NATIONAL ACADEMY OF NEUROPSYCHOLOGY

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HHS Office of the Assistant Secretary for Planning and Evaluation (ASPE)
Room 424E, Humphrey Building
200 Independence Avenue, SW
Washington DC, 20201

Re: Draft HHS National Plan to Address Alzheimer Disease
Comments from the Professional Affairs & Information Committee
National Academy of Neuropsychology

Dear HHS:

We are writing on behalf of the National Academy of Neuropsychology (NAN). NAN is a professional association with 3,500 members dedicated to the advancement of neuropsychology as a science and health profession. The majority of our members provide direct care to individuals who suffer from neurodegenerative diseases such as Alzheimer's disease, neurodevelopmental disorders, and many other neurological disorders. Our members work in many medical settings, interface closely with other medical and mental health specialties, and receive referrals from neurologists, physiatrists, neurosurgeons, oncologists, radiologists, family physicians, pediatricians, and many other healthcare professionals. We have expertise in the evaluation of normal and abnormal brain functioning, and our assessments are utilized in complementary fashion to neuroimaging and other neurodiagnostic activities. In addition to our work as diagnosticians, clinical neuropsychologists are actively involved in the research, diagnosis, and treatment/management of persons suffering Alzheimer's dementia and in supporting their caregivers (including educating and counseling loved ones, and consulting with staff in assisted living and long term care facilities).

NAN applauds your efforts to aggressively address Alzheimer's Disease (AD), and we offer our support and services as researchers and clinicians in this process. We have reviewed the HHS National Plan to Address Alzheimer Disease and have the following comments that we hope will help facilitate your efforts in this regard.

Comments/Suggestions:

General: The language of the document is almost entirely directed toward physicians. Clinical neuropsychology offers its services as researchers and clinicians to the cause of addressing the burden of AD on patients and caregivers.

Strategy 1.C: Stresses the importance of the use of biological markers in the diagnosis of AD.

Please consider adding sensitive neuropsychological measures to this section in support of the biological measures. While the National Institute on Aging-Alzheimer's Association workgroup on diagnostic guidelines for Alzheimer's disease has recommended continued research on biological markers, they continue to consider AD to be a clinical diagnosis based on neurocognitive and functional data.[1,2]

[1]McKhann, G.M., Knopman, D.S., Chertkow, H, et al. The diagnosis of dementia due to Alzheimer's disease: recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimer's Dementia*, 2011; 7(3):263-269. (From the abstract: "The core clinical criteria for AD dementia will continue to be the cornerstone of the diagnosis in clinical practice, but biomarker evidence is expected to enhance the pathophysiological specificity of the diagnosis of AD dementia.")

[2]Jack, C.R. Jr, Albert, M.S., Knopman, D.S., et al. Introduction to the recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. Alzheimer's Dement. 2011 (May);7(3):257-262. Epub 2011 Apr 21. (From the Biomarkers of AD section of the pre-print e-published article: "Progression of clinical symptoms closely parallels progressive worsening of neurodegenerative biomarkers," and "In the *symptomatic predementia, MCI, phase* biomarkers are used to establish the underlying etiology responsible for the clinical deficit." Both of these statements, and others in the article, emphasize the importance and effectiveness of neuropsychological/neurocognitive measures in the identification and tracking of clinical symptoms of AD.)

Neuropsychologists have developed very sensitive neurocognitive test measures that can be used along with biological measures to help characterize early, subtle symptoms of AD, which can then be used to stage neurocognitive decline and/or the effectiveness of experimental biological and/or behavioral interventions for AD. The above citations support the conclusion that neurocognitive assessment is the most effective means of measuring disease progression and functional status.

Goal 2, Strategy 2.A, & Strategy 2.D: Mentions healthcare providers except neuropsychologists and psychologists.

Please consider mentioning neuropsychologists along with other care providers. Neuropsychologists provide a high quality of care and service to patients with dementing conditions and to their families and other caregivers.

Strategy 2.B: States "Research has helped identify some assessment tools that can be used to rapidly assess patients showing signs and symptoms of Alzheimer's disease...(citation #5)."

Citation #5 (Jack et al., 2011, above) does not mention specific assessment tools, but assessment of cognition and function are hallmarks of the practice of neuropsychology. Please consider mentioning that neuropsychologists can be useful in the administration and interpretation of cognitive and functional assessment measures, and assisting in the accurate diagnosis of AD.

In general, the cognitive screening tests used in the medical context lack sensitivity to early cognitive decline[3], and this is further complicated by when assessing premorbidly intellectually bright or well-educated patients as well as other factors. Neuropsychological assessment, using standardized and demographically normed tests of cognition, is known to be more sensitive to early cognitive decline.[4]

[3]Stephan, B. C., Kurth, T., Matthews, F. E., Brayne, C., & Dufouil, C. (2010). Dementia risk prediction in the population: are screening models accurate? *Nat Rev Neurol, 6,* 318-26.

[4]Smith, G. E., Ivnik, R. J., & Lucas, J. A. (2008). Assessment techniques: Tests, test batteries, norms, and methodological approaches. In: *Textbook of Clinical Neuropsychology*. J Morgan and J Ricker (Eds.). New York: Taylor & Francis.

Strategy 2.C: "...even though a physician has identified cognitive impairment..."
Please consider including neuropsychologists as one source of identification of cognitive impairment (this is our specialty and physicians and other providers and care givers routinely refer to us for diagnosis).

Strategies 3:A,B,C: The language is neutral regarding professionals.
Goal 4: "Health care providers..."

Many neuropsychologists, as well as social workers, nurses, etc., provide care to dementia sufferers and their caregivers (e.g., families, long term care facilities), and it may be helpful to mention this in these sections and in other relevant areas in the draft.

Strategy 5.B: "The National Plan is intended to be a roadmap for accomplishing its five goals. It is a document that is designed to be updated regularly. HHS is committed to tracking progress and incorporating findings into an updated National Plan annually."

The National Academy of Neuropsychology would be pleased to be involved in this annual review process.

Thank you for your time in reviewing our comments. Please let us know if you have any questions or concerns.

Respectfully,

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