

# National Alzheimer's Project Act (NAPA)

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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>

A close-up photograph of a hand holding a single wooden block, poised to place it on top of a wall of other wooden blocks. The background is a soft, out-of-focus blue gradient. The text 'TIME TO BUILD' is overlaid on the top left of the image.

# TIME TO BUILD

Action Steps and Recommendations to Update the  
'National Plan to Address Alzheimer's Disease'

Alzheimer's Foundation of America  
December 2012

**The Alzheimer's Foundation of America (AFA)**, based in New York, is a national nonprofit organization that unites more than 1,600 member organizations nationwide with the goal of providing optimal care and services to individuals confronting dementia, and to their caregivers and families. AFA is dedicated to meeting the educational, social, emotional and practical needs of individuals with Alzheimer's disease and related illnesses, and their caregivers and families. Its services include counseling and referrals made by licensed social workers via phone, e-mail, Skype and live chat; educational materials; a free quarterly magazine for caregivers; community and respite care grants; professional training; and a comprehensive memory screening initiative.

Advocating for meaningful public policy on behalf of individuals with Alzheimer's disease and related illnesses and their family caregivers is integral to AFA's mission. Through the representation of AFA's president and CEO, Eric J. Hall, on the Advisory Council on Research, Care and Services, which was established by the National Alzheimer's Project Act (NAPA) to advise on a national plan, and AFA's "No Time to Waste" and "The Time to Act Is Now" reports, which incorporated comments from AFA stakeholders and advisory board members, we have articulated numerous recommendations and action steps that are necessary to ensure proper support of individuals with dementia and caregivers, as well as prevent, delay or cure this disease by 2025.

"Time to Build," our new report, brings stakeholders and policymakers up to date on this critical and timely topic. This report examines the historic "National Plan to Address Alzheimer's Disease," which the U.S. Department of Health and Human Services (HHS) released in May 2012. It identifies gaps in the national Alzheimer's plan's goals and strategies; measures the progress of its implementation; and offers recommendations for the revised plan set to be released in April 2013.

"Time to Build" was authored by Eric J. Hall, AFA's president and CEO, along with Eric W. Sokol, AFA's vice president of public policy. It was reviewed and edited by Carol Steinberg, AFA's executive vice president.

In addition we would like to thank members of AFA's Medical and Scientific Advisory Board and AFA's Memory Screening Advisory Board for their continuing input and help in educating and formulating AFA policy.<sup>1</sup>

Contact Information:

**Alzheimer's Foundation of America**

322 Eighth Avenue, 7th Floor

New York, NY 10001

866.232.8484

**[www.alzfdn.org](http://www.alzfdn.org)**

**[info@alzfdn.org](mailto:info@alzfdn.org)**



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<sup>1</sup>Numerous members of AFA's advisory boards have reviewed and contributed issues and recommendations in this report, but advisory board members do not endorse any specific policy recommendations made in this report.



## **Introduction: The Historic National Plan to Address Alzheimer's Disease**

The Alzheimer's Foundation of America (AFA) commends President Obama, U.S. Department of Health and Human Services (HHS) Secretary Kathleen Sebelius and Congress for uniquely recognizing and responding to the implications of the Alzheimer's disease (AD) epidemic through the mandate for a national plan and HHS' subsequent release of the historic "National Plan to Address Alzheimer's Disease" in May 2012. This recognition is essential for action, and their courage and commitment have forged enormous opportunity to address this chronic disease with urgency.

The national Alzheimer's plan provides solid stepping stones toward substantial change. It paves the way for transforming how our nation and the world view Alzheimer's disease, altering the trajectory of this tragic disease and changing lives forever. It substantiates the plight of millions of Americans and validates the concerns of generations to come. For the first time, we are making progress toward defeating this escalating public health crisis.

The plan sets out laudable goals for clinical research, compressing clinical pathways, developing better training of healthcare professionals and best practices for family caregivers, and enhancing public awareness. It calls for greater collaborative efforts among federal government agencies and new partnerships between public and private entities.

As this report will illustrate, many of the plan's initial strategies have been implemented or are underway. Among them, there is now greater intergovernmental agency cooperation and meetings concerning the issue. The federal government has undertaken a public awareness campaign that centers on a new comprehensive government Web site, [Alzheimers.gov](http://Alzheimers.gov). HHS, related agencies and their private and public partners are developing initial training materials.

However, more needs to be done. And given the enormity of this disease state, the federal government must take the lead. Alzheimer's disease research must be a priority and necessary resources must be dedicated if we are to make progress, as the national plan states, toward preventing and effectively treating Alzheimer's disease by 2025. In the interim, we need adequately-funded federal, state and community programs to provide long-term care support services to family caregivers.

Our nation has the opportunity to dig even deeper to fill remaining gaps. Further action on the plan's initial strategies and additional goals and strategies can produce a more defined response to this crisis and make a greater difference in people's lives.

The protocol for the national plan presents such an opportunity. A living document, the national Alzheimer's plan is required to be reviewed and updated annually. The Advisory Council on Research, Care and Services, a public-private group established by the National Alzheimer's Project Act (NAPA), is structured to meet regularly, analyze the effectiveness of current strategies and offer new recommendations. Based on the council's input and its own due diligence, HHS is charged with producing an updated plan annually.

To this end, with this report, AFA presents a look back and a look forward at the national agenda, and offers recommendations for consideration in the revised national Alzheimer's plan set to be released in April 2013.

AFA's recommendations for the amended national plan are not overly ambitious; rather, they are unquestionably necessary at this juncture. To highlight a few of the numerous suggestions made in this report, AFA urges the federal government to:

- compile basic, reliable statistics on the scope of Alzheimer's disease, including demographics and costs;

- strengthen efforts to build a high-quality dementia care workforce by, among other proposals, making student loans for geriatrics and gerontology eligible for federal loan forgiveness, and establishing a 24-hour call center for dementia healthcare professionals;
- expand memory screening efforts and the promotion of the benefits of screenings and early detection of Alzheimer’s disease;
- provide additional initiatives to support family caregivers, including expanding “participant-directed” programs that would allow participants to hire family members as paid caregivers, adoption of family-friendly workplace policies, availability of federal tax credits for family members who are primary caregivers and tax deductions for out-of-pocket costs for reasonable and necessary long-term care services, greater access to home- and community-based care services under both Medicare and Medicaid, increased funding of Administration on Aging (AoA) programs like respite care and caregiver training, and extension of Medicare benefits and AoA program eligibility to all people with Alzheimer’s disease regardless of age;
- specify a target number of demonstration projects to implement new care models for Alzheimer’s disease that will shed light on the best models for different populations and provide substantial data to adequately measure costs and utilization;
- require licensure and/or accreditation of facilities that care for people with dementia, including training in cultural sensitivities, to ensure that facilities are utilizing the latest training and best practices when providing treatment, care or support services to people with Alzheimer’s disease and their family caregivers; and
- encourage the U.S. Department of Housing and Urban Development (HUD) and other Alzheimer’s stakeholders to develop new, cost-effective transitional housing models for people with Alzheimer’s disease as an alternative to more expensive institutionalization.

So far, plan implementation has brought welcome and remarkable progress. The low hanging fruit is being cleared. A foundation is being laid. Now is the time to build.

## **I. PLAN IMPLEMENTATION: A FOUNDATION BEING LAID**

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

*Strategy 1.A: Identify research priorities and milestones*

#### **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 (NIH) convened a research summit, Alzheimer’s Research Summit 2012: Path to Treatment and Prevention. The two-day meeting coincided with HHS’ release of the nation’s first Alzheimer’s plan. Workshop groups identified research priorities and the types of infrastructures, resources and new public-private partnerships needed to successfully achieve the agenda.

According to NIH, strategies include intensifying scientific efforts to deepen the understanding of the complex pathobiology of Alzheimer’s disease; providing an expedited review track for applications focused on drug discovery, preclinical and clinical drug development for Alzheimer’s disease; initiating treatment trials for asymptomatic, at-risk individuals; and exploring the effectiveness of nonpharmacological interventions.

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

HHS is continuing to seek feedback from the public on Alzheimer's disease research. Specifically, NIA has issued a Request for Information (RFI) that invites public and private input on government-funded research addressing Alzheimer's disease and related dementias. The RFI calls for research proposals in genetic analysis, target identification and validation, Phase I clinical trials for Alzheimer's disease therapeutics, and prevention trials.

### **Action 1.A.3: Regularly update the national plan and refine Goal 1 strategies and action items based on feedback and input**

HHS will craft an updated Goal 1 that reflects the priorities, milestones and timeline elements identified through these processes to accelerate research in this area. This goal 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**

NIH and NIA will hold a workshop on May 1 and 2, 2013 at the Natcher Auditorium, NIH Campus, Bethesda, MD to solicit input and develop recommendations on research priorities and timelines for Alzheimer's disease-related dementias. The workshop topics will include frontotemporal dementia (FTD) and Alzheimer's disease-related tauopathies, dementia with Lewy bodies, vascular contributions to Alzheimer's disease-related dementia, and mixed dementias.

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

To ensure that the plan's research priorities and milestones reflect the broad input of the scientific community and the public, the advisory council will focus one meeting per year on this area. A relevant subcommittee focused on research or Goal 1 will collect input and recommend priorities and milestones for the advisory council to consider presenting as official recommendations. As appropriate, the council will invite researchers in the field to present at these meetings.

*Strategy 1.B: Expand research aimed at preventing and treating Alzheimer's disease*

### **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**

NIA's integrated interdisciplinary basic science research agenda will continue to advance understanding of the molecular, cellular and tissue level mechanisms and networks involved in the Alzheimer's 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 is undertaking 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 Alzheimer's disease. 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.

In conjunction with the plan's release, the Obama Administration allocated an additional \$50 million for Alzheimer's disease research in fiscal year 2012 and an additional \$80 million for fiscal year 2013. Fiscal year 2012 initiatives funded with the \$50 million allocation included:

- Alzheimer’s disease genome sequencing by National Human Genome Research Institute Genome Centers;
- New induced pluripotent stem cell methods to obtain insights into the cellular processes of Alzheimer’s disease.
- Small Business Alzheimer’s Disease Research (STTR) R41/R42-Phase I, Phase II, and Fast-Track/Small Business Innovation Research (SBIR) R43/R44 Grant-Phase I, Phase II, and Fast-Track.
- Two Alzheimer’s disease clinical trials--one treatment and one prevention:
  1. Pilot Trial of Intranasal Insulin for Alzheimer’s and Mild Cognitive Impairment (treatment).
  2. Amyloid PET Scans in Presymptomatic Early-Onset Alzheimer’s Disease, the first prevention trial in people at the highest risk for the disease.

For the additional \$80 million anticipated in fiscal year 2013, NIH has identified areas of highest need/opportunity, based on findings from the Alzheimer’s Summit and other input. The extra funding will allow NIH to support more grants and/or investigator-initiated research.

**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, prevention and ultimately a cure for Alzheimer’s disease. Participants in clinical trials and other research gain access to the latest available experimental approaches and care by clinical research staff.

NIA recently issued a Request for Information (RFI) to Alzheimer’s disease stakeholders, including national patient advocacy groups, in an effort to gather comments on the following:

- strategies (support and coordination) for the short-term and long-term that should be more widely adopted to enhance participation in Alzheimer’s research among various subsets, including people at different stages of the disease (including pre-clinical), normal controls, individuals with a family history of Alzheimer’s disease, and racial and ethnic minorities;
- the effective role for government agencies and funders (federal, state and local) to support and facilitate coordination of Alzheimer’s clinical trial recruitment efforts; and
- the use of registries to support Alzheimer’s disease and related clinical trials and studies, including the need for a centralized registry and coordinating existing registries and tools to be used more effectively.

The RFI can be found at <http://grants.nih.gov/grants/guide/notice-files/NOT-AG-12-017.html>. The deadline for responses is March 15, 2013. In addition, NIA also plans to meet during early 2013 with interested groups and researchers on this topic.

**Action 1.B.4: Monitor and identify strategies to increase enrollment of racial and ethnic minorities in Alzheimer’s disease studies**

NIH is continuing to monitor enrollment of racial and ethnic minorities in its Alzheimer’s disease studies and to 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 Alzheimer's disease, 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*

**Action 1.C.1: Identify imaging and biomarkers to monitor disease progression**

HHS is expanding 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.

A worldwide ADNI conference was held in Vancouver, Canada on July 13, 2012, with the goal of harmonizing projects and results across different geographical sites, and encouraging and standardizing data management and availability to investigators around the world. These projects are currently underway in Argentina, Australia, Europe, Japan, Korea, North America and Taiwan.

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

HHS has been working to maximize the effectiveness of research findings in neuroimaging and biomarkers through partnerships, meetings and conferences with the private sector, U.S. Food and Drug Administration (FDA) and other federal agencies. These collaborations 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*

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

NIA and the Alzheimer's Association have been collaborating on the Common Alzheimer's Disease Research Ontology (CADRO), a project designed to conduct a comparative analysis of each entity's research portfolios. The project had coded more than 2,000 unique research projects using the CADRO (for 2008 to 2011) across multiple funding organizations, including the NIH, VA, Centers for Disease Control and Prevention (CDC), Agency for Healthcare Research and Quality, and the Alzheimer's Association.

The suggested uses of CADRO for Alzheimer's disease research portfolio analysis include:

- quantifying and analyzing the collective investment in Alzheimer's disease



research funding over time across multiple funding organizations (beginning with 2008);

- establishing a baseline to measure future performance and progress, including implementation of initiatives in response to NAPA and Alzheimer's Disease Summit recommendations;
- developing a trend analyses of awarded research by CADRO categories, topics and themes;
- pinpointing areas of overlap, duplication and potential opportunities for collaboration among funding organizations;
- Identifying emerging areas of science and opportunities for translation; and
- detecting potential research gaps and areas that may be underfunded.

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

NIA, in collaboration with the Alzheimer's Association, has developed an International Alzheimer's Disease Research Portfolio (IADRP) that categorizes areas of Alzheimer's research worldwide according to the common language used by investigators. The ultimate goal of IADRP is to enable funders of Alzheimer's research to coordinate their investments, leverage resources, encourage collaboration, and identify research gaps and unnecessary duplication. IADRP also will provide a metric to chart the progress of research on Alzheimer's disease. The new database is available at <http://iadrp.nia.nih.gov/cadro-web/>.

The objectives for working with international partners are to:

- share/compare best practices across countries that have or are developing government plans to address Alzheimer's disease;
- facilitate the sharing of crucial information that can potentially head off research paths that are not as fruitful as other paths or build on information that exists in "precompetitive space"; and
- leverage work among scientists worldwide to bring attention to the challenges of Alzheimer's disease and draw international focus to the disease.

There has also been interest in convening government officials responsible for each of their country's plans to discuss the first two objectives listed above. Conversations are ongoing with Alzheimer's Disease International and HHS' Office of Global Affairs to set up an official meeting.

In addition, the Alzheimer's Disease and Dementia Leadership Council (ADDLC), a joint collaboration of the New York Academy of Sciences and One Mind for Research, has formed four working groups focused on basic research, early development and translational research, prevention trials, and policy for public-private partnerships.

ADDLC's next steps and potential actions to coincide with the national plan include:

- organizing an international Alzheimer's disease research summit to be held at the New York Academy of Sciences in May 2013 with cross-sector participation to showcase work on basic/preclinical research plans, early development/translational tools and models for public-private partnerships; and
- conducting an economic assessment of the Alzheimer's disease environment to establish a business case for companies and public-private entities to come together and co-invest.

*Strategy 1.E: Facilitate translation of findings into medical practice and public health programs*

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

HHS is convening a group of federal and private officials to examine the current average timeframe for bringing pharmacological treatments to market, and ways to speed up the processes, including identifying and validating therapeutic targets; developing new interventions; testing efficacy and safety; and regulatory approval. The group will include representatives from FDA, the Office of the Assistant Secretary for Planning and Evaluation (ASPE) and NIH, and they 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**

NIH will partner with other federal agencies to disseminate research findings to healthcare systems 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, 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**

Federal agencies, including HHS and VA, are expanding 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 of dementia. NIA's Alzheimer's Disease Education and Referral (ADEAR) Center will continue its focus in this area, and work with AoA and CDC to increase outreach to include the findings of studies that center on community and public health interventions.

## **Goal 2: Enhance Care Quality and Efficiency**

*Strategy 2.A Build a workforce with the skills to provide high-quality care*

### **Action 2.A.1: Educate healthcare providers**

HHS is undertaking a comprehensive Alzheimer's disease education effort that targets healthcare providers such as physicians, nurses, direct care workers and other professionals. The effort will be carried out through Geriatric Education Centers (GECs) throughout the United States, which are administered by HHS' Health Resources Services Administrations (HRSA) to improve the training of healthcare students, faculty and practitioners in geriatrics.

HRSA received \$2 million through the Prevention Public Health Fund to focus on geriatric continuing education to healthcare providers. HRSA has provided each of 45 GECs with \$43,000 to partner with other entities to revise and update existing evidence-based practice curricula related to Alzheimer's disease and to use the curricula to provide continuing education to multi-professional teams of healthcare practitioners at no cost.

Training must include clinical guidelines on how to: work with persons with the disease and their families; manage the disease in the context of other health conditions; provide referrals to appropriate clinical trials and long-term services and supports in the community; and recognize and treat signs of caregiver burden and depression.

In addition, providers will be trained on tools to detect cognitive impairment and appropriate assessment processes for the diagnosis of Alzheimer's disease. These tools are being developed collaboratively by the Centers for Medicare & Medicaid Services (CMS), NIA and CDC to help providers detect cognitive impairment as required in the Medicare Annual Wellness Visit included in the Affordable Care Act.



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

HHS is enhancing 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 geropsychiatric 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 inter-professional 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 is creating and marketing 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. HHS will seek input from public and private entities in developing the clearinghouse and ensure that its content is evidence-based. It will host and regularly update the clearinghouse on a Web site available to the public.

### **Action 2.A.4: Strengthen the direct-care workforce**

In order to strengthen the nursing home direct-care workforce, HHS has developed a new training program that focuses on high-quality, person-centered care for people with Alzheimer's disease. This program was established by Congress in the Affordable Care Act. The training includes collaboration with partner organizations around:

- provider and prescriber training;
- surveyor training, review of surveyor guidance, protocols and challenges related to assessing compliance in these areas;
- research;
- quality measurement;
- public reporting;
- communication strategies such as local and national conference presentations, and press releases; and
- developing dissemination strategies in states and regions, and a sustainable national plan for ongoing monitoring and evaluation of these issues.

Questions to be pursued by partner organizations include:

- What should we collectively do to achieve better outcomes?
- What should we know that we might not know?
- What quality measures will most meaningfully drive improvements towards better outcomes?
- Which outcomes are the highest priorities to focus on?

### **Action 2.A.5: Strengthen state aging workforces**

HHS is coordinating with states to develop workforces that are capable and culturally competent to care for people with Alzheimer's disease. AoA will ask states to specify

strategies to meet these objectives in their state aging plans and relevant grant applications. These strategies may include enhancing Alzheimer's disease competencies among AoA's National Aging Network (composed of State Units on Aging, federal Area Agencies on Aging, Native American aging programs, service providers and volunteers); developing Alzheimer's disease-capable community health and long-term care options counseling at Aging and Disability Resource Centers---a collaborative effort of AoA and CMS designed to streamline access to long-term care.

#### **Action 2.A.6: Support state and local Alzheimer's strategies**

Since much of the work required to support caregivers and the direct-care workforce should and will occur at the local level, as reflected in the 24 existing state-based plans to tackle Alzheimer's disease, HHS and its federal government partners will identify ways that are most helpful to support states and localities in their efforts. These efforts may include disseminating information, translating effective strategies and sharing best practices.

*Strategy 2.B: Ensure timely and accurate diagnosis*

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

Family members are often the first to notice symptoms of Alzheimer's disease in a loved one and to report their concerns to medical professionals. Thus, public awareness of the warning signs of Alzheimer's disease is an important step toward timely diagnosis. Moreover, people with concerns and/or symptoms and their families need access to formal diagnostic and support services.

To that end, HHS will expand data sharing between its disease support and community information centers supported by NIH and AoA. NIH's 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 AoA's National Aging Network to help connect families and people with symptoms of Alzheimer's disease with appropriate resources, including diagnostic services through the ADEAR Center when available.

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

The Medicare Annual Wellness Visit created by the Affordable Care Act includes "detection of any cognitive impairment." After a review of research findings, HHS has identified seven assessment tools that clinicians can use in a variety of outpatient clinical settings to assess cognition. The recommended tools include the:

- Ascertain Dementia (AD8)
- Short Blessed Test (SBT)
- Mini-Cog
- Mental Status Questionnaire (MSQ)
- Six-Item Screener (SIS)
- Short Test of Mental Status (STMS)
- Short Portable Mental Status Questionnaire (SPMSQ)

CMS noted that these seven tools are not exclusive. Information from families and self-reports by individuals also are important in the detection of cognitive impairment. According to CMS, issues in assessment testing that need to be addressed include: language accessibility, screening versus detection, cross-cultural awareness, low literacy and socioeconomic status. CMS also noted that risk factors and risk assessment, including demographic epidemiologic lifestyle variables that identify high-risk individuals should be used to help determine which individuals merit additional testing.





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

### **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 Alzheimer's disease 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, people with Alzheimer's disease and their families need specialized assistance in planning for care 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 National Aging Network, to meet the unique needs of people with Alzheimer's disease and their caregivers. HHS will incorporate new training to strengthen the ability of existing long-term services and supports systems, such as those provided by AoA's National Aging Network, to meet the unique needs of people with Alzheimer's disease and their caregivers.

## *Strategy 2.D: Identify high-quality dementia care guidelines and measures across care settings*

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

HHS is working to facilitate coordination among groups such as medical professional societies and organizations representing persons with Alzheimer's disease, caregivers or direct-care workers to delineate best dementia care practices and evidence-based guidelines. In 2012, the Physician Quality Reporting System (PQRS) a CMS quality improvement program, adopted nine dementia quality measures. PQRS provides incentives for physician participation; physicians who report quality measures receive up to 0.5 percent of total Medicare allowed charges.

The Foundation for the National Institutes of Health on December 3, 2012 convened an Alzheimer's Disease Measurement Improvement (AD-MI) conference in Baltimore, MD. AD-MI is a voluntary, multi-stakeholder mega community around improving measurement of Alzheimer's disease progression to aid in achieving better outcomes for individuals with Alzheimer's disease. At the conference, three primary working groups presented their findings and general recommendations on:

- drafting a conceptual framework for measurement in Alzheimer's disease, including developing specific definitions for constructs, concepts or domains and define the meaning of "alignment";
- conducting an environmental scan to understand the measurement landscape in Alzheimer's disease, including clinical practice guidelines, clinical pathways, measures and measurement gaps; and
- developing an overall research agenda for the Alzheimer's community to improve measure development in Alzheimer's disease.

## *Strategy 2.E: Explore the effectiveness of new models of care for people with AD*

### **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 healthcare services. CMS' Center for Medicare and Medicaid Innovation

(CMMI) is currently carrying out both the Multi-Payer Advanced Primary Care Practice Demonstration and the Comprehensive Primary Care initiative to measure the effectiveness of medical home models.

CMMI has also funded a Health Care Innovation Award for a three-year project at the University of California, Los Angeles, to evaluate a new care model to support effective care transitions for people with Alzheimer's disease. The program will provide comprehensive care to persons with Alzheimer's disease and their caregivers, and help them navigate the service delivery system. It has three main components: a dementia registry, a needs assessment of people listed in the registry, and individualized dementia-care plans based on those assessments. The model extends beyond the confines of physician's offices into the community setting with intensive dementia care monitoring and care coordination by advanced practice nurses and other health professionals.

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

The Independence at Home Demonstration, conducted by CMMI, 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 for Medicare beneficiaries with chronic conditions, including those with Alzheimer's disease. CMMI will conduct subgroup analyses to examine whether this demonstration improves health and functional status outcomes among participants.

*Strategy 2.F: Ensure that people with AD experience safe and effective transitions between care settings and systems*

#### **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 and complications, and improving care transitions. CMMI will identify practices that benefit people with complex needs, including people with Alzheimer's disease, and 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 is examining how to improve care during transitions for people with Alzheimer's disease through Medicare's Community-Based Care Transitions Program and AoA's Aging and Disabilities Resource Center (ADRC) Evidence-Based Care Transitions Program. The 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 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 is working with federal partners and private entities to develop a toolkit on care transitions for people with Alzheimer's disease. 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*

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

HHS is convening 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 Alzheimer's disease. HHS will also review the evidence comparing the effectiveness of various structures, processes and interventions on the health and psychosocial outcomes of people with Alzheimer's disease in long-term care settings and their caregivers.

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

HHS is supporting 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 healthcare to beneficiaries. HHS will evaluate the impact of these models. CMMI, in partnership with CMS' Medicare-Medicaid Coordination Office, provides an opportunity to test and evaluate promising models of care for people with Alzheimer's disease.

*Strategy 2.H: Improve care for populations disproportionately affected by Alzheimer's disease and for populations facing care challenges*

### **Action 2.H.1: Create a task force to improve care for these specific populations**

HHS is convening 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 young-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 Alzheimer's disease for practitioners who do not normally specialize in care for people with Alzheimer's disease, 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**

HHS' AoA, Office on Disability and Administration on Intellectual and Developmental Disabilities (AIDD) will work together to address access to long-term services and supports for younger people, including people with intellectual disabilities who develop Alzheimer's disease early and people with young-onset Alzheimer's disease. The agencies will identify barriers to these supports and make recommendations to the advisory council and HHS on ways to address them.

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

*Strategy 3.A: Ensure receipt of culturally sensitive education, training, and support materials*

### **Action 3.A.1: Identify culturally sensitive materials and training**

HHS is reviewing culturally-sensitive resources related to Alzheimer's disease and identifying areas where new resources need to be developed. HHS and private entities will develop relevant new culturally-sensitive resources as needed.

HHS has also convened The Specific Populations Task Force involving three subgroups: individuals young-onset dementia, and racial/ethnic minorities, and individuals with intellectual disabilities such as Down syndrome. The task force first met in August 2012 and since has had a number of meetings involving caregivers and key stakeholder groups, including AFA. Its major finding is the need for primary care practitioners who interact with these populations to heighten their awareness of dementia and acquire training and education.

### **Action 3.A.2: Distribute materials to caregivers**

HHS is working with its agencies, other federal departments, and state and local networks to distribute training and education materials to caregivers. This will include dissemination

through AOA's National Aging Network, state public health departments and public Web sites.

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

HHS will identify an agenda for priority actions to support the use of informatics to assist caregivers and persons with the disease. Reports from the National Research Council, a public research organization that is part of the National Academies, have reinforced the need for health information technology applications for caregivers as well as for persons with Alzheimer's disease and providers. There are many opportunities for informatics to support the needs of these groups, including cognitive support to help with reminders; messaging between caregivers, persons with Alzheimer's disease and providers; in-house monitoring tools; pharmacy error checking; and enhanced decision support for self-care.

*Strategy 3.B: Enable family caregivers to continue to provide care while maintaining their own health and well-being*

### **Action 3.B.1: Identify unmet service needs**

HHS is analyzing 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 Alzheimer's disease. HHS will publish and disseminate these findings 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 systems, there is no consistent information about best practices in caregiver assessment. HHS will explore a public-private partnership to identify best practices in caregiver assessment and referral use in states, including those used in state Medicaid waiver programs. It will disseminate its findings.

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

There are a number of evidence-based nonpharmacological programs for individuals with Alzheimer's disease and their caregivers. Some have been shown to be effective for a decade or more, yet none are widely available across the country. To explore these models, in June 2012, HHS and the Alliance for Aging Research co-hosted a meeting of researchers and community-based implementers of evidence-based interventions to support people with Alzheimer's disease and their caregivers at home and in the community. The objectives of the working meeting were to highlight programs that have been brought to scale; discuss programs that did not translate well into the community; and identify gaps in the research. Findings from the June 2012 meeting are in a report entitled, "Translating Innovation to Impact," which indicates that the current state of the art of nonpharmacological treatments and care practices is more advanced than previously reported and more hopeful than might have been expected. It is expected to be released before the end of 2012.

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

HHS is implementing 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 long-term services and supports systems designed to meet the needs of caregivers of people with Alzheimer's disease. Through these efforts, aging service providers will be encouraged to identify and address caregivers' needs when caregivers seek assistance from state or local home- and community-based services systems for themselves or for persons with Alzheimer's disease. Caregivers will be connected to supportive services such as respite care, and 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 AoA identifies additional effective interventions, HHS will work with its partners to implement them in appropriate settings.

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

VA has a number of programs that 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. Through quarterly meetings with other federal representatives, VA officials will share the lessons learned from implementing these programs and their impact on both caregivers and people with Alzheimer's disease.

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

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.

AoA and NIA, working with the National Alzheimer's Call Center and the ADEAR Center, presented a Webinar in June 2012 for NIA-funded Alzheimer's Disease Centers and other federal partners that highlighted the availability of the National Alzheimer's Call Center to support caregivers in crisis situations. With the same goal, AoA, in partnership with the National Alzheimer's Call Center, will present a series of conference calls for the National Aging Network in 2013.

*Strategy 3.C: Assist families in planning for future care needs*

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

To better understand why middle-aged adults do or do not plan for long-term care needs, HHS plans to 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 is expanding public knowledge of the risks of Alzheimer's disease and the implications for future care needs through its 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*

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

HHS is working to educate legal service professionals about the vulnerabilities of people with Alzheimer's disease and how to most effectively serve this population through AoA's

National Legal Resource Center (NLRC) and the American Bar Association Commission on Law and Aging.

This collaboration has yielded “The Legal Resources and Alzheimer’s Webinar Series” that will cover legal issues related to people with Alzheimer’s disease and their caregivers. The goals are for Webinar participants to be able to identify legal professionals trained in assisting clients with dementia care issues; understand the essentials of care planning; learn about counseling clients with dementia; be knowledgeable about assessing the decision-making capacity of clients with dementia; receive strategies for referrals for further assessment; and become aware of best practices for attorneys. The series began on November 14 with a session for attorneys on how to assess the decision-making capacity of clients; and continued on December 4 with a session for attorneys on advance financial and health care planning. Future sessions, with dates to be determined, are for Aging Network staff on finding dementia capable legal assistance; and for legal professionals on elder abuse, neglect and exploitation of clients with dementia.

### **Action 3.D.2: Monitor, report and reduce inappropriate use of antipsychotics in nursing homes**

HHS is identifying 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, called Partnerships in Dementia, to reduce inappropriate and off-label use of antipsychotic and behavior-modifying agents in nursing homes; to improve behavioral health among nursing home residents with dementia; and to protect residents from unnecessary drug use. The first-year goal is to reduce the rate of antipsychotic drug use in long-stay nursing home residents by 15 percent by the end of 2012.

In addition, CMS has held several state implementation calls with various groups, including Quality Improvement Organizations that monitor the appropriateness, effectiveness and quality of care provided to beneficiaries, state-based agencies, and the Learning in Action Network—an improvement initiative that brings together healthcare professionals, patients and other stakeholders around an evidence-based agenda to achieve rapid, wide-scale improvement. The intent is to create and enhance coalitions focusing on advancing behavioral management techniques and the behavioral health of nursing home residents, as well as to improve training for providers.

*Strategy 3.E: Assess and address the housing needs of 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. Their agenda will include examining housing sites that combine health care and long-term services and supports. In addition, the project will combine HUD and HHS data to understand the characteristics of the older adult population in HUD housing, including their healthcare utilization.

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

HHS is undertaking 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, prepared for HHS, to better understand the level of cognitive impairment among residents and the types of services provided in assisted living facilities. HHS will use the results to identify areas that the national plan should address in future years.



## **Goal 4: Enhance Public Awareness and Engagement**

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

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

HHS, through its Administration on Community Living (ACL), designed a multifaceted public awareness, outreach and education initiative, the Alzheimer's Awareness Campaign. The initiative is being carried out in collaboration with states, local governments and non-governmental entities. Formative research on population targets will provide demographic data to help fine-tune outreach efforts. The target audience is caregivers aged 60 to 75, especially spouses; information is available in English and Spanish. The fiscal year 2012 budget for the Alzheimer's Awareness Campaign is \$4 million. The purpose of the campaign is to connect caregivers with existing resources. Utilizing plain language coaching communication, the two key message points of the campaign are:

1. Acknowledge caregivers.
2. You don't have to go it alone.

HHS also unveiled [Alzheimers.gov](http://Alzheimers.gov), an online consumer resource that is organized by topic and disease stage, written in plain language and accompanied by a full Spanish-language site. The new Web site includes testimonials by real caregivers who have "been there," using language that is authentic and speaks to the target audience.

The Web site will evolve over time with assistance and periodic updates from a working group of subject matter experts. There are currently new topics in development, and future content will be based on consumer preferences. The public can offer suggestions through the Web site.

*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*

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

HHS is convening national leaders from state and local government organizations to identify steps for increasing Alzheimer's disease awareness and readiness in their jurisdictions. These leaders will create an agenda for partnering and supporting the efforts described in the national Alzheimer's 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 Alzheimer's disease efforts across federal departments and agencies so participants can gain a better understanding of each other's roles and responsibilities on this issue. 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, and share research findings, innovative or best practices, and information about new or upcoming initiatives.

*Strategy 4.C: Coordinate U.S. efforts with those of the global community*

HHS will expand outreach to international partners on Alzheimer's disease through its Office of Global Affairs 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**

*Strategy 5.A: Enhance the federal government's ability to track progress*

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

HHS is convening federal partners to identify current and future policy research questions that cannot be answered with existing data. The partners will utilize these findings to evaluate whether objectives in the national plan are being addressed. Topics will include Medicare and Medicaid expenditures among people with Alzheimer's disease, as well as the impact of caregiver supports on health outcomes.

### **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 new surveys.

*Strategy 5.B: Monitor progress on the national plan*

### **Action 5.B.1: Designate responsibility for action implementation**

HHS designated Helen Lamont, Ph.D., long-term care policy analyst at HHS' office of the assistant secretary for planning and evaluation (ASPE), as the key government staff person for the national Alzheimer's plan. ASPE is responsible for overseeing the plan's implementation, reporting on progress, convening the advisory council and issuing reports to Congress on the national plan.

### **Action 5.B.2: Track plan progress**

HHS is tracking the national plan's progress to determine whether actions are being completed as stated in the plan and the extent to which implemented actions contribute to the desired outcomes associated with each strategy. HHS and its federal partners will identify challenges to the successful completion of strategies and actions, and recommend next steps for addressing them.

HHS has developed a Web-based resource for strategic planning that will be pilot tested with the national plan. Its utility is to strengthen agency capacity to develop interconnected strategic and implementation plans and to be able to report on progress. It will also assist staff in connecting state-adopted Alzheimer's plans to each other, leveraging resources, reducing duplication of effort, and ensuring coordination when appropriate.

The tool enables federal staff to sort and organize information, filter terms in various ways, and more effectively create charts and graphs. The tool, however, will not be accessible to entities outside of HHS.

### **Action 5.B.3: Update the national plan annually**

HHS and the advisory council will monitor progress towards the goals of the national plan and make recommendations for priority actions and updates. HHS will incorporate its findings and the advisory council's recommendations to update the national plan annually.



## II. BUILDING ON THE FOUNDATION: RECOMMENDATIONS TO UPDATE THE NATIONAL PLAN

To build upon the goals and strategies already implemented in the national plan and to fill in some of the gaps in policy, the Alzheimer's Foundation of America (AFA) sets forth critical, potentially life-changing recommendations for the revised "National Plan to Address Alzheimer's Disease."

### HIGHLIGHTS

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

- Develop more efficient and expeditious methods to determine diagnosis, prognosis and response to therapies using appropriate biomarkers and genetic markers.
- Convene a working meeting of public, private and industry partners to develop a realistic roadmap for Alzheimer's disease research.
- Encourage development of "coopetition"—a strategy in which industry competitors share certain knowledge and research among research industry partners that compete for market share.
- Develop proper standards and measures to be incorporated into research proposals to ensure quality research.
- Establish large-scale patient registries to facilitate faster and less expensive clinical trial recruitment.
- Call on public and private sectors to work together to address the unique circumstances of individuals with Alzheimer's disease and their ability to provide informed consent for clinical trial participation.
- Encourage all new and ongoing federally-funded and industry-sponsored Alzheimer's disease clinical trials to use the same Alzheimer's disease data standards developed by the Clinical Data Interchange Standards Consortium (CDISC) in order to facilitate data sharing and review by FDA.
- Adopt the term "presymptomatic Alzheimer's disease treatment" to refer to interventions that are initiated before a person's apparent cognitive decline and that are intended to reduce the chance of developing Alzheimer's disease-related symptoms.
- Establish a central Alzheimer's disease research coordinating entity within NIH that has the authority and ability to convene inter-agency and non-government constituencies, both domestically and internationally.
- Develop an international Alzheimer's plan that will standardize biomarkers and surrogate end-points, coordinate drug surveillance and enhance global regulatory cooperation.
- Establish an international fund to collect revenues to support Alzheimer's disease clinical research.
- Endorse efforts to increase research collaboration, compress clinical trial pathways and disseminate research findings to Alzheimer's stakeholders and the general public.

#### Goal 2: Enhance Care Quality and Efficiency

- Strengthen efforts to build a high-quality dementia care workforce by:



- making student loans for geriatrics and gerontology eligible for federal loan forgiveness;
  - urging CMS to require geriatric competencies and dementia training for primary care clinicians;
  - requiring certified nursing aides and home care aides and their supervisors to take at least 120 hours of training, including explicit geriatric care and gerontological content;
  - funding nursing home staff training related to behavioral interventions
  - establishing a government-funded 24-hour call center specifically for dementia healthcare professionals.
- Expand memory screening efforts and promotion of the benefits of memory screening and early detection of Alzheimer’s disease by CMS and its partners, as well as provide individuals who are ultimately diagnosed with access to federal
  - Institute a new benefit for Medicare beneficiaries for diagnostic and care planning services specifically for Alzheimer’s disease and related dementias
  - Provide additional initiatives to support family caregivers in the revised national Alzheimer’s plan, including:
    - adoption of family-friendly workplace policies, with federal incentives to carry them out;
    - availability of federal tax credits for family members who are primary caregivers and tax deductions for out-of-pocket costs used for reasonable and necessary long-term care services, including premiums paid for long-term care insurance;
    - greater access to home- and community-based care services under both Medicare and Medicaid to allow individuals with Alzheimer’s disease to stay in the home setting as long as possible;
    - increased funding of AoA programs, like respite care and caregiver training, that help reduce the burdens on family caregivers; and
    - extension of Medicare benefits and AoA program eligibility to all those with Alzheimer’s disease, regardless of age.
  - Expand publicly-funded “participant-directed” (aka “consumer-directed,” “cash and counseling,” “self-directed care”) programs that allow participants to hire family members—including spouses, adult children and even teens—as paid caregivers.
  - Make adult day services a mandatory benefit under Medicaid.
  - Develop high-quality care measures that are culturally competent and tailored to each stage of the disease and each type of care setting.
  - Reimburse healthcare professionals more adequately under federal health programs for services such as longitudinal evaluations and management services, acute and chronic psychiatric management, evaluation of cognitive functioning, and caregiver education and counseling.
  - Specify a target number of demonstration projects for CMMI to implement new care models for Alzheimer’s disease which will shed light on the best models for different populations and provide a substantial caseload to generate data to adequately measure costs and utilization.
  - Establish dementia-specific protocols for emergency rooms, as well as for patients that will decrease length of hospital stays and lower readmission rates.

- Establish regional Memory Evaluation and Treatment Centers through public-private partnerships that focus on developing, improving and disseminating best practices for clinical care for persons with Alzheimer's disease and their family caregivers.
- Develop a specialized palliative care program under Medicare and Medicaid for persons with Alzheimer's disease and related dementias.
- Expand all federal programs associated with Alzheimer's disease treatment, care and support to serve to all persons with Alzheimer's disease, regardless of age.

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

- Require licensure and/or accreditation of facilities that care for, treat and support people with dementia.
- Expand and provide adequate funding for federal programs that help family caregivers, which include:
  - Older Americans Act – provides grants to states for family planning and social services, research and development projects, and training in the field of aging;
  - Lifespan Respite Care Act – provides grants to support statewide respite care service providers, and training, recruiting and outreach;
  - National Family Caregivers Support Program – provides grants to help families pay for myriad support services for family and informal caregivers; and the
  - Missing Alzheimer's Disease Patient Alert Program – provides grants to help local communities and law enforcement officials quickly find persons with Alzheimer's disease who become lost and reunite them with their families.
- Adopt transparent training requirements for crisis call centers that serve individuals with Alzheimer's disease and their caregivers, and require that referrals must be non-exclusive.
- Adopt federal incentives to purchase long-term care insurance, including tax credits or premium support models that will encourage younger individuals to enter the market.
- Require accountants, financial planners, estate managers and CPAs who provide financial, estate planning and investment services to people with Alzheimer's disease and their families to have specialized training through AoA.
- Increase oversight of all institutional facilities (not just nursing homes) that use antipsychotic medications to control behavioral symptoms in people with dementia.
- Undertake further research regarding antipsychotic medications, with an eye on a careful clinical decision-making process that takes into account the risk-benefit ratio per individual.
- Encourage HUD and other Alzheimer's stakeholders to develop new, cost-effective transitional housing models for people with Alzheimer's disease as an alternative to more expensive institutionalization.

### **Goal 4: Enhance Public Awareness and Engagement**

- Continue funding the new Alzheimer's Awareness Campaign, a comprehensive campaign utilizing multi-media platforms.



- Kick off a parallel awareness campaign geared to physicians and other healthcare professionals about the benefits of early detection and diagnosis of Alzheimer’s disease.
- Promote the Medicare Annual Wellness Visit in both campaigns as a vehicle for healthcare professionals and individuals to talk about memory problems and cognitive function.

#### **Goal 5: Improve Data to Track Progress**

- Compile basic, reliable statistics in peer-reviewed studies on the scope of Alzheimer’s disease, its demographics, economic impact, caregiver demographics and cost of services.

### **RECOMMENDATIONS**

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

##### ***Additional Recommendations for Strategy 1A: Identify research priorities and milestones***

AFA believes researchers need to develop more efficient and expeditious methods to determine diagnosis, prognosis and response to therapies using appropriate biomarkers and genetic markers. The tools needed to quantify the outcomes of interventional approaches must be more sensitive—but relevant—indicators of therapeutic effectiveness. Moreover, better methods to study individuals who are non-symptomatic or have mild cognitive impairments are needed to effect better prediction of risk factors, primary and secondary prevention, and delay disease progression.

AFA also calls on NIH and FDA to convene a working meeting of public, private and industry partners to develop a realistic roadmap for Alzheimer’s disease research. Such a roadmap will increase coordination; set forth goals, timelines and requisite steps to move forward; and identify gaps in funding and ways to more efficiently move toward standard biomarkers and endpoints.

NIH should also encourage development of “coopetition” among research industry partners—a business strategy in which industry competitors share certain knowledge and research at the same time that they compete for market share. Shared databases of clinical trial research and other findings in the precompetitive space will help speed up research outcomes while lowering costs by avoiding expensive duplication of efforts.

Just as the national Alzheimer’s plan calls for quality care, the plan should call for quality research as well. Proper standards and measures need to be developed and incorporated into research proposals to ensure that researchers are testing the best research hypotheses.

##### ***Additional Recommendations for Strategy 1.B: Expand research aimed at preventing and treating Alzheimer’s disease***

The revised national Alzheimer’s plan should call for the use of large-scale patient registries to facilitate faster and less expensive clinical trial recruitment. To assist this effort, AFA calls on the public and private sectors to work together to address the unique circumstances of individuals with Alzheimer’s disease and their ability to provide informed consent for clinical trial participation. Further, a mechanism should be developed to let trial participants opt into having their de-identified data used for broader research purposes that advance understanding, treatment and prevention of Alzheimer’s disease.

In addition: in order to facilitate data sharing and FDA review, the updated plan should encourage all new and ongoing federally-funded and industry-sponsored Alzheimer’s disease clinical trials to use the same Alzheimer’s disease data standards developed by the



Clinical Data Interchange Standards Consortium (CDISC) in order to facilitate data sharing and FDA review.

***Additional Recommendations for Strategy 1.C: Accelerate efforts to identify early and presymptomatic stages of Alzheimer’s disease***

The national plan should adopt the term “presymptomatic Alzheimer’s disease treatment” to refer to interventions that are initiated before a person’s apparent cognitive decline and that are intended to reduce the chance of developing Alzheimer’s disease-related symptoms. This terminology will accelerate efforts to identify early and presymptomatic stages of Alzheimer’s disease, address uncertainties surrounding the term “prevention,” and be more acceptable to regulatory agencies conducting reviews of clinical trials. In addition, a reliable cognitive assessment tool should be developed that can be used to assess therapies at earlier stages of Alzheimer’s disease.

***Additional Recommendations for Strategy 1.D: Coordinate research with international and public and private entities***

AFA supports the establishment of a central Alzheimer’s disease research coordinating entity within NIH that has the authority and ability to convene inter-agency and non-government constituencies, both domestically and internationally.

AFA proposes that health ministries and national departments of health worldwide develop an international Alzheimer’s plan that will standardize biomarkers and surrogate end-points, coordinate drug surveillance and enhance global regulatory cooperation. Toward this goal, AFA is calling for an international meeting between the United States and countries that have existing Alzheimer’s disease plans or plan to adopt such strategies.

AFA also supports the establishment of an international fund to collect revenues to support Alzheimer’s disease clinical research. Such a fund would recognize the global nature of the Alzheimer’s crisis, as people’s life expectancy increases all over the world. In addition, all countries, especially those that are experiencing negative economic impact due to the increasing cases of Alzheimer’s disease, have a stake in funding prevention, treatment and a cure for the disorder.

***Additional Recommendations for Strategy 1E: Facilitate translation of findings into medical practice and public health programs***

AFA supports efforts to increase research collaboration, compress clinical trial pathways and disseminate research findings to Alzheimer’s stakeholders and the general public. To this end, AFA has endorsed legislation that calls for a partnership between HHS and non-governmental and non-profit venture entities with proven track records and expertise in developing and bringing therapies to market. Funds would be directed to goal-oriented and milestone-driven research initiatives; and FDA would streamline the review process of therapies developed through the program to cut the length and cost of the pipeline. Lastly, the national plan should call for FDA funding at \$2.66 billion for fiscal year 2013, up from \$2.5 billion in fiscal year 2012, to ensure adequate resources to properly evaluate and test pharmaceutical treatments for Alzheimer’s disease before they enter the market. This level of funding is in line with the appropriations request recommended by both the Alliance for a Stronger FDA and the Coalition to Accelerate Cure/Treatments for Alzheimer’s Disease (ACT-AD).

**Goal 2: Enhance Care Quality and Efficiency**

***Additional Recommendations for Strategy 2.A: Build a workforce with the skills to provide high quality care***

AFA recommends the national Alzheimer’s plan build on recommendations set out in Action 2.A by:



- making student loans for training in geriatrics and gerontology eligible for federal loan forgiveness and offering other incentives, like tax deductions or credits, to boost enrollment in these medical disciplines;
- urging CMS to require geriatric competencies and dementia training for primary care clinicians and staff to improve detection, treatment and care for people with Alzheimer's disease;
- requiring certified nursing aides and home care aides and their supervisors to take at least 120 hours of training (up from the current federal minimum of 75 hours), including explicit geriatric care and gerontological content; and creating minimum training standards/competencies for non-clinical direct-care workers in order to help ensure fewer complications, more positive outcomes and cost savings through less hospitalizations;
- funding nursing home staff training related to behavioral interventions, including recreational arts therapies, as an alternative to antipsychotic treatments, and enforcing CMS requirements that safeguard the use of antipsychotics for persons with Alzheimer's disease and other related dementias; and
- establishing a government-funded, 24-hour call center specifically for dementia healthcare professionals.

***Additional recommendations for Strategy 2.B: Ensure timely and accurate diagnosis***

A key characteristic of the national plan is its innovative public-private partnerships. Multiple Alzheimer's disease and caregiving organizations exist today that can help push forward both diagnostic and supportive programs to meet the anticipated growing demand for such services.

Memory screening and early Alzheimer's detection have been a hallmark of AFA's mission of providing optimal care and services to individuals confronting dementia. AFA has long supported efforts that increase awareness of memory screening, as evident by its National Memory Screening Day that has been held each November since 2003 to promote early detection and treatment of memory problems, including Alzheimer's disease and related dementias. Screening results do not represent a diagnosis, but screeners encourage participants to follow up with practitioners for full evaluation. While screening marks an enormous first step toward detection, people with memory problems need access to clinicians well trained in dementia to take the next step in the process and to avoid misdiagnosis and under-diagnosis.

AFA recommends the expansion of memory screening efforts. Federal and state health facilities can be utilized as screening sites, and CMS can promote screenings through outreach to its public health partners. Moreover, individuals who are ultimately diagnosed must have access to federal health programs for proper treatment and supportive services.

While the memory assessment tools suggested by CMS in the national Alzheimer's plan are sound, AFA suggests that the agency replace some older tests with new models that are more efficient, more directive and developed with modern test theory, which helps determine best items (words/phrases, etc.) to test and how to score. Objective self-assessment tools should be developed as well as new technologies like smart phone applications that track assessments and communicate this data to health professionals.

In addition, AFA recommends that families and individuals with the APOE gene have access to genetic counseling through federal health programs. Individuals with the APOE gene who experience concussions or other head injuries may have an increased risk in developing early-onset Alzheimer's disease. Genetic counseling can help explain the genetic risks with APOE and provide suggestions for risk management.

AFA also sees a greater role for Medicare in caring for beneficiaries with Alzheimer's disease. AFA urges a new benefit for Medicare beneficiaries for diagnostic and care planning services specifically for Alzheimer's disease and related dementias. Such care delivery models, with coordinated care and access to long-term care support services, can increase positive outcomes and enhance cost savings.

***Additional Recommendations for Strategy 2.C: Educate and support people with AD and their families upon diagnosis***

Providing support services, education and training upon diagnosis is vital so that individuals with Alzheimer's disease and their families can adequately plan for the responsibilities and life changes that occur post-diagnosis. CMS and its contractors must ensure people with Alzheimer's disease have access to necessary and appropriate services. Advancing the plan's goal of public-private partnerships, AFA and its member organizations stand ready to work with federal agencies to enhance and expand the reach of services benefiting the Alzheimer's community.

For example, AFA currently operates a toll-free hot line, 866-232-8484, with referrals to local resources (both AFA member and non-member organizations) across the nation; licensed social workers respond to queries via phone, e-mail, Skype and live chat. AFA believes services such as a consumer call center must take an all-encompassing approach—one that mandates both non-exclusive referrals to local and national organizations and utilization of licensed professionals. Additional organizations must work in collaboration with the AoA-funded National Alzheimer's Call Center to expand capacity.

AFA recommends a number of additional initiatives to support family caregivers in the revised national Alzheimer's plan, including:

- adopting family-friendly workplace policies, with federal incentives to carry them out, such as flextime, work-at-home options, job-sharing, counseling, dependent care accounts, information and referral to community services, and employer-paid services of a care manager;
- providing federal tax credits to family members who are primary caregivers for a loved one, and income tax deductions for out-of-pocket costs used for reasonable and necessary long-term care services, including premiums paid for long-term care insurance;
- expanding access to home- and community-based care services under both Medicare and Medicaid to allow individuals with Alzheimer's disease to stay in the home setting as long as possible; and
- increasing funding of AoA programs, like respite care and caregiver training, that help reduce the burdens on family caregivers.

In addition, AFA urges CMS to expand and promote the Resources for Enhancing Alzheimer's Caregiver Health (REACH) program systemwide for Medicare and Medicaid beneficiaries through CMS' CMMI.

Any national plan must recognize that all members of the family—young and old—can serve as caregivers. AFA urges CMS and AoA to develop new ideas for supporting younger family members such as teens and young adults who are taking on caregiving responsibilities.

The revised national plan must call for further expansion of publicly-funded "participant-directed" (aka "consumer-directed," "cash and counseling," "self-directed care") programs that allow participants to hire family members—including spouses, adult children and even teens—as paid caregivers. Currently, more of these programs are being set up with funding primarily from the Medicaid waiver program, as well as through Medicaid state plans,

general state funding, and veterans' programs, but restrictions exist on disease states and the type of family member that qualifies.

Lastly, the national plan must direct Congress to make adult day services a mandatory benefit under Medicaid. Such programs provide socialization and stimulation to people with Alzheimer's disease and provide respite to family caregivers. They also provide family caregivers an avenue to maintain a worker/caregiver balance, which may enable them to stay economically productive in the workforce while serving as primary caregivers.

***Additional recommendations for Strategy 2.D: Identify high-quality dementia care guidelines and measures across care settings***

AFA supports the development of high-quality care measures that are culturally competent and tailored to each stage of the disease and each type of care setting. Specifically, there needs to be more precise measurement of severity, a longitudinal measurement observed in a wide variety of subjects over time and analysis with respect to the continuum of Alzheimer's disease to establish proper measurement for advancing diagnostic and therapeutic approaches for the brain disorder.

It is imperative, however, to more adequately reimburse healthcare professionals under federal health programs for services such as longitudinal evaluations and management services, acute and chronic psychiatric management, evaluation of cognitive functioning, and caregiver education and counseling.

***Additional recommendations for Strategy 2.E: Explore the effectiveness of new models of care for people with AD***

By designing a special benefit for Medicare beneficiaries with Alzheimer's disease that combines care management with access to home care services, and then measuring the costs/utilization of services to Medicare, it will be feasible to identify the potential cost savings of care coordination and access to long-term care support services to these beneficiaries.

AFA urges that the updated national plan specify a target number of demonstration projects for CMMI to implement new care models for Alzheimer's disease over the next five years. Not only will these demonstrations shed light on the best care models for different populations, they will provide a substantial caseload to generate hard data to adequately measure costs and utilization. CMS should then incorporate the successful projects into the systemwide Medicare program.

***Additional Recommendations for Strategy 2.F: Ensure that people with AD experience safe and effective transitions between care settings and systems***

AFA believes that a hospital's recognition of the special needs of individuals with Alzheimer's disease can vastly improve emergency room and inpatient care. Representative of what we can learn from best practices in other countries, Herzog Hospital in Israel has developed guidelines for specialized emergency rooms for behavioral and psychiatric issues, and all staff persons—from physicians to social workers—are trained in geriatric approaches to care. In addition, psychosocial support services must be available to families. These guidelines should be adopted for all emergency rooms in hospitals in the United States.

AFA recommends that hospitals establish protocols for patients with dementia. The requirement for both training and standards will help avoid complications, such as delirium, and lower rates of re-hospitalizations—with resulting cost savings. To this end, AFA recommends that CMMI establish demonstration projects focused on reducing hospital length of stay and readmissions of people with Alzheimer's disease.

The revised national plan should also establish regional Memory Evaluation and Treatment

Centers through public-private partnerships; these centers will leverage existing resources and focus on developing, improving and disseminating best practices for clinical care for persons with Alzheimer's disease and their family caregivers. Such centers, which could be set up as freestanding units or under the umbrella of Alzheimer's organizations, hospitals or other facilities, can serve as one-stop depositories for people seeking memory evaluation and diagnosis, information on Alzheimer's disease and its treatment, and available community resources.

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

AFA believes that access to palliative care services, while often beneficial, are nevertheless underutilized. Palliative care relieves suffering while affirming life for individuals with chronic diseases such as Alzheimer's. AFA recommends that the updated national Alzheimer's plan calls for the development of a specialized palliative care program under Medicare and Medicaid for persons with Alzheimer's disease and related dementias.

Expansion of palliative care services would fill a much-needed gap, providing care to individuals prior to their qualification for hospice and alleviating the process of multiple re-certifications necessary for continuing hospice care.

***Additional Recommendations for Strategy 2.H: Improve care for populations disproportionately affected by Alzheimer's disease and for populations facing care challenges***

The number of persons with early-onset Alzheimer's disease (also known as young-onset), which affects people under age 65 and even in their 30's and 40's, is increasing. AFA is grateful that the national plan recognizes this population, their special needs and the barriers to their effective treatment.

However, government programs like Medicare require beneficiaries to be 65 years and older and, thus, persons with young-onset Alzheimer's disease may have to wait years or even decades before they become eligible, should they even survive that long. AFA recommends that all federal programs associated with Alzheimer's disease treatment, care and support be made available to all persons with Alzheimer's disease, regardless of age.

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

***Additional recommendations for Strategy 3.A: Ensure receipt of culturally sensitive education, training, and support materials***

AFA supports efforts for federal programs and state governments to mandate licensure and/or accreditation of facilities that care for people with dementia, including training in cultural sensitivities, to ensure that facilities are utilizing the latest training and best practices when providing treatment, care or support services to people with Alzheimer's disease and their family caregivers. Institutions that require this certification should include assisted living facilities, nursing homes, hospices, adult day centers and home health agencies.

***Additional recommendations for Strategy 3.B: Enable family caregivers to continue to provide care while maintaining their own health and well-being***

There are several federal programs available to help family caregivers, but they are extremely underfunded and will be even more strained as the dementia population increases. The revised national plan must call for the expansion and adequate funding for these programs, which include:

- Older Americans Act – provides grants to states for family planning and social services, research and development projects, and training in the field of aging.
- Lifespan Respite Care Act – provides grants to support statewide respite care service providers, and training, recruiting and outreach.







- National Family Caregivers Support Program – provides grants to help families pay for myriad support services for family and informal caregivers.
- Missing Alzheimer’s Disease Patient Alert Program – provides grants to help local communities and law enforcement officials quickly find persons with Alzheimer’s disease who become lost and reunite them with their families.

Expansion of these programs is vital to ensuring the health and well-being of individuals with dementia and family members. In particular, these programs should address the much-overlooked needs of teens and young adults, who are often saddled with very adult caregiving responsibilities of their loved ones at a time when many are still engaged in their education and early career paths.

These programs should further address behavioral symptoms of Alzheimer’s disease, which contribute significantly to caregiver burnout. Increased funding under the Missing Alzheimer’s Disease Patient Alert Program that would enable families to secure the most technologically-advanced tracking devices would ultimately save costs and lives.

AFA supports standards for crisis call centers that provide counseling services to people with Alzheimer’s disease and their caregivers. Licensed social workers who have been trained in dementia and the latest in crisis counseling techniques need to staff the call centers in order to truly provide crisis services and reliable information. Referrals must be non-exclusive—made nationwide and communitywide to public and private support groups, program and education providers, etc., and not just funneled to affiliates of any one non-profit, private or government agency.

AFA urges that the revised national plan include the adoption of transparent training requirements for crisis call centers that serve individuals with Alzheimer’s disease and their caregivers. In addition, AFA recommends utilization of existing resources that when coupled with the AoA’s National Call Center can expand the reach of these support services and increase the number of individuals with dementia and caregivers who receive assistance.

***Additional Recommendations for Strategy 3.C: Assist families in planning for future care needs***

More needs to be done to encourage the development of long-term care insurance policies that provide the necessary long-term care support service benefits and are reasonable in cost.

AFA calls for the updated national plan to rectify this situation by instituting appropriate incentives that will encourage consumers to purchase long-term care protection. The government can adopt tax credits or premium support models for those persons below a certain age who purchase long-term care insurance. It is essential that younger, healthy people have incentives to buy long-term care insurance to ensure a proper risk pool that will make such products affordable for people of all ages, and enable insurers to market more viable long-term care policies.

In addition, provisions of the Community Living Assistance Services and Supports (CLASS) program, a component of the Affordable Care Act that has been suspended, need to be resurrected. The CLASS program offers a mechanism for working adults to obtain long-term care insurance coverage regardless of health status, providing some protection for a larger segment of the workforce. The CLASS Act had established a government administrative structure under which participants would pay a monthly premium to be eligible for modest benefits for their long-term care needs after five years.

Lastly, AFA supports expansion of the Medicare program that would provide chronic and long-term care services to all Medicare beneficiaries.

***Additional Recommendations for Strategy 3.D: Maintain the dignity, safety and rights of people with Alzheimer’s disease***

AFA supports efforts to provide specialized training to professionals whose clients have dementia or a loved one with dementia. Such training should go beyond legal service professionals, as called for in the national plan. AFA recommends that the revised plan require accountants, financial planners, estate managers and CPAs who provide financial, estate planning and investment services to people with Alzheimer's disease and their families to have specialized training through AoA's NLRC.

AFA also urges greater public awareness of elder abuse and exploitation, dedicated resources to enforce elder abuse laws, and punitive damages for professionals who defraud clients with Alzheimer's disease or related dementias.

AFA also supports increased oversight of all institutional facilities (not just nursing homes) that use antipsychotic medications to control behavioral symptoms in people with dementia. Such interventions should only be used as a last resort, such as if there is the potential for harm to the person with Alzheimer's disease or others. Health professionals, caregivers and families should be educated in behavioral intervention strategies to diffuse symptoms as an alternative to antipsychotics.

While antipsychotics are known to be associated with significant side effects and an increased risk of mortality, recent published evidence raises questions about the possible increased risk of relapse and worsening of symptoms with the institution of systematic discontinuation of these medications in individuals who receive them. Further research in this area and a careful clinical decision-making process that takes into account the risk-benefit ratio per individual is advised.

***Additional Recommendations for Strategy 3.E: Assess and address the housing needs of people with AD***

In order to foster the concept of aging in place, AFA believes the specific housing needs of people with Alzheimer's disease and their families must be taken into consideration. AFA is currently discussing ideas with HUD and other Alzheimer's stakeholders on how to develop new transitional housing models for people with Alzheimer's disease as an alternative to institutionalization. Such models hold out the promise of not only providing federal cost savings, but also of fostering independence and improving quality of life.

**Goal 4: Enhance Public Awareness and Engagement**

***Additional Recommendations for Goal 4: Enhance Public Awareness and Engagement***

To better educate the public about Alzheimer's disease and help erase stigmas, AFA supports the initial efforts of the government's new public service campaign, the Alzheimer's Awareness Campaign, and urges continued funding of this comprehensive, multi-media campaign that incorporates broadcast and print media, and online and social media platforms. The government needs to allocate additional funds to ensure gains made to date are not erased.

In addition, the government should initiate a parallel awareness campaign geared to physicians and other healthcare professionals about the benefits of early detection and diagnosis of Alzheimer's disease.

Both campaigns should include promotion of the Medicare Annual Wellness Visit as a vehicle for healthcare professionals and individuals to talk about memory problems and cognitive function. The campaigns should also include specific efforts to reach diverse communities and populations, including individuals with young-onset dementia and persons with intellectual disabilities.

AFA suggests that HHS' Administration on Community Living (ACL) reach out to pharmaceutical companies to collaborate on such campaigns. Many pharmaceutical companies have demonstrated that they are effective direct-to-consumer advertisers and

have established digital media forums to conduct such campaigns.

### **Goal 5: Improve Data to Track Progress**

#### ***Additional Recommendations for Goal 5: Improve Data to Track Progress***

AFA recommends that the updated plan requires the federal government to compile basic, reliable statistics on the scope of Alzheimer's disease, including patient and caregiver demographics, economic impact and cost of services. Just as there is an effort to quantify and inventory Alzheimer's disease clinical research, the same must be done on the services side. Moreover, while some of this research may have already been conducted, studies must be peer-reviewed before they can be deemed accurate and disseminated.

### **Conclusion: Voices Working Together to Build**

Things are moving fast. New treatments are being explored, best practices are being developed and creative care models are being tested. The only thing moving faster is the pace of Alzheimer's disease. Currently, an estimated 5.1 million Americans have Alzheimer's disease. With the prevalence of the disease doubling every five years after age 65, the number of cases of Alzheimer's disease is expected to mushroom as our nation's 65+ population soars from 40 million in 2010 to 72.1 million in 2030.

To remain relevant and responsive, the "National Plan to Address Alzheimer's Disease" needs to adapt to the changing landscape in research, clinical and caregiving trends. We must cultivate and collect continued input from healthcare professionals, clinicians, researchers, people with Alzheimer's disease, family caregivers and other stakeholders. Their voices must be heard, and their participation is vital to the process.

As the voice of individuals with Alzheimer's disease and related dementias and their caregivers, AFA holds to its mission to solicit comments and help shape their messages into practical recommendations. AFA will continue to act as this conduit between Americans who deal with the challenges of this disease, day in and day out, and policymakers tasked with developing a comprehensive and effective national strategy. Only by working together will the plan's action steps be fully implemented and the overall goals to tackle this crisis achieved.

Implementation to date of existing action steps is impressive and marks an important first step in establishing a comprehensive national strategy. With the required annual iteration of the national Alzheimer's plan giving us the opportunity to reach even further, we now must continue to act on the input, experience and voice of the Alzheimer's community. We need to further shape and refine a national approach to this devastating disease. It's time to build.



*"Caring for the Nation...One Person at a Time"*

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