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# Alzheimer's Disease Demonstration Grants to States Program: California

## Final Report

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**ALZHEIMER'S DISEASE DEMONSTRATION GRANTS TO STATES:  
CALIFORNIA**

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## EXECUTIVE SUMMARY

California's Asian and Pacific Islander Dementia Care Network project is the most recent of a series of Alzheimer's Disease Demonstration Grants to States (ADDGS), which began with the El Portal: Latino Alzheimer's Project in 1992. These projects were implemented by the Alzheimer's Association of Los Angeles, Riverside, and San Bernardino Counties (the Los Angeles Chapter). The California Department of Aging coordinates the Grants and leads a state government-level steering committee for the Grants that includes representatives of the Los Angeles Chapter and the Department of Public Health, which operates Alzheimer's disease resource centers in the state.

The current Grant project combines a much-replicated promising practice—the El Portal Dementia Care Network model—and an evidence-based approach—the Resources for Enhancing Alzheimer's Caregiver Health (REACH) model. The El Portal Dementia Care Network model, developed during an earlier ADDGS project, has been used in the state's other ADDGS projects to provide ethnic communities with an array of culturally competent dementia services. Under the model, mainstream agencies, with their technical understanding of Alzheimer's disease and dementia, form partnerships with agencies based in ethnic communities, with their expertise in cultural competence, to provide a range of supportive services. Care Advocates make these services accessible to caregivers by assessing the needs of caregivers through in-home evaluations and linking caregivers to service providers. The REACH model, which developed and tested new ways to help families manage the daily activities and stresses of caring for people with Alzheimer's disease, emphasizes flexibility and the need to recognize and accept the values and beliefs of a community's culture.

Since the beginning of the ADDGS program, the California Grants have sought to enhance the capacity of local health and social service providers to serve the Latino, African American, and Asian and Pacific Islander communities in the state. The current Grant serves Vietnamese, Korean, and Chinese dementia-affected families. The service delivery portion of the Grant is being carried out through four Dementia Care Networks, two serving the Korean and Chinese communities in Los Angeles County and two serving Vietnamese and Chinese communities in Northern California.

The lesson of the El Portal model is that the development of an effective intervention for caregivers in an ethnic community requires action on both the system and personal levels. On the system level, an effective intervention must have:

- An alliance of trust among the community's service organizations. In El Portal and subsequent projects, provider agencies have come together to work as a team within a Dementia Care Network, fostering communication, mutual understanding, and joint planning to address the needs of the community.
- Technical expertise on dementia care and fund-raising among the members of the Dementia Care Network. In El Portal and subsequent projects, training for service providers in dementia care and assistance for provider agencies in identifying sources of ongoing financial support have been provided by the Los Angeles Chapter.

With a functioning Dementia Care Network in place, outreach to ethnic caretakers must:

- Respect and incorporate the cultural beliefs and language of the caregivers in the counseling process and in planning for support services. The El Portal model studies the beliefs and language of the community through focus groups and translates the findings into culturally appropriate support materials and personal outreach through the Care Advocate.
- Approach the caregivers in ways appropriate to their level of literacy and at the institutions where they can be reached. The current project follows the El Portal model in providing bilingual materials appropriate for children and parents through the schools.
- Acknowledge and address the caregivers' fears of discrimination. The current project follows the El Portal model in using Care Advocates from the same or similar ethnic backgrounds to establish a relationship of trust through in-home counseling. Working directly for community-based programs and trained in dementia, the Care Advocate brings culturally appropriate support and coordination services directly to Asian and Pacific Islander family caregivers.
- Acknowledge and address limits that the poverty of many caregivers places on their ability to obtain services. The El Portal model does this through helping service providers develop alternate sources of support for services to these individuals.
- Maintain flexibility in overcoming practical barriers. The El Portal model stresses the need to be flexible in areas such as client eligibility, data gathering, communication with non-English speakers, and complex family organization when implementing the model in other communities.

The California ADDGS Grants have built on the El Portal model, which has shown that it is a promising practice that can be replicated with a variety of ethnic groups. It is a model that works to create an ongoing change in community dynamics and service delivery.

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## INTRODUCTION: OVERVIEW OF ADDGS PROGRAM AND CASE STUDIES

Alzheimer's disease is a devastating degenerative disease that causes memory loss, challenging behavior problems, and severe functional limitations. A person with late-stage Alzheimer's disease requires constant supervision, support, and hands-on care. While many persons with Alzheimer's disease are admitted to nursing homes, the majority of people with the disease live in the community, where their families provide most of the care.

To improve services to persons with Alzheimer's disease, Congress established the Alzheimer's Disease Demonstration Grants to States (ADDGS) program, which is administered by the U.S. Administration on Aging. The program's mission is to "expand the availability of diagnostic and support services for persons with Alzheimer's disease, their families, and their caregivers, as well as to improve the responsiveness of the home and community-based care system to persons with dementia. The program focuses on serving hard to reach and underserved people with Alzheimer's disease or related disorders (ADRDs)" (U.S. Administration on Aging, no date).

This paper discusses one of five case studies conducted by the ADDGS National Resource Center in 2005 on the activities of selected state programs. The goals of the case studies are to:

- Document "promising practices."
- Identify policy issues relevant to providing services to people with Alzheimer's disease and their families.
- Identify strategies for accomplishing program goals.
- Identify implementation barriers and ways of overcoming them.
- Assess how selected sites are addressing the goals of the ADDGS program.

Two of the themes of the case studies are *evidence-based practices* and *replication of promising practices*. In both themes, the key question is how to adapt key elements of an existing or previous intervention into a different community setting for which the initiative was not originally designed. In these case studies:

- *Evidence-based practice* refers to using services and programs that are based on rigorous research methods and findings. An example would be using the National Institute on Aging-funded Resource for Enhancing Alzheimer's Caregiver Health (REACH) research to identify what services should be provided and how or using the Colorado ADDGS grantee of the "Savvy Caregiver" training program developed and evaluated by the University of Minnesota. Another example is ADDGS Grantees building research and evaluation activities into the project so that the impact of the initiatives can be determined objectively.
- *Replicating promising practices* refers to implementing initiatives that have not been rigorously evaluated but seem worthy of replicating in other settings. For example,

the California ADDGS Grantee applied the concepts of the Hispanic-focused El Portal model to other ethnic groups, even though the original project had not been evaluated using sophisticated research methods.

To illuminate the issues involved in implementing evidence-based and promising practices, California and Colorado were selected for case studies.<sup>1</sup> California was selected as a case study site because it serves a large minority population and has extensive experience in implementing effective practices in minority community settings. Its initial project, El Portal: Latino Alzheimer's Project, provided innovative dementia care and information to the Latino population, originally in Los Angeles. This approach has been widely reported on and replicated in other parts of the country. The system developed and provided culturally and linguistically competent educational, social, and supportive services for persons with dementia and their caregivers. Through its ADDGS Grants, California used the El Portal model for Latino groups, African Americans, and Asians and Pacific Islanders.

The overall goal of the current California ADDGS Grant for 2004-2007 is to enhance the capacity of local health and social service providers to serve Vietnamese, Korean, and Chinese dementia-affected families through a Dementia Care Network, following the model developed under the El Portal Project. **Exhibit 1** lists the objectives of the current grant.

**Exhibit 1. Main Components of California's ADDGS Grant, 2004-2007**

- Improve state policies and practices on culturally competent dementia care through partnerships with state agencies, Area Agencies on Aging, the statewide network of aging service providers, and Alzheimer's Disease Research Centers.
- Recruit, train, and use bilingual, bicultural, paraprofessional service coordinators, known as Care Advocates, to support caregiving families.
- Foster development and expansion of four Dementia Care Networks serving the Korean, Vietnamese, and Chinese communities. These networks support older adults with dementia by coordinating a collaborative, community-based model of assistance.
- Provide community educational opportunities and professional training, including REACH-derived psycho-educational workshops for caregivers, project staff, Care Advocates, and network partners.

Information for this case study was gathered by reviewing administrative files at the Administration on Aging and Web sites and by conducting an in-person site visit in June 2005 in Los Angeles, California. As part of the site visit, RTI staff interviewed ADDGS staff, state officials, research experts, providers, and consumer groups.

The principal findings of the California case study are presented in **Exhibit 2**.

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<sup>1</sup>The other theme of the case studies is systems and sustained change. ADDGS programs in Maine, North Carolina, and Oklahoma were selected to illustrate those issues.

## Exhibit 2. Principal Findings from the California Case Study

The El Portal model suggests that a number of system-level and network-level elements are needed to change the care environments in ethnic communities.

*On the system level, an intervention must have:*

- An alliance of trust among the community's service organizations, forming a Dementia Care Network to address the needs of the community as a whole.
- Technical expertise on dementia care and fund-raising among the members of the Dementia Care Network.

*With a functioning Dementia Care Network in place, outreach to ethnic caregivers must:*

- Respect and incorporate the cultural beliefs and language of the caregivers in the counseling process and in planning for support services.
- Approach the caregivers in ways appropriate to their level of literacy and at the institutions where they can be reached.
- Acknowledge and address the caregivers' fears of discrimination.
- Acknowledge and address limits that the poverty of many caregivers places on their ability to secure support.
- Maintain flexibility in overcoming practical barriers.



## **BACKGROUND ON THE CALIFORNIA ADDGS GRANTEE**

The Grantee for the Alzheimer's Disease Demonstration Grants to California has been the California Department of Aging, the State Unit on Aging. The Department of Aging also administers the Medicaid Older Adults Home and Community-Based Services Waiver and certifies adult day health care centers to operate. The California Department of Aging has been active in improving services for people with Alzheimer's disease, although its ability to seek and monitor grants has been affected in recent years by the state of California's financial problems.

The Department of Aging has contracted with the Alzheimer's Association of Los Angeles, Riverside, and San Bernardino Counties (the Los Angeles Chapter) to conduct ADDGS Grant activities. The Los Angeles Chapter has been the contractor for a series of ADDGS Grants, beginning with the 1992 El Portal: Latino Alzheimer's Project, which developed the Dementia Care Network model used in the current Grant. The Department of Aging monitors the progress of Grant activities and makes reports to the U.S. Administration on Aging. The Department of Aging also convenes and participates in a state government-level steering committee for the Grant. The Department of Public Health, which operates Alzheimer's Disease Research Centers in the state and assisted with the grant application, and the Los Angeles Chapter are also represented on the committee.

The Los Angeles Chapter is a multicultural organization devoted to providing education and assistance to individuals with Alzheimer's disease and their families. It employs about 55 persons, with offices in three counties. It was founded in 1980 but has experienced major growth since 1992, partly as a result of its activities as a contractor for the California ADDGS Program. In 1990, it established a multicultural outreach advisory board with representatives from a number of local and community aging and cultural groups.

Under the leadership of its multicultural outreach advisory board, the Los Angeles Chapter conducted outreach activities into underserved ethnic communities predating its involvement with the ADDGS Program. Through these outreach activities, it was the first of the major nonprofit health organizations to work in East Los Angeles. Although the Los Angeles Chapter was still a small organization in 1990, it began that year to make small grants of \$500 to direct service providers in underserved ethnic communities, funded by contributions by the board. By 1992, the Los Angeles Chapter had raised funds to provide \$5,000 of technical assistance grants, which were given to enhance adult day care programs serving ethnic areas. Since 1992, the Los Angeles Chapter has become increasingly involved in multicultural Alzheimer's disease and dementia education and support, and now participates in multiple advisory boards related to the ADDGS grants. Many of the members of the original multicultural outreach advisory board have joined the Los Angeles Chapter or its governing board, further institutionalizing the multicultural nature of the Chapter's approach.

Since 1992, the Los Angeles Chapter has grown from a small organization that primarily depended on volunteers to a large organization of paid staff supported by an array of funding sources, including federal, state, and private grants. The Los Angeles Chapter has received the support of entertainment and other celebrities with ties to Los Angeles and family members dealing with Alzheimer's in staging fund-raising activities.

The original El Portal: Latino Alzheimer's Project, which supported family caregivers in the Latino community of Los Angeles, continues to be the main model used in subsequent Los Angeles Chapter programs. Since this initial grant was funded, additional programs have been established to provide Dementia Care Networks and El Portal model services in African American and Asian and Pacific Islander communities within the Los Angeles area and later in the San Francisco area of the state.

## THE EL PORTAL: LATINO ALZHEIMER'S PROJECT

The El Portal: Latino Alzheimer's Project, initiated in 1992, created a Dementia Care Network model that has been used by the Los Angeles Chapter in subsequent ADDGS Grants. Funded by the first ADDGS Grant to California, the El Portal Project used this Dementia Care Network to bring the Los Angeles Chapter together with community-based agencies for ethnic communities. As the mainstream agency, it provided technical understanding of Alzheimer's disease and dementia, while the community-based agencies provided expertise in cultural competence. Together the Dementia Care Network they formed provided the Latino community with an array of culturally competent community services. A Care Advocate position created as a part of the project conducted outreach, provided community education, and assessed the needs of caregivers through an in-home evaluation. The El Portal Project also conducted an intensive public relations and outreach campaign, including print and electronic media, marketing presentations to consumer and provider groups, and community fairs (Aranda et al., 2003).

The Care Advocate was a critical component of the Dementia Care Network developed under the El Portal Project. Bicultural, paraprofessional Care Advocates were hired by the subcontracting local provider organizations in the network for their skills in providing culturally appropriate care and were then trained in dementia by the Los Angeles Chapter. The Care Advocates conducted outreach and community education to identify families needing services, helped family caregivers coordinate Alzheimer's care, and served as dementia resource consultants to other staff in the subcontracting local organizations.

The Care Advocate provided services to families in a unique manner. Ordinarily, providing a care manager would not have qualified as part of the direct service requirement under this federally funded grant project, but the Care Advocate, by going into the home, sitting with the families, and providing direct support, went beyond standard care management to provide a level of support that qualified as direct service. The Care Advocate worked with the families to determine the most effective way to address their needs by assessing, educating, supporting, and connecting families to the services provided by the network; helping clients understand and respond to governmental regulations and requirements; and leading support groups. In addition to respite services, the Care Advocate was able to help families access medications, home safety equipment and modifications, and transportation.

Under the model, outreach was culturally appropriate, including the development of bilingual materials. In recognition of the need to educate the community about Alzheimer's disease and available services, the basic brochure for the project listed and defined the available services in terms that people could use in calling a Care Advocate for help. El Portal also pioneered the use of a postcard-style outreach brochure that the Care Advocates distributed.

As the first demonstration grant to address the needs of Latino families dealing with Alzheimer's and dementia, the project had to address resistance to change by service providers. Prior to El Portal, service provider agencies were accustomed to public programs with structured regulations that limited flexibility. In contrast, El Portal adopted an approach designed to allow providers to experiment with new and different ways to help families. The staff of the Los Angeles Chapter worked closely with the staff and management of the provider agencies, helping them to understand the demonstration project and the need to document these efforts so that they

could be shared with project partners. The project leadership bolstered its credibility with providers and social services professionals by assembling a project advisory board of experts to support the program.

Another issue faced by the project was the need to establish trust among the provider agencies to enable them to work as a team within the Dementia Care Network. Remarkably, during the El Portal Project, the executive directors of the service agencies shared agency strategic plans, indicating a high level of trust among the network. They also established a joint approach to fund-raising in which the agencies shared information about funding opportunities and recommended each other's funding applications. The Los Angeles Chapter aided the agencies' fund-raising efforts with technical assistance and recommendations to funding sources.

### **Structure of the El Portal Alzheimer's Dementia Care Network Model**

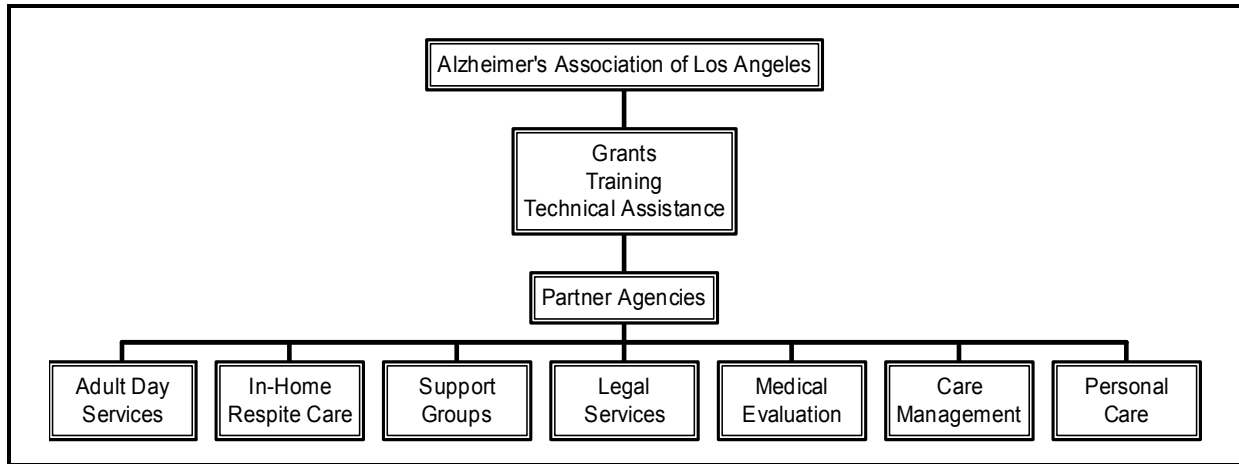
The Dementia Care Network developed under the El Portal: Latino Alzheimer's Project is "an interorganizational community-based collaborative model established to provide dementia care services to an ethnic community" (Alzheimer's Association, 2004). The four major goals of a Dementia Care Network are to:

- Establish linkages with local community organizations, service providers, and informal neighborhood networks through a comprehensive awareness campaign for the targeted geographic area.
- Facilitate the coordination of existing services in the target area and identify gaps and barriers to service delivery.
- Identify agencies in the targeted communities that can provide families and caregivers with culturally appropriate and dementia-knowledgeable care.
- Evaluate existing translated information, develop linguistically and culturally appropriate materials, and disseminate them to the community through provider networks.

The general organization of a Dementia Care Network is illustrated in **Exhibit 3**. The network is directed by a lead agency with expertise in dementia, which for the El Portal Project was the Alzheimer's Association of Los Angeles, Riverside, and San Bernardino Counties. The prime responsibilities of the lead agency are to provide programmatic oversight and fiscal management, training according to the needs of the subcontracted providers, and support and technical assistance.

Partner agencies having expertise as service providers and with cultural competency for the target population are subcontracted by the lead agency to provide the direct services. Under the El Portal Project these services included adult day care, respite services, support groups, legal services, medical evaluation, care planning and coordination, and personal care services. Care

### Exhibit 3. Components of a Dementia Care Network



Advocates in the employ of the partner agencies conduct outreach, assist the families in accessing these services, and provide caregiver and professional education. Respite services are congregate or in-home, and clients are also directed to appropriate diagnostic services and medical follow-up. The network also makes the Alzheimer's Association Safe Return program available to families.<sup>2</sup>

#### Replication of the El Portal Dementia Care Network Model

From their experience with the El Portal Project, the Los Angeles Chapter developed five key considerations for any agency considering replication of a Dementia Care Network on the El Portal model (Alzheimer's Association, 2004). Specifically, agencies should conduct an internal review of their capacity in the areas of:

- Dementia care.
- Existing and potential partnerships to provide network services.
- Capacity to communicate productively with the target population.
- Ability to commit the significant amount of time required to establish a relationship with the community to build rapport and identify service needs.
- Ability to identify and respect the cultural values of the population.

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<sup>2</sup>The Safe Return program is a nationwide initiative of the Alzheimer's Association, an identification, support, and enrollment program that provides assistance when a person with Alzheimer's or a related dementia wanders and becomes lost locally or far from home. When a missing person is reported, Safe Return faxes the enrolled person's information and photo to local law enforcement. The person carries Safe Return identification, including an 800 number, so that when they are found their location can be reported to the Safe Return headquarters, which then notifies listed contacts.

Once an agency has determined that it has capacities in these five areas, there are four major steps in implementing this model of Dementia Care Network: planning, start-up, implementation, and continuation. The planning phase, which begins with the assessment described above, also includes bringing stakeholders together and assigning roles for the development of the network, followed by an assessment of existing and needed services and resources. Under the start-up phase, an advisory group should be formed and funding and staff brought into place, so that network outreach can begin. In the implementation phase, with the partners providing network services to the population, activities include the mentoring and support of the Care Advocates and a study of the effectiveness of services. In the continuation phase, the agency addresses the need for ongoing funding, building support for the network, and reassessing community service needs (Alzheimer's Association, 2004).

A Dementia Care Network Replication Manual prepared by the Los Angeles Chapter describes the elements of an El Portal-type Dementia Care Network and also provides suggestions for culturally appropriate communication (Alzheimer's Association, 2004). The Los Angeles Chapter also has written Dementia Care Network Policy/Procedures, which has been updated for the current ADDGS project. This document provides examples of practices, policies, and procedures being implemented under the El Portal model with the present ADDGS Grant (Alzheimer's Association, 2005).

## **SUBSEQUENT ADDGS GRANTS**

The Los Angeles Chapter has administered three other grant projects employing the El Portal Dementia Care Network model:

- African American Education and Outreach Project (initiated in 1995).
- Asian and Pacific Islander Dementia Care Network Grant (2000-2004).
- Asian and Pacific Islander Dementia Care Network Grant (2004-ongoing).

### **African American Education and Outreach Project (1995+)**

This project was launched in 1995 as an extension and replication of the El Portal Alzheimer's Disease Demonstration Grant (the El Portal Project). With additional funding from the California Endowment and the California Office of Minority Health, the Los Angeles Chapter first facilitated the formation of an African American Outreach Work Group. This Work Group developed a plan for outreach to the African American community in the West-Central area of Los Angeles County. Based on this plan, the Los Angeles Chapter organized a West-Central Dementia Care Network in 1998 and held a series of focus groups in 1999, leading to partnerships with African American faith-based organizations to reach out to their communities and develop a Dementia Care Network with community service providers. Following the approach used in the original El Portal model, Care Advocates were hired to work with families and guide them to available services. Because churches were highly trusted and visible in this community, they were instrumental in the outreach and educational aspects of the project and as a base for peer support groups (Alzheimer's Association, 2001).

### **Asian and Pacific Islander Dementia Care Network Grant (2000-2004)**

The direct predecessor of the current project was the ADDGS Grant to California's Asian and Pacific Islander Dementia Care Network project (2000-2004), which implemented the El Portal model in four communities: Chinese and Japanese communities in Los Angeles and Chinese and Vietnamese communities in Santa Clara County. As is the case with the current Asian and Pacific Islander Grant, this project was designed to enhance the capacity of the local health and social service providers to serve dementia-affected families in these communities through improved statewide policies and practices on culturally competent dementia care; the development of Dementia Care Networks to create and facilitate access to services; and the development of training programs for caregivers and ethnically diverse professional providers.

Additionally, this 2000-2004 ADDGS Grant included funding for summative research based on client demographic data, responses from focus groups of all the participating communities, and satisfaction surveys and service utilization logs submitted by the subcontractors in the communities. Three years of funding were originally authorized for this first Asian and Pacific Islander grant, and funding for a fourth year was also made available by the Administration on Aging.

**Asian and Pacific Islander Dementia Care Network Grant (2004-ongoing)**

The ADDGS Grant currently being implemented by the Los Angeles Chapter seeks to enhance the capacity of local health and social service providers to serve Vietnamese, Korean, and Chinese dementia-affected families. It again employs the El Portal model to provide direct services and support to Alzheimer’s family caregivers through Dementia Care Networks. Although the target populations are somewhat different, this project has the same three initiatives (listed above) as the previous grant. The California Department of Aging awarded the 3-year contract for the project to the Los Angeles Chapter on October 15, 2004, with total project funding of \$933,000 including the state and contractor match.

The process of improving statewide policies and practices under the current grant is the work of the grant steering committee, which includes representatives from the California Department of Health Services, including the Center for Gerontology’s Alzheimer’s Disease Program; representatives from the California Department of Aging; and representatives from the Los Angeles Chapter and several statewide leaders in dementia care. The steering committee is examining project results for opportunities to recommend more culturally appropriate policies and practices for minority-focused dementia care.

The service delivery portion of the Grant is being carried out through four Dementia Care Networks, two located in Los Angeles County and two located in Northern California. The Los Angeles Chapter serves as the lead agency for the two networks in Los Angeles County, and the Alzheimer’s Association of Northern California and Northern Nevada is the lead agency for the two networks located in the San Francisco area. The Chinese Dementia Care Network in Los Angeles and the Vietnamese Dementia Care Network in Santa Clara County, which were part of the prior ADDGS Grant, and new Dementia Care Networks are being organized to serve the Korean community in Los Angeles and the Chinese community in San Francisco.

The Dementia Care Networks for the Grant are summarized in **Exhibit 4**.

**Exhibit 4. Dementia Care Networks**

<b>Area and Community Served</b>	<b>Relation to Previous Asian/Pacific Islander Grant</b>	<b>Provider Agency</b>
<b>Los Angeles Area</b>		
Chinese community	Continuing network	Chinatown Service Center
Korean community	New network	Korean Health, Education, Information and Research (KHEIR) Center
<b>San Francisco</b>		
Chinese community	New network	Self-Help for the Elderly
<b>Santa Clara County</b>		
Vietnamese community	Continuing network	Pope John XXIII Multi-Service Center



The Los Angeles area will be served by the Chinatown Service Center and the Korean Health, Education, Information, and Research (KHEIR) Center. Established in 1971 with a single bilingual worker, the Chinatown Service Center ([www.cscla.org](http://www.cscla.org)) is the largest community-based Chinese American health and human service organization in Southern California. The Los Angeles Chinese community is the largest and the poorest in California. KHEIR ([www.koreanhealth.org](http://www.koreanhealth.org)) serves the Korean community in Los Angeles, which has not previously had a Dementia Care Network. Established in 1986, the mission of KHEIR is to connect low-income, recently immigrated, monolingual or limited English-speaking Koreans with health care and social assistance.

The Northern California and Northern Nevada chapter of the Alzheimer's Association ([www.alznorcal.org](http://www.alznorcal.org)) is a subcontractor to the Los Angeles Chapter under the Grant and serves as the mainstream dementia service agency for the northern part of the state. It has subcontracted with two provider agencies for the Dementia Care Networks in the northern part of the state. Self-Help for the Elderly ([www.selfhelpelderly.org](http://www.selfhelpelderly.org)), serving the Chinese community in San Francisco, began as a "War on Poverty" program in 1966 and has grown into a full-service care provider. Catholic Charities of San Jose serves the Vietnamese community in Santa Clara County through their facility at the Pope John XXIII Multi-Service Center and its Day Break II Adult Day Support Center program ([www.ccsj.org](http://www.ccsj.org)). Although the organization is part of the missionary work of the Catholic Church, it serves people of all beliefs, cultures, ethnicities, and ages.

As with the original El Portal Project, the training provided under the grant includes a variety of linguistically appropriate materials for caregivers and professionals, along with an updated replication manual based on the experiences of the current project, and tip sheets for professionals working with the target populations in a culturally competent manner.

## EVIDENCE-BASED AND PROMISING PRACTICES

### **Background, Selection of Evidence-Based and Promising Practices, and Prior Study Findings**

The main model on which the current Grant is based is the El Portal Dementia Care Network. For the current project, the California Department of Aging selected the National Institute on Aging-funded REACH project as an evidence-based program to incorporate into the current project. Both approaches worked collaboratively in local communities to provide appropriate, culturally sensitive, and accessible dementia services to Alzheimer's family caregivers. In addition, both approaches reported similar conclusions about effective practices in serving family caregivers of persons with Alzheimer's disease in minority communities (Aranda et al., 2003; Gallagher-Thompson et al., 2003). The grantee concluded that the principles developed for minority caregivers were particularly appropriate to the elderly within the Asian and Pacific Islander communities. Fully 70 percent of seniors in these communities in California are foreign-born, with 46 percent unable to converse effectively in English (Asian Pacific American Legal Center, 2004). Members of these communities also often viewed dementia as a condition normal to aging and were unaware that it is a disease and that services are available.

#### Studies of the Original El Portal Dementia Care Network

The developers of the El Portal model recognized early on that they needed to have a process in place to study the project as it became operational. Both a nationally based and a locally sponsored research study were conducted during the early years of the project, using data obtained from focus groups with community providers and Alzheimer's disease family caregivers in the Latino community, as well as information from comprehensive intake forms and follow-up satisfaction surveys with caregivers developed in partnership with the federal government.

The nationally based research study examined the El Portal Project as part of the national evaluation of the ADDGS program by the U.S. Administration on Aging and noted the importance of establishing trust among providers. A key part of building trust during the formative stages of El Portal was ensuring that each agency delivered the resources or services it promised to the joint effort (Montgomery, 2002). Montgomery also highlighted the importance of project leadership. In this case, leadership was provided by a person who was well known and respected by both Latinos and providers.

The locally sponsored research study employed the same data the Los Angeles Chapter gathered for the national evaluation of the El Portal model. The Chapter employed a series of experts from area universities to produce a research article. In addition, it supported the writing of an article outlining the organization of the grant and of the Dementia Care Networks, highlighting the cultural characteristics of the target audience, and describing service utilization under the project (Aranda et al., 2003).

#### Studies of the First Asian and Pacific Islander ADDGS Grant

The first Asian and Pacific Islander Alzheimer's Disease Demonstration Project produced a detailed report of outputs from the initial assessment and reassessment data collected by the

project, including demographic and socioeconomic characteristics of clients and caregivers, along with caregiver depression, competence, and service utilization (Moon, 2003). As noted previously, the project also developed the Dementia Care Network Policy/Procedures manual (Alzheimer's Association, 2005) with detailed instructions for implementing all parts of the Dementia Care Network program and the Dementia Care Network Replication manual (Alzheimer's Association, 2004) detailing the philosophy and practice of the Dementia Care Network model. The Replication Manual has been distributed to Area Agencies on Aging across California.

Before initiating Dementia Care Network services under this Grant, the project studied the Chinese, Vietnamese, and Japanese communities it would serve by conducting a series of focus groups held during 2002 and 2003. The study (Houston, 2003) recommended a number of ways to provide culturally sensitive dementia care:

- Publicizing services through linguistically relevant ethnic press; posting and distributing promotional flyers at culturally relevant churches, temples, and supermarkets; and using bilingual direct mailings to major employers in areas with large Asian populations.
- Expanding the availability of Asian and Pacific Islander caregiver support groups.
- Expanding in-home support services for Asian family caregivers, including bilingual home health training for family and professional caregivers.
- Broadening needs assessment efforts among Asian populations to determine the specific attitudes and needs of Asian caregivers.

The Los Angeles Chapter recommends that people interested in developing programs using the El Portal model take advantage of the many culturally sensitive materials (including caregiver training manuals, replication manuals, public relations materials, and intake and outreach forms) that have been developed and revised for various population subgroups.

Another study sponsored by the Los Angeles Chapter drew on the Dementia Care Network experience under a contract with the state of California in 2000 to lead a statewide effort to develop an evidence-based educational campaign. In this project, the Los Angeles Chapter built on previous work funded by the California Department of Health Services, along with its El Portal experiences, to develop evidence-based practice guidelines for primary care physicians in managing Alzheimer's disease (Cherry et al., 2004; Cummings et al., 2002a; 2002b; California Workgroup, 1999). The Los Angeles Chapter then translated these guidelines into a program to empower caregivers, specifically including ethnic caregivers, to perform critical patient self-management activities. The program, "Partnering with your Doctor," developed informational materials in English and Spanish for a workshop that was disseminated and conducted across California (Barclay, Cherry, and Mittman, forthcoming).

## Studies of the Current ADDGS Grant

Although the current ADDGS Grant contains no funding or provision for a summative evaluation of the project, the Los Angeles Chapter and its partners plan to conduct a limited number of evaluation activities. A satisfaction survey begun in the previous grant project has been continued. Sent by mail, it has produced a response rate of about 67 percent for the Chinese community and about 25 percent for the Vietnamese community. Project leaders also report that the subcontracting agencies plan to add questions related to grant services to their satisfaction surveys.

In addition, the Chapter leadership has personal relationships with faculty at area universities and has been able to draw on those relationships for some support. For example, the University of Southern California has made available the results of a series of focus groups with Korean caregivers conducted by a graduate student. These results have been useful in developing materials, including tip sheets on community attitudes and appropriate language for Care Advocates and key providers.

Los Angeles Chapter leadership would like to work with its service agencies to do a more intensive evaluation. However, many of the subcontracting agencies are relatively new, work with recently immigrated communities, and are supported predominately by public funding to serve a poor population. As a result, few if any funds are available for data collection efforts.

At the current time, the sole requirement of service provider agencies is to provide the Los Angeles Chapter with routine quantitative reports of their activities, including support group attendance, the number and type of caregiver and community education activities, and attendance at similar outreach activities.

## REACH

The researchers who evaluated the REACH I project reported that to conduct an effective Alzheimer's disease caregiver intervention program, medical and social service professionals need to educate themselves about the nuances of cultural and ethnic groups. According to the evaluators, an effective intervention is based on a recognition and acceptance of the values and beliefs of the community culture. Effective practices include the use of bilingual/bicultural staff, training in cultural awareness and mental health skills, and development of promotional and educational materials that were translated in a culturally sensitive manner (Gallagher-Thompson et al., 2003).

For the current ADDGS Grant, Care Advocates, along with project staff from the Dementia Care Network provider agencies, are receiving training from Dr. Delores Gallagher-Thompson, one of the lead researchers from the REACH project. Dr. Gallagher-Thompson, who is based in the San Francisco Bay area, and her staff will draw on their experience with the now second-generation REACH Project, known as REACH II.

## **Challenges in Applying Evidence-Based and Promising Practices**

The Los Angeles Chapter has considerable prior experience working with the REACH model and access to professional staff who have already implemented this model in other

community settings. The REACH model also has been readily accessible to the Los Angeles Chapter, through both the availability of numerous articles describing its work and the previously existing relationship between the Los Angeles Chapter and Dr. Dolores Gallagher-Thompson.

While the original El Portal Project anticipated and formally incorporated a discussion of potential barriers in its application of the model to specific community settings (as described below), the adaptation of this model to the Asian and Pacific Islander communities has been relatively straightforward given the flexibility built into the design of this approach. Each Dementia Care Network has developed in response to the unique characteristics and cultural sensitivities of the population being served. For example, for the African American project, the church was given a pivotal role in developing the African American Dementia Care Network. Similarly, for the Asian and Pacific Islander projects (both current and prior Grants), project staff ensured that both eastern medicine and western medicine were available as supportive service options for family caregivers and their loved ones.

The following cultural/philosophical issues were among those anticipated and addressed by the originators and subsequent staff helping to implement the El Portal model.

### Cultural and Philosophical Barriers

#### *Cultural Beliefs about Dementia and the Role of the Family Caregiver*

An important limitation imposed by cultural beliefs is often the language used in describing dementia. In the African American community, for instance, the term “forgetfulness” was commonly used. In Korean and Chinese communities, people with dementia were commonly considered “bad” or described as having a curse. Another issue was the need for sensitivity to community religious beliefs, such as beliefs in the power of folk healers and shamans to cure disease, and the need to incorporate a tolerance of these attitudes into the Care Advocate’s activities.

The approach of the El Portal model to addressing these cultural beliefs is a three-step process: a community needs assessment, development of culturally appropriate printed materials describing the program and its services to the community, and outreach delivered through a culturally sensitive approach implemented by the Care Advocate. The Los Angeles Chapter has found that the community focus groups held for the first Asian and Pacific Islander Grant were a very effective approach in determining these cultural beliefs. With the information about language and beliefs gathered from these groups, the next step is to produce flyers using appropriate language and guidance for Care Advocates about sensitive issues. Finally, the Care Advocate makes a personal contact, casting the available services in an appropriate and attractive context for the caregiver.

#### *Low Literacy and Language Differences*

Low literacy, which may include difficulty with English or an inability to read and write in the caregiver’s native language, creates a barrier to reaching some caregivers.

Under the El Portal model, it is useful to establish contact with families through pre-existing relationships with local institutions or businesses; in the current project, organizers have identified the public schools as a venue to contact families through the children. School

presentations are an effective way of reaching children, who often are family caregivers. Information can also be distributed to them in bilingual flyers, which the children can take home and read to the older members of the family in either English or their native language. In addition to making materials available in the appropriate language, these flyers need to be written at a level that people in the community can comprehend. Another group that can be reached through the schools is the “sandwich generation” of adults who have access to educational presentations at existing “Parent Centers” at the junior high and high schools.

#### *Discrimination and a Resultant Lack of Trust in Institutional Providers*

Discrimination against ethnic communities has made many members of those communities hesitant to trust anyone outside the community, or even the immediate family. To address this issue, Care Advocates are usually of the same or similar ethnic background as the caregiver. In addition, training in culturally appropriate approaches is provided. The in-home visit is helpful in overcoming this distrust, particularly in cases where much of the community is newly arrived or the caregiver does not go outside the home.

#### *Limited Income, or Limited or No Health Insurance*

Overwhelming poverty in parts of the community can lead to situations in which the need for support in a caregiving situation becomes as basic as the need for a refrigerator. Poverty can also affect service providers, who are totally dependent on government programs or foundation grants for support. This makes them financially insecure.

While not an antipoverty program, the El Portal model has addressed this barrier by working to make the service providers more financially stable through two mechanisms. One mechanism is to encourage service providers to reach out to more affluent segments of the communities, identifying both those caregivers who do have personal resources and those who may be eligible for Medicaid and state support. The other mechanism is to assist service providers in developing the skills to seek private funding. Under the El Portal model, community network teams develop joint strategy and mutual support among service providers. Service providers are also expected to develop grant support to cover the matching funds requirements of the project grant and receive technical support from the Los Angeles Chapter when developing grants.

#### Practical Barriers

The following practical challenges have been addressed by prior and/or current project staff of the El Portal Project.

#### *Resistance by Physicians*

Doctors have resisted signing diagnosis forms because of scams involving securing diagnoses of dementia in Los Angeles and San Jose. One scam was for a respite provider to arrange for the diagnosis of a client and then make false insurance claims for days of service the client did not receive.

The El Portal Project addressed this difficulty and the delays caused by limited capacity at memory assessment clinics by being lenient in enforcing the requirement for a diagnosis to provide services and allowing services to be provided for up to 6 months prior to diagnosis.

#### *Overly Complicated Client Intake Forms*

The ten-page intake form used under the first Asian and Pacific Islander Grant, though useful for data collection, asked many very personal questions. Caregivers were often embarrassed in responding to the questions, and the Care Advocates reported that it could take multiple visits to complete the form. This restricted the time available for counseling the family and planning services.

The Los Angeles Chapter decided to stop using this form in December 2004 after the end of the national data collection effort by the University of Kansas, although data were collected until the end of June 2005. The Care Advocates report that a new, much shorter and less personal intake form is facilitating their contacts with caregivers.

#### *Large Number of Dialects Spoken*

The number of Chinese dialects is an ongoing challenge in addressing that community. The large number of dialects creates difficulties in completing the intake forms and compromises their function as data-gathering tools for research. The number of dialects also has made it difficult to develop support groups for Chinese caregivers.

In dealing with the intake form, the Care Advocates employed their own knowledge of dialects when possible, and when that was not possible, they tried to get assistance from a service provider colleague. On occasion, it was necessary to rely on family members as translators or for the interviewer to suggest language to the interviewee, less than ideal solutions, which to some degree compromised the role of the intake form in data collection. The issue of support groups for Chinese caregivers was resolved by developing smaller groups so that caregivers with different dialects would have their own groups.

#### *Complex System of Family Caregiving*

In Asian American communities, the official caretaker of parents is typically the oldest son, but it is usually the son's wife or the oldest daughter who does the actual caregiving. As a result, Care Advocates have learned that it is necessary to approach the son before contacting and helping the actual caregiver.

## **GRANT STRATEGIES FOR SYSTEMS CHANGE AND SUSTAINABILITY**

### **Strategies Used by Earlier Grants**

In California, the leveraging of funding for the grant is the responsibility of the contractor agency, the Los Angeles Chapter, which has developed expertise in grant writing. The Chapter also has required that its community partners contribute their own funds and begin to develop the capacity to become self-supporting once demonstration funds are exhausted. The Los Angeles Chapter leadership has introduced these requirements because of its concern that these Dementia Care Networks will not be able to continue without additional external funding.

During the previous Asian and Pacific Islander Grant, the Los Angeles Chapter was able to generate a number of additional grant-funded sources of support, including:

- Eisai/Pfizer, Inc.—2002: a \$5,000 grant for educational outreach in which the 10 warning signs of Alzheimer’s disease were printed on grocery bags.
- Weingart Foundation—2003: a \$50,000 2-year grant to support direct services to Chinese families in the San Gabriel Valley.

The Los Angeles Chapter has experienced some success in continuing the previous grant projects that used the El Portal model. Since the end of the 1992 El Portal ADDGS Grant in 2000, for instance, a number of the services have continued to be able to secure grant or private funding. Among these are some of the adult day care operations, support groups, and legal clinics. The service agencies that partnered in the network recognized the value of the collaborative efforts and of the Care Advocate in developing their business models and in serving families. They have continued to hold discussions with their network partners and have incorporated the Care Advocates into their regular organizations. The Care Advocates have had to assume more generalist duties, but the grant trained service managers and other organization staff to the point that knowledge of dementia issues is diffused throughout the service agency organizations and continues to affect service delivery.

Similarly, since the end of the African American project funding in 2000, the City of Inglewood, a service provider for the project, has maintained its Care Advocate, and the care network formed for the project continues to meet, with support groups continuing and growing in size. Charles Drew University, a partner in the original African American Dementia Care Network, operates a memory screening program that serves members of the African American community. The clinic program director also partners with the Los Angeles Chapter for research studies targeting the community, and the program staff provides support in reaching the community with chapter services.

The two Dementia Care Networks from the previous Asian and Pacific Islander Grant (serving the Japanese community in Los Angeles and the Chinese community in Santa Clara County) were self-sustaining from fee-paying clients and private grants by the end of 2004 and have continued to function and provide services. The Little Tokyo agency serving the Japanese community in Los Angeles made the Care Advocate position permanent.



The Los Angeles Chapter also continues activities directly related to supporting these efforts. It has established a Dementia Care Network alumni group for service providers who remain active members of the community committees established by the Grant. Those providers are charged lower rates for training offered by the Chapter for their employees. Former Care Advocates, who may be working for service providers or contracting their advocacy services independently, continue to meet with and receive mentoring support from the project manager for the current Grant program at the Los Angeles Chapter.

### **Strategies Used by the Current Grant**

The Los Angeles Chapter has continued to develop a strategy of incorporating sustainability into its contract with its service providers. For the current Grant, it is requiring in-kind matching by direct service providers, a plan to develop capacity for writing grants so that service providers apply for other funding opportunities, and the development of internal expertise in dementia care at the service provider level.

Specifically, service providers were selected with the expectation that they would continue to support these contractually required levels of in-kind funding for the care coordination, program, and personnel costs of providing network services past the funding period. Subcontractors also are expected to seek additional funding from foundations, corporations, and other donations to continue and expand the project after the original grant, and they receive technical assistance from the chapter to support their efforts.

Coupled with this financial strategy is a nonfinancial strategy for sustaining network services by disseminating dementia expertise throughout the subcontracting agencies. Subcontracting agencies are required to send staff members to participate in dementia training. This training, coupled with the intense training provided to the Care Advocates, provides these agencies with dementia expertise. They are then able to incorporate the approach to services promoted by the project in the course of their usual service activities. The Los Angeles Chapter will support continuing dissemination of expertise through the preferred rates for training offered to staff of former contractors who continue to support network services.

As with the previous grant project, the Los Angeles Chapter continues its own efforts to secure grant support and has so far received one award, funding from the Queenscare Foundation in 2005 for \$25,000 for educational activities in the Koreatown area of Los Angeles.

The Los Angeles Chapter is making efforts to disseminate the El Portal model to state Area Agencies on Aging and to other chapters and states. As mentioned above, the Replication Manual has been sent to all the state Area Agency on Aging directors. This was to encourage them to use some of their Older Americans Act Title III–E National Family Caregiver Support Program funding to institute similar programs in their communities, although none have done so yet. The San Diego Alzheimer’s Association chapter has adopted the model and has secured money from the California Endowment to establish a Latino Dementia Care Network. With the manual, the Chapter also offers limited technical assistance and has provided support to projects in Alaska, Puerto Rico, New Mexico, and Arizona.

## CONCLUSION

The El Portal: Latino Alzheimer's Project Alzheimer's Disease Demonstration Grant to California and the subsequent ADDGS Grants based on the El Portal model have provided intensive outreach to ethnic minority communities in the Los Angeles and San Francisco areas of the state. These Grant projects have followed the model developed by the El Portal Project in developing Dementia Care Networks and using Care Advocates.

The El Portal model emphasizes the necessity of shared expertise between Alzheimer's disease experts and community-based programs with an in-depth understanding of the community culture. The model also includes a flexible person-based approach. Implemented by an experienced contractor, the Alzheimer's Association of Los Angeles, Riverside, and San Bernardino Counties, these projects have provided support, educational, and respite services to caregivers in the Latino, African American, Chinese, Japanese, Vietnamese, and Korean communities. The most recent ADDGS Grant project has used the lessons of the REACH Project (<http://www.edc.gsph.pitt.edu/REACH/>), which also encourages those designing programs to support family caregivers, to be flexible, and to recognize and accept the values and beliefs of the community culture (Schulz, 2005).

The lessons of the El Portal model, as also expressed in its implementation during the El Portal and subsequent projects, are that the development of an effective intervention for caregivers in an ethnic community requires action on both the system and personal levels.

On the system level, an effective intervention based on the El Portal model must have:

- An alliance of trust between the community's service organizations, forming a Dementia Care Network to address the needs of the community as a whole. The El Portal model does this through community networks that foster communication, mutual understanding, and joint strategy.
- Technical expertise among the members of this network in both dementia and fund-raising. The El Portal model calls for training in dementia care by the mainstream dementia service agency to provide training in dementia care and to assist the provider agencies in identifying and successfully approaching sources of ongoing financial support beginning during the course of the original grant-funded project.

With a functioning Dementia Care Network in place, outreach to ethnic caregivers must:

- Respect and incorporate the cultural beliefs and language of the caregivers in the counseling process and in planning for support services. The El Portal model researches the beliefs and language of the community through focus groups and translates the findings into culturally appropriate support materials and personal outreach through the Care Advocate.
- Approach caregivers in ways appropriate to their level of literacy and at the institutions where they can be reached. One way in which the El Portal model does this is by distributing bilingual materials appropriate for children and parents through the schools.

- Acknowledge and address the caregivers' fears of discrimination. The El Portal model does this through Care Advocates of the same or similar ethnic backgrounds who establish trust through in-home counseling.
- Acknowledge and address limits that the poverty of many caregivers in these communities places on their ability to secure support. The El Portal model does this through helping service providers develop alternate sources of support for service to these individuals.
- Maintain flexibility in overcoming practical barriers. The El Portal model requires the flexibility to adapt in such areas as client service eligibility, data gathering, use of multiple languages, and complex family organization.

In reaching caretakers, the Care Advocate is a key player. Working directly for community-based programs and trained in dementia, this individual brings culturally appropriate support and coordination services directly to Asian and Pacific Islander family caregivers in their homes. The Care Advocates receive the training they need to understand the caregiver's needs, provide counseling, and serve as a connection to appropriate community services. The resulting flexibility coupled with expert support, provides the Care Advocates with a mechanism for overcoming a series of potential barriers related to cultural, economic, literacy, and trust issues.

Under the direction of the Los Angeles Chapter, the El Portal model has served as the basis for a series of grant-supported interventions to assist dementia caregivers. Employing a culturally appropriate approach to promote enduring change in community dynamics and service delivery, the El Portal model has brought increased dementia services to a wide range of ethnic communities.

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