

National Alzheimer's Project Act (NAPA)

The information that follows was included as an attachment to an email submitted by the public.

For more information about NAPA, visit the NAPA website at:

<http://aspe.hhs.gov/national-alzheimers-project-act>

Draft National Plan To Address Alzheimer's Disease

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 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.

Taking Immediate Action to Fight Alzheimer's Disease

Building on the preliminary work on this plan, on February 7, 2012, the Obama Administration announced a historic \$156 million investment to tackle Alzheimer's disease.

This investment includes:

Immediately increasing Alzheimer's disease research funding. The National Institutes of Health (NIH) immediately dedicated an additional \$50 million from its fiscal year 2012 funding to Alzheimer's disease research.

Sustaining and growing the Alzheimer's disease research investment. The President's fiscal year 2013 budget includes \$80 million in new Alzheimer's disease research funding. Together, the fiscal years 2012 and 2013 investments total \$130 million in new Alzheimer's disease research funding over two years.

Supporting people with Alzheimer's disease and their families and educating the public and providers. The initiative also includes \$26 million to support the goals of the National Plan, including:

- Education and outreach to improve the public's understanding of Alzheimer's disease;
- Outreach to enhance healthcare providers' knowledge of the disease;
- Expanded support for people with Alzheimer's disease and caregivers in the community;
- Improved data collection and analysis to better understand the impact of Alzheimer's disease on people with the disease, families and the health and long-term care systems.

This initiative aims to take immediate action on Alzheimer's disease without waiting for Congress to act. And, it provides support for ideas being developed through this National Plan.

The National Plan

This is the first National Plan. This plan includes a detailed listing of current federal activities and, as directed by NAPA, initial recommendations for priority actions to expand, eliminate, coordinate or condense programs. 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 goals that will require numerous actions to achieve. This is a National Plan and not a federal plan. It will require the active engagement of public and private sector stakeholders to achieve. In the case of many of the long-range goals, 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 add additional transformative actions.

This draft of the National Plan is being submitted to the Advisory Council for consideration and input. It will also be open for public comment. Comments can be submitted to Helen Lamont (helen.lamont@hhs.gov) and will be accepted until March 30, 2012.

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 (amyloid plaques) and tangled bundles of fibers (neurofibrillary tangles). Brain plaques and tangles, in addition to the loss of connections between neurons, are the main features of AD.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 40s or 50s.

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 U.S. 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 an enormous emotional 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 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 When the person with AD moves to a nursing home to receive 24-hour care, the financial costs to families are great: an estimated \$78,000 per year.⁸

Caring for people with Alzheimer's disease also strains the health and long-term care systems. Individuals with Alzheimer's disease use a disproportionate amount of healthcare resources; for instance, they are hospitalized 2–3 times as often as people the same age who do not have the disease.⁹ Similarly, while people living in nursing homes are a small percentage of the older population, nearly half (48%) of nursing homes 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 has 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 constant need to provide care can take a toll, 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 healthcare 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, 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 affecting AD. This inventory will be included as an appendix to the final plan. 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 looks to 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. Optimize 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.

Key to advancing this goal is the Obama Administration’s investment of \$50 million in new Alzheimer’s disease research funding in fiscal year 2012 and \$80 million in new Alzheimer’s disease research funding in fiscal year 2013. These investments will open new opportunities in Alzheimer’s disease research and jumpstart efforts to reach the 2025 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.

Action 1.A.1: Convene an Alzheimer’s disease research summit with national and international scientists to identify priorities, milestones, and a timeline

In May 2012, the National Institute on Aging (NIA) of the National Institutes of Health will convene a research summit, Alzheimer’s Research Summit 2012: Path to Treatment and Prevention, to provide expert input into identification of research priorities, to explore public and private research collaborations, and to establish strategies and milestones for an ambitious plan to slow progression, delay onset, and prevent Alzheimer’s disease. The summit will include national and international experts in Alzheimer’s disease and dementia research, public and private stakeholders, and members of the Advisory Council on Alzheimer’s Research, Care, and Services. Summit proceedings will be open to the public.

Action 1.A.2: Solicit public and private input on Alzheimer’s disease research priorities

HHS will continue to seek input and feedback from the public on its Alzheimer’s disease research. Specifically, NIA will issue a Request for Information (RFI) to invite public and private input on funded research addressing Alzheimer’s disease and related dementias.

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.

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

HHS will expand the work undertaken in Actions 1.A.1 and 1.A.2 to address non-Alzheimer's dementias. NIH will hold a scientific workshop in 2013 to solicit input on special research priorities and timelines for addressing related dementias.

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.

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 in clinical trials enough people 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 also enables volunteers to have access to the latest experimental approaches available and provides them care by clinical research staff. HHS will convene representatives from across the federal government, state and local governments, academic medical research institutions, and the private sector to create an action plan for increasing enrollment in clinical trials, including through the building of registries. The partners will identify approaches and coordination points for these efforts to implement the action plan.

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.

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

HHS and the 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 also pursue research partnerships with the private sector.

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 fluids have made it possible to detect the onset of Alzheimer's disease, track its progression, and monitor the effects 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, 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.

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

Beginning in 2012, HHS will build on an ongoing effort by NIA to complete, disseminate, maintain, and annually update an inventory of national and international Alzheimer's disease research investments. This inventory will inform and facilitate coordination among researchers, their organizations, and funders. NIA will use the Alzheimer's disease research ontology, recently developed in collaboration with the Alzheimer's Association, as a framework for collecting, organizing, and comparing the portfolios of national and international public and private Alzheimer's disease research funders. HHS will compile the portfolio information and make it available to the public through a searchable online database.

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

HHS will expand outreach to international partners on Alzheimer's disease research. NIA will continue to collaborate with the Canadian Institutes of Health Research and the Research Councils of the United Kingdom and reach out to the additional eight countries that are developing Alzheimer's disease or dementia research plans. HHS will invite these colleagues to meet and discuss ongoing research priorities, and to provide research project information and categorization for the inventory.

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 Food and Drug Administration, the Office of the Assistant Secretary for Planning and Evaluation (ASPE), and NIH who will consult with academic researchers and representatives from private industry.

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, the Administration on Aging (AoA) and NIH will continue their collaboration on translational research focused on helping older adults maintain their health and independence in the community. 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, and

behavioral symptoms. The NIA's Alzheimer's Disease Education and Referral (ADEAR) Center will continue its focus in this area, and work with AoA and the Centers for Disease Control and Prevention (CDC) to expand outreach to include the findings of studies that center on community and public health interventions.

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, given the complex care needs of people with Alzheimer’s disease, high-quality and efficient care is dependent on smooth transitions between care settings and coordination among healthcare and long-term services and supports providers.

To educate health care providers on ways to better identify and treat Alzheimer’s disease, the Obama Administration’s Alzheimer’s disease announcement includes a new \$6 million investment over two years for provider education and outreach. Provider training and awareness is essential to effectively detecting Alzheimer’s disease and caring for people affected by this devastating disease.

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 healthcare 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 at home or in long-term care facilities. These providers need accurate information about caring for someone with Alzheimer’s disease including the benefits of early diagnosis and how to assist caregivers. Physicians need information on how to implement the “detection of any cognitive impairment” requirement in the Medicare Annual Wellness Visit included in the Affordable Care Act. Major efforts by both VA and the Health Resources and Services Administration (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.

Action 2.A.1: Educate Healthcare Providers

HHS will undertake a comprehensive provider education effort targeting healthcare providers such as physicians, nurses, direct care workers and other professionals. The

effort will be carried out through HRSA's Geriatric Education Centers and will focus on educating providers about Alzheimer's disease. It will include the latest clinical guidelines and information on how to work with people with the disease and their families. Healthcare providers will learn how to manage the disease in the context of other health conditions, and how to link people to support services in the community. Training will also discuss signs of caregiver burden and depression that providers should recognize and address. Healthcare providers will also be trained on the tools available to detect cognitive impairment and appropriate assessment processes for diagnosis of AD. These are being developed through a CMS, NIA, and CDC collaboration to help providers detect cognitive impairment detection in the Medicare Annual Wellness Visit.

[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 healthcare professionals, direct-care workers, and informal caregivers. The clearinghouse will be hosted on a publicly-available website and updated regularly. HHS will seek input from public and private entities in developing the clearinghouse and ensure that its content is evidence-based.

[Action 2.A.4: Strengthen the direct-care workforce](#)

HHS will strengthen the nursing home direct-care workforce through new training focused on high-quality, person-centered care for people with AD. This program was established by Congress in the Affordable Care Act. The training will be released in Spring 2012, and will be available to all nursing homes to share with their staff. This training will be available for both new and established aides.

[Action 2.A.5: Strengthen state aging workforces](#)

HHS will coordinate with states to develop aging 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.

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 disseminating information, translating effective strategies, and sharing best practice.

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 healthcare 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 healthcare workforce needs tools that can help ensure timely and accurate diagnoses. Research has helped identify some assessment tools that can be used to rapidly assess people showing signs and symptoms of Alzheimer’s disease and to help healthcare providers make a diagnosis or refer for further evaluation.¹⁹ The actions below will facilitate appropriate assessment and give healthcare providers tools to make timely and accurate diagnoses.

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

Family members and loved ones are often the first to notice symptoms of AD and report their concerns to medical professionals. Thus, public awareness of the warning signs of Alzheimer’s disease is important for timely diagnosis. Once warning signs are identified, people with these symptoms and their families need access to formal diagnostic and support services. To that end, HHS will expand linkages between its disease support and community information centers supported by NIH and AoA. NIH’s Alzheimer’s Disease Education and Referral (ADEAR) Center will continue to educate the public and providers about the latest evidence on the signs, symptoms, and current methods of diagnosing the disease. AoA’s National Alzheimer’s Call Center will work with the Aging Network to help connect families and people with symptoms of AD with AD-capable resources, including diagnostic services through NIH-funded Alzheimer’s Disease Centers when available.

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

The Affordable Care Act created 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 and risk for dementia.

Strategy 2.C: Educate and support people with AD and their families upon diagnosis

Often, even though a physician 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 physicians are involved in planning and counseling.²² The actions below will address this gap by educating physicians and other healthcare 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 healthcare providers about accessing long-term services and supports

One barrier to counseling and support is that healthcare 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 healthcare provider community to identify steps to effectively educate physicians and other healthcare 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.

Action 2.C.2: Enhance assistance for people with AD 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 will work to strengthen the ability of existing long-term services and supports systems, such as those provided by AoA's Aging Network, to meet the unique needs of people with AD and their caregivers. HHS will strengthen 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.

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 are needed to ensure people with Alzheimer's disease receive high-quality, culturally-competent care in the many different settings where they are treated. These guidelines should be tailored to the stages of the disease and cover the myriad care settings in which care is delivered, such as in the home, physician's office, and long-term care facility. 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. Quality measures should be based on such guidelines and track

whether recommended care is being provided. 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.

[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 and long-term services and supports providers, families, and patients, and can also serve as a foundation to guide the identification and development of metrics that promote high-quality dementia care in all settings.

[Strategy 2.E: Explore the effectiveness of new models of care for people with AD](#)

The Affordable Care Act created the CMS Center for Medicare and Medicaid Innovation (CMMI) 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 these studies are not designed to focus on people with AD in particular, a number of the initiatives underway at CMMI are expected to provide valuable information on care for people with Alzheimer's disease. The Secretary can expand the duration and scope of models that are shown to reduce spending and improve quality, including implementing them at a national level. Through the actions below, HHS will leverage the efforts that are already underway at CMMI as potential new AD-specific initiatives are identified.

[Action 2.E.1: Evaluate the effectiveness of medical home models for people with AD](#)

Medical homes utilize a team approach to provide care and to improve the quality and coordination of health care services. CMMI is currently carrying out the Multi-payer Advanced Primary Care Practice Demonstration and the Comprehensive Primary Care initiative to measure the effectiveness of medical home models. CMMI will conduct subgroup analyses to examine changes in care quality and care coordination among people with AD to explore whether these models lead to more effective and efficient care.

[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. CMMI will conduct subgroup analyses to examine whether health and functional status outcomes are improved among people with AD in this demonstration.

Strategy 2.F: Ensure that people with AD 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. 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.²³

Action 2.F.1: Identify and disseminate models of hospital safety for people with AD

The Partnerships 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. CMMI 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.

Action 2.F.3: Develop an AD-specific toolkit on care transitions

In order to improve outcomes during high-risk transitions between settings, HHS will work with federal partners and private entities to develop a toolkit on care transitions for people with AD. This toolkit will be made available to providers free of charge.

Strategy 2.G: Advance coordinated and integrated health and long-term services and supports for individuals living with AD

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.

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

HHS will convene federal partners and outside experts to review the research on care coordination models for people with Alzheimer's disease. This review will include an in-depth examination of promising models of care to help identify key components that improve outcomes for people with AD. HHS will also review the evidence comparing the effectiveness of structures, processes, and interventions on health and psychosocial outcomes of people with AD in long-term care settings and their caregivers.

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. The Centers for Medicare and Medicaid Services (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 healthcare to beneficiaries. HHS will evaluate the impact of these models. The CMS Center for Medicare and Medicaid Innovation, in partnership with the CMS Medicare-Medicaid Coordination Office, provides an opportunity to test and evaluate promising models of care for people with AD.

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 certain intellectual disabilities 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.

Action 2.H.1: Create a taskforce to improve care for these specific populations

HHS will convene one or more groups of experts, both within and outside of the government, to take steps to address the unique care challenges faced by people with younger-onset Alzheimer's disease, racial and ethnic minorities, and people with intellectual disabilities. This group will focus on how to improve accurate and timely diagnosis, access to care, education on AD for practitioners who do not normally specialize in care for people with AD, and special considerations for these populations.

Action 2.H.2: Identify steps to ensure access to long-term services and supports for younger people with AD

The Administration on Aging (AoA), Office on Disability, and Administration on Developmental Disabilities (ADD) will work together to address access to long-term services and supports for younger people, including people with intellectual disabilities

who develop AD early and people with younger-onset AD. Together these agencies will identify barriers to these supports and make recommendations to the Advisory Council and HHS on ways to address these barriers.

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 doctor’s 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.

To help respond to the challenges faced by families and other caregivers, the Obama Administration’s Alzheimer’s disease announcement makes a new investment of \$10.5 million in fiscal year 2013 to support the needs of caregivers of people with Alzheimer’s disease.

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 to distribute training and education materials. This will include dissemination through the Aging Network, state public health departments and public websites.

Action 3.A.3: Utilize informatics for caregivers and persons with AD

Reports from the National Research Council have reinforced the need for health information technology (HIT) applications for caregivers as well as patients and providers.^{26,27} There are many opportunities for informatics to support caregiver needs including cognitive support to help with reminders; messaging between caregivers, patients, and providers; in-house monitoring tools; pharmacy error checking; and enhanced decision support for self-care. HHS will identify an agenda for priority actions to support the use of informatics 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 often 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, and highlighting supports during crisis situations.

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 work with its partners at the state and local levels to identify unmet service and respite needs.

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

While most states conduct caregiver assessments through their long-term services and supports system, there is not consistent information about best practices in caregiver assessment. HHS will explore a public-private partnership to identify best practices in caregiver assessment and referral. This effort will examine caregiver assessment tools used in states, including those used in state Medicaid waiver programs. Best practices related to caregiver assessment will be disseminated.

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

HHS will partner with private organizations to convene a meeting of leading scientists and practitioners to review the state of the art of research and translational activities related to evidence-based interventions that can be delivered by community-based organizations. The meeting will be focused on interventions that have been effective in improving the health and well-being of persons with Alzheimer's disease and their caregivers. The outcome of the meeting will be a white paper outlining strategies for accelerating the identification of promising models for research and the translation and expansion of research-based models into practice at the community level.

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

HHS will implement strategies defined in Action 3.B.3. HHS will expand its support for research and conduct trials 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 AD-capable systems

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, aging service providers will be encouraged to identify and address caregivers' needs when they seek assistance from state or local home and community-based services systems for themselves or for the person with AD. Caregivers will be connected to supportive services such as respite care. Caregivers will 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.

Action 3.B.6: Share lessons learned through VA caregiver support strategies with federal partners

VA has a number of programs which support caregivers of veterans, including the Caregiver Support Program, REACH-VA, Home-Based Primary Care, other in-home care and community-based services, and respite care. VA officials will share the lessons learned from implementing these programs and examining their impact on both caregivers and people with AD with other federal representatives through quarterly meetings.

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

The AoA's National Alzheimer's Call Center provides expert advice, care consultation, information, and referrals at the national and local levels regarding Alzheimer's disease. Services include crisis counseling and detailed follow-through to ensure consumers receive appropriate and high-quality responses to their concerns. In partnership with the National Alzheimer's Call Center, AoA will present a series of conference calls for the Aging Network highlighting the availability of the National Alzheimer's Call Center to support caregivers in crisis situations. The AoA and NIA, working with the National Alzheimer's Call Center and the Alzheimer's Disease Education and Referral (ADEAR) Center, will present a webinar for NIA-funded Alzheimer's Disease Centers and other federal partners highlighting the availability of the National Alzheimer's Call Center to support caregivers in crisis situations.

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.

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

HHS will expand public knowledge of the risks of Alzheimer's disease and the implications for future care needs through the Long-Term Care Awareness Campaign. Since 2005, the Campaign has been making individuals and families more aware of their potential need for long-term services and supports and the significant advantages of planning ahead. HHS will incorporate information about Alzheimer's disease into its materials for the Campaign.

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, which is charged with responding to and resolving alleged abuse. State survey and certification agencies investigate abuse in licensed facilities, which may include nursing homes, assisted living facilities, and board and care homes. AoA's National Long-Term Care Ombudsmen are advocates for residents of nursing homes, board and care homes, assisted living facilities, and similar adult care facilities and can help address issues related to potential abuse or neglect. The actions below will help ensure that people with AD have their dignity, safety, and rights maintained.

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

HHS will work to educate legal service professionals about the vulnerabilities of people with Alzheimer's disease and how to most effectively serve this population by developing and providing AD-specific training through AoA's National Legal Resource Center (NLRC).

Action 3.D.2: Monitor, report and reduce inappropriate use of anti-psychotics in nursing homes

HHS has identified the inappropriate use of some medications, including anti-psychotic 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 Alzheimer's Disease Education and Referral (ADEAR) Center, education of providers, prescribers, surveyors and families.

Strategy 3.E: Assess and address the housing needs of people with AD

Stable housing is essential to helping people with Alzheimer’s disease remain in the community and is a crucial platform for delivering the necessary health and supportive services. Recognizing these links, HHS and the 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 treatment.³⁵ These 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.

The Obama Administration’s Alzheimer’s disease announcement invests \$8.2 million over two years, beginning this year, to support public awareness and to improve public knowledge and understanding of Alzheimer’s disease.

Strategy 4.A: Educate the public about Alzheimer’s disease

Greater public awareness of Alzheimer’s disease 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

HHS will design a multifaceted public awareness, outreach, and education initiative. The initiative will be carried out in collaboration with states, local governments, and non-governmental entities. Formative research on population targets will inform the initiative.

Strategy 4.B: Work with state and local governments to improve coordination and identify model initiatives to advance Alzheimer’s disease awareness and readiness across the government

State 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.

Action 4.B.1: Convene leaders from state and local governments

HHS will convene national leaders from state and local government organizations to identify steps for increasing AD awareness and readiness in their jurisdictions. These leaders will create an agenda for partnering and supporting the efforts described in this National Plan. HHS will engage key stakeholders from a range of constituencies whose participation is important for the success of this effort.

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.

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. 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.

The Obama Administration's Alzheimer's disease announcement responds to this goal with a \$1.3 million investment in fiscal year 2013 to improve data collection to better understand Alzheimer's disease's impact on people with the disease, their families and the healthcare system.

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.

Action 5.A.1: Identify major policy research needs

HHS will convene federal partners to identify current and future policy research questions that cannot be answered with existing data. Some topics this group will discuss include Medicare and Medicaid expenditures among people with Alzheimer's disease, as well as the impact of caregiver supports on health outcomes. The partners will identify gaps in data to evaluate progress on the National Plan that should be addressed.

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 will be added to existing surveys, be part of supplements to existing surveys, or form the basis of a new survey.

Strategy 5.B: Monitor progress on the National Plan

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

Action 5.B.1 Designate responsibility for action implementation

HHS will designate an office and a contact person responsible and accountable for implementing each action step in the National Plan. The Office of the Assistant Secretary for Planning and Evaluation (ASPE) will be responsible for overseeing implementation, reporting on progress, convening the Advisory Council on Alzheimer's Research, Care, and Services, and issuing reports to Congress.

Action 5.B.2: Track plan progress

HHS will track 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 or Medicare Current Beneficiary Survey, to assess the extent to which progress is being made. For each *action*, HHS will track implementation to determine whether actions are completed in a timely and successful manner. Additionally, HHS will work to incorporate measures related to AD into other efforts to monitor population health, such as Healthy People 2020 which, for the first time ever, is tracking the care received by people with Alzheimer's disease.

Action 5.A.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 Plan. HHS will incorporate its findings and the recommendations of the Advisory Council to update the National Plan on an annual basis.

Appendix: List of Participating Departments and Agencies

ACF – Administration for Children and Families
ADD – Administration on Developmental Disabilities
AoA – Administration on Aging
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
CMMI – Center for Medicare and Medicaid Innovation
CMS – Centers for Medicare and 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
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
ONC – Office of the National Coordinator of Health Information Technology
SAMHSA – Substance Abuse and Mental Health Services Administration
VA – Department of Veterans Affairs

References

1. Hebert LE, Scherr PA, Bienias JL, et al. Alzheimer's disease in the U.S. population: Prevalence estimates using the 2000 census. *Arch Neurol*. 2003;60:1119–1122.
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. MetLife Mature Market Institute. Market Survey of Long-Term Care Costs. October, 2011.
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 revised criteria for the diagnosis of Alzheimer's disease: National Institute on Aging and the Alzheimer's Association workgroup. *Alzheimers Dement* 2011;7:in press.
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. Cavalieri TA, Latif W, Cieselski J, Ciervo CA Jr, Forman LJ. How physicians approach advance care planning in patients with mild to moderate Alzheimer's disease. *J Am Osteopath Assoc.* 2002;102(14):291-298.
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, M.S., Roth, D.L., Haley, W.E., & Zarit, S.H. 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: PsycholSci*, 2004.59B, P27-P34.
29. Sörensen S, Pinquart M, Duberstein P. "How effective are interventions with caregivers? An updated meta-analysis." *The Gerontologist*. 2002; 42(3):356-72. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/12040138>.
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 L. K, 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 (2011). Elder justice: Stronger Federal leadership could enhance national response to elder abuse. 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.