

dementia care network

Replication Manual

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alzheimer's  association™

Dementia Care Network Replication Manual

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Alzheimer's Association of Los Angeles, Riverside, and San Bernardino Counties Chapter, Inc.
5900 Wilshire Boulevard, Suite 1100
Los Angeles, California 90036
Phone: (323) 938-3379

Dementia Care Network

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Introduction

Alzheimer's disease and other dementia disorders are affecting people of all races, cultures and communities at rapidly increasing rates. Because increasing age is the greatest risk factor for Alzheimer's disease, the shifting demographics of the United States' (U.S.) aging population have a direct impact on the disease's prevalence. It is estimated that, by the year 2030, the minority elder population will triple and one out of four elders in the U.S. will belong to a minority racial or ethnic group (U.S. Bureau of the Census).

Ethnic and cultural minorities in the United States encounter obstacles that limit access to information, care, and health resources. In response to the unmet needs of culturally diverse communities, the Alzheimer's Association of Los Angeles, Riverside, and San Bernardino Counties Chapter, Inc. (hereon referred to as the Alzheimer's Association unless otherwise specified) developed the Dementia Care Network—a service delivery model defined as *“an interagency and community approach to ethnic specific dementia care service delivery.”* The model is characterized by care management and services provided by a consortium of non-profit human service providers, community representatives, and government agencies.

This manual was created for community-based service providers and agencies that wish to replicate the Dementia Care Network model in their communities. It is important to note that this service delivery model was created and implemented in larger, urban communities where existing agencies were established. The information presented is intended to serve only as a guide and is based solely upon the experiences of the Alzheimer's Association. Replication in other settings must be tailored to the unique needs of specific communities.

This manual is structured in eight sections: an Introduction; a general overview of the Dementia Care Network model; Structure and Components; Key Considerations; Phases of Development; Profiles of the three Demonstration Projects; Appendices; and Sample Forms. An accompanying CD provides sample forms that can be adapted to suit the needs of individual projects.

Background

Addressing the needs of diverse communities has been a long-standing priority for the Alzheimer's Association. The formation of its Multicultural Outreach Committee dates back to 1991. *(For further details, see Appendix 5.)*

In 1992, California was selected as one of fifteen states under the federal Health Resources and Services Administration (HRSA) Alzheimer's Demonstration Initiative. The Alzheimer's Disease Demonstration Grants to States were to identify and serve dementia-affected populations in underserved communities and to assist in planning, program development, service delivery and information dissemination. The Demonstration Grants have since enabled agencies to develop programs to reach specific underserved populations in rural areas and various cultural/ethnic groups including African Americans, Native Americans, Asians and Pacific Islanders, Euroanglos, and Hispanics/Latinos. It is through this Demonstration Grant that the Alzheimer's Association developed and implemented the Dementia Care Network.

The Demonstration Grants have made it possible to address the critical and growing gap for dementia care and services among underserved communities. Through cooperation and collaboration among a variety of service providers, with an emphasis on bringing together the best set of resources possible—the Dementia Care Network has assisted families by improving access to care and services.

“El Portal: Latino Alzheimer's Project,” was established in 1992 as the first and most extensive of the Chapter's three projects to date targeting specific ethnic communities. The El Portal Project has received national attention and acknowledgement through numerous awards, including recognition from HRSA as a model for reaching underserved communities. The Project also received

the GlaxoSmithKline SHARE Award for improving the health and well being of older adults, and the Project's director received the Robert Wood Johnson Community Health Leadership Award.

"I was feeling so overwhelmed and alone. I was sure no one understood what was happening to my family. [It helped] just to know that you understand and can understand why I get so angry and frustrated with her when she can't understand. I was afraid to tell anyone and just kept it bottled up inside. I was afraid that I just had to deal with this alone and I just didn't think I could. I was losing hope, until I found you...."
(El Portal Project family caregiver)

Following El Portal's success, the "West-Central Dementia Care Network" was developed in 1997 to address the needs of the underserved African American community. In 2000, the Chapter partnered with the Alzheimer's Association of Northern California & Northern Nevada to launch its third ethnic-specific outreach endeavor, the "Asian/Pacific Islander (A/PI) Dementia Care Network," targeting specific Chinese, Japanese and Vietnamese communities.

Acknowledgements

There are many funders, agencies, individuals, and other supporters that have made the Dementia Care Network model possible. Regrettably, there are far too many to name than space allows. However, it is necessary to acknowledge the tireless efforts and generous support of the following who contributed to the model's success over the years. The federal HRSA and Administration on Aging (AoA), and the California Department of Health Services (DHS) and California Department of Aging (CDA), have provided invaluable support through dedicated staff resources, and HRSA Alzheimer's Disease Demonstration Grants to States. In addition, the local collaborative efforts of El Portal: Latino Alzheimer's Project, the West-Central Dementia Care Network, and the Asian/Pacific Islander Dementia Care Network developed the foundation upon which the Dementia Care Network model is based. In particular, partnership with the Alzheimer's Association of Northern California & Northern Nevada made it possible to implement the model beyond Southern California borders. Special recognition is due to the families and individuals affected by dementia who had sufficient trust to participate in the projects as they evolved. Without them, the Dementia Care Network model—and the critical services it makes possible—would not have been realized.

Replication Manual Writers and Contributors

California Department of Aging:

Edmond P. Long, M.S. Gerontology

Alzheimer's Association Staff:

Debra Cherry, Ph.D.

Susan Chapman Howland, M.S.G.

Coleen Nakamura, M.P.H

Meyling Eliash-Daneshfar

Kathleen Taylor

and many other members of the Alzheimer's Association staff, past and present.

The Dementia Care Network

The Dementia Care Network is an interorganizational community-based collaborative model established to provide dementia care services to an ethnic community. The model brings together nonprofit human services providers, program consumers, community representatives and government entities. So far, the model has been applied to specific Latino, African American, Chinese and Japanese communities in Southern California, and Chinese and Vietnamese communities in Northern California's Santa Clara Valley. It has enhanced dementia care service capacity and contributed to alleviating the psychological, emotional, and financial stress associated with caregiving.

Major Project Goals

The four major goals of the Dementia Care Network have remained constant over the three Dementia Care Network Projects. Individual programs may develop more specific goals and objectives according to the needs of their target populations.

1. Community Outreach, Networking and Awareness

Goal: To establish linkages with local community organizations, service providers and informal neighborhood networks, through a comprehensive awareness campaign for the targeted geographic area.

Results from various needs assessments, conducted both prior to and during the Dementia Care Network Projects, determined a great need for education and increased awareness about Alzheimer's disease. Knowledge and beliefs about dementia ranged from the perception that it is a normal part of aging, to its being associated with mental illness or spiritual punishment.

Members of ethnic/racial minorities are often unaware of services available for adults affected by dementia. Or, if aware, they may not

know how to go about gaining access to such services, or simply do not feel the need for them. In most communities, a vast amount of outreach must be conducted to help overcome the stigma and misperceptions related to Alzheimer's disease and dementia.

2. Coordination of Services and Service Delivery

Goal: To facilitate the coordination of existing services in the target area and to identify gaps and barriers to service delivery.

Uncoordinated services create significant barriers that prevent families from getting the help they need. The Dementia Care Network model provides direct services to families through Care Advocates, paraprofessionals who provide care coordination.

Communities differ in the richness of their resources. Through the course of a project and attempts to help families access needed care and services, a Dementia Care Network identifies gaps and barriers that need to be addressed.

3. Program Expansion and Development

Goal: To identify agencies in the targeted communities that can provide families and caregivers with culturally appropriate and dementia knowledgeable care.

Service gaps for ethnic minority families affected by dementia occur in nearly every community, whether they are large urban settings rich with resources and services or small rural areas with as few as one social service agency. As gaps and barriers to service delivery are identified, the Dementia Care Network can strategize for the development and expansion of programs to meet the needs of dementia-affected families in a particular community.

4. Materials Evaluation, Development and Dissemination

Goal: To evaluate existing translated information, develop linguistically and culturally appropriate materials, and disseminate them to the community through provider networks.

Education and outreach are critical components of the Dementia Care Network. Information needs to be evaluated for the cultural appropriateness of its content. In communities where languages other than English are utilized, the development and dissemination of linguistically appropriate information at the correct level of health literacy is essential.

Structure and Key Components

Lead Agency

In the Dementia Care Network Demonstration Projects, the Alzheimer's Association served as the lead agency and subcontracted with other agencies for direct services to families in their respective communities. The model is flexible in terms of the lead agency choosing to subcontract services with one or more partner organizations. In some situations, the lead agency may choose to provide services directly without subcontracting with another service provider.

Grants, Training, and Technical Assistance

When an organization functions as a lead agency, its three primary functions are to 1) provide programmatic oversight and fiscal management; 2) provide training in areas according to the needs of the subcontracted providers; and 3) provide support and technical assistance.

The staffing pattern for individual programs will depend upon the resources and funding available. Some projects may be able to hire a full complement of staff dedicated to the program. Others may integrate the program into its existing structure with the addition of the Care Advocate.

Program Development Consultants

In the Dementia Care Network model, consultants were recruited for their specific skills in identified areas of need. The services of consultants have varied according to the needs and budgets of individual projects. In the case of El Portal, the largest of the three Projects, the availability of technical expertise was a vital component of the development process. A team of experts was made available to management and line staff. In addition to hands-on program development, consultants' tasks included program monitoring activities and written reports of their findings and recommendations.

**Care Advocates:
the “heart” of the
Network**

Care Advocates

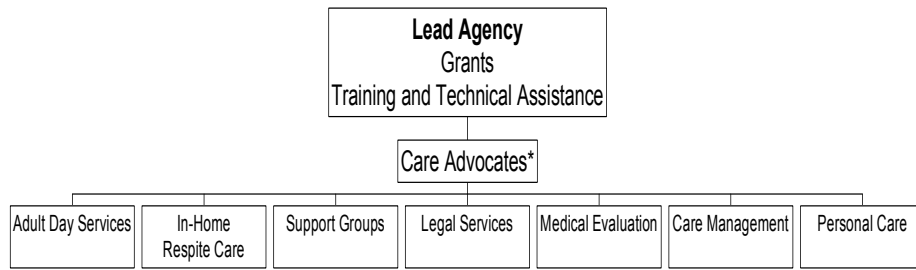
Often known as the “heart” of the Dementia Care Network, the Care Advocate is the primary contact for the family and has a dual role of providing education/outreach and family assistance. With roots in the development of El Portal, the term “Care Advocates” rather than “Case Managers” was preferred to better reflect the role of an advocate who facilitates access to care for a historically underserved population. Individuals who have been hired as Care Advocates do not necessarily need to be “graduate degree qualified.” Past Care Advocates who have worked for the Dementia Care Network Projects have ranged from relatively inexperienced individuals with undergraduate degrees to graduate level professionals with extensive experience. With adequate support and training, an individual can develop the skills and knowledge for the position.

The Care Advocate serves as the point person for home visits, care planning, purchase of services, service coordination, monitoring and follow-up. During the initial home visit, the Care Advocate’s goal is to identify clients’ immediate needs for a dementia diagnosis and dementia-focused services. Both the patient’s and family’s level of functioning and support are evaluated.

The funding and staffing structure of a start-up project can have a direct effect on the Care Advocate’s workload. In some projects, the Care Advocate position was part-time and the individual carried additional responsibilities under other agency programs. In the early stages of the project, the majority of the care advocate’s time was spent on education and outreach, to identify families who could benefit from the project. Once the caseload grew, the balance of time spent on education and outreach gradually reversed.

As funding allows, other positions, such as Program Manager, Education and Outreach Coordinator, and support staff, may be included. Many grants require matching or in-kind staff time from the grantee. In these cases a certain amount of agency staff time is designated toward the project.

The following is a diagram of the basic Dementia Care Network model. The structure will vary depending upon whether or not the lead agency chooses to contract with partner agencies. The scope of services will vary depending on what resources are available in a particular community.



**Care Advocates may be part of the lead agency.*

Cultural and Linguistic Competency

It is important to keep in mind that extra effort may be needed when trying to understand other cultures, practices and modes of communicating. For example, in some cultures, maintaining direct eye contact, particularly between members of the opposite sex, can be viewed as disrespectful and inappropriate.

Verbal Communication

The level of ability to communicate with families has a direct impact on the program's service quality. In addition to language used, verbal communication includes:

- Tone of voice
- Rhythms of speech and the kinds of stress put on some words
- Volume and speed of speech

In some cultures, such as African American or Filipino, it is more appropriate for a younger person to address an elder by using the honorific, "Mr. _____," rather than by the first name only. Other approaches may be viewed as disrespectful.

Nonverbal communication

It is said that as much as 80 percent of communication is nonverbal.

When working with families and individuals with dementia, an awareness of what is communicated to the person through body language is especially important. Therefore, some things to keep in mind are:

- How much gesture is used (e.g., hand and head motions)
- Facial expressions
- Personal space (space between people)
- Physical touch (varies widely and cannot be generalized)
- Manner of dress/grooming

Written Communication

In communities where language differences exist, capacity for translation of written materials is one of the most important components of the program. Education, a critical component of the program services, involves written materials to be translated and read in other languages. [See Appendix 4: “Steps for Developing/Translating Materials.”]

Health literacy is defined as the capacity of individuals to obtain, interpret and understand basic health information and services, as well as the competence and motivation to use such information and services in ways that enhance their health. (*Health Literacy*, Keifer, Kristen, MPP, Center for Medicare Education, February 2001.) Based on the results of a national survey on Adult Literacy, many people have difficulty understanding what they read and applying that information to their particular situation. It is also likely that many in this situation are either too intimidated to say that they do not understand or too uncertain to know what to ask. It does not help that delivery of health care generally—and long term care in particular—is fragmented or that health plans generally do not finance coordination and patient assistance. Seniors with English as a second language have the lowest level of literacy.

Some suggestions for written communication are:

- Look for materials incorporating the cultural beliefs and practices of your target population.
- Use words and phrases used by the target population; avoid

Quality Assurance and Evaluation

professional or technical jargon.

- Use printed material designed at a reading level that it is easy to understand.
- Use pictures, posters, drawings or visual materials appropriate for people who may have limited reading ability.
- Be sensitive to preferred methods of learning and allow time for the education to occur.
- Encourage and initiate dialogue. Ask questions to assess the understanding of the information provided.

(Adapted from: Doak, C.C., Doak, L.G., and Root, J., 1996. Teaching Patients with Low Literacy Skills, 2nd Edition. Philadelphia, J.B. Lippincott.)

Quality Assurance and Evaluation

Evaluation is a critical part of the quality assurance process. It is ongoing and can be conducted in many ways, both formally and informally.

Data Collection and Documentation

Data collection can be helpful because it enables an agency to compile actual service delivery units. Measurable data is useful when gathering information for funding proposals and grant applications. As funding allows, data collection and analysis may be designed as a research project through a local university. At a minimum, data should be collected in-house to track service units and/or hours. It is recommended that files be kept for each client/family. It is important to remember that documentation is essential for care advocacy and that files for clients shall be kept confidential. *[Sample forms are available on the accompanying CD.]*

Program Audits

Program audits serve as:

1. A tool to ensure overall compliance
2. An opportunity to keep abreast of the overall project's evolution
3. A continuous quality improvement tool for local site management
4. A point of comparison for validating local monitoring efforts
5. An added level of accountability for all involved

A periodic review of client files can be conducted to determine the quality of certain aspects of service delivery. Upon completion of a quality assurance review, site management and direct service staff can be given verbal feedback and formal, written recommendations may follow. The on-site exchange allows for clarification and ensures adherence to policy in areas of diagnosis, referral to other services, and development of care planning goals, with appropriate documentation on progress toward achieving goals. On-site exchange also allows for the identification of ongoing training and technical support needs.

Core Staff Meetings

Project staff meetings held on a regular basis with line and supervisory personnel at the focal point agency sites can serve as a forum for areas of mutual concern and discussions of quality issues. Typically, agenda items include project updates, case discussions, training opportunities, dissemination of information, and problem solving.

Feedback

Consistent and timely feedback is a critical component of any new or ongoing program. Written reports contain an overview of findings, areas of improvement based on last review, areas of improvement based on immediate review, recommended remedial action, and a timeline for implementation of the remedial steps.

Family Satisfaction Surveys

There are different methods that can be used to obtain feedback on family satisfaction levels. For the Demonstration Projects, both telephone and written surveys were used. The telephone method involved direct personal contact between the family member and non-staff interviewer. The written/paper surveys were multiple choice. A personal call from the Care Advocate to the family ahead of time was shown to significantly increase the response level. However, results may need to be received with the understanding that giving direct negative feedback is less acceptable in some cultures.

If written surveys are used, it is helpful to know the literacy levels of

families and accommodate language needs. For example, in the last year of the Asian/Pacific Islander Dementia Care Network Project, simple, bilingual survey forms were developed and distributed with English on one side of the page and another language on the other side (e.g., English and Chinese, English and Japanese, and English and Vietnamese). *(A sample form in English is available on the accompanying CD.)*

Elder Abuse Reporting

It is important to note that, in California, Care Advocates and project staff are mandated reporters for elder abuse and need to comply with the reporting laws. Since people with dementia are particularly vulnerable to abuse, Care Advocates may encounter situations involving suspected elder abuse and must be aware of their role as mandated reporters. Types of elder abuse include, but are not limited to, physical, financial, mental, and neglect. Local law enforcement or human service agencies can be contacted for specific reporting protocols.

Range of Services

The range of services offered through a Dementia Care Network will vary according to the available resources and degree of existing or developed partnerships between organizations. It may be helpful to keep in mind that the underlying goal of the Dementia Care Network is to help families access needed dementia care and related services. Services described below are examples of what has been offered through the Demonstration Projects.

“[Care Advocate] has been a great help to me and my family. Without her, we would not have had the chance to try out so many community resources.”

Family member, Asian Pacific Islander Dementia Care Network

Minority elders generally are in poorer health, suffer more functional impairments, have more limited education, and lower income than the general population. They face significantly higher burdens from out-of-pocket costs. Other structural barriers include logistical difficulties, including a lack of transportation, language barriers, and low literacy. Transportation difficulties disproportionately affect lower income racial and ethnic minority leaders.

Care Management

Care Management is a service that helps people determine their needs and find the best available resources to meet those needs. In the Dementia Care Network, the Care Advocate conducts a needs assessment of the person with dementia and assists with access to appropriate care and services.

Care advocacy can be considered the core service of the Dementia Care Network model. One of the critical functions of the Care Advocate is to coordinate diagnostic and support services for the memory-impaired client and primary caregivers. Minority elders and their families face multiple structural and cultural barriers to service access.

Counseling

There are a variety of supportive services available to assist caregivers and people with dementia during the various stages of the disease process. While many caregivers benefit from support groups, some may find they need additional support. Counseling can help reduce feelings of irritability, tearfulness, insomnia, lack of appetite, and difficulty concentrating.

Dementia affects not only the diagnosed individual but also the entire family. During the intake process, caregivers are screened for depression using standardized assessment tools. High scores on depression screening tools are common among caregivers interviewed during the intake process. Translated assessment tools are utilized where appropriate. In some cultures, the stigma attached to mental health concerns can be a barrier to services, even when help is available. The Care Advocate plays an important role in helping the family to access the needed care in cases where intervention is clearly necessary. Knowing how and when it is appropriate to suggest counseling is very important, especially during the initial intake process when trust and rapport with the family is being developed. In the Dementia Care Network Projects, Care Advocates found that the intake process involves several telephone calls and visits.

Adult Day Services

Adult day services programs are designed to provide stimulation in a safe environment during the day for adults with physical and mental or cognitive functional impairment, including individuals with Alzheimer's disease and related disorders. These programs offer an opportunity for social interaction, promote health maintenance, foster independence and provide much needed respite for family caregivers.

In Los Angeles County, prior to the El Portal Project, only one of seven Alzheimer's Day Care Resource Centers served the target population and only one out of 66 known dementia support groups accommodated Spanish speakers. Funding for El Portal allowed for the development of five culturally and linguistically appropriate social model day centers in the service area. These centers provided individualized non-medical care to meet the needs of functionally

impaired adults. The types of adult day services programs available in include:

Adult Day Health Care Centers (ADHC)

An ADHC provides an organized day program of health, therapeutic, and social services and activities on less than a 24-hour basis to adults aged 18 and older with physical or mental impairments. The purpose is to restore or maintain participants' optimal capacity for independence and self care. ADHC services are designed to serve the specialized needs of participants, and are provided by a team of licensed or certified health professionals and trained staff. ADHC services are covered by Medicaid (Medi-Cal in California), private fees, and some long term care insurance plans. These centers are licensed as health facilities by the Department of Health Services, and certified for participation in the Medicaid program by the California Department of Aging.

Adult Day Programs (ADP)

An ADP center is a community-based facility or program that provides non-medical care on less than a 24-hour basis to persons 18 years of age or older in need of personal care services, supervision, or assistance essential for sustaining activities of daily living or for the protection of the individual. The Department of Social Services licenses these programs as community care facilities. Medi-Cal does not pay for ADP services.

Alzheimer's Day Care Resource Centers (ADCRC)

An ADCRC is a community-based program that provides specialized day care on less than a 24-hour basis to persons in the moderate-to-severe stages of Alzheimer's disease or related dementias. ADCRCs offer enhanced staffing and specialized activities to meet the needs of persons with dementia. In addition, ADCRCs act as community resources for information on dementia and caregiver support. ADCRC programs are funded through grants from the California Department of Aging, and are available on a sliding-fee-scale. Most ADCRC programs are co-located in licensed ADPs or ADHCs.

Obtaining Diagnoses

Diagnostic centers provide complete medical, neurological and psychological examinations to determine the possible causes of a person's symptoms. Alzheimer's diagnostic centers conduct either screenings or evaluations to determine if a person suffers from symptoms of memory impairment. Alzheimer's research centers specialize in evaluating and treating people with symptoms of Alzheimer's disease and related dementias. *(Source: Alzheimer's Association Resource Directory, Los Angeles County, 2004-2005)*

The utilization of health and human services among minority elders and their families does not reflect the projected rates of dementia and related problems. They are much less likely when ill to visit a doctor or be hospitalized, and tend to seek help much later in the course of a disease or condition. Ethnic minority elders are among the most chronically ill in the United States and the most in need of both health and social support services. Individuals with Alzheimer's commonly have other diseases and conditions that are often easily overlooked and go untreated.

In the Dementia Care Networks, a diagnosis of dementia within 30 days has been required for program participation. If a screening or diagnosis is needed, program staff assists families in accessing appropriate diagnostic services. The family may need to be informed of the necessity of a good medical examination and evaluation to rule out treatable causes of dementia. The family may pursue the work-up with their regular source of health care unless culturally and linguistically appropriate diagnostic centers or physicians are unavailable. The lack of diagnostic centers with bilingual/bicultural services is a common problem in communities where English is not the predominant language for patients. In the Demonstration Projects, facilities that did have appropriate services sometimes had long waiting periods of several months because of the high level of need.

Early and careful evaluation is important because many conditions, including some that are treatable or reversible, can cause or mimic dementia. Potentially reversible conditions include depression, adverse drug reactions, metabolic changes, and nutritional deficiencies.

Educational Materials

The 2000 U.S. Census indicated that there are about 47 million people who speak a language other than English in the home. Among households that speak a language other than English at home, Asian households have the highest levels of linguistic isolation. Twenty-eight million are Spanish-speakers, and of those, about 14 million report that they speak English “less than very well.” Communication barriers make access to medical care and accurate assessments difficult.

One of the major goals of the Dementia Care Network is to evaluate existing translated information, develop linguistically and culturally appropriate materials, and disseminate them to the community through provider networks. The Dementia Care Network Projects have developed and produced numerous publications that have been disseminated not only to the target communities, but also to communities beyond their borders.

The development of printed materials includes more than just translated information. For example, publications developed for the African American community have been in English, but careful thought has been required for the design and images used. This applies to publications for other audiences as well, since images have the power to speak volumes louder than words alone.

Information and Assistance

Inquiries for information and assistance are received in many different forms. In the Dementia Care Network model, the Care Advocate functions as the point person between the family and the program and needs to be or become familiar with the community resources available.

A solid collection of resource directories and lists of services in the area are helpful when making referrals for various needs. It is common for Dementia Care Network program staff to receive calls about needs beyond dementia care. Care Advocates in some of the Demonstration Projects have expressed that, because of the lack of appropriate and available resources, they often become the people to whom the family looks to meet a wide variety of needs.

Legal Assistance

Helpline

An important service implemented during the El Portal Project was a Spanish language helpline. This toll-free helpline assists callers who are monolingual or have limited English proficiency. The Alzheimer's Association has made the helpline available 24-hours a day through its national network. It has also contracted a secondary translation service to accommodate calls in other languages.

Overcoming language barriers is just one of the challenges of reaching out to underserved communities and populations. If an agency conducts outreach to a particular community or target group, it is important to consider whether it has the capacity to appropriately respond to that population's specific needs.

Seeking the early advice of a lawyer and financial advisor about legal and financial arrangements can help families avoid difficult situations later. It is recommended that legal and financial planning take place soon after a diagnosis of dementia is made. Asset protection, advance directives and conservatorships are important components of future plans. Also, support is needed with issues that surround immigration status. Many of the larger, metropolitan communities have existing legal service organizations that provide legal services at no cost (*pro bono*) or on a sliding scale basis. Such organizations are key partners in the Dementia Care Network because certain services require qualified legal professionals.

Care Advocates consider legal service needs as part of the care coordination. Legal assistance with documents related to decision-making is an important aspect of planning and care management. In El Portal, legal services were subcontracted to a local legal service agency. When the initial grant funding ended, the partnership continued and extended to other communities through The Older Americans Act and Area Agencies on Aging funding.

Many private advisors will provide the first interview at no charge. In communities where no legal service agencies are available, the local

Outreach

Bar Association can be contacted for information from the Attorney Referral Service. Ideally, the advisor would be someone who has experience dealing with situations in which the client has Alzheimer's or a related disorder. It is helpful to establish whether the initial interview is free of charge and what applicable follow-up fees will be.

In many cultures, dementia is considered to be a natural part of the aging process, rather than a disease. In others, it may be feared that the individual experiencing dementia is "crazy" and negative connotations are attached to any "mental" disease. For example, Chinese and Japanese written language characters for *dementia* literally translate into "catatonic" and "crazy or foolish." Too often, families come into contact with the formal service system only during an identified crisis.

Members of ethnic/racial minorities are often unaware of services available to dementia-affected adults. Or, if aware, they may not know how to go about gaining access to such services, or simply do not feel the need for them. The amount of outreach greatly exceeds the degree of actual program utilization. In most communities, a vast amount of outreach must be conducted to help overcome the stigma and misperceptions related to Alzheimer's disease and dementia. Outreach is an ongoing component of the Dementia Care Network that continues throughout the life of the project. Experience with past projects has determined that presentations on topics related to memory changes or tips to improve and maintain memory are less threatening and tend to draw larger groups.

Some questions to consider when planning outreach efforts:

- ◆ Where are the congregate sites for the target population?
- ◆ Where are the formal and informal gathering places?
- ◆ Where are social activities held?
- ◆ Can or how will my agency respond to the influx of calls/contacts from the target community?

In the Dementia Care Network, Care Advocates perform home safety assessments to identify potential safety hazards and make recommendations for preventive equipment. For example, grab bars in the bath or shower can help prevent slips and falls. If it is determined that such bars would be helpful and the family is willing to have them installed, the Care Advocate will assist the family with arrangements.

Other items such as hospital beds, wheelchairs, mattress pads or other durable medical equipment assist individuals requiring extra assistance with activities of daily living. Assistive technology resources work to enhance the capacity to use telephones, computers, and daily living or work spaces for individuals requiring assistance due to physical or mental impairments.

Safe Return™

Another safety consideration is whether the family benefit from the Alzheimer's Association Safe Return™ program. This program is a national registry and identification bracelet program for people who are at risk of wandering. The Safe Return™ program includes:

- identification products, including wallet cards, jewelry, and clothing tags
- national photo/information database
- 24-hour, toll-free emergency crisis line
- Alzheimer's Association local chapter support
- wandering behavior education and training for caregivers and families.

If the individual wanders and is found, the person who finds him/her can call the Alzheimer's Association Safe Return™ toll-free number located on the wanderer's identification wallet card, jewelry, or clothing tag. The Safe Return™ telephone operator immediately alerts the family members or caregiver listed in the database, so they can be reunited with the loved one. The Safe Return™ program results in hundreds of lives saved annually. If a person is reported missing by a family member or caregiver, Safe Return™ immediately alerts local law enforcement agencies. Photo flyers can be created and faxed to

Respite Grants and Subsidies

hospitals and law enforcement agencies to aid in the search. Local Alzheimer's Association chapters provide family support and assistance while police conduct the search and rescue. For further information on the Safe Return™ program, call the nearest Alzheimer's Association chapter.

The word "respite" is defined as "reprieve" or an "interval of rest." A family member taking care of a frail, elderly relative needs time off to protect his or her own physical and mental health. Respite services give the family member or caregiver a break from giving continuous care, reducing physical and emotional stress. Respite care includes day services and in-home support such as personal care, skilled nursing care, companions, as well as homemakers.

With many low-income elderly individuals, even "free" services have hidden costs to the client. Even when services are available in the area, lack of transportation can be a major barrier. A family member or friend needing to take time off from work means incurring a loss of wages. Many services require co-payments or deductibles that can be insurmountable barriers to care if resources are needed for other necessities such as food and lodging. Even when relatives want to help, many are financially unable to do so. In the Dementia Care Network, families are reimbursed for a certain amount of funds spent on respite related services.

"I cannot begin to tell you how much I appreciate the respite care from your grant. I seriously felt like I was going nuts from being the sole caregiver for my parent. The burden is too much for one person. So, I appreciate this! Thank you for allowing me to get away to relax and recuperate."

(A Dementia Care Network family caregiver)

The Dementia Care Network also provides limited funds to assist family members who care for someone with Alzheimer's disease or related dementia at home, enabling them to delay placement in a long term care facility. In the past, respite funds assisted caregivers in

obtaining services for their loved ones such as transportation, counseling, diagnosis. Scholarships were provided for identification bracelets, medical equipment, and incontinence products. In addition, environmental and home safety modifications necessary to facilitate caregiving and improve the quality of life of the patient were also considered for reimbursement.

Purchased Services

In past projects, this category provided limited, one-time only reimbursements for services such as legal assistance, counseling and transportation needs. It also covered home safety modification, which included equipment such as ramps, grab bars, rails, commodes-on-wheels, bathseats, locks, fire extinguishers, and alarms to help prevent a person from wandering. The cost for personal care products such as incontinence supplies and dietary supplements were also reimbursed under this fund. Without this intervention, the individual's health may have quickly led to the need for hospitalization and institutional care.

Emergency Funds

Emergency Funds were funds available to families in a dementia-related crisis. Applications were considered on the basis of need, including financial and individual circumstances. For example, a caregiver may have needed to be hospitalized and requested support to hire someone to care for a dementia-affected loved one at home.

Support Groups

Lack of formal/informal support networks about dementia can lead to increased levels of caregiver stress. In many communities, cultural expectations impact the role of the family in caregiving. In some cultures, caring for a family member is seen as a shared responsibility with a reluctance to seek help from outside sources.

The caregiver support groups help caregivers learn more about Alzheimer's disease, how to manage difficult behaviors, and how to cope with the emotional, physical and financial stresses of being a caregiver. There can be specialized support groups for early stage patients, bereaved caregivers, spouses and adult children who are

caregivers. Support groups can also be offered in languages other than English where needed.

Support groups can be led by the Care Advocate or other trained program staff, or trained volunteers with staff support. At the Alzheimer's Association, a formal support group leader training program has been developed.

In addition to helping families access services, Dementia Care Networks provide education and training for families and caregivers. "Caregiver Stress" and "How to Work with Confused Older Adults" are examples of topics from which caregivers have benefited, presented both in English and other languages. Training is provided on an individual basis with families enrolled in the program, as well as through group settings.

Key Considerations for Replication

The success of a Dementia Care Network in any community depends on a wide variety of factors. Outlined below are some considerations that may help determine whether an organization may want to pursue the development of a Dementia Care Network in a particular community.

Internal assessment of agency's programs and services

One of the most important considerations before proceeding with the development of a Dementia Care Network is the assessment of the agency's capacity for such a program. At what levels are the current/existing programs, dementia care capacity, and cultural competency? (See page 35 for suggested topics on dementia care capacity.)

Partnerships and networks

Recognize the importance of partnerships, relationship building and working with existing provider networks. The Dementia Care Network model is built upon the concept of agencies partnering and collaborating to meet the needs of families affected by dementia. What partnerships currently exist? What relationships would need to be established? Is it feasible?

Language, translation and health literacy

Being sensitive to linguistic nuances can mean the difference between creating and losing rapport. For example, in many cultures, it is inappropriate to address an elder person by his or her first name. In some communities where people have had limited educational opportunities, even in the native language, sensitivity to literacy levels is important. What is the current capacity to accommodate language needs? What would be needed to bridge gaps?

Flexibility and time commitment

Developing a new program like the Dementia Care Network requires flexibility and time for relationship building and the implementation of

effective service delivery. Plans may change according to the needs of the community.

Cultural values

General information about culture and cultural competency is included in this manual. However, an attitude/approach of respect and non-judgment are equally important as knowledge about different communities. Are there individuals/agencies who can provide needed specific training on cultural issues related to the target audience?

Dementia Competency

The level of dementia care training for each project is tailored to the experiences and skills of each agency's staff. Training is an important component of the Dementia Care Network, as it supports the model's guiding principles of self-determination and empowerment.

The following is an outline of suggested topics:

1. Alzheimer's disease and related dementias (*See Appendix 1.*)
2. Stages of Alzheimer's disease and planning needs
3. Working with individuals with early stage Alzheimer's disease
4. Dementia care resources in the targeted community
5. Understanding challenging behaviors
6. Home safety and environmental needs
7. Understanding the caregiver experience
8. Caregiver stress
9. An overview of legal issues
10. Advance directives
11. Grief and loss

Note: The suggested topics listed above are provided as examples and do not constitute an exhaustive list. Detailed information and resources are available on the Alzheimer's Association website: www.alz.org or your local Alzheimer's Association Chapter.

Culture and Cultural Competency

Cultural competency is a critical component of the Dementia Care Network because culture shapes how people experience their world. Understanding culture is vital to how effectively services are both delivered and received. Cultural competence begins with an awareness of one's own culture and practices, and recognition that people of other cultures may not share them. This means more than speaking another language or recognizing the cultural icons of a certain group of people. It means changing the prejudgments or biases one may have regarding another's cultural beliefs and customs.

Health beliefs, perceptions of illness, ways of responding to stress, and the willingness to ask for help are all affected by culture. These beliefs help shape a family member's perception of dementia and their access to care and services. For example, people from some cultural groups may not view Alzheimer's as a disease but as a normal part of aging. Others could never imagine placing a family member with Alzheimer's disease in a long term care facility because it is not acceptable in their culture.

To do the work needed for historically underserved communities, agencies and professionals must keep certain characteristics in mind as they progress in their program development efforts. For example, providers need to be aware of the cultural perceptions of dementia and how they can affect service delivery. Assessment and management strategies require sensitivity to language, customs and other cultural factors. Lack of utilization may also be based upon geographic distribution and availability of services. For example, prior to the implementation of the El Portal Project, of nine support groups offered in the target area, only one was offered in Spanish. Similarly, of the seven State-supported ADCRCs (Alzheimer's Day Care Resource Centers) in Los Angeles County, only one was located in the target area and it served very few Latinos. Services, though "available," may be perceived as inaccessible.

Acculturation and Assimilation

Acculturation and assimilation are important concepts to understand when reaching out to ethnically diverse populations. Acculturation is a term used to discuss the adaptation of the ethnic minority group to the dominant cultural value system. For example, less acculturated populations in the U.S. are generally limited in English proficiency and adhere more closely to the cultural traditions of their countries of origin.

Levels of acculturation vary. For example, in East Los Angeles, home of the El Portal Project, a high concentration of Mexican Americans are bilingual and bicultural because they have lived in the area for generations. In other areas of the city, large pockets of newly arrived Latinos populate sectors where other groups traditionally lived. Physical appearance is a poor indicator of acculturation because members of groups at different levels of acculturation may look the same. The same may be true among other communities, such as the African American and Asian American communities, where generalizations cannot be made based on appearance.

On another note, the 2000 U.S. Census reminds us of a growing percentage of people who are members of more than one race. Thus, it is essential to become familiarized with the target population rather than to make assumptions.

Elements of Cultural Competency

Although these five elements are focused on ethno-cultural groups, the same may apply to diversity from the perspective of geography and sexual orientation. The bottom line is to be open-minded, respectful, and non-judgmental.

1. Value diversity/awareness and acceptance of differences—understand the way a “person/client” defines health and family.
2. Have self-awareness—understand how one’s own culture influences how one thinks and acts. Have the capacity for cultural self-assessment.

3. Be sensitive to the dynamics of difference—be conscious of the dynamics inherent when cultures interact—two people may misjudge each other’s actions based on learned expectations. Both will bring culturally prescribed patterns of communication, etiquette and problem solving. Also, both may bring stereotypes or underlying feelings about working with someone who is from a different culture. Without an understanding of their cultural differences, misinterpretation or misjudgments may occur.
4. Develop and maintain knowledge of the client’s culture—institutionalize cultural knowledge and become familiar with aspects of culture.
5. Adapt service delivery based on an understanding of cultural diversity—develop programs and services that reflect an understanding of diversity between and within cultures. Adapt the helping approach so it “fits” cultural differences and preferences.

(Adapted from Administration on Aging’s Guidelines for Culturally and/or Linguistically Competent Agencies)

Understandings of a Culturally Competent Agency

The following principles of a culturally competent system of care were adapted and used in the development and implementation of the Dementia Care Network Projects. They have been included with the hope that agencies/providers considering replication may more completely understand the core values and principles of the Projects.

A culturally competent agency or provider understands that:

1. The family, as defined by each culture, is the primary source of support and the preferred point of intervention.
2. Agencies/providers must recognize that minority populations are compelled to be bicultural, and this status creates a unique set of issues to which agencies/providers must be equipped to respond.

3. Individuals and families make different choices based on cultural forces that must be considered if services are to be helpful.
4. Practices should be driven in agencies/providers by culturally preferred choices, not by culturally blind and culturally free intervention.
5. The agency/provider must sanction and in some cases mandate the incorporation of cultural knowledge into practice and policy making.
6. In order to apply the helping principles of “starting where the clients is,” it is necessary to understand the client’s level of acculturation/assimilation.
7. It is necessary to understand cultural preferences in order to support client self-determination.
8. In order to provide services, clients must be viewed within the context of their cultural group and experience of being part of that group.
9. Acceptance of a client’s culture without judgment is needed when adapting service delivery.
10. It is best to work in conjunction with natural, informal support networks within the minority community.
11. A community takes responsibility for creating solutions that fit the context of the culture.
12. The services need to be matched to the client’s needs and self-seeking behavior.

(Adapted from the National Institute Mental Health/Child Adolescent Service System Program, Minority Initiative Resource Committee of CASSP Technical Assistance Center, Guiding Principles of a Culturally Competent System of Care, 1989)

Ten Steps to Providing Culturally Sensitive Dementia Care

1. Consider each person as an individual, as well as a product of his/her country, religion, ethnic background, language, and family.
2. Understand the linguistic, economic, and social barriers that prevent access to healthcare and social services. Try to provide services in a family's native language.
3. Understand that families from different cultures consider and use alternatives to Western healthcare philosophy and practice.
4. Do not place everyone in a particular ethnic group into the same category, assuming that there is one approach for every person in the group.
5. Respect cultural differences regarding physical distance and contact, appropriate eye contact, and rate and volume of voice.
6. Cultivate relationships with families over time; do not expect immediate trust and understanding.
7. Consider the family's background and experience when determining what services are appropriate.
8. Consider the culture's perceptions of aging, caring for elderly family members, and memory impairment.
9. Understand that a family's culture impacts their choices regarding ethical issues, such as artificial nutrition, life support, and autopsies.
10. Understand that the faith community is a critical support system for various cultures.

(Adapted from the Alzheimer's Association's Diversity Toolbox, www.alz.org)

More Tools for Developing Multicultural Understanding

1. Assume the responsibility for communication.
2. There is much diversity among and within ethnic groups, so avoid assumptions.
3. Ask for and offer clarification.
4. Acknowledge differences rather than deny them.
5. Try to accept different outlooks.
6. Try to accept that different worldviews exist.
7. Try to look beyond surface conditions such as dress, customs, and environmental conditions.
8. Where a set of negative attitudes exists toward an ethnic group member, try balancing them with positive attributes.
9. Avoid stereotypes.
10. Treat cultural differences as a resource, stressing positive relations.
11. Develop ways of handling uncertainty.
12. Get educated on the ethnic group's beliefs about dementia.

(Source: Trejo, L. adapted from A Guide for Volunteers at Adult Day Services Centers: Administrator's Supplement, 1999)

Cultural Competence Checklist for Success

While it is understood that there is no recipe for “success,” the following tips are just a few “ingredients” that reflect a culturally competent organization.

- ☐ The environment is welcoming and attractive according to clients’ cultural norms.
- ☐ Stereotyping and misapplication of scientific knowledge is avoided.
- ☐ Community input is included at the planning and development stages.
- ☐ Educational approaches and materials that will capture the attention of the intended audience are used.
- ☐ The community is given opportunities to take the lead.
- ☐ There is a balance between community priorities and agency mission.
- ☐ Staff represents the client population.
- ☐ It is understood that cultural competency is continually evolving.
- ☐ Creative ways are used to communicate with groups who have limited English speaking proficiency.

(Adapted from material developed for the National Center for Cultural Competence, Georgetown University Child Development Center.)

Phases of Development

Phase One: Planning

1. *Assess agency capacity*

One of the first steps in the planning phase is to assess the agency's capacity to implement a dementia care network project. The purpose is to determine what is needed in order to move forward. Some simple steps to consider are:

- Create a list of current services.
- Review each current service and determine whether it should be considered for the Dementia Care Network.
- For each service that may be included in the Dementia Care Network, determine whether it needs to be specialized for the target population.
- Identify resources available to specialize each service (i.e., languages your staff and volunteers speak, existing relationships your agency has with other agencies serving ethnic populations, etc.).
- Explore logical options to avoid “re-inventing the wheel.”
- Do community resources exist that will fill the agency void?

(Source: Adapted from the Alzheimer's Association Multicultural Outreach Manual)

2. *Convene a meeting*

Bring stakeholders together to discuss vision and goals for all involved. It is important to determine whether potential partners share common interests before proceeding with actual planning. If reaching out to different communities is new for an agency, it is important for the organization to have support from its Board of Directors.

3. *Establish roles and a mutual desire to address needs*

In most cases, this is a key step that needs to take place prior to seeking funding. Certain funding agencies may be more

inclined to support new and collaborative efforts. Also, to avoid later confusion, it is important to determine shared interests and roles before proceeding.

4. *Evaluate existing and needed services*

Conducting a needs assessment helps determine gaps between what is available and what is needed. A needs assessment can be broadly defined as a collection of data that determines the need for services, products, or information. [*For more information on needs assessments, see Appendix 2.*]

Some questions to consider when developing new programs are:

- Who is the program for? Why would they want to use the services?
- Where will the program be located? Is it easy to get there?
- Will your agency's brochures or flyers describing services and programs need to be in languages other than English?
- Will it be easy for elderly individuals with limited English proficiency to understand your agency's rules and/or eligibility-criteria?
- Will the agency have bilingual or bicultural outreach personnel who already work with the target group?
- Has the agency developed strategies to address the barriers that may prevent target group elders from seeking or receiving services?
- Has the agency completed an assessment of needs and problems in the target community?
- Does the agency involve a culturally representative number of persons/elders in the development of agency programs?
- How familiar are agency personnel with cultural/ethnic organizations and programs/services that they offer in the community?
- What attempts have been made to coordinate services with other community-based organizations in the community?

5. *Identify key community leaders and resources*

- Identify people who could provide cultural information

about the target population.

- Determine who could be an “expert” on the ethnic group’s values and belief system.
- Determine who could be a spokesperson for the outreach program.
- Leaders may be found in a variety and wide range of roles: professionals, agency staff associated with the target population, and non-professionals who have connections with the target population.
- Network with the target community through individuals, groups, agencies, events, etc.

Phase Two: Start-Up

1. *Secure or award funding*

Securing partnerships through the signed contract agreements is a critical step to ensure a mutual understanding exists between the funding source and grantee. Clarifying details regarding roles and responsibilities at the beginning is a critical step in preventing problems in the future.

2. *Convene an advisory group*

Integrating the Project into the target community occurs at multiple levels of the project. Participation from diverse representatives of the communities being served may include clergy, business people, local service providers, public officials and caregivers.

Participation by key decision-makers is critical to the long-term success of any program. For projects like the Dementia Care Network, interagency collaboration requires a great deal of commitment by the various stakeholders. For organizations that subcontract with other agencies, participation in a community-based council could offer a more local, "hands on" leadership opportunity. The primary focus of these groups is to assist in local marketing and outreach, identify service gaps, problem solve, etc. In the past, advisory group members have identified, facilitated, and in some cases conducted the outreach themselves.

3. *Hire program staff*

Staffing patterns depend upon variables such as available funding and the capacity of partnering agencies and community resources. The critical staffing component for the Dementia Care Network model is the Care Advocate. If possible, consider hiring individuals who are either from, or familiar with, the target community.

Funding and program requirements will determine other

positions and agency time allocated to the project.

Examples of other positions are:

Project Manager: Responsible for overall project management.

Coordinator: Responsible for outreach and education, developing and disseminating educational materials, coordinating outreach and educational events.

Support Staff: Maintains databases and client files, processes intake packets and reimbursement requests, and provides clerical support.

4. *Monitor and mentor*

The plan for monitoring and mentoring will depend on the funding requirements, staffing structure, skills and experience of personnel assigned to the project, and areas requiring quality assurance. Ideally, Care Advocates will receive clinical supervision from a licensed social worker or mental health professional at their agency. Mentoring, in the context of the Dementia Care Network, involves building capacity within communities by fostering the growth of care advocates into dementia specialists.

5. *Establish project protocol manual*

It is essential to have a handbook that reflects program design goals, policies, and procedures to guide and set standards for programs and staff. Over time the protocol will become a record of how services and processes evolved over time. The handbook can be especially helpful when staff changes occur. Rather than relying on the recollections of individuals within agencies, written guidelines can help orient new staff. Actual policies and procedures are best tailored to each individual project.

Important note: Maintaining and adhering to statutory and professional standards on privacy and confidentiality are essential. The development of policies and procedures on these important issues is strongly recommended.

6. *Outreach and education*

Outreach typically precedes the project and continues throughout its life. Outreach and education are very much interrelated. In communities with existing stigmas about Alzheimer's disease and support groups, education is an effective tool to help people access information and support.

7. *Conduct dementia and cultural competency training*

A major aspect of the project is to ensure that all staff shares a basic working knowledge of dementia, cultural diversity and their impact on service delivery. The specific level of training will depend upon the skills and experience of the program staff designated for the program. If dementia care and cultural competency are not within the expertise of the agency that desires to develop a Dementia Care Network, training can be conducted by other agencies that specialize in those areas.

Phase Three: Implementation

1. *Conduct orientation and training*

All staff will need to receive training in program operations and be familiarized with program policies and protocols. (*See the suggested topics for training on page 35.*)

2. *Mentor Care Advocates*

The level of experience and training that Care Advocates will have upon hire will vary. Because the Care Advocate is really the “heart” of the program model, it may be more important to hire individuals whose characteristics align with the purpose of the program than to hire those with advanced degrees or years of experience. It is common in not-for-profit service organizations for a more experienced staff member to mentor new members. In the Dementia Care Network, depending on the staffing structure, the mentor may be from the same agency as the Care Advocate or from the lead agency, if there is one. In any case, mentoring and support for the Care Advocate is an essential part of community leadership development.

3. *Assess client satisfaction*

Obtaining feedback during the early stages of the program can help determine how well the services are meeting the actual needs of families. Feedback can be both verbal and written, using both formal and informal methods of communication. When selecting methods for obtaining feedback, it is important to remember that culture can affect the accuracy of responses and feedback.

4. *Develop evaluation tools*

Process evaluations are especially important for new programs because they are conducted throughout the life of the program, allowing for adjustments and improvements to better meet the needs of the clients. Process evaluations occur during the course of the program, unlike program evaluations which are

conducted after a program ends and measure how well the clients' and families' needs were met.

Designing such evaluations in advance will help determine what information is needed. Responses during the early phases of development, either verbal or written, can represent a range of views that may influence further program development and policy direction. Comments and recommendations can be categorized to measure the following:

- Expectations during the start-up period
- Key accomplishments during start-up
- Adaptations made to better meet the needs of the target population
- Decision making within agencies
- Communication among the various components of the Dementia Care Network
- Helpfulness of components in relation to one another
- Effectiveness of training events or programs
- Current strengths of the project
- Suggestions for improvements and subsequent steps

5. *Develop material*

Print materials such as program brochures are important tools needed to launch a new program. For programs that target communities where English is not the dominant language, translation is an important consideration. *[See Appendices 3 and 4 for more information on print materials and media.]*

6. *Build capacity*

The Dementia Care Network is designed around the concept of self-determination. Program developers should envision contracted agencies building internal capacity and the ability to sustain dementia care services on their own. This is the model in its ideal form, rather than the agency continuing to depend on another organization for funding.

Phase Four: Continuation

1. *Secure other sources of funding*

Projects such as the Dementia Care Network are usually funded by time-limited, restricted grants and will require other funds to continue. Plans for the continuation of funding need to start well before existing funding ends.

2. *Continue advisory committee and key events*

An advisory committee that remains active throughout the continuation of the program can help sustain program success. Committee representation is likely to change over time as partner agencies and participation levels change.

Outreach and networking events can function as way to celebrate program successes and express appreciation to individuals.

3. *Maintain and establish new relationships*

Because the Dementia Care Network model is designed around the concept of people and organizations connecting in order to bridge service gaps, the importance of maintaining positive relationships cannot be stressed enough. In addition, as individual contracted agencies build capacity to sustain and maintain dementia care services on their own, the Dementia Care Network can be expanded to serve other underserved communities in the area. In order for this to happen, it is important to establish new relationships with individuals and organizations in different communities.

4. *Reassess community need*

Communities have been known to change and evolve over time. It is important to consider this fact and keep abreast of the changes that may occur in the target communities.

Reassessing community needs can be done both formally and informally. An example of a more informal assessment would

be to randomly or systematically poll key leaders from the communities targeted for outreach. An example of formal methods would be to collect updated data and conduct surveys or focus groups and interviews.

5. *Allow model to evolve with community*

As the community evolves, specific aspects of the program may also change. For example, the language used to conduct support groups may change as the primary language of participants change.

Guiding Principles and Philosophy

This Section briefly explains the guiding principles behind the Dementia Care Network model, and short summaries highlighting the three Dementia Care Networks implemented between 1992 and 2004. El Portal: Latino Alzheimer's Project in East and Southeast Los Angeles; the West-Central Dementia Care Network Project; and the Asian/Pacific Islander Dementia Care Network Project in Los Angeles and Northern California's Santa Clara County.

The Dementia Care Network model is based on a combination of principles and theoretical models. Combining the strengths of the public, private, and academic sectors, community-based agencies are brought together with mainstream agencies to provide an array of coordinated services to ethnic minority dementia-affected adults and their family caregivers. Some of the guiding philosophies and principles for the model include:

Community Empowerment and Self-Determination

When individuals and groups are empowered, they become change agents and solvers of their own problems. Through community based programming, individuals, agencies, institutions, and organizations work together to identify problems and find cost-effective solutions. Community empowerment results in self-determination, or the capacity to chart one's own course in life.

Capacity building

Community capacity building aims to enable a community to mobilize itself to address problems and strengthen its assets. The Dementia Care Network attempts to create models of service delivery that empower the community by: 1) enhancing the capacity of grassroots health and human services agencies to offer dementia-specific services and 2) enhancing the capacity of mainstream dementia care services to serve dementia-affected adults and their families.

In the Dementia Care Network model, capacity building occurs among all partners involved. In the Dementia Care Network Projects, the Alzheimer's Association was the lead contracting agency. By partnering with established organizations with a history of serving the target communities, the model helped to build capacity for culturally sensitive service delivery. Through the Project, partner agencies that may have had limited experience with dementia acquired the expertise necessary to continue providing dementia care services following the initial grant period.

Mutual and Reciprocity

Another guiding principle of the Dementia Care Network is that its partnerships are built upon mutual and reciprocal exchanges. Partnering agencies each have their individual strengths and expertise that can be shared to build capacity among other agencies and providers. The underlying goal is for agencies to work from positions of cooperation and independence, to positions of collaboration and interdependence.

Community Organizing

Although it is not a new phenomenon for social workers, an *interorganizational collaborative* is defined as an organizational structure made up of autonomous organizations or groups that make a joint commitment toward achieving common outcomes through specified tasks and joint decision making (Abramson & Rosenthal, 1995; Bailey and McNally Koney, 1996). Interorganizational community-based collaboratives aim to enhance linkages among local agencies, consumers, and other community residents. Funders often mandate this form of service provision.

Theoretical Framework

Theoretical framework used in the design of this model include: Iglehart and Becerra's Ethnic Sensitive Practice Models, Mendoza's Hispanic Helping Networks, and Valle's Indigenous Service Broker Profile. It has been argued that beliefs about what prevents minorities from greater utilization of services are, in fact, preconceptions that emphasize differences as deficits. Services that do not recognize and accommodate the differences implicitly present insurmountable barriers to the provision of care. The adoption of the "difference" rather than "deficit" view requires alternative concepts about minority groups and the ways to serve them.

Freimuth and Mettger suggest that more appropriate concepts include:

- (1) beginning with an assumption of competence in people from different cultures or social strata;
- (2) taking a learner-centered approach to education;
- (3) finding ways to understand how members of the target group "make sense of their everyday lives," and
- (4) ensuring that communication is a dialogue rather than a unilateral/linear process.

El Portal: Latino Alzheimer's Project

The purpose of the *El Portal: Latino Alzheimer's Project* was to develop a model program to assess service needs, to find ways to meet such needs with existing resources, and to create linguistically and culturally competent programs to serve the Latino population residing in East and Southeast Los Angeles during the 1980s.

The project enhanced the capacity of local health and social service agencies by providing them with training, support and technical assistance through a coalition of public, private, and voluntary agencies in Los Angeles County.

Marketing

A coalition of service providers was formally established in order to link local community organizations, programs, and informal neighborhood networks that launched a comprehensive awareness campaign for the targeted geographic area. Bilingual flyers, articles about memory problems, program brochures, and other print materials were written and reviewed by people with varying degrees of knowledge about the disease, with different levels of command of the Spanish language, and from various countries of origin. This ensured that the materials were linguistically and culturally appropriate for the population in East and Southeast Los Angeles. Additionally, a Spanish language Helpline and a Speakers Bureau were developed to respond to new inquiries generated by the campaign. Both programs are currently maintained and run by the Alzheimer's Association.

A sound marketing plan should include:

- Assessment of internal capacity
- Establishment of policies and procedures
- A clear understanding of how clients will access services
- A media plan with specific and measurable goals and activities
- Pilot testing of marketing materials
- Assessment and evaluation of activities.

Outreach

El Portal coalition members were creative, inventive and extremely resourceful. The motto was “think outside of the box.” Success stories were shared about innovative ways to distribute information and reach out to the community. One of the coalition members’ most successful tactics was to enlist the assistance of beauticians and auto mechanics whose shops were conveniently located in the heart of East Los Angeles. The strategy was to talk to individuals informally about the disease and have them share the knowledge with customers about the services being developed, including support groups and legal services. Soon, callers began inquiring directly about those services and shared the news with other people.

Some specific activities that took place

Literature review: Revision of partner agencies’ literature and development of materials that complemented existing ones. Printing of new materials, such as a bilingual card to promote the new toll free number which was illustrated by the daughter of a man with advanced dementia.

Community profile: East and Southeast Los Angeles were at the time widely populated by newly arrived Latino families who had mostly immigrated from Mexico and Central America. The coalition studied how families interacted with each other by considering affiliations with schools, and access to community based organizations and services offered by local shops, churches, and civic organizations.

Relationship building: Coalition partners created meeting opportunities and developed cross-training workshops to learn about each other’s services, clientele, and needs. Educational presentations about memory loss, treatment options, and services were offered throughout the service area.

Information and materials development: The El Portal materials were carefully developed with input from community partners and stakeholders. The results were filled with photographs and useful information. These materials were distributed by each partner who

Internal Capacity

enlisted the help of auto mechanics, hairdressers and other key community members.

Additionally, the coalition found new ways to bring caregivers together. For example, female caregivers were invited to a Mexican Mothers Day. The celebratory luncheon provided participants with a break from their daily tasks and an opportunity to meet peers in a friendly environment. The event acknowledged the hard work and contributions made for the well being of families.

Most of the El Portal paid and volunteer staff was bilingual and bicultural, thus mirroring the ethnic profile of the community. As the services expanded and attracted more people, educational materials, presentations and strategies that addressed the needs of all people affected by dementia were developed in both languages. However, those materials were not translated literally. The message was carefully crafted so the same idea was conveyed clearly and effectively to each community. For instance, concepts such as caregiver stress were challenging since many native Spanish speakers saw their role as caregiver as an honor, as an inherited role, or simply as a duty that left no room for personal stress.

These findings called for ongoing communication and cross-training among the coalition members, as more community agencies' existing services received funds to expand or develop care advocacy, support groups, in-home respite, legal consultations, and day care services. Other coalition members provided complementary services such as dementia diagnostic services.

A special effort was made to enrich adult day care centers in the target area that served few Latino dementia-affected adults. The concept of this service was foreign to many immigrants from Latin American countries where funds were limited or unavailable for this purpose. Although the dominant sense of family duty clashes with the realities of working families in this country, many Latinos did not know how or where to find a center for their loved one. With the assistance of trained advocates and outreach workers, more families began to

consider the centers as an option. When day care centers were hospitable and able to provide services, many Latino families embraced their services and referred friends and families.

Some key considerations regarding internal capacity:

- Select potential staff candidates through a panel interview process to ensure common goals and affinity
- Assess language proficiency of job applicants by requesting written samples and ask specific questions in Spanish
- Specify the days and time of program operation
- Consider utilizing answering machines, fax cover sheets, and personal telephone greetings when promoting new services.

Media

Ethnic media is an ever-expanding market in the United States with more than 500 magazines, newspapers, television, and radio stations, as well as on-line publications. In California, more people in key metropolitan areas now get their news from ethnic newspapers or broadcast outlets than from traditional media. Ethnic media plays an important role in keeping new immigrants connected to their native cultures while helping them to assimilate in their new homeland.

El Portal coalition members knew that local publications had a strong penetration in Los Angeles and used their connections to speak with representatives from various Spanish language television channels. The response was positive, and as articles were published or aired, more people outside of areas began to call the Helpline and inquire about Alzheimer's disease and the services available in their communities. Eventually, El Portal coalition members' event planning methods included a media strategy, which varied from simply faxing a calendar of events to sending a bilingual press release.

Media outlets expand, are sold, or disappear as communities change and evolve. Therefore, special attention is needed regarding the maintenance of contacts and relationships that can be essential for the expansion or creation of services.

Continuation of Partnerships

Here are some additional ideas to develop a successful ethnic media outreach plan:

- Ask community members how they learn about community events.
- Gather free publications available in supermarkets and drug and discount stores.
- Make a list of these publications and add any other outlets using media directories, telephone books, etc. to a database
- Identify the publications' target audience, circulation, etc.
- Develop culturally and linguistically appropriate ads, articles, billboards, and radio or television public service announcements.
- Conduct focus groups to ensure that the message meets the needs of the community.
- Fax or e-mail materials to the media and follow up with a telephone call.
- Send a personalized thank you note to the reporter, editor, or person who facilitated the promotion of the activities.

The strength of a Dementia Care Network is crucial for the longevity of every program. The El Portal partners recognized that interpersonal relationships impacted the personal and professional growth of its members. Thanks to formal and informal support from different coalition members, many staff members from different organizations in the El Portal network went back to college and achieved advanced degrees in gerontology, elder law, and other related fields. Many young professionals currently entering the elder social services field realize that the service provider community is comprised of a close small group of professionals. This group has developed a level of expertise over a long period of time that, coupled with their community ties, makes them an integral part of the service arena. Ongoing collaboration and long-term commitment to improving the services for Latino elders makes the Los Angeles aging network strong and diverse.

Key Stakeholders

These are some of the ways in which El Portal partners have stayed connected:

- Collaborated in the development of new projects and programs by subcontracting with each other as grants became available
- Staffed boards, committees, and subcommittees
- Served as test pilot sites
- Co-sponsored educational conferences and workshops
- Cross-referenced web pages
- Co-authored articles

During the early years of the El Portal Project, there were few agencies in Los Angeles that provided services and programs to people affected by dementia. East and Southeast Los Angeles was no exception. Nonetheless, several key agencies and individuals were identified through formal and informal networking. Several community providers were involved in the development and implementation of this project including the County's Department of Mental Health, a legal services agency, three adult day care center providers, a university center for applied gerontology, the local Area Agency on Aging (AAA), as well as an Alzheimer's diagnostic center.

One of the most important components of the development of the El Portal Project was a multi-phase training program on diversity in the workplace, offered as part of the human resource development services to all El Portal participating agencies. The primary goal of this effort was to sensitize direct service providers to cultural differences and service access barriers. Participation in training also resulted in the opportunity to monitor the personnel's performance.

Additionally, many of those professionals also chose to participate in the Alzheimer's Association's Speakers Bureau program. Training included an orientation and five subsequent sessions on topics such as caregiving, current research, community resources and behavior management. In addition providers engaged in such other collaborative activities as developing complementary work plans to promote referrals, communication and to strengthen the coalition's goals, and professional training.

For more than a decade, the individuals involved in the El Portal Project labored hard to meet the needs of the families served by their programs. While the day-to-day tasks were paramount in a service delivery arena that lacked infrastructure and experience, these individuals made time to maintain, expand, and create other programs, such as a bilingual Helpline, that still serve Spanish-speaking families in Los Angeles, Riverside and San Bernardino counties.

Collaboration on the short and long-term planning was vital for the economic survival of the Project. Funding was sought in response to the most pressing needs of the community and in accordance with the client satisfaction interviews that were conducted periodically.

African American Education and Outreach

African Americans represent 12 percent of the U.S. population. Currently, persons 65 years and over, constitute 8 percent of the African American population. By 2030, it is projected that African American elders will represent 17 percent of the total African American population. This increase in population will impact the need for culturally sensitive programs and services to meet the needs of older African American adults and caregiving families affected by Alzheimer's disease and related dementias.

The use of culturally sensitive programs and services targeting the African American community has been well documented. Noted researcher Dr. O. H. Airhihenbuwa stated that *"To develop maximally effective programs for African Americans, researchers and health educators must have a greater understanding of the cultural and social factors operating within the African American community."* Education and outreach efforts targeting the African American community should incorporate traditional norms and values reflective of the community.

The following are culturally sensitive recommendations to provide outreach to African American communities:

Literature Review

- Conduct a literature review to identify cultural competency resources and information about African American culture
- An emphasis should be placed on the dynamics of family relationships, religious beliefs, health practices, illness beliefs, and communication

Community Profile

- Identify target geographic area(s)
- Identify African American population demographics
- Conduct an assessment of local community-based organizations,

churches, agencies, service providers, and local ethnic media resources

Relationship Building

- Use assessment data to identify potential community partners
- Conduct focus groups with potential community partners to identify needs for services
- Cultivate relationships with community stakeholders
- Create strategies for education and outreach efforts based on focus group recommendations

The following are examples of the Alzheimer's Association's efforts to establish relationship building within the African American community:

In 1995, the Alzheimer's Association convened an African American Outreach Work Group. Under the auspices of this group, recommendations were given to develop a plan to provide outreach in the African American community. The target areas for outreach were based on demographic data that identified large clusters of African Americans 65 years of age and older, residing in the West-Central area of Los Angeles County.

In 1998, the Alzheimer's Association convened the West-Central Dementia Care Network. This interagency model is a community-based approach to provide programs and services for African American elders and caregiving families affected by Alzheimer's disease and related dementias.

In 1999, the West-Central Dementia Care Network conducted five focus groups with community participants. Focus group data identified strategies to enhance service delivery in African American communities for education and outreach efforts.

In 2000, community partnerships were established with African American faith-based communities. The Clergy Outreach Program

provides education, outreach, and access to services for African American elders and caregiving families in faith-based communities.

Information and Materials

- Develop culturally sensitive brochures, fact sheets, and visual aids depicting African American culture
- Conduct community focus groups to critique drafted materials.
- Revise materials based on focus group recommendations
- Identify locations and events to distribute materials in the community

The following are examples of the Alzheimer's Association's efforts to provide culturally sensitive information and materials for the African American community:

In 2000, the Alzheimer's Association developed a clergy booklet, *Faith-Centered Partnerships: A Model for Reaching the African American Community*. The clergy booklet was developed from focus group data collected from a cross-section of community residents, clergy members, and service providers. Based on recommendations from focus group participants, several strategies were identified to enhance outreach efforts to faith-based groups in African American communities. The purpose of the clergy booklet is to provide agencies with culturally sensitive strategies to establish successful partnerships with faith-based groups in the African American community.

In 2002, the Alzheimer's Association implemented a Vascular Dementia Project to promote awareness about stroke-related memory loss (vascular dementia) in the African American community. Based on data from six community focus groups, the Alzheimer's Association developed two culturally sensitive brochures to promote awareness for stroke-related memory loss in the African American community.

Education and Outreach Activities

Collaborate with community partners to host education and outreach events at sites within the community such as churches, community

centers, grass roots organizations, restaurants, barbershops and salons.

Model for Education and Outreach

An example of community education and outreach efforts targeting the African American community is the West-Central Dementia Care Network model. The West-Central Dementia Care Network is a collaborative effort among the Alzheimer's Association and community partner agencies to provide services for African American caregiving families affected by Alzheimer's disease and stroke-related memory loss. The West-Central Dementia Care Network provides a range of social services and supportive resources to help families handle the burdens associated with caregiving. Partnering with churches, faith-based groups and community-based organizations has enhanced education and outreach efforts to reach families in need of support and services. The Clergy Outreach Program provides education, outreach, and access to services for African American elders and caregiving families in faith-based communities. Through collaborative efforts with community partners, the West-Central Dementia Care Network provides community education and outreach in the African American community. Care Advocates provide caregiving families affected by dementia with case management and referral services.

Ethnic Media

The use of local ethnic media outlets is an effective method to promote awareness to African American communities about various programs, services and community events. For example, the Alzheimer's Association West-Central Dementia Care Network successfully promoted awareness about stroke-related memory loss (vascular dementia) in the African American community. A communications plan was developed to incorporate the use of ethnic media outlets.

Model for Ethnic Media Promotions

The following strategies were implemented:

- Identify target geographic area(s)
- Identify African American population demographics
- Identify local ethnic media outlets that circulate in the targeted

Marketing

area(s)

- Develop culture-specific newspaper ads, articles, billboards, and radio and TV public service announcements
- Conduct focus groups to critique drafted materials. Revise materials based on focus group recommendations
- Promote media messages using selected ethnic media outlets

The development of a marketing plan is recommended for the strategic distribution of culture-specific program products targeting the African American community. For example, the West-Central Dementia Care Network successfully marketed and distributed program products to promote awareness about stroke-related memory loss (vascular dementia) in the African American community. A marketing plan was strategically developed and coordinated to promote programs and services.

Model for Marketing Program Products

The following marketing strategies were implemented:

- Identify target geographic area(s) for product distribution
- Partner with community agencies as sites for product placement
- Establish community libraries accessible to the public to serve as resource sites in such places as churches, community centers, grass roots organizations, restaurants, barbershops, and salons.

Capacity Building

Building the capacity of existing programs and services is an effective method to support program longevity. Capacity building establishes linkages in the community to enhance service delivery. Capacity building enables agencies to enhance internal programs with community partners. For example, the Clergy Outreach Program successfully provided capacity building for clergy community partners. The Church Liaison partnership was established within the health ministries of several churches. Through the partnerships, service delivery was enhanced in the areas of education, outreach, and services for caregiving families and seniors affected by Alzheimer's disease and related dementias.

Program Longevity

Model for Capacity Building

The following strategies were implemented to enhance programs and services for capacity building efforts:

- Identify community partners that have existing programs that target African American populations.
- Cultivate relationships with potential partners
- Compare work plans, programs and services
- Identify activities that could be enhanced with capacity building
- Incorporate education and outreach efforts into existing programs and services
- Provide technical assistance and training for program enhancement

Implementing strategies to sustain community programs is key for continuous service delivery. For example, the West-Central Dementia Care Network continues to increase the knowledge of the general public, healthcare providers, and community volunteers about the impact of Alzheimer's disease and related dementias by implementing and preserving the mission of the organization.

Model for Program Longevity

The Alzheimer's Association continues to apply the following strategies to maintain program longevity and service delivery for the African American community:

- Continuous relationship building with current community partners
- Identify and cultivate new relationships with community stakeholders
- Use ethnic media to advertise programs and services
- Use marketing strategies to promote programs and services
- Collaborate with community partners to build the capacity of existing programs and services
- Maintain and identify funding resources for program stability.

Asian/Pacific Islander Dementia Care Network

For the past three decades, Asians and Pacific Islanders have been the fastest growing major racial/ethnic group in Los Angeles County. Asians and Pacific Islanders are currently the fastest growing ethnic group over the age of 65 in the United States and the second largest ethnic elderly group in Los Angeles County. As this group grows in numbers, so will the numbers of individuals and families affected by Alzheimer's disease and other dementia-related disorders.

In 2000, the Alzheimer's Association received a three-year federal Administration on Aging grant from the California Department of Aging to develop the Asian/Pacific Islander (A/PI) Dementia Care Network. The central goal of the Project was to identify unmet service needs in three Asian communities in Northern and Southern California, and to develop culturally appropriate service models to address the needs of these communities. The grant was extended to include a fourth year to further implement its goals and objectives.

Target Communities

According to the 2000 U.S. Census, the A/PI population is comprised of more than 45 distinct ethnic groups and a multitude of cultures speaking more than 28 languages. This can make outreach particularly challenging in some of the larger, metropolitan areas. The Alzheimer's Association partnered with two community-based agencies in Southern California to serve the Chinese and Japanese communities. The Alzheimer's Association in Northern California was contracted to serve the Chinese and Vietnamese populations. (Santa Clara County reportedly has the largest community of Vietnamese persons living outside of Vietnam.)

In both Dementia Care Network sites, partner organizations were established that are well-known and respected in their respective communities: John XXIII Multi-Service Center in San Jose; Little Tokyo Service Center and Chinatown Service Center, both in Los

Education and Outreach

Angeles. The careful selection of appropriate partner agencies is a strategic step in the development of a Dementia Care Network.

Outreach through the Dementia Care Network has included a variety of activities. Information tables at various community health and cultural fairs have been just one way to support other organizations and increase awareness of services.

Educational sessions have been conducted throughout the target communities by staff (Care Advocates, education coordinator, project manager) and members of the Alzheimer's Association volunteer Speaker's Bureau. Presentations have been a major component of outreach and education. Standardized modules created by the Alzheimer's Association, such as "Memory Loss and Aging," are being translated into other languages. Presenting information in the language of the participants has been much more effective than relying on translators.

Culturally appropriate in-home care

While the demand for quality bilingual in-home support is high in many Asian American communities, the supply is often scarce. In the Asian Pacific Islander Dementia Care Network, the curriculum, "How to Work with Confused Older Adults" was translated into Chinese and pilot tested with 25 monolingual in-home workers. This curriculum was developed as a "train the trainer" model for other providers to adapt to their communities.

Support Groups

Through interagency partnerships, six caregiver support groups were established, with groups conducted in English, Mandarin, Vietnamese, and Japanese. Incorporating education into the monthly support groups helped to overcome some of the cultural stigmas associated with dementia and support groups. In Northern California, support group participation also increased when congregate respite was offered during the Vietnamese group meeting times.

Encouraging participation in support groups in Southern California's Chinese community was a continuing challenge throughout the span

of the Project. Despite a variety of education and outreach efforts, the cultural stigma associated with support groups and Alzheimer's disease continued to interfere with the growth of this service. However, in Northern California support group participation increased when on-site congregate respite care was implemented. This program also proved to be a successful way to introduce families to the benefits of adult day services. Scheduling and announcing a guest speaker on topics of interest often resulted in increased participation among the Japanese support groups.

Primary marketing efforts were conducted through community networking. Program brochures were produced in English, Chinese, Japanese, and Vietnamese. Information was distributed to service providers such as adult day centers, nutrition and meal programs, churches, and senior living sites, as well as at health fairs and community gatherings.

One of the characters in best selling author Amy Tan's book, *The Bonesetter's Daughter* was based on her mother who had Alzheimer's disease. The Amy Tan Grocery Bag Project reached Southern California's Chinese and Japanese communities by distributing 100,000 bags through popular Asian supermarkets in Southern California. The support of grocery stores enabled the Dementia Care Network to print Project information, the 10 warning signs of Alzheimer's disease, and an image of Amy Tan and her mother on each grocery bag.

Media

to have brochures they could take home to read on their own.

Among the translated materials was a series of six brochures produced in Chinese. Topics included caregiver stress, Alzheimer's disease, obtaining a diagnosis, caring for someone with Alzheimer's disease, and related legal planning issues. The Alzheimer's Association used its several-step translation protocol to maintain the consistency of translated materials.

Care Advocates learned to be sensitive to the fact that some families were not comfortable with the term "Alzheimer's disease." The preferred terms were "memory loss" or "dementia," with memory loss being most preferred.

Standardized forms with questions asking for a "primary" or "secondary" caregiver were not always practical for the intake process. In many cultures, caregiving is a responsibility shared by several members of the family—no one particular family member is designated as "primary." Wherever possible, program participation is to be viewed in the appropriate context, with a designated contact person.

To announce the Project's launch, a media event was held with featured speaker, George Takei, a caregiver and actor noted for his role on *Star Trek*. Ethnic media representatives were very supportive of the event. Both print and broadcast media outlets helped to promote the Project, especially during the start-up phase.

Chinese newspapers in Northern California helped reach an audience of nearly 300,000. In Southern California, a Japanese language television station devoted a ten-minute segment to the Little Tokyo Service Center program, reaching thousands of Japanese families throughout Southern California. An increase in telephone inquiries was experienced by Project staff following radio broadcast announcements about the Project.

Appendix 1:

Alzheimer's Disease and related Dementias

What is dementia?

Dementia is the loss of mental function in two or more areas such as language, memory, visual and spatial abilities, or judgment severe enough to interfere with daily life. Dementia itself is not a disease but a broader set of symptoms that accompanies certain diseases or physical conditions. Well-known diseases that cause dementia include Alzheimer's disease, multi-infarct dementia, Parkinson's disease, Huntington's disease, Creutzfeldt-Jakob disease, Pick's disease, and Lewy body dementia. Other physical conditions may cause or mimic dementia, such as depression, brain tumors, head injuries, nutritional deficiencies, hydrocephalus, infections (AIDS, meningitis, syphilis), drug reactions, and thyroid problems. **Individuals experiencing dementia-like symptoms should undergo diagnostic testing as soon as possible.** An early and accurate diagnosis helps to identify reversible conditions, gives patients a greater chance of benefiting from existing treatments, and allows them and their families more time to plan for the future.

Alzheimer's disease

Alzheimer's (pronounced Alz's-hi-merz) is a disease of the brain that causes a steady decline in memory. This results in dementia — the loss of intellectual functions (thinking, remembering, and reasoning) severe enough to interfere with everyday life.

When German physician Alois Alzheimer first described the disease in 1906, it was considered rare. Today, Alzheimer's disease is the most common cause of dementia, affecting 10 percent of people 65 years old, and nearly 50 percent of those 85 and older. An estimated 4 million Americans have Alzheimer's.

Alzheimer's disease usually begins gradually, causing a person to forget recent events and to have difficulty performing familiar tasks. How rapidly the disease advances varies from person to person, causing confusion, personality and behavior changes, and impaired judgment. Communication becomes difficult as the person with Alzheimer's struggles to find words, finish thoughts, or follow directions. Eventually, a person with Alzheimer's becomes totally unable to care for himself or herself.

Creutzfeldt-Jacob Disease

Crutzfeldt-Jacob disease (CJD) is a rare, fatal brain disease caused by

infection. Symptoms are failing memory, changes in behavior and lack of muscular coordination. CJD progresses rapidly, usually causing death within a year. No treatment is currently available.

Multi-Infarct Dementia

Multi-infarct dementia (MID), or vascular dementia, result from brain damage caused by multiple strokes (infarcts) within the brain. Symptoms can include disorientation, confusion, and behavioral changes. MIS is neither reversible nor curable, but treatment of underlying conditions (e.g., high blood pressure) may halt progression.

Normal pressure hydrocephalus (NPH)

Normal pressure hydrocephalus is a rare disease caused by obstruction in the flow of spinal fluid. Symptoms include difficulty in walking, memory loss, and incontinence. NPH may be related to a history of meningitis, or brain injury, and is often correctable with surgery.

Pick's disease

Pick's disease is a rare brain disease that closely resembles Alzheimer's with personality changes and disorientation that may precede memory loss. As with Alzheimer's disease, diagnosis is difficult, and can only be confirmed by autopsy.

Parkinson's Disease

Parkinson's disease (PD) is a disease affecting control of muscle activity, resulting in tremors, stiffness, and speech impediment. In late stages, dementia can occur, including Alzheimer's disease. Parkinson drugs can improve steadiness and control, but have no effect on mental deterioration.

Huntington's Disease

Huntington's disease (HD) is a hereditary disorder characterized by irregular movement of the limbs and facial muscles, a decline in thinking ability, and personality changes. In contrast to Alzheimer's, Huntington's can be positively diagnosed and its movement disorders controlled with drugs. The progressive nature of the disease cannot be stopped.

Depression

Depression is a psychiatric condition marked by sadness, inactivity, difficulty in thinking and concentration, feelings of hopelessness, and, in some cases, suicidal tendencies. Many severely depressed persons also display symptoms of memory loss. Depression can be reversed with proper treatment.

Source: Alzheimer's disease and Related Disorders Association, Inc. All Rights Reserved

Appendix 2: Needs Assessment Methods

There are many different ways to conduct a needs assessment. Perhaps among the three most common are: secondary data sources, surveys and focus groups.

Secondary Data Sources

Data collected and formally reported, such as that by the United States Census Bureau, is one of the most valid sources. Published survey data and reports are also useful.

Surveys

Surveys are among the most commonly selected methods for conducting needs assessments because they can easily generate a significant amount of numerical or quantitative data. Surveys are a cost-effective means of collecting information from a large number of individuals, often with little assistance needed by respondents. They can be efficiently administered to large numbers of respondents and are more likely to produce results that are representative of the target population. Quantifying responses, such as those related to attitudes, perceptions and service needs, is an important attribute of this method.

Surveys can be conducted by mail, telephone, or in person. Generally, the larger the sample or number of participants in the survey, the greater the reliance is on structured or fixed-choice questions. Additionally, funders and other external stakeholders often prefer the quantitative results that surveys provide, because the numbers suggest quantities of attributes being measured. Quantified attributes can be compared to those of other areas, national estimates, or to the same area but at a different time. Thus, scope and content requirements are determined by the sponsoring organization, other stakeholders and the resources and time available.

Focus Groups

Focus groups usually consist of eight to ten participants with a moderator (or facilitator). Optimal meeting times range from 40 minutes to three hours, depending on the breadth and depth of topics. To avoid participant fatigue, groups should meet for a maximum of three hours at a time. Focus groups benefit the needs assessment process because of their concentration on the quality, not the quantity, of the information.

As with any small group or sample, the particular participants selected will determine the representation of the group's responses to broader populations. Focus groups work best when researchers seek the views of homogenous subpopulations such as a certain ethnic population of caregivers. Understanding who the participants are and what groups they represent is the key to interpreting and generalizing the outcome of focus groups. For example, participants may come from a certain country, belong to a certain socioeconomic class, or live in a certain area. The facilitator or discussion moderator typically prepares a guide and a list of topics or questions to be discussed. Without such guides, facilitators may find the important topics are not discussed. Although facilitators help guide the discussion, they do not impose great restrictions on it. However, they do need to ensure that the range of important topics is covered.

Appendix 3:

Tips for Publications and Media

1. Avoid literal translations of existing material as they lose their meaning when syntax and vocabulary are not within cultural contexts. In publications, use pictures that the target group can relate to.
2. Explore the use of community-based media outlets (such as minority newspapers and magazines, minority college campus newsletters, local minority radio, cable television programs, etc.) and use prepared public service announcements, simple articles, flyers and posters as a way to get information out to minority populations.
3. Find places that target audiences frequent. Identify places that are natural sites for presentations, brochures, flyers, and posters. Take your information and presentation to areas where high volume of “people traffic” can be found.
4. Distribute program literature at hair salons, barber shops, day spas, Laundromats, dry cleaners, shops, grocery stores, libraries and restaurants that are frequented by the target population.
5. Arrange to conduct outreach in targeted churches, communities, and clubs. Making community service announcements during church services is an excellent method of attracting interest.
6. Look for ways to penetrate trusted pathways. For example, use religious radio broadcasts for public service announcements and gatherings to circulate print materials.
7. Identify key minority focus information web sites as a way of educating younger caregivers and the growing number of elder website users.
8. Exhibit information and educate minority caregivers through professional meetings, conferences and publications (e.g. national associations of minority physicians, nurses, media professionals, attorneys, etc.)

(Source: *Achieving Cultural Competence*, Administration on Aging, January 2001)

Appendix 4:

Steps for Developing/Translating Materials

The following are guidelines that may be helpful when developing translated materials. The steps presented can be modified according to available funding and what is feasible for agencies.

1. Finalize the intended message of the materials being developed/translated.
2. Select a translator (in-house or consultant) and verbally explain the intended message to the translator.
3. Have the translator develop a draft of the materials in the second language that best sends the desired message to the target audience.
4. Have a second, bilingual staff member, consultant, or appropriate volunteer back-translate the draft into English. The back-translated English draft and original English document will be given to a supervisor for review.
5. Have the translator edit the second language document based on the supervisor's feedback. This process should continue until both the second language and back-translated pieces have been approved with no further revisions.
6. Have draft materials reviewed by at least three representatives from the target audience, or conduct a focus group. Ask the reviewers to verbally describe, in their language, the content and message of the materials. Get feedback from the reviewers on graphics such as photos. If the reviewers wish to provide photos of individuals they feel will be more appropriate, make sure that a media release form is completed.
7. Make revisions based on reviewers' comments. In addition to the initial reviewers, ask three representatives of the target audience to review the revised materials for the content and message. Verbal feedback should be given directly to the "expert(s)" and the translator. Continue repeating this step until the intended message is clearly relayed in the materials.
8. Arrange printing of the final version of the second language material with the assistance of the agency media/print consultant. For some jobs, consider asking community agencies/volunteers to recommend printers.

Appendix 5:

History of the Los Angeles Alzheimer's Association's Diversity Efforts Prior to the A/PI Dementia Care Network

- 1990 The Multicultural Outreach Advisory Board (MOAB) was founded and the Chapter began to translate educational materials, contact media outlets with diverse audiences, and contact community agencies to co-sponsor educational events in diverse ethnic communities.
- 1991 A Spanish-speaking professional was hired to lead the multicultural efforts. Previously mentioned activities continued. The Chapter's program committees and Board of Directors began to address diversity issues in volunteer recruitment and service delivery.
- 1992 Chapter became the lead agency under the Human Resources Services Administration (HRSA)-funded El Portal Project, which sought to develop a dementia care network in East and Southeast Los Angeles targeting Latinos (\$500,000 a year for three years). Chapter initiated search for an African American agency with which to partner for service development (Adult Day Care Committee.). Previously mentioned activities continued.
- 1993 Chapter funds People Coordinated Services with a \$240,000 three-year grant to develop an adult day care center and support group in the Crenshaw District targeting African Americans. An African American professional was hired to lead the multicultural efforts. Chapter receives a small grant (\$4,000) to initiate A/PI outreach. A training program was developed targeting social service professionals in A/PI communities. Efforts to recruit multicultural volunteers for the Speakers Bureau become formalized. Program committees actively recruit members from diverse ethnic communities. Previously mentioned activities continue.
- 1994 Chapter starts African American Outreach Program with funds from two small grants (about \$12,000). Centers serving diverse ethnic communities are prioritized for funding by the Adult Day Care Committee. Previously mentioned activities continue.
- 1995 A workgroup is convened to seek private funds to support El Portal Project when the public dollars stop. HRSA funding continues for an unexpected fourth year (\$400,000). The brochure targeting African American communities is developed. A Latino Outreach postcard is developed and an Outreach Worker is hired to distribute it. With funding from HRSA, Chapter staff and staff of other agencies in the El Portal Project receive diversity training. The MOAB elects to receive diversity training. Diversity training helps Chapter staff to conceptualize our organization's strengths and weaknesses and to plan for growth.
- 1996 Strategic planning process examines and addresses diversity issues in each program area. A professional staff person from an A/PI community is hired to work in Patient & Family Services. Five percent of her time is committed to A/PI Outreach. An African American Outreach Worker is hired. The MOAB disbands and members are recruited for other activities. An A/PI workgroup is assembled.

Internet Resources

The following websites are listed as possible resources only. Please use them to locate resources on services for older persons and their families and caregiver, Alzheimer's disease and related dementias, and cultural competency and diversity.

Administration on Aging, Professionals > Addressing Diversity: www.aoa.gov

Alzheimer's Association (National) Diversity Toolbox: www.alz.org

Alzheimer's Disease: Unraveling the Mystery: www.alzheimer's.org.unravel.html

American Bar Association Commission on Law and Aging: www.abanet.org/aging

American Society on Aging: www.asa.org

Andrus Gerontology Center Library: www.usc.edu/locations/science/gerontology

Care Guide: www.careguide.com

National Academy of Elder Law Attorneys: www.naela.org

National Association of Area Agencies on Aging – Eldercare Locator: www.n4a.org

National Association of Professional Geriatric Care Managers: www.caremanager.com

Sage Publications – publisher of journal, books, and electronic media with an emphasis on ethnically diverse communities: www.sagepub.com

Selected Literature

The following are references from the Alzheimer's Association Diversity Toolbox, which provides items of interest for those working with Alzheimer's disease in diverse communities. The list is not exhaustive and selections do not constitute endorsement. For more listings, see the Diversity Toolbox at www.alz.org.

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