

ADDGS Lessons Learned in Cultural Outreach

Overview

The primary goal of the Alzheimer's Disease Demonstration Grants to States (ADDGS) program is to improve access to home and community-based long-term care services for people with dementia. The program has a strong emphasis on providing services to individuals who are members of racial or ethnic minority groups, people with limited proficiency in speaking English, and individuals living in rural areas. Within many minority communities, Alzheimer's disease and dementia carry stigmas. This issue brief examines approaches ADDGS grantees have taken to overcome cultural barriers to providing community-based dementia services.

In March 2007, the Alzheimer's Disease Demonstration Grants to States (ADDGS) Technical Assistance Center hosted a web-based teleconference to discuss successful cultural outreach strategies for dementia programs. All the teleconference participants have used ADDGS funds to develop innovative methods of communicating with culturally diverse populations. Individuals participating in the web-based meeting included:

- **Beth O'Grady**, Director, Coalition for Limited English Speaking Elderly. Located in Chicago, the Coalition for Limited Speaking Elderly educates a wide range of limited English speaking populations about Alzheimer's disease and dementia
- **Kenneth Hepburn, PhD**, Emory University, is the developer of the evidence-based caregiver training program *Savvy Caregiver*. Currently, Dr. Hepburn is in the process of translating the Savvy Caregiver program into a product that is effective in Spanish speaking Latino communities
- **Susan Howland, MSG**, Director of Education, Alzheimer's Association California Southland Chapter. The Southland Chapter works with Asian, Latino, and African American communities to provide information and resources about Alzheimer's disease
- **Deborah Danner, PhD**, University of Kentucky, Sanders-Brown Center on Aging and Alzheimer's Disease Center. The Sanders-Brown Center on Aging hosts the African American Dementia Outreach Partnership

Grantee Recommendations

Although each of these programs serves distinct minority populations and the foci of their projects vary widely, the ADDGS web conference participants agreed upon the following principles for conducting cultural outreach. In their view, successful cultural outreach programs must:

1. Identify, acknowledge and address cultural and organizational obstacles early
2. Develop partnerships within the community to be served
3. Sustain relationships beyond the grant cycle

1. Identify, acknowledge, and address cultural and organizational obstacles early

Everyone has preconceptions about individuals, organizations, and Alzheimer's disease and dementia. To overcome these preconceptions, dementia care organizations need to work with partners to identify cultural preconceptions and acknowledge their own biases up front. Organizations engaged in a cultural outreach dementia care partnership need to take the opportunity to learn from one another.

Understand the current practices of partner organizations and respect their other obligations

Cultural outreach partner organizations and community leaders often serve a multitude of community needs, from assistance with language issues to provision of counseling services to financial planning information. Alzheimer's disease is just one of many issues these organizations will encounter. A request to establish a dementia care partnership is likely to be only one of numerous and similar requests being considered by the cultural outreach organization. This factor needs to be taken into account when determining a role for the cultural outreach organization.

Be Flexible

Organizations with dementia care expertise should be prepared to have some their typical educational techniques and cultural preconceptions challenged. Also, it is important to keep in mind that the community's needs and the needs of cultural outreach partner organizations are fluid. Dementia care entities should be prepared to adjust their plans or partnership arrangements when necessary.

2. Develop partnerships within the community to be served

Individuals from underserved communities are more likely to respond to existing community leaders than they are to respond to an unfamiliar organization. Similarly, community members likely have a better understanding of how to reach out to their peers. Developing partnerships with community agencies and leaders is key to the success of a dementia outreach program.

Be open, honest, and trusting with your partners

Minority community leaders are often approached by social services or health care organizations to assist with their outreach efforts. Dementia experts need to be open about the limitations and specifications of the program being proposed. If from the beginning, dementia care experts share with minority leaders their expectations about what they hope will be gained through partnership activities, community leaders will be more inclined engage in those activities.

Do not be afraid to mentor and be mentored by your partners

Sometimes, it is necessary to educate community outreach organizations about how to navigate the systems that can provide quality dementia services to their customers. At other times, dementia care organizations will need help in learning how to work within the framework of a given community's traditions. Partners on both sides of the equation should expect and not fear changing roles.

3. Sustain relationships beyond the grant cycle

Relationships developed with partner organizations and community leaders can last for years. While the grant funding which served as a catalyst to establish the partnership will inevitably end, that does not mean the partnership has to end. Organizations engaged in a dementia care cultural outreach partnerships can benefit from considering alternative means of keeping collaborative projects alive and keeping the door open for future collaboration.

Background on ADDGS Grant Programs Discussed

Coalition of Limited English Speaking Elderly (CLESE)

CLESE serves the older population in the Chicago metropolitan area. The Coalition is comprised of 45 member organizations serving immigrant, refugee, or migrant older adults. CLESE connects older adults with social service organizations designed to serve people from similar linguistic and cultural backgrounds.

As part of the Illinois ADDGS grant, CLESE partners with the Cognitive Neurology and Alzheimer's Disease Center at Northwestern University Feinberg School of Medicine. Another partner is the Alzheimer's Association Greater Illinois Chapter which works with existing social services organizations serving persons with limited English speaking ability.

CLESE originally received a three-year ADDGS grant to reach out to Chinese, Korean, Polish, Russian, and Spanish language organizations about Alzheimer's and dementia. After the conclusion of that grant, they received a subsequent three-year ADDGS grant to work within the Arabic, Assyrian, Bosnian, Hindi, and Urdu speaking communities.

In working with community organizations serving culturally diverse populations, CLESE undertakes the following actions:

- When beginning to work with the organizations serving culturally diverse populations, CLESE convenes a meeting to discuss the definition of Alzheimer's disease, how it might translate into the languages spoken by those served by the community organizations, and how persons with dementia are treated in the "home country."

- Next, CLESE works with the organizations to translate four power point presentations, a medical history form, the Safe Return enrollment form and a short story emphasizing the need for diagnosis.
- Subsequently, CLESE organizes visits to bi-lingual physicians to provide them with a manual on the assessment protocol for diagnosis of dementia and refers persons with memory problems to the bi-lingual physicians that speak the language in which they are most confident.
- Finally, CLESE assists persons with dementia with enrollment in the Alzheimer's Association Safe Return program.

Kenneth Hepburn, Ph.D.

Ken Hepburn is the principal designer of the *Savvy Caregiver* program, a transportable dementia family caregiver training tool. *Savvy Caregiver* was developed, in part, through funding from an ADDGS grant. Additionally, using ADDGS funding the program has been implemented in several states. The program's success led to the desire of some researchers to translate the program into Spanish.

After a somewhat unsuccessful attempt at directly translating *Savvy Caregiver* into Spanish, Dr. Hepburn recruited a group of researchers from the University of Texas Health Sciences University to collaborate on a project to transform the *Savvy Caregiver* into a program that is not only translated into Spanish but is also culturally appropriate for Latinos. The result will be an evidence based dementia family caregiver training program presented in the style of a *telenovela*.

A *telenovela* is a short, Spanish-language soap opera. To make the program culturally relevant for Latinos, key elements of *Cuidando con Carino* will include:

- Presentation of materials in an informative and entertaining format, rather than a traditional classroom setting
- Consideration of the family as student, rather than one specified caregiver
- Use of narrative to teach caregiving principles

Alzheimer's Association California Southland Chapter

The Alzheimer's Association California Southland Chapter serves Los Angeles, Riverside, and San Bernadino counties. The chapter has developed programs to reach out to the Latino, African American, Japanese, Chinese, and Korean communities to provide information and services for Alzheimer's families. The Chapter currently receives ADDGS funding to work with the Chinese and Korean communities.

When initiating a relationship with a cultural community, the chapter takes the following steps.

- First, it develops relationships within the communities, working with members of the community to identify caregivers, provide education, and start support groups.

- Next, in each community, the chapter implements the Dementia Care Network model which is a framework to provide dementia services to ethnically diverse communities through a collaborative network of partners (from African American churches to Asian markets).
- The Dementia Care Network replication manual (available on AoA's website) describes what a dementia care network is, and provides step-by-step information on how to develop and sustain a network. The manual provides insights about and examples of how to properly assess the environment for implementing a dementia care network. Key topics addressed include:
 - Community outreach, networking and awareness
 - Coordination of services and service delivery
 - Program expansion and development
 - Evaluation of existing materials and further dissemination

University of Kentucky Sanders-Brown Center on Aging and Alzheimer's Disease

Deborah Danner developed and manages the African American Dementia Outreach Project (AADOP) through her work with the Sanders-Brown Center on Aging. The AADOP is funded, in part, through ADDGS grant funds. Project objectives are to:

- Increase awareness of Alzheimer's disease through community education.
- Provide culturally sensitive clinical care and family support at a memory care clinic located in an area where many African Americans live.
- Establish and monitor support groups and free memory check ups.

To achieve these goals, the program took the following actions.

- Educational outreach efforts were implemented by creating advisory councils comprised of community and church leaders.
- Next, the program worked with the local Alzheimer's Association chapter to develop community presentations and to plan and deliver conferences.
- The AADOP hired an African American nurse to provide in-home assessments to potential Alzheimer's patients prior to the clinic visit.
- In developing support groups, program staff found that the phrase "support group" did not encourage African Americans participation. Instead, they redesigned the groups into the more culturally appropriate "fellowship groups."
- At the request of partner ministers and with their input, AADOP developed a resource manual "The Book of Alzheimer's" with comprehensive information under one cover and a chapter on maintaining the spirit of the individual with Alzheimer's disease. This resource guide was provided to African American churches for their libraries.

Obstacles to Culturally Based Dementia Outreach Programs

Cultural Preconceptions

Upon embarking on each of their distinct culturally based outreach efforts, our experienced teleconference participants quickly came to understand that there are cultural preconceptions of

Alzheimer's and dementia. One key recommendation from multiple participants was not to assume that the community to which you are reaching out has the same understanding of Alzheimer's disease as you have.

Misconceptions about Alzheimer's disease and dementia

There are many misconceptions about Alzheimer's within the general U.S. population. Some believe dementia is a natural process of aging; others believe that dementia is a 'mild form' of Alzheimer's. The communities with which ADDGS grantees worked are no different.

- **Language Barriers:** According to Beth O'Grady of CLESE, "In most other languages, there is no equivalent translation of 'Alzheimer's disease.' It may translate as 'crazy' or 'dumb' or otherwise have connotations of negative mental illness." In order to overcome this initial stigma, CLESE has adopted the use of the phrase 'memory problems' to describe Alzheimer's and dementia. O'Grady does not believe that the use of this term entrenches the misconception that Alzheimer's is a normal part of aging. Susan Howland seconds O'Grady's concern, citing "preconceived ideas from the community about the disease" as a major obstacle to overcome.
- **Cultural Stigma:** Language is not the only barrier to understanding Alzheimer's disease. Deborah Danner of the AADOP notes, "The stigma associated with Alzheimer's disease was a major obstacle that kept individuals from seeking help" in the African American community. The stigma among African Americans in Lexington, KY is similar to those noticed by O'Grady—that people with dementia are "crazy" or insufficiently cared for by their families.

Defining the role of family caregiver

Perceptions of the term 'family caregiver' also vary among cultural communities.

- **Caregivers have Broader Meaning:** Ken Hepburn notes that one of the reasons simply translating *Savvy Caregiver* into Spanish was not suitable for the Latino community is that the concept of a primary caregiver is not prevalent in Latino families. Instead, the entire family takes part in supporting the person with the disease. As a result, the entire format of *Savvy* needed to be redesigned for families rather than individual caregivers.
- **Reluctance to Ask For Support:** Danner found similar ideas about caregiving in the African American community. One of the AADOP advisory groups suggested that the reason the term "support group" was not well-received in Lexington's African American community is that "African Americans are unlikely to acknowledge that they need support" because they are culturally inclined to "take care of their own." Providing care for one's aging parent is considered a natural role and not a burden.

Organizational Barriers

In addition to facing cultural barriers to providing dementia care, each of our ADDGS grantee participants also encountered organizational obstacles. Most of these obstacles involved misconceptions about the communities to which the organizations were attempting to reach out.

Fear of Collaboration

All four advisors recommended avoiding assumptions and keeping an open mind about those with whom you are working. It can be difficult to recognize existing misunderstandings and to adjust one's own view of his or her work in order to understand outside perspectives. For example, ADDGS teleconference participants cited the following examples.

- ***Misconceptions About Who You Are:*** Susan Howland cited a distrust of the Alzheimer's Association in the communities she serves as an obstacle. Many members of the African American and Asian communities in the Los Angeles area thought of the Association as a white, Jewish organization.
- ***Impact of Past History:*** Danner faced similar barriers to reaching the African American community in Lexington. She writes, "An often unspoken yet enduring barrier was related to the historical treatment of African Americans in Kentucky. Many African Americans currently suffering from Alzheimer's disease remember when they had to file a lawsuit to attend the University of Kentucky. At the beginning of this grant, these older African Americans did not want to have anything to do with the University of Kentucky." She goes on to discuss the mistrust of health care providers and the community ministers' fears of their congregations being used as 'guinea pigs'.
- ***Sharing Ownership to Achieve Goals:*** Hepburn encountered unexpected difficulty in his own ability to share ownership of a product that he had designed and allow it to become something culturally relevant for Latinos. He describes it this way, "It's been a great learning experience for me, watching something I feel great ownership for (Savvy Caregiver) get turned over in a way that some new entity (Cuidando con Carino) was produced for which I feel considerably less ownership. These issues remain somewhat unresolved but not contentious." While he quickly learned that he would need to collaborate in order to develop an appropriate product, he learned that he needed to share ownership of the new project in order to redesign his model for a Latino audience.

Logistics of Collaboration

Determining what one agency or organization can offer another in terms of time, resources, and financial support for a project can be cumbersome. In some of our participant's situations, the size of the organizations involved and their major foci varied. Below are descriptions of some key lessons learned in partnership.

- ***Respect Other Priorities:*** For O'Grady, based in Chicago, working with small, ethnic-specific social services organizations means that she has to consider that while her work is about Alzheimer's disease, the agencies with which she is partnering address a

multitude of issues. It has been important for her to remember that they have other priorities.

- ***Understand Partnership Expectations:*** Howland, based in Los Angeles, notes that local agencies are often approached by multiple organizations and voluntary health associations. She recommends that those embarking on this type of relationship “respect their time and other obligations.” She also cautions that the financial support of partnerships often comes with specific obligations. All participants in these arrangements must fully understand the expectations of the partnership.
- ***Make Promises You Can Keep:*** Danner in Lexington stresses the importance of being honest with partners and not making promises you cannot keep. She continues, “The community is justified in asking what will happen to your program when grant funding ends. Organizations working in underserved communities should be prepared to answer this question.”

Developing Partnerships to Overcome Obstacles

The most often cited recommendation of our experienced ADDGS program developers was to develop partnerships with leaders or gatekeepers within the communities to be served. These partnerships come in many forms, from hiring staff from those communities, to entering into formal contracts with ethnicity based organizations, to forming advisory committees of community leaders.

Hiring within the Communities to be Served

Examples of how projects hired staff and worked with culturally appropriate collaborators include:

- ***Hire Culturally Appropriate Staff and Volunteers:*** Danner recommends hiring staff and recruiting volunteers from within the community you are trying to serve as often as possible. Her clinic hired an African American physician on the advice of one of her advisory committees. She found that the African Americans in the community sometimes feel more comfortable visiting an African American physician. Much of this is attributed to the historic relationship between the University of Kentucky and the African American community.
- ***Work with Culturally Appropriate Collaborators:*** Hepburn found Latino researchers who worked in a clinical setting that already served a Latino community to collaborate on his project.

Working with Key Culturally Based Organizations

ADDGS Grantees have identified several ways to reach out to culturally diverse populations. Some examples can be found below.

- ***Keep the Umbrella Open:*** CLESE currently works with seven ethnicity based social services agencies under the ADDGS grant. Two of the agencies requested to be included in the dementia outreach program after hearing about it and identifying people with possible dementia in their communities.
- ***Support Local Businesses:*** The Alzheimer’s Association California Southland Chapter works with some local ethnicity based organizations but also strongly recommends developing relationships with community members by supporting local businesses. Some examples are advertising on grocery bags at ethnic food stores or purchasing food from local retailers for support group and advisory group meetings.
- ***Offer Key Leaders A Seat At The Table:*** Danner developed her advisory group of ministers by contacting ministers of well-known African American congregations in the area. This proved tremendously effective, as the ideas for successful programs such as the well attended (300+) dementia conferences for African Americans were developed by the ministers.

Sustaining Effective Programs Beyond the ADDGS Grant Cycle

According to ADDGS web conference participants, a major benefit of focusing grant efforts on outreach and education is that the outcome of your grant never expires. Once a bilingual physician or an ethnic agency staff person is educated about the availability of supportive services for persons with dementia and their families, those individuals will continue to refer persons with dementia to appropriate resources. Additionally, the relationships developed through the grants often continue to function after the grant cycle has concluded.

Some examples of the enduring impact of ADDGS Cultural Outreach grant activities can be found below.

- ***Developing Evidence of Program Adaptability :*** Hepburn, having worked to develop a replicable training program, believes that *Cuidando con Respeto* will be useful until the caregiving strategies become outdated. This project has demonstrated the transferability of *Savvy Caregiver*.
- ***Development of Reusable Products:*** O’Grady notes that translated materials and community education will last for some time, but adds, “What cannot be sustained is to educate additional physicians or to provide the intense counseling that usually accompanies enrolling a client in the program.” These are services for which CLESE plans to identify additional funding in order to continue its dementia outreach program in its current form.

- ***Building Something to Sustain with Existing Organizational Resources:*** Howland agrees. She suggests that the Alzheimer's Association California Southland Chapter will continue its outreach efforts at some level without grant funds. However, the formal and large scale outreach, including full-time staff, program supplies, media placement, agency staff training, and other program costs cannot be funded through existing organizational funds. Grant funds were used to initiate the formal and large-scale outreach in communities previously not reached, but the resources necessary to continue work in the communities once they have been reached formally can be imbedded within existing organizational budgets.
- ***Community Leaders Adopt Program as their Own:*** The African American Dementia Outreach Partnership, under the leadership of Deborah Danner, has formed strong enough relationships in the community to secure outside funds. When the program first began, the community was wary of becoming involved in a demonstration program, fearing that the community members would be used as 'guinea pigs.' Deborah secured a commitment from the Sanders-Brown Center on Aging that the memory care clinic for African Americans would be sustained without ADDGS funds. The memory clinic will be funded in part through a National Institute on Aging Alzheimer's Disease Center grant and partly through University funds. What the University could not sustain on its own were the successful dementia conferences. Upon receiving word that future conferences would not be possible without additional funds, the African American partner churches offered to fund between \$30,000 and \$50,000 for continued community outreach efforts.