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Editorial

Prospects for designating Alzheimer's disease research a national priority

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Abstract This editorial evaluates the prospects of the National Alzheimer's Project Act (NAPA) succeeding to shape public policies that would substantially increase national expenditures for research on Alzheimer's disease. The essay identifies, in the context of 30-year history, some of the difficult challenges the NAPA Advisory Council must address and offers specific recommendations for an action plan by the Secretary, Department of Health and Human Services (DHHS).

Keywords: Alzheimer's disease; Research; Funding; Public policies; Strategic plan; Congress; Legislation; National Alzheimer's Project Act; PAD2020; Alzheimer's Association; Prevention; Treatment

1. Introduction

The aim of this perspective paper is to assess the potential impact of the National Alzheimer's Project Act (NAPA) on a *national strategic plan* for mobilizing research resources to alter the course of an impending public health catastrophe. The critical issue confronting us is whether this endeavor will at last deliver the "Promised Land of Milk & Honey" to the research community or become yet another "Bridge to Nowhere." We evaluate NAPA in the context of a 30-year effort to designate Alzheimer's research a national priority, asking what NAPA offers or pledges to the research community that will enable it to achieve this goal where past attempts have failed (Table 1). This essay will analyze the thorny scientific, administrative, and financial challenges that NAPA's Advisory Council on Alzheimer's Research, Care, and Services must address to bring about radical changes in current research paradigms aimed at preventing or slowing the progression of the disease.

The legislative mandate of NAPA covers a broad array of issues related to research, care, and services. This article, however, will focus on questions regarding public policy options and recommendations for significant expansion of national research capabilities.

In 2007, the Alzheimer's Study Group (ASG) was launched with support from the Alzheimer's Association (AA) and the leaders of the Congressional Task Force on Alzheimer's Disease. In 2009, the ASG, led by former Speaker of the House of Representatives Newt Gingrich and former Senator Bob Kerrey, published a report calling for the creation of a National Alzheimer's Strategic Plan by 2010; thus, the idea of a National Alzheimer's Project was born. Since then, the AA became one of the strongest supporters of the national strategic planning effort to address Alzheimer's disease (AD). The Association, along with other key stakeholders, actively collaborated with Congressional leaders at every step in the evolution of NAPA. The Act was passed by both houses of Congress and signed into law (PL 111-375) by President Obama on January 4, 2011, mandating:

a. Creation of National Strategic Plan to address the Alzheimer's crisis
b. Coordination of AD efforts across the federal government
c. Formation of an Advisory Council and
d. Annual reports to Congress, which will provide:
    1. Updates on the National Strategic Plan
    2. Recommendations for priority actions

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3. Evaluation of all federally funded efforts in Alzheimer's research

The role of NAPA's Advisory Council is to (a) make recommendations to the Secretary of the Department of Health and Human Services (DHHS), who has the ultimate authority for preparing the final National Strategic Plan; (b) coordinate federal agencies conducting Alzheimer's research; and (c) participate in the evaluation and strategic planning process.

The membership of the Advisory Council* has been constituted to reflect the diversity of constituencies involved in different aspects of research, care, and services. The heterogeneity of interests and the multiplicity of perspectives embodied by the Council are both a potential strength and a weakness. The "Achilles' heel" of this deliberative body is the possible danger that competing or narrow agendas of its members could weaken the actual advice given to the Secretary (DHHS). The propensity of focusing on the "trees" rather than "forest" was evident during discussions of the Council's inaugural meeting on September 27, 2011 in Washington, DC. For example, discussions at that meeting appeared to focus more on explaining or justifying current programs across federal agencies rather than outlining a forward-looking bold vision to solve the problem by answering questions such as what are some of the scientific obstacles that must be surmounted and the types of additional resources that will be required. The ultimate effectiveness and utility of the Council will depend on a set of recommendations to the Secretary (DHHS) that are transformative rather than those that promote business-as-usual solutions, aimed at protecting individual turfs.

2. Why NAPA is important for the future funding of Alzheimer's research

The great hope of the research community is that NAPA will finally succeed in designating Alzheimer's research a national priority. Potentially, PL 111-375 promises to create the same successes as have been demonstrated in the battles against other diseases, such as HIV/AIDS, influenza and pneumonia, and stroke. For the first time in the history of Alzheimer's research, NAPA will enable Congress, by the required annual review process, to assess whether the nation is meeting the challenges of this disease. This course of action will allow the public and Congress to determine each year whether research is making satisfactory progress in the fight against Alzheimer's.

Questions regarding the potential significance of NAPA for future prospects of funding Alzheimer's research should be weighed against a 30-year history of similar efforts within the DHHS, NIH, and National Institute on Aging (NIA). Since 1978, with the inception of NIA's efforts to develop national programs of research on brain aging and AD, there were numerous efforts and initiatives launched with the same laudable intentions of designating Alzheimer's research as a high-priority national goal; calling for substantial increases of funds [1]. Unfortunately, virtually all of these initiatives during the past 3 decades failed to fulfill the expectations of the Alzheimer's research community. For example, during the period of 1984 to 1994, a series of "reports" known as *Alzheimer's Disease: Report of the Secretary's Task Force on Alzheimer's Disease* offered specific action plans with budget recommendations to the Secretary (DHHS). These reports, which reflected the collective advice of key opinion leaders in Alzheimer's, were largely ignored by DHHS/NIH [2]. Some of the factors that contributed to the lack of success of these earlier efforts are informative lessons for the NAPA initiative. These include:

- The scientific community was fragmented into groups with mixed loyalties, different interests, and no overriding interest in advocating for public policy.
- Despite NIA's effort, successive Directors of NIH did not explicitly support or endorse the idea of designating Alzheimer's a high priority for NIH or DHHS.
- Alzheimer's advocacy was Balkanized and was not effective in mobilizing grassroots support and speaking with one voice.

In contrast to earlier efforts, NAPA has the best chance to succeed because it has (a) at least the nominal support of Congress, the President, and the Secretary of the DHHS (and therefore the NIH); (b) the unanimous support of all constituencies; and (c) a research community that has become engaged in the planning process.

Recognizing the history of disappointments, this author, along with the AA, the Campaign to Prevent Alzheimer's Disease by 2020 (PAD2020),[†] and the research community,

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*The federal representations on the Advisory Council include Administration on Aging, Agency of Healthcare Research and Quality, Centers for Disease Control and Prevention, Centers for Medicare and Medicaid Services, Department of Veterans Affairs, Food and Drug Administration, Indian Health Service, National Institutes of Health (NIH), National Science Foundation, and the Surgeon General. The nonfederal representations (two each) include AD caregivers, AD patient advocates, health care providers, researchers with AD experience, state health departments, and voluntary health associations.

[†] PAD2020 is a Maryland-based, 501(c)(3) nonprofit corporation (www.pad2020.org). PAD2020 executive committee members are Zaven S. Khachaturian, PhD, President, Potomac, MD; Virginia Lee, PhD, University of Pennsylvania, Philadelphia, PA; Ronald Petersen, MD, PhD, Mayo Clinic, Rochester,MN; Peter Snyder, PhD, Lifespan Affiliated Hospitals, Providence, RI; John Trojanowski, MD, PhD, University of Pennsylvania, Philadelphia, PA; Ara S. Khachaturian, PhD, Alzheimer's and Dementia: Journal of the Alzheimer's Association, Rockville, MD; and Stanley Prusiner, MD (Noble Laureate), University of California San Francisco, San Francisco, CA.

PAD2020 is affiliated with the AA through a "Memorandum of Understanding." All PAD2020 work groups and "Think Tank" meetings will be organized in collaboration with the AA. The strategic plans and policy recommendations of PAD2020 will be implemented through the Public Policy Office of the AA.