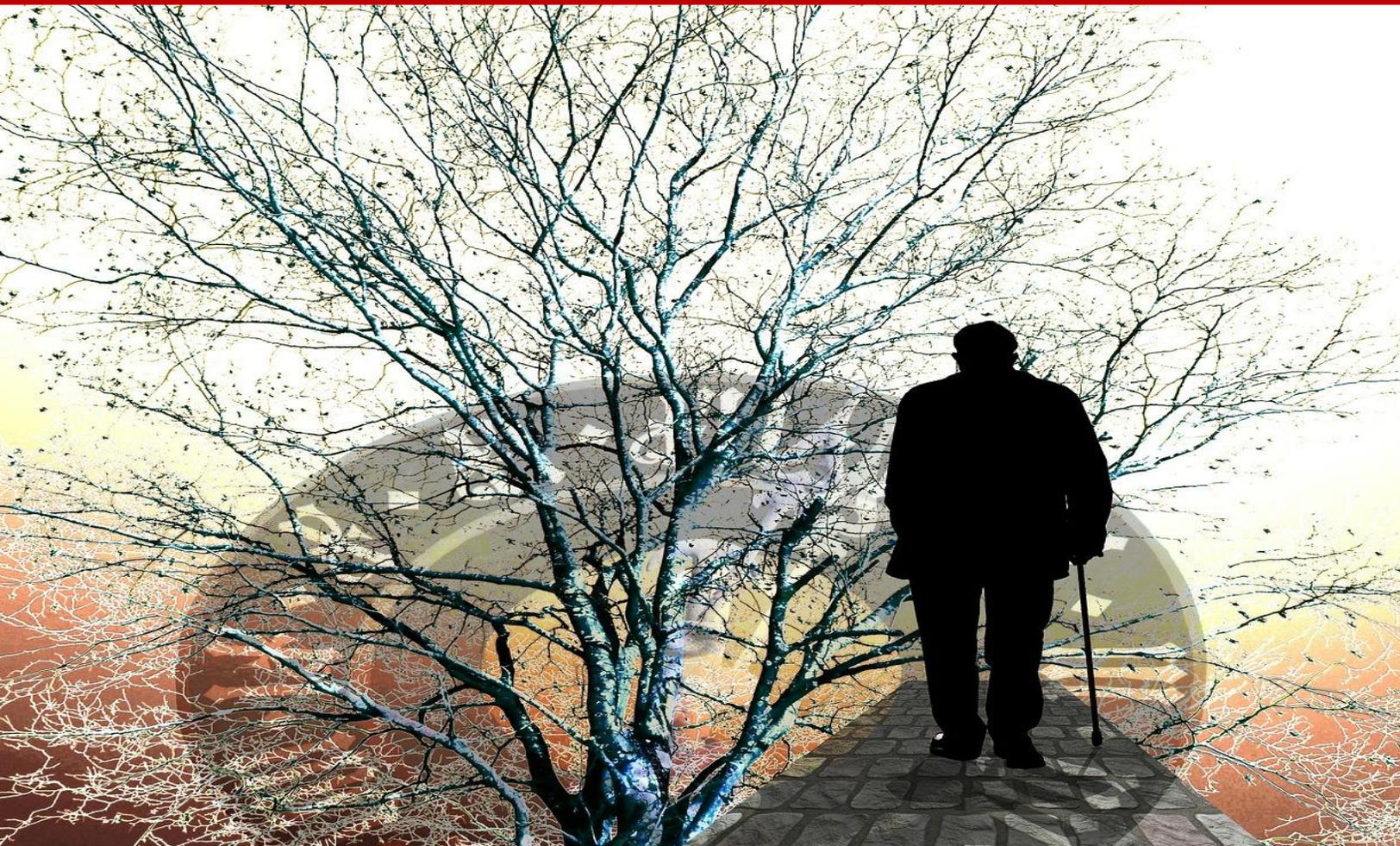




Overcoming Alzheimer's Disease



Introduction: Voices From Around the Country

The Alzheimer's Foundation of America (AFA), our 1,600+ member organizations and the millions of families they serve, as well as AFA's national partners were honored to play a significant role in the passage—and now implementation—of the National Alzheimer's Project Act (NAPA). AFA organized 14 national organizations and more than 90 state and local organizations in nearly 30 states to actively support NAPA. In addition, AFA worked with legislators to ensure that a national voice representing various local organizations would have a place at the table on the Advisory Council on Alzheimer's Research, Care and Services (Advisory Council).

Millions of Americans who have been touched by Alzheimer's disease and related dementias view NAPA as a once-in-a-lifetime opportunity to change the conversation about a mentally, physically, emotionally and financially devastating illness to one about comprehensive support services, quality care, cost effectiveness, a robust research environment and an eventual cure. As a nation, we must do better, and NAPA is the vehicle to meaningful transformation—but only if we do it right.

In the nearly nine months since NAPA was signed by President Obama, AFA has consistently heard from family caregivers, clinicians, researchers, long-term care professionals, direct care professionals, law enforcement officers, policymakers and the general public about their personal and professional experiences with Alzheimer's disease, their recommendations for change, and their hopes that this process goes beyond a "check the box" exercise. We have heard from them in the field, by organized conference calls, and through their many e-mails, letters and calls to our office.

This report is a compilation of their voices shared with AFA and our own beliefs regarding the necessary components of what the NAPA statute defines as "an integrated national plan to overcome Alzheimer's." Many of these recommendations will take time to develop and implement, but some can be started today.

The one idea that we can all agree on is that there is no time to waste.

Be Bold and Be Practical

One of the themes that emerged from the first meeting of the Advisory Council on September 27 is that we must stop the current incremental approach to solving the Alzheimer's disease crisis and instead advance a bold and transformative strategy. To be clear, AFA is very supportive of setting ambitious, benchmark-specific goals and formulating solutions within—as well as outside of—current government programs to ultimately "defeat" Alzheimer's disease.

However, AFA also believes that defeating Alzheimer's disease cannot be done in one fell swoop. It will likely happen in a series of small victories. We had a victory when NAPA passed. We earlier had a victory in getting the "detection of any cognitive impairment" included in the new Medicare Annual Wellness Exam—and hopefully we will be victorious in the future in requiring the use of a cognitive screening tool as part of the exam. **We are also engaged in other pressing issues right now that we must make a concerted effort to address. They include: FY 2013 budget planning that will impact dollars for Alzheimer's disease research and programs; and deliberations by the Joint Select Committee on Deficit Reduction to potentially overhaul future Medicare and Medicaid benefits that would financially squeeze our population even further.** We must engage in these issues together—and press the White House for accountability on them—as we seek a bold solution to Alzheimer's disease.

Change Starts with Public Awareness

Public awareness of Alzheimer's disease is unfortunately similar to where cancer and heart disease were decades ago. **An integrated national plan to overcome Alzheimer's disease must include public awareness campaigns to educate the public, press and policymakers about the true prevalence of this disease; its social and economic impact on families, government and society; signs and symptoms of cognitive problems in general, and Alzheimer's disease and related dementias specifically; how healthcare professionals should screen, diagnose and treat cognitive problems; services and supports available for individuals with Alzheimer's disease and all members of their families, including children and young adults; and the dire need for more private and public funding for both research and care-related services.**

As with breast cancer, HIV/AIDS and other diseases, Alzheimer's disease and related dementias carry a tremendous stigma. Most people are not inclined to discuss memory concerns with their healthcare providers, often because of fear or shame. A survey conducted during AFA's annual National Memory Screening Day in 2007 found that 68 percent of respondents had concerns about their memory. However, while more than 44 percent had visited their primary care physician within the last six months, fewer than one in four of those with self-identified memory problems had discussed the issue with their physician.¹ Similar results among family members were found in a survey conducted on behalf of the Alzheimer's Disease Screening Discussion Group.²

There are additional barriers³ to early detection⁴ of dementia:

- Individuals are often unaware, deny or minimize the severity of symptoms.
- Access to quality care is a key issue for all individuals with dementia and for those of minority racial and ethnic backgrounds in particular.
- Clinician evaluation may be time-consuming and not well reimbursed.
- Many, especially minority populations, believe that memory loss and cognitive decline are a normal part of aging.

For racial and ethnic minorities, the barriers to early detection are often magnified. One survey found that African-American and Hispanic caregivers were significantly more likely (37 percent versus 33 percent) than caregivers of other races (23 percent) to believe that Alzheimer's disease is a normal part of the aging process. About one-third (33 percent) of overall respondent caregivers reported that their loved one's concern about stigma delayed diagnosis, while about a quarter (26 percent) indicated that their own concern about stigma was a reason for the delay. African-American caregivers were significantly more concerned about stigma (36 percent) than Hispanic (22 percent) and other race

¹ Powers RE, Hall E, Ashford JW, Howard G. Self reported features of 2178 respondents undergoing memory screening during National Memory Screening Day in 2007 as sponsored by the Alzheimer's Foundation of America. 2008 ICAD Poster Session. June 30, 2008.

² Alzheimer's Disease 2008: Current Attitudes and Perceptions Survey, Harris Interactive Survey on behalf of the Alzheimer's Disease Screening Discussion Group, released September 24, 2008.

³ Solomon PR, Murphy CA. Should we screen for Alzheimer's disease? A review of the evidence for and against screening for Alzheimer's disease in primary care practice. *Geriatrics*. 2005, 60(Nov): 26-31.

⁴ Knopman D, Donohue JA, Guterman EM. Patterns of care in the early stages of Alzheimer's disease: impediments to timely diagnosis. *J Am Geriatr Soc*. 2000 Mar;48(3):300-4.

(18 percent) caregivers. Other reasons for the delay in diagnosis included not wanting to face the possibility of something being wrong, fear of the responsibility of caregiving, not being offered a memory screening and resistance to visiting a doctor.⁵

Much of the public fear of Alzheimer's disease is based on observed behaviors exhibited on the part of the individuals with the disease, coupled with the helplessness that people feel to effect change. It will be necessary to humanize these behaviors and shift the focus from fear to acceptance of the disease. Lessening the social chasm between "us and them" will be a huge step toward ameliorating the stigma.

Public awareness campaigns are essential to spark an impactful and long-lasting national dialogue about Alzheimer's disease and to effect change. First, all levels of government, which includes federal agencies as well as the White House, must develop and roll out wide-scale public awareness campaigns. The White House has waged campaigns against many diseases and chronic conditions, from breast cancer and HIV/AIDS to autism and obesity. Such campaigns not only educate, they generate additional interest from the public and private sectors to invest resources and time. In addition, public-private partnerships with national and local Alzheimer's disease organizations, industry, and corporate interests will be the key to successful public awareness.

AFA supports the perspective that there is value in knowing whether someone's cognitive impairment is different from normal aging, and that individuals have the right to information to help them make educated choices.

No one entity "owns" the Alzheimer's disease issue or has the answers to address every need. AFA has been, and always will be, about working with as many constituencies as possible to influence meaningful change. AFA looks forward to working further with government, non-profit and corporate partners and others in the months and years ahead on public awareness campaigns that change the conversation about Alzheimer's disease in the United States.

Don't Reinvent the Wheel

It is no secret that the United States is nationally behind the curve of seven countries⁶ and more than 25 states in our nation that already have Alzheimer's disease plans in place. We have much work ahead of us, but we can learn from what has already been done overseas and in our own country at the state level—both in planning and in political commitment.

The federal government should review existing state plans to learn more about needs as well as innovation at the local level that may be replicated nationally. In states where funding for local implementation has been an issue, the federal government should consider appropriating support.

⁵ ICAN2: Investigating Caregivers' Attitudes and Needs. Harris Interactive for the Alzheimer's Foundation of America. February 9, 2007, www.alzfdn.org.

⁶ <http://www.alz.co.uk/alzheimer-plans>

In addition to a comprehensive review of existing state plans, the next crucial step is to convene an international meeting by the second quarter of 2012. AFA would be honored to serve as an NGO supporting partner in such an effort and would be glad to work with Alzheimer's Disease International (ADI) and others. In AFA's view, the international meeting would ideally consolidate how other countries have approached their plans and would produce a compendium with common threads. Such a meeting would help us craft our national strategy and help us begin to flesh out a global approach to this pandemic.

The meeting would also include a day or more of panel discussions on established policies and innovative care programs abroad as well as insight into the many effective programs in the United States. There is little doubt we can get there faster by reviewing what has already been done, what has been successful, and what to avoid.

Representative Chris Smith (R-NJ), a co-chair of the bipartisan Congressional Task Force on Alzheimer's Disease, has led the charge in Congress on this idea. In June of this year, Chairman Smith convened an historic hearing on "Global Strategies to Combat the Devastating Health and Economic Impacts of Alzheimer's Disease" before the United States House of Representatives Committee on Foreign Affairs Subcommittee on Africa Global Health, and Human Rights.⁷ Representative Smith and Representative Ed Markey (D-MA), the co-chair of the Task Force, as well as AFA, called for an international meeting between the United States and countries with existing Alzheimer's disease plans. **AFA supports Representative Smith's effort to include \$750,000 in the State, Foreign Operations, and Related Programs in FY 2012 Appropriations for the United States to organize and host a high-level meeting of leaders from nations with existing Alzheimer's disease plans by June 30, 2012.**

Representatives Smith and Markey, as well as 28 other Task Force members, also called on the United Nations General Assembly to include Alzheimer's disease in its September 2011 high-level summit on the prevention and control of non-communicable diseases.⁸ Due to these efforts, the United Nations specifically identified Alzheimer's disease as an important cause of death and contributor to the global non-communicable disease (NCD) burden. The United Nations declaration states, in part, that General Assembly members "recognize that mental and neurological disorders, including Alzheimer's disease, are an important cause of morbidity and contribute to the global NCD burden for which there is a need to provide equitable access to effective programmes and health care interventions."⁹

Framing and Categories

There was discussion at the first meeting of the Advisory Council on September 27 about how to frame a national plan and what categories or "buckets" to use when making recommendations. AFA believes that the framework should include a timeline, with short-term (i.e., within a year of release of the final plan) and long-term (i.e., longer than one year) goals.

⁷ http://foreignaffairs.house.gov/press_display.asp?id=1879

⁸ http://chrissmith.house.gov/UploadedFiles/6_15_11_Final_letter_to_UN_Pres_Deiss_re_Alzheimers_w_signatures.pdf

⁹ http://www.un.org/ga/search/view_doc.asp?symbol=A%2F66%2FL.1&Lang=E

The existing categories for recommendations in research, clinical care and long-term care are a solid framework. However, AFA recommends that each category should include:

- a public awareness strategy as described above (e.g., a campaign on clinical trial recruitment for research, including strategies to increase ethnic minority recruitment; a national conversation on exactly what Alzheimer's disease is and what to expect with a diagnosis; and programs and resources available for family caregivers of all demographics);
- a funding strategy, including promotion of public-private partnerships;
- a public safety and legal system strategy that addresses issues such as falls; medication adherence; driving; becoming lost; neglect, abuse and exploitation; and competency for medical and legal decision-making;
- an early-onset strategy that addresses the needs of younger individuals with Alzheimer's disease;
- a "co-morbid and related dementias" strategy that targets vascular dementia, caused by stroke or blockage of blood supply; alcoholic dementia, caused by sustained use of alcohol; post concussive dementia, caused by head injury; frontotemporal dementia; Lewy body dementia; and other uncommon diseases;
- an education and workforce strategy (e.g., mandatory dementia care training for all healthcare and long-term care professionals who have direct access to persons with dementia); and
- a data collection strategy to better inform policy (e.g., number of families served by existing Administration on Aging programs).

Research

Recommendation One: Raise the Budgets of the National Institute on Aging and the National Institutes of Health in FY 2013

We cannot create a comprehensive national plan to defeat Alzheimer's disease without addressing public funding, particularly in a challenging economic environment where private sector resources are also limited. AFA has heard President Obama's call for continued strategic investments into basic medical research, and we echo that appeal.

The National Institute on Aging (NIA) is the primary agency at the National Institutes of Health (NIH) responsible for Alzheimer's disease research and receives nearly 70 percent of the NIH Alzheimer's disease research funding. As the lead NIH institute on related genetic, biological, clinical, behavioral, social and economic studies, the NIA will not be able to move toward a breakthrough toward the prevention, treatment, cure and care of Alzheimer's disease without a substantial investment in Alzheimer's disease research.

In 2010, total Alzheimer's disease care costs to all payers in the United States were estimated at \$172 **billion**, but the institute-wide federal investment at NIH in Alzheimer's disease research is estimated to be only \$469 **million**.¹⁰ The anticipated growth in the affected population over

¹⁰ Lewin Group for the Alzheimer's Association, Changing the Trajectory of Alzheimer's Disease: A National Imperative, May 2010; National Institutes of Health Office of the Budget <http://report.nih.gov/rcdc/categories/>.

the next 10 years will widen the cost to research investment discrepancy. While the current dollars appropriated to NIA seem to have risen significantly since FY 2003, when adjusted for inflation, they have gone down almost 18 percent in the last nine years. According to the NIH Almanac, out of each dollar appropriated to NIH, only 3.6 cents goes toward supporting the work of the NIA—compared to 16.5 cents to the National Cancer Institute, 14.6 cents to the National Institute of Allergy and Infectious Diseases, 10 cents to the National Heart, Lung and Blood Institute, and 6.3 cents to the National Institute of Diabetes and Digestive and Kidney Diseases.¹¹

AFA urges the President to work with Congress to raise NIH and NIA funding based on the Biomedical Research and Development Price Index (BRDPI, also known as “birdpie”) as opposed to gross domestic product (GDP). The annual change in the BRDPI indicates how much the NIH budget must change to maintain purchasing power. The BRDPI was developed and is updated annually by the Bureau of Economic Analysis at the Department of Commerce under an interagency agreement with the NIH. The projections for future year values are prepared in the Office of Science Policy at NIH.¹²

AFA urges the Administration to include \$1.4 billion at a minimum—an increase of at least \$300 million from FY 2011—for NIA in the President’s proposed FY 2013 budget. This funding is essential to increase the NIA’s baseline to a level consistent with comparable research initiatives conducted under the auspices of the NIH and to support additional research into Alzheimer’s disease and related dementias.

Recommendation Two: Fund the Cures Acceleration Network

The health reform law established the Cures Acceleration Network (CAN) within the Office of the Director of the NIH. CAN seeks to cut the time between discovery and development of drugs and therapies through new grant-making mechanisms at NIH. A board of 24 diverse members from several fields, including research, FDA, venture capital and patient advocacy, will oversee CAN. In addition, CAN will work with the FDA to coordinate approval requirements with the goal of expediting the development and approval of safe and viable new products. The Senate Appropriations Committee included \$20 million to initiate CAN in FY 2012, and its report stated, “The average length of time from target discovery to FDA approval of a new drug is 14 years, a delay that is costing lives and prolonging human suffering.”¹³ Funding for this initiative is critical to appropriately engage the private sector and aid in speeding the translation of basic scientific discoveries into treatments for diseases such as Alzheimer’s.

Recommendation Three: Increase Resources for the Food and Drug Administration

Drug development is a crucial component of research. In order to maintain robust investment in Alzheimer’s disease from the private sector, new approaches are needed to accelerate therapeutic development and create corresponding incentives for innovation to produce better treatments that will prevent and cure this disease. It will be critically important that the FDA has sufficient funding to carry out these approaches.

¹¹ <http://www.nih.gov/about/almanac/appropriations/index.htm>

¹² <http://officeofbudget.od.nih.gov/gbiPriceIndexes.html>

¹³ <http://www.gpo.gov/fdsys/pkg/CRPT-112srpt84/pdf/CRPT-112srpt84.pdf>

Recent annual increases in the FDA's budget have been essential in strengthening the agency. Nonetheless, there remains an extraordinarily large gap between the FDA's responsibilities and its resources. Every year, the agency's responsibilities become scientifically complex and more difficult to implement. Congress enacts new laws affecting the FDA with some regularity, further straining the FDA's ability to meet the expectations of Congress and the American people.

AFA recommends a \$495 million increase or more for the FDA in the President's proposed FY 2013 budget. This is the amount we believe is needed to make further progress against existing responsibilities. Any new legislation must come with the assurance that there will be larger "budget authority" appropriations to cover the cost of the additional work.

According to the Alliance for a Stronger FDA:

FDA's annual appropriation is quite small, especially when matched against its jurisdiction over one-quarter of consumer spending, 80% of the food supply and all of the drugs, biologics, medical devices, animal drugs, cosmetics and dietary supplements used anywhere in the United States. FDA must also deal with the food and medical products that are sourced from overseas. Despite three years with appropriations above the break-even point, the FDA still gets only \$2 billion per year. There cannot be many agencies in the US government that have such a vast scope of responsibilities and so few dollars to get the job done.¹⁴

Recommendation Four: Balance Basic Research With Clinical Research

Consensus feedback to AFA includes a strong call for an increased focus on clinical research. It was striking to hear in NIA Director Dr. Richard Hodes' September 27 overview of federal research funding that only about \$30 million of the \$469 million devoted to Alzheimer's disease research at NIH goes toward clinical research in Alzheimer's disease care, training and support. While we are all hopeful about finding an eventual cure for Alzheimer's disease, we must also keep clinical research needs in mind for people who currently have the disease as well as individuals who will be diagnosed in the years to come. Continued and expanded research is needed in earlier diagnosis and prevention; better treatments; safety issues; non-pharmacological behavioral interventions; end-of-life care; and support and dementia care training for family caregivers of all ages and ethnic backgrounds, clinicians—including primary care physicians, and direct care employees.

Clinical Care

Recommendation One: Promote Earlier Detection Through Cognitive Screening

Unfortunately, there are serious deficiencies in the healthcare system's ability to recognize dementia. A 2009 article in the American Journal of Geriatric Psychiatry found that general

¹⁴ "Written Testimony of the Alliance for a Stronger FDA," March 26, 2010, <http://strengthenfda.org/resources/>

practitioners miss about half of all dementia cases.¹⁵ Persons with dementia cannot rely simply on relatives and friends, with whom they may have limited contact, to notice or be educated about memory problems. Physicians must play a greater role in discussing memory problems and in case identification. **In addition, it will be vital to have Administration support for a public awareness campaign to drive earlier detection.**

The NIA recognized in its 2008 report entitled "Alzheimer's Disease: Unraveling the Mystery" that "it is best to find out sooner rather than later," because there are important medical and practical benefits to early detection. As NIA noted: "The drugs now available to treat AD can help some people maintain their mental abilities for months to years;" and "the sooner the person with AD and the family have a firm diagnosis, the more time they have to make future living arrangements, handle financial matters, establish a durable power of attorney and advance directives, deal with other legal issues, create a support network, and even consider joining a clinical trial or other research study."¹⁶ The value of knowing includes supporting the individual's right to information to make the best healthcare and support choices.

The success achieved in including "detection of any cognitive impairment" in the new Medicare Annual Wellness Exam needs to be taken a step further. AFA strongly suggests that the Centers for Medicare and Medicaid Services (CMS) revisit its definition of "detection of any cognitive impairment" in the annual wellness visit. Currently, the definition is based on observation and patient and third party reporting. Unlike heart disease, breast cancer and high blood pressure, there is no screening test for dementia included in the wellness visit. **AFA strongly believes that the Medicare annual wellness visit should include a cognitive screening.**

A cognitive screening is a simple and safe evaluation tool that assesses memory and other intellectual functions and indicates whether additional testing is necessary. It is important to note that screening is neither a diagnostic nor case finding process. Screening tests in general simply help determine whether diagnostic tests should be considered. A "positive" result from a cognitive screening should never be interpreted as a diagnosis of Alzheimer's disease or a related illness or other illnesses—no more than a "positive" mammogram means an individual has breast cancer.

Multiple screening instruments are available to assess individuals for cognitive decline.¹⁷⁻¹⁸ The length of the screening test ranges from less than five minutes for the Brief Alzheimer's Screen (BAS) to approximately 15 minutes for the Mini-Mental Status Examination (MMSE).¹⁹⁻²⁰ A broad range of instruments, such as the GPCOG, Mini-Cog and MIS, are

¹⁵ Pentzek M, Wollny A, Wiese B, et al. Apart From Nihilism and Stigma: What Influences General Practitioners' Accuracy in Identifying Incident Dementia? *Am J Geriatr Psychiatry*. 2009 Nov;17(11):965-975.

¹⁶ National Institute on Aging, National Institutes of Health, "Alzheimer's Disease; Unraveling the Mystery," September 2008, 48-49, available at http://www.nia.nih.gov/NR/rdonlyres/0FA2EE06-0074-4C45-BAA3-34D56170EB8B/0/Unraveling_final.pdf.

¹⁷ Burns A, Lawlor B, Craig S. *Assessment scales in old age psychiatry*. London: Martin Dunitz Ltd, 1999.

¹⁸ Ashford JW. Screening for Memory Disorder, Dementia, and Alzheimer's Disease. *Aging Health*. 2008 4(4):399-432.

¹⁹ Mendiondo MS, Ashford JW, Kryscio RJ, Schmitt FA. Designing a Brief Alzheimer Screen (BAS). *J Alzheimers Dis*. 2003 Oct;5(5):391-8.

²⁰ Folstein MF, Folstein SE, McHugh PR. "Mini-mental state." A practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res*. 1975 Nov;12(3):189-98.

available with acceptable levels of sensitivity and specificity as well as interrater or rate-rater reliability.²¹⁻²²

Several distinct methodologies include face-to-face screening, telephone-based screening and computer-based screening of at-risk persons. Many dementia screening tests have been developed and studied in numerous populations, using both prospective and retrospective analyses, and have been recommended for consideration.²³⁻²⁴⁻²⁵⁻²⁶⁻²⁷⁻²⁸⁻²⁹

It is not necessary for CMS to be prescriptive about the specific instrument, except that the instrument has well-established psychometric properties that would make it suitable for the purposes of the wellness exam.

Several screens have adequate sensitivity and specificity to serve as routine, cost-worthy evaluations. In fact, cognitive screening instruments demonstrate 80 percent to 90 percent or higher sensitivity and specificity in reviewed studies³⁰—similar to other established screening tests such as a mammography³¹ and Pap smear.³²

Screening tests may be short cognitive tools administered to individuals, high-sensitivity questions asked of individuals themselves, questions asked of family members, or some combination of all of these approaches. Several comparative reviews on the application of screening tests for Alzheimer's disease and other dementias are available.³⁴⁻³⁵ The qualifications of the healthcare professional depend upon the screening instrument used, but

²¹ Brodaty H, Clarke J, Ganguli M, Grek A, et al. Screening for cognitive impairment in general practice: toward a consensus. *Alzheimer Disease and Associated Disorders* 1998;12(1):1-13.

²² Burns A, Lawlor B, Craig S. *Assessment scales in old age psychiatry*. London: Martin Dunitz Ltd, 1999.

²³ Borson S, Scanlan JM, Watanabe J, et al. Simplifying detection of cognitive impairment: comparison of the Mini-Cog and Mini-Mental State Examination in a multiethnic sample. *J Am Geriatr Soc*. 2005 May;53(5):871-4.

²⁴ Brodaty H, Pond D, Kemp NM, Luscombe G, et al. The GPCOG: a new screening test for dementia designed for general practice. *J Am Geriatr Soc*. 2002 Mar;50(3):530-4.

²⁵ Buschke H, Kuslansky G, Katz M, et al. Screening for dementia with the memory impairment screen. *Neurology*. 1999 Jan 15;52(2):231-8.

²⁶ Mendiondo MS, Ashford JW, Kryscio RJ, Schmitt FA. Designing a Brief Alzheimer Screen (BAS). *J Alzheimers Dis*. 2003 Oct;5(5):391-8.

²⁷ Shankle WR, Romney AK, Hara J, et al. Methods to improve the detection of mild cognitive impairment. *Proc Natl Acad Sci U S A*. 2005 Mar 29;102(13):4919-24.

²⁸ Ashford JW. Screening for Memory Disorder, Dementia, and Alzheimer's Disease. *Aging Health*. 2008 4(4):399-432.

²⁹ Milne A, Culverwell A, Guss R, et al. Screening for dementia in primary care: a review of the use, efficacy and quality of measures. *Int Psychogeriatr*. 2008 Oct;20(5):911-26.

³⁰ Solomon PR, Murphy CA. Should we screen for Alzheimer's disease? A review of the evidence for and against screening for Alzheimer's disease in primary care practice. *Geriatrics*. 2005, 60(Nov): 26-31.

³¹ National Cancer Institute. Breast Cancer Screening Modalities. <http://www.nci.nih.gov/cancertopics/pdq/screening/breast/HealthProfessional/page5>.

³² Kulasingam SL, Hughes JP, Kiviat NB, et al. Evaluation of human papillomavirus testing in primary screening for cervical abnormalities: comparison of sensitivity, specificity and frequency of referral. *JAMA*. 2002 Oct 9;288(14):1749-57.

³³ Ashford JW, Borson S, O'Hara R, et al. Should older adults be screened for dementia? *Alzheimer's & Dementia*. 2006;2:76-85.

³⁴ Shulman KI, Herrmann N, Brodaty H, et al. IPA survey of brief cognitive screening instruments. *Int Psychogeriatr*. 2006 Jun;18(2):281-94.

³⁵ Lorentz WJ, Scanlan JM, Borson S. Brief screening tests for dementia. *Can J Psychiatry*. 2002 Oct;47(8):723-33.

registered nurses, and sometimes trained office staff, can perform most brief screening tests.³⁶ After receiving and reviewing the results, primary care providers have the opportunity to discuss the findings with screened individuals during an office visit.

Recommendation Two: Require Geriatric Competencies and Dementia Training

One of the main concerns we hear from our member organizations and from family caregivers is that clinicians do not spend enough time explaining what to expect after a diagnosis of Alzheimer's disease, including care options and issues to consider as the disease progresses. One of the most telling comments came during a national call organized by AFA. "What we are proposing is a culture shift," said a caller from Tyler, TX. "One barrier of reaching professionals is that dementia has been around a long time; therefore, people think they don't need to learn anything new, even though we know so much more about Alzheimer's disease and dementia now."

As the baby boom generation has begun to turn 65 in huge numbers each year and the corresponding numbers of people with Alzheimer's disease increases, dementia training will prove to be more important than ever. It is incorrect to assume expertise in geriatrics or dementia based on a physician's patient load of older people. Many primary care physicians and non-physician providers have little or no exposure to formal instruction in specialty areas such as geriatrics, geriatric psychiatry/psychology or neurology that train in dementia diagnosis and care, and medical students are generally not required to complete rotations in these areas. In addition, incentives must be developed so that those clinicians who obtain training are better reimbursed for the dementia services they provide.

AFA believes that adequate education of and reimbursement for primary care clinicians and staff are essential to improving earlier detection, treatment and care for people with Alzheimer's disease—as well as supporting family caregivers.

Inadequate primary care training in geriatrics, chronic care management and long-term care leads to misdiagnoses, medication errors, increased institutionalization, poor care coordination and unnecessary stress on family caregivers—resulting in substandard care and higher costs. Training must take into account that people under age 65 can have Alzheimer's disease as well (known as young-onset or early onset). Training must also include a focus on the identification and management of behavioral issues that may accompany dementia. Behavioral issues are a main reason that clinicians prescribe psychoactive medications in long-term care settings, which may result in increased confusion, falls and mortality.

CMS should require all healthcare professionals who treat persons with Alzheimer's disease to have certification and training in geriatrics and/or dementia: Physicians who treat people with Alzheimer's disease and related dementias should be able to demonstrate either Geriatric Board Certification or evidence of adequate continuing medical education (CME) in Geriatric Medicine; nurse practitioners should either have Geriatric Certification or CME in Geriatrics and Dementia Care; physician assistants should have CME in Geriatrics and Dementia Care; social services/case management staff should be required to have Dementia Certification; and nursing staff (RNs and LPNs), medical assistants and utilization review staff should be required to have dementia training.

³⁶ Solomon PR, Murphy CA. Should we screen for Alzheimer's disease? A review of the evidence for and against screening for Alzheimer's disease in primary care practice. *Geriatrics*. 2005, 60(Nov): 26-31.

Long-Term Care

Recommendation One: Expand and Promote Family Caregiver Training and Support Across the Continuum of Care

The Resources for Enhancing Alzheimer's Caregiver Health (REACH) program includes proven strategies, such as skills training, environmental interventions and behavior management, for helping family caregivers manage the stress and emotional burden of caring for people with dementia. Studies about the program show that it produces a significant improvement in caregivers' sense of burden, social support, depression and health, as well as in the care recipients' behavior problems and mood.³⁷ **REACH is now implemented at all facilities operated by the U.S. Department of Veterans Affairs, and it should also be implemented system-wide for Medicare and Medicaid beneficiaries by CMS through the Center for Medicare and Medicaid Innovation, known as the Innovation Center.**

We need new ideas for supporting younger family members who may be helping with care, such as teens and young adults. This is especially critical when parents of children and young adults are living with young-onset Alzheimer's disease. Results from the 2008 AFA "ICAN: Investigating Caregivers' Attitudes and Needs" survey suggest that Alzheimer's disease care is a family affair. Most "sandwich caregivers"—the parents or guardians of children under 21 who also care for an aging parent, other relative or friend with Alzheimer's disease—said their children were assisting with caregiving responsibilities that range from attending doctors' appointments to feeding and dressing their loved ones. Among children, ages 8 to 21, who are involved in caregiving, many are reported as taking on significant tasks: about one-third of young adults (18 to 21) assist with doctors' appointments; 42 percent of young adults assist with transporting loved ones with Alzheimer's disease; and about one-quarter of young adults and teens (13 to 17) assist with activities of daily living, such as feeding and dressing.³⁸

Family caregivers, particularly women and members of low-income families, are faced with tremendous stress. Families and friends who provide this unpaid care often do so at the expense of their own physical and mental health and financial well-being. Business productivity losses related to family caregiving in the United States have been estimated as high as \$33.6 billion per year.³⁹ Many caregivers get caught in a difficult spiral of negative consequences. They are forced to take time off from work, forgo promotions and maybe even drop out of the workforce altogether to care for relatives. Consequently, they work less and

³⁷ <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2577188/>

³⁸ <http://www.alzfdn.org/Publications/surveys.html>. Founded in 2002 by a teenager, AFA Teens seeks to mobilize teenagers nationwide to raise awareness of Alzheimer's disease and to engage teenagers in the cause. The award-winning program is aimed at teens with family members affected by the disease and those purely interested in the cause. AFA Teens' dedicated Web site, www.afateens.org, creates an online community for teens, giving them support from experts and the opportunity to share experiences and connect with each other through a bulletin board and blog. AFA Teens awards a \$5,000 college scholarship to a college-bound student each year. The scholarship is designed to provide an outlet for teenagers to express their thoughts about Alzheimer's disease and to engage the younger generation in this cause.

³⁹ Feinberg, Lynn, Reinhard, Susan C., Houser, Ari, Choula, Rita. "Valuing the Invaluable: 2011 Update The Growing Contributions and Costs of Family Caregiving," AARP Public Policy Institute.

earn less, which reduces the Social Security and pension benefits they receive. And women, who generally live longer than men, must stretch their meager resources much further.

We need to work on multiple solutions to help family caregivers aid the ones they love, including:

- family friendly workplace policies;
- tax credits for individuals with substantial long-term care needs or for their family caregiver(s);
- parity for home- and community-based care with the Medicare and Medicaid eligibility levels for nursing home care;
- full funding for existing programs that seek to reduce family caregiver burden and reduce institutionalization, including the Lifespan Respite Program, the National Family Caregiver Support Program, and the Alzheimer's Disease Supportive Services Program; and
- Medicare and Medicaid coverage for adult day and respite services, including post-acute services and non-medical service models.

AFA has received overwhelming feedback that presses the point of family support services. A recent AFA conference call participant from West Palm Beach, FL noted, for example: "This is a family disease. Whatever type of funding, the service needs to always incorporate the caregiver and the patient."

Among other points that would assist family caregivers, participants stressed the need for uniform dementia training and certification for healthcare workers, including primary care doctors; training for law enforcement who interact with people with dementia who have gone missing; funding for recreational therapies for individuals with dementia; more services for people with young-onset Alzheimer's disease; and greater collaboration among federal, state and local agencies that provide resources to family caregivers and people with Alzheimer's disease.

Recommendation Two: Make Care Coordination Systemwide

Proven pilot and demonstration programs such as Independence at Home (IAH) and other care coordination models should be implemented systemwide by CMS.

Numerous studies show that IAH and other CMS-tested care coordination programs for high-cost Medicare beneficiaries with two or more chronic conditions—including Alzheimer's disease—reduce healthcare expenditures, improve quality of care and enhance health outcomes.

IAH is a unique clinical, financial and legal healthcare delivery model, compatible with other models, that will be tested under Medicare in a demonstration beginning January 1, 2012 and is being implemented by Medicare Advantage, Medicaid and private health plans to reduce healthcare costs "where they are the highest and improve outcomes where they are the worst."

IAH focuses on the 5 percent to 25 percent of people who account for 43 percent to 85 percent of costs and receive the worst care. IAH takes primary care to the person in the home, tailors the care team to the individual's needs and coordinates care across all treatment settings on a 24/7 basis. Practitioners are strictly held accountable for a minimum savings of 5 percent annually, positive outcomes and patient/caregiver satisfaction. Funding for IAH is entirely from the savings it achieves, and savings sharing will permit reinvestment in three types of technology (health information technology, telemonitoring, and mobile miniaturized

diagnostics) that will allow even more people to avoid unnecessary hospitalizations, emergency room visits and nursing home admissions in the future. IAH has proven effective in hundreds of programs that have operated in every state and the District of Columbia for decades.

Recommendation Three: Expand the Geriatrics Workforce

Many of the healthcare professionals who reached out to AFA with suggestions emphasized the importance of expanding the eldercare/geriatrics workforce. Our nation faces an impending healthcare crisis as the number of older individuals with Alzheimer's disease and other complex health needs increasingly outpaces the number of healthcare providers with the knowledge and skills to adequately care for them. If current workforce trends do not change, we will continue to fail to ensure that every older American is able to receive high-quality care. The Institute of Medicine's (IOM) April 2008 report entitled "Retooling for an Aging America: Building the Health Care Workforce" calls for immediate investments in enhancing the geriatric competencies of the entire workforce, increasing the recruitment and retention of geriatric specialists and caregivers, and improving the way that care for older adults is delivered.⁴⁰

The Eldercare Workforce Alliance⁴¹ (EWA), a group of 28 national organizations (including AFA) that joined together to address the immediate and future workforce crisis in caring for an aging America, recommends several significant policy changes to expand the eldercare workforce. Direct-care workers provide critical support to older adults in need of long-term care, providing eight out of every ten hours of paid service delivered.⁴² This field, which is increasing at three times the rate of other jobs within the United States economy, provides the best opportunity for caring individuals to obtain vital employment positions.⁴³ **To ensure that all direct-care workers are able to provide the highest quality care to all long-term care consumers, these positions should offer comprehensive training, certification and career advancement opportunities; livable, family-sustaining wages; affordable health insurance and other benefits; full-time hours, if desired; and balanced workloads.**

EWA also notes that there is also a significant shortage of health professionals and direct-care workers with specialized training in geriatrics and an even greater shortage of the geriatrics faculty needed to train the entire workforce. Title VII Geriatrics Health Professions programs are the only federal programs that increase the number of faculty with geriatrics expertise in a variety of disciplines and offer critically important geriatrics training to the entire healthcare workforce. Title VIII Geriatrics Nursing Workforce Development Programs are the primary source of federal funding for advanced education nursing, workforce diversity, nursing faculty loan programs, nurse education, practice and retention, comprehensive geriatric education, loan repayment and scholarship. **AFA believes these programs are essential in order to have the faculty needed to train providers.**

⁴⁰ <http://www.iom.edu/Reports/2008/Retooling-for-an-Aging-America-Building-the-Health-Care-Workforce.aspx>

⁴¹ www.eldercareworkforce.org

⁴² C.A. McDonald, "Recruitment, Retention and Recognition of Frontline Workers in Long-Term Care," *Generations: Journal of the American Society on Aging* (Fall 1994), Vol. XVIII, No 3).

⁴³ Paraprofessional Healthcare Institute, *Direct-care Health Workers: The Unnecessary Crisis in Long-Term Care*. The Aspen Institute, January 2001.

Even if more students enter geriatrics training, incentivizing them to stay will require loan forgiveness options. In May, Senator Barbara Boxer (D-CA) introduced S. 1095, the “Caring for an Aging America Act” that would amend the National Health Service Corps (NHSC) requirements to permanently add geriatrics and gerontology to the eligible fields for loan forgiveness. This small change in the language governing eligibility for NHSC loans would mean that geriatrics and gerontology specialists would always be eligible for NHSC loans as opposed to the current situation in which these specialists can only participate in the program if the HHS Secretary so designates it. An additional advantage is that the loan forgiveness would be fully funded through the NHSC. **AFA supports passage of S. 1095, the Caring for an Aging America Act.**

Finally, EWA estimates that by 2030, our nation will require 3.5 million additional healthcare professionals and direct-care workers to fulfill the growing demand for care. The National Health Care Workforce Commission, established by the Affordable Care Act, will play a central role in formulating a national strategy for bolstering the healthcare workforce in order to meet the needs of the escalating number of older Americans.

Recommendation Four: Preserve Medicaid Benefits for Those in Need

Few individuals with Alzheimer’s disease or other types of dementia and their families either have sufficient long-term care insurance or can afford to pay out-of-pocket for long-term care services for as long as the services are needed. Medicaid is the only federal program that will cover the long nursing home stays that many people with dementia require in the late stages of their illness—and, according to CMS, nearly half of nursing home residents have a diagnosis of Alzheimer’s disease or other dementia. Medicaid is also a growing source of financing for home- and community-based services for people with Alzheimer’s disease, such as home health, personal care and adult day services.

A majority of people with Alzheimer’s disease rely on help from family caregivers, who provide more than \$200 billion annually in unpaid care. However, many others do not have children, spouses or others to take care of them, or these relatives are unable to provide such care. With the annual cost of caring for one individual with Alzheimer’s disease ranging from nearly \$18,500 to more than \$36,000 depending on the stage of the disease, many individuals and their families are already being forced to deplete all of their assets to pay for this type of care. Medicaid plays a critical role for people with dementia and their families who can no longer afford to pay for long-term care expenses on their own.

AFA believes that a blended rate may lead to deep reductions in Alzheimer’s disease care under Medicaid. Under a blended rate proposal, states would have to resort to such strategies as requiring higher cost-sharing from already low-income individuals. States would also be very likely to cut or eliminate specific benefits, especially for home- and community-based services—which are particularly valuable to people with Alzheimer’s disease. For instance, states may cut the number of hours a home health aide may assist a beneficiary. Reducing basic Medicaid services such as annual exams and home health services will only balloon Alzheimer’s-related Medicare and Medicaid costs in the near future for acute care needs such as broken hips, undiagnosed or untreated bed sores or diabetic ulcers, or exasperation of other co-morbidities such as diabetes, hypertension, or coronary heart disease because beneficiaries did not remember to take their medications.

We recognize that cash-strapped states are urging Congress to give them flexibility in how they manage the program. However, **AFA strongly opposes efforts to eliminate “maintenance of effort” (MOE) rules that curb enrollment limits.** Eliminating MOE will mean many people with Alzheimer’s disease would have less access to Medicaid.

In addition, cuts to Medicaid benefits would mean cuts to the eldercare workforce. With the direct-care workforce totaling more than 3 million in 2008, employment projections predict the need for an additional 1.1 million direct-care jobs by 2018.⁴⁴ Medicaid is the primary source of funding for these jobs. If Medicaid reduces payments for long-term services and supports, the workforce will shrink, thereby increasing unemployment, hurting local communities, and limiting access to the long-term services and supports that many older adults and people with disabilities need to live in dignity in their homes and communities, rather than in institutions.

The delivery of home- and community-based services is much less costly than institutional care. Forcing older adults and people with disabilities to receive care in institutions, due to cuts in home- and community-based services under Medicaid, will negate cost savings.

We recognize the financial situation our government currently finds itself in; however, any solutions to our budget deficit or long-term debt problems should not come about at the expense of low-income older adults and Americans with high-cost diseases like Alzheimer’s.

Conclusion

The Alzheimer’s Foundation of America (AFA) brings a unique, pragmatic perspective to its recommendations for a national plan. We have many struggles ahead in our effort to defeat Alzheimer’s disease, and AFA looks forward to working with the U.S. Department of Health and Human Services (HHS), other government agencies and the White House, as well as our partners and member organizations each step of the way. Public awareness will need to play a central role, as will review of existing plans both at the state and international levels. Educating the public, press and policymakers about the scope of Alzheimer’s disease and related dementias must be an integral part of any national plan.

In addition, several issues cut across all three categories of research, clinical care and long-term care, and strategies should be developed to incorporate them. With the following recommendations, it is possible for HHS to develop a comprehensive and meaningful integrated national plan to overcome Alzheimer’s disease:

Research:

- AFA urges the President to work with Congress to raise funding for the National Institutes of Health (NIH) and National Institute on Aging (NIA) based on the Biomedical Research and Development Price Index (BRDPI, also known as “birdpie”) as opposed to gross domestic product (GDP).
- AFA urges the Administration to include \$1.4 billion at a minimum—an increase of at least \$300 million—for NIA in the President’s proposed FY 2013 budget.

⁴⁴ <http://www.directcareclearinghouse.org/download/NCDCW%20Fact%20Sheet-1.pdf>

- AFA urges the Administration and Congress to fund the Cures Acceleration Network to engage the private sector and aid in speeding the translation of basic scientific discoveries into treatments for diseases such as Alzheimer's.
- AFA urges the Administration and Congress to significantly increase resources for the Food and Drug Administration.
- AFA urges HHS and NIH to balance basic research with clinical research in earlier diagnosis and prevention; better treatments; safety issues; non-pharmacological behavioral interventions; and end-of-life care.
- AFA urges HHS to support dementia care training for family caregivers of all ages and ethnic backgrounds as well as for clinicians—including primary care physicians, and direct-care employees.

Clinical Care:

- AFA urges Administration support for a public awareness campaign to drive early detection.
- AFA urges the Centers for Medicare and Medicaid Services (CMS) to include cognitive screening in the Medicare Annual Wellness Exam.
- AFA urges 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.
- 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' Innovation Center.
- AFA urges CMS and the Administration on Aging (AoA) to develop new ideas for supporting younger family members who may be helping with care, such as teens and young adults.
- AFA urges the Administration and Congress to work on multiple solutions to help family caregivers aid the ones they love, including:
 - family friendly workplace policies;
 - tax credits for individuals with substantial long-term care needs or for their family caregiver(s);
 - parity for home- and community- based care with the Medicare and Medicaid eligibility levels for nursing home care;
 - full funding for existing AoA programs that seek to reduce family caregiver burden and reduce institutionalization, including the Lifespan Respite Program, the National Family Caregiver Support Program, and the Alzheimer's Disease Supportive Services Program; and
 - Medicare and Medicaid coverage for adult day and respite services, including post-acute services and non-medical service models.

Long-Term Care:

- AFA urges CMS to implement systemwide proven pilot and demonstration programs such as Independence at Home (IAH) and other care coordination models.
- AFA urges the Health Resources and Services Administration (HRSA) to provide immediate investments in enhancing the geriatric competencies of the entire workforce, increasing the recruitment and retention of geriatric specialists and caregivers to improve the way that care for older adults is delivered.

- AFA urges the Administration to ensure that direct-care workers are able to provide the highest-quality care to all long-term care consumers by requiring employers to offer comprehensive training, certification and career advancement opportunities; livable, family-sustaining wages; affordable health insurance and other benefits; full-time hours, if desired; and balanced workloads.
- AFA urges the Administration and Congress to support full funding for Title VII Geriatrics Health Professions Programs and Title VIII Geriatrics Nursing Workforce Development Programs.
- AFA urges Congress to pass S.1095, the Caring for an Aging America Act.
- AFA urges the Administration to implement the National Health Care Workforce Commission to formulate a national strategy for bolstering the healthcare workforce in order to meet the needs of the escalating number of older Americans.
- AFA opposes efforts to eliminate “maintenance of effort” (MOE) rules that curb Medicaid enrollment limits or to promote blended rates, both of which would result in cost shifting to Medicaid beneficiaries.



Part: 2

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 recertifications 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

¹ 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.

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. 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, 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 "cooperation" 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.



“This course was developed from the public domain document: No Time to Waste: Recommendation for an Integrated National Plan to Overcome Alzheimer’s Disease (2011), The Time to Act is Now: Action Steps and Recommendations to the Draft National Plan to Address Alzheimer’s Disease (2012), Time to Build: Action Steps and Recommendations to Update the National Plan to Address Alzheimer’s disease (2012) – Alzheimer’s Foundation of America (AFA).”