improving quality of life among dementia patients, their caregivers, and long-term care staff.

(New) Action 1.E.8: Leverage research in areas related to neurodegeneration

The U.S. Department of Defense (DoD) and VA will begin a series of meetings to discuss leveraging research in several areas related to neurodegenerative disease. Focus areas include, but are not limited to: (1) health care delivery; (2) quality of life; (3) access to care; and (4) strategies to build new partnerships across DoD and VA based on existing models such as the Chronic Effects of Neurotrauma Consortium. These focus areas are congruent to both the National Plan and the Executive Order on Improving Access to Mental Health Services for Veterans, Service Members, and Military Families-National Research Action Plan [http://www.whitehouse.gov/sites/default/files/uploads/nrap_for_eo_on_mental_health_august_2013.pdf]. These focus areas may provide the preamble to further discussions regarding: (1) diagnostics and interventions for neurodegenerative disease; and (2) improving delivery of health care to Veterans and active duty military with dementia-related disorders.

Goal 2: Enhance Care Quality and Efficiency

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

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

The workforce that cares for people with Alzheimer's disease includes health care and LTSS providers such as primary care physicians; specialists such as neurologists, geriatricians, and psychiatrists; registered nurses and advanced practice nurses; community health workers; social workers; psychologists; pharmacists; dentists; allied health professionals; and direct care workers like home health aides and certified nursing assistants, who provide care across the care continuum. These providers need accurate information about caring for someone with Alzheimer's disease including the benefits of early diagnosis, how to address the physical, cognitive, emotional, and behavioral symptoms of the disease, and how to assist caregivers as they cope with the physical and emotional aspects of their caregiving responsibilities. CMS provides information for physicians and other health care providers on how to implement the "detection of any cognitive impairment" component of the Medicare Annual Wellness Visit established by the Affordable Care Act. Major efforts by both VA and HRSA, including expanded training opportunities created in the Affordable Care Act, support geriatric training for physicians, nurses, and other health workers.[22] Enhanced specialist training is also needed to prepare these practitioners for the unique challenges faced by people with Alzheimer's disease. In addition, work is needed to expand the capacity of the primary care community to serve people with Alzheimer's disease. Dementia-specific capabilities within the direct care workforce need to be expanded and enhanced. The actions below will facilitate AD-specific training for care professionals in order to strengthen a workforce that provides high-quality care to people with Alzheimer's disease.

(Updated) Action 2.A.1: 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 GEC. During the first year of this initiative, 45 GEC grantees partnered with 538 community stakeholders to provide 653 interprofessional education offerings to over 34,000 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 Alzheimer's disease. 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 2013, 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 patients with Alzheimer's disease and improve early detection in primary care and outpatient settings.

In 2014, HRSA will expand these efforts by extending its training to direct care workers and lay and 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. HRSA will also begin the process to develop short and long-term targets, strategies and milestones for ensuring 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.

Action 2.A.2: Encourage providers to pursue careers in geriatric specialties

HHS will enhance three programs that encourage providers to focus on geriatric specialties. The CGEP, as mandated by the Affordable Care Act, provides traineeships to support students pursuing advanced degrees in geriatric nursing, LTSS, and gero-psychiatric nursing. Seventy-five students currently receive traineeship support with enhanced training in caring for people with AD.

In addition, HRSA continues to support training projects that provide fellowships for individuals studying to be geriatricians, geriatric dentists, or geriatric psychiatrists. HRSA also continues to support the career development of geriatric specialists in academia through the "Geriatric Academic Career Awards Program." Currently 73% of program awardees provide interprofessional clinical training on Alzheimer's disease.

Action 2.A.3: Collect and disseminate dementia-specific guidelines and curricula for all provider groups across the care spectrum

HHS will create and market a clearinghouse of dementia curricula and practice recommendations for providers across the care continuum, including physicians, nurses, social workers, psychologists, other health care professionals, direct care workers, and informal caregivers. The clearinghouse will be hosted on a publicly-available website and updated regularly. HHS will seek expert input from public and private entities in developing the clearinghouse and ensure that its content incorporates existing evidence-based guidelines.

(Completed) Action 2.A.4: Strengthen the direct care workforce

HHS strengthened the ability of the nursing home direct care workforce to provide high-quality, person-centered care for people with AD through enhanced training. A series of videos, "Hand in Hand," were developed and disseminated to every nursing home in the country. States and facilities report that they are using the training videos, which have been well-received by staff.

(Updated) Action 2.A.5: Strengthen state aging, public health, and intellectual and developmental disability workforces

HHS will coordinate with states to develop workforces in aging, public health, and intellectual and developmental disabilities that are AD-capable and culturally-competent. ACL/AoA will work with HRSA to make AD training available to the Aging Network. For example, the New Jersey GEC has developed basic training which it has provided to the Area Agencies on Aging (AAA) in New Jersey. The GEC will make these webinars available to the entire Aging Network in 2014. ACL/AIDD will disseminate relevant training through the intellectual and developmental disability networks and private partners. CDC will work with its partners to identify public health contributions at the state and local levels and continue to work with AoA on enhancing the interface of the aging and public health networks.

(Updated) Action 2.A.6: Support state and local Alzheimer's strategies

Much of the work required to support caregivers and the direct care workforce should and will occur at the local level. This is reflected in the many state-based plans to tackle Alzheimer's disease.[23] Thus, HHS and its Federal Government partners will identify ways that are most helpful to support states and localities in their efforts such as conducting research and translating successful interventions that address management of AD symptoms, and supports for paid and unpaid caregivers. During 2013, ACL/AoA funded a report analyzing the results of 6 years of ADSSP grants, which revealed that states have successfully translated interventions and implemented innovations to support caregivers of those with dementia and sustained many of these programs. In addition, ADSSP learning collaboratives produced three reports on assessment of cognitive impairment, dementia care training, and quality assurance measures. ACL state grantees continue to translate eight evidence-based interventions for family caregivers [http://www.aoa.gov/AoARoot/AoA_Programs/HPW/Alz_Grants/index.aspx]. HHS will disseminate information and best practices developed as part of ongoing ADSSP work.

Action 2.A.7: Develop and disseminate a unified primary care Alzheimer's disease curriculum

HHS will develop a voluntary unified curriculum for primary care practitioners to become more knowledgeable about Alzheimer's disease and enhance the skills necessary to provide high-quality dementia-capable care. Through the GECs, HRSA will partner with provider organizations and other experts such as NIA-supported ADCs to develop education and training curriculum on Alzheimer's disease for primary care practitioners. The curriculum will include topics such as the recognition of risk factors and signs and symptoms, as well as AD among specific diverse populations and those with intellectual disabilities. The training from this curriculum will be delivered to providers through HRSA's network of GECs, in collaboration with NIA ADCs Education and Outreach Cores.

(Updated) Action 2.A.8: Ensure Aging Network providers have access to research-based up-to-date information on Alzheimer's disease

It is important for service providers to have up-to-date information about Alzheimer's disease to ensure they are providing their clients with the most accurate information and appropriate services. NIA and ACL/AoA collaborated in 2013 to offer webinars to provide the aging workforce with the most up-to-date and culturally-appropriate information about Alzheimer's disease. The 2013 webinars included information on health disparities related to dementia, advanced dementia and younger-onset dementia. ACL and NIA's partnership will expand to CDC in 2014 and include topics such as successful community collaborations addressing dementia. Additionally, ACL/AoA will plan webinars for grantees focused on a variety of areas such as person-centered care, service provision to persons with younger-onset dementia, strategies for reaching diverse populations with dementia, and programs for identifying and preventing elder abuse and neglect in persons with dementia. Recordings of the webinars will be available at http://www.aoa.gov/AoARoot/AoA_Programs/HPW/Alz_Grants/index.aspx after their presentation.

(Updated) Action 2.A.9: Engage the public health workforce on brain health

CDC released *The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013-2018* [http://www.cdc.gov/aging/pdf/2013-healthy-brain-initiative.pdf], which outlines how state and local public health departments and their partners can promote healthy cognitive functioning, address cognitive impairment for individuals living in the community, and help meet the needs of care partners. Specific actions are addressed in four traditional domains of public health: monitor and evaluate, educate and empower the nation, develop partnerships, and assure a competent workforce. CDC will work with partners to implement public health actions in the Road Map and will track progress over time.

To further support the engagement of the public health network on this topic, CDC partnered with the National Association of Chronic Disease Directors and released the first ever opportunity grants awarded to five states. The grants focus on how state and local public health agencies and their partners can promote cognitive functioning and address cognitive impairment for individuals living in the community by implementing action items from *The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013-2018*.

In 2014, CDC will work with public and private partners to implement the action items from the Road Map through a series of partner meetings and webinars. CDC will also explore opportunities to promote public health understanding of dementia and enhance the Healthy Brain Initiative Network.

Action 2.A.10: Educate providers about federal programs to address Alzheimer's disease

Through HRSA's Geriatrics Program, HHS will educate health care providers about ADRDs. HRSA will hold a series of webinars to teach Geriatrics Program grantees about existing federal programs and opportunities to partner and collaborate with grantees in other federal agencies. The goal is to reduce redundancy and optimize resources to efficiently and effectively educate the health care workforce, direct service workforce, and lay and family caregivers on Alzheimer's disease. Three of the HHS agencies have provided webinars to the Geriatrics Program grantees. An additional six agencies will be participating in webinars over the coming months.

Action 2.A.11: Strengthen the ability of primary care teams in Indian Country to meet the needs of people with dementia and their caregivers

HHS will expand awareness of care issues for Native Americans with AD and improve the dementia-capability of professional staff in Indian Country. The Indian Health Service (IHS) will use the Chief Medical Officer Rounds series, the IHS Primary Care Provider, and other existing trainings and meetings to disseminate information on ADRD.

(New) Action 2.A.12: Enhance the ability of long-term care ombudsmen to support people with Alzheimer's disease

Long-term care ombudsmen are advocates for residents of nursing homes, board and care homes, assisted living facilities, and similar adult care facilities. They work to resolve problems of individual residents and to bring about changes at the local, state, and national levels to improve care. ACL/AoA's National Ombudsman Resource Center (NORC) will train long-term care ombudsmen to become "Hand in Hand" trainers on caring for people with AD for training nursing home and other direct care staff. This training exemplifies person-centered dementia care practices and includes a module on abuse, neglect and exploitation identification and prevention. The NORC will evaluate these trainings and the impact on nursing home staff.

(New) Action 2.A.13: Strengthen states' ability to provide and sustain dementia capable home and community-based services

HHS will work with states to help ensure that people with dementia and their caregivers have access to home and community-based systems that are dementia capable and sustainable. ACL will provide technical assistance to state grantees to assist them in developing methods for ensuring that staff have appropriate training to provide quality person-centered care, as well as methods to measure dementia capability within systems. Through a learning collaborative process, a tool will be created to help states measure whether they are improving the dementia capability of their systems.

(New) Action 2.A.14: Fill service gaps in dementia capable systems by expanding the availability of specialized services and supports to target previously underserved populations

In 2014, through grants to states and other entities working within dementia-capable systems, ACL/AoA will enhance service provision to underserved populations. For example, grantees may focus on identification of and services for individuals living alone with AD or quality and effectiveness of services for individuals aging with intellectual and developmental disabilities.

(New) Action 2.A.15: Strengthen the long-term care workforce

In October 2013, the U.S. Department of Labor (DoL) published a final rule extending the Fair Labor Standards Act's (FLSA's) minimum wage and overtime protections to most of the nation's workers who provide essential home-based assistance to older people, such as those with Alzheimer's disease. This change, which takes effect in January 2015, will result in nearly 2 million direct care workers -- such as home health aides, personal care aides, and certified nursing assistants -- receiving the same basic protections already provided to most United States workers. It will also help guarantee that those who rely on the assistance of direct care workers have access to consistent and high-quality care from a stable and increasingly professional workforce.

CMS is supporting the implementation of the FLSA by providing ongoing technical assistance to states on how to be compliant with these rules in relation to relevant issues including self-direction, quality oversight, and person-centered planning. CMS has developed a toolkit to help states develop their transition plans towards compliance with the new FLSA rule.

(New) Action 2.A.16: Improve home and community-based long-term services and supports provided through state Medicaid waivers

In January 2014, CMS issued a final rule about HCBS provided through state Medicaid waivers (1915(c), (i), and (k)).The rule includes a description of new flexibilities enacted under the Affordable Care Act to offer expanded HCBS and to target services to specific populations. It also defines person-centered planning requirements. CMS is holding webinars and national calls with key stakeholders, including state Medicaid agencies, state operating agencies, key national associations, key provider groups, and advocates about the rule so that states can improve the services provided for people with long-term care needs, including those with Alzheimer's disease.

Strategy 2.B: Ensure Timely and Accurate Diagnosis

Far too many people with Alzheimer's disease are not diagnosed until their symptoms have become severe.[24] Timely diagnosis gives people with the condition and their families time to plan and prepare for the future, leading to more positive outcomes for both.[25,26] For many, the inability to access health care due to a lack of insurance is a major concern. This is particularly important for individuals with younger-onset disease who may not yet be eligible for Medicare. Much of that insecurity will be alleviated as the Affordable Care Act, with its elimination of pre-existing conditions limitations and expansion of insurance coverage, is implemented. Even with access to affordable care for individuals, the health care workforce needs tools that can help ensure timely and accurate diagnoses. Research has helped identify some assessment tools that can be used to detect cognitive impairment that may indicate the need for a comprehensive diagnostic evaluation for Alzheimer's disease.[27] The actions below will facilitate appropriate assessment and give health care providers tools to make timely and accurate diagnoses.

Action 2.B.1: Link the public to diagnostic and clinical management services

In 2012 and 2013, ACL/AoA and NIA offered a webinar series with presentations by NIA/ADEAR Center, NIA-funded ADCs, National Alzheimer's Call Center, and Eldercare Locator. These webinars described resources and services related to Alzheimer's diagnosis and management, clinical trials, and caregiving so that Aging Network providers can share this information with the people they serve. The webinars are ongoing and available at http://www.aoa.gov/AoARoot/AoA_Programs/HPW/Alz_Grants/index.aspx.

(Updated) Action 2.B.2: Identify and disseminate appropriate assessment tools

In 2013, NIA created a database of assessment tools, "Instruments to Detect Cognitive Impairment in Older Adults." Clinicians and researchers can use this searchable database, available on the NIA website at http://www.nia.nih.gov/research/cognitive-instrument, to identify published instruments for use in their outpatient practice or community studies. The database, which contains information about 116 instruments, was created by NIA staff at NIH, in consultation with experts in the field. Users may search by specific criteria, such as time to administer, language, or format. They can also identify instruments that have been evaluated in specific populations (for example, African-American and Hispanic) or for specific diagnoses. HHS will explore options for disseminating these assessment tools.

(New) Action 2.B.3: Educate family and service providers of persons with intellectual disabilities about changes that may indicate the onset of dementia

ACL/AIDD will work with the National Task Group on Intellectual Disabilities and Dementia Practice to develop fact sheets and tools for family and service providers to use in identifying whether an individual with intellectual or developmental disabilities may be developing AD. These fact sheets will be disseminated through networks of the intellectual disability community and the Aging Network.

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

Often, even though a physician or another health care provider has identified cognitive impairment, the patient and his or her family are not told of the diagnosis.[28] Further, once a diagnosis is made and disclosed, as few as half of patients and families receive counseling, support, or information about next steps.[29] This information is important, especially for early stage patients who experience positive outcomes when they are involved in planning and receive appropriate services.[30] The actions below will address this gap by educating physicians and other health care providers, incentivizing discussions with people with AD and their families, and enhancing the ability of other networks to assist people with Alzheimer's disease and their families with addressing their needs.

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

One barrier to counseling and support is that health care providers are not aware of available services or how to access them. To increase knowledge of these resources among doctors, nurses, and hospitals, HRSA is partnering 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 AD and their caregivers. These activities will continue.

(Completed) Action 2.C.2: Enhance assistance for people with Alzheimer's disease and their caregivers to prepare for care needs

Outside of the clinical care setting, families and people with AD need specialized assistance in planning for AD-specific needs and accessing appropriate services. HHS has strengthened the ability of existing LTSS systems, such as those provided by ACL/AoA's Aging Network, to meet the unique needs of people with AD and their caregivers. This occurred through strengthening the Aging Network's awareness of available family caregiver assessment tools, resource materials from across the government, and support programs designed to educate caregivers and persons with the disease.

(Updated) Action 2.C.3: Connect American Indian and Alaska Natives to Alzheimer's disease resources

ACL, IHS, and NIH will continue to coordinate efforts to improve the dissemination of information on dementia in Indian Country. ACL will publish materials on its website pertaining to funding and activities under Older Americans Act Title VI [http://Olderindians.aoa.gov]. HHS will continue work to improve dementia care among Native Americans through the NIA-sponsored ADCs. Alzheimer's disease will be raised as an issue among the trans-NIH Program Interest Group focused on Native American research and the trans-NIH American Indian and Alaska Native Health Communications and Information Work Group. HHS will disseminate information and increase access to resources for people with Alzheimer's disease and their caregivers adding links to relevant websites. Finally, ACL and IHS will collaborate to include resources for elders and families addressing Alzheimer's disease in the Resource Manual for the Older Americans Act Title VI programs, which serve Indian Country.

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

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

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

HHS will work with private partners including the National Quality Forum to facilitate groups such as medical professional societies and organizations representing persons with AD, caregivers, and direct care workers working together to delineate best dementia care practices and evidence-based guidelines. This effort will include identification of evidence-based dementia care guidelines developed both in the United States and in other countries. This work can serve to inform clinical, behavioral health, and LTSS providers, families, and people with AD, and can also serve as a foundation for the development of aligned electronic clinical guidelines, decision support tools, and quality measures that promote high-quality dementia care in all settings.

(Updated) Action 2.D.2: Identify and review measures of high-quality dementia care

HHS is working with the National Quality Forum to identify and review measures of high-quality dementia care in eight areas: (1) diagnosis, treatment, and care; (2) timeliness and accuracy of diagnostic evaluation; (3) patient and caregiver quality of life; (4) evaluation of behavioral symptoms and comorbid conditions; (5) care coordination; (6) assessment and management of caregiver burden; (7) training and provider knowledge; and (8) patient-centered outcomes and goals of care. A draft conceptual framework for measurement of dementia care quality has been developed and reviewed by public stakeholders. As a next step, the stakeholders will include the identification of dementia quality measure gaps and help HHS identify which concepts should be translated into performance measures.
[http://www.qualityforum.org/projects/prioritizing_measures/alzheimers_disease/]

(Updated) Action 2.D.3: Convene an expert panel on advanced dementia

In accordance with the recommendation of the Advisory Council, HHS supports the Institute of Medicine to convene a meeting of experts on advanced dementia. The experts are considering and making recommendations about how providers such as primary care physicians and hospitals should address patient-centered goals of care, as well as issues such as infection management, feeding and nutrition problems, falls and injury prevention, transitional care and hospitalizations, and communication. The experts will discuss models to improve the care for those with advanced dementia.

(New) Action 2.D.4: Solicit stakeholder input on meaningful outcomes to drive quality measurement

In February 2014, CMS held a listening session to solicit stakeholders perspectives on outcomes to health care service delivery that are desirable, meaningful, and feasible for people with Alzheimer’s disease. The stakeholders also provided input on what information they perceive providers to need to improve care in a meaningful way for patients across the continuum of the condition. The input and discussion will help inform guideline development and focus for quality measurement and improvement efforts.

(New) Action 2.D.5: 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 develop information for physicians on privacy, autonomy, and safety issues. This resource will help providers better understand these issues and the balance between safety, privacy, and autonomy. HHS will disseminate this information through the trainings provided through the GECs through Action 2.A.1.

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

Work is underway at both CMS and VA to identify models that provide more effective and efficient care for people with Alzheimer’s disease. The Affordable Care Act established the CMS Center for Medicare and Medicaid Innovation (Innovation Center), which is charged with testing innovative payment and service delivery models to reduce expenditures in Medicare and Medicaid while maintaining or enhancing the quality of care received by program beneficiaries. While most Innovation Center models are not designed to focus on people with AD in particular, a number of the initiatives underway at the Innovation Center may provide information relevant to the care for people with Alzheimer’s disease. The HHS Secretary can expand the duration and scope of care models that are shown to reduce spending and improve quality, including implementing them at a national level.

Action 2.E.1: Evaluate the effectiveness of relevant Innovation Center models for people with Alzheimer’s disease

The Innovation Center is currently testing several models that can include testing payment and delivery models for improving care for Medicare beneficiaries with AD. The Innovation Center will evaluate the effectiveness of the Health Care Innovation Awards, including those that focus on people with AD. In addition, the Multi-payer Advanced Primary Care Practice Demonstration and the Comprehensive Primary Care initiative will measure the effectiveness of medical home models, which utilize a team approach to provide care and to improve the quality and coordination of health care services. The Innovation Center may explore the impact of these models on subgroups, such as people with AD.

Action 2.E.2: Evaluate the effectiveness of the Independence at Home Demonstration

The Independence at Home Demonstration is testing a payment and service system that uses physicians and nurse practitioners to coordinate home-based primary care with LTSS. If possible, the Innovation Center will conduct subgroup analyses to examine whether health and functional status outcomes are improved among people with AD in this demonstration.

Action 2.E.3: Share results and lessons learned about new models in the Veterans Health Administration system with federal partners

The Veterans Health Administration (VHA) within VA is implementing innovative programs to provide patient-centered alternatives to long-term institutional care. New models of care include programs focusing on dementia care, care coordination and/or caregiver support. VA officials will share a summary report of completed non-institutional long-term care pilot programs that include dementia components with other federal representatives.

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

People with dementia have higher rates of emergency room visits and hospitalizations, two settings where they are vulnerable to stress, delirium, and unnecessary complications. A transition between providers and care settings is a complex time of care delivery for all people, but especially for frail elders or other individuals with Alzheimer's disease who often have multiple chronic conditions. Transitions include moves into acute care hospitals, from hospitals to post-acute settings such as skilled nursing facilities or the home, or from nursing facilities to hospitals. People with AD are at high risk of adverse events due to poor communication and other care process deficiencies during transitions and need support to help them determine the best timing for transition and site of care.[31]

(Updated) Action 2.F.1: Identify and promote safer hospital care for persons with Alzheimer's disease

The Partnership for Patients is a public-private partnership that helps improve the quality of care and safety in hospitals. Through this initiative, hospitals will identify best practices for reducing injuries, complications, and improving care transitions. CMS will identify practices that benefit people with complex needs including people with Alzheimer's disease. CMS will share these findings broadly. More information is available at http://innovation.cms.gov/initiatives/partnership-for-patients/.

Action 2.F.2: Implement and evaluate new care models to support effective care transitions for people with Alzheimer's disease

HHS will examine how to improve care during transitions for people with Alzheimer's disease through Medicare's Community-Based Care Transitions Program and the Aging and Disabilities Resource Center (ADRC) Evidence-Based Care Transitions Program. Medicare's Community-Based Care Transitions Program is an ongoing demonstration that links hospitals with community-based organizations to encourage shared quality goals, improve transitions, and optimize community care. The ADRC Evidence-Based Care Transitions Program supports state efforts to strengthen the role of ADRCs in implementing evidence-based care transition models that meaningfully engage older adults, individuals with disabilities, and their informal caregivers. More information is available at http://acl.gov/Programs/CDAP/OIP/EvidenceBasedCare/index.aspx.

(Completed) Action 2.F.3: Enhance understanding of avoidable hospitalizations and emergency department use among people with Alzheimer's disease

HHS examined patterns of avoidable hospitalizations and emergency department use among people with Alzheimer's disease. High rates of hospitalization and emergency department use among community-based people with cognitive impairments, both overall and for potentially avoidable conditions, may be attributable to multiple factors, such as challenges in providing adequate ambulatory care for people with cognitive impairments in community settings. In comparison, most nursing homes are equipped to provide medical and nursing care for many conditions that would be difficult to manage in community settings. Moreover, given the high prevalence of dementia in nursing homes, these facilities may be more used to treating people with ADRD than are community-based physicians. Although people with cognitive impairment in nursing homes do not have higher rates of hospitalizations and potentially avoidable hospitalizations than people without cognitive impairment, the high nominal rates for both groups suggests the importance of reducing unnecessary hospitalizations of nursing home residents.

Action 2.F.4: Identify and disseminate information on interventions to reduce preventable hospitalizations

CDC will work with partners to conduct a review of interventions that are effective in 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."

(New) Action 2.F.5: Assess the adequacy of health information technology (HIT) standards to support the exchange of information at times of referrals and transitions in care for persons with ADRD

ASPE will work with Office of the National Coordinator for Health Information Technology (ONC) and partners in exploring the feasibility and timing of activities to assess and identify gaps in accepted HIT standards to support the interoperable exchange and reuse of information needed to support consultation requests, consultation reports, and transitions in care for older adults, including persons with ADRD.

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

Coordinating the care received by people with Alzheimer's disease in different settings by different providers can help reduce duplication and errors and improve outcomes.[32] Despite a general consensus that care coordination is important, more research is needed to determine how best to provide such care in a high-quality and cost-efficient manner. The actions under this strategy will focus on learning from the existing evidence regarding care coordination and using this information to implement and evaluate care coordination models for people with AD.

(Completed) Action 2.G.1: Review evidence on care coordination models for people with Alzheimer's disease

In Agust 2013, ASPE released a report summarizing the research literature on care coordination models. Although the results from a few programs appear promising, the evidence on the efficacy of care coordination for persons with Alzheimer's disease and their caregivers is still equivocal. Future efforts to examine care coordination for these populations would benefit from larger sample sizes, longer time frames for follow-up and broader outcome measures. [http://aspe.hhs.gov/daltcp/reports/2013/alzcc.shtml]

Action 2.G.2: Implement and evaluate care coordination models

HHS will support states in developing new approaches to better coordinate care for people who are enrolled in both Medicare and Medicaid, many of whom have cognitive impairments. CMS has established a new technical assistance resource center, the Integrated Care Resource Center, authorized under the Affordable Care Act, to assist states in designing and delivering coordinated health care to beneficiaries [http://www.integratedcareresourcecenter.com/]. HHS will evaluate the impact of these models. The CMS Innovation Center, in partnership with the CMS Medicare-Medicaid Coordination Office, provides an opportunity to test and evaluate promising models of care for people with AD.

Action 2.G.3: Evaluate evidence on care integration

HHS will 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 functionally impaired Medicare and Medicaid beneficiaries with Alzheimer's disease.

(New) Action 2.G.4: Assess the adequacy of HIT standards for care plans to support the needs of persons with ADRD

ASPE will work with ONC and partners in exploring the feasibility and timing of activities to assess, identify, and fill gaps in accepted HIT standards for the representation of care plans to represent the health concerns, goals, interventions, and other information identified by caregivers and patients/family members needed in caring for individuals receiving LTSS, including persons with ADRD.

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

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

(Completed) Action 2.H.1: Create a task force to improve care for these specific populations

The Federal Interagency Task Force was convened and included representative federal agencies engaged in dementia issues and with specific populations from HHS, VA and the U.S. Department of Education (DoE). The Task Force reviewed the inventory of federal activities prepared to inform the 2012 National Plan. After this review, the Task Force pursued four priority areas identified within the National Plan. The Task Force members identified steps to gathering additional information/input from experts within and outside Federal Government. Task Force members solicited input through a variety of mechanisms, summarized input gathered by the members, and discussed possible gaps. Members also offered information based on their own training and expertise. The Task Force developed a list of broad recommendations based on the input it received, which were shared in a report released in June 2013 [http://aspe.hhs.gov/daltcp/reports/2013/AlzSpPop.shtml].

(Completed) Action 2.H.2: Identify steps to ensure access to long-term services and supports for younger people with Alzheimer's disease

Since improving care for specific populations included those with younger-onset dementia, the Federal Interagency Task Force addressed LTSS in its work on Action 2.H.1. The Task Force developed a list of broad recommendations based on the input it received, which were shared in a report released in June 2013 [http://aspe.hhs.gov/daltcp/reports/2013/AlzSpPop.shtml].

(New) Action 2.H.3: Create an opportunity for providers to discuss services for persons with younger-onset dementia

In one of ACL/AoA's dementia webinars, presenters will discuss younger-onset dementia, the services these individuals may require and how to provide those services. The webinar will be recorded and made publicly available shortly after being broadcast at http://www.aoa.gov/AoARoot/AoA_Programs/HPW/Alz_Grants/index.aspx.

(New) Action 2.H.4: Enhance understanding of models of family support for people with intellectual disabilities as they age

HHS will explore promising models of family support, specifically those that maximize the ability of families to provide home-based care for individuals with intellectual disabilities as they age. HHS hopes to identify the characteristics of these models and the factors that facilitate or hinder effective model implementation. The project will include a focus on issues related to aging of both family caregivers and people with intellectual disabilities, such as stressors related to Alzheimer's disease.

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 Alzheimer's disease and their families and caregivers requires giving them the tools that they need, helping to plan for future needs, and ensuring that safety and dignity are maintained. Under this goal, the Federal Government and partners will undertake strategies and actions that will support people with the disease and their caregivers.

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

Caregivers report that they feel unprepared for some of the challenges of caring for a person with Alzheimer's disease -- for example, caring for a loved one with sleep disturbances, behavioral changes, in need of physical assistance, or advanced dementia can be an enormous challenge.[33] Giving caregivers the information and training that they need in a culturally sensitive manner helps them better prepare for these and other challenges. The actions to achieve this strategy include identifying the areas of training and educational needs, identifying and creating culturally-appropriate materials, and distributing these materials to caregivers.

(Updated) Action 3.A.1: Identify culturally sensitive materials and training

HHS will review culturally sensitive AD resources and identify areas where new resources need to be developed. HHS and private entities will develop relevant new culturally sensitive AD resources as needed. ACL/AoA conducted a webinar for the Aging Network in 2013 on diversity and health disparities related to dementia [http://www.aoa.gov/AoARoot/AoA_Programs/HPW/Alz_Grants/index.aspx]. This will be a topic of a webinar in 2014.

(Updated) Action 3.A.2: Distribute materials to caregivers

HHS will continue working with its agencies, other federal departments, and state and local networks and Tribal governments to distribute training and education materials. This will include dissemination through the Aging Network, the public health network, call centers and clearinghouses, and public websites. ACL/AoA's 2013 webinar on diversity and health disparities related to dementia included materials for caregivers [http://www.aoa.gov/AoARoot/AoA_Programs/HPW/Alz_Grants/index.aspx]. In addition, ACL/AoA created fact sheets targeted to caregivers which address advanced illness and dementia for its Eldercare Locator [http://www.eldercare.gov/eldercare.NET/Public/Resources/Advanced_Care/Index.aspx]. ACL and NIH, with input from other HHS agencies and external organizations, will continue to review and update the public website http://www.alzheimers.gov with current information and resources.

(Updated) Action 3.A.3: Utilize health information technology for caregivers and persons with Alzheimer's disease

Reports from the National Research Council have reinforced the need for HIT applications for caregivers as well as people with AD and providers.[34,35] Many opportunities exist for using technology to support people with AD and their caregivers. Opportunities include assistance with reminders, communications, and monitoring. HHS will identify and evaluate electronic services that can support older adults and their caregivers. For example, AHRQ is supporting a grant that is using integrated information and communication technology to facilitate aging in place. Through this grant, the University of Wisconsin-Madison, developed Elder Tree, a suite of electronic services support older adults, particularly those who are isolated. This tool is being evaluated to

assess the impact on independence and quality of life of users.
[http://aarc.chess.wisc.edu/?page_id=80]

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

Even though informal caregivers usually prefer to provide care to their loved ones in their home or other community settings, eventually the round-the-clock care needs of the person with AD may necessitate nursing home placement. While they are providing care, supports for families and caregivers can help lessen feelings of depression and stress and help delay nursing home placement.[36,37,38] The actions below will further support informal caregivers by identifying their support needs; developing and disseminating interventions; giving caregivers information they need, particularly in crisis situations; and assisting caregivers in maintaining their health and well-being. ACL has two major programs addressing services for people with dementia and their family caregivers. The ADSSP focuses on promoting state implementation of dementia capable HCBS systems and translating research-based interventions for family caregivers into community settings. The new Alzheimer's Disease Initiative-Specialized Supportive Services (ADI-SSS) is designed to expand the availability of specialized services and supports to people with dementia and their families at the state and local level. See Action 3.B.5 and Action 3.B.13.

Action 3.B.1: Identify unmet service needs

HHS will analyze surveys and datasets, such as the Caregiver Supplement to the National Health and Aging Trends Study, to identify the service needs of caregivers of people with AD. These findings will be published and disseminated to federal partners and the public. HHS will also meet with state and local officials and stakeholders to discuss unmet needs in their communities.

(Completed) Action 3.B.2: Identify and disseminate best practices for caregiver assessment and referral through the long-term services and supports system

ACL/AoA partnered with the National Family Caregiver Alliance to create *Selected Caregiver Assessment Measures (2nd Edition): A Resource Inventory for Practitioners* [http://caregiver.org/caregiver/jsp/content/pdfs/SelCGAssmtMeas_ResInv_FINAL_12.10.12.pdf]. This inventory provides a compendium of caregiver assessment measures that is practice-oriented, practical and addresses the multidimensional aspects of the caregiving experience. A 50-state survey of caregiver assessment in the Medicaid Home and Community-Based Services Waiver Programs is also now available.

(Completed) Action 3.B.3: Review the state of the art of evidence-based interventions that can be delivered by community-based organizations

In summer 2012, ACL/AoA partnered with the Alliance for Aging Research and the MetLife Foundation to review the state of the art of non-pharmacological treatments and care practices for people with Alzheimer's or other dementias and their family caregivers. A white paper was produced to summarize the review titled *Translating Innovation to Impact: Evidence-Based Interventions to Support People with Alzheimer's Disease and Their Caregivers at Home and in Their Communities* [http://www.aoa.gov/AoARoot/AoA_Programs/HPW/Alz_Grants/index.aspx].

Action 3.B.4: Develop and disseminate evidence-based interventions for people with Alzheimer's disease and their caregivers

HHS will expand its support for research and conduct trials, systematic reviews, and demonstration projects for evidence-based interventions to support individuals with Alzheimer's disease and their caregivers, work to identify emerging opportunities for the development of new interventions, and translate and disseminate findings immediately.

(Updated) Action 3.B.5: Provide effective caregiver interventions through Alzheimer's disease-capable systems

ACL/AoA will continue to expand efforts to develop more AD-capable LTSS systems designed to meet the needs of AD caregivers. In 2013, five states received funding to support the creation and sustainability of comprehensive dementia capable HCBS systems. A dementia capable system identifies those with dementia and helps ensure that the staff and providers who help them have appropriate training. Through this effort, ACL/AoA works with lead state agencies across state government and with the Aging Services Network to identify and address caregivers' needs when they seek assistance from state or local HCBS systems for themselves or for the person with AD. Caregivers are connected to supportive services such as respite care. Caregivers are also linked to evidence-based interventions. ACL/AoA's ADSSP Resource Center has analyzed the program's closed grants for their impacts and periodically updates the report and makes related presentations at major meetings [http://www.aoa.gov/AoARoot/AoA_Programs/HPW/Alz_Grants/index.aspx]. As additional effective interventions are identified, HHS will work with its partners on implementation in appropriate settings.

(Completed) Action 3.B.6: Share lessons learned through U.S. Department of Veterans Affairs caregiver support strategies with federal partners

Two meetings were convened in 2012 to educate federal partners about VA's Caregiver Support Program. VA officials shared the lessons learned from implementing an overall Caregiver Support Program, as well as a specific intervention designed to support family caregivers, Resources for Enhancing Alzheimer's Caregivers' Health-VA (REACH-VA), examining their impact on both caregivers and people with AD with other federal representatives through scheduled informational meetings.

(Completed) Action 3.B.7: Support caregivers in crisis and emergency situations

A webinar convened as a collaboration between ACL/AoA's Aging Services Network and NIA's ADCs was titled, *On-line Tools and Resources to Assist Individuals with Dementia and Caregivers: National Alzheimer's Contact Center, Eldercare Locator and ADEAR*. The webinar focused on highlighting the availability of resources to support caregivers in crisis and disaster situations. Over 500 participants registered for the webinar.
[http://www.aoa.gov/AoARoot/AoA_Programs/HPW/Alz_Grants/index.aspx]
[http://www.aoa.gov/AoARoot/AoA_Programs/HPW/Alz_Grants/docs/13June2012_webinar.ppt]

Action 3.B.8: Provide education about respite care for caregivers of people with Alzheimer's disease

HHS will enhance knowledge about respite care for people with dementia and their caregivers. ACL/AoA will develop and disseminate information on respite care considerations in dementia situations, as well as younger-onset and dementia among persons with intellectual disabilities. ACL/AoA will collaborate with other federal agencies and with private partners to develop and disseminate this information.

(Updated) Action 3.B.9: Collaborate to share information on long-term services and supports with Tribal providers

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

(Completed) Action 3.B.10: Share information on caregiver support services between the Aging Network and U.S. Department of Veterans Affairs

HHS and VA enhanced the ability of caregivers to access appropriate services through either system by though training staff at both organizations. VA provided training to ACL/AoA staff and their Aging and Disability Network partners about VA's structure and services available to veterans and family caregivers. ACL/AoA provided training to VA staff regarding ACL/AoA's structure and services available to family caregivers through the Older Americans Act and the Aging Network. Webinars occurred in May 2013 and are available at http://www.adrc-tae.acl.gov/tiki-index.php?page=vdhcbskey&filter=all (search this site for Administration for Community Living Presentation to the VA Network and VA Presentation to the Aging & Disability Services Network).

(Updated) Action 3.B.11: Pilot evidence-based interventions for caregivers in Indian Country

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

(New) Action 3.B.12: Continue to promote use of the National Alzheimer's Call Center to provide information, advice and support to people with dementia or their caregivers

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

(New) Action 3.B.13: Improve the dementia capability of the long-term services and supports systems so they can better meet the needs of people with Alzheimer's disease and their caregivers

In 2014, the new ADI-SSS will award grants to dementia capable systems related to three topics:

1. Provision of effective supportive services to persons living alone with ADRD in the community.
2. Development of dementia-capable systems individuals aging with intellectual and developmental disabilities.
3. Behavioral symptom management training and expert consultation for family caregivers.

(New) Action 3.B.14: Develop resources to encourage collaboration between Veteran Health Administration and State Lifespan Respite programs

Respite is critical for family caregivers of Veterans of all ages. As VA expands respite options for caregivers, ACL and VA will work to connect these efforts with State Lifespan Respite programs. ACL and VA are developing resources to support partnerships coordinating respite options, including those serving caregivers of and Veterans with Alzheimer's disease and related disorders.

(New) Action 3.B.15: Educate family caregivers about disaster preparedness planning

Family caregivers care for their loved ones with health or functional needs, including those with dementia. These caregivers need to develop emergency plans for themselves and those they support. The HHS Office of the Assistant Secretary for Preparedness and Response (ASPR) and ACL will offer a webinar and related print materials for the aging and disability networks to help family caregivers plan for emergencies and disasters. The webinar will highlight the unique needs of vulnerable populations during disasters and considerations for developing and maintaining emergency plans.

(New) Action 3.B.16: Enhance understanding of state regulations on residential care and adult day health services

HHS will explore state approaches to oversight of long-term care settings regulated at the state level including residential care and adult day health services. HHS will develop a compendium of state policy and regulation for residential care facilities (including assisted living) and a compendium of state policy and regulation for adult day services. The compendia will include detailed regulatory information for each state and a discussion of relevant Medicaid policy. These reports will help people working on Alzheimer's disease at the state and local levels understand how residential care and adult day health services policies influence service delivery for people with AD.

(New) Action 3.B.17: Examine technological solutions to support family caregivers

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

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

The vast majority of people do not think about or plan for the LTSS they will need until they experience a disability or AD. Many Americans incorrectly believe that Medicare will cover most of the costs of these supportive services.[39,40] Unfortunately, by the time care is needed, it is difficult to get coverage in the private long-term care insurance market, and options are limited.[41] Educating people about their potential need for LTSS and the significant advantages of planning ahead for these services encourages timely preparation. Planning ahead can help ensure that individuals with AD receive care in the setting they prefer and that their dignity is maintained.

Action 3.C.1: Examine awareness of long-term care needs and barriers to planning for these needs

HHS is working to better understand why middle-aged adults do or do not plan for long-term care needs. HHS will conduct a national survey to examine attitudes toward long-term care. It will also identify barriers to long-term care planning.

(Completed) Action 3.C.2: Expand long-term care awareness efforts

ACL has planned, funded and implemented Alzheimer's awareness activities, including Alzheimers.gov and a section on dementia in http://www.longtermcare.gov.

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

People with Alzheimer's disease are particularly vulnerable to financial exploitation, physical or emotional abuse, and neglect both at home and in care facilities.[42] Reports of elder abuse are handled by state Adult Protective Services (APS), which investigate allegations, provide protective services, and refer cases to law enforcement when appropriate. Not all APS programs cover residents of long-term care facilities. State survey and certification agencies receive funding from CMS to survey Medicare or Medicaid-certified nursing facilities and to investigate abuse complaints in these facilities. State licensing agencies may investigate complaints of abuse in other types of facilities, such as assisted living. State Long-Term Care Ombudsman programs advocate for residents of nursing homes and other adult care facilities, and work to resolve complaints on behalf of residents, including those related to abuse, neglect, and exploitation. The actions below will help ensure that people with AD have their dignity, safety, and rights maintained.

(Completed) Action 3.D.1: Educate legal professionals about working with people with Alzheimer's disease

A webinar series on legal issues and Alzheimer's disease was co-hosted by ACL/AoA and the American Bar Association. The four webinars covered legal issues of people with Alzheimer's disease and their caregivers. The webinars were designed to help ensure that people with AD have their dignity, safety, and rights maintained by providing a unique training opportunity to legal and aging professionals. The series is archived at http://www.aoa.gov/AoARoot/AoA_Programs/HPW/Alz_Grants/index.aspx.

(Updated) Action 3.D.2: Monitor, report and reduce inappropriate use of antipsychotics in nursing homes

HHS has identified the inappropriate use of some medications, including antipsychotic drugs, to manage difficult behaviors of nursing home residents, many of whom have Alzheimer's disease. CMS is leading a collaborative effort to reduce inappropriate and off-label use of antipsychotic and behavior modifying agents in nursing homes. This will be achieved through a multifaceted approach that includes updated surveyor guidance, stricter enforcement of rules, efforts to eliminate conflicts of interest by pharmacists, and, in partnership with the ADEAR, education of providers, long-term care ombudsman, prescribers, surveyors and families. Advancing Excellence in America's Nursing Homes, a public-private partnership which focuses on reduction of inappropriate use of antipsychotic drugs that especially affect individuals living with dementia, is a resource for more information about this issue [https://www.nhqualitycampaign.org/star_index.aspx?controls=welcome].

(Updated) Action 3.D.3: Enhance training to address the needs of individuals living in long-term care settings

HHS will enhance the ability of long-term care ombudsmen to protect and appropriately address the needs of people with dementia in long-term care settings. ACL/AoA's NORC will update trainings for long-term care ombudsmen to provide additional information on addressing the needs of individuals with dementia. To better assist individuals with AD and their families plan for advanced illness and health care decision making the ACL/AoA's NORC will provide specialized training for long-term care ombudsmen on these topics. ACL/AIDD's intellectual and developmental disability networks will provide input into the training.

Action 3.D.4: Incorporate elder abuse awareness into Aging Network activities

ACL/AoA will expand awareness and detection of elder abuse and neglect among the population of people with dementia. ACL/AoA will encourage the Eldercare Locator and other Aging Network and prevention program providers to become knowledgeable about warning signs of abuse. These providers will also disseminate information on elder abuse, with a particular focus on the vulnerable population of people with AD.

Action 3.D.5: Translate and disseminate information on abuse of people with dementia

ACL/AoA, NIH, and the U.S. Department of Justice (DoJ) have funded research to identify the factors associated with elder mistreatment. HHS will work with the private sector to translate these findings into educational materials and resources on abuse of people with dementia. ACL/AoA National Center on Elder Abuse will partner with the Rosalyn Carter Institute to disseminate these materials and raise caregivers' awareness of abuse, neglect, and exploitation of persons with dementia through research briefs, fact sheets and webinars.

(Updated) Action 3.D.6: Improve the ability of legal services to address the needs of people with Alzheimer's disease

ACL/AoA has three related activities underway to improve legal services for people with AD. In July 2013, ACL/AoA awarded seven grants designed to enhance statewide legal assistance delivery systems. One aspect of these demonstration grants is the promotion of dementia-capable legal service delivery systems by involving organizations with substantial expertise and experience in serving persons, families, and communities affected by Alzheimer's disease.

Collaborations are occurring among stakeholders, including legal services providers and Alzheimer's organizations. These collaborations will focus on the identification of and responses to legal problems affecting persons with AD, including issues related to abuse, neglect and financial exploitation. For example, in 2013, a partnership between the NORC and the NLRC lead to a webinar on legal strategies to address transfer, discharge and eviction from long-term care facilities (http://www.ltcombudsman.org/issues/transfer-discharge). These form the most common group of nursing home residents' complaints.

Action 3.D.7: Improve the ability of Alzheimer's disease information and referral systems and Long-Term Care Ombudsmen to identify or report abuse and neglect

ACL/AoA and NIA will work with national AD information and referral system grantees and partners on refining or creating protocols to train call takers on identifying abuse, neglect and exploitation among people with AD and making appropriate referrals to APS. This may include information on warning signs from caregivers indicating risk of abuse or neglect.

(Completed) Action 3.D.8: Educate fiduciaries about managing the finances of people with Alzheimer's disease

To ensure that those charged with handling the finances of older adults with AD have the tools they need to appropriately manage the individual's funds, the Consumer Finance Protection Bureau (CFPB) developed guides for "lay fiduciaries." Fiduciaries are often family members and other non-professionals with legal authority to handle finances, including agents under powers of attorney, guardians, Social Security representative payees, and VA fiduciaries. The guides [http://www.consumerfinance.gov/blog/managing-someone-elses-money] explain what a fiduciary does, and review critical basics to manage a vulnerable adult's money. The guides also teach lay fiduciaries to spot financial exploitation and protect assets from unfair, deceptive, and abusive practices by third parties.

(New) Action 3.D.9: Develop public-private partnerships to combat abuse and exploitation of Social Security beneficiaries

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

(New) Action 3.D.10: Educate law enforcement about interacting with Alzheimer's disease

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

(New) Action 3.D.11: Work with communities to develop best practices for protecting people with Alzheimer's disease

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

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

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

Action 3.E.1: Explore affordable housing models

HUD and HHS will explore models of affordable housing that provide coordinated housing, health and LTSS for individuals as they age in the community. This work will include examining housing sites that link health and LTSS. In addition, the project will link HUD and HHS data to understand the older adult population in HUD housing, including their health care utilization.

(Completed) Action 3.E.2: Examine patterns of housing and services

The CDC analyzed the National Survey of Residential Care Facilities to better understand the level of cognitive impairment among residents and the types of services provided in assisted living facilities. They found that in 2010, 17% of residential care communities had dementia special care units. Residential care communities with dementia special care units were more likely than those without to have more beds, be chain-affiliated, and be purposely built as a residential care community, and less likely to be certified or registered to participate in Medicaid. The full data brief is available at http://www.cdc.gov/nchs/data/databriefs/db134.htm.

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. Alzheimer's disease is also one of the most feared health conditions. Yet there are widespread and significant public misperceptions about diagnosis and clinical management.[43] Misperceptions lead to delayed diagnosis and to people with the disease and their caregivers feeling isolated and stigmatized. Enhancing public awareness and engagement is an essential goal because it forms the basis for advancing the subsequent goals of the National Plan. A better understanding of Alzheimer's disease 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

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

(Updated) Action 4.A.1: Design and conduct a national education and outreach initiative

In 2012, HHS designed http://alzheimers.gov and built a multifaceted public awareness initiative to direct caregivers and people with AD to the information and services they need. In 2013, HHS enhanced this campaign through updated and new content on Alzheimers.gov, developed in partnership with federal agencies and other experts. The site includes expanded information on special populations affected by AD and other topic areas of special interest. In 2014, HHS will design a national educational and outreach campaign focused on awareness of cognitive impairment. HHS, CMS, ACL/AoA, HRSA, NIH/NIA, CDC, IHS, and VA will collaborate to support this campaign by helping providers access the resources they need to care for people who identify concerns about their cognition. The campaign will be developed with HHS and non-governmental stakeholders to take advantage of investments already made in this area, and will include an examination of public health messages to promote awareness of dementia.

Action 4.A.2: Enhance public outreach about Alzheimer's disease

HHS will enhance information and resources and expand communication methods to raise awareness and educate persons with Alzheimer's and caregivers about the disease and the services available at the national, state, and local levels. NIA/NIH will update HHS web information about the disease, research, participation in clinical trials, and possible interventions for patients and caregivers. ACL/AoA will update http://www.eldercare.gov to include enhanced descriptions of resources for people with Alzheimer's and their caregivers. ACL/AoA and NIA/ADEAR will disseminate information about Alzheimer's disease through social media, including information about special topics such as participating in research, abuse and neglect, and caregiver stress.

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

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

(Completed) Action 4.B.1: Convene leaders from state, Tribal, and local governments

In April 2013, ASPE, CDC, and the HHS Office of Intergovernmental and External Affairs (IEA) convened a group of partners from state, local, and Tribal leadership organizations and staff from IHS to discuss how to partner on AD awareness. The groups also discussed opportunities to get input from their member organizations to inform HHS's work.

Action 4.B.2: Continue to convene federal partners

The Interagency Group on Alzheimer's Disease and Related Dementias, convened on an ongoing basis since April 2011, provides a forum for discussion of AD efforts across federal departments and agencies. Participants in this group have gained a better understanding of the roles and responsibilities of other departments and agencies for addressing Alzheimer's disease. Together, the group has identified existing resources and new opportunities for collaboration, best practices, and initiatives. HHS will continue to convene federal partners to collaborate on Alzheimer's disease. The group will share research findings, innovative or best practices, and information about new or upcoming initiatives.

Action 4.B.3: Build upon lessons learned to improve the dementia-capability of state and local service systems

HHS will improve the dementia-capability of state and local service systems through the ACL/AoA's ADSSP. ADSSP grantees, partners and other collaborators will work in peer-led groups on specific activities to make state and local-level improvements related to dementia-capability. The peer-led groups will develop practical tools to promote the adoption of dementia-capable practices at the state and local-levels. HHS will help states and communities meet the needs of people with AD through an expanded Dementia Capability Toolkit and other, related resources [http://www.aoa.gov/AoARoot/AoA_Programs/HPW/Alz_Grants/index.aspx]. Additional materials will result from similar 2014 program activities.

Action 4.B.4: Get Tribal input on Alzheimer's disease

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

(New) Action 4.B.5: Support improved coordination between IHS, Tribal, and Urban Indian Health programs and the Tribal Aging Network around four person-centered goals

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

1. I was diagnosed in a timely way.
2. I know what I can do to help myself and who else can help me.
3. Those helping to look after me feel well supported.
4. My wishes for care are supported.

IHS, Tribal, Urban Indian Health programs, and the Tribal Aging Network will address these goals through the following activities:

1. ***Diagnosis and Assessment***. IHS and ACL will pilot test a campaign focused on recognition of dementia warning signs, adapting a current VA approach and piloting this in clinical and community-based settings. IHS will also develop decision support for the evaluation of an individual with possible dementia for the IHS electronic health record.

2. ***Information and Referral***. IHS and ACL will partner with Alzheimer's advocacy organizations to link state and local chapters with Tribal Senior Centers and Tribal, IHS, and Urban Indian health facilities.

3. ***Family and Caregiver Support***. The IHS will assess the current pilot test of REACH-VA caregiver support program for expansion through training of public health and community health nursing programs. ACL will pilot test REACH-VA in Tribal Senior Centers receiving funding under Older Americans Act Title VI, Part C (caregiver support).

4. ***Self-Directed, Person-Centered Planning***. ACL will support the use of funds awarded under Older Americans Act Title VI, Parts A and C for tools to assist persons with dementia in communicating their wishes for care. ACL and IHS will identify strategies for coordination between the Tribal Aging Network and clinical services to foster self-direction and person-centered planning for persons with AD.

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

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

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

HHS will partner with other nations to continue the work begun during the G8 Dementia Summit hosted by the United Kingdom in December 2013. HHS will participate in the legacy meetings hosted throughout 2014. HHS will host the final legacy meeting in February 2015 in conjunction with the United States. *Alzheimer’s Disease Research Summit* described in Action 1.A.1. International partners will be invited to participate in both the Research Summit and the legacy meeting to discuss a shared research agenda and steps to move forward globally to fight Alzheimer’s disease.

Goal 5: Improve Data to Track Progress

The Federal Government is committed to better understanding AD and its impact on people with the disease, families, the health and long-term care systems, and society as a whole. Data and surveillance efforts are paramount to tracking the burden of AD on individual and population health and will be used to identify and monitor trends in risk factors associated with AD, 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

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

(Completed) Action 5.A.1: Identify major policy research needs

ASPE convened a meeting with partner agencies to talk about policy research data needs. Understanding the health care utilization patterns of people with Alzheimer's disease represented a major gap in knowledge identified by the group, including the need for a core set of International Classification of Diseases, 9th revision (ICD-9) codes for Alzheimer's disease.

(Updated) Action 5.A.2: Identify needed changes or additions to data

HHS will work with federal partners and researchers to identify the data and data infrastructure needed to address the policy issues identified in Action 5.A.1. These changes or additions may include new or improved measures, new data collection efforts, or links between existing data sets. ACL's 2013 assessment of the needs of elders served under Title VI programs included additional questions about Alzheimer's disease and brain health in Indian Country. These data should be analyzed in 2014. IHS will assess data available through the IHS Data Warehouse that contributes to an understanding of AD in Tribal communities.

Action 5.A.3: Make needed improvements to data

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

(Updated) Action 5.A.4: Summarize data on cognitive impairment across states

CDC released reports using surveillance data about increased confusion or memory loss and caregiving. In May 2013, CDC reported the first ever data for 21 states from the state-based Behavioral Risk Factor Surveillance System (BRFSS) concerning adult's aged 60 and older self-reported changes in increased confusion and memory loss during the past 12 months [http://www.cdc.gov/mmwr/pdf/wk/mm6218.pdf]. State-specific results from the 21 states were provided to the states to correlate with the report's release, and several states provided outreach and education to increase state-level awareness about issues raised in the report. In August 2013, CDC reported BRFSS data about the characteristics and differences in well-being, by caregiver age and caregiving status [http://www.cdc.gov/pcd/issues/2013/pdf/13_0090.pdf]. Additionally, authors from CDC and the CDC Healthy Aging Research Network reported results from the Porter Novelli Doc Styles and Health Styles surveys about the beliefs and communication practices regarding cognitive functioning among consumers and primary care providers in the United States [http://www.cdc.gov/pcd/issues/2013/pdf/12_0249.pdf].

CDC will conduct additional analyses of these data and make the data available in Summer 2014.

(Updated) Action 5.A.5: Develop and disseminate measures of awareness of Alzheimer's disease

HHS will improve the ability to track awareness and perceptions of cognitive impairment and AD by collecting and disseminating survey questions. CDC will identify validated survey questions that can be used at the national, state, and local levels to track awareness and perceptions about cognitive health and impairment, including decline in cognitive functioning.

(New) Action 5.A.6: Summarize existing data on people with Alzheimer's disease and their caregivers

Although there are various sources of information on characteristics of people with Alzheimer's disease, their caregivers, and the care and supports that they receive, there is no single source of government-sponsored information. HHS will develop a chartbook that presents data on key indicators about people with dementia, their caregivers, and the care they receive. Some of these indicators may include demographic characteristics, number of comorbid conditions, levels of disability, informal caregiver characteristics, and utilization of LTSS.

(New) Action 5.A.7: Develop a consistent set of ICD-9/ICD-10 codes for Alzheimer's disease and dementia for federal agencies to use in analyses of administrative data

Across the departments and agencies working to address ADRDs, a number of different ICD-9 codes are used to identify the population with Alzheimer's disease when analyzing administrative claims. HHS will form an interagency group to identify which codes should be used consistently across these entities so that analyses and publications are describing the same population. In addition, this group will crosswalk the ICD-9 codes to the ICD-10 codes in advance of the transition to ICD-10. Finally, the group will look at how these codes relate to Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-V).

Strategy 5.B: Monitor Progress on the National Plan

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

(Completed) Action 5.B.1: Designate responsibility for action implementation

HHS has designated ASPE as responsible for overseeing implementation, reporting on progress, convening the Advisory Council, and issuing reports to Congress.

Action 5.B.2: Track National Plan progress

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

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

Action 5.B.3: Update the National Plan annually

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

Appendix 1: List of Participating Departments and Agencies

ACF -- Administration for Children and Families

ACL -- Administration for Community Living

AIDD -- Administration on Intellectual and Developmental Disabilities

AHRQ -- Agency for Healthcare Research and Quality

AIDD -- Administration on Intellectual and Developmental Disabilities

AoA -- Administration on Aging

ASPA -- Office of the Assistant Secretary for Public Affairs

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

ASPR -- Office of the Assistant Secretary for Preparedness and Response

CDC -- Centers for Disease Control and Prevention

CFPB -- Consumer Finance Protection Bureau

CMS -- Centers for Medicare and Medicaid Services

CNCS -- Corporation for National and Community Services

DoD -- Department of Defense

DoE -- Department of Education

DoJ -- Department of Justice

DoL -- Department of Labor

DSRTF -- Down Syndrome Research and Treatment Foundation

FDA -- Food and Drug Administration

HHS -- Department of Health and Human Services

HRSA -- Health Resources and Services Administration

HUD -- Department of Housing and Urban Development

IEA -- Office of Intergovernmental and External Affairs

IHS -- Indian Health Service

NHGRI -- National Human Genome Research Institute

NIA -- National Institute on Aging

NIH -- National Institutes of Health

NINDS -- National Institute of Neurological Disorders and Stroke

NSF -- National Science Foundation

OASH -- Office of the Assistant Secretary for Health

OD -- Office on Disability

OGA -- Office of Global Affairs

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

OSG -- Office of the Surgeon General

SAMHSA -- Substance Abuse and Mental Health Services Administration

SSA -- Social Security Administration

VA -- Department of Veterans Affairs

VHA -- 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 2013 and 2014
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 Alzheimer's Disease Research Summit to update priorities.	Convene second Summit in 2015.	NIH/NIA	HHS NAPA Federal Research Subgroup, academia, industry, professional & advocacy groups.	First Summit 2012 Second Summit February 2015	http://www.nia.nih.gov/about/events/2012/alzheimers-disease-research-summit-2012-path-treatment-and-prevention
1.A.2	Solicit public & private input on AD research priorities.	RFI inviting public & private input on funded research addressing AD & related dementias.	NIH/NIA	Alzheimer's Association	Ongoing	Funder meeting was held in July 2012 at the Alzheimer's Association International Conference to encourage input. Periodic teleconferences of the IADRFC coordinated by the Alzheimer's Association, working with NIA at NIH, facilitate continuing dialogue among funders. 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.	HHS/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.	HHS/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	http://aspe.hhs.gov/daltcp/napa/milestones/index.shtml

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2013 and 2014
1.A.7	Create milestones for research goals based on the recommendations from the 2013 ADRD conference.	Create milestone document.	NIH/NINDS		February 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	HHS NAPA Federal Research Subgroup, academia, industry, professional & advocacy groups.	December 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.	NIA/NIH	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]
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	Alzheimer's Disease Sequencing Project--sequenced the whole genomes of more than 580 volunteers & made the data freely accessible to researchers [https://www.niagads.org/]

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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 collaborated on the ROAR project: Program in 2013 to promote research participation by connecting researchers in the aging & public health networks [http://www.hhs.gov/idealab/innovate/roar/] Alzheimer's Prevention Registry was launched in October 2012 by the Banner Alzheimer's Institute (1 of 27 NIA-funded Alzheimer's research centers) [http://www.endalznow.org/] An NIA RFI sought ideas on how to increase participation in Alzheimer's clinical trials [http://grants.nih.gov/grants/guide/notice-files/NOT-AG-12-017.html] Ongoing webinars available at 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	ACL	Ongoing	Ongoing webinars on need to enroll racial & ethnic minorities for networks available at http://www.aoa.gov/AoARoot/AoA_Programs/HPW/Alz_Grants/index.aspx http://www.nia.nih.gov/newsroom/announcements/2013/05/2013-webinar-series-alzheimers-disease-and-resources#webinar3/

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2013 and 2014
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/] 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] 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]
1.B.6	Continue clinical trials on the most promising lifestyle interventions.	Conduct annual reviews of the status & progress of clinical trials.	NIH/NIA	CDC, 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]
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]

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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 Alzheimer's Association International Conference [http://www.alz.org/aaic/overview.asp] European Union Joint Programming Initiative on Neurodegenerative Diseases Research [http://www.neurodegenerationresearch.eu/] 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	FDA	January 2015	

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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	http://alzheimers.gov/
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	NIA ADEAR, ACL, CDC, FDA, CMS, HRSA, VA, partner organizations	Ongoing	ADEAR Center [http://www.nia.nih.gov/alzheimers]
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		December 2014	Draft Guidance for Industry: Alzheimer's disease: 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, NIA/NIH	December 2014	
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	
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		December 2014	
1.E.8	Leverage research in areas related to neurodegeneration.	Initiate series of joint meetings.	DoD	VA	December 2014	

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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 GECs 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 AD.	HRSA	CMS-NIA-CDC collaboration	Ongoing	
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	December 2014	

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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	Ongoing	ACL/AOA conducted presentations about the ability of the ADSSP grants to translate caregiver interventions & innovations. A closed grant report is continuously updated. ADSSP reports include the results of learning collaboratives on identification of persons with dementia, training of dementia care providers, & quality assurance. These materials are available at http://www.aoa.gov/AoARoot/AoA_Programs?HPW/Alz_Grants/index.aspx.
2.A.7	Develop & disseminate a voluntary unified primary care AD curriculum.	Develop a voluntary curriculum for primary care practitioners.	HRSA	CMS, NIA/NIH, VA	September 2016	
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, the NIA 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, NIA/NIH	CDC	Ongoing	

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2.A.9	Engage the public health workforce on brain health.	Conduct briefings with federal, state, & local public & private partners regarding The Healthy Brain Initiative: The Public Health Road Map for State & National Partnerships, 2013-2018.	CDC	ACL, NIH/NIA	February 2015	The Healthy Brain Initiative: The Public Health Road Map for State & National Partnership, 2013-2018 is available at 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	October 2014	
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		May 2015	
2.A.12	Enhance the ability of long-term care ombudsman to support people with AD.	Train long-term care ombudsman as "Hand-in-Hand" trainers. Conduct evaluation if funding is made available	ACL/AoA	CMS	September 2016	
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	September 2014	

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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.	ACL/AoA	CMS	September 2014	
2.A.15	Strengthen the long-term care workforce.	Provide technical assistance to states.	DOL, CMS	HHS	TA 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		Ongoing	2012 & 2013 webinars are available at http://www.aoa.gov/AoARoot/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 at http://www.nia.nih.gov/research/cognitive-instrument

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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	September 2014	
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	

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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, NIA	November 2014	
2.D.3	Convene an expert panel on advanced dementia.	Convene panel & report on discussion.	HHS/ASPE	IOM, outside experts	March 2015	First meeting was held on January 28, 2014. Second meeting is scheduled for July 2014. Third meeting will in January 2015.
2.D.4	Solicit stakeholder input on meaningful outcomes to drive quality measurement.	Hold listening session.	CMS	ASPE	Completed	
2.D.5	Clarify & disseminate information on privacy, autonomy, & safety issues to physicians.	Develop information & disseminate.	HHS/ASPE, HRSA		December 2015	

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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	NIA/NIH	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	
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 2014	
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	Ongoing	
2.F.3	Enhance understanding of avoidable hospitalizations & emergency department use among people with AD.	Release report.	ASPE		Completed	A report is available at 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	December 2014	

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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	January 2015	
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 work groups to define the health & psychosocial outcomes on which the interventions will be evaluated.	ASPE		Completed	Report available at 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/
2.G.3	Evaluate evidence on care integration.	Issue report on findings.	ASPE		March 2015	
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	January 2015	
Strategy 2.H: Improve Care for Populations Disproportionally Affected by Alzheimer's Disease and for Populations Facing Care Challenges						
2.H.1	Create a taskforce to improve care for these specific populations.	Convene a taskforce; develop a strategic plan with action steps.	HHS/ASPE, ACL/AIDD	ACL, NIH, OD, NIMH	Completed	Report available at 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	HHS/ASPE	Completed	Report available at http://aspe.hhs.gov/daltcp/reports/2013/AlzSpPop.shtml

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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		August 2014	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.	HHS/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	Identify culturally sensitive materials & training.	Survey individuals who use AD resources to assess whether they are culturally-appropriate.	ACL		Ongoing	Webinars available at http://www.aoa.gov/AoARoot/AoA_Programs/HPW/Alz_Grants/index.aspx
3.A.2	Distribute materials to caregivers.	Distribute training & education materials through federal agencies & state & local networks.	ACL	NIH/NIA, ADEAR	Ongoing	Information available at http://www.alzheimers.gov Fact sheets available at http://www.eldercare.gov/eldercare.NET/Public/REsources/Advanced_Care/Index.aspx
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		August 2014	

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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	Available at 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	Available at 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.	NIA/NIH	AHRQ, CMS, CDC, ACL/AoA	Ongoing	
3.B.5	Provide effective caregiver interventions through AD-capable systems.	Work with states to identify caregiver interventions for dissemination.	ACL/AoA		Ongoing	Grants will be awarded September 2014. Closed grant reports available at http://www.aoa.gov/AoARoot/AoA_Programs/HPW/Alz_Grants/index.aspx
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 available at http://www.aoa.gov/AoARoot/AoA_Programs/HPW/Alz_Grants/index.aspx

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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	August 2014	
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 at 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	Ongoing	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	
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	

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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.	HHS/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 & adult day services regulations.	HHS/ASPE	CMS	January 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		January 2015	
3.C.2	Expand long-term care awareness efforts.	Develop campaign materials. Select states. Implement campaign.	ACL		Completed	See 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 available at 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 antipsychotics in nursing homes.	Safe Use Initiative.	CMS	ACL/AoA, NORC	Ongoing	Information for Ombudsman Program available at http://www.theconsumervoice.org/advocate/antipsychotic-drugs. http://www.theconsumervoice.org/advocate/antipsychotic-drugs#education Other information available at 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 long-term care ombudsmen.	ACL/AoA	NORC	December 2014	
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, factsheets & 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	SUAs, Legal assistance developers, NLRC	Ongoing	Grants were awarded in July 2013. National Long-Term Care Ombudsman program held a webinar on legal issues related to nursing facility discharge available at http://www.ltcombudsman.org/issues/transfer-discharge
3.D.7	Improve the ability of AD information & referral systems to identify abuse or neglect.	Refine protocols to train call takers on identifying abuse, neglect & exploitation among people with AD.	ACL/AoA	NIH/NIA, private partners, grantees	Ongoing	
3.D.8	Educate fiduciaries about managing the finances of people with AD.	Release lay fiduciary guide.	CFPB	ACL/AoA	Completed	Lay fiduciary guides available at http://www.consumerfinance.gov/blog/managing-someone-elses-money/

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2013 and 2014
3.D.9	Develop public-private partnerships to combat abuse & exploitation of Social Security beneficiaries.	Create 1 urban & 1 rural pilot program to recruit representative payees for Social Security beneficiaries.	SSA, ACL	CNCS, CFPB, private organizations	June 2015	
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	August 2014	The first report from this project is available at http://aspe.hhs.gov/daltcp/reports/2012/ValueAdd.shtml.
3.E.2	Examine patterns of housing & services.	Study where people with AD live & availability of services in those settings.	HHS/ASPE, CDC/NCHS	ACL	Completed	Data brief available at 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	CDC, CMS, HRSA, IHS NIH/NIA, HHS/ASPE, VA	September 2015	
4.A.2	Enhance public outreach about AD.	Update website & ADEAR site/publications & disseminate information through social media.	ACL, NIH/NIA		Ongoing	http://www.eldercare.gov

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2013 and 2014
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 available at 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	

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2013 and 2014
4.B.5	Support improved coordination between IHS, Tribal, & Urban Indian health programs & the Tribal Aging Network around 4 person-centered goals.	IHS & ACL will adapt the VA approach to dementia warning signs & pilot test it in clinical & community-based settings. IHS & ACL will partner with Alzheimer's 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 will participate in legacy meetings throughout 2014. The US will host the final legacy meeting in February 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		Summer 2014	

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2013 and 2014
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.	HHS/ASPE	CDC/NCHS, NIH/NIA, ACL/AOA	April 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.	HHS/ASPE	CMS, VA, NIH, IHS	January 2015	
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	

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List of Acronyms Used

AAA	Area Agency on Aging
ACL	Administration for Community Living
ACTIVE	Advanced Cognitive Training for Independent and Vital Elderly
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
ADNI	Alzheimer’s Disease Neuroimaging Initiative
ADRC	Aging and Disabilities Resource Center
ADRD	Alzheimer’s Disease-Related Dementias
ADSSP	Alzheimer’s Disease Supportive Services Program
AHRQ	Agency for Healthcare Research and Quality
AIDD	Administration on Intellectual and Developmental Disabilities
AMP	Accelerating Medicines Partnership
AoA	Administration on Aging
APS	Adult Protective Services
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
CAMD	Coalition Against Major Diseases
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
DLB	Dementia with Lewy Bodies
DNA	Deoxyribonucleic acid
DoD	U.S. Department of Defense
DoE	U.S. Department of Education
DoJ	U.S. Department of Justice
DoL	U.S. Department of Labor
DSM-V	Diagnostic and Statistical Manual of Mental Disorders, 5th Edition
DSRTF	Down Syndrome Research & Treatment Foundation
FDA	Food and Drug Administration
FLSA	Fair Labor Standards Act
FTD	Frontotemporal Dementia
FY	Fiscal year
GEC	Geriatric Education Center
HCBS	Home and community-based services
HHS	U.S. Department of Health and Human Services
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
IEA	Office of Intergovernmental and External Affairs
IGAP	International Genomic Alzheimer’s Project
IHS	Indian Health Service
iPSC	Induced pluripotent stem cell
LTSS	Long-Term Services and Supports
NAPA	National Alzheimer's Project Act
NHGRI	National Human Genome Research Institute
NIA	National Institute on Aging
NIH	National Institutes of Health
NINDS	National Institute of Neurological Disorders and Stroke
NLRC	National Legal Resource Center
NORC	National Ombudsman Resource Center
ONC	Office of the National Coordinator for Health Information Technology
RDS	Research Down Syndrome
REACH-VA	Resources for Enhancing Alzheimer’s Caregivers’ Health-VA
RFI	Request for Information
RNA	Ribonucleic acid
ROAR	Recruiting Older Adults into Research
SSA	Social Security Administration
VA	U.S. Department of Veterans Affairs
VHA	Veterans Health Administration

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