

California: The Dementia Care Network Model: Enhancing Caregiving for Persons with Alzheimer's and other Dementias in Culturally Diverse Groups

Since its founding, the Dementia Care Network Model has demonstrated enhanced dementia care service capacity and contributed to alleviating the psychological, emotional, and financial stress associated with caregiving.

Overview

In 2015, an estimated 678,446 Californians aged 55 or older will be living with Alzheimer's disease.¹ In California, the leading causes of death, disability, and diminished quality of life include mental health conditions and Alzheimer's disease.² Alzheimer's disease and other dementias are affecting people of all races, cultures, and communities at rapidly increasing rates. By 2060, Hispanics will comprise nearly half (48 percent) of all Californians.^{3 4} Consequently, California will no longer have a single racial majority group. According to the Alzheimer's Association, although the incidence of Alzheimer's is projected to double by 2030 in the California general population older than 55, it will triple among the Asian/Pacific Islander populations.⁵ Between California's rapidly growing Hispanic population and the Asian/Pacific Islander populations' increasing health needs, the state is experiencing a burgeoning need for culturally competent dementia care.

Care for people with dementia, such as Alzheimer's disease, is often provided in the home by family members or friends. As lifespans lengthen and the population becomes proportional older, a corresponding increase is expected in the number of individuals providing care, the length of time spent caregiving, and the breadth of required tasks. Although these caregivers provide a tremendous service to persons with Alzheimer's or other dementias and society, they are at greater risk for developing health problems.⁶

In 1992, the California Department of Public Health, in partnership with the state Department of Aging, were awarded a HRSA Alzheimer's Disease Demonstration Grant. This grant program is designed to encourage partnerships between state agencies, local Alzheimer's Association chapters, and other community organizations so they can better reach and serve culturally diverse populations of family caregivers and patients. With its grant, the state focused on the growing population of Latinos in East and Southwest Los Angeles County and selected the Alzheimer's Association, California Southland Chapter to be the lead agency for local implementation. The first network was called El Portal: Latino Alzheimer's Project and supported the creation of culturally competent, linguistically matched materials and support services for Latino families and professionals.

El Portal, as the first network, built the Dementia Care Network Model that the California Southland Chapter used to bring together nonprofit service providers, program consumers, community representatives, and government entities. Under this model, networks are developed in response to the need for community-based, long-term care services resulting from an unprecedented increase in the number of ethnically diverse dementia-affected individuals. By partnering with agencies that are trusted in their communities and have deep understandings of cultural norms, network members can share knowledge, establish trust, and build on each member's strengths to develop a culturally acceptable set of supports for people with dementia and their families.

Steps Taken

In partnership with the state Departments of Aging and Public Health, the Alzheimer's Association, California Southland Chapter convened a network of community-based organizations that served older Latinos and concerned community members. The California Southland Chapter initially conducted a needs assessment to help identify gaps in service. Over several years, providers received training on the delivery of culturally and dementia competent care. Local agencies adept at serving Latinos included the AltaMed Health Services Corporation, Los Angeles County Department of Mental Health, and the International Institute of Los Angeles. El Portal also established five bilingual adult day centers, two legal clinics, and two Los Angeles County sites for care management. Overall, El Portal's services included awareness activities, outreach, caregiver support and education, adult day centers, support groups, legal clinics, and care management. El Portal also conducted an intensive public relations and outreach campaign, including print and electronic media, marketing presentations to consumer and provider groups, and held community fairs to raise awareness about Alzheimer's disease among Latinos.

In 1998, the California Southland Chapter convened the West-Central Dementia Care Network, which replicated the El Portal approach to provide programs and services for African American elders and caregiving families affected by Alzheimer's disease and other dementias. Community focus groups highlighted the strength of faith-based community partnerships to enhance service delivery, education, and outreach efforts for African American communities. Informed by facts from the Alzheimer's Association that an emerging public health crisis among African-Americans, the California Southland Chapter implemented a vascular dementia project to promote awareness about stroke-related memory loss. Data from longitudinal studies suggested that high cholesterol and high blood pressure may be significant risk factors for Alzheimer's disease, in some cases four times as likely.⁷ To reach this population, the chapter developed culturally sensitive brochures, because written materials were often preferred by caregiving families to absorb the information on their own.⁸ To date, this network of service providers continues to meet quarterly and provides dementia risk-reduction education for African Americans through healthy lifestyle choices.

In 2000, the California Southland Chapter was awarded a three-year federal grant through the California Department of Aging and from the Administration on Aging to develop the Asian/Pacific Islander Dementia Care Network. The goals were to identify services and outreach gaps in three Asian communities in Northern and Southern California and develop culturally appropriate service models to address gaps. One of the major gaps identified constituted a scarce supply of quality bilingual in-home support. The Asian/Pacific Islander Dementia Care Network developed a pilot curriculum, "How to Work with Confused Older Adults," that was translated into Chinese and tested with 25 monolingual in-home workers. This curriculum was designed as a train-the-trainer model for providers to better serve their evolving communities.

In 2009, with funding from the Harry and Jeanette Weinberg Foundation, the California Southland Chapter expanded existing Japanese and Chinese networks to include Filipino Americans for a combined Asian/Pacific Islander Dementia Care Network to bridge the service gap in Los Angeles. The chapter conducted a community needs assessment that identified significant gaps in the information on culturally appropriate day care and end-of-life services. As a result, several agencies established delivery services and support groups, including day care services and information and trainings on end-of-life

option. These programs have steadily been attended by five to 15 caregivers. Additionally, leader training programs for attorneys, physicians, health educators, and social workers have been developed designed to increase their capacity to service cognitively impaired older adults and their family caregivers.

To date, El Portal and the Dementia Care Network Model demonstrate how the practical application of community organization strategies, training and technical assistance, and funding can improve access, service, and consumer satisfaction among underserved ethnic groups. The model reduces health disparities for dementia-affected families by building capacity within communities.

Results

The Dementia Care Network Model leaves positive lasting impacts on the caregivers and communities it touches with significant increases in the use of ethnically diverse community and care services.

Reach and Effectiveness:

- The El Portal services were provided to more than 6,000 Latino families.⁹
- Spanish-language Helpline calls, offered during El Portal, increased by 50% from the pre-program period with nearly 90% of all callers identifying themselves as Latino and caring for someone with memory loss.⁹
- In 2009, the latest iteration of the model focusing on Asian/Pacific Islander communities in Los Angeles, 89 out of 127 participating caregivers completed a six-month post-test assessment, which revealed a statistically significant increase in the use of case management, information and referrals, caregiver support groups, caregiver training programs, and chore services among caregivers and use of transportation and legal services for care recipients. The post-test results revealed a statistically significant decrease in the level of depression.¹⁰

Implementation and Replication:

- For each dementia care network population, the Alzheimer's Association, California Southland Chapter undertook a needs assessment. Based on what it learned, the network developed a continuum of care for caregivers that included a combination of awareness activities, outreach, caregiver services, support groups, and care management and sometimes adult day care centers and legal clinics.
- Although the model began with Latino caregivers, it has been expanded and replicated for African American, Chinese, Japanese, Filipino, Korean, and Vietnamese communities in Southern California, as well as Chinese and Vietnamese communities in Northern California. The California Southland Chapter has prepared the "[Dementia Care Network Replication Manual](#)" with elements of El Portal and also provides suggestions for culturally appropriate communication.
- The California Southland Chapter dementia care network model has been replicated across local and state jurisdictions, including San Diego, Seattle, and Minnesota.

Lessons Learned

Implementing these initiatives resulted in several lessons learned, including the importance of establishing mutual trust and respect for close partner collaboration and securing substantial funding upfront that can be sustained.

- “The dementia care network is a scaffolding, it is not necessarily a structure meant to exist forever.”¹¹ A population’s dementia-related needs will evolve over time, so organizations leading dementia care networks should be flexible and tweak their programs as-needed. In the areas where El Portal was implemented, support groups, several adult day healthcare programs and PACE (program of all-inclusive care for the elderly) sites trained in bilingual dementia management remain; however, El Portal is no longer needed in the same way because the infrastructure was constructed to allow for growth and adaptation over time.
- Mutual trust and respect are a prerequisite for collaboration. Mutual learning about dementia and cultural differences and similarities brought the collaborating partners closer.
- Substantial funding should be secured to get the dementia care networks off the ground, which may be difficult to sustain.
- Many dementia care network resources and delivery outlets are still active today as a result of the development and maintenance of synergistic partnerships within the community.

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² California Department of Public Health. “California Wellness Plan 2014.” Available at: [http://www.cdph.ca.gov/programs/cdcb/Documents/CDPH-CAWellnessPlan2014%20\(Agency%20Approved\).FINAL.2-27-14\(Protected\).pdf](http://www.cdph.ca.gov/programs/cdcb/Documents/CDPH-CAWellnessPlan2014%20(Agency%20Approved).FINAL.2-27-14(Protected).pdf). Accessed 3-11-2014.

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⁵ Ross LK, Brennan C, Nazareno J, *et al.* “Alzheimer’s disease facts and figures in California: Current status and future projections.” Alzheimer’s Association. 2009. Available at: <http://www.cdph.ca.gov/programs/alzheimers/Documents/CADDataReport-full-corrected3-2.pdf>. Accessed 3-22-2014.

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⁷ Alzheimer's Association. "African-Americans and Alzheimer's Disease: The Silent Epidemic." Available at: http://www.alz.org/national/documents/report_africanamericansilentepidemic.pdf. Accessed 4-17-2014.

⁸ Alzheimer's Association. "Dementia Care Network Replication Manual." Available at: http://www.alz.org/social/documents/professional_aadcmanual.pdf. Accessed 3-11-2014.

⁹ Aranda MP, Villa VM, Trejo L, *et al.* "El Portal Latino Alzheimer's Project: Model program for Latino caregivers of Alzheimer's disease-affected people." *Social Work*. 2003. 48:259-71. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/12718421>. Accessed 3-4-2014.

¹⁰ Kally, Z., Cherry, D., Howland, S., Villarruel, M. (in press) Asian Pacific Islander Dementia Care Network: A model of care for under-served communities. *Journal of Geriatric Social Work*.

¹¹ Cherry D. Personal Communication. Feb. 27, 2014.