



AMERICAN  
PSYCHOLOGICAL  
ASSOCIATION

March 28, 2012

Helen Lamont, Ph.D.  
Office of the Assistant Secretary for Planning and Evaluation  
Room 424E, Humphrey Building  
U.S. Department of Health and Human Services  
200 Independence Avenue, S.W.  
Washington, DC 20201

Dear Dr. Lamont:

On behalf of the American Psychological Association (APA), I would like to commend the Department of Health and Human Services, the Advisory Council on Alzheimer's Research, Care, and Services, and the Interagency Group on Alzheimer's Research, Care, and Services for your efforts to develop and refine the National Plan to Address Alzheimer's Disease.

Enclosed are our APA comments in response to the draft plan released on February 22, 2012. APA is a scientific and professional organization representing psychology in the United States, with 154,000 members and affiliates. APA's mission is to advance the creation, communication, and application of psychological knowledge to benefit society and improve people's lives.

APA is eager to collaborate with the Advisory Council, federal agencies, and other organizations in the continued planning and implementation of the National Plan. We will continue to promote the involvement of our members in this important effort and stand ready to recommend psychologists (including researchers, clinicians, and educators) with expertise in a wide array of areas that are critical to the plan's success. These areas include: cognitive aging; neuropsychological and capacity assessment; evidence-based interventions for individuals with Alzheimer's disease and their caregivers; implementation research, public education and social marketing; palliative care; designing culturally appropriate programs and materials; health provider education and training; integrated health and care coordination models; and dementia guideline development.

Please direct any questions, comments, or concerns to Deborah DiGilio, MPH, Director of APA's Office on Aging. She can be reached at (202) 336-6135 or [ddigilio@apa.org](mailto:ddigilio@apa.org).

Sincerely,

A handwritten signature in cursive script that reads "L. Michael Honaker".

L. Michael Honaker, Ph.D.  
Deputy Chief Executive Officer

Enclosure

## American Psychological Association Comments on Draft National Plan

The American Psychological Association (APA) appreciates that the Draft National Plan is responsive to some of the concerns that we raised in January. In particular, we are pleased to see greater attention to clinical trials to test lifestyle interventions, including exercise and cognitive training. These interventions show promise as ways to improve cognitive health, and may in time be shown to prevent or slow the progression of Alzheimer's disease (AD). The second draft's emphasis on recruiting diverse participants to clinical trials is also important.

The ability to image biomarkers has significantly advanced the study of Alzheimer's. What continues to be missing in the current draft is an acknowledgement of the critical role of neuropsychological testing and assessment to measure changes in cognitive performance. Real clinical benefits for those with AD depend on fully understanding how biomarkers relate to cognition and behavior. It is fundamentally important to understand why people with similar amounts of beta amyloid may have very different cognitive profiles. The National Institute on Aging and its funding partners are urged to support additional research that links the presence of biomarkers with changes in cognition and functional behavior.

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

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

APA supports the convening of a summit to help set research priorities to reach the goals articulated in the National Plan, and the additional strategies to receive broad input and refine and update research goals and priorities as the Plan is put into effect. APA also supports the convening of a workshop on non-Alzheimer's dementias, and offers assistance for this project.

***In order to clarify the types of research being discussed, APA suggests the following wording changes - with underlined text to be added and struck-through text to be deleted:***

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

"HHS and its federal partners will expand clinical trials on pharmacologic and ~~non-pharmacologic~~ behavioral ways to prevent Alzheimer's disease and manage and treat its symptoms."

**Rationale:** APA prefers that behavioral studies be given their own name, and that they not be defined only by whether they include a pharmaceutical.

"Action 1.B.1: Expand research to identify the molecular, cellular, and cognitive mechanisms underlying Alzheimer's disease, and translate this information into potential targets for intervention. "

**Rationale:** Certainly molecular and cellular work is vitally important. However, an 'integrated interdisciplinary basic science agenda' for Alzheimer's must also include basic cognitive and behavioral research.

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

“Identifying and linking imaging biomarkers and behavioral/cognitive markers 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.”

**Rationale:** Biomarker research is tremendously important, but it is neuropsychological and cognitive measures that enable scientists to link biomarkers to observable clinical symptoms. Biomarker research advances are leading to the ability to diagnose and track AD, but findings cannot be considered complete in the absence of behavioral data. Therefore, the two areas of research should be linked in the plan’s language.

Current research demonstrates that neuropsychological measures function well as diagnostic, prognostic, and disease progression indicators (Blacker et al., 2007; Gomar et al., 2011; Jacobs et al., 1995; Tabert et al., 2006). Cognitive measures are critical in the practical and operational (not theoretical) level within all three recognized stages of AD — pre-clinical, mild cognitive impairment (MCI), and AD dementia — in recently updated diagnostic guidelines by the NIA-Alzheimer’s Association. Therefore, cognitive measures hold the promise of identifying people at the highest risk of developing AD up to 20 years or more before the disease is diagnosed, and are the best measures of potential impact of interventions on disease progression. Particularly as treatments are worked into preclinical phases of AD, improvements in the sensitivity of the cognitive measures to reliable change over time is critically important.

Recent studies in 2010 and 2011, many using ADNI data, have shown that neuropsychological measures are more accurate, earlier predictors of progression to AD when compared to MRI, FDG-PET, and amyloid imaging (Gomar et al., 2011). There is considerable promise in broadening and improving the measurement of cognitive markers of AD. Every piece of the expansion and improvement of AD research will require good (and better) cognitive assessments.

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

*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, neuropsychologists, 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.~~ social workers, psychologists, dentists, pharmacists, counselors, and allied health professionals.”

**Rationale:** We believe it is important as this plan will direct future efforts and funding in this area, that all geriatric disciplines be explicitly mentioned. Psychologists, social workers, and other health care providers play an integral role in VA interdisciplinary teams to meet the needs of individuals with dementia and their caregivers. Accordingly, they are included in the ACA expanded training provisions, and are listed on the BHPR website.

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

“The Affordable Care Act created the Medicare Annual Wellness Visit. ‘Detection of any cognitive impairment’ must be included as part of the wellness visit. HHS is using research findings to identify the most appropriate assessment tools that can be used in a variety of outpatient clinical settings to assess cognition. The recommended tools will be distributed to practitioners to aid in identification and evaluation of cognitive impairment and risk for dementia,” and to determine the need for referral for a comprehensive neuropsychological evaluation.

**Rationale:** Neuropsychological evaluation remains a critical component of differential diagnostic methods in discriminating neurodegenerative changes from normal age-related cognitive decline, cognitive difficulties that are related to psychiatric conditions or medical morbidities, and other related disorders. Neuropsychological measures are accurate, early predictors of progression to AD and provide useful information to individuals with dementia and their families regarding the functional capacities of the individual and potential impact of interventions on disease progression.

**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 the prevention, diagnosis, disease management, and treatment.” In addition, there is a lack of public understanding of the differences between normal age-related cognitive change and pathological change.

These misperceptions can lead both to delayed diagnosis when family members falsely attribute behavioral and memory issues to normal aging and to faulty diagnosis and harmful avoidance behaviors when families become paralyzed with concern about the stigma and decline associated with Alzheimer’s disease. Both misconceptions can prevent families from obtaining needed and appropriate supports. They can also lead to inaction in adopting health promoting behaviors such as physical activity, maintaining a healthy weight, and refraining from smoking, which may prevent or slow any disease process. “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.”

**Rationale:** Two top tier messages of this campaign should be: 1) AD is not a normal part of cognitive aging; and 2) there are modifiable risk factors for AD (including diabetes, midlife hypertension, midlife obesity, smoking, depression, cognitive inactivity or low educational attainment, and physical inactivity) AND actions individuals can take now to reduce their risks. A recent study (Barnes et al, 2011), notes that up to half of AD cases worldwide are attributable to seven potentially modifiable risk factors — and that a 10—25% reduction in all seven risk factors could potentially prevent as many as 1.1—3.0 million AD cases worldwide.

#### 4.A: Educate the public about normal cognitive aging and Alzheimer's disease

"Greater public awareness of normal cognitive aging and Alzheimer's disease can encourage individuals and families to participate in cognitive health promoting behaviors and seek assessment, reduce isolation and misunderstanding felt by caregivers, and help link people in need to accurate information, resources and services," when needed.

#### References

- Barnes, D.E., & Yaffe, K. (2011). The projected effect of risk factor reduction on Alzheimer's disease prevalence. *Lancet Neurology*, *10*, 819-828.
- Blacker, D., Lee, H., Muzikansky, A., Martin E., Tanzi, R., McArdle, J., Moss, M., & Albert, M. (2007). Neuropsychological measures in normal individuals that predict subsequent cognitive decline. *Archives of Neurology*, *64*, 862-871.
- Gomar J. J., Bobes-Bascaran, M. T., Conejero-Goldberg, C., Davies, P., & Goldberg, T. E. & Alzheimer's Disease Neuroimaging Initiative (2011). Utility of combinations of biomarkers, cognitive markers, and risk factors to predict conversion from mild cognitive impairment to Alzheimer disease in patients in the Alzheimer's disease neuroimaging initiative. *Archives of General Psychiatry*, *68*, 961-969.
- Jacobs, D.M., Sano, M., Dooneief, G., Marder, K., Bell, K. L., & Stern Y. (1995) Neuropsychological detection and characterization of preclinical Alzheimer's disease. *Neurology*, *45*, 957-962.
- Tabert, M.H., Manly, J.J., Liu, X., Pelton, G. H., Rosenblum, S., Jacobs, M., Zamora, D., Goodkind, M., Bell, K., Stern, Y., & Devanand, D. P. (2006). Neuropsychological prediction of conversion to Alzheimer's disease in patients with mild cognitive impairment. *Archives of General Psychiatry*, *63*, 916-922.