Strengthening Community-Based Services for Asian American and Pacific Islanders Affected by Dementia
INTRODUCTION

Richard Lui, a Chinese-American news anchor for NBC and MSNBC, grew up in a large, multi-generation family. When Richard’s dad, Steve, was diagnosed with Alzheimer’s disease, Richard and his siblings came together and created a plan to support their mother, who is Steve’s primary caregiver. “Asian-American and Pacific Islander (AAPI) families take on the responsibility of caregiving without thinking twice – an unwritten and sometimes unspoken practice that family is number one,” says Richard, whose life reflects this cultural value. He changed his work schedule to become a part-time anchor and flies from New York City to San Francisco each week for his caregiving shift.

“We’ve always been a tight-knit extended family. At Christmas, we would have 90 people together – cousins, aunts and uncles all celebrating the holiday. We were close, and we will always be close. It’s just how we are. Caregiving is an extension of that. It was never explicitly said, ‘You have to take care of your family,’ it was simply understood,” he explains.

While cultural factors, like a strong sense of responsibility for caring for one’s parents, are characteristic of AAPI families, Richard notes that these families often face the disease in isolation. “Interestingly, despite this core family strength, few talk about their caregiving activities, nor share best practices openly.”

As an Alzheimer’s Association® Celebrity Champion, Richard uses his platform as a public figure to speak out about his family’s experience with Alzheimer’s, raising critical awareness for all those affected by the disease and showing other AAPI families they are not alone.

As Richard Lui’s story illustrates, ethnicity and cultural factors can significantly impact the way AAPI families cope with Alzheimer’s. To assist these families, community-based service providers need a basic understanding of AAPI culture and the resources available to help them.

This guide is intended to educate and empower community service providers in their work with AAPI families. It’s one of the tools created by The National Asian Pacific Center on Aging (NAPCA) and the Alzheimer’s Association through their national partnership to improve the quality of life for AAPI individuals with Alzheimer’s and their caregivers. Here you will find information and action steps that will strengthen your knowledge and skills to help this fast-growing segment of the population.
Alzheimer’s disease is our nation’s largest under-recognized public health crisis, impacting more than 5 million people living with the disease and over 16 million family members and friends who serve as their unpaid caregivers. Age is the greatest known risk factor for Alzheimer’s disease and with the aging of the baby-boom generation, the number affected is expected to soar.

The AAPI community within the United States is diverse and encompasses many ethnicities, including Chinese, Filipino, Indian, Vietnamese, Korean, Japanese, Samoan and Native Hawaiian. AAPIs are the fastest growing minority group in America, and between 2010 and 2030, the AAPI older adult population is projected to increase by 145 percent. This growth will also impact the number of AAPI older adults with Alzheimer’s: For example, during this time frame, California, which is home to the nation’s largest population of AAPI older adults, expects Alzheimer’s disease to nearly triple among AAPIs.

Although the AAPI community is diverse, when it comes to caregiving, its members share many common characteristics. AAPIs are significantly more likely to assume caregiving roles, with 42 percent of AAPIs providing care to an older adult, compared to 22 percent of the general population. Additionally, 17 percent of AAPIs live in multigenerational households, compared to seven percent of the total population. With a strong cultural value placed on devotion to caring for parents – “filial piety” – and larger households, AAPI caregiving often involves multiple family members, each serving a specific role.

Even with multiple caregivers, AAPI families may underestimate the physical and emotional toll daily caregiving can take on them and will need guidance and support to find professional resources, like adult day services and respite, that can help maintain their caregiving system.

**BARRIERS TO GETTING ASSISTANCE**

**Stigma**

Many AAPIs do not report symptoms of dementia to a medical professional and consequently, AAPIs are unlikely to receive a diagnosis of Alzheimer’s disease in the early stage. One reason that AAPI elders are less likely to report symptoms is cultural stigma. For example, in Chinese, dementia translates as “crazy catatonic” and the signs and symptoms of dementia are interpreted as a mental illness. Not surprisingly, in Chinese communities dementia can trigger intense
negative responses that may deter people from seeking a diagnosis, information and assistance. However, research has shown that brief exposure to information about the symptoms of dementia leads to a reduction in stigma among Chinese, so community education may play a critical role in reducing this barrier to early detection. 4

Language

Along with cultural attitudes and beliefs about dementia, language can be one of the biggest barriers to AAPIs receiving a dementia diagnosis and follow-up services. U.S. Census data found that Asian Americans had the highest level of limited English proficiency when compared to other groups. 9

Complicating the language barrier is the fact that many AAPI languages, like Chinese, have multiple dialects (Mandarin, Cantonese). To be truly helpful to AAPIs affected by dementia, information and assessment tools should be translated into languages they understand. Many such materials already exist and are listed in the appendices at the end of this guide.

**STEPS YOU CAN TAKE TO MORE EFFECTIVELY SERVE AAPI FAMILIES**

As a community-based service provider, you have likely encountered people of different backgrounds and observed firsthand how they make choices based on cultural factors. Understanding and accepting these factors is the first step to providing effective services. For example, as Richard Lui’s story illustrates, in AAPI culture, families are usually viewed as a primary source of support and are often a critical resource in providing care for a person living with dementia.

The following steps will help strengthen your work with AAPI individuals and families affected by Alzheimer’s.

**STEP 1: MAKE DIVERSITY TRAINING AND EDUCATION A PRIORITY.**

A basic understanding of a person’s background and beliefs helps in building a trusting relationship. Knowing about the person’s culture is a key part of that understanding, as culture may impact the way someone perceives and uses community-based services.

Prioritizing training in diversity and cultural competency empowers you to feel more confident and capable to serve AAPI families affected by dementia.

There are many resources that provide education and training for staff working with the AAPI community, including:

- Agency self-assessments
- Webinars
- Fact sheets
- Manuals

A complete listing of these resources is included in Appendix A.
STEP 2: CREATE CULTURALLY AND LINGUISTICALLY APPROPRIATE INFORMATION ABOUT YOUR SERVICES.

Once you have learned about the AAPI community in general, and the particular ethnicities in your area, you can plan your outreach efforts. Effective outreach depends on effective communication, so first consider how assimilated someone may be to the U.S. and your community, as well as how they prefer to communicate; verbally or through written material. Keep this in mind as you evaluate your existing program materials like brochures, web content, ads, phone scripts, etc.

Consider convening a focus group of AAPI consumers and local experts in your area to provide feedback on current and proposed materials. Check with community groups, churches, schools and local government as possible sources for focus group participants.

Finally, don’t reinvent the wheel! There are many organizations that have already created materials in a wide range of AAPI languages which you may be able to use in your work. Have your focus group review these materials with you to see how relevant they are for your area. See Appendix B for listings of these types of materials as well as guides and translation services that can help.

STEP 3: DISTRIBUTE INFORMATION ABOUT YOUR SERVICES THROUGHOUT YOUR COMMUNITY.

Now that you have reworked the information you use to recruit and inform participants in your program(s), it’s time to distribute it as widely as possible in your community. Your organization may already be part of a local service network, and through your efforts to learn about and create communication tools for an AAPI audience, you have likely grown that network to include new contacts. Look for opportunities to get your information out into the AAPI community and to make your usual contacts aware of your desire and capacity to serve this population. Here are some places you can share your materials:

- Community information boards or health fairs
- Libraries
- Hospital social work departments
- Online — websites and social media platforms
- Ethnic newspapers
- Ethnic radio stations
- Public schools
- Ethnic service groups
- Village or township newsletters/e-newsletters
STEP 4: HELP MORE AAPI FAMILIES ACCESS LOCAL DEMENTIA-CAPABLE, LONG-TERM SERVICES AND SUPPORTS.

We all know it “takes a village” to help a family in need, and when cultural factors are considered, the “village” should expand to include specialized services. Some states and cities have developed networks of care for AAPI families, and their examples may offer insights or ideas that you can use as you grow your outreach and service efforts.

Other State and City Examples

- South Shore Elder Services, an Area Agency on Aging (AAA) in Massachusetts, has included their Asian outreach program within their area plan. To develop a successful outreach program, primarily to older Chinese adults and their caregivers, the AAA employs an Asian outreach worker who speaks Cantonese and understands the Chinese culture, helping caregivers connect to resources, services and support. They also partner with Quincy Asian Resources, Inc. to administer Asian outreach support services.

- Massachusetts’ Multicultural Coalition on Aging comprises 75 agencies, institutions and individuals providing health and social services to older people in many racial, cultural and linguistic groups in Boston. The coalition holds workshops and conferences educating caregivers about resources in the area.

- In California, Keiro offers support to individuals with dementia and other cognitive impairments, as well as their family members and caregivers, by providing them with tools and resources through fact sheets, information and referral services. Keiro offers a caregiver conference annually to address caregiving issues. Partnering with Providence Health & Services, Keiro also offers the Keiro-Providence Whole Person Care Program to bring palliative care services to the Japanese community in Southern California.

- The Alzheimer’s Association Illinois Chapter has partnered with the Chinese American Service League (CASL), the largest, most comprehensive social service agency in the Midwest dedicated to serving the needs of Chinese Americans, on a number of dementia initiatives, including:
  - A Chinese-language dementia resource center, consisting of both written and online resources.
  - Training that enables CASL staff to offer a caregiver education program to their constituents in Chinese and English.
  - The development of a Chinese-language dementia training curriculum for CASL elderly services staff.
  - The development of a pilot community grant program that offers small grants to organizations serving diverse communities to provide the “Know the 10 Signs” program in Chinese to elderly services staff (in-home, adult day and residential services) as well as to local constituents.

See Appendix C for more model programs that include care consultation, respite and adult day services.
ALZHEIMER’S ASSOCIATION

Immediately available to anyone at anytime is the Alzheimer’s Association 24/7 Helpline (800.272.3900) which provides reliable information and support to individuals impacted by Alzheimer’s disease or other dementias, in more than 200 languages and dialects. The Helpline’s highly trained and knowledgeable staff can assist with:

- Understanding memory loss, dementia and Alzheimer’s disease
- Challenging behaviors.
- General information about aging and brain health
- Skills to provide quality care and to find the best care from professionals
- Legal, financial and living-arrangement decisions
- Caregiver stress

The Helpline also includes:

- Confidential care consultation provided by master’s-level clinicians who can help with decision-making support, crisis assistance and education on issues families commonly face.
- Referrals to local community programs, services and ongoing support.

The Alzheimer’s Association also offers both in-person training and e-learning for caregivers, including:

- Know the 10 Signs: Early Detection Matters
- Understanding Alzheimer’s and Dementia
- Dementia Conversations: Driving, Doctor Visits, Legal and Financial Planning
- Effective Communication Strategies
- Living with Alzheimer’s for Caregivers: (available for early-, middle- and late-stage Alzheimer’s)
- Healthy Living for Your Brain and Body: Tips from the Latest Research
- Legal and Financial Planning for Alzheimer’s Disease
- Living with Alzheimer’s

NAPCA

In 2015, NAPCA’s National Resource Center on AAPI Aging was established to provide technical assistance in the form of education and information and to build the cultural and linguistic capacity of long-term service providers and systems. This web-based resource center responds to requests from professionals by tailoring webinars, fact sheets, reports, and culturally and linguistically appropriate educational resources to meet training needs. These resources include:

- Connecting with AAPIs About Dementia: An Action Guide for Service Providers
- AAPI Cultural Competency Course
STEP 5: COLLECT DISAGGREGATED ETHNICITY DATA TO STRENGTHEN SERVICE DELIVERY SYSTEMS.

AAPIs represent over 50 subpopulations, with over 100 different languages, unique cultural traditions, diverse immigration histories and vast differences in health status and disparities.

Until we can measure the size, characteristics, needs and outcomes of our services for AAPI families affected by dementia, it will be hard to create interventions that truly help. Data cannot not only grow our understanding, it is also a powerful tool when advocating for public policies that can have a wider impact than just one organization working on its own.

AAPIs represent over 50 subpopulations, with over 100 different languages, unique cultural traditions, diverse immigration histories and vast differences in health status and disparities. Federally, there is low collection and reporting of disaggregated race and language data on AAPI older adults and caregivers, which is vital to understanding the differences between AAPI subpopulations. By collecting this data, providers can more effectively serve AAPI older adults and their caregivers.

As a best practice, service providers should collect a maximum number of race data elements, with at least the same number used in the detailed groups included within the 2010 Census (see list in Appendix D).

Collecting this data will help you and your organization to:

- Know who you’re reaching — and not reaching.
- Customize your materials to fit the needs of your community. For example, this may involve translating materials into a different language.
- Prioritize outreach to a specific segment of the population.
- Monitor your efforts on an ongoing basis to find opportunities for improvement.
- Track year-over-year comparisons of populations reached.

CONCLUSION

AAPI families have unique strengths and challenges in providing care for family members living with Alzheimer’s. The steps described above can strengthen community-based service providers’ work in a variety of ways, first by growing your own appreciation and knowledge about AAPI cultures, and then finding ways to increase AAPIs’ use of services in your communities.
REFERENCES


APPENDIX

APPENDIX A: TRAINING AND EDUCATIONAL MATERIALS

• The National Resource Center on AAPI Aging has:
  
  – An action guide for service providers working with AAPIs with dementia.
  
  – Several archived webinars on AAPI cultural competency.
  
  – Two fact sheets, Identifying Population Counts Within Your Community and Identifying Languages Within Your Community, that will help service providers navigate the U.S. Census data to determine the specific AAPI subpopulations within specific communities and the languages they speak.
  
  – Two organizational tools, Asian American and Pacific Islander Inclusion: A Self-Assessment for Organizations and Seven Best Practices When Conducting a Community Needs Assessment with Asian American and Pacific Islander Older Adults, that will help service providers raise their awareness, evaluate areas for improvement to increase inclusion and track organizational change as they strengthen their work with AAPI older adults and their caregivers within their communities.
  
• The Asian-American Profile and Native Hawaiians/Pacific Islanders Profile from the U.S. Department of Health and Human Services, Office of Minority Health, provide demographics and health-related facts and disparities.

• The National Association of States United for Aging and Disabilities (NASUAD IQ) has an online course, developed in partnership with the National Resource Center on AAPI Aging, Strengthening Cultural Competence in I&R/A Work with AAPI Older Adults.

• The Asian Pacific Islander Health Forum has a database on their website with resources specific to AAPI subpopulations, such as health briefs on Cambodians, Chamorros, Chinese, Filipinos, Hmong, Japanese, Koreans, Native Hawaiians, Samoans, South Asians and Vietnamese in the United States.

• The U.S. Department of Commerce developed The Asian Population: 2010 and The Native Hawaiian and Other Pacific Islander Population: 2010, which provide comprehensive information about the demographic, social and economic characteristics of AAPIs.

• Stanford University offers hour-long, self-paced, ethnogeriatric cultural competence training for care of Asian Indian, Chinese, Filipino, Hawaiian and Pacific Islander, Hmong, Japanese, Korean, Vietnamese and Pakistani.

• Act on Alzheimer’s website includes links to additional resources for providers on cultural competency training.

• Hawai‘i Alzheimer’s Disease Initiative has an online database of culturally responsive dementia resources.

• The American Psychological Association has Guidelines on Multicultural Education, Training, Research, Practice and Organizational Change for Psychologists. This is relevant to psychologists working with minority groups.
### Chart of Resources Available in AAPI Languages

#### Chinese

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<tr>
<th>Organization</th>
<th>Resources</th>
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<tr>
<td>Alzheimer’s Association</td>
<td>- 10 Warning Signs&lt;br&gt;- Website, available in Chinese, also includes many other in-language resources</td>
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<tr>
<td>Family Caregiver Alliance</td>
<td>- Is This Dementia and What Does It Mean?&lt;br&gt;- Dementia&lt;br&gt;- Behavior Management Strategies for Dementia&lt;br&gt;- Alzheimer’s Disease&lt;br&gt;- Early Stage Alzheimer’s Disease&lt;br&gt;- Many other Chinese language fact sheets on website</td>
</tr>
<tr>
<td>Other websites that offer Alzheimer’s disease information in Chinese</td>
<td>- Hong Kong Alzheimer’s Disease Association&lt;br&gt;- Alzheimer’s Australia; several Cantonese and Mandarin help sheets are available&lt;br&gt;- TADA – Chinese Taipei</td>
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#### Hindi

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#### Indonesian

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<td>International websites that offer Alzheimer’s disease information in Taiwanese</td>
<td>- Alzheimer’s Australia; several Indonesian language help sheets available&lt;br&gt;- Alzheimer Indonesia</td>
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#### Japanese

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</tbody>
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### Khmer

**International websites that offer Alzheimer’s disease information in Khmer**

- Alzheimer’s Australia; several Khmer language help sheets available

### Korean

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<th>Alzheimer’s Association</th>
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<td>Dementia, Caregiving and Controlling Frustration</td>
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<td></td>
<td>Many other Korean language fact sheets on website</td>
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**Other websites that offer Alzheimer’s disease information in Korean**

- Alzheimer’s Australia; several Korean language help sheets available
- Alzheimer’s Association Korea

### Lao

**International websites that offer Alzheimer’s disease information in Lao**

- Alzheimer’s Australia; several Lao language help sheets available

### Marshallese

**Hawai’i Alzheimer’s Disease Initiative**

- Definitions of Alzheimer’s Disease
- Differentiating Normal Aging and Dementia
- Sundowning, Sleeplessness and Night Wandering

### Pohnpeian

**Hawai’i Alzheimer’s Disease Initiative**

- Communicating with Confused Persons
- Differentiating Normal Aging and Dementia
- Sundowning

**University of Hawai’i**

- 10 Warning Signs

### Punjabi

**International websites that offer Alzheimer’s disease information in Punjabi**

- Alzheimer’s Australia; several Punjabi language help sheets available
### Samoan

Hawai‘i Alzheimer’s Disease Initiative
- [Communicating with Confused Persons](#)
- [Differentiating Normal Aging and Dementia](#)
- [Sundowning](#)

### Tagalog

Hawai‘i Alzheimer’s Disease Initiative
- [Communicating with Confused Persons](#)
- [Differentiating Normal Aging and Dementia](#)
- [Sundowning](#)

Other websites that offer Alzheimer’s disease information in Tagalog
- Alzheimer’s Australia; several Tagalog language help sheets available

### Thai

International websites that offer Alzheimer’s disease information in Thai
- Alzheimer’s Australia; several Thai language help sheets available
- [Alzheimer’s Association of Thailand](#)

### Vietnamese

Alzheimer’s Association
- [10 Warning Signs](#)
- [Website](#), available in Vietnamese, also includes many other in-language resources

Family Caregiver Alliance
- [Alzheimer’s Disease & Caregiving](#)
- [Caregiver’s Guide to Understanding Dementia Behaviors](#)
- [Dementia: Is This Dementia and What Does It Mean?](#)
- [Mild Cognitive Impairment](#)
- Many other Vietnamese language fact sheets on [website](#)

Other websites that offer Alzheimer’s disease information in Vietnamese
- Alzheimer’s Australia; several Vietnamese language help sheets available
2. Translation Resources

There are various local and national translation resources available with a wide range in pricing.

A. Translators

NOTE: To ensure quality translations for AAPI families affected by Alzheimer’s, it is important to orient translators to terminology, sensitivities and nuances in dementia-related language so they can keep them in mind while translating.

- The American Translation Association (ATA) hosts an online directory of individual translators and interpreters, searchable by geography, language and those who are ATA certified, among other criteria.

- Local chapters of the ATA often post pro-bono volunteering opportunities for nonprofit organizations in need of translation or interpretation services (see the Northern California Translators Association as an example).

- Some organizations or businesses will provide translation free to nonprofits (for example, Translators Without Borders).

- AAPI-serving community-based organizations generally employ native speakers for the communities they serve. Developing partnerships with these organizations is a great way to approach translation of information on dementia and caregiving, and in addition to assisting with translation, these organizations have direct access to AAPI constituents who can provide feedback on the in-language materials.

- State/local government (local translation and interpreting agencies).

- Local universities and colleges.

B. Glossaries

Organizations often lack even the basic terminology to discuss various aspects of Alzheimer’s disease. To help organizations learn to use the correct terminology, the Alzheimer’s Association has created Chinese and Korean glossaries relating to Alzheimer’s disease.
Care Consultation and Navigation

To help individuals identify their needs and available resources, care consultation and navigation services in their own language are preferred. The language barrier and the unfamiliarity of the health and social care systems make it important to offer care consultation and navigation by agencies that have the capacity to serve growing AAPI communities. Examples of bicultural and bilingual programs models include:

- **Asian and Pacific Islander Dementia Care Network Project** ADDGS program provided bicultural, bilingual “Care Advocates” who conducted needs assessments and assisted constituents in accessing appropriate care and services.

- **Hawai’i’s Alzheimer’s Disease Initiative (HADI)**, has developed several tools for providers, including a Care Coordination Practice Tool and Memory Care Navigator Roadmap. The project is building the capacity of professionals and organizations to support older adults with memory loss or dementia and their caregivers. In addition to other culturally responsive services, HADI has developed a Memory Care Navigator Program, a service implemented through partnerships with community-based organizations, many of whom primarily serve AAPI older adults and caregivers.

Respite Care

Caregivers provide continuous hours of care to their family members, but this dedication can result in neglect of their own health and well-being. Culturally and linguistically sensitive respite services can ease the burden of caregiving. Respite services range from in-home care to nursing care. Innovative programs include the following examples:

- Washington’s **Kin On** Health Care Center in Seattle is a community-owned, nonprofit facility established to respond to the health care needs of Chinese elderly. With support from an ADDGS grant and Seattle-King County Aging and Disability Services, the Alzheimer’s and Dementia Support Center at Kin On provides respite services in addition to many other community programs.

- Hawai’i’s **Project Dana** implements an interfaith volunteer caregiver program to provide in-home respite care for caregivers.

- Washington’s Asian Counseling and Referral Services, based in Seattle, offers a **Home Care Aide Training program** for AAPI home care providers to support the delivery of culturally-competent and high-quality care for older adults.

Adult Day Care Services

Adult day care services not only benefit individuals with dementia, but also provide respite to caregivers. AAPI families often look to programs that offer culturally appropriate activities and have staff they can communicate within their own language. Examples of these programs include:

- Minnesota’s **Hmong Day Elders Adult Day Program**, a program provided by Volunteers of America, provides center-based program activities to Hmong older adults, including those with dementia.

- California’s **Daybreak II Respite and Caregiver Support Services**, supported by Catholic Charities in Sunnyvale, offers culturally appropriate center-based day program activities and in-home respite for Chinese and Vietnamese senior citizens.

- California’s Self-Help for the Elderly **Jackie Chan Center** in San Francisco offers respite services to caregivers, by providing quality day care for persons with Alzheimer’s disease or other dementias.
addition, the program provides Alzheimer’s disease education and training and referral and support services. All services are offered in multiple Chinese dialects.

- California’s KHEIR Adult Day Healthcare Centers in Los Angeles, Koreatown and South Bay (Gardena) provide daily health care services, including Alzheimer’s and dementia care programs, for frail Korean elders.

- The Alzheimer’s Association Illinois Chapter has partnered with the Chinese American Service League to offer “Know the 10 Signs” training in various community-based settings, including adult day service programs.
APPENDIX D

Detailed groups for AAPI race data collection included within 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, Marian 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.