

# National Alzheimer's Project Act (NAPA)

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The information that follows was included as an Advisory Council meeting handout.

For more information about NAPA, visit the NAPA website at:

<http://aspe.hhs.gov/national-alzheimers-project-act>

**For Panel 3**  
**Successful Interventions in Racial and Ethnic Communities**  
**Living with Alzheimer's disease**  
**Alzheimer's Association**  
**Northern California and Northern Nevada Chapter**

**Presented by Gerri Woolfolk, NAPA Advisory Committee member**

Underserved communities are disproportionately affected by Alzheimer's due to various cultural, linguistic and socioeconomic barriers. The Alzheimer's Association continues to address these barriers to ensure we are inclusive in our mission. We do this by addressing each area of our mission to the underserved communities in different ways. We tailor the program to meet the needs of that particular region and need. We are always assessing and reviewing our approach to community engagement. We've held focus groups to assess how to effectively communicate Alzheimer's in various communities.

**Stigma** - In many communities, the stigma of Alzheimer's prevents people from seeking a diagnosis to getting professional help caring for their loved one.

- Many LGBT individuals go back in the closet when in need of services out of fear of discrimination. The LGBT Dementia Care Project will provide LGBT dementia training to service providers.
- Chinese individuals typically seek a diagnosis 18 months later than Caucasians due to stigma, shame and embarrassment. The Alzheimer's Association has changed the terminology used to describe Alzheimer's and dementia in Chinese from "crazy catatonic disease" to the phonetic translation of Alzheimer's. This has made a difference in how people feel about their own diagnosis.

**Education** - For many people Alzheimer's is still associated with normal aging or mental illness. We have found that people are receptive to education about the disease and how to manage dementia behaviors. The Association provides a number of culturally relevant educational forums to inform the general public about the disease and caregiver issues.

- The African American Caregiving and Wellness Forum is an annual event attended by 100-200 people, presented by mostly African American field experts (researchers, doctors, social workers).
- Likewise, we offer similar forums in Chinese and Spanish.
  - The Chinese Alzheimer's Forum held in San Jose this year had 400 people in attendance and was presented entirely in Chinese.
  - The Latino Education Forum recently occurred in Oakland, and last year in Concord serving several hundred Spanish speaking Caregivers

**Ethnic Media** - Our engagement of ethnic media is providing positive outcomes. Chinese press and Spanish television and radio are extremely open to airing stories related to Alzheimer's. Paid advertisement is also effective and costs are nominal. The Sun Reporter and Post print media serve the African American Community, especially as a resource to the churches and Sunday services.

**Culturally Relevant Programs** - It matters to people to meet and speak to people whom they identify with culturally when dealing with such an emotional disease.

- The Association's Lunch and Learn group is a long standing African American support group.
- We also have support groups in Spanish, Cantonese and Mandarin, and support groups that are LGBT specific.
- We distribute culturally relevant materials in language as appropriate at our Walk to End Alzheimer's (17 over all of Nor Cal and Nor Nevada) as well as health fairs and other events.

**Engagement and Advocacy** - The Association's Advocacy program engages volunteers from every community in teams who engage Federal and State legislators in making Alzheimer's a priority. We have several culturally specific advisory councils to engage constituents in the full mission of the Alzheimer's Association. They are active in participating in Advocacy and Policy activities, like State Advocacy Day, in Walk to End Alzheimer's, as well as raising concern and awareness.

- This year we are holding a series of conversations with outreach staff in all our communities to raise the diverse participation in State Advocacy Day and for the Forum. Offering transportation and group meeting points is one way to encourage people to travel together.
- Lining up meetings at Advocacy day with events of the Asian/Pacific Islander Caucus, African American Caucus and Women's Caucus are also planned to enhance visibility and awareness
- The San Francisco Live Alone Grant (ADSSP) is a multi-year, Federal grant of which we are in the 2<sup>nd</sup> year, also known as The Dementia Safety Net, collaborates with the Village in SF and other community agencies to identify people with dementia who live alone, and who might be receptive to services. Many of these individuals do not have family nearby but have a robust community support network that can be engaged to provide a "circle of friends" that can support the individual. Some individuals are staunchly non receptive to support, and are more challenging to serve, especially as dementia progresses. Our staff sometimes call this the "leave me alone" project, because people who wish to be left alone, can no longer be because of their dementia.

- We also have received Measure H funding in San Mateo County to duplicate this service, and in this funding stream may be more sustainable as to our ability to continue this over time.
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- **Advocacy and Policy Engagements:**
  - The African American advisory council strongly advocates for more visibility in the community, they are passionate about addressing health disparities in the community and may work with the State African American Caucus to influence policy. This group encompasses a variety of community, medical and service professionals, as well as Caregivers who wish to influence public awareness and engagement for their community.
  - The Chinese advisory council engages University alumni groups in the South Bay area to raise awareness and focuses on education.
  - The Latino Advisory Council in Fresno a very large rural community, is highly active in advocacy, engaging local Congressional members in our issues and recruiting advocates to participate in Walk, and both State Policy and National policy activities.
  - We have learned that simplifying the messages and portraying Latino families as opposed to a single individual is important. We are in the process of discussing how to communicate about advocacy in a culturally relevant way for Latinos.

**For more information –**

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