

# National Alzheimer's Project Act (NAPA)

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

# THE TIME TO ACT IS NOW

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



Alzheimer's Foundation of America  
March 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. 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; 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 to advise on a national plan, and AFA's "No Time to Waste" report, which incorporated comments from all AFA stakeholders and advisory board members, we have articulated a number of 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.

"The Time to Act Is Now" is AFA's response to the "Draft National Plan To Address Alzheimer's Disease," released by the U.S. Department of Health and Human Services (HHS) in February 2012, and further expands upon AFA's stance on strategies to attack the Alzheimer's disease crisis.

The report 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 to members of AFA's Medical and Science Advisory Board and AFA's National Memory Screening Advisory Board, AFA has been collaborating with the following individuals in the development of recommendations for the national Alzheimer's plan:

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## **Introduction: The Final National Plan Must Do More**

The Alzheimer's Foundation of America (AFA) applauds the Obama Administration for embarking on the development of a national plan to prevent and effectively treat Alzheimer's disease by 2025 and to expand services, training and support for people with Alzheimer's disease and their families. The initiative demonstrates an understanding of the growing need and a proactive approach to problem solving that defines leadership. Tackling such a complex and costly issue as Alzheimer's disease in the current economic environment poses even greater challenges, necessitating creative solutions and innovative partnerships to effectively solve problems.

February 2012 marked AFA's 10th anniversary of its formation, with the mission of providing optimal care and services to individuals confronting dementia, and to their caregivers and families through, today, more than 1,600 member organizations. It is our duty, therefore, to be a voice for those in the shadows and to make Alzheimer's disease a national priority. 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 to advise on a national plan, and AFA's "No Time to Waste" report, which incorporated comments from all AFA stakeholders and advisory board members, we have articulated a number of recommendations and action steps that are necessary to ensure proper support of individuals with dementia and caregivers, as well as prevent, delay or, representing the biggest win, eradicate this disease by 2025.

AFA is pleased that "The Draft National Plan to Address Alzheimer's Disease" ("draft national plan") released by the U.S. Department of Health and Human Services (HHS) in February 2012 incorporates many of our proposed strategies to address the needs of Americans who currently are affected by Alzheimer's disease or who face this fate in the future. The draft national plan marks a solid first step in establishing a comprehensive policy to fight Alzheimer's disease and related dementias.

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 the government and private entities. What it fails to do, however, is take bold and decisive action to achieve the ultimate objective of quelling this growing crisis.

The final National Alzheimer's Plan to Address Alzheimer's Disease can and must do more. As a national plan, not a federal one, it should not be tied to the current debate over the federal deficit. Under the status quo, the economic impact of Alzheimer's disease is already costing the U.S. economy hundreds of billions of dollars and, if left unchecked, this number could hit \$1 trillion by 2050.

The final national plan to address Alzheimer's disease needs to build upon the draft national plan and reach higher and farther. Gaps such as more attention to the special needs of Americans with young-onset Alzheimer's disease, greater investment in government programs like Medicare, assistance so more Americans can practically and financially afford to age in place, and reforms in the tax code to support family caregivers need to be included as action steps. The plan must state accountable and measureable metrics, through specific deadlines and time frames, so that the government and stakeholders can effectively measure the plan's progress.

With this report, AFA continues to provide a voice to individuals with Alzheimer's disease, and their caregivers and families as the national plan takes shape. It is up to all of us now to speak up louder than ever to ensure that we keep moving forward on this historic opportunity to present our nation with a bold and transformative national plan.

## What Is at Stake

Alzheimer's disease in the U.S. is at crisis proportions. In the decades ahead, the number of people affected by the brain disorder will increase exponentially. Alzheimer's disease currently affects more than five million Americans, and the incidence is rising in line with the nation's aging population; prevalence of the disease doubles every five years after age 65. A rarer form of the disease, known as young-onset, which can affect people as young as in their 30's, is also on the rise.

Recent death statistics place Alzheimer's disease as the sixth leading cause of death in the U.S. and the fastest growth category among chronic illnesses. It is also the only disease in the top ten leading causes of death that cannot be prevented, cured or modified.

The nature of Alzheimer's disease and related dementias is both unique and heartbreaking. As the disease progresses, symptoms like memory loss, confusion, personality changes, and ultimately loss of independence, worsen over time. Typically, for each person with the disease, there are multiple caregivers, who respond to 24/7 needs related to activities of daily living. Caregiving duties often fall on family members who are overwhelmed both emotionally and physically, and whose health and well-being often suffer as they fulfill this role.

As the U.S. population ages, both the numbers of persons with Alzheimer's disease and cost of their care will grow exponentially, with costs expected to exceed \$1 trillion by 2050.

Given the enormity of what is at stake, the federal government must take the lead in spearheading clinical research, ensuring support services for family members of all backgrounds and age groups, and providing adequate coverage of long-term care needs for people with Alzheimer's disease and related dementias. The final national plan must be comprehensive, extensive and reflect the full compassion of our society.

The following is a critical look at the draft national plan. AFA appreciates the opportunity to provide comments, and it is our hope that these recommendations will be incorporated into the final national Alzheimer's plan—a plan that holds the promise of changing the trajectory of Alzheimer's disease and changing lives.

## AFA's ANALYSIS OF DRAFT NATIONAL PLAN TO ADDRESS ALZHEIMER'S DISEASE

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

*Research continues to expand our understanding of the causes of, treatments for, and prevention of Alzheimer's disease. This goal seeks to develop effective prevention and treatment modalities by 2025. Ongoing research and clinical inquiry can inform our ability to delay onset of Alzheimer's disease, minimize its symptoms, and delay its progression. Under this goal, HHS will prioritize and accelerate the pace of scientific research and ensure that as evidence-based solutions are identified they are quickly translated, put into practice, and brought to scale so that individuals with Alzheimer's disease can benefit from increases in scientific knowledge.*

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

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

*Research agencies undertake research planning processes on an ongoing basis, but a special effort is needed to identify the priorities and milestones to achieve Goal 1. The actions below will identify the priorities, establish milestones, and ensure that appropriate stakeholders are involved in the planning process aimed at minimizing Alzheimer's disease as a health burden by 2025.*



## **AFA Comments on Action 1.A: Identify research priorities and milestones**

AFA agrees that to use research dollars more efficiently, the national plan must establish priorities, and the investment in promising research must be targeted and increased. Further, clinical pathways for promising pharmaceutical need to be compressed to ensure early entry into the market. To this end, AFA recommends:

- Development of methods to more efficiently and expeditiously determine diagnosis, prognosis and response to therapies using appropriate biomarkers and genetic markers.
- Development of methodologies and tools needed to quantify the outcomes of interventional approaches that are more sensitive—but relevant—indicators of therapeutic effectiveness.

While such research should include biomarkers and genetic markers, the primary focus should be related to the identification of more relevant clinical endpoints. It is essential that such research be closely aligned with the U.S. Food and Drug Administration (FDA) so that any progress in the field can undergo more rapid review by regulators, thereby expediting regulatory clearance of, and patient access to successful therapeutics.

- Development of better methods to study individuals who are non-symptomatic or have mild cognitive impairments to effect better prediction of risk factors, primary and secondary prevention, and effective delay in progression.

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

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

## **AFA Comments on Action 1B: Expand research aimed at preventing and treating Alzheimer's disease**

AFA has long advocated the use of patient registries to facilitate faster, more efficient and less costly clinical trials. AFA is pleased to see that the draft national plan adopts this registry approach in Action 1.B.3.

To make progress on this front, AFA offers additional recommendations to be considered under this draft national plan action step. AFA believes that any national plan should encourage the standardization of data by using standards established by the Clinical Data Interchange Standards Consortium (CDISC), which will facilitate data sharing and review with the FDA. AFA also urges full funding of the Cures Acceleration Network to engage the private sector in speeding the translation of basic scientific discoveries into treatments for Alzheimer's disease. Finally, AFA supports the development of a public awareness campaign around recruitment, with special outreach in minority communities, for clinical research trials.

### *Strategy 1.C: Accelerate efforts to identify early and presymptomatic stages of Alzheimer's disease*

*Significant advances in the use of imaging and biomarkers in brain, blood, and spinal fluids have made it possible to detect the onset of Alzheimer's disease, track its progression, and monitor the effects of treatment in people with the disease. Without these advances, these neurodegenerative processes could only be evaluated in non-living tissues. Accelerated research will improve and expand the application of biomarkers in research and practice. These*



*advances have shown that the brain changes that lead to Alzheimer's disease begin up to 10 years before symptoms. Identifying imaging and other biomarkers in presymptomatic people will facilitate earlier diagnoses in clinical settings, as well as aid in the development of more efficient interventions to slow or delay progression.*

### **AFA Comments on Action 1.C: Accelerate efforts to identify early and presymptomatic stages of Alzheimer's disease**

AFA supports the use of the term "presymptomatic" to refer to those interventions that are initiated before apparent cognitive decline. Such terminology will accelerate efforts to identify early and presymptomatic stages and develop effective interventions and tools to help slow or delay progression. In addition, AFA believes a reliable assessment tool needs to be developed and validated that can be used to analyze the effectiveness of interventions during the presymptomatic stage.

Further, more aggressive efforts are necessary to capture people in the early stages of Alzheimer's disease. This requires a multi-pronged approach, including greater awareness of, and education about symptoms among consumers and clinicians, wider utilization of validated memory screening tools, enhanced access to healthcare, and higher provider reimbursement.

#### *Strategy 1.D: Coordinate research with international public and private entities*

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

### **AFA Comments on Strategy 1.D: Coordinate research with international public and private entities**

AFA supports efforts to inventory Alzheimer's research data and to calculate the investment needed for further research and clinical trials. AFA also agrees that further international outreach and collaboration is needed.

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 supports the efforts of U.S. Representatives Christopher Smith (R-NJ) and Edward Markey (D-MA) in calling for an international meeting between the U.S. and countries with existing Alzheimer's disease plans.

AFA also supports the establishment of an international fund to collect revenues for Alzheimer's disease clinical research. Such a fund will 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 with the growing number of cases of Alzheimer's disease, have a stake in funding a cure.

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

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

## **AFA Comments on Strategy 1.E: 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 the "Spending Reductions through Innovations in Therapies (SPRINT) Agenda Act of 2012." Under SPRINT, targeted public investments will be made in the most promising research areas through 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 will be directed to goal-oriented and milestone-driven research initiatives; and the 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 funding of the FDA at \$2.66 billion for fiscal year 2013 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 being recommended by 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**

*Providing all people with Alzheimer's disease with the highest-quality care in the most efficient manner requires a multi-tiered approach. High-quality care requires an adequate supply of culturally-competent professionals with appropriate skills, ranging from direct-care workers to community health and social workers to primary care providers and specialists. High-quality care should be provided from the point of diagnosis onward in settings including doctor's offices, hospitals, people's homes and nursing homes. Care quality should be measured accurately and coupled with quality improvement tools. Further, given the complex care needs of people with Alzheimer's disease, high-quality and efficient care is dependent on smooth transitions between care settings and coordination among healthcare and long-term services and supports providers.*

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

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

*The workforce that cares for people with Alzheimer's disease includes healthcare and long-term services and supports providers such as primary care physicians; specialists such as neurologists, geriatricians, and psychiatrists; registered nurses and advanced practice nurses; community health workers; social workers; psychologists; pharmacists; dentists; allied health professionals; and direct-care workers like home health aides and certified nursing assistants, who provide care at home or in long-term care facilities. These providers need accurate information about caring for someone with Alzheimer's disease including the benefits of early diagnosis and how to assist caregivers. Physicians need information on how to implement the "detection of any cognitive impairment" requirement in the Medicare Annual Wellness Visit included in the Affordable Care Act. Major efforts by both VA and the Health Resources and Services Administration (HRSA), including expanded training opportunities created in the Affordable Care Act, support geriatric training for physicians, nurses, and other health workers. Enhanced specialist training is also needed to prepare these practitioners for the unique challenges faced by people with Alzheimer's disease. In addition, work is needed to expand the capacity of the primary care community to serve people with Alzheimer's disease. Dementia-specific capabilities within the direct-care workforce need to be expanded and enhanced. The actions below will facilitate AD-specific training for care professionals in order to strengthen a workforce that provides high-quality care to people with Alzheimer's disease.*



## **AFA Comments on Action 2.A: Build a workforce with the skills to provide high-quality care**

AFA supports all the recommendations set out in Action 2.A, but proposes that the final national plan builds on this emphasis on geriatric training for practitioners and improving skills of professional caregivers caring for people with Alzheimer's disease and related dementias. Among these additional recommendations are:

- Making geriatrics and gerontology eligible for federal loan forgiveness and other efforts 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, including explicit geriatric care and gerontological content; and create minimum training standards/competencies for non-clinical direct-care workers. Exposure to such training will ensure fewer complications, more positive outcomes and cost savings through less hospitalizations.
- Funding for nursing home staff training related to behavioral interventions, including recreational arts therapies, as an alternative to antipsychotic treatments, and enforcement of CMS requirements safeguarding the use of antipsychotics for persons with Alzheimer's disease and other related dementias.
- Establishing a government-funded, 24-hour call center specifically for dementia healthcare professionals.

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

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

### **AFA Comments on Strategy 2.B: Ensure timely and accurate diagnosis**

A key characteristic of the draft plan is its innovative public-private partnerships. Multiple Alzheimer's 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, sponsoring its National Memory Screening Day 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 avoid mis-diagnosis and under-diagnosis.

AFA recommends that memory screening efforts be expanded. Federal and state health facilities can be utilized as screening sites, and CMS can promote screenings through outreach to its public health partners.

Moreover, those ultimately diagnosed must have access to federal health programs to ensure they get proper treatment and therapy. AFA also sees a greater role for Medicare in caring for beneficiaries with Alzheimer's disease. AFA would like to see 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.

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

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

#### **AFA Comments on Action 2.C. Educate and support people with AD and their families upon diagnosis**

CMS has the tools and infrastructure to implement this policy. HHS should include this strategy as one of their immediate action steps to be released with the next draft plan.

Providing support services, education and training upon diagnosis is vital to ensuring that families can adequately plan for the responsibilities and life changes that occur after a loved one is diagnosed with Alzheimer's disease. CMS and its contractors must ensure people with Alzheimer's disease have access to necessary and appropriate services. AFA has learned of certain instances where Medicare has denied claims for necessary and appropriate behavioral therapy services just because a beneficiary has an Alzheimer's disease diagnosis. These blanket denials are overly broad, and unfairly deny training and support services to people in need.

Advancing the goal of public-private partnerships recommended in the draft national plan, 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 at 866-AFA-8484 with referrals to local resources (both AFA member and non-member organizations) across the U.S.; 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 organizations and utilization of licensed professionals. Additional organizations must work in collaboration with the Administration on Aging (AoA)-funded National Alzheimer's Call Center to expand capacity.

AFA recommends a number of additional initiatives that support family caregivers and must be included in a national plan. These proposals include:

- Urging adoption of family-friendly workplace policies, with federal incentives to carry them out. Examples of family-friendly workplace policies include: 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.

- Use of tax incentives to support family caregivers. Federal tax credits should be available for family members who are primary caregivers for a loved one. In addition, out of pocket costs used for reasonable and necessary long-term care services, including premiums paid for long-term care insurance, should be fully deductible from income.
- 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.

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’ Center for Medicare and Medicaid Innovation (CMMI) Center.

Any national plan must recognize that all members of the family 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 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 caregivers. Currently, these programs are increasing with funding primarily from the Medicaid waiver program, as well as through Medicaid state plans and general funding from a state, and veterans’ programs, but restrictions exist on disease states and the type of family member that qualify.

Lastly, Congress must make adult day services a mandatory benefit under Medicaid. Such programs provide socialization and stimulation to people with Alzheimer’s disease and allow family caregivers some respite. They also provide family caregivers an avenue to maintain a worker/caregiver balance, which will allow them to stay economically productive in the workforce while remaining primary caregivers.

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

*Guidelines for delivery of high-quality care and measures of quality are needed to ensure people with Alzheimer’s disease receive high-quality, culturally-competent care in the many different settings where they are treated. These guidelines should be tailored to the stages of the disease and cover the myriad care settings in which care is delivered, such as in the home, physician’s office, and long-term care facility. These guidelines should also take into account how care might be modified for diverse populations and in the context of co-occurring chronic conditions in people with AD. Quality measures should be based on such guidelines and track whether recommended care is being provided. The actions below will advance the development of guidelines and measures of high-quality care, as well as the ability of the provider community to improve the quality of the care they provide.*

**AFA Comments on 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. 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.



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

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

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

Integrated and coordinated long-term care services will lower overall costs of treating beneficiaries with Alzheimer's disease. It will reduce incidences of hospitalizations as a result of beneficiaries who fail to take prescribed medication, suffer injuries from unsafe environments or face other avoidable circumstances. Further, respite care provided to family caregivers will allow them to better balance caregiving with their professional and other family responsibilities, and enable them to remain financially productive and in the workforce. In addition, respite can help reduce the risk of caregivers' mental and physical deterioration, thus ultimately saving healthcare costs.

AFA is proposing that CMS adopt new care delivery models that recognize the benefit of care coordination integrated with access to home care services. As an example, one such model could: 1) extend "homebound" status to beneficiaries diagnosed with Alzheimer's disease and having two or more compromised activities of daily living (ADLs); 2) assign a case manager to Medicare beneficiaries with Alzheimer's disease to coordinate care services and ensure smooth transitions across care settings; 3) track the amount of services utilized by the Medicare beneficiaries in the demonstration; 4) make health assessments of family caregivers and track healthcare costs of these family caregivers under the Medicare program; 5) require HHS to issue a report at the end of the demonstration period comparing costs of Medicare services provided to those under the demonstration to the costs of similarly-situated Medicare beneficiaries with Alzheimer's disease and their caregivers who were not part of the demonstration.

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

AFA urges that the national plan specify a target number of demonstration projects for CMMI to implement new care models for Alzheimer's disease in the next five years. Not only will the demonstrations shed light on which care models work best for different populations, they will ensure an adequate number of cases to generate hard data numbers to adequately measure costs and utilization.

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

*People with dementia have higher rates of emergency room visits and hospitalizations, two settings where they are vulnerable to stress, delirium, and unnecessary complications. A transition between providers and care settings is a complex time of care delivery for all people, but especially for frail elders or other individuals with Alzheimer's disease. Transitions include moves into acute-care hospitals, from hospitals to post-acute settings such as skilled nursing*

*facilities or the home, or from nursing facilities to hospitals. People with AD are at high risk of adverse events due to poor communication and other care process deficiencies during transitions.*

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

Improved emergency room and inpatient care can be vastly improved through the recognition of the special needs of individuals with Alzheimer's disease. 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 U.S. hospitals.

While specialized training for emergency room staff is essential, AFA also recommends that all hospitals establish protocols for patients with dementia. Such standards and training will help avoid complications, such as delirium, and lower rates of re-hospitalizations.

The national plan should also establish regional Memory Evaluation and Treatment Centers, through public-private partnerships, that 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.

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

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

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

AFA supports efforts to advance coordination among care settings and is pleased to see this recommendation in the draft national plan. AFA also 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 national plan develop 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.

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

*Some populations are unequally burdened by Alzheimer's disease, including racial and ethnic minorities and people with intellectual disabilities. Racial and ethnic minorities are at greater risk for developing Alzheimer's disease and face barriers to obtaining a diagnosis and services after onset. People with certain intellectual disabilities almost always develop AD as they age. In addition, because AD primarily affects older adults, the population with younger-onset AD faces*



*unique challenges with diagnosis, care, and stigma. HHS will undertake the actions below to better understand the unique challenges faced by these groups and create a plan for improving the care that they receive.*

### **AFA Comments on 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 draft national plan recognizes this population, their special needs, and the barriers to their effective treatment. Government programs like Medicare require beneficiaries to be 65 years and older and, thus, persons with early-onset Alzheimer’s disease may have to wait 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.

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

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

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

AFA supports efforts for both private and public entities to provide licensure and accreditation on the treatment of dementia to ensure that facilities are utilizing the latest training and best practices when providing care or support services to people with Alzheimer’s disease and their family caregivers. Institutions that require certification should include: assisted living facilities, nursing homes, adult day centers and home health agencies.

This is another example of a strategy that can and should be implemented immediately. CMS could require institutions it partners with in its Medicare and Medicaid programs to require specialized training in the care of individuals with dementia. To ensure compliance, CMS could incorporate this policy into its survey and certification process.

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

*Even though informal caregivers usually prefer to provide care to their loved ones in their home or other community settings, eventually the round-the-clock care needs of the person with AD often necessitate nursing home placement. While they are providing care, supports for families and caregivers can help lessen feelings of depression and stress and help delay nursing home placement. The actions below will further support informal caregivers by identifying their support needs, developing and disseminating interventions, and highlighting supports during crisis situations.*

### **AFA Comments on 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. The national plan should and must call for the expansion and

adequate funding for these programs whose capacities will be strained as more persons are diagnosed with Alzheimer's disease or a related dementia. Some of these federal programs vital to family caregivers 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 – grants are used to support statewide respite care service providers and are used for training, recruiting and outreach.
- National Family Caregivers Support Program – grants are used to help families pay for myriad support services for family and informal caregivers.
- Missing Alzheimer's Disease Patient Alert Program - helps local communities and law enforcement officials quickly find persons with Alzheimer's disease who wander away from home 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 oft-overlooked needs of teens and young adults, often saddled with very adult caregiving responsibilities of their loved ones at a time when many are still engaged in their education and career starts. As well, 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 made 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 the national plan to adopt transparent training requirements for crisis call centers that serve individuals with Alzheimer's disease and their caregivers. In addition, AFA urges that the national plan tap into existing resources that, when coupled with the AoA's call center, can expand the reach of these support services and increase the number of individuals with dementia and caregivers who receive assistance.

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

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

### **AFA's Comments on 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. The draft national plan notes that, "[U]nfortunately, by the time care is needed, it is difficult to get coverage" at lower cost.

AFA urges the national plan to rectify this unfortunate set of circumstances by instituting appropriate incentives that will encourage consumers to purchase long-term care protection. Tax credits or premium support models can be adopted for those persons below a certain age who purchase long-term care insurance. It is essential that younger, healthy people have incentives to purchase 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 CLASS Act could be resurrected to provide some long-term care protection for a larger segment of the workforce. Lastly, AFA supports expansion of the Medicare program that would provide chronic and long-term care services to all Medicare beneficiaries.

*Strategy 3.D: Maintain the dignity, safety and rights of people with Alzheimer's disease*

*People with Alzheimer's disease are particularly vulnerable to financial exploitation, physical or emotional abuse, and neglect both at home and in care facilities. Reports of elder abuse are handled by state Adult Protective Services, which is charged with responding to and resolving alleged abuse. State survey and certification agencies investigate abuse in licensed facilities, which may include nursing homes, assisted living facilities, and board and care homes. AoA's National Long-Term Care Ombudsmen are advocates for residents of nursing homes, board and care homes, assisted living facilities, and similar adult care facilities and can help address issues related to potential abuse or neglect. The actions below will help ensure that people with AD have their dignity, safety, and rights maintained.*

**AFA Comments on 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. AFA recommends that the final national plan requires lawyers, accountants, financial planners, estate managers and CPAs who provide legal, financial, estate planning and investment services to people with Alzheimer's disease and their families to have specialized training through the National Legal Resources Center. AFA also recommends 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 is also supportive of 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.

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

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

### **AFA Comments on Strategy 3.E: Assess and address the housing needs of people with AD**

AFA is supportive of the action steps outlined in this strategy. Addressing the housing needs of people with Alzheimer's disease and their families in order to foster the concept of aging in place, and provide alternatives to nursing home placement, should be part of any comprehensive national plan. AFA encourages HUD to look at the existing Housing Opportunities for People with AIDS (HOPWA) program as a possible model. HOPWA provides short-and long-term rental assistance, operates community residences or makes use of other supportive housing facilities developed to address needs of persons who are living with HIV/AIDS and related challenges. Similar services should be offered to persons living with Alzheimer's disease and their families.

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

*Most of the public is aware of Alzheimer's disease; more than 85 percent of people surveyed can identify the disease and its symptoms. Alzheimer's disease is also one of the most-feared health conditions. Yet there are widespread and significant public misperceptions about diagnosis and treatment. These misperceptions lead to delayed diagnosis and to people with the disease and their caregivers feeling isolated and stigmatized. Enhancing public awareness and engagement is an essential goal because it forms the basis for advancing the subsequent goals of the National Plan. A better understanding of Alzheimer's disease will help engage stakeholders who can help address the challenges faced by people with the disease and their families. These stakeholders include a range of groups such as health care providers who care for people with AD and their caregivers, employers whose employees request flexibility to care for a loved one with the disease, groups whose members are caregivers, and broader aging organizations. The strategies and actions under this goal are designed to educate these and other groups about the disease.*

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

### **AFA's Comments on Goal 4: Enhance Public Awareness and Engagement**

The draft national plan cites a study concluding that 85 percent of people can identify Alzheimer's disease and its symptoms. Yet this is counter to many other studies that show the need for greater public education and awareness of Alzheimer's disease. A national study conducted in 2007 examining public opinion about Alzheimer's disease among blacks, Hispanics and whites found that "misconceptions about AD remain among large segments of the population, that Alzheimer's disease remains a source of significant concern, and that continued efforts are needed to educate the public about this disease." The stigma of the disease, moreover, is also prevalent, demonstrating the need for greater public understanding of the disease and exposure to people with Alzheimer's disease.

To better educate the public about Alzheimer's disease and help erase stigmas, AFA supports the rollout of a multi-media platform public service campaign targeting Alzheimer's disease. This campaign should hone in on various aspects of the disease, including symptoms, early detection, availability of current and emerging treatments, clinical trials, and supportive services. AFA would suggest that the Centers for Disease Control (CDC) reach out to pharmaceutical companies to collaborate on such a campaign. Many pharmaceutical companies have demonstrated that they are effective direct-to-consumer advertisers and have established digital media forums to conduct such campaigns.

Since early detection is one of the best channels at our disposal to improve quality of life, this must be a key topic area in any public awareness campaign. AFA urges that the national plan require funding or collaboration with private partners to support public awareness around memory screening, and early detection and treatment of Alzheimer's disease.

Since 2003, AFA has been sponsoring National Memory Screening Day (NMSD) each November in conjunction with National Alzheimer's Disease Awareness Month. Qualified healthcare professionals have provided free, confidential screenings to hundreds of thousands of individuals on NMSD over the past nine years. AFA recognizes that such screening tests are not diagnostic tools but rather the beginning of a discussion between a person and his or her healthcare professional about memory problems that could ultimately result in proper diagnosis of Alzheimer's disease or a related dementia. As such, memory screening can improve quality of life and lead to more cost-effective care. With early detection, individuals with Alzheimer's disease can learn more about the illness, including available and emerging medical treatments; get counseling and other social services support in their community; address legal, financial and other planning issues; and have more of a say in decision-making.

Culture in the workplace must also change, with employers supporting the needs of individuals with dementia and caregivers. AFA believes that the national plan must provide incentives to employers that adopt family-friendly policies 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. Tax credits, access to small business loans through the Small Business Administration, or preferences in the bidding for government contracts are all possible tools that could be used to encourage employers to adopt such family-friendly policies.

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

*The federal government is committed to better understanding AD and its impact on people with the disease, families, the health and long-term care systems, and society as a whole. HHS will make efforts to expand and enhance data infrastructure and make data easily accessible to federal agencies and other researchers. This data infrastructure will help HHS in its multi-level monitoring and evaluation of progress on the National Plan.*

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

### **AFA Comments on Goal 5: Improve Data to Track Progress**

While AFA commends the draft national plan's inclusion of an infrastructure to make data about Alzheimer's disease more accessible to federal agencies, we have concerns over the approach in the draft plan to monitor and evaluate progress. AFA recommends that the

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<sup>1</sup> Connell, Cathleen M PhD; et. al., Public Opinion About Alzheimer Disease Among Blacks, Hispanics, and Whites: Results From a National Survey, Alzheimer Disease & Associated Disorders: July/September 2007 - Volume 21 - Issue 3 - pp 232-240



final plan includes action steps that are accompanied by deadlines, and that timeframes are established for accomplishing certain goals. As opposed to a multi-level monitoring approach, AFA would recommend that a dedicated federal official or high-ranking office be appointed to be fully accountable for the plan's progress. In addition, a system should be in place to seamlessly enable Alzheimer's stakeholders to weigh in on the evolution of the plan.

In conjunction with implementation of the national plan, AFA also recommends that the government compile basic, reliable statistics on the scope of Alzheimer's disease, its demographics, its economic impact, caregiver demographics, 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

AFA's role as an advocate for individuals with Alzheimer's disease, and their caregivers and families is central to our mission. AFA is grateful to the Administration for its efforts in developing a national plan and is appreciative of opportunities to provide recommendations and feedback on draft plans and through representation on the Advisory Council on Research, Care and Services.

In this capacity, AFA is providing a voice for Americans in the shadows, for those families with little resources and nowhere to turn. As we struggle to find a cure for Alzheimer's disease, we can't lose focus on the individuals living with dementia as well as on their caregivers who struggle every day with the overwhelming economic, psychological and physical impact of the brain disorder.

There is no time to waste. AFA urges HHS to immediately implement strategies in the draft national plan that require no statutory authority or additional resources, like interagency collaborations and the sharing of information resources and data. HHS should identify and implement these action steps even before it introduces the final national plan.

It is clear that the national plan will rely on innovative collaborations to extend the reach of public resources. AFA and our more than 1,600 member organizations nationwide are committed to making Alzheimer's disease a national priority and stand ready to coordinate and partner with federal, state and private stakeholders to advance the plan's strategies. Our combined expertise can assist in developing new care delivery models; expanding or establishing call centers; utilizing memory screening; widening access to care services; educating consumers, clinicians and policymakers; conducting public awareness campaigns; and implementing other steps in the plan.

Now is the time to build on the momentum of the national discussion on Alzheimer's disease. Now is the time to seize the moment, and craft and implement a final national plan that will mark a strategic turning point in cure and care.



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

