National Plan to Address Alzheimer's Disease: 2014 Update

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National Plan to Address Alzheimer's Disease: 2013 Update

U.S. Department of Health and Human Services

National Plan to Address Alzheimer's Disease: 2013 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), 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.
- Improve outcomes 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

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. Some of the accomplishments since then are described below. Additional details are in the descriptions of actions that have been completed.

In May 2012, the National Institutes of Health (NIH) and HHS convened the *Alzheimer's Disease Research Summit 2012: Path to Treatment and Prevention* to bring together national and international researchers and advocacy groups to develop recommendations on how to best advance Alzheimer's research. The Summit recommendations, which are designed to capitalize on current scientific opportunities, will inform Alzheimer's research for years to come. [http://www.nia.nih.gov/announcements/2012/05/alzheimers-research-summit-may-14-15-2012]

In 2012, the National Institute on Aging (NIA) in partnership with the Alzheimer's Association launched the **International Alzheimer's Disease Research Portfolio** (IADRP) database. This web-based portal

houses the AD research portfolios of federal and non-federal funding agencies in the United States and abroad classified using a common AD research ontology (CADRO). IADRP is a resource that will give the public a full picture of the scale of ongoing research on AD and enable funders of Alzheimer's research to coordinate planning, leverage resources, avoid duplication, and identify new opportunities for collaboration.

With the Administration's investment of $50 million in 2012 for Alzheimer's disease research, NIH supported five new research projects in key areas of need and opportunity:

- Whole genome sequencing to identify new genetic variants that either increase risk (risk factors) or reduce risk (protective factors) for AD.
- A treatment trial to test the effectiveness of intranasal insulin in individuals with mild cognitive impairment (MCI) or mild Alzheimer's dementia on cognition and daily functioning.
- A trial to test the ability of an antibody called crenezumab to bind to and clear away abnormal amounts of amyloid protein in the brain and prevent cognitive decline in people with early-onset AD. Crenezumab is being tested among members of a unique and large family population in Colombia sharing a genetic mutation known to cause observable signs of AD at around age 45 along with a smaller number of participants ages 30 and older in the United States.
- Use of new induced pluripotent stem cell methods to obtain insights into the cellular processes of Alzheimer's.
- Support to the "Atherosclerosis Risk in Communities (ARIC) Neurocognitive Study" (ARIC-NCS) focused on prediction of cognitive impairment from mid-life vascular risk factors and markers.

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, in November 2012, 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. TREM2 is involved in inflammation and immune response. This finding may offer a target for interventions.

In addition, 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. For more information on scientific discoveries, see the **2011-2012 Alzheimer's Disease Progress Report** [http://www.nia.nih.gov/alzheimers/publication/2011-2012-alzheimers-disease-progress-report].

A number of efforts have also helped improve the quality of care received by people with AD. The Health Resources and Services Administration (HRSA) issued grants totaling $2 million to its network of Geriatric Education Centers (GECs) to enhance the ability of the health care workforce to meet the needs of people with AD. Over 10,000 providers, including physicians, nurses, and direct care workers received training on topics such as dementia diagnosis and treatment and effective behavior management for persons with dementing diseases and their caregivers.

The Centers for Medicare and Medicaid Services (CMS) and NIH worked together to identify a set of brief tools that physicians can use to assess cognitive impairment. These tools all require 5 minutes or less to administer, are available free of charge with simple access, and have been validated within the last 12 years among the older adult population in the United States. These tools will be available for providers to use to assess cognitive impairment during the Annual Wellness Visit covered by Medicare.

The CMS Center for Medicare and Medicaid Innovation (Innovation Center) is testing innovative payment and service delivery models relevant to people with Alzheimer's disease, including the *Health Care Innovation Awards*. In the first round, CMS awarded funds to 107 projects, several of which aim to identify how to improve care for people with AD. For example, Indiana University's "Dissemination of the Aging Brain Care Program" is working to improve care for Medicare beneficiaries with dementia or late-life

depression. The model is providing individualized and integrated care through a multidisciplinary care team; developing patient-specific care plans, delivering evidence-based protocols, and responding to real-time monitoring and feedback. Another project, "UCLA Alzheimer's and Dementia Care: Comprehensive, Coordinated, Patient-Centered," is providing coordinated, comprehensive, patient and family-centered, and efficient care for approximately 1,000 Medicare and Medicaid beneficiaries with Alzheimer's disease or other forms of dementia. The model is training providers, expanding a dementia registry, conducting patient needs assessments, and creating individualized dementia care plans.

In May 2013, the Innovation Center announced a second round of *Health Care Innovation Awards*, specifically soliciting proposals in four specific categories of care. One of the four categories, "improve care for populations with specialized needs," designates proposals that target care for persons with AD as a priority population for funding. The Innovation Center expects to make awards for this second round by the beginning of 2014. Other relevant models may include the "Multi-payer Advanced Primary Care Practice Demonstration," the "Comprehensive Primary Care" initiative, and the "Independence at Home Demonstration." Participants in each of the models share key learning experiences during the testing or performance period with the objective of accelerating dissemination of promising practices within the model, such as improved care plans for people with AD.

HHS convened a Specific Populations Task Force to identify the unique challenges faced by groups unequally burdened by Alzheimer's disease: racial and ethnic minorities, people with intellectual disabilities, and people with young onset AD. The Task Force collected information from over 40 organizations and reviewed hundreds of comments. Some of the challenges identified by the Task Force are addressed by actions described in this 2013 Update.

NIH hosted a meeting in April 2013 to advance a research agenda aimed at developing successful interventions to address Alzheimer's disease for people with Down syndrome. Representatives from academia, industry, federal agencies and private foundations explored how current research activities and resources could create new opportunities to develop therapeutics. Recommendations and a summary of the meeting will be published online.

CMS has taken important steps to ensure that people with dementia are not inappropriately receiving antipsychotic medications to manage their behavior in nursing homes. CMS and public and private partners have made major presentations to national, state, and local groups, educated providers, and completed 200 nursing home case studies focused on how decisions are made to use antipsychotic medication. CMS developed two training videos for survey staff. CMS also developed two quality measures and will be analyzing data to track progress toward the goal of reducing antipsychotic drug usage by 15 percent.

In the summer of 2012, the Administration for Community Living/Administration on Aging (ACL/AoA) partnered with the Alliance for Aging Research, with funding from 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].

In partnership with the National Family Caregiver Alliance, ACL/AoA published **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 resource provides a compendium of caregiver assessment measures that providers can use to help identify the caregiver's needs and build upon their strengths to create a care plan that addresses the individualized needs of the care recipient and the caregiver.

In order to enhance public awareness of Alzheimer's disease and link caregivers and people with a diagnosis to the resources they need, HHS launched http://www.alzheimers.gov/ and fielded an

awareness campaign. The campaign included a commercial shown during evening news and daytime television, print advertisements, and web advertisements. There were over 200,000 visits to Alzheimers.gov in the first 10 months. The 30-second commercial won a Silver Addy Award from the *2013 American Advertising Awards* in DC.

NIA joined forces with ACL to create "Connecting to Combat Alzheimer's," a series of free webinars and presentations that served to connect both the research and aging services communities. 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). The program received the *HHSinnovates Award* and received a second honor as the People's Choice among projects highlighted.

The Centers for Disease Control and Prevention (CDC) collaborated with the Alzheimer's Association and many partners to develop the second in a series of Road Maps to advance cognitive health as a vital, integral component of public health. **The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013-2018** outlines how state and local public health agencies and their partners can promote cognitive functioning, address cognitive impairment for individuals living in the community, and help meet the needs of care partners. Over 200 stakeholders from private, non-profit and governmental agencies were involved in the development of the Road Map, which is scheduled to be released in July 2013. Leadership Committee members included representation from NIA, ACL/AoA and CDC as well as national, state and local partners.

HHS is committed to tracking the progress of the National Plan. A detailed timeline with steps for each of the new actions is available in Appendix 3.

2013 Update

This is the 2013 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

Alzheimer's disease is an irreversible, progressive brain disease that affects as many as 5.1 million Americans.[1] It slowly destroys brain function, leading to cognitive decline (e.g., memory loss, language difficulty, poor executive function), behavioral and psychiatric disorders (e.g., depression, delusions, agitation), and declines in functional status (e.g., ability to engage in activities of daily living and self-care).[2] In 1906, Dr. Alois Alzheimer first documented the disease when he identified changes in the brain tissue of a woman who had memory loss, language problems, and unpredictable behavior. Her brain tissue included abnormal clumps (amyloidal plaques) and tangled bundles of fibers (neurofibrillary tangles). Brain plaques and tangles, in addition to the loss of connections between neurons, are the main features of Alzheimer's disease.[3]

In this plan, the term "Alzheimer's disease," or AD, refers to Alzheimer's disease and related dementias, consistent with the approach Congress used in NAPA. Related dementias include frontotemporal, Lewy body, mixed, and vascular dementia. 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. Unless otherwise noted, in this plan AD refers to 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. 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.[4,5]

In more than 90 percent 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.[6] 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. 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.[7]

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 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.[8]

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.[9] Similarly, while people living in nursing homes are a small percentage of the older population, nearly half (48 percent) of nursing home residents have Alzheimer's disease.[10] 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.[11,12]

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 [http://aspe.hhs.gov/daltcp/napa/NatlPlan.shtml#append3]. 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.

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* [http://www.nia.nih.gov/about/events/2012/alzheimers-disease-research-summit-2012-path-treatment-and-prevention] 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 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 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.

(Completed) 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 to encourage input. NIA continues to discuss priorities through ongoing teleconferences.

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 Summit 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

NINDS, in collaboration with NIA, convened a research workshop on *Alzheimer's Disease Related Dementias, May 1-2, 2013* [https://meetings.ninds.nih.gov/?ID=4077] 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. NIH will release a report summarizing the workshop recommendations. 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.

(New) Action 1.A.6: Create a timeline 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 [http://aspe.hhs.gov/daltcp/napa/042913/Mtg8-Handout1.pdf]. This document will be updated regularly to reflect progress.

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.

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 disease process to enable the identification and selection of therapeutic targets.

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

NIH will undertake a new initiative 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. This research is expected to yield novel targets for drug development, provide improved diagnostics for screening and disease monitoring, and ultimately help define strategies for disease prevention.

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 will consult with representatives from across the Federal Government, state and local governments, academic medical research institutions, and the private sector to plan approaches and coordinate and implement action steps for increasing enrollment in clinical trials, including through the use of existing or planned registries.

As part of this effort, HHS will continue to expand awareness of clinical trial opportunities among providers of long-term services and supports and health care providers so that they may inform interested people about these opportunities. NIA and ACL will create an action plan to enhance collaboration between researchers at NIA-funded ADCs and the ACL-funded aging network to improve mutual referrals and increase awareness of research opportunities among people with dementia, older adults and family caregivers receiving supportive and other services.

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.

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 and other dementias.

HHS will inform service providers about the need to enroll more racial and ethnic minorities in Alzheimer's disease research studies. NIA and ACL will collaborate to offer webinars with representatives from the aging network, service providers, ADCs, Quality Improvement Organizations, and other federal partners to raise awareness of the need for participation of racial and ethnic minorities in Alzheimer's disease studies. [http://www.nia.nih.gov/newsroom/announcements/2013/05/2013-webinar-series-alzheimers-disease-and-resources].

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. NIA is a primary funder of large investigator-initiated clinical trials including the Alzheimer's Disease Cooperative Study (ADCS). Clinical trials will continue to advance the development of interventions and evaluate their effectiveness. 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.

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.

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.[13]

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.

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.

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.

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

The IADRP [http://iadrp.nia.nih.gov/cadro-web] is a new, 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 will enable 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. Alzheimer's Research United Kingdom is the first international entity to join the collaboration.

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

The Alzheimer's Association and the NIA co-hosted a funders meeting at the *Alzheimer's Association International Conference* in July 2012. The Alzheimer's Association and NIA 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" (JPND). The Office of Global Affairs (OGA) is exploring with foreign Ministries of Health opportunities to include joint activities on Alzheimer's disease in bilateral initiatives.

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.

Action 1.E.3: Educate the public about the latest research findings

HHS, VA, and other federal agencies will expand their outreach efforts to more effectively inform the public about research findings, including results from clinical trials and studies regarding the non-pharmacological management of physical, cognitive, emotional, and behavioral symptoms. The NIA's Alzheimer's Disease Education and Referral Center (ADEAR) will continue its focus in this area, and work with ACL and CDC to expand outreach to include the findings of studies that center on community and public health interventions.

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

FDA will issue recommendations about standards for evaluating the effectiveness of treatments for early stage Alzheimer's disease. It is currently difficult to assess the impact of treatments on patients with early AD or who may be at risk of developing the disease, because they may have only minor or no clinical signs of the disease. The guidance will include recommendations about diagnostic criteria for evaluating therapeutic impact on early Alzheimer's disease, strategies for demonstrating the impact through outcome measures, and the role of biomarkers.

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

HHS will review the literature on co-occurring chronic conditions and dementia, including Alzheimer's disease, to understand the effect of dementia on various outcomes such as depression, disease management, or morbidity. The findings of this review will be disseminated through CDC's public health network, ACL/AoA's Aging Services Network, and the NIA research network.

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 is dependent on smooth transitions between care settings and coordination among health care and long-term services and supports providers.

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 long-term services and supports 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. Physicians and other health care providers need information on how to implement the "detection of any cognitive impairment" component of the Medicare Annual Wellness Visit included in 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.[14] 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. Funded by HRSA through its GEC Program, during the first 6 months of this initiative 45 GEC grantees partnered with 248 community stakeholders to provide 178 interprofessional educational offerings to over 10,000 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. Data for the remaining 6 months will be available in October 2013. In 2013, this effort will continue 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.

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 "Comprehensive Geriatric Education Program," as mandated by the Affordable Care Act, provides traineeships to support students pursuing advanced degrees in geriatric nursing, long-term services and supports, and gero-psychiatric nursing. In addition, HRSA will continue to support training projects that provide fellowships for individuals studying to be geriatricians, geriatric dentists, or geriatric psychiatrists. These programs prepare professionals to address the needs of people with Alzheimer's disease through service rotations in different care settings. HRSA will also continue to support the career development of geriatric specialists in academia through the "Geriatric Academic Career Awards Program." Currently 65 percent of these 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.

Action 2.A.5: Strengthen state aging and public health workforces

HHS will coordinate with states to develop aging and public health workforces that are AD-capable and culturally-competent. AoA will ask states to specify strategies to improve the AD-capability of the workforce in their State Aging Plans and relevant grant applications. These strategies may include enhancing Alzheimer's disease competencies among Aging Network staff, developing AD-capable community health and long-term care Options Counseling in Aging and Disability Resource Centers, and linking State Long-Term Care Ombudsmen programs to AD-specific training and resources. ACL/AoA will work with HRSA to make AD training available to the Aging Network. 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.

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.[15] 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. HHS will disseminate information about these interventions, and share best practices.

(New) 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.

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

It is important that service providers 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 will collaborate to offer webinars with representatives from the aging network, ADCs, the ADEAR, the National Alzheimer's Call Center, Eldercare Locator, Alzheimers.gov, and other federal partners to ensure aging and public health workforces receive recent, updated and culturally-appropriate information.

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

CDC will release **The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013-2018**, 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.

(New) 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 Alzheimer's disease and related dementias (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.

(New) 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 nurses 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 HHS will incorporate training for Alzheimer's disease into the online continuing education curriculum for IHS/Tribal/Urban nursing programs. IHS will review current offerings and, if needed, add additional content and will track trainings provided with the curriculum.

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.[16] 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.[17,18] 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.[19] 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 the summer of 2012, ACL/AoA launched 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 consumers they serve. These webinars will be ongoing.

Action 2.B.2: Identify and disseminate appropriate assessment tools

The Affordable Care Act established coverage of the Medicare Annual Wellness Visit. "Detection of any cognitive impairment" must be included as part of the wellness visit. HHS is using research findings to identify the most appropriate assessment tools that can be used in a variety of outpatient clinical settings to assess cognition. The recommended tools will be distributed to practitioners to aid in identification and evaluation of cognitive impairment. Once cognitive impairment has been detected, practitioners will be able to consider potential causes of cognitive impairment and determine the need for a comprehensive diagnostic evaluation for AD.

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.[20] Further, once a diagnosis is made and disclosed, as few as half of patients and families receive counseling, support, or information about next steps.[21] This information is important, especially for early stage patients who experience positive outcomes when they are involved in planning and receive appropriate services.[22] 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.

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, HHS will work with its 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. This work will be coordinated with the provider education effort in Action 2.A.1.

(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 long-term services and supports 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.

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

ACL and NIH will continue to coordinate efforts to improve the dissemination of information on dementia working through the ACL Office for American Indian, Alaska Natives and Native Hawaiian programs. NIA-supported ADCs will continue with their work to improve dementia care among Native Americans. A newly established trans-NIH Program Interest Group will focus on Native American research including dementia among this underserved population. In addition, HHS will help American Indians and Alaska Natives to access resources about Alzheimer's disease by adding links to the National Plan and to Alzheimers.gov from the IHS Elder Care website.

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.

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

HHS will work with private partners 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 work can serve to inform clinical, behavioral health, and long-term services and supports providers, families, and people with AD, and can also serve as a foundation to guide the identification and development of metrics that promote high-quality dementia care in all settings.

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

HHS will work with consensus-based entities 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. This work will lead to a conceptual framework for measurement of dementia care quality and help HHS identify which concepts should be translated into performance measures.

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

In accordance with the recommendation of the Advisory Council, HHS will support the Institute of Medicine to convene a meeting of experts on advanced dementia. The experts will consider and make 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 may discuss models to improve the care for those with advanced dementia.

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

Work is underway both and CMS and the VA to identify models that provide more effective and efficient care for people with Alzheimer's disease. The Affordable Care Act established the CMS 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 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 carrying 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 long-term services and supports. The Innovation Center will conduct subgroup analyses to examine whether health and functional status outcomes are improved among people with AD in this demonstration.

(New) 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 the 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.[23]

Action 2.F.1: Identify and disseminate models of hospital safety for people 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. The Innovation Center will identify practices that benefit people with complex needs including people with Alzheimer's disease. CMS will share these findings broadly.

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.

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

HHS will identify patterns of avoidable hospitalizations and emergency department use among people with Alzheimer's disease. This work will highlight additional risk factors for such hospitalizations and emergency department use and will be used to tailor interventions to this population.

(New) 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."

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.[24] 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

A review of the evidence on care coordination specifically for people with Alzheimer's disease was completed in spring 2013. ASPE will release a report summarizing the research literature on care coordination models in August 2013.

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. 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.

(New) Action 2.G.3: Evaluate evidence on care integration

HHS will explore how service delivery models that integrate acute care and long-term services and supports 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.

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 taskforce 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.

(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 long-term services and supports in its work on Action 2.H.1. The Task Force developed a list of broad recommendations based on the input it received, will be shared in a report expected to be released in June 2013. [http://aspe.hhs.gov/daltcp/reports/2013/AlzSpPop.shtml]

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, or in need of physical assistance can be an enormous challenge.[25] 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.

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.

Action 3.A.2: Distribute materials to caregivers

HHS will work 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.

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 health information technology (HIT) applications for caregivers as well as people with AD and providers.[26,27] 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 an agenda for priority actions to support the use of technology to assist caregivers and persons with the disease.

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.[28,29,30] 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.

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.

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

ACL/AoA will expand efforts to develop more AD-capable long-term services and supports systems designed to meet the needs of AD caregivers. Through these efforts, ACL/AoA will work 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 home and community-based services (HCBS) systems for themselves or for the person with AD. Caregivers will be connected to supportive services such as respite care. Caregivers will also be linked to interventions shown to decrease burden and depression among caregivers and enhance the care received by people with Alzheimer's disease. 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.

(New) 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 young 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.

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

HHS will use two mechanisms to share information on long-term services and supports and care of the person and family with ADRD with Tribal providers. Through a webinar series involving IHS, ACL/AoA, and CMS, federal partners will share lessons learned about interventions to support improved quality of care for persons with dementia and support for family caregivers. In addition, through the annual conference on Tribal aging programs, ACL/AoA will highlight programs that specifically address persons with ADRD and/or their caregivers and provide specific training on care for persons with ADRD in the community.

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

HHS and VA will enhance the ability of caregivers to access appropriate services through either system though trainings to both organizations. VA will provide 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 will provide training to VA staff regarding ACL/AoA's structure and services available to family caregivers through the Older Americans Act and the Aging Network.

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

HHS and VA will partner to pilot REACH-VA in a small number of Tribes, focusing on American Indian and Alaska Native Veterans and their families. The IHS will invite IHS, Tribal, and Urban Indian health programs who serve American Indian and Alaska Native Veterans with dementia to obtain the REACH-VA training and materials for providing the caregiver support intervention. This cohort of programs and staff will provide us with insight to how well the REACH-VA program works in the IHS system.

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

The vast majority of people do not think about or plan for the long-term services and supports 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.[31,32] 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.[33] Educating people about their potential need for long-term services and supports 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.[34] 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.

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, prescribers, surveyors and families. ACL/AoA's long-term care ombudsman programs also provide education to families and residents to support reduction of inappropriate antipsychotic medication use in long-term care facilities.

(New) 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 National Ombudsman Resource Center will update trainings for long-term care ombudsmen to provide additional information on addressing the needs of individuals with dementia.

(New) 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.

(New) 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.

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

ACL/AoA will implement demonstration grants that promote 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 between legal services providers and Alzheimer's organizations would include formalized memorandums of agreement and cross-training activities involving Older American's Act Title III-B legal providers, Senior Legal Hotline attorneys, Protection and Advocacy attorneys, Aging and Disability Resource Center Options Counselors, APS, and Long-Term Care Ombudsmen focusing on the identification and legal responses to legal problems impacting persons with AD, including issues related to abuse, neglect and financial exploitation.

(New) Action 3.D.7: Improve the ability of Alzheimer's disease information and referral systems to identify abuse or 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.

(New) 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) will create a set of guides for "lay fiduciaries." These family members and other non-professionals with legal authority to handle finances include agents under powers of attorney, guardians, Social Security representative payees, and VA fiduciaries. The guides will explain what a fiduciary does, and review critical basics to manage a vulnerable adult's money. In addition, the guides will teach lay fiduciaries to spot financial exploitation and protect assets from unfair, deceptive, and abusive practices by third parties.

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 long-term services and supports for individuals as they age in the community. This work will include examining housing sites that link health and long-term services and supports. In addition, the project will link HUD and HHS data to understand the older adult population in HUD housing, including their health care utilization.

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

HHS will undertake analyses of existing studies and surveys to better understand where people with Alzheimer's disease live and the availability of services in these settings. This will include an in-depth analysis of 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. The results of these studies will be used to identify areas that the National Plan should address in future years.

Goal 4: Enhance Public Awareness and Engagement

Most of the public is aware of Alzheimer's disease; more than 85 percent 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.[35] 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.

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

In 2012, HHS designed 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 will enhance this campaign through updated and new content on Alzheimers.gov, developed in partnership with federal agencies and other experts. The site will include expanded information on special populations affected by AD and other topic areas of special interest. HHS will seek to form partnerships with private organizations to broaden the effectiveness of the effort and explore a Public Service Announcement strategy over paid media.

(New) 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. A follow-up meeting will be held in summer 2013.

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.

(New) 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 "Alzheimer's Disease Supportive Services Program" (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**.

(New) 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.

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.

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

HHS will expand outreach to international partners on Alzheimer's disease through its OGA and other relevant federal agencies. HHS will invite colleagues and representatives of other countries and international organizations to meet and discuss ongoing Alzheimer's disease plans. These meetings will focus on shared research agendas, recent research findings, best practices in care across the continuum, and supports for informal caregivers.

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 ICD-9 codes for Alzheimer's disease.

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.

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.

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

CDC will summarize data on self-reported cognitive decline from the **Behavioral and Risk Factor Surveillance Survey** (BRFSS) collected from 23 states in 2012. The data provide state-specific information about the adults who experience cognitive decline. The information can be linked to other information about preventive health practices and risk behaviors, as well as chronic diseases, injuries, and preventable infectious diseases.

(New) 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.

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 Behavioral Risk Factor Surveillance System 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 3 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/AoA -- Administration for Community Living/Administration on Aging

AIDD -- Administration on Intellectual and Developmental Disabilities

AHRQ -- Agency for Healthcare Research and Quality

ASPA -- Assistant Secretary for Public Affairs

ASPE -- Assistant Secretary for Planning and Evaluation

CDC -- Centers for Disease Control and Prevention

CFPB -- Consumer Finance Protection Bureau

CMS -- Centers for Medicare & Medicaid Services

DoD -- Department of Defense

FDA -- Food and Drug Administration

HHS -- Department of Health and Human Services

HRSA -- Health Resources and Services Administration

HUD -- Department of Housing and Urban Development

IEA -- Office of Intergovernmental and External Affairs

IHS -- Indian Health Service

NIA -- National Institute on Aging

NIH -- National Institutes of Health

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

VA -- Department of Veterans Affairs

Appendix 2: Crosswalk of National Plan to Address Alzheimer's Disease with Other HHS Strategies and Plans

National Alzheimer's Plan (2012)	Multiple Chronic Conditions: A Strategic Framework (2010)	HHS Action Plan to Reduce Racial and Ethnic Health Disparities (2011)	National Prevention Strategy (2011)	HHS Strategic Plan (2010-2015)
Research				
Goal 1: Prevent & Effectively Treat AD by 2025. Strategy 1.A: Identify research priorities & milestones. Strategy 1.B: Expand research aimed at preventing & treating AD. Strategy 1.C: Accelerate efforts to identify early & presymptomatic stages of AD. Strategy 1.D: Coordinate research with international public & private entities. Strategy 1.E: Facilitate translation of findings into medical practice & public health programs.	Goal 4: Facilitate research to fill knowledge gaps about, & interventions & systems to benefit, individuals with multiple chronic conditions. Objective A: Increase the external validity of trials. Objective B: Understand the epidemiology of multiple chronic conditions. Objective C: Increase clinical, community, & patient-centered health research. Objective D: Address disparities in multiple chronic conditions populations.		Strategic Direction 4 -- Elimination of Health Disparities. 4.4 -- Support research to identify effective strategies to eliminate health disparities.	Goal 2: Advance Scientific Knowledge & Innovation. Objective A: Accelerate the process of scientific discovery to improve patient care. Objective B: Foster innovation to create shared solutions. Objective D: Increase our understanding of what works in public health & human service practice.

National Alzheimer's Plan (2012)	Multiple Chronic Conditions: A Strategic Framework (2010)	HHS Action Plan to Reduce Racial and Ethnic Health Disparities (2011)	National Prevention Strategy (2011)	HHS Strategic Plan (2010-2015)
Quality Workforce and Evidence-based Strategies				
Goal 2: Enhance Care Quality & Efficiency. Strategy 2.A: Build a workforce with the skills to provide high-quality care. Strategy 2.B: Ensure timely & accurate diagnosis. Strategy 2.C: Educate & support people with AD & their families upon diagnosis. Strategy 2.D: Identify high-quality dementia care guidelines & measures across care settings. Strategy 2.E: Explore the effectiveness of new models of care for people with AD. Strategy 2.F: Ensure that people with AD experience safe & effective transitions between care settings & systems. Strategy 2.G: Advance coordinated & integrated health & long-term services & supports for individuals living with AD. Strategy 2.H: Improve care for populations disproportionally affected by AD & for populations facing care challenges.	Goal 1: Foster health care & public health system changes to improve the health of individuals with multiple chronic conditions. Objective A: Identify evidence-supported models for persons with multiple chronic conditions to improve care coordination. Goal 3: Provide better tools & information to health care, public health, & social services workers who deliver care to individuals with multiple chronic conditions. Objective A: Identify best practices & tools. Objective B: Enhance health professionals training. Objective C: Address multiple chronic conditions in guidelines.	Goal 2: Strengthen the Nation's Health & Human Services Infrastructure & Workforce. Strategy 2.A: Increase the ability of all health professions & the health care system to identify & address racial & ethnic disparities. Goal 3: Advance the health, safety, & well-being of the American people. Strategy 3.A: Reduce disparities in population health by increasing the availability & effectiveness of community-based programs & policies.	Strategic Direction 4 -- Elimination of Health Disparities. 4.2 -- Reduce disparities in access to quality health care. 4.3 -- Increase the capacity of the prevention workforce to identify & address disparities.	Goal 2: Advance Scientific Knowledge & Innovation. Objective D: Increase our understanding of what works in public health & human service practice. Goal 3: Advance the Health, Safety, & Well-Being of the American People. Objective C: Improve the accessibility & quality of supportive services for people with disabilities & older adults. Goal 5: Strengthen the National Health & Human Service Infrastructure & Workforce. Objective B: Ensure that the Nation's health care workforce can meet increased demands. Objective C: Enhance the ability of the public health workforce to improve public health at home & abroad. Objective D: Strengthen the Nation's human service workforce.

National Alzheimer's Plan (2012)	Multiple Chronic Conditions: A Strategic Framework (2010)	HHS Action Plan to Reduce Racial and Ethnic Health Disparities (2011)	National Prevention Strategy (2011)	HHS Strategic Plan (2010-2015)
Individual and Family Supports				
Goal 3: Expand Supports for People with AD & Their Families. Strategy 3.A: Ensure receipt of culturally sensitive education, training, & support materials. Strategy 3.B: Enable family caregivers to continue to provide care while maintaining their own health & well-being. Strategy 3.C: Assist families in planning for future care needs. Strategy 3.D: Maintain the dignity, safety & rights of people with AD. Strategy 3.E: Assess & address housing needs of people with AD.	Goal 2: Maximize the use of proven self-care management & other services by individuals with multiple chronic conditions. Objective B: Facilitate HCBS.	Goal 1: Transform Health Care. Strategy 1.A: Reduce disparities in health insurance coverage & access to care. Strategy 1.B: Reduce disparities in access to primary care services & care coordination. Strategy 1.C: Reduce disparities in the quality of health care.	Strategic Direction 2 -- Clinical & Community Preventive Services. 2.4 -- Support implementation of community-based preventive services & enhance linkages with clinical care. 2.5 -- Reduce barriers to accessing clinical community preventive services, especially among populations at greatest risk. Strategic Direction 1 -- Healthy & Safe Community Environments. 1 -- Coordinate investments in transportation, housing, environmental protection, & community infrastructure to promote sustainable & healthy communities.	Goal 3: Advance the Health, Safety, & Well-Being of the American People. Objective C: Improve the accessibility & quality of supportive services for people with disabilities & older adults. Goal 1: Transform Health Care. Objective B: Improve health care quality & patient safety. Objective C: Emphasize primary & preventive care linked with community prevention services.

National Alzheimer's Plan (2012)	Multiple Chronic Conditions: A Strategic Framework (2010)	HHS Action Plan to Reduce Racial and Ethnic Health Disparities (2011)	National Prevention Strategy (2011)	HHS Strategic Plan (2010-2015)
Informed Stakeholders				
Goal 4: Enhance Public Awareness & Engagement. Strategy 4.A: Educate the public about AD. Strategy 4.B: Work with state & local governments to improve coordination & identify model initiatives to advance AD awareness & readiness across the government. Strategy 4.C: Coordinate US Efforts with Those of the Global Community			Strategic Direction 3 -- Empowered People. 3.3 -- Engage & empower people & communities to plan & implement prevention policies & programs. Priority 7 -- Mental & Emotional Well-being. 7.3 -- Provide individuals & families with the support necessary to maintain positive mental well-being.	
Quality Data				
Goal 5: Improve Data to Track Progress. Strategy 5.A: Enhance the Federal Government's ability to track progress. Strategy 5.B: Monitor progress on the National Plan.		Goal 4: Advance Scientific Knowledge & Innovation. Strategy 4.A: Increase the availability & quality of data collected & reported on racial & ethnic minority populations.		Goal 4: Increase Efficiency, Transparency, & Accountability of HHS Programs. Objective C: Use HHS data to improve the health & well-being of the American people.

Appendix 3: Implementation Milestones

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status
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 August 2015
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		Completed
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, members of the Advisory Council	Completed
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 for achieving Goal 1.	Create & update timeline document.	NIH/NIA		Ongoing
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
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

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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, ACL, VA, CDC, HRSA, CMS, in partnership with the private sector	Ongoing
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
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
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
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
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
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 and other private sector partners	Completed

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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	Completed
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.	ASPE, NIH	FDA	Ongoing
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
1.E.3	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
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 2013
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, & the NIA research network.	CDC	ACL/AoA, NIA/NIH	Summer 2013
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	July 2014

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2.A.2	Encourage providers to pursue careers in geriatric specialties.	Educate providers about opportunities through: (1) the Comprehensive Geriatric Education Program, (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 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	October 2013
2.A.4	Strengthen the direct care workforce.	Release training for the nursing home direct care workforce.	CMS	AHRQ	Completed
2.A.5	Educate the Aging Services Network staff about AD.	A series of 4 webinar-based trainings will be provided to AAA/ADRC staff to increase their knowledge about AD & issues to consider in assessing the needs of the individual with cognitive impairment & their caregivers to facilitate access to long-term services & supports.	HRSA	ACL/AoA	July 2014
2.A.6	Support state & local AD strategies.	Share best practices with states.	ACL/AoA	ASPE, CDC, HRSA	Ongoing
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	July 2014
2.A.8	Ensure aging 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		Ongoing

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2.A.9	Engage the public health workforce on brain health.	Release **The Healthy Brain Initiative: The Public Health Road Map for State & National Partnerships, 2013-2018**.	CDC	ACL, NIH/NIA	October 2014
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, 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 2014
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. Connect families & people with symptoms of AD with AD-capable resources, including diagnostic services through NIH-funded ADCs. Convene representatives from National Alzheimer's Call Center, ADEAR, & Aging Network to establish inventory of resources available to the public. Host at least 1 conference call or webinar for the Aging Network to learn about ADCs.	ACL, NIH/NIA		Ongoing

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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. Survey providers who have used the toolbox.	CMS, NIH/NIA	CDC	January 2014
2.C.1	Educate physicians & other health care providers about accessing long-term services & supports.	Increase knowledge of available resources among doctors, nurses, & hospitals.	CMS	HRSA, VA, ACL	Ongoing
2.C.2	Enhance assistance for people with AD & their caregivers to prepare for care needs.	HHS will strengthen the ability of existing long-term services & supports 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 and Alaska Natives to AD resources.	Add link to the National Plan & to Alzheimers.gov to the IHS Elder Care Website.	IHS		June 2013
2.D.1	Explore dementia care guidelines measures.	Review OAA Title II-E services to identify potential improvements in serving people with dementia; convene meetings with public & private organizations to discuss dementia care practices; identify 3-5 measures within the first year; submit measures & guidelines to National Quality Forum.	CMS		Ongoing

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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	September 2014
2.D.3	Convene an expert panel on advanced dementia.	Convene panel & report on discussion.	HHS/ASPE	IOM, outside experts	March 2014
2.E.1	Evaluate the effectiveness of medical home models for people with AD.	Examine changes in care quality & care coordination among people with AD	CMS/ Innovation Center	NIA/NIH	July 2014
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		July 2015
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	September 2013
2.F.1	Explore the effects of new payment models on AD care & costs.	Perform subgroup analysis of Innovation Center models.	CMS/ Innovation Center		July 2015
2.F.2	Implement & evaluate new care models to support effective care transitions for people with AD.	Evaluate Community-based Care Transition Program demonstration programs	CMS	ACL	October 2014
2.F.3	Enhance understanding of avoidable hospitalizations & emergency department use among people with AD.	Release report.	ASPE		November 2013
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	December 2014

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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
2.G.2	Implement & evaluate care coordination models.	Implement & evaluate care coordination models	CMS		Ongoing
2.G.3	Evaluate evidence on care integration.	Issue report on findings.	ASPE		March 2015
2.H.1	Create a taskforce to improve care for these specific populations.	Convene a taskforce; develop a strategic plan with action steps.	ASPE, ACL/AIDD	ACL, NIH, OD, NIMH	Completed
2.H.2	Identify steps to ensure access to long-term services & supports 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	ASPE	Completed
3.A.1	Identify culturally sensitive materials & training.	Survey individuals who use AD resources to assess whether they are culturally-appropriate.	ACL	HHS, federal partners, & private entities	Ongoing
3.A.2	Distribute materials to caregivers.	Establish a strategy with federal agencies & state & local networks to distribute training & education materials; distribute training materials.	ACL	NIH/NIA, ADEAR	Ongoing
3.A.3	Utilize HIT for caregivers & persons with AD.	Convene meeting with stakeholder groups to identify priority actions; publish report on findings.	AHRQ		July 2013
3.B.1	Identify unmet service needs.	Release report summarizing analysis of NHATS data.	ASPE		August 2013
3.B.2	Identify & disseminate best practices for caregiver assessment & referral through the long-term services & supports 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
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

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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
3.B.6	Share lessons learned through VA caregiver support strategies with federal partners.	Two 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
3.B.8	Provide education on respite for caregivers of people with AD.	Develop & disseminate information on respite care for individuals with dementia.	ACL	ACL/AoA, ARCH National Respite Network	July 2014
3.B.9	Collaborate to share information on long-term services & supports with Tribal providers.	Hold webinar series on interventions to support improved quality of care for persons with dementia & support for family caregivers & highlight programs for people with ADRD & their caregivers in annual conference on Tribal aging programs.	ACL/AoA	IHS, CMS	August 2013
3.B.10	Share information on caregiver support services between the Aging Network & VA.	Webinars & trainings.	ACL/AoA	VA	June 2013
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.	IHS	VA	June 2014
3.C.1	Examine awareness of long-term care needs & barriers to planning for these needs.	Finalize LTC Awareness Survey; Conduct survey; analyze results; release final report.	ASPE		January 2014
3.C.2	Expand long-term care awareness efforts.	Develop campaign materials. Select states. Implement campaign.	ACL		Completed

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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
3.D.2	Monitor, report & reduce inappropriate use of antipsychotics in nursing homes.	Safe Use Initiative.	CMS	ACL/AoA	Ongoing
3.D.3	Enhance training to prevent abuse in long-term care setting.	Updated trainings for long-term care ombudsmen.	ACL/AoA	National Ombudsman Resource Center	June 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 demonstration grants.	ACL/AoA	SUAs, Legal assistance developers, NLRC	Ongoing
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	October 2013
3.E.1	Explore affordable housing models.	Examine housing sites that link health & long-term services & supports. Link HUD & HHS data to understand the older adult population in HUD housing.	ASPE, HUD	ACL	December 2013
3.E.2	Examine patterns of housing & services.	Study where people with AD live & availability of services in those settings.	ASPE, NCHS	ACL	July 2013
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, SAMHSA, SG	Ongoing

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4.A.2	Enhance public outreach about AD.	Update www.eldercare.gov & ADEAR site/publications & disseminate information through social media.	ACL, NIH/NIA		Ongoing
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		Ongoing
4.B.4	Get Tribal input on AD.	Convene Tribal leaders.	IHS	ASPE, ACL/AoA	Ongoing
4.C.1	Work with global partners to enhance collaboration.	Convene global partners.	ASPE		Ongoing
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	Completed
5.A.2	Identify needed changes or additions to data.	Work with federal partners & researchers.	ASPE	CMS, CDC, NIH/NIA, ACL/AoA, VA	October 2013
5.A.3	Make needed improvements to data.	Develop questions to be fielded for data collection. Add to surveys.	ASPE	NCHS/CDC, NIH/NIA	Ongoing
5.A.4	Summarize data on cognitive impairment across states.	Report on 2012 BRFSS data on cognitive decline.	CDC		Summer 2014
5.A.5	Develop & disseminate measures of awareness of AD.	Release report on validated survey questions.	CDC		October 2014
5.B.1	Designate responsibility for action implementation.	Designate office.	ASPE		Completed

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status
5.B.2	Track plan progress.	Track progress on the plan, & incorporate measures into other efforts to monitor population health such as Healthy People 2020.	ASPE		Ongoing
5.B.3	Update the National Plan Annually.	Release updated National Plan.	ASPE		Ongoing

References

1. Hebert LE, Weuve J, Scherr PA, Evans DA. Alzheimer's disease in the United States (2010-2050) estimated using the 2010 census. Neurol. 2013; 80: 1778-1783.

2. Burns A, Iliffe S. Alzheimer's disease. BMJ. 2009; 338: b158.

3. Alzheimer's Disease Education & Referral (ADEAR) Center. Alzheimer's disease fact sheet. U.S. Department of Health and Human Services, National Institutes of Health. NIH Publication No. 11-6423. July 2011.

4. National Institute on Aging. 2009 Progress report on Alzheimer's disease: Translating new knowledge. U.S. Department of Health and Human Services, National Institutes of Health. NIH Publication no. 10-7500. November 2010.

5. Alzheimer's Disease Education & Referral (ADEAR) Center. Alzheimer's disease fact sheet. U.S. Department of Health and Human Services, National Institutes of Health. NIH Publication No. 11-6423. July 2011.

6. National Institute on Aging. 2009 Progress report on Alzheimer's disease: Translating new knowledge. U.S. Department of Health and Human Services, National Institutes of Health. NIH Publication no. 10-7500. November 2010.

7. Mahoney R, Regan C, Katona C, Livingston G. Anxiety and depression in family caregivers of people with Alzheimer's disease: The LASER-AD study. J Am Geriatr Soc. 2005; 13(9): 795-801.

8. Hurd M, Martorell P, Delavande A, Mullen K, Langa K. Monetary Costs of Dementia in the United States. N Engl J Med. 2013; 368:1326-1334. Available at: http://www.nejm.org/toc/nejm/368/14/.

9. Maslow K. How many hospital patients have dementia? In Silverstein N and Maslow K, eds. *Improving Hospital Care for People with Dementia*. New York, NY: Springer; 2006.

10. Magaziner J, German P, Zimmerman SI, Hebel JR, Burton L, Gruber-Baldini AL, May C, Kittner S. The prevalence of dementia in a statewide sample of new nursing home admissions aged 65 and older. Gerontol. 2000; 43(4): 514-520.

11. Yaffe K, Fox P, Newcomer R, Sands L, Lindquist K, et al. Patient and caregiver characteristics and nursing home placement in patients with dementia. JAMA. 2002; 287: 2090-2094.

12. Taylor DH, Ezell M, Kuchibhatia M, Ostbye T, Clipp EC. Identifying the trajectories of depressive symptoms for women caring for their husbands with dementia. J Am Geriatr Soc. 2008; 56(2): 322-327.

13. Lo RY, Hubbard AE, Shaw LM, et al. Longitudinal change of biomarkers in cognitive decline. Arch Neurol. 2011; 68: 1257-1266.

14. Health Resources and Services Administration website. Geriatrics & Allied Health: Comprehensive geriatric education programs. Available at: http://bhpr.hrsa.gov/grants/geriatrics/.

15. Alzheimer's Association. State government Alzheimer's disease plans. Available at: http://www.alz.org/join_the_cause_state_plans.asp. Accessed November 28, 2011.

16. Bradford A, Kunik ME, Schulz P, et al. Missed and delayed diagnosis of dementia in primary care: Prevalence and contributing factors. Alzheimer Dis Assoc Disord. 2009; 23(4): 306-314.

17. Gaugler JE, Kane RL, Kane RA, et al. Unmet care needs and key outcomes in dementia. J Am Geriatr Soc. 2005; 53: 2098-2105.

18. Mittelman MS, Haley WE, Clay OJ, et al. Improving caregiver well-being delays nursing home placement of patients with Alzheimer disease. Neurology. 2006; 67: 1592-1599.

19. Jack CR Jr, Albert M, Knopman DS, et al. Introduction to the recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease: National Institute on Aging and the Alzheimer's Association workgroup. Alzheimers Dement. 2011 May; 7(3): 257-62. Epub 2011 Apr 21.

20. Johnson H, Bouman WP, Pinner G. On telling the truth in Alzheimer's disease: A pilot study of current practice and attitudes. Int Psychogeriatr. 2000; 12(2): 221-229.

21. Chodosh J, Mittman BS, Connor KI. Caring for patients with dementia: How good is the quality of care? Results from three health systems. J Am Geriatr Soc. 2007; 55(8): 1260-1268.

22. Banerjee S, Willis R, Matthews D, Contell F, Chan J, Murray J. Improving the quality of care for mild to moderate dementia: An evaluation of the Croydon Memory Service Model. Int J Geriatr Psychiatry. 2007; 22(8): 782-788.

23. Cohen CA, Pushkar D. Transitions in care: Lessons learned from a longitudinal study of dementia care. Am J Geriatr Psychiatr. 1999; 7(2):139-146.

24. Callahan CM, Boustani MA, Unverzagt FW, et al. Effectiveness of collaborative care for older adults with Alzheimer disease in primary care: A randomized controlled trial. JAMA. 2006; 295: 2148-57.

25. DesRoches C, Blendon R, Young J, et al. Caregiving in the post-hospitalization period: Findings from a national survey. Nurs Econ. 2002; 20: 216-221,224.

26. Charness N. Matching care to people in their home environments. In The Role of Human Factors in Health Care: Workshop Summary. Washington, DC: National Academies Press; 2010.

27. Demiris G. Information and systems in home health care. In The Role of Human Factors in Health Care: Workshop Summary. Washington, DC: National Academies Press; 2010.

28. Mittelman MS, Roth DL, Haley WE, Zarit SH. Effects of a caregiver intervention on negative caregiver appraisals of behavior problems in patients with Alzheimer's disease: Results of a randomized trial. J Gerontol B Psychol Sci Soc Sci. 2004; 59(1): 27-34.

29. Sörensen S, Pinquart M, Duberstein P. How effective are interventions with caregivers? An updated meta-analysis. The Gerontologist. 2002; 42(3): 356-72.

30. Mittelman MS, Haley WE, Clay OJ, Roth DL. Improving caregiver well-being delays nursing home placement of patients with Alzheimer disease. Neurol. 2006; 67(9): 1592-1599.

31. Kemper P, Harriet LK, Alecxih L. Long-term care over an uncertain future: What can current retirees expect? Inquiry. December 2005; 42(4): 335-350.

32. MetLife Mature Market Institute. MetLife long-term care IQ: Removing myths, reinforcing realities. September 2009.

33. Mathematica Policy Research, Inc. Shoring up the infrastructure for long-term care: What do vulnerable adults know about their options? Issue Brief. July 2004.

34. Government Accountability Office. Elder justice: Stronger Federal leadership could enhance national response to elder abuse. 2011. Available at: https://secure.ssa.gov/apps10/poms.nsf/lnx/0423022385. Accessed November 15, 2011.

35. Blendon RJ. Georges J. et al. Key Findings from a five-country survey of public attitudes about Alzheimer's disease. Poster presented at AAIC, July 2011.

36. Eiken S, Sredl K, Burwell B. Table U. Distribution of Medicaid LTC Expenditures, All Populations. Cambridge, MA: Thomson Reuters; 2011. Available at: http://hcbs.org/files/193/9641/FY2009InstitutionCommunityRankings.pdf.

37. Hyde J, Perez R, Forrester B. Dementia and assisted living. The Gerontologist. 2007; 47(Special Issue III): 51-67.

38. Eiken S, Sredl K, Burwell B. Table U. Distribution of Medicaid LTC Expenditures, All Populations. Cambridge, MA: Thomson Reuters; 2011. Available at: http://hcbs.org/files/193/9641/FY2009InstitutionCommunityRankings.pdf.

39. Mollica RL. State Medicaid reimbursement policies and practices in assisted living. Washington, DC: National Center for Assisted Living, American Health Care Association; 2009. Available at: http://www.ahcancal.org/ncal/resources/documents/medicaidassistedlivingreport.pdf. Accessed 2012.

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