



Helen Lamont, Ph.D.  
HHS Office of the Assistant Secretary for Planning and Evaluation  
Room 424E, Humphrey Building  
200 Independence Avenue, SW  
Washington DC, 20201

March 30, 2012

**Re: Alzheimer's Association comments on the Draft National Plan to Address Alzheimer's Disease**

Dear Dr. Lamont,

Thank you for the opportunity to comment on the U.S. Department of Health and Human Services (HHS) *Draft National Plan to Address Alzheimer's Disease*. The Alzheimer's Association is committed to ensuring that the full potential of the National Alzheimer's Project Act (P.L. 111-375) is realized, and we stand ready to support the successful implementation of the law. Founded in 1980, the Alzheimer's Association is the world's leading voluntary health organization in Alzheimer's care, support and research. Our mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

Today, there are an estimated 5.4 million Americans living with Alzheimer's disease and 15.2 million unpaid caregivers. Alzheimer's is the 6th leading cause of death and the only cause of death among the top 10 in America without a way to prevent, cure, or even slow its progression. Currently, there are no survivors. Alzheimer's kills more Americans than diabetes, and more than breast cancer and prostate cancer combined. Individuals with Alzheimer's and other dementias are high consumers of hospital, nursing home, and long-term care services. Average per person Medicare costs for those living with Alzheimer's and other dementias are nearly three times higher and Medicaid spending is 19 times higher than for those without these conditions. Care for those living with Alzheimer's and other dementias is estimated to cost Medicare and Medicaid \$140 billion this year alone.<sup>1</sup>

Alzheimer's cannot wait. Individuals living with this devastating disease and their families cannot wait. Strengthening the financial underpinnings of Medicare and Medicaid cannot wait. We are at a critical moment. Barring the development of medical breakthroughs to prevent or treat the disease, Alzheimer's impact on our country will grow year by year. By 2050, as many as 16 million Americans will have the disease, and the escalating cost of care will reach \$1.1 trillion annually (in today's dollars). Costs to Medicare and Medicaid are estimated to increase nearly 500 percent over this period.

However, this does not need to be our future. If the federal government makes a meaningful commitment to finding a treatment and cure through the National Alzheimer's Plan, the long-term payoff will be substantial. For example, a treatment that delayed onset of the disease by five years (similar to the effect of anti-cholesterol drugs on preventing heart disease) would cut government spending on caring for those with Alzheimer's by nearly half in 2050.<sup>2</sup> Similarly, profound advances can be achieved through improvements to Alzheimer's care quality and

---

<sup>1</sup> Except as otherwise noted, all statistics regarding Alzheimer's in this report are from: Alzheimer's Association. 2012 Alzheimer's disease facts and figures. *Alzheimer's and Dementia: The Journal of the Alzheimer's Association*. March 2012; 8:131-168. [www.alz.org/facts](http://www.alz.org/facts).

<sup>2</sup> Alzheimer's Association. Changing the Trajectory of Alzheimer's: A National Imperative. May 2010. [www.alz.org/trajectory](http://www.alz.org/trajectory)

effectiveness and through improved supports for individuals with Alzheimer's and their families. The challenge and the potential promise of the National Alzheimer's Plan is our opportunity to change the trajectory of this heartbreaking disease.

The Alzheimer's Association is pleased the important strengths contained within the Draft Framework were preserved in this initial draft of the National Alzheimer's Plan. As was the case with the Framework, this first draft is comprehensive in scope, addressing many of the issues that are critically important to the Alzheimer's community. We do see key opportunities to further strengthen this draft plan prior to its next iteration. The Association's comments address specific areas to fortify; for instance, palliative care and transportation issues, which are particularly important for the one in seven Americans with Alzheimer's who live alone.<sup>3</sup>

In addition to the specific comments that follow, the Alzheimer's Association would like to emphasize several broader themes.

**Research:**

The Alzheimer's Association strongly urges that the National Alzheimer's Plan build on the momentum of the Administration's recent, commendable action on Alzheimer's research funding by indicating in the plan the full scale and scope of research funding required to achieve the Administration's goal of preventing and effectively treating Alzheimer's disease by 2025. To this end, we believe recent work by leading Alzheimer's researchers to be available in April 2012 will provide a very solid foundation for these projections.<sup>4</sup> As we previously noted in our comments submitted for the Draft Framework, we believe that the firm deadline of 2025 is bold and transformative. While intermediary milestones are needed, the Department is to be commended for including a clear, accountable goal for the availability of urgently-needed treatment advances.

**Economic burden:**

The bipartisan, unanimously passed National Alzheimer's Project Act calls for the identification of priority actions to reduce the economic impact of Alzheimer's disease on the Medicare and Medicaid programs, as well as on American families, while improving health outcomes. In addition to the estimated \$140 billion in Medicare and Medicaid costs this year, families caring for people with this heartbreaking disease will still incur high out-of-pocket costs for care – an estimated \$33.8 billion in 2012. Given the high costs of adult day centers, assisted living facilities and nursing home care, and the duration of the disease, individuals affected by Alzheimer's will often deplete their savings and assets, and ultimately come to rely on Medicaid for assistance. Though the theme of better health outcomes is present in several places in this draft, the attention to addressing the economic burden is, in our judgment, insufficient. The distinct financial burdens of Alzheimer's disease were a pervasive theme among the more than 40,000 Americans who participated in the Alzheimer's Association public input process on the National Alzheimer's Plan last year. We urge this be directly addressed in the next draft.

**Public health:**

While we applaud the draft plan's emphasis on strengthening the Aging Network to deal with the burden of Alzheimer's disease, it does little to frame Alzheimer's as a top national public health challenge and to engage the full resources of the public health community at the federal, state and local levels. In this regard, the draft can draw from an important and encouraging trend in leading states where the public health network has been actively evaluating the burden of Alzheimer's. It also can draw from important work developed by the Centers for Disease Control and Prevention (CDC) assessing the public health dimensions of Alzheimer's. The Alzheimer's Association

---

<sup>3</sup> For a profile of the particular challenges faced by those with Alzheimer's and other dementias who live alone, see the special report in the Alzheimer's Association's *2012 Alzheimer's Disease Facts and Figures*. [www.alz.org/facts](http://www.alz.org/facts).

<sup>4</sup> Upon release, this report will be transmitted to the Department of Health and Human Services, and will also be available through the Alzheimer's Association website ([alz.org/napa](http://alz.org/napa)).

strongly believes public health surveillance and comprehensive data collection are crucial to understanding the burden of the disease and assessing ways to reduce its impact. Complementing the strong emphasis on the Aging Network by highly engaging the CDC in the National Alzheimer's Plan will ensure Alzheimer's is addressed as a public health priority.

**Accountability:**

It would be difficult to overstate just how critical we believe Strategy 5B, "Monitor Progress on the National Plan," is to securing important outcomes in the first year of the plan's implementation. We urge this monitoring be done in a timely, transparent way to ensure accountability for both the implementation of action steps and the meaningfulness of this activity.

This is important for several reasons. First, this transparency is a clear expectation of Congress as expressed in and embedded throughout the statute (P.L. 111-375). Second, this is necessary for the Advisory Council if the Council is to fulfill its obligation under the law to meaningfully report directly to Congress and to the Secretary of Health and Human Services on an annual basis. Finally, it is a fundamental expectation of the Alzheimer's community. Accountability is a precondition for the successful pursuit of all that follows throughout the plan.

**Specific Comments**

The following are specific comments on the various proposed goals and actions as outlined in the *Draft National Plan to Address Alzheimer's Disease*.

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

As previously stated, establishing a firm deadline of 2025 is bold and transformative. However, research funds must increase to the Alzheimer's research community's recommendation of \$2 billion in order to achieve this goal.

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

The Alzheimer's Association believes it is good to set and update priorities by garnering outside input. We also believe in addition to the National Institute on Aging (NIA), all Institutes and Centers of the National Institutes of Health (NIH) that are funding Alzheimer's research should be an integral part of this planning process, including the National Center for Advancing Translational Sciences (NCATS) and the National Institute of Neurological Disorders and Stroke (NINDS). We look forward to additional details as to how the priority setting activities will feed through to the peer review process so suitable funds are recommended for appropriate studies, and how the planning process will inform decision-making across the entire NIH and not just the NIA. We also look forward to a detailed research plan and timeline for activities soon following the May Summit.

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

In addition to informing the implementation of the National Alzheimer's Plan with feedback from the Alzheimer's Research Summit and the Request for Information (RFI), HHS and its federal partners should also seek input from the public and experts in the field when regularly updating the plan.

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

The Alzheimer's Association commends the National Alzheimer's Plan for addressing other dementias, in keeping with the intent of P.L. 111-375.

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

The Advisory Council meeting should be held each year at a time most relevant to informing the President's annual budget for Alzheimer's research.

***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***

The development of effective treatments that can delay, prevent and treat Alzheimer's will require a significant investment in our basic understanding of the disease. It will be critical that basic science receive sufficient funds to ensure adequate fundamental knowledge of the disease. To make this action meaningful and effective, the plan must include additional details on how this important research will be prioritized and expanded, what networks and mechanisms will be used to expedite translation of the basic science, and what level of funding will be committed in the future.

***Action 1.B.3: Increase enrollment in clinical trials and other clinical research through community, national, and international outreach***

The Alzheimer's Association strongly believes that increasing enrollment in clinical trials is critical to developing new treatments and eventually overcoming Alzheimer's disease. Groundbreaking research that could have a substantial impact on individuals with the disease now and in the future is significantly slowed by a lack of volunteers for Alzheimer's clinical trials. Recruiting and retaining trial participants is now the greatest obstacle, other than funding, to developing the next generation of Alzheimer's treatments. We believe HHS can expand registries through the promotion of existing Alzheimer's disease clinical trial matching services such as the Alzheimer's Association TrialMatch service.

The Alzheimer's Association TrialMatch is a free service that makes it easy for people with Alzheimer's, caregivers, families and physicians to locate clinical trials based on personal criteria (diagnosis, stage of disease) and location. The Alzheimer's Association TrialMatch lets interested individuals search trials quickly and easily, and narrows results to those trials where there is a reasonable chance to be accepted for enrollment, saving time for both the participant and the researcher.

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

Monitoring enrollment of racial and ethnic minorities in Alzheimer's disease studies should not be limited to the NIH. Tracking race and ethnicity should also be encouraged in the outreach recommended in Action 1.B.3. This tracking should also be done by the private sector.

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

The Association encourages greater specificity regarding the intent of this action as the norm in drug development is for clinical trials on the most promising pharmacologic interventions to be conducted by private industry. Although there is a government role in clinical development of non-proprietary interventions, we urge care be taken not to divert resources to areas already well covered by private industry at a time when research resources for Alzheimer's are stretched so thin.

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

While there have been great strides in the use of imaging and biofluids biomarkers over the last several years, to ensure this action is successful, significant research is still needed and will require a substantial investment. This action should also require assembling and maintaining a large cohort of subjects in all stages of the disease, including preclinical.

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

Collaborations must include multi-disciplinary partners, including experts in clinical care, epidemiology, and public health. The Food and Drug Administration (FDA) should be an active participant in these collaborations.

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

The research ontology is an important classification system that provides a framework for collective portfolio analysis and introduces opportunities for coordinated strategic planning and initiatives among partner organizations and research funders. The Association was pleased to work with the NIA on this important project and is looking forward to the possibilities of having a global view of what Alzheimer's research is being conducted.

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

As a global leader in Alzheimer's research, the Alzheimer's Association operates in a spirit of inclusiveness, seeking partnerships throughout the scientific community to propel the field of Alzheimer's research forward. In addition to connecting with the countries listed in the Action, connecting with established international organizations, such as Alzheimer's Disease International (ADI), would be valuable. We look forward to additional details on how the information gathered from this meeting will be turned into additional action plans and new research partnerships.

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

This Action should also include a review of regulatory science needs, biomarker qualification, clinical trial infrastructure barriers, new or adaptive clinical trial design and guidance on designing/approving prevention or disease-modifying trials. In addition to NIH, FDA and the Office of the Assistant Secretary for Planning and Evaluation (ASPE), the consultation list should include private and non-profit funders of Alzheimer's research as well as the Department of Defense (DoD). A well-defined timeline for meetings and an action plan for this group should be established to ensure accountability and progress.

***Action 1.E.2: Leverage public and private collaborations to facilitate dissemination, translation, and implementation of research findings***

The Alzheimer's Association encourages the Secretary of HHS, the Secretary of Veteran Affairs, and the Secretary of Defense to work together to reduce barriers to working with private entities on agreed upon national strategic goals in Alzheimer's research. The federal government must increase its engagement with the private sector to move science forward as quickly as possible. Public-private partnerships present a key opportunity to leverage both public and private resources in this scarce fiscal environment. Government funders of Alzheimer's science should make available contracts, grants, or cooperative agreements to facilitate new and innovative partnerships between public and private entities. This may include private or public research institutions, institutions of higher education, medical centers, biotechnology companies, pharmaceutical companies, disease advocacy organizations, patient advocacy organizations, or academic research institutions.

We believe that effectively achieving this strategy requires a single, dedicated office to oversee and manage this coordination, particularly internationally. This office could also be charged with coordinating all Alzheimer's-related efforts across the federal government, including care and support, thereby fulfilling the charge of the National Alzheimer's Project Act (P.L. 111-375) to ensure "coordination of Alzheimer's research and services across all Federal agencies."

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

The CDC's Healthy Aging Program, specifically the Healthy Brain Initiative (HBI), is an important example of their role in educating the public about the latest research findings connected to Alzheimer's disease.

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

The Alzheimer's Association appreciates the Administration's announcement that \$6 million will be dedicated over two years for provider education and outreach. While the \$6 million is a great first step, we urge the Administration to dedicate additional funds for this endeavor to be successful.

To begin work under this area, the Association recommends targeted outreach to various provider groups. We believe HHS should promote an understanding of dementia among health care providers through a variety of mechanisms including the development of guidelines and quality measures. Once these guidelines are created, the development of online training modules would be most efficient. Additionally, it is important to develop Alzheimer's disease-specific quality measures so care can be evaluated. Assisted living facilities should be added to the list of settings where high-quality care should be provided.

***Action 2.A.1: Educate Healthcare Providers***

The Alzheimer's Association strongly supports a robust and well-educated workforce as an essential component to providing high-quality care to those with Alzheimer's disease. An adequate number of health care providers who are properly trained to understand the complexities of dementia will help ensure individuals with Alzheimer's disease have access to coordinated, quality care and ultimately drive us toward a dementia-capable health care system.

While the Association applauds the efforts outlined in the plan, we are concerned that the education component within this strategy may be limited. Many individuals with Alzheimer's disease enter the health care system through their primary care provider. To reach this target population, we encourage the Centers for Medicare and Medicaid Services (CMS) to play a major role in educational outreach, particularly to the Medicare provider community. CMS should issue guidance to providers outlining information that should be discussed with individuals and their caregivers after a diagnosis such as managing dementia with other chronic illnesses and referrals to existing community supports and services. CMS could partner with relevant stakeholders, such as the Alzheimer's Association, to develop resources to share with providers. Providers' education should also include guidance on the appropriateness and benefits of palliative and end-of-life care services, such as hospice, for individuals with Alzheimer's disease. This effort should include how and when providers should discuss the issue with the individual and their representative.

We also encourage the plan to address educating physicians and other health care providers on the value of an early diagnosis. Too often providers do not see or understand the value of an early diagnosis and therefore fail to diagnose and/or document Alzheimer's disease. Even among willing providers, a lack of training on the use of assessment tools and methods to encourage follow-up often delays detection of cognitive impairment and diagnostic evaluations.

It should also be noted that state and local public health departments should be included in this action item. The public health community is very good at educating health care providers. There are a number of evidence-based interventions for educating providers in a variety of settings that can be applied to Alzheimer's disease. We encourage HHS to support the necessary infrastructure to help state and local departments offer this type of education in public health settings.

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

Funding and incentives for individuals interested in pursuing careers in geriatric specialties, particularly those that care for people with dementia, should be expanded.

***Action 2.A.3: Collect and disseminate dementia-specific guidelines and curricula for all provider groups across the care spectrum***

We believe this strategy is vitally important, particularly with regard to the development of quality indicators. HHS should promote existing evidence-based guidelines and curricula. Where unavailable, HHS should work with relevant stakeholders who have developed evidence-based quality care guidelines, such as the *Alzheimer's Association's Dementia Care Practice Recommendations*, which incorporate the latest research and field evidence. Once appropriate quality indicators are identified and validated, efforts should be undertaken to integrate them into the health care system.

In addition, the Alzheimer's Association urges HHS to ensure that content within the proposed clearinghouse is current and easily accessible.

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

Section 6121 of the Affordable Care Act (ACA) requires that all certified nursing aides (CNAs) that work in nursing homes receive training on care for persons with dementia. As implementation of this provision progresses, the Association urges CMS to include a mechanism that ensures any recommended education materials are fully understood and absorbed. Further, CMS should publically establish the survey guidelines that will accompany this new requirement to ensure CNAs are appropriately trained.

The Association would like to see the plan also recommend that all direct care workers, including those in assisted living facilities and home- and community-based settings, be required to meet a similar standard.

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

HHS should coordinate with states to develop Alzheimer's disease coordinators and workforces in state and local public health departments that will develop and implement Alzheimer's disease strategies. Strategies may include early detection and diagnosis campaigns, provider education campaigns, surveillance work, implementation of state Alzheimer's disease plans, and other essential public health services. HHS should also work with Aging Network staff to recognize the warning signs of dementia and be trained to assist individuals and their families when they seek appropriate medical care for detection and diagnosis.

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

To continue connecting families and people with symptoms of Alzheimer's disease to Alzheimer's-capable resources and meet growing demand, the Administration on Aging's (AoA) National Alzheimer's Call Center will require additional funding. The National Alzheimer's Call Center provides 24-hour, 7 day a week, year-round telephone support, crisis counseling, care consultation, and information and referral services in 140 languages for persons with Alzheimer's disease, their family members and informal caregivers. Trained professional staff and master's-level mental health professionals are available at all times. Since 2003, the National Alzheimer's Call Center has served more than 2 million people in the community. Additionally, it is important to note that the Alzheimer's Disease Centers, funded by NIA, are only available to certain areas of the country. As such, we urge HHS to include a solution in the final plan to ensure areas without resources have access to assistance, such as the Call Center.

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

To diagnose an individual with Alzheimer's disease, cognitive impairment must first be detected in a clinical setting. As discussed, the ACA created the Medicare Annual Wellness Visit (AWV) which includes the detection of cognitive impairment. To enhance the AWV, the Association believes the CDC should revise the model Health Risk Assessment (HRA), which is part of the AWV, to include questions about memory and other indicators of cognitive impairment.

We also recommend including a strategy on enhancing detection in a clinical setting in addition to the Medicare Annual Wellness Visit. While the draft plan refers to some of the issues involved in detecting cognitive impairment – namely, assessment tools – we believe it is important to emphasize detection of cognitive impairment as the precursor to a comprehensive diagnostic evaluation for Alzheimer’s disease.

***Action 2.C.1: Educate physicians and other healthcare providers about accessing long-term services and supports***  
***and***

***Action 2.C.2: Enhance assistance for people with AD and their caregivers to prepare for care needs***

The Alzheimer’s Association strongly believes health care providers should be educated about available supports for newly-diagnosed individuals and their caregivers to provide better counsel through this difficult disease. This should include information medical and non-medical supports and services. Further, the Association believes Medicare should cover a visit in which a health care provider discusses current and future care planning, with the caregiver, with or without the beneficiary present, to ensure families receive vital information to navigate this difficult disease. The Alzheimer’s Association stands ready and willing to partner with HHS to develop a list of appropriate resources to share with the provider community. In fact, our chapters are currently conducting outreach on the local level to make providers aware of the available supports in their own community.

As stated in the Association’s *2012 Alzheimer’s Disease Facts and Figures*, at least 800,000 individuals with Alzheimer’s disease live alone and as many as half do not have an identifiable caregiver. We strongly encourage HHS to further develop assistance for this particularly vulnerable population.

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

While developing dementia care guidelines and measures, it is important to develop Alzheimer’s disease-specific quality measures so that care can be evaluated. In addition, the guidelines should include criteria and provisions for quality palliative and end-of-life care, including hospice care.

We would encourage HHS to build on existing quality initiatives, such as the Alzheimer’s Association’s *Campaign for Quality Residential Care*, which takes a person-centered approach and covers the basics of good care in six areas. The Association supports the development of additional quality measures and evidence-based care guidelines, and can serve as a resource in this effort.

***Action 2.E.1: Evaluate the effectiveness of medical home models for people with AD***

While the medical home model holds promise, these models of care would need to be flexible to accommodate the specific needs of individuals with Alzheimer’s disease, as they may require additional time and services to be effective for the Alzheimer’s community. Moreover, it is recommended that care coordination designed specifically for Alzheimer’s disease be highlighted for evaluation.

Furthermore, models should focus on aspects that seem to be particularly beneficial for individuals with Alzheimer’s disease, including face-to-face meetings with care coordinators and care coordinators located in primary care provider offices. Due to the nature of Alzheimer’s disease, coaches and telephone disease management may not be particularly effective for this population.

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

Acute care settings should implement Alzheimer’s disease training for all health care practitioners to facilitate greater safety for people with the disease.

While it is critical to identify and disseminate models of hospital safety for people with Alzheimer's disease, there should be similar action on identifying and disseminating models of safety to be used by nursing homes, assisted living facilities and other residential care settings. Additionally, there should be similar action on this for emergency personnel and first responders.

***Action 2.F.2: Implement and evaluate new care models to support effective care transitions for people with Alzheimer's disease***

Most notably absent from the discussion of improving care transitions is the importance of making a documented diagnosis in an individual's medical record. Further, an individual should have a list of relevant medications documented in their medical record, especially prior to any care transition. The use of electronic medical records may also facilitate the availability of this information and should be explored particularly in the context of safer care transitions for patients with dementia.

Some individuals have behavioral problems related to Alzheimer's disease. Therefore, appropriate community mental health services should be developed to include systems that strengthen the care needs of individuals with behavioral disturbances.

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

As mentioned in Action 2.E.1, the focus of these models should include aspects of the models are particularly beneficial for individuals with Alzheimer's disease, including face-to-face meetings with care coordinators and care coordinators located in primary care provider offices.

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

Individuals with Alzheimer's disease who are dually eligible for Medicare and Medicaid are likely to use more health care services and have less desirable outcomes without quality care coordination. For example, people with serious medical conditions and Alzheimer's or another dementia are more likely to be hospitalized than those with the same medical conditions but no Alzheimer's or dementia.

Initially, the evaluation of these integrated models of care should be weighted towards effective care coordination, rather than cost-savings, since individuals may have increased access to services that didn't have before. This is especially important when considering cost increases, which may occur in Medicaid services since individuals with Alzheimer's may not have had previous access to long-term care services and supports due to long waiting lists and state fiscal constraints.

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

The National Alzheimer's Plan must identify specific action steps to be undertaken to improve the care of those disproportionately affected by Alzheimer's disease. We appreciate the acknowledgement that people with younger-onset Alzheimer's disease, racial and ethnic minorities, and people with intellectual disabilities are disproportionately burdened by Alzheimer's and related dementias.

***Goal 3: Expand Patient and Family Support***

The National Alzheimer's Plan provides a unique and important opportunity to widely deploy effective, evidenced-based strategies to help family caregivers. Often, financial barriers prevent families from accessing the support they need to provide care for their loved one. Although there are a number of strategies and actions to address support for individuals with Alzheimer's disease and their families, the plan does not clearly address additional funding for respite care – whether it be in day centers or within the home.

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

As HHS considers which agencies, federal departments, and state and local networks to distribute materials, it should also consider including the CDC's Healthy Aging Program.

***Action 3.B.5: Provide effective caregiver interventions through AD-capable systems***

In addition to developing more services, the Alzheimer's Association believes existing services to support caregivers should be promoted, supported, and expanded. Furthermore, while this action mentions respite care, it does so only in terms of providing referrals and does not include increased funding so that families can access such services.

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

HHS should look for ways to promote the National Alzheimer's Call Center and its services as a crisis resource for caregivers.

***Action 3.C.1: Examine awareness of long-term care needs and barriers to planning for these needs and******Action 3.C.2: Expand long-term care awareness efforts***

We encourage the plan to consider addressing all aspects of long-term care, including financial planning, driving, and safety issues. Increasing the awareness of future care planning could help individuals and their families address challenges earlier and help avoid crises later.

We would encourage HHS to examine the barriers to long-term care, which may include studying the availability and impact of long-term care insurance as people with Alzheimer's disease, particularly those with younger-onset, may face unique challenges when trying to purchase insurance.

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

The education of legal professionals should be expanded to include other entities in the legal system, including law enforcement, first responders, prosecutors, and judges.

Broader awareness of Alzheimer's disease may help prevent or reduce arrests of individuals with Alzheimer's who are charged with crimes for which they have no intent, such as unintentional trespassing. Further, it may help legal professionals and first responders to spot abuse – physical and non-physical – against people with the disease. In addition, State Adult Protective Service (APS) agencies are overburdened and understaffed, resulting in a limited ability to provide any support except in the most dire of circumstances. We encourage the plan to address the need for additional resources dedicated to protecting the safety and rights of individuals with Alzheimer's.

Finally, the plan must acknowledge the large number of individuals with Alzheimer's who live alone – many of whom do not even have an identifiable caregiver. In maintaining the dignity, safety, and rights of those with the disease, special attention must be given to this population. We hope that the plan considers guidance for legal professionals seeking to balance autonomy and individual safety.

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

Individuals living with dementia may experience behavioral and psychotic symptoms (BPSD) during the course of their disease due to the alterations in processing, integrating and retrieving new information that accompanies dementia. Non-pharmacologic approaches should be tried as a first-line alternative to pharmacologic therapy for the treatment of BPSD. The Association recommends training and education for both professional and family caregivers on psychosocial interventions. Further, we recommend the plan call for similar monitoring and reporting in assisted living facilities.

**Action 3.E.1: Explore affordable housing models**

At least 800,000 Americans with Alzheimer's disease live alone. Compared to those with Alzheimer's who live with someone else, on average, people with Alzheimer's who live alone are more likely to live in poverty and require assistance performing tasks such as managing money, shopping, traveling, housekeeping, preparing meals and taking medications correctly. We encourage HHS to explore affordable housing models that will allow this unique population to live safely within their communities.

**Goal 4: Enhance Public Awareness and Engagement****Action 4.A.1: Design and conduct a national education and outreach initiative**

The public awareness campaign in Action 4.A.1 must be culturally-sensitive and reach those in underserved locations.

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

Obtaining a more definitive picture of Alzheimer's, cognitive impairment, and related caregiving burdens is essential to any successful strategy to combat the disease. Public health surveillance and comprehensive data collection will not only assist the federal government in addressing policy questions and planning new initiatives, they will provide the research, caregiving, and public health communities a better understanding of people with cognitive impairment and Alzheimer's, and identify opportunities for reducing the impact of the disease at all levels of government.

At a minimum, this should include state-by-state public health surveillance on cognitive impairment and caregiver burden, preferably through the Behavioral Risk Factor Surveillance System (BRFSS), coordinated by the CDC. Moreover, this strategy should also include improving existing federal surveys such as the Medical Expenditure Panel Survey and the National Health Interview Survey so that they can adequately capture information about those with Alzheimer's and other dementias.

**Action 5.A.1: Identify major policy research needs  
and****Action 5.A.2: Identify needed changes or additions to data**

The CDC has been a leader in incorporating measures of cognitive health into other population health monitoring efforts. The CDC Healthy Aging Program has worked on identifying databases, worked with partners to add questions on cognitive impairment and caregiving to the BRFSS and added questions on cognitive impairment to the National Health and Nutrition Examination Survey (NHANES) The CDC is currently analyzing data from these datasets as they become available. In particular, BRFSS data are unique and allow for state- and local-level data that can highlight the needs of diverse populations in the United States.

The CDC Healthy Aging Program developed a 10-question BRFSS module on Perceived Cognitive Impairment. Twenty-two states included the module on their state BRFSS in 2011 and an additional 16 states are including the module in 2012 for a total of 38 states, including the District of Columbia. The CDC Healthy Aging Program is working with partners, including states, to expand the module in 2013 to all 50 states. They are also producing reports and publications regarding these data to inform decision-makers about the perceived impact of cognitive impairment at the state and local levels.

**Action 5.A.3: Make needed improvements to data**

Using data to improve and track progress is essential and we commend its inclusion in the draft plan. This critical information should be publically available, as well as to the Advisory Council. In monitoring progress, it would be useful to have de-identified data that corresponds to the disease stage (preclinical through end-of-life) to identify areas for improvement in care and services.

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

The Alzheimer's Association commends the intent to designate responsibility for each action step. However, we urge designation of individual accountable for each action, rather than simply a "contact person."

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

Tracking on plan progress as described in this action step should be provided to the public on no less than a quarterly basis. In general, we urge that the reporting on progress regarding each action be paired with greater clarity and specificity regarding desired outcomes than has been provided in the draft plan.

***Action 5.B.3: Update the National Plan annually***

The Alzheimer's Association urges that updates to the plan be done with the same transparency and opportunities for comment that has characterized the formulation of this initial National Alzheimer's Plan.

**Conclusion:**

The National Alzheimer's Plan should allow us, for the first time to answer this simple question: *Did we make satisfactory progress in the fight against Alzheimer's disease?* For too many individuals living with Alzheimer's and their families, the system has failed them, and today we are unnecessarily losing the battle against this devastating disease. A successful National Alzheimer's Plan offers us the opportunity to change that, and set a new trajectory for this rapidly expanding global epidemic through American leadership.

As we all know, a plan accomplishes nothing without thorough and effective implementation that is coupled with transparency and accountability for those actions. The Alzheimer's Association looks forward to a final National Alzheimer's Plan that is urgent, transformational, achievable and accountable. The recommendations listed above, **combined with the recommendations of the Advisory Council subcommittees**, will help to build the strongest possible National Alzheimer's Plan to overcome the escalating burden of Alzheimer's disease on American families.

We sincerely appreciate this opportunity to comment on the *Draft National Plan to Address Alzheimer's Disease*. If you wish to discuss any of these issues further, please feel free to contact Rachel Conant, Alzheimer's Association Director of Federal Affairs at [rachel.conant@alz.org](mailto:rachel.conant@alz.org) or 202.638.7121.

Sincerely,



Robert Egge  
Vice President, Public Policy