

Serving Asian and Pacific Islander Families

HOME AND COMMUNITY-BASED SERVICES
FOR PEOPLE WITH DEMENTIA AND THEIR CAREGIVERS



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A TOOLKIT FOR
THE AGING NETWORK


INTERNATIONAL

HOME AND COMMUNITY-BASED SERVICES FOR PEOPLE WITH DEMENTIA AND THEIR CAREGIVERS



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About This Toolkit: Serving Asian and Pacific Islander Families Home and Community-Based Services for People with Dementia and Their Caregivers

Alzheimer's disease is a growing concern within the Asian community. Asian and Pacific Islanders (APIs) comprise a diverse group of people originating from as many as 50 nations and speaking more than 100 different languages and dialects. A number of barriers such as cultural beliefs and language can prevent early diagnosis and treatment of Alzheimer's disease. API families need awareness training about dementia and access to dementia-capable services from their local community. **This toolkit describes actions states can take to increase awareness about dementia and caregiver support by providing culturally appropriate information and links to dementia-capable services in the API community.**

The Serving Asian and Pacific Islander Families Toolkit:

- Focuses on the importance of outreach and support for API families coping with dementia.
- Illustrates how outreach and support play a critical role in increasing home and community-based services while decreasing reliance on institutional care.
- Defines dementia-capable services and explains how states can best serve API families.
- Provides a range of choices for state officials to use when developing programs by linking to resources that are model programs or unique examples. Many of these programs are funded by the U.S. Administration on Aging through the Alzheimer's Disease Demonstration Grants to the States (ADDGS) program.
- Summarizes four key actions states can take when providing dementia outreach and services for API families coping with dementia. These key actions are:
 1. Provide culturally appropriate information on dementia and caregiving.
 2. Increase awareness through community outreach, education, and networking.
 3. Link to local dementia-capable resources and services.
 4. Support caregivers by developing dementia-capable services in the community.

This toolkit provides information on promising practices, with hyperlinks to material available on the Internet.

Promising Practices: Serving Asian and Pacific Islander Families

Home and Community-Based Services for People with Dementia and Their Caregivers

Why Address Outreach and Support Options for Asian and Pacific Islander (API) Families with Dementia?

- Alzheimer's disease is a devastating degenerative disease that causes memory loss, challenging behavior problems, and severe functional limitations. In the United States, there are over 14 million Asians and just under 1 million native Hawaiians and Pacific Islanders. Asians account for 5 percent of the U.S. population. This number represents an increase of 63 percent from the 1990 census, which makes Asian Americans the fastest growing major racial/ethnic group. The number of APIs is expected to grow to 33.4 million by the year 2050.
- Asians, Native Hawaiians, and Pacific Islanders are more likely to be uninsured than the general population.
- A variety of barriers keep Asian and Pacific Islanders from receiving dementia services:
 - Cultural barriers. Many API populations are unfamiliar with the Western health care system. This unfamiliarity, coupled with the medical community's lack of understanding of API health practices and beliefs, can create distrust. Asians and Pacific Islanders also may opt for an integrative approach to health care based on their belief in the interconnectedness of mind, body, and spirit.
 - Language barriers. API populations have high rates of limited English proficiency. More than three-quarters of all Asian Americans speak a language other than English at home.
 - Limited services. Accessible and culturally proficient services for API families are limited.
 - Lack of awareness. The general lack of awareness of dementia contributes to stigma in the API community. APIs tend to consider dementia as a normal part of aging and are less likely to seek services during the early stage of the disease. As a result, many APIs may not know about available dementia-capable services.

What Are Dementia-Capable Services?

To provide dementia-capable services, individuals who assist consumers in accessing home and community-based services must be

- skilled at identifying people with Alzheimer's disease,

- knowledgeable about the kinds of services that can help people with dementia and their caregivers, and
- capable of providing linkages to other agencies and community organizations that can help.

To best serve API families, home and community-based services programs must recognize that:

- Families are the primary source of support.
- Families make different choices based on cultural forces that must be considered if services are to be effective.
- Acceptance of cultures is important when adapting service deliveries.

Serving Asian and Pacific Islander Families

States can engage in four key activities to provide outreach and support for API families coping with dementia:

1. Provide culturally appropriate information on dementia and caregiving.
2. Increase awareness through community outreach, education, and networking.
3. Link to local dementia-capable resources and services.
4. Support caregivers by developing dementia-capable services in the community.

Promising Practices for Each Key Activity

1. Provide culturally appropriate information on dementia and caregiving

One of the first steps in creating an effective diversity outreach program is to understand API populations and cultures and disseminate easy-to-understand materials in the appropriate languages.

Each ethnic community not only has its own demographics, but it also possesses its own unique culture. Understanding communities and cultures is at the core of a successful outreach program. Therefore, to assist the API community, it is essential to understand the impact of Alzheimer’s disease on the specific community, the cultural perception of the disease, and caregiving practices. For example, age is the greatest risk factor for Alzheimer’s disease. API women have the highest life expectancy (85.8 years) of any ethnic group in the United States.

The following publications provide insight into API communities:

- The [*Asian American/Pacific Islander Profile*](#) and [*Native Hawaiians/Other 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 Asian Pacific Islander Health Forum has developed 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 [We the People: Asians in the United States](#) and [We the People: Pacific Islanders in the United States](#), which provide comprehensive information about the demographic, social, and economic characteristics of APIs.

Preconceived notions about dementia can hinder the development of a successful outreach program. Beliefs about dementia vary; it may be viewed as normal aging, a form of mental illness, a source of shame, or even the result of fate. The translation of dementia can also perpetuate the stigma. For example, in Chinese, dementia commonly translates as “crazy catatonic.”

Acculturation and method of communication are important factors to consider in designing outreach efforts. The preference for receiving information in written or oral format can vary in API communities depending on proficiency in both the native language and English. Caregiving in the API community also is different because it often involves multiple caregivers who each serve a specific caregiving role.

Once the community has been identified and researched, information needs to be disseminated in a culturally appropriate manner. States can evaluate existing materials and determine whether those resources will meet the needs before they develop any new materials. One effective way to evaluate existing materials is to convene an API focus group to review those materials. Following are examples of brochures and dementia-proficient education materials available in API languages:

Chinese

ADDGS grantees developed many of the following resources for the Chinese population. These materials can be found in the [Administration on Aging Alzheimer’s Disease Page](#).

- *Asian American Dementia Care Network*
- *Assessing Memory Problems*
- *Caregiver Education and Training Curriculum*
- *Caregiver Intake Form*
- *Client Environmental Assessment Form in Chinese*
- *Client Environmental Assessment Form in Chinese and English*
- *Community Care Options for the Alzheimer’s Family*
- *A Guide to Alzheimer’s Disease*
- *How to Respond to Difficult Behavior*

- *Memory Problems: What Can Be Done*
- *Showing Respect*
- *Understanding Alzheimer's Disease and Where to Turn for Help*
- *Who Stole Grandmother's Memory?*

The [Family Caregiver Alliance](#) and the [Alzheimer's Association](#) have a special section on their respective Web sites listing dementia-proficient brochures in Chinese. A few examples are:

- [Alzheimer's Disease Fact Sheet in Chinese](#) (Family Caregiver Alliance)
- [Dementia, Is This Dementia and What Does It Mean?](#) (Family Caregiver Alliance)
- [Ten Warning Signs of Alzheimer's Disease](#) (Alzheimer's Association)
- [Living With Early-Onset Alzheimer's Disease](#) (Alzheimer's Association)

Korean

ADDGS grantees developed many of the following resources for the Korean population. These materials can be found in the [Administration on Aging Alzheimer's Disease Program page](#).

- *Assessing Memory Problems*
- *Community Care Options for the Alzheimer's Family*
- *Grandmother's Memory*
- *How to Respond to Difficult Behaviors*
- *Memory Problems: What Can Be Done*
- *Showing Respect*
- *Understanding Alzheimer's Disease and Where to Turn for Help*

[Alzheimer's Association Korean Communities Diversity Toolkit](#) lists educational materials, outreach materials, and assessment tools specifically for the Korean community. Some examples include:

- [Getting Diagnosis & Support Group](#) (Alzheimer's Association, Delaware Valley Chapter)
- [Common Behaviors Exhibited by a Person with Alzheimer's Disease – Depression & Korean Support Group Introduction](#) (Alzheimer's Association, Delaware Valley Chapter)

Vietnamese

ADDGS grantees developed many of the following resources for the Vietnamese population. These materials can be found in the [Administration on Aging Alzheimer's Disease Program webpage](#).

- *Alzheimer's Disease Guide*
- *Asian American Dementia Care Network*
- *Caregiver Education and Training Curriculum*
- *Caregiver Intake Form*

A need still exists for additional materials on dementia and caregiving for API communities. States can seek language guidance when developing materials or translating existing materials. It is important when creating translated materials to understand that many API languages have multiple dialects and regional differences in vocabulary. For example, the written Chinese language is universal, but the vocabulary will vary depending on the dialect, such as Mandarin or Cantonese. States can develop materials incorporating regional differences by involving constituents from the targeted communities and regions. Resources include:

- [A Patient-Centered Guide to Implementing Language Access Services in Healthcare Organizations](#), developed by the Office of Minority Health, is a step-by-step guide to help agencies and health care organizations implement effective language access services to meet the needs of limited English proficient clients, thereby increasing the clients' access to health care. Starting on page 88, this guide gives ideas on how to make materials available in other languages, tips on cultural implications, developing new materials versus translating existing materials, and other recommendations on written materials.
- The [Dementia Care Network Replication Manual](#) offers tips to developing written information to the API population. This manual, funded by an ADDGS grant and produced by the Alzheimer's Association, California Southland Chapter, includes steps for developing/translating materials.
- 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 a [Chinese Glossary of Terms](#) and [Korean Glossary of Terms](#) relating to Alzheimer's disease.

2. Increase awareness through community outreach, education, and networking

In API culture the younger generation customarily cares for the elderly generation, but caregivers frequently underestimate the physical and emotional tolls of caregiving. Education and outreach can link caregivers and families to community-based organizations and services that are needed to support and prolong family

care. Among the most successful ways to build an effective outreach program is to partner with community-based organizations by:

- training community-based organizations about dementia, and
- providing information about how to link to community services capable of serving individuals with dementia and their families.

Examples of these programs include:

- **California's** [Asian American Dementia Care Network](#) is a model ADDGS program for developing partnerships and dementia-friendly services in the Chinese, Korean, Vietnamese, and Japanese communities of northern and southern California. Services include education, training, and outreach to Alzheimer families, case management, adult day care, in-home respite, support groups, legal assistance, transportation, and home safety interventions. The [Dementia Care Network Replication Manual](#) provides details on how states can replicate this program.
- **Massachusetts'** The Chinese Dementia Awareness and Intervention Project offers a "train-the-trainer" program, which educates bilingual Chinese individuals from various agencies to become dementia specialists who can conduct presentations about dementia to families.

3. Link to local dementia-capable resources and services

By the time families seek help, they may be in serious need of resource options because their family member's dementia may have already progressed. API families coping with dementia need assistance to understand the options and to access available services. States can develop programs that guide API families to support services and additional resources. Specific examples of state resources providing community-level information are:

- **Illinois'** ADDGS program works with the [Coalition of Limited English Speaking Elderly](#) (CLESE) and the Alzheimer's Association to serve the immigrant and refugee populations. Agencies representing various ethnicities formed CLESE to advocate for elders and to help them navigate through the public health care system to secure services such as case management, homemaking, and adult day care.
- **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.

The local dementia network system should be linked to the state or community single points of entry (SPOE) system. SPOE, such as [Aging and Disability Resource Centers \(ADRCs\)](#), are one-stop systems that offer consumers information, access to

support, and linkages to local care services. ADRCs reduce service fragmentation and simplify access to dementia-capable support and services.

States and communities can offer programs that connect caregivers to community agencies with expertise in dementia care:

- The Alzheimer's Association's [24/7 Helpline](#), supported in part by the Administration on Aging, provides reliable information and support to individuals impacted by Alzheimer's disease or related dementias. The toll-free number is available 24 hours a day at **1-800-272-3900**. The 24/7 Helpline serves people with memory loss and their families, caregivers, health care professionals, and the public. 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

Key features also include:

- 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;
- help in a caller's preferred language using a translation service that features over 140 languages; and
- referrals to local community programs, services and ongoing support.

4. Support caregivers by developing dementia-capable services in the community

The prevalence of Alzheimer's disease increasing among the API population, so the need for culturally proficient care will continue to grow. Families and caregivers need access to dementia-capable services in their local communities to support the ongoing care they provide at home. States can identify gaps in services where API families reside and can develop or enhance programs to include API populations. Services include but are not limited to:

- care consultation
- respite
- adult day care services

A. Care consultation

To help individuals identify needs and available resources, care consultation services in their own language must be provided. The language barrier and the unfamiliarity of the health care system make it important to offer care consultations by agencies that have the capacity to serve the growing API community. Examples of bicultural and bilingual programs include:

California's [Asian American Dementia Care Network](#) ADDGS program includes bicultural, bilingual Asian American "Care Advocates" who conduct a needs assessment and assist with access to appropriate care and services. Care Advocates serve as the point people for home visits, care planning, purchase of services, service coordination, monitoring, and follow up.

- **Massachusetts'** The Chinese Dementia Awareness and Intervention Project created a Chinese dementia helpline for caregivers. The helpline offers information about dementia from diagnosis to treatment options.

B. 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.
- **Hawaii's** [Project Dana \(The Project\)](#), an ADDGS program that collaborates with the state Executive Office on Aging, implements an interfaith volunteer caregiver program to provide in-home respite care for caregivers.

C. Adult day care services

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

- **California's** [Daybreak II Respite and Caregiver Support Services](#), supported by Catholic Charities in San Jose, offers culturally appropriate center-based day program activities and in-home respite for Chinese and Vietnamese senior citizens.

- **California's [Adult Day Services – 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. In 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.

Additional Information

The Administration on Aging has developed eight toolkits in this series that focus on different aspects of providing home and community-based services to people with dementia and their caregivers. These online toolkits are available at [AoA's Alzheimer's Disease Program page](#). Toolkit subjects include:

1. Consumer-Directed Care
2. Disaster Preparedness
3. Resources for Individuals and Families
4. Serving African American Families
5. Serving Asian and Pacific Islander Families
6. Serving Hispanic Families
7. Single Point of Entry Systems
8. Supporting Family Caregivers

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- Alzheimer's Association (2008). *2008 Alzheimer's Disease Facts and Figures*.
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