



Connecting with AAPIs About Dementia

AN ACTION GUIDE FOR POLICYMAKERS

This action brief is for policymakers working to reinforce systems that support Asian American and Pacific Islander (AAPI) communities about dementia. This brief contains:

- Why dementia is such an important issue for the AAPI community,
- Recent findings from a research study to test culturally appropriate messages to improve early identification of dementia by engaging adult children and their families,
- Recommendations and resources for better reaching the AAPI community.

Background

Asian Americans and Pacific Islanders (AAPI) are the fastest growing minority group in America.¹ Between 2010 and 2030, the AAPI older adult population is projected to increase by 145%.¹ As this aging population rapidly increases, AAPI older adults face a public health crisis similar to older adults from other ethnic backgrounds, as age is the largest risk factor for Alzheimer's disease.²

The prevalence and incidence of Alzheimer's disease and related dementias within AAPI communities is not well understood. Researchers acknowledge that data on AAPI subpopulations is lacking.³ Limited disaggregated research unveils that Vietnamese older adults have a disproportionately high prevalence of cognitive problems (16.6%), more than double the rate for Koreans at 7.6%.⁴ Native Hawaiians and Pacific Islanders have a higher risk of cognitive issues and activities of daily living impairments, which is two times the risk as compared to Chinese older adults.⁴

In 2011, 13.8% of older AAPIs reported an increase in confusion or memory loss, which was the second highest of all ethnic groups.⁵ Despite this alarming statistic, there is scarce data on unique AAPI subpopulations. Limited data suggests there to be variations by subpopulation, but we need more research to understand it. Therefore, AAPIs must be prioritized through Alzheimer's disease research, funding, and policies.

Price of Inaction

Alzheimer's disease is the most expensive disease in America, costing more than cancer and heart disease.⁶ In 2017, the direct costs to care for those with Alzheimer's will total an estimated \$259 billion, with nearly one in every five Medicare dollars being spent on someone with the disease.⁶ Increasing age is the greatest risk factor for Alzheimer's disease, and with a rapidly increasing AAPI population, inaction will have profound financial – as well as social – impacts.

Policy Landscape for this Action Guide

Several national- and state-level policies provide guidelines for improving services and supports for underserved communities including AAPIs:

- *The National Plan to Address Alzheimer's Disease*, which was authorized through the 2011 National Alzheimer's Project Act (NAPA) (Public Law 111-375), was designed to address the major national challenges presented by Alzheimer's Disease and related dementias.⁷ One of their strategies is to facilitate translation of research findings into medical practice and public health programs.
- The Center for Disease Control (CDC) and Prevention's and Alzheimer's Association's *Healthy Brain Initiative's (2013-2018) Public Health Road Map for State and National Partnerships* goal is to **increase public awareness and early detection through public health messaging engaging adult children.**⁹
- *The Washington State Plan to Address Alzheimer's Disease and Other Dementias* which has goals about increasing public awareness, engagement and education and ensuring access to comprehensive supports for family caregivers.¹⁰

Research Study to Evaluate Public Health Messages for the AAPI Community

In 2016, the CDC-funded Healthy Brain Research Network (HBRN) at the University of Washington (UW) collaborated with the Washington State Department of Health and the National Asian Pacific Center for Aging (NAPCA) to test public health messages with the AAPI community. These messages were developed and evaluated by University of Pennsylvania to encourage adult children to take their older loved one in for a cognitive evaluation with **a memory specialist, a trained healthcare provider who can evaluate memory and thinking issues and diagnose dementia.** Our study assessed eight messages that encouraged contacting the Alzheimer's Association. UW HBRN and NAPCA conducted six focus groups with Chinese and Japanese adults in King County, Washington with at least one living older parent/step-parent/parent-in-law age 65 and older. Several findings were presented in a companion action guide for public health and aging service providers.

"One thing that it makes me think with these messages, like the other one says to go with your person to the doctor... I feel like well, what do you want me to do? How am I going to get there? How am I going to take off all of this time from work? Not that I am complaining to take them, but how am I supposed to do that? - 28 year old Chinese woman

Based on findings from this study, and in alignment with The National Plan to Address Alzheimer's Disease and the Healthy Brain Initiative, four recommendations are presented for policymakers:

1. Expand prevention and treatment research, ensuring inclusion of AAPIs.

With a rapidly increasing population, the urgent need for AAPI inclusion in Alzheimer's research is well documented.⁷ Alzheimer's disease is a complex public health challenge, and within AAPI communities, there are important questions in need of answers. The conclusion of UW HBRN and NAPCA's study unveiled that additional targeted research with AAPIs is needed to:

- Understand the extent of Alzheimer's disease and related dementias among AAPIs;
- Understand barriers in reaching AAPIs with cognitive concerns/issues;
- Test public health messaging to increase awareness, education, evaluation, treatment, and supports; and,
- Explore cultural barriers and solutions to overcome these challenges.

2. Improve national data on AAPIs with Alzheimer's disease and related dementias.

AAPI participation in research must reflect the extreme diversity of a minority group that represents over 50 unique ethnicities and 100 different languages. **Aggregating AAPIs into a homogenous population masks unique subpopulation variations that are vital to better understand and more effectively serve this diverse population.**

When AAPIs are viewed as a homogenous population, this leads to sweeping generalizations that AAPIs are the highest-income, best-educated, and healthiest racial group in the country, with few, if any, needs; these generalizations promote the 'model minority' myth. The 'model minority' myth has been used to describe the history of exclusion and discrimination against AAPIs that contributed to failure to recognize critical health disparities, differences, and priorities between AAPI subgroups—and resulted in limited governmental resources and philanthropic investments in AAPI communities.

Improving national data on AAPIs with Alzheimer's disease and related dementias requires a federal mandate for the collection of disaggregated race data. The Office of Management and Budget (OMB) must require all federal departments and agencies collect a maximum number of race data elements, with at least the same number used in the detailed groups included within the 2010 Census.

Asian Americans: Asian Indian, Bangladeshi, Bhutanese, Burmese, Cambodian, Chinese, Taiwanese, Filipino, Hmong, Indonesian, Iwo Jiman, Japanese, Korean, Laotian, Malaysian, Maldivian, Mongolian, Nepalese, Okinawan, Pakistani, Singaporean, Sri Lankan, Thai, Vietnamese, Other Asian, not specified.

Native Hawaiian and Pacific Islanders: Native Hawaiian, Samoan, Tahitian, Tongan, Tokelauan, Other Polynesian, Guamanian or Chamorro, Mariana Islander, Saipanese, Palauan, Carolinian, Kosraean, Pohnpeian, Chuukese, Yapese, Marshallese, I-Kiribati, Other Micronesian, Fijian, Papua New Guinean, Solomon Islander, Ni-Vanuatu, Other Melanesian, Other Pacific Islander.

To illustrate commitments to the improvement of national data on AAPIs, federal and state governments can enact policies and allocate resources to the development of Alzheimer's disease and related dementias plans.

3. Accelerate efforts to identify early stages of Alzheimer's Disease for AAPIs.

In addition to education for AAPIs, accelerating early detection and diagnosis of Alzheimer's disease requires sufficient clinical resources. Policies must ensure reimbursement for primary care provider cognitive assessment. Additionally, resources must be allocated to culturally appropriate training for new (e.g. higher education, certification) and existing providers (e.g. CEU) to do cognitive evaluations with AAPIs.

4. Expand support for AAPI caregivers.

AAPIs are significantly more likely to assume caregiving roles, with 42% of AAPIs providing care to an older adult, compared to 22% of the general population.¹¹

Expanding support for AAPI caregivers is paramount to sustaining the informal care network of many AAPIs with Alzheimer's disease and related dementias. Findings from UW HBRN and NAPCA's study highlighted the need for policies that provide additional support to family caregivers, increased funding for respite care other culturally appropriate and linguistically accessible long-term services and supports and services for caregivers of individuals with Alzheimer's disease, ensuring such caregivers are eligible for such respite services regardless of the age and financial status of the person with the disease.

Can we mitigate this public health crisis?

YES! We need to adopt strategic recommendations, such as those outlined in this action brief – which are in alignment with *The National Plan to Address Alzheimer’s Disease and the Healthy Brain Initiative Public Health Road Map* – and adequately fund implementation. Through bipartisan support and a national commitment, we can end Alzheimer’s Disease for all Americans, including AAPIs.

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Acknowledgements

This project was supported in part by the following organizations:

- A grant from the U.S. Administration for Community Living (ACL), Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official ACL policy.
- The University of Washington Healthy Brain Research Network (HBRN), a Prevention Research Centers program funded by the Healthy Aging Program-Healthy Brain Initiative through a cooperative agreement (#U48 DP 005013) from the Centers for Disease Control and Prevention (CDC). The findings and conclusions in this document are those of the author(s) and do not necessarily represent the official position of the CDC.
- Alzheimer’s Association grant #22194 “The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013-2018” awarded to the Washington State Department of Health from 2016 – 2017.
- The Dementia Action Collaborative (DAC), working to facilitate connections and responding to needs identified in the Washington State Plan to Address Alzheimer’s Disease and Other Dementias.
- We also wish to thank Heather Chun, MSW, and Nikki Eller, MPH, as well as HBRN and NAPCA focus group participants and moderators, for their invaluable contributions for making this action brief possible.



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