

## **Response to Draft National Plan to Address Alzheimer's Disease**

### **Submitted on behalf of the Healthy Brain Workgroup of the Centers for Disease Control and Prevention-funded Healthy Aging Research Network (CDC-HAN)**

The Healthy Brain Workgroup of the Centers for Disease Control and Prevention-funded Healthy Aging Research Network (CDC-HAN) strongly supports the vision statement of the National Alzheimer's Project Act (NAPA) presented by President Barack Obama, which aims to alleviate the suffering and burden associated with Alzheimer's disease (AD) and to *"confront the challenge it poses to our public health."*

The Healthy Aging Research Network (HAN) was formed in 2001 to help develop and implement a national research and dissemination agenda related to the public health aspects of healthy aging. The HAN consists of a coordinating center, seven member and affiliate universities, and representation from and participation by over 10 national agencies with interests in the well-being of older adults, including AARP, the Alzheimer's Association, the American Medical Association, the US Administration on Aging, the National Association of Chronic Disease Directors, the National Council on Aging, and the U.S. Environmental Protection Agency. This network has played a vital role in national initiatives to ensure the inclusion of AD, cognitive impairment, and cognitive health promotion in the Healthy People 2020 Older Adult objectives. The network has also worked successfully to inform the National Public Health Road Map to Maintaining Cognitive Health, released in June 2007 by the CDC and the Alzheimer's Association [1].

Between 2005 and 2009, the HAN conducted community-based research with over 600 diverse older adults, caregivers, and healthcare providers. Interviews and focus groups were conducted in English, Spanish, Mandarin, Cantonese, and Vietnamese, with representation from African American, American Indian, Asian American, Hispanic, and Non-Hispanic White communities, in urban and rural locations across nine states. [2-4]. These older adults and those who care for older adults represent the stakeholders to whom NAPA is targeted. Findings from this large-scale, multi-site initiative (published in *The Gerontologist*, volume 49, supplement 1, June 2009) indicated that older adults, regardless of gender, race, ethnicity, language, or geographic region, agree that cognitive health is essential to healthy aging [5, 6]. Older adults also stated that existing media messages about cognitive health and its association with lifestyle factors can be conflicting and confusing [7]. It is imperative that researchers, educators, and policymakers continue to examine communication strategies to better inform the public about the evolving science of maintaining cognitive health and reducing the risk of cognitive impairment. Based on its strong track record, the HAN is well positioned to participate in such efforts.

As currently written, the NAPA does not explicitly state the impact of AD and other dementias on public health or the role that public health can play in this important area. We therefore strongly recommend the explicit inclusion of HAN expertise in public health research and practice in addressing each of the goals outlined in the NAPA. This document provides recommendations for roles that the HAN might fill in implementing the Plan.

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

Public health has a long history of fielding prevention research and educational efforts in

multiple chronic diseases such as heart disease, musculoskeletal disease, and cancer. HAN member centers have helped develop, evaluate, and implement successful health promotion programs in primary care, senior centers, and other community-based organizations. HAN researchers, in partnership with community collaborators, have developed and tested effective, evidence-based, and widely-used older adult exercise programs, including EnhanceFitness [8-9], Fit and Strong! [10, 11], and A Matter of Balance [12-14] and have demonstrated chronic illness risk reduction and improved health outcomes in these investigations. Although research is still needed about the impact of such lifestyle changes on AD [15], epidemiological and early randomized clinical trials (RCTs) show promise [16]. A cadre of experts within the HAN can help advance this work, both by conducting focused reviews of existing literature and large datasets, and by planning and implementing large scale lifestyle-enhancing initiatives. In addition, as noted above, the HAN has a proven track record in partnering with diverse groups who represent the growing numbers of racial and ethnic minorities in the US and recruiting them to participate in research and the implementation and dissemination of evidence-based findings.

## **2. Optimize Care Quality and Efficiency**

Initiatives focused on expanding dementia-specific capabilities in primary care settings are already underway within the HAN. HAN centers have examined primary care providers' perceptions and practices regarding AD and cognitive impairment [17, 18]. A current CDC-funded Special Interest Project (SIP 10-37; PI: M. Snowden) is reviewing the scientific literature to determine the impact of cognitive impairment on co-occurring chronic illnesses, including morbidity, mortality, and how AD and dementias influence the medical care that an individual receives. The project will also identify and catalogue the elements of existing research databases for use in future studies to better understand the relationship between dementia and chronic conditions. The HAN member centers' established associations with racial and ethnic minority, low income, and rural populations provide resources and expertise for assessing and addressing the complications and obstacles faced by these groups who are at high risk for inadequate health care.

## **3. Expand Supports for People with Alzheimer's Disease and Their Families**

There is a need for more broadly distributed evidence-based services through involvement of a variety of service providers, including State Health Departments, Area Agencies on Aging, non-profit organizations, faith-based organizations, and other facilities within local communities. Public health has a long history of working within these organizations, and can help mobilize communities to meet these challenges. HAN members and affiliates are actively engaged in working with the Administration on Aging (AoA) in this effort (e.g., University of Washington HAN investigators are currently working with the states of Washington, Oregon, and Ohio on translating evidence-based interventions for individuals with dementia and their family caregivers into existing community health systems [19]).

## **4. Enhance Public Awareness and Engagement**

The Department of Health and Human Services should take advantage of the formative investigation already conducted by the HAN that was cited earlier [2-7]. This investigation found low health literacy and lack of access to culturally relevant information about cognitive health across all ethnic and language groups, and in both rural and urban environments. Older adults often reported that recommendations that they heard were ambiguous, contradictory, or impossible to comply with, and recommendations from health providers were often vague and lacked specific planning processes [7]. Thus, there is an urgent need for culturally and

educationally appropriate materials and resources for individuals with cognitive impairment, individuals at risk for dementia, caregivers, and providers. The HAN comprehensive data set can provide guidance about messages and media that will be most effective in disseminating this information. The HAN has tremendous reach for public health and aging focused message testing and awareness campaign development, implementation, and evaluation.

In addition, each HAN site has worked for over 10 years with community advisory groups to facilitate communication between and among state and local government agencies, nonprofit partners, racial and ethnic minority service providers, and academic public health researchers. These partnerships have actively developed and disseminated healthy aging programs, and can be leveraged to promote dementia-prevention education and intervention programs.

### **5. Track Progress and Drive Improvement**

Public health researchers have long been instrumental in evaluating large-scale programs to promote health in older adults, including both lifestyle (e.g., exercise, nutrition) and primary prevention (e.g., immunization) interventions. Any effort to measure and evaluate the impact of NAPA on health outcomes for older adults and caregivers and on policy change must be informed by public health, taking advantage of existing expertise in population-level evaluation planning, data collection, analysis, interpretation, and dissemination. The HAN has been involved in developing aging-specific questions for a number of large surveys [18, 20], and has a long history of experience and expertise in this area. It should be noted that the CDC Healthy Aging Program (funder of the HAN) developed a 10-question Behavioral Risk Factor Surveillance System (BRFSS) module on Perceived Cognitive Impairment. Twenty-two states included the module on their state BRFSS in 2011; an additional 16 states are including the module in 2012 (total 38 states, including the District of Columbia). The CDC Healthy Aging Program is working with partners, including the states, to expand the module in 2013 to all 50 states.

In summary, to achieve the goals of NAPA, collaboration with and among public health researchers across the nation is needed. The HAN is an example of a successful and productive collaborative effort, and we look forward to helping move the science forward to address this important public health issue.

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