EXECUTIVE SUMMARY

STUDY THREE:

QUALITATIVE INTERVIEWS WITH KEY DELIVERY STAFF
TO DOCUMENT SUCCESSFUL STRATEGIES FOR ADDRESSING
CULTURAL BARRIERS TO SERVICE USE

OBJECTIVES

The primary purpose of this study was to explore more fully the ethnic, geographic and familial contexts of service from the perspective of service providers. To a large extent, the success that providers experienced with developing and implementing culturally appropriate support services appeared to reflect their insights into the cultural contexts of the families that they served. This qualitative study was designed to more fully capture these understandings of staff members through in-depth interviews. These experiences and perceptions of staff members are valuable for interpreting and corroborating findings from the quantitative studies.

METHODS

Fifty qualitative interviews were completed. Forty-two interviewees were frontline staff members and eight were administrators. Interviews were conducted by telephone and then tape recorded for later transcription. Questions followed the Interview Guide and proceeded in an open ended, in-depth format in accordance with qualitative methodology. Upon completion of the transcription of the interviews and assurance of their accuracy, the full analysis was undertaken.

RESULTS

Providers from the ADDGS project offered specific and detailed advice for those who wish to develop acceptable and appropriate services for diverse populations. Additionally, staff members, as a group, made several general recommendations that are pertinent to all programs, regardless of the cultural groups that comprise their client populations.

General Lessons for Service Delivery

- Become familiar with your service community!
    - Get to know both the culture and language of the community.
    - Become aware of other available resources and services.
    - Understand the issues related to service use, such as socio-economic levels, education, employment status, and other key factors.
    - Understand family structures and caregiving beliefs.
- Develop Appropriate and Responsive Service Programs!
    - Use culturally appropriate materials and activities.

- o Hire and train bicultural staff members (from the community if possible).
- o Individualize care plans when possible.
- o Match hours available to caregiver needs.
- o Create homelike environment with friendly, welcoming staff.
- o Use "socializing" context for support groups.
- o Use "sliding fees" to negate "welfare" stigma.
- Build trusting relationships!
  - o Stress honesty in interactions.
  - o Create clear expectations for care with clients.
  - o Follow through! Follow through! Follow through!
  - o Recognize and reward excellent staff members.
  - o Hold Team meetings so all staff members can provide input.
- Educate the Community!
  - o Provide information about Alzheimer's disease.
  - o Let families know about the purpose and availability of respite services.
  - o Explain about the value of dementia-specific services.
  - o Inform how support services can enhance family care.

Providers also shared issues and advice unique to specific cultural groups. These service aspects, they are quick to add, are second to developing a caring, compassionate service. Understanding the community and building trusting relationships can overcome differences. However, special attention to some of the unique needs of the various cultures can smooth the transition for new service users and ensure greater satisfaction of all users. Providers offered the following lessons.

Lessons for Rural Communities
- Creativity, flexibility, and innovation are needed to address isolation, transportation needs, and lack of resources.
- Respite should be promoted as an support for, not a replacement of, family care.
- Charging a small fee can address the welfare or handout stigma.
- Focus on empowering clients in their relationships with medical professionals.
- Assign familiar aides to families when possible.

Lessons for Black/African-American Communities
- Work with key community leaders to develop trust with residents.
- Address the needs of working caregivers.
- Promote respite as an aid to, not replacement of, family care.
- Create a social atmosphere, preferably with food.
- Match workers and clients by race when possible.

Lessons for Hispanic/Latino Communities
- Develop bicultural expertise in staffing.
  - o Mirror the community, ethnically and culturally when possible.
- Incorporate folk medicine into educational approaches.
- Educate about the medical aspects of Alzheimer's disease.
- Providing familiar food and activities can create more comfortable environments.
- Reassure caregivers that they are not alone.
- Assure caregivers that using respite is not selfish or neglectful.
- Create social, friendly environments for service provision.

STUDY THREE:

**QUALITATIVE INTERVIEWS WITH KEY DELIVERY STAFF
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CULTURAL BARRIERS TO SERVICE USE**

INTRODUCTION

Prior to the Alzheimer's Disease Demonstration Grants to States project (ADDGS), the majority of support services delivered to families of individuals with Alzheimer's disease were directed to urban, White, middle class populations. Likewise, most scholarly work concerned with Alzheimer's disease caregiving and service provision was also similarly narrow in its focus (Tennstedt et al., 1998).   The few studies that did attempt to address the omission of minority populations failed to differentiate adequately among minority groups, often treating all nonwhites as a homogenous group (Bass et al., 1992). While this approach provided some insight about urban, White, middle class communities, there were still significant gaps in the service populations, knowledge, and literature.   The ADDGS project was developed to specifically address this limitation by funding both service provision for, and research on, support services to ethnically diverse families.

Through the demonstration, many lessons about how to serve diverse Alzheimer's populations have been learned. The quantitative data collected has provided a wealth of information about "who" uses "what" and "when". Whereas previous, interviews with caregivers have identified the key elements for client satisfaction with respite services (Montgomery et al., 1997). From the site visits and conversations with frontline providers, the variety in cultural expectations and the similarity in care issues for Alzheimer's families have been noted. Thus, the ADDGS has broadened the intellectual understandings of the differences in serving families of ethnically, geographically, and familial diversity while highlighting the analogous care needs of families of individuals with Alzheimer's disease.

To serve diverse groups effectively, it is important to understand clients within their ethnic, geographic, and familial cultural contexts. It is essential to identify cultural differences in caregivers' beliefs about Alzheimer's disease and medical care, social norms, views of "helping" agencies, and formal service utilization expectations for care provision from family members. However, it is also important to realize that within these diverse cultural contexts, the families'

care needs are disease driven and, thus, their service needs for support may not be equally diverse. This is demonstrated by the commonality of respite services—though not their delivery mechanisms--offered through the ADDGS project.

Since its inception in 1992, the ADDGS project has been delivering services to many hard-to-reach and under-served populations. In order to do this successfully, service delivery staff members have learned about their target populations' needs and expectations. They have also identified existing barriers to be addressed. Project staff has also developed innovative service delivery approaches to reach these new populations. This study of the research project was undertaken to document these insights from the perspective of local delivery personnel.

Caregiving and Cultural Context

Caregiving is a dynamic process that is accomplished within a cultural context with attendant meanings, symbols, and rituals for the participants. More than merely attitudes and behaviors, caregiving is a process that emerges out of a previous relationship that varies with regard to generation, gender, and individual family histories. Even when non-family members perform caregiving tasks, their cultural understanding of the process as well as previous individual experiences influence each participant--the caregiver and the care recipient.

It is currently estimated that over 6.7 million elderly individuals need some form of assistance with one or more ADLs or IADLs (Hing & Bloom, 1990), though others place the estimate even higher (Ory & Duncker, 1992). Indeed the number of individuals over the age of 65 in the United States is predicted to double within the next four decades and the "frail elderly", those over 85 years of age, will represent the largest percentage increase (Sterneck, 1990). More assistance will be provided to these elders than ever before (Longino et al., 1990). While most of these individuals rely exclusively on help from family or other informal (non paid) persons, these networks of informal support are generally weak (Wilcox & Taber, 1991). Thus, there is a growing percentage of elderly who either exhaust or do not have these familial resources and, in turn, come to rely on paid formal caregivers for all their essential needs (Lyons & Zarit, 1999).

Formal homecare workers often fill that gap between family support and elder need. As individuals age or become incapacitated due to illness or disability, many are seeking and using assistance from home-based services as a preference to institutionalization. In-home respite care is the most frequently required (Wallace, 1990) and requested form of formal assistance

(Montgomery & Kosloski, 1995). Indeed, families caring for cognitively impaired elders identify respite care as one of their core needs (Lawton et al., 1989; Friss, 1990; Petty, 1990). A study of 85 year olds or older in the community noted that nearly half (49.5%) needed assistance due to functional limitations (Hobbs, 1996). Others project that currently, for every person institutionalized for care, there are four or more individuals in the community requiring some form of *formal* long term care (Ory & Duncker, 1992).

These projected needs are further complicated as one notes that the United States is experiencing a demographic shift from a predominately White, European population to a multi-ethnic, multi-cultural society (Zinn, 1995). This is likely to lead to an even larger percentage of elderly individuals with functional and other care needs due to the differences in health and social status. Black/African-Americans and Hispanic/Latinos have lower socio-economic levels than their White counterparts (Taeuber, 1993). This results in general states of poorer health with greater functional disabilities for Black/African-Americans and Hispanic/Latinos (Wallace et al., 1994;). In spite of this increased need for assistance, Black/African-Americans and Hispanic/Latinos are often under represented in service utilization (Kemper, 1992). However there is evidence that these populations do use services when services are provided in culturally appropriate ways (Montgomery et al., 1997). In fact, Wallace et al. (1994) found no difference in use rates between Latinos and Whites.

Study Purpose

The primary purpose of this study is to explore, in a more thorough manner, the differences found among cultural groups in the larger evaluation project (Montgomery et al., 1997). This qualitative study was designed to corroborate as well as to interpret the quantitative findings by seeking perceptions and insights of staff members for developing and implementing culturally appropriate support services for diverse populations. In other studies the insights of service staff have been found to be profoundly helpful and instructive in understanding the care delivery process as well as discerning how to best provide useful, efficient, quality services (Karner et al., 1998; Karner, 1999).

Methods

Sample

Fifty interviews were completed. Of those, forty-two interviews were conducted with frontline staff members and eight were conducted with administrators. Fifteen of these staff members worked for programs that targeted urban dwelling Hispanic/Latino families and ten served urban Black/African-Americans. Of the twenty-five staff members working in programs that served rural populations, eight worked to provide respite to Black/African-American families while four served rural Hispanic/Latinos. The remaining thirteen staff members were employed in programs that served rural families of all ethnic groups. (See Appendix 3.A).

Interview Process

Initially, letters were sent to the state coordinators of the eight selected demonstration states requesting them to identify eight to ten staff members appropriate for interviews. Since the purpose of these interviews was to document successful strategies for serving diverse populations and to identify culturally specific needs, coordinators were asked to identify staff members who had at least one to two years of experience with the demonstration project. Appropriate staff members would also have a broad understanding of the cultural needs of the target population, and knowledge of the various ways the program had attempted to serve them—both those that were successful and those that were not. Ideally, staff members would be actively involved with targeting and serving under represented populations. Sixty-nine staff members were identified and their names and contact information were forwarded to the University of Kansas team.

A letter providing information about the study and the anticipated format of the interviews was sent to each of the identified staff members (see Appendix 3B). Staff members were informed that the interviews would be an effort to systematically compile some of the field expertise developed through the demonstration project. Furthermore, the interviews were to capture the "how to" information needed to create or replicate successful programs elsewhere. The interviews were scheduled to be completed in approximately one hour. Approximately two weeks after receiving the letter each staff member was contacted by The University of Kansas Interviewer who answered any questions the respondent had about the study and then scheduled an interview with those persons agreeing to participate.

Interviews were conducted by telephone and then tape recorded for later transcription. Questions followed the Interview Guide (see Appendix 3C) and proceeded in an open ended, in-depth format in accordance with procedures of qualitative methodology. This methodology focuses both on language and interpretation of the respondents—that is, it is not only the answer given that is considered as data, but the meaning that is attached to the answer by the interviewee is also important. This orientation is particularly appropriate for research such as this, which focuses on the identification of cultural, geographic, and familial beliefs. The qualitative approach "emphasizes the relationship between personal experience and the historical, social, and cultural contexts—the link between people and settings, self, and society" (Riessman, 1990: xii).

When appropriate, follow up questions were used to elicit further specificity in the responses. This method of interviewing allows the respondents to be integral participants in the interview process. By using their own words (as opposed to response categories), interviewees use their own cultural views and meaning structures to respond. Additionally, they may "lead" the interviewer into topics that may have been overlooked, yet have significance. This can aid the researcher in understanding the issues more broadly.

Analysis

Following the tenets of qualitative methodology, the analysis proceeded through a series of stages (Lofland & Lofland, 1984; Glaser & Strauss, 1967), beginning with the transcription and reporting of the interviews without any analytic frame. The data were then read thoroughly for emerging themes, connections and main concepts. This constituted the *rudimentary* classification of the major subjects of interest (Charmaz, 1988; Strauss, 1987). For this project, the rudimentary classifications were framed by the proposed research questions. The next analytic phase sought to *refine* the classifications further into conceptual categories. These categories are organized by the research question topics. At this point, the text data was further ordered by pertinent issues within the research question. By referring to the staff members' own phrasing and terminology, the analysis can facilitate clearer understanding among providers and offset any potential error due to research jargon.

Research Questions

In order to gain the most insight about service delivery barriers and successful strategies used to address them, a broad, open-ended format of questions was used. Specific study questions to be answered include:

1. What are the special characteristics of the target service population?
2. What is the prevalent view of Alzheimer's disease in the target population?
3. What is the prevalent view of using support services in the target population?
4. How willing are members of the target population to receive services from staff of different backgrounds?
5. What barriers to service use have been identified for the target population?
6. How has service delivery been modified to address identified barriers? Have these efforts been successful?
7. How has staff hiring or training been modified to address the needs of the target population?
8. What are the key components to successfully provide respite services to the target population?

RESEARCH QUESTION #1: WHAT ARE THE SPECIAL CHARACTERISTICS OF THE TARGET SERVICE POPULATION?

This study focuses on three populations served by the demonstration: Rural, Black/African-Americans, and Hispanic/Latinos.   Each population has its own history in the United States and its own culture. The uniqueness and special characteristics of each group is highlighted and discussed below.

The Lost Ones—Rural Communities

> I call them the **lost ones** because … most of them are the farmers in rural counties who have worked real hard all their lives and they are faced with the choice of either giving up everything they have or surviving (35, emphasis added).[1]

The rural demonstration projects, included in this research, have served extremely isolated rural communities in northern Maine and the Upper Peninsula in Michigan as well as agricultural communities in North Carolina, South Carolina and southern Florida. Clients who live in rural areas are thought to face specific logistic barriers in accessing services. The demonstration, however, has brought the importance of understanding the cultural aspects of rural communities to the forefront. Staff members are quick to point out the unique aspects of living in a remote areas and small communities.

In rural areas, one provider tells us, "people are more apt to stay on their little fifteen acres of land and take care of their problems on that side of the hill" to illustrate the self sufficiency and social isolation that are prevalent (31).   Another staff member believes that it is the sense of privacy and independence that contributes to the belief that rural folks try to take care of their own by themselves. "They've been through a lot of hard times," she continues, "and they have pride in the fact that they've been able to go through these times and do well" (18). Another staff member agrees,

> I think there is a lot of pride in being hard-working and strong and well. When someone in the family gets Alzheimer's … [They think] they can do it themselves. Or when they have to ask for help, they think they may be somewhat of a failure, that they should have been able to do it themselves (23).

This belief that asking for help is admitting that they have failed is particularly strong with spouse caregivers.

> I took a vow 65 years ago that I will stand by this woman, or this man, for better or worse, until one of us is gone, and that's what I'm going to do." And they might start crying, because they feel that they're breaking that [vow] by bringing me in, or bringing my volunteers in, because **they** should be doing that. "Nobody can take care of my husband" (27).

Family relationships play a central role in rural communities according to providers. "I see a lot of family caring, people pulling it together the best they can" states one staff member (21). Another provider explains that family priorities are very strong and different than she believes exist in non-rural areas.

> I think that their priorities are different. Their priorities are usually centered around the family. They're very family oriented, family focused, and work oriented. A lot of people up here do not have a hobby (18).

This sense of family and family expectations runs throughout the interviews with rural providers. A client told a provider, "You have to do that because mom and dad has taught us that's what you do, you take care of each other" (30). The expectations for family also include the notion of privacy. "They are private people, and they're not used to expressing family matters" (41).

Churches also play a key role in rural communities. A provider in South Carolina explains that the church is the focal point of the town (36). It provides a "glue" that holds groups together. Rural churches also serve as extended family in some communities. The churches can be the community lifelines (21). One provider paraphrases the church in her community as saying, "This is our family, this is our job, [and] it's a big job" (27).

General isolation can play a role in enhancing the tendency to pull together as a family, church, and community. Many clients live several miles from the nearest store, and basic services like paper delivery do not exist (27). This translates into a greater dependency on those around you or as a particularly remote provider points out, a great dependency on one's car and one's ability to get to town for services, information, and health care. "Our agency serves four counties and they are very rural… People depend on their cars, and … you know that many folks as they age are not able to continue to drive very far" (21).

Providers tell us that individuals from rural areas often have less education so literacy is a common issue especially for elderly rural. Many do not have access to medical services on a regular basis, while others are very loyal to their family doctors and do not see a need for specialists or advanced assessments (28).   However, if the clients are adult children caregivers, staff report that they are more likely to be educated, interested in gaining information about Alzheimer's disease and using services (27).

Language is also a unique problem in upstate, rural Maine as many individuals speak only French or very little English. One provider explains, "They have been so intent on preserving their language that many of the older people refuse to speak English" (18). Additionally, she continues, that there are "a lot of negative comments about the French people… they're perceived as less intelligent [because] they have more of a difficult time expressing themselves" (18). Thus she has to address the subtle prejudice as well as the language barrier. Unfortunately, this is not only an issue in Maine. In another area, a staff member explains, "there's a lot of bigotry going on in this area" (28). She continues to warn that it is "well hidden, the prejudice in this area" (28).

In general, the rural residents who receive demonstration services share characteristics unique to their geographic location. Isolation has led them to rely on themselves, and take pride in their self-sufficiency. Family relationships play an important role in the lives of rural citizens, and family members often feel a resultant duty to care for sick members. The church also occupies a central place, functioning to hold communities together.

Rural residents have had relatively few educational opportunities. They have been similarly limited in their access to regular medical care, although this is less so for adult children

caregivers. Even though rural areas are more homogeneous than many urban areas, discrimination based upon ethnic origin exists in rural areas, only in a more covert form.

Strong Extended Families -- Black/African-American Clients

The Black/African-Americans served through the demonstration come from a variety of backgrounds and cultures. In the southern states of North Carolina and South Carolina, the Black/African-American communities are descended from the days of slavery and have a culture that reflects that history. In Michigan and the District of Columbia, the Black/African-American communities developed through the northern migration of southern blacks for industrial opportunities after WWII. Whereas the Black/African-Americans served in Florida are often the more recent first or second generation immigrants from Haiti, the Bahamas, and the Dominican Republic who came in search of a better life and went to work in the fields. Each of these communities has a distinctive worldview that has been influenced through diverse experiences.

> Even though they are African-Americans, there is diversity. … You cannot use one broad stroke to paint all African-Americans, so that even within the older population, there are differences (38).

This diversity has prompted providers to remember, "Every family is different. You can't totally generalize" (11). Though staff members do observe that family and community relationships are strong in Black/African-American communities. "I'm going to say that we're more family oriented, because we want to keep everything in the family" (16), states one staff member. Another provider concurs, Black/African-Americans "sort of take in each other" (14). The women in the family seem to be at the core of this cohesion and caring.

> It's also a female dominated caregiving community in many, many ways. The daughters and the wives are major caregivers. It sounds kind of hokey but music, ties to church, family meals, laughter—It all seems to be a part of the culture (43).

This inter-family caregiving extends to older persons. The "extended family … has always been the bedrock in the African American family" (8).

> There is a strong preference … in the African American culture to help a person remain at home … no matter what. It is a very strong feeling … that the care provided by the family is going to be better and [that] the person prefers to stay at home (11).

The family ties are conceived of broadly, staff members observe that children raised by other family members (aunts and uncles, or grandparents) often become their caregivers in old age and refer to them as Mom and Dad (14). Thus the familial titles in Black/African-American communities may not relate to the stereotypical blood relationship and staff needs to be mindful

not to jump to conclusions. Additionally, family ties often extend into the community. In urban areas where "direct" family may not be living near, one provider finds that there will be "a neighbor, or friend, a church member, someone who is taking an interest in helping them" (11).

In spite of the extensive family network within the Black/African-American community, there still appears to be one primary caregiver. A northern, urban provider laments,

> … a lot of my participants have large families. They have a number of children. They have sisters and brothers who are still alive, and on the majority of the cases, there is only one person that is caring for this person. There is only one primary caregiver. There are other siblings or [family] members who are … basically on the outside looking in (26).

Ironically, in a southern rural area, the demonstration staff has come to the same conclusion despite increased involvement of family members.

> If there is a senior or elderly person that is sick, the whole family takes turns taking care of that person. … The siblings continue to go off to work and they tend to be there at night, but during the day, the sole responsibility would still be on the wife or … designated child (35).

Furthermore, extended family can mean conflicting care needs.

> Many times there are multi-generations living in a household, so they're not only taking care of someone who has dementia, but they're also providing for children who are in school, or providing for other relatives who have few resources of their own (39).

Thus, having more family members in close proximity can mean more assistance and support, but often means less support and multiple care needs to be filled.

Another aspect of family care is the perception of self-sufficiency. A provider who serves Black/African-American clients explains, "the people in this rural area have a tendency to do for themselves and not really reach out to others. … They take care of their own … [and] that probably keeps a lot of them from turning to us for help that is available" (14). Another rural provider of services to Black/African-American families agrees, "for some people it's very ingrained in them that you just don't reach out for help … you do it yourself" (37). This is also found in urban settings. A northern provider further explains,

> We [African-Americans] don't like to admit that we have faltered. It's like you don't want to admit that … you actually need help because you feel like you're looked down upon if you are not able to handle things on your own (26).

The preference for family care also relates to a distrust of non-family and formal services in Black/African-American communities. There are "a lot of non-trust issues which I feel is (sic)

cultural" explains one provider (37). "I think it has a lot to do with … being African-American, living in more isolated communities where they've relied on each other [due to] past injustices," a staff member observes,

> … also sort of a general mistrust of the medical system, and that's because of not understanding and sometimes lack of education. And sometimes, health professionals not respecting their own methods of taking care of their family … (39).

The mistrust of doctors and medical services is contradictory in the experience of a northern, urban provider. She finds that many elderly individuals will not seek a doctor's care "because they don't trust them" (26). However, she continues, "if they *do* go to doctors, they tend to take the doctor's word as God's word. It's almost like golden. And it's not to be questioned" (26). Other times, she has seen the use of "home remedies … goose grease, all kinds of things" (26) in an effort to take care of their own.

This distrust also extends to the government. Many providers have to distinguish the services that they provide from "government programs".

> They think the government's going to come in and take their property … There's a misconception about the whole system. We've had to work with that. Sometimes they'll think we are part of the government just because we've had some federal and state funds, and so we have to try our best to try to explain to them that we're not connected with that, we're not going to come take anything away from them (37).

This general distrust of formal care services could also be the result of limited funds as well as education. In some cases "it was strictly knowledge; they didn't know what was available, or how to access it in the community" (39). Other times, the issue is limited financial resources (11). One provider discusses the disparity in her service area,

> Here we've got very upscale suburban neighborhoods with wealthy people, and then five or ten miles away…you have people without electricity, who really don't understand what's going on (37).

Another aspect of limited resources is reflected in the number of caregivers that work outside the home. There is a greater prevalence of adult child caregivers in the Black/African-American communities (Montgomery et al., 1997). And "most cannot afford to quit their jobs" (8). "There are so many households that the caregiver has to also work as well as take care of the client or loved one with the disease" (16). The providers find that these working caregivers are often the most receptive to using services and the least apprehensive about using formal help,

> … because they need these things. They are adult children and they're trying to work. They're trying to take care of their children. … They are less suspicious of people coming in to try to help them (26).

Another issue that providers mention as important in serving Black/African-Americans is the need to be respectful, as respect is something this community has been denied in the past. A staff member observed, "I think that some of these people are still living in the 19th century … there were the owners who had the money and there were the workers who worked in the fields. That was that" (14).   One client explained it this way to a provider,

> And she says, "We [African-Americans] were not respected in the community at large, and so we absolutely had to respect each other within our homes, and within our churches." And that really was a tremendous insight to me, because that's what you see many times is mutual respect (39).

The expression of respect is important for providers to address. Something as simple as using titles can make a difference. "I call them [my clients] Mr. or Miss out of respect. You owe them that" (17). A staff member warns against using first names without permission, "because you have almost been disrespectful to them by not calling them Mrs. Sara Jones or Ms. Jones" (8). Using titles in the Black/African-American community is symbolic of a broader form of respect as one provider explains,

> [During] slavery no one ever had titles. And you have to realize, if you're dealing with someone with Alzheimer's, they're in their '70's and '80's most of them, and these people have never had titles. They've always been Mary … because they were brought up by slave parents … like my grandmother was a slave and … her name was Mary, but I knew him [the white master] as Mr. Smith and that's what everybody called him, even though my grandmother and he were the same age and she was there when he was little. … So you have a lot of people that had grandmothers that were brought up in slavery or came when there wasn't slavery … but were still living on property that was owned by someone that was white, and so they never had a title (17).

As this discussion illustrates, such symbolic demonstrations of respect may be extremely important to family caregivers, especially adult children, in entrusting the care of their parents or grandparents to formal providers.

Providers also mention the importance of church membership and the spiritual community in Black/African-American populations. "Most of their [African-Americans] social life was pretty much surrounded around church activities" one staff member tells us (40). "The church is one of the major supports for the African American community" another provider adds (26). "I see faith as a core issue" one staff member clarifies, "[it has a] positive influence on allowing deviant

behaviors to be tolerated" (39). This acceptance can be applied to the behavioral symptoms of Alzheimer's disease as well as to acceptance of the role of caregiver. A provider explains further, "Whether it's their beliefs or whether it's their cultural background—probably in some cases it is sort of like 'We're going to accept this'" (37).   There is recognition "that this is a child of God and a basic person to be respected regardless" (39).

The ability to care as well as accept is attributed to individual faith or spiritual beliefs.

> In the African American community, especially those that I serve, faith is a big part. I believe that faith is what keeps the family itself strong, and I believe that they pull from their faith, especially to deal with types of diseases like this (16).

> These are people who are highly religious. They have some type of spiritual guidance in their lives … spirituality plays a large role in our caregivers' lives. A lot of them believe there is a possibility that things will get better. That someone can come out of this [Alzheimer's disease] … So even though we tell them, there's still hope (26).

Another staff member describes the importance of personal spirituality,

> It gives them a firm foundation for hope. They have a faith that they have learned. Some things they've learned to accept as they are and to be grateful for what they do have, and the focus of their devotion has basically been that they thanked the Lord for another day. So each day is one more chance. … It is their faith that gives them that encouragement to keep on, and that's an intricate part of their daily life, to give thanks for the life that they have (38).

Religion and spirituality appear to play a key role in the Black/African-American community and may be related to the low reports of caregiving burden and stress (see Study One: Table 8).

A surprising concern of providers targeting services to southern Black/African-American communities was the importance of understanding diet and nutritionally related health issues. "A lot of African-Americans in the south are eating greasy, salty food, and that really complicates the high blood pressure and the diabetes" (39). Another warns, "We have to be very much concerned about dietary factors," and she advocates, "to move away from the traditional southern cooking" (38).

Providers who serve Black/African-American clients make several generalizations about the individuals that they serve. They perceive a strong sense of family and community ties, which includes the extended family. This has created a greater prevalence of caregivers who are more distant relatives in the Black/African-American community, and involvement by more family members in caregiving. However, it is still most common that one person bears primary responsibility for caregiving, and simply receives input from others. Spirituality and organized

religion also have important roles, both to the Black/African-American community in general, and as support structures for caregivers.

Black/African-Americans, like their rural White peers, possess great pride in their ability to remain self-sufficient and "take care of their own". A related idea is the pervasive mistrust of government assistance and the medical system. In order to remain independent in the face of limited financial resources, many Black/African-American caregivers continue to work while providing care.   The concept of respect among community members is also highly valued, due to past injustices.

Earning their Crown in Heaven—Hispanic/Latino Americans

> The more I suffer, the more I'm going to earn in heaven. … Suffering in silence because this is … my duty. I'm supposed to do this. It is expected of me and therefore I'm a better Catholic, a better person. … [I'm] earning my crown in heaven (5).

The Hispanic/Latino demonstration clients included in this study are those in East Los Angeles, California, the Little Havana area of Miami, Florida, and those in Seattle, Washington and the surrounding rural areas.   In East Los Angeles, the population is predominately from Mexico and other Central and South American countries. Many are recent immigrants while others are second- and third-generation. East Los Angeles is a Spanish-speaking enclave in the heart of an urban center. The street signs are all in Spanish and all business can be conducted in Spanish—individuals can live in the community and have no need to learn or speak the English language. Little Havana, in Miami, Florida is similarly accessible in Spanish. Many residents do not speak English. The majority of Little Havana's population came from Cuba in the early years of the Castro regime and are first- or second-generation immigrants. Recently, however, other Central American individuals are coming to Little Havana. In Washington, the Hispanic population is mostly comprised of migrant farm workers from Mexico and other Central and South American countries or their first- or second-generation descendents.

As one provider reminds us, "when we use the term Latino or Hispanic, we're talking about people from over twenty different Spanish-speaking countries who have a great amount of differences and experiences" (5). "So we really have had to be tuned in to … how we should approach people a little differently from the different countries—even though they might speak the same language," another adds (43). Furthermore, the Spanish language is not spoken the same in each country (48). Different words have different meanings among the Spanish

speaking cultures. For example, the word _tortilla_ in Mexico refers to the corn _tortilla_ that we have come familiar within the United States, whereas in El Salvador it refers to a sweet cake and in Spain _tortillas_ are open-faced omelets. The variety of cultures and the variance in the language adds complexity to addressing the language barrier.

Communication issues have been the most acknowledged barrier to serving Hispanic/Latino populations. It is not enough for staff members to be bilingual--they need to be bicultural. Bicultural knowledge reflects the need for an awareness of the larger cultural protocols beyond language and word usage. For example, cultures have what can be called "speaking protocols" that refer rules about who can speak to whom and how.

> The communication is different—where in [North] American we tend to lay everything right out on the table and be very frank about things. Especially our health care. The Spanish speaking population is embarrassed by that frankness. You wouldn't sit down with them and out of the blue ask them a ton of questions about their health (44).

This protocol has relevance for how providers discuss client needs and accomplish service intake forms. "If they don't know you," a staff member explains, "They're not going to tell you anything" (45). For this population, communication is predicated upon trust and confidence building (45).

> So it's really important for them to see the face behind the name … it's important for them to see that you care because if not, they will not use your services, they will not feel comfortable using your services, they will not see a need for your services (5).

Another provider adds that, "if you want to establish a rapport with someone, you will have to divulge some personal information" (1). "They'll want to know about your background," she continues, " … Are you married? Are you not? Do you have kids? Do you not? And do you live alone? … I think that's important to them because they need to feel that they know you" (1). One staff member offers an example of a successful intake process.

> What it really took was a person from the community … to bridge the gap. It was just a real different approach from what we normally use when someone … would come to find out information. We'd sit down and talk about the program and what we have to offer. … [For] most of our Hispanic or Latino families, the way we would do intakes would be to go to them, sit in their kitchen with them, and talk to them about what we do, maybe have coffee with them, and then maybe come back again and talk to them. And then at that point ask them, "Would you be willing to come over and try having lunch with us one day?" There's a whole different process (50).

Another communication issue concerns showing respect. Speaking protocols for respectful communication between genders, generations, or providers and clients need to be acknowledged. One provider shared the story of her grandfather's expectations,

> When you come up to a Hispanic elder and you cross your arms, it's not out of disrespect. I remember we used to have to do that. We would come up to my grandfather to speak with him, and we could not just hang our arms down at the side. He expected us to show him respect by crossing our arms (45).

The format of communication is also an issue to consider. Within the Hispanic/ Latino populations, there is a high rate of illiteracy, especially with the elders (1, 43). This means that written information, newspaper announcements, or mailings may not be very effective formats with a large segment of this group (5). These individuals rely more heavily on the "human relationship" in making decisions about services (43). They want to have a sense that they know the staff member or outreach worker; families want to know that they *care* and they will *take care* of their relative (43).

The fact that many of the Hispanic/Latino individuals served by this demonstration project live in Spanish speaking enclaves further isolates them from mainstream information and services. "The language barrier has made them more isolated" (44). Recent immigrants are "…thrown in a four wall apartment. Nobody to speak their language. No friends. Everybody looks at you … suspicious" (48). "They need interpreters" to interact with the broader English speaking community (49). Alzheimer's disease issues further complicate this, "The doctors did not speak Spanish and they didn't have all of their needs communicated" (3). Consequently, families seldom know that they have a right to ask for a referral to a specialist.

As with other immigrant groups, Hispanic/Latinos have a tendency to idealize the way things are done in their home countries or in the old days. One staff member tells us, "They don't have the family support that we had in our country" (13). Another adds, "The older people in Latin America care for our children—they're cooking all day" (49). There is a belief that all care needs were taken care of within the family.

> Family is the base of society … The family should provide each of the members all of their needs. … Families traditionally cared very much for their elderly (24).

> We have a very extended family since we are growing up. We have … the Godfather and the Godmother and you know *compadres*, God's brother and *comadres*, God's sister. You have the grandfather, the grandmother, the uncles, the second uncles, the

> third generation of uncles, … the cousins, the older cousins, the baby cousins. … It's a
> beautiful extended family. People that care about you (48).

These idealized ways are still the foundation of current expectations for family care even though
their lives may be very different in the United States.

Many of these Hispanic/Latino individuals immigrated due to turmoil and political problems in
their home country. This may seem at odds with the idealized notions of days past, yet it
similarly results in a preference for family care.

> They come from countries where their political entities and government units are very
> restrictive, so they're not very trusting of services in general, and they don't seek help
> from government agencies … They're very likely to just care for their own because of
> fear (7).

After immigration, most family members work to assist the family (13, 45). Thus, with all
potential caregivers working outside the home, there is no one available to provide all the
informal care recalled in their previous countries. Often, working parents will assist their
mother's emigration to have someone to help with the children. This situation reinforces the
mother's isolation from community. "She came to follow one or two of her children and all her
extended family remains back home [with] all her friends" (48). This ensures that there will be
fewer caregivers available when the mother ages and needs care. Support and care can
happen,

> … but is harder and harder, and as people's lifestyles change, you have people going off
> to school after graduation, and there's not the concept of get out of school and stay
> home with a parent. … So all of those things impact, and if that person has just arrived
> a year ago, it's going to be different (45).

These changes in lifestyle have not altered the cultural expectations for family care.
Hispanic/Latino families prefer to "keep things within the home" (1). They believe that family
care needs are their responsibility—their job and they do not want to impose on others (1).
There is also a sense of pride.

> Pride that I can take care of my own—that I don't have to go out there and ask anyone
> because I am responsible and … this is my duty as a daughter, as a wife, as a husband
> (4).

Most often it is a wife or daughter that is the primary caregiver. "They assume, this is my duty
[and] … it would reflect poorly on me if I seek help" (5). Additionally, familial care keeps the
behavioral issues of dementia private.

In the Hispanic/Latino groups served by the demonstration grant, multigenerational family households were not uncommon (3). In spite of this, there is generally one primary caregiver (7) and it's usually female—a wife, daughter, or daughter-in-law (3). "Very, very few families will join forces and be a cooperative effort to care for a loved one" (3).

> What I found in this population was that nobody would help [the primary caregiver] but when it came to make a big decision, they would step in and say, no you can't do this, no you can't do that. No, we don't want mama to go to a day care center. No, leave her with the same doctor. … They wouldn't help but when it came to making the decision, they would step and try to stop them (4).

Another cultural issue of import in Hispanic/Latino culture is religion. As mentioned above, suffering is equated with heavenly rewards. Thus asking for help would be giving up celestial bounty. In contrast, "There's a very strong belief in fatalism in that religion [Catholicism]," one provider explains, "You know, what have we done, what has this person done to deserve this" (5)? This inference of bad behavior or blame reinforces the preference for family care to avoid social stigma. "A lot of families were ashamed to admit that their loved ones had dementia, and/or because of their cultural belief system, it was something that was shunned" (7).

The degree of religiosity also leads to use of alternative medicines as one provider explains,

> There are many alternative Latino beliefs in medicine. For example, *cura medicimo*, a belief in shamans or for lack of a better term, witchdoctors. …But alternative herbal medicines can cure the problem, spiritual leaders that can cure the problem, a high belief in religiosity and faith and how that influences things (5).

Another staff member correlates the use of alternative means with lack of resources as well as beliefs.

> A lot of the family members were really adamant about [not] taking their parents to be diagnosed because of the cost and/or they didn't have access to transportation, or language variances. And yet … they would take them to folk healers and they would pay tons of money, because they folks would promise them an instant cure. For example, if you give them this sort of tonic or if you do this ritual three times a day, your person will be cleared of their possession. It was very interesting to try to see how the myths, the folklore, the traditional cultural belief systems were more dominant than their belief in the traditional Western medical care (7).

Several general characteristics of the demonstration's Hispanic/Latino clients can be identified. The term "Hispanic/Latino" represents a great diversity in cultures, dialects, and etiquette. Gestures of respect are considered important, and differ by group within the culture. Many clients are monolingual Spanish-speakers with relatively low levels of literacy, which results in

isolation from mainstream services, and a greater valuation of one-on-one relationships with service providers.

Despite the diversity in cultural norms within the Hispanic/Latino community, each nationality displays a very strong reliance on the family unit to solve problems and provide care. Immigrants bring with them traditional expectations for family care.

Ethnic and Geographic Diversity

Though all families were confronted by the common needs in caring for someone with Alzheimer's disease, each cultural population had its own history and understanding of how care was to take place. Rural families stressed self-sufficiency and were isolated with fewer opportunities for information, services, and other resources. Black/African-American families were accepting of the care needs, had strong extended family ties, and supportive church community ties. Hispanic/Latino families conceptualized caretaking as a spiritual matter and faced the most communication barriers.

These families shared the desire to provide care within the family. Providers also mentioned that showing respect was an important component of serving both Black/African-Americans and Hispanic/Latinos.

RESEARCH QUESTION #2: WHAT IS THE PREVALENT VIEW OF ALZHEIMER'S DISEASE IN THE TARGET POPULATION?

Providers report that there is an increased general awareness of Alzheimer's disease within the general populous. "Folks are hearing more about it [Alzheimer's disease] on public spots—President Reagan's disease and so on" (21). A staff member adds, "Alzheimer's has certainly been out there in the media and there's so much in the news about it now that I think times have changed and the perspective has changed in recent years, just in the past two or three years" (22). Another elaborates,

> I think people know about what it [Alzheimer's disease] is, just because … there's been a lot of movies and articles and things. I think maybe they tend to think the worst--that all people with Alzheimer's wander, or all of them are violent. But I think most people are aware of Alzheimer's. I don't think they know exactly what it is and how it works, but they are aware of it (23).

"Everybody I've talked to, the family caregivers at least, have heard of it," a case manager said, though "they cannot conceptually understand it" (11). An administrator explains, "The average view … is that it is a terrible, devastating disease, in which the person is totally not themselves (sic) and is going to do terrible things and have an awful death" (39).

Shared Beliefs

Even though there is an awareness of Alzheimer's as a disease, misconceptions about the symptoms persist. Many of these notions were common across cultural groups.

Alzheimer's Disease as Mental Illness
Many individuals still believe that Alzheimer's disease is a form of mental illness with the attendant social stigmas. The terms "crazy" and "insane" are mentioned frequently to describe individuals with Alzheimer's disease.

> …People are going to look at her or him as insane—that they're crazy and they use the word a lot. … They equated it with a mental illness (4).

> … Alzheimer's disease means that they're crazy and they've lost their mind. You hide it … whoever had it; they [the family] hid them at home. They were embarrassed, like "that's mental health—that person's crazy" (17).

> … some of them in these real rural island areas actually lock that person up in a room and call them "crazy head" because they don't understand the disease (37).

> They just … don't want to talk about Alzheimer's disease because, … someone may think that I have crazy people in my family (8).

Though found in all the demonstration populations studied, this is perhaps most pronounced in the Hispanic/Latino communities. Hispanic/Latino populations "consider that [Alzheimer's disease] being crazy, and that's like a blot on their family" one provider explains (15). Another mentions that Alzheimer's disease is seen as "a weakness in the family" (42). "The word dementia in Spanish means crazy," a staff member explains, "Not in the dictionary, but for the people, it means crazy" (24).

Normal Aging Process
Frequently, providers mentioned the prevalence of the belief that memory loss is part of the normal aging process. One staff member illustrates a client's belief by noting … "My mother

has memory loss because this is normal for an older person to get to lose their memory". Furthermore, another provider states that caregivers often do not look for services or assistance in the early stages because "they assume that whatever is happening is part of normal aging and not a disease—they think that memory loss and these behavior problems are something that just happens" (5). In the rural areas, some local physicians further this misconception. One provider says, "[Doctors] can hardly say the word [Alzheimer's] much less diagnose it" (31). She offers a story of a client whose doctor said, "Yes, she is forgetful but it is not unusual for a woman her age" (31). Another rural service provider paraphrases the local physician in her community, "The doctor will laugh it off and say, 'Well what do you expect, you're getting older!'" (21).

Family Denial
Believing that dementia symptoms are part of normal aging facilitates family denial with regard to Alzheimer's disease. Providers mention family denial as a challenge that they face in the three populations included in this study. One staff member paraphrases her clients,

> We will not admit and that is the problem. It could be like shame, you know. Why? How? It's not possible that people are going to find out that Mom is behaving this way. This is not normal and it should be kept in the family (48).

Family denial can take many forms. Some are reluctant to use the "A-word".

> I've had a number of families tell me, "Please … when you come out to our home do not say the A-word." It's like a … curse word almost. "Don't say it in front of my mother. I don't want her to hear that word" (11).

> … it's that word. Nobody wants to use that word. I mean I've been told a zillion times … "Oh, she has dementia, she doesn't have Alzheimer's" and you know, it's just that word itself, and it's okay to be forgetful but not to say that she has Alzheimer's (31).

Others believe that their relative is "just acting like they don't understand" (47) or its "a misbehavior or something that the person could control if they wanted to" (42). Families "want that person to be what they used to be, and they're not" (17). According to a few staff members, the likelihood of denial varies among family members with different educational levels. "The more educated the caregiver, the more denial they have" (17) one says. Another explains, "The ones that were more educated, it bothered them more so when their loved one was acting out in a way that was not appropriate" (30).

Denial further complicates things, as family members may not acknowledge the symptoms and behaviors associated with Alzheimer's disease.

> A lot of times they're in complete denial that there's anything wrong. …Sometimes I'll go out and they'll say "Sometimes they're a little bit forgetful, but they're fine." And then I go out and do an assessment, and I'm like, "Oh my gosh, they're not safe." There's a lot of dynamics in that because it could be that they're really good at covering up (28).

The need to save face or cover up tends to be more of an issue with spouse caregivers, especially wives.

> I find more with female caregivers that they will not tell me what the husband is doing, if it's a husband-wife situation, all the things that are going on because I think that she might be trying to save face for him. The children are more apt to come right out and say, "Mom or Dad's doing this," but spouses tend not to do that (27).

Sometimes caregivers still hold out hope that things will get better somehow. This form of denial may be deeply rooted in religious or other beliefs. Many clients "still have that faith that there is a possibility that things may turn around" (26).

> … even though she had read up on Alzheimer's, her thing was that her husband was going to get better. … She read up all this information about how different types of vitamins would help stimulate your memory… and she was adamant about giving him his vitamins every day (10).

The fluidity of Alzheimer's disease symptoms can facilitate this belief. One provider shared her experiences,

> There are some caregivers that just say, "She has her good days, and she has her bad days." But really through faith they're praying and hoping that it will get better, or it will just leave, or some type of miracle will take place (16).

Other times "caregivers sometimes feel that if they could just do a better job of caregiving, that this would be getting better sooner … many folks have self doubts, as 'maybe I shouldn't have done this' or 'I wonder if that caused it?'" (21). Worse may be the times when family members blame the caregiver for the individual's symptoms.

> [Caregivers] understand what is happening but you have siblings, you have grandchildren, you have brothers and sisters of these clients, [and] … they don't understand what is happening. They blame the caregiver. "It's your fault Mom's crazy. It's your fault she forgets things. … There is a denial because they don't understand the illness (3).

Family denial often leads to higher stress levels. "When they [caregivers] come in denial and deny that their loved one has Alzheimer's, they're usually stressed out" (10). It can also be the difficulty in coping with behavioral problems that make no sense (3) that contribute to the caregiver stress levels. Families may be reticent to seek a formal diagnosis as "they don't want to confirm the reality of the problem" (47). But providers see relief in a diagnosis that makes

sense of the odd behaviors for the individuals as well as the families. "I think once they're told, there is some relief, like, 'Oh my god, I'm not losing my mind'" (28). Another provider paraphrases her clients, "I thought I was going crazy and I'm almost relieved to know that I'm not—I'm not happy having Alzheimer's but at least I'm relieved to know I'm not crazy" (21).

> I think people really want to know … as opposed to wondering what it is. They know
> something is wrong, and putting a name on it that they're familiar with … isn't too much.
> But some of the behavior, if its inappropriate or exposing themselves or doing things like
> that, I think is a problem, but not the disease itself (23).

Embarrassment and Fear

Most families are "fearful of Alzheimer's disease … they just don't know what to expect" (14). This fear has several aspects. Some are afraid of having Alzheimer's disease and worry that it could be contagious. They worry that they might get it (35). Others are afraid that their relative "is not going to recognize them" (47), while other families express fear of embarrassment caused by some of the behavioral symptoms of the disease (47). For others, it's the stigma that Alzheimer's disease is a sign of previous bad deeds.

> Some people think it's an embarrassment. Folks will say … he must have done
> something then to have caused it (21).

Some families fear burdening others with their private issues and are uncomfortable taking their relative with Alzheimer's disease out into the community. Many caregivers don't want "to visit other people and burden them if the person has any type of behavior problems—they'd just rather stay home and not go out" (1). A large number of families prefer not to let anyone know that their relative has Alzheimer's disease (32, 13). "It's an embarrassment for the family…so please don't let anyone know," one staff member explains, "because people will look at you as that [your] whole family is crazy" (30). Families "try to keep it private and conceal the disease" (16). Others are "afraid that people will think that they have Alzheimer's" too (2). Families may be reacting to general societal beliefs that Alzheimer's disease is "something really, really bad" that they "don't want to get near" (3).

> … they're afraid. Sort of like, "not in my backyard," if you will. "It's most unfortunate that
> Mr. So-and-so has Alzheimer's and I want the best for him, but I really would rather not
> be his next-door neighbor, because that may mean that I'll have some awkward
> moments, or I'll have to be concerned about him, or those kinds of things" (22).

Cultural Views of Alzheimer's Disease

Providers from all three cultural groups under study mentioned the belief that Alzheimer's disease is a mental illness, or a part of normal aging among the communities they serve. Family responses of denial, fear and embarrassment were also not limited to specific ethnic populations. However, among this commonality, there were some comments that were particular to individual groups.

Rural Communities

Demonstration providers explain that there is a lack of general knowledge and understanding of Alzheimer's disease in rural areas. Most families are dependent upon their family doctors for dementia information (28, 20) as there are fewer resources in rural communities. Though some staff members mentioned local physicians that were Alzheimer's aware, more noted the lack of awareness in their community doctors (31, 20). This lack of knowledge and informational resources leaves families with little understanding of the disease and the disease process (30, 36).

The other perspective that is relatively unique to rural communities is the likelihood that residents tend to know a lot about each other's lives. For example, one provider explains,

> Chances are that if you are a long-standing member of the community, you're related to everybody in the community. And if you do something inappropriate in public, chances are about the [whole] town will know about it by the end of the night (27).

This lack of privacy enhances the social stigma of Alzheimer's disease behavioral symptoms and makes family denial and face saving much more difficult.

Black/African-American Communities

In Black/African-American communities, providers note that Alzheimer's disease is more accepted. "People here tend to be more realistic—this is it—this is life" explains a staff member (14). One administrator adds that Black/African-Americans "would not conceal … the disease, and would accept help more readily" (39). Another provider observes that this acceptance leads to "tremendous family responses" (43). She relayed a story of one family,

> They completely reorganized their life in order to do the care … We watched a young woman who has three teenage kids and her mother has got severe dementia and she sees humor in it. I've noticed that a lot in the African American community. There is some acceptance and ability to laugh and then a strong commitment to caregiving (43).

Hispanic/Latino Communities

Some Hispanic/Latino families place their understandings of Alzheimer's disease in the spiritual realm. They often believe that caring for a relative is just "their cross to bear" (5). Hispanic/ Latino communities have folk beliefs about Alzheimer's disease and its cause. "Some people do see it as they've been cursed [or] they have done something bad in their life span" (5). Other times, people may believe that they are "being possessed with spirits, or all kinds of different religious explanations" for the dementia (46). A staff member notes that these beliefs are more likely to be seen in less educated, first generation immigrant families (46).

Believing in curses, punishment, and possession leads individuals to seek non-medical cures.

> If you believe the illness is because of some physical dysfunction in your body, then you are going to see a doctor. But if you believe the illness is caused by the witch next door that covets your husband then that's something from the spiritual realm (5).

Providers also spoke of families going to *curanderos* who act as shaman and can dispel curses (5).

Views of Alzheimer's Disease

Among the cultural groups included in this study, there was more commonality in approaches and responses to Alzheimer's disease than differences. The belief that Alzheimer's disease is a mental illness or a part of normal aging was shared across cultures, as were family responses of denial, fear and embarrassment. Rural communities were unique in the lack of information readily available and were more likely to be part of a community where privacy was at a minimum. Black/African-American populations were seen as more accepting and realistic in their approach to caring for a family member with Alzheimer's disease. And Hispanic/Latino families often viewed Alzheimer's disease in spiritual or religious terms.

RESEARCH QUESTION #3: WHAT IS THE PREVALENT VIEW OF USING SUPPORT SERVICES IN THE TARGET POPULATION?

There are several common beliefs about support services and their use that are shared by the three cultural groups included in this study. There seems to be a widespread lack of understanding and awareness of just what "respite services" are and how they are used. As one provider explained, "If I say the term respite, nine times out of ten people don't know what respite means" (8). Another provider adds,

> … a lot of times people don't understand what our purpose is—what home respite is.
> So, … that was a challenge in the beginning, to get people to realize what respite is (26).

Shared Views of Support Services

Confusion About What Respite is

Often, caregivers will call dementia information phone lines with little expectation that services

might exist. "We get phone calls from people saying, 'I was told to call; I have no idea what you

can help me with'" (8). Even though the general public awareness of Alzheimer's disease may

have increased, most individuals are still quite unaware that dementia-specific services exist

(16; 3).

> Most people are not aware of support services. And I think that's across the board,
> across all cultures. …It is not something you think about everyday. … In general, the
> whole system of service delivery for older adults is completely fragmented. So if you
> receive home delivered meals, you might not know that older adults are also eligible for
> transportation, unless you're a social worker. Most people don't have the slightest idea
> what services are out there in the community (5).

This lack of understanding seems to be more pronounced with day care services than in-home

respite. The concept of day care for adults is a "relatively new service and people just don't

realize there is a possibility of having adult day care" (42). Families are "reluctant at first …

they're not familiar about what it [DC] is" (1). "People don't understand it [DC]—they don't

understand the benefits somebody can have from it" (21).

In-home respite may seem more familiar as families are often aware of home health services, or

in some cases domestic workers or maids. Confusions around in-home respite more often

revolve around the role of the aides while in the house. "A lot of times they consider them

maids and not … [respite] aides. We have a constant battle with that. They think they're out

there sometimes just to do housecleaning" (35). For many families, it is difficult to have a

stranger come into their home,

> … and usually when they accept the service, they're thinking that they're getting a
> homemaker, in other words, a maid … that is going to go there and clean and cook.
> Where really, the in-home service [at this agency] is companionship, it's like a social visit
> … Of course, they do some help … but they're not a maid … and usually what they want
> is a maid, and sometimes there's a conflict. It's a very touchy thing (15).

Families find it easier to relinquish the household tasks to "strangers" than the care of their

relative.

In other cases, families' sense of dementia stigma or denial will keep them from using dementia-specific services but they will use home health or other non-stigmatizing services. "I don't know what the stigma is, but they're just hesitant to come out and use the services" says one provider (34). Another staff member relayed the story of a family that would bring their mother to the senior center for an exercise class, but refuses to use the day care offered there. "The family refuses to bring her because to be involved in this group, everybody knows that you have memory loss" (31). Other times, providers come up against families that hire domestics to care for their elder.

> … with the white community up there in the rural section, they have hired housekeepers and people that come in and sit during the day and take care of their person. They are not trained, they are merely maids or domestics, pretty much. But that's the way they've always done it, and they don't see any reason to change it. They don't seem to understand … that there is value to respite services for the person that has the disease as well as value to the caregiver (40).

This confusion between the roles of domestic workers and respite aides points to the broader issue of value. Because the disease is seen as hopeless, inevitable decline, many do not comprehend that dementia-specific services can make a difference for the individual.

The Value of Dementia-Specific Services

Once an individual is diagnosed with Alzheimer's disease, general deterioration is thought to be unavoidable. This thinking facilitates an acceptance of whatever decline occurs rather than working to maintain as much as possible for as long as possible. As one provider explains,

> A lot of times people are surprised that we are dementia specific. … That we do activities that are specifically geared to try to allow people to maintain where they are as long as possible. … So there is surprise at what we do. And they [family] are surprised, "Well, she won't do this at home … how'd you all get her to do this?" … Because a lot of times people get the diagnosis of Alzheimer's disease, people will assume that they no longer can do anything. And they don't give them the opportunity to be who they are (26).

Another staff member adds that she tries to, "emphasize on how important it is if you keep them socially stimulated. Stimulation," she continues, "keeps it [the deterioration] at a certain level for a while" (4). Families often don't realize this possibility. Additionally, when families believe that their relative's symptomatic behavior is "just part of normal aging," they are less likely to seek services. These families do not see any value in support services as they also see decline as inevitable (11).

Family Care is Better Care

Families often believe that, because of their emotional attachment, no one else can care for their relative as well as they can. One provider refers to this as, "letting go" (3). She explains that families have difficulty "letting go—letting someone else take care of their loved one—[it means that they are] admitting that they need help" (3). Another provider concurs; families believe,

> that they actually can do it better, that nobody else is going to really take care of their person, really see them as an individual like they do. And so they are reluctant to use [respite], because they don't think that their family member will be respected for who they are" (39).

Only the person that's closest to them," she continues, "can give them the emotional support on an on-going basis" (39). Providers are left with the task of assuring clients "that we're going to be able to give the kind of care that they want us to give" (50).

Another provider believes that there can be co-dependency in caregiving that deepens and complicates the issues surrounding service use. She sees that these caregivers are often reluctant to use services, even though they may be clearly overwhelmed, because their identity is tied to caregiving, being needed, and being the relative's only support.

> I even have support group meetings on … co-dependency… They'll say, "I'm so tired. This is not what I planned on doing, it was supposed to be a family thing. Everyone's supposed to share it. Everybody's supposed to do it." And I just stop her and say, "They hold a gun to your head, and make you take all of the responsibility?" I have to get into it further before I can talk with them like that. I say, "Nobody made you do this. You're doing this because you want to do it, so don't blame anybody… If you don't want to do this, put them in a home or let somebody else do it (17).

Thus the decision to let go and share caregiving responsibilities is tied to any possible permutation of family dynamics. Some providers have found that overwhelmed caregivers will often use services in spite of the family dynamics or other considerations. Once they reach a certain point, they welcome the help (8).

> Most of the time [we're] getting people at whit's end. They've tried to manage this person at home … and it's like we're a refuge now. They come here and it's like, "Oh my God, where have you been all my life (9).

Family Guilt

Much family guilt comes from normative expectations for family caregiving in our society. Families internalize this belief and then members feel guilty when they cannot live up to such expectations. A provider shared a farm wife's story, "[she] will basically totally wear herself out

taking care of the husband because of being proud and thinking she should be all and do all…they feel like they're supposed to do it all … that's the way they were brought up" (35). Other times, family members have "made commitments to their family members, saying 'I will never…'" (26). This is common for married couples who promised to care for "better or worse". Often they feel that they would be abdicating their responsibilities if they were to let someone else assist with the care needs (31).

Using support services, in these cases, is a confession that the caregiver cannot meet the care expectations. It means, "they have to admit that they can't do it, and that's hard for them to do" (31). Families struggle with the guilt of not meeting their expectations. "Just admitting that they can't handle it themselves is a tremendous hurdle" that must be met before they will consider using services (22). Using services also can mean a loss of independence for the caregiving spouse (23). In other cases, caregivers will use the service and continue to feel guilty. A provider mentioned the story of one family using services where the caregiver was "the guilty daughter who is working full time and they can afford it, but they just feel bad about it" (46).

Another component of family guilt is found among those who are concerned about using too much of the service. One provider mentioned that some of her clients, "felt that they were taking money away from someone else that might need it more than they did" (40). Other families will use the social programs, but not the personal care services, as "they prefer to keep the more intimate care in the family" (44). There are others, however, "will just go with a minimal amount of care rather than having to worry about something else, which to them would be filling out more forms and applications" (22).

Embarrassment
In some cases, families are embarrassed to look for services because it means admitting the symptomatic behaviors of their relative.

> A lot of people are afraid to call and say I need help for my parent because they're forgetting things or I have a wife that forgets things or my husband wanders off and I'm afraid that he's going to get hurt. It is … an embarrassment to admit that (3).

Caregivers sometimes try to "save face" for their relative and don't want others to know about his or her behavior. A provider mentioned a husband who "didn't want other people to know that she does these things" (31). Sometimes caregivers are even reluctant to let other family members know. "They don't even want the other family members to know what is going on so they don't even look for services… they are ashamed" (13).

Other times, caregivers are afraid that if they tell someone about what they are experiencing, that their relative would be institutionalized against their will.

> [If they] know that my loved one has a problem then they are going to come in and they are going to take her. They are going to place her or they are going to … try to get her into a mental institution because she is not acting the way that society says she should be acting (30).

Sometimes caregivers isolate themselves and their relative,

> They don't go to church anymore; they don't go to family functions—Sometimes [caregivers] feel that if these folks were to find out that they were asking for help outside the family unit or their close friends, that person will get hurt (7).

They don't want anyone to know and they don't want to face the family stigma about using services.

Anxiety and Trust

When families do decide to use services, they can be quite anxious about trusting someone else to care for their relative. "I think that most of them are like a new mother putting her child in daycare for the first time. That is the fear and anxiety that I see when they come in" (9). To overcome this, it's important to develop a sense of trust between clients and staff. "In order for them to feel comfortable with you, they have to trust you" (37). In some cases, the process of trust building can be gradual. One provider shared the story of a husband who accompanied his wife to the day care.

> At the beginning, he was going with her every single day until finally, I think it was a matter of trust. He realized that everything was fine. [Then] he started attending another day care once a week by himself … [and] he started attending the nutrition sites. He … never did [completely] detach from his wife… He was … there at least every other day until he died (48).

Family dynamics play a significant role in whether a caregiver will use services and in the process whereby that decision can be made.

Younger Caregivers are more willing to use

> Younger caregivers are more apt to try and seek help. To ask for someone else to come in to give them a break—give them a day off. The older caregivers have that commitment, that obligation. Especially if it is a spouse. They are very protective of their spouse. They don't want anyone to come in and take over (3).

This may be due to their generational cohort or to family relationship. "I see with them [younger caregivers] it's not quite as difficult to convince them that it's okay to get some help in caring for

their parents" (50). One provider speculates that adult child caregivers are more often working full time (11). He goes on to explain that taking care of one's parent is

> … not something that is expected in [the] life processes. … We understand there is the aging life process … so when fraility and cognitive impairment happen in old age, we kind of understand that as a life process, but if it happens in your 50s … it is much more devastating (11).

He believes that younger caregivers' willingness to use services has more to do with where they are in the life process rather than generational effects. Younger caregivers also make the decision to increase or expand service use more quickly than older caregivers regardless of family relationship. Another provider speculates that willingness to use support services has to do with greater life exposure to a variety of events and places (40). Younger caregivers have often experienced much more diversity in life than their parents. They are also likely to be better educated, and therefore would be more open to trying different approaches to caregiving than would someone older.

Providers also note that adult children or younger caregivers are much more likely to see support groups as useful. Older caregivers are often suspicious of support groups believing that they are only "for alcoholics and drug addicts and stuff like that" (8). Older caregivers "don't want that kind of help. It's just not what they're accustomed to but their children are a little more open to it" (19). Another provider paraphrases her clients,

> I think [that to] a lot of my clients that counseling means there's something wrong with you. There is something mentally wrong with you to go to a caregiver's support group and I'm not crazy. She's the one that's crazy—the person with Alzheimer's is the one that's crazy (30).

The Welfare or Handout Stigma

Since respite services are often offered at a low or no cost, some families see these services as welfare or a handout. "That's such a barrier… people think that [this agency] is for indigents… [and] the unique thing … is that we serve everybody" (28). The general public "look[s] at any type of help as welfare," says one provider (30). Another staff member explains that this view is more prevalent among older individuals, "they think of programs as welfare—well I can do it by myself…that sort of thing" (20). In other cases, it may be the privacy about finances that is the hurdle providers face. "They're very private about their financial status and issues, and [have] some reluctance … to accept what they may see as welfare" (22). Other times it is just about being seen as a "user". There is "the stigma of being a user, someone who drains the system

… it is a huge stereotype" (5). Families "just don't want anyone to think that they are trying to get a handout" (30).

> [Caregivers]… seem to somehow find that services like this is sort of a welfare program. … The tag of welfare, we have difficulty [with that]. We're trying to persuade them that this is a service and it's not welfare. We do hit a brick wall with that sometimes. The neighbor may say that even if it's not food stamps or something like that, the neighbor may see the caregiver and sometimes [be] thinking under the welfare tag (35).

A provider explains, "it gets back to … pride. I'll hear them say, 'I never took a handout in my life!' or 'I worked all my life so I wouldn't have to be on Medicaid'" (28). The notion of handouts and welfare seems to be a pervasive misconception.

In contrast, however, in urban environments with more educated caregivers there is less "welfare" stigma about using services. This may, in part, be related to the fact that urban providers are more likely to charge some sort of fees, even if they may be on a sliding scale.

> We have not really had any problem in gaining acceptance for this kind of service. … I actually feel that people are expecting support services. In fact, they feel that they deserve and want them and are entitled to them and should get them (12).

Another urban staff member has a similar view, "most families are very grateful to receive our services" (11). He continues to explain how support services fill in a gap between the poor and the rich.

> If you are very wealthy you can afford to pay privately for home care and if you're poor, you have medical assistance, which will pay for home care services. But if you are in that gray area where you are [in] … that low to moderate income, you're over the Medicaid eligibility line and you're kind of stuck in the middle. And you need the help but you cannot afford to pay privately so fortunately, because of the funding that we get, we are able to provide services at a reasonable cost (11).

Even though the "funding" that this agency receives is from the federal government, it is not perceived as welfare at the client level. However, it is related to another consideration providers hear from their clients—fear of the government.

Government Help

There seems to be a general reluctance to accept "help" from the government across the three cultural groups studied. However, this distrust has different explanations in different groups. In Maine, there is a fear that the government will take everything they own.

> You need to know the history of the area, [but] … a lot of individuals… do not want services if they're quote, unquote, government based services and it's been very difficult to alleviate fears. A lot of times in the past when people accepted any service that had

> Medicaid attached to it, they would have to pay the money back and people had their land and their house that had leans on them as a result. People still remember that (18).

In other rural areas, it can be an issue of privacy. Families "don't want to give out private information—they feel like their income or what their assets are are private" (37). In Black/African-American communities, providers believe that it is a lot of distrust and often mention the Tuskegee experiment as an example. "Being African-American, the history of trust is not there… they've lost confidence somewhat in the system" (40).

This distrust, seen by providers in Black/African-American families, is also evident in a lack of willingness to participate in research projects as well. "There has been a great deal of reluctance to participate in that [research] program because … people have a tendency to believe there is still some undertones… there's still some fears" (26). However, in contrast, providers to Hispanic communities find presenting the demonstration services as a research project is better received than talking about it as a government program.

> I won their confidence [by] telling them this is a research study…"Please allow me to help you so that we can learn together. Me by helping you. You by allowing us to understand what you are going through (4).

Fear of the government appears strong within the Hispanic/Latino communities. Many times, this fear comes from families' experiences with the governments in their country of origin (5). Or it may be that they are in this country illegally (24). Other times, families can be concerned about privacy. A provider in California relayed a story about a man who had been a citizen for many years. He told the provider, "[If] it was a government thing that was going into his business and he didn't want to tell anybody anything" (4). Additionally, there are some people that just "have a long standing institutional bias against health organizations or other programs because in the past those organizations have not met their needs" (5).

Culturally Diverse Views of Support Services

Though the majority of views about support services are shared among the groups studied here, there were a few issues that only providers to the Hispanic/Latino communities mentioned. This cultural group differed mainly due to issues relating to their immigration. The Hispanic/Latinos served by the demonstration came from a variety of other countries. Most of these countries had little or no support service system.

> …especially if you are talking about recent immigrants from other nations. Those countries don't have social support infrastructures at all. So the expectation that there might be something in the community to help you out is not there. Rather, the assumption is, your family's role [is] to take care of that person (5).

Thus, these individuals are less likely to be aware of support services or have any idea what they are, who they are for, and how to access them. Indeed, the culture of their previous country enhances the notion that "the family is to provide for every need of every member and that means that they are a little ashamed or offended if they need to have services from outside the family" (24).

Additionally, because of a family's prior experience with another government regime, they may be especially fearful of all government programs. A provider in Washington state mentioned a client from Columbia that was so fearful he went into hiding with his wife who had dementia (48). Protective services can be reminiscent of individuals who disappeared in their home countries. Of course, if the family or some of their members are in this country illegally, that also complicates serving them as well (24).

The other issue that is germane for Hispanic/Latino populations is that of language. As one provider explains, if they can "read and write in English, it makes it easier for them to get services" (3). Communication is a key component to both understanding what a service is and how to access it.

Client Views of Support Services

For the most part, client views about support services did not vary by cultural grouping. Indeed, most providers found a general lack of understanding of just what "respite" is and a limited appreciation of the value of dementia-specific services among their clientele. Staff members faced the notion that family care is better than professional or paid care because of the emotional component. Families of all cultural groups expressed guilt at using services, embarrassment about the behavior symptoms of Alzheimer's disease, as well as anxiety and trust issues in letting someone else provide care. Providers also reported that younger caregivers, regardless of their family relationship or ethnicity, were more receptive to service use than older caregivers.

Providers mentioned having to address the stigma that support services are a form of welfare or a public handout. However, this was more pronounced among rural and less educated families. There was also a general distrust of the government in rural and ethnic communities. In addition to the above views, agency staff in Hispanic/Latino communities mentioned that their clients' perceptions of support services and government programs had been shaped by their experiences in their countries of origin. These providers also mentioned that the language barrier inhibits their clients' awareness of traditional support services and ability to access them.

RESEARCH QUESTION #4: HOW WILLING ARE MEMBERS OF THE TARGET POPULATION TO RECEIVE SERVICES FROM STAFF OF DIFFERENT BACKGROUNDS?

In developing services to reach new populations, staffing considerations have been important. Agencies have used workers of backgrounds both similar and dissimilar to their clients. In some cases, racial bias has been a challenge. In rural areas, racial similarity is strongly desired by caregivers. However, familiarity, community membership, religious affiliation and common gender can take precedence over racial similarity at times. In Black/African American communities, there is a prevalent mistrust for White workers that originates from a history of oppression. Hispanic/Latino families desire staff members that are both familiar with the culture and language, as well as cognizant of national diversities. In spite of these challenges, the delivery of quality services, along with the demonstration of respect and caring by providers, can overcome ethnic differences in many caregiving settings.

Rural Areas—The Value of Familiarity

Providers in rural areas serve a population that is simultaneously uniform and divergent. Although rural residents of varying backgrounds share many of the same influences and barriers due to their relative isolation, they perceive subtle differences between themselves and their peers that may affect their judgements about support services and providers. Providers discuss several elements of "background" that caregivers and elders seemed to include in their evaluation of respite staff members.

Ethnicity
As might be expected, providers frequently mention ethnic differences as occasional problem areas for acceptance of staff. Some have dealt with care recipients who were not receptive, and even abusive, to staff members of different ethnicities. A provider remembers,

sending an African-American volunteer into a Caucasian family,…and the patient actually treated the volunteer quite badly…But not in all cases, this has probably happened 10% of the time, but that 10% makes a big impact on you (27).

Racial biases of elders also come into play in a multi-racial day care setting.   When care was provided intermittently by both White and Black/African-American staff members, one provider has observed differential treatment of Black/African-American staffers by White clients. "We have heard really negative and terrible language, just calling them names and expecting them to be like the hired help"(28). She attributes this overt bigotry primarily to their up-bringing, and the decline in social inhibitions brought on by dementia. "They're demented, and we're not going to be able to change what has been going on their whole life and how they were raised"(28). In the absence of abusive behavior, elders may find other ways of protesting care by a person of another race. A Black/African-American provider was sometimes amused by White elders' reactions to her:

> I had a referral from a family member, and this lady [elder] didn't like African-American people, but her caregiver was not available at the time so her son called here. I went out to do an assessment, and she stayed in the bathroom all the time I was there (29)!

Care recipients are not the only ones for whom ethnicity matters. Members of the elder's immediate family may also be against the idea of their family member interacting with someone of another race. The ethnic composition of care recipients at a particular agency can prevent family members from seeking their services. In regard to her agency, a provider in rural Florida comments that "there are some people, some of the white people in town who wouldn't send their loved one here because of the large population of Black people we have in the day care" (14). Even after the barrier of beginning service is past, family members may not feel comfortable with care that is provided by an ethnically dissimilar staff member. One provider laments, "I have had family members actually comment to me, and the staff, 'I don't want that person touching my husband,' or whatever…It's difficult" (28). According to providers, this reaction to staffers of different ethnicities is not uncommon. A Black/African-American provider going to an in-home assessment of a White elder in a White area of town foresaw this problem and asked a White volunteer to accompany her.

> Sure enough, after we got there and introduced ourselves and why we were there and were taking notes, the phone rang and the husband answered the phone. His statement was, 'One is, and one is not.' So my volunteer looked at me, and I looked at her, and we had a big smile (29).

Community Recognition and Similarity

In rural areas, a unique aspect of staff members' backgrounds is their family background and recognition within the community. The limited size of rural communities often breeds greater familiarity between citizens, as well as their extended families. This can create a greater feeling of comfort with those who are known, in contrast to "outsiders". Thus staff members who are known to the families of care recipients, regardless of ethnicity, are likely to be better received than those who are not.

> You can see it and you can hear it in their voice when I call them or if I tell them so-and-so [is coming to provide care], and you get this, 'Phew, I know this person.' Or even if they don't know the person, but if a cousin three times removed was married to a relative of this person or something, it's just like old home week. So it makes a difference (27).

A common response on the part of providers was to preempt possible conflict by sending a staff member from a similar background whenever possible. As one provider says,

> I will send somebody else of their race and see if that works. And if that works, then so be it, because we are here to please and to satisfy. We can't change a person's feelings or the way they think. We can only be there to serve them (29).

Thus, providers try to give clients what they expect and what makes them most comfortable, regardless of the biases that drive those expectations. This decision is also motivated in part by desire to protect staff members from entering tense situations. Another provider states frankly, "If we get a referral, and we know by the conversation that they are reluctant to receive, say, a Native American, we don't send that person in there. I will not send my volunteer in there knowing what the situation is" (27).

Several providers mentioned other characteristics of a staff person's background that might influence a client's decision to accept or reject services. The importance of religion to life in a rural area can make a staff person's faith relevant to her acceptance. Elders may also prefer to be served by a staff person of the same gender as themselves due to modesty, "a lot of times these older gentleman, rural country farmers…don't like a woman giving him a bath" (35).

Overriding Value of Care

In contrast to these problems dealing with staff diversity, some providers in rural areas found that the value of respite to caregivers can outweigh other issues. Once families of care recipients know that services are of high quality, they are less concerned about the ethnicity and background of the person delivering them. One provider discusses an example where,

> We'll have an African-American aide providing care to a Caucasian family…Let's say a
> month and that caregiver is saying she's like family because they're there and they're
> willing to help and they're asking what can I do and it doesn't take long to discover the
> client's routine, the client's ritual, and you're just a part of it (30).

Rural clients desire care providers to share the same ethnicity, but also accept familiar
members of the community regardless of race and will use services delivered by those of
different backgrounds once the quality service is established. Members of rural communities
also value religious affiliation and common gender as an important element of care.

Black/African-American Clients—The Relevance of History

Although there were agencies that served only one race, many agencies in both rural and urban
areas served and were staffed by a mixture of Whites and Black/African-Americans. Providers
from these agencies were able to compare the opinions of their Black/African-American clients
and families toward staff persons of both ethnic groups. Like their peers in more rural areas,
they see distinctions between the elders' and caregivers' attitudes.

Elders' Views of Ethnicity

Most providers could not recall instances in which Black/African-American elders mistreated
White staff members. However, some did sense a level of apprehension from the elders about
the prospect of receiving care from a White person, particularly in Southern states. "I think that
the older African-Americans…do not feel that a Caucasian aide should be out there helping
them. That's something that has been embedded in them" (30). The provider went on to
explain that, despite changes in racial attitudes in the general population, some Black/African-
American elders were still influenced by the roles and attitudes that were common in their youth.

> You [Black/African-Americans] don't mix period and certainly you don't ask them
> [Whites] to come in and help you at all because you are supposed to take care of them,
> because in the past a lot of African-Americans were housekeepers or nannies. So they
> were the ones going in and assisting the Caucasian families and so for the roles to be
> reversed, it's just difficult for them to even imagine that a **Caucasian** is supposed to
> come in here and assist **me**. I'm so accustomed to taking care of them (30).

The sense of inappropriateness in receiving care from a White person is not restricted to
Southern elders. Similar attitudes have been observed in other parts of the country, perhaps
due in part to the large-scale exodus of Black/African-Americans from the South in the late
1940's and early 1950's. A provider in the northwest comments that, "I see a lot [of] African-
American older women from the South being very reverent to White staff, or other clients, and

you know, 'Yes ma'am,' and in ways that they have all their life, as they were working as a laborer for someone in their home" (46).

The flip side of this coin is the greater control over elders' problematic behaviors that White staff can sometimes exert by virtue of ethnicity. A Black/African-American daughter whose mother received in-home care suggested that her mother acted out less with the White staff than with her. The provider explains, "Her mother had always been a domestic, and had worked in White households, and so Whites were more of an authority figure and you kind of went along with the flow when there was a White person involved"(40).

Providers were quick to add that elders' reactions to White companions and staff members were less disapproving than one might expect. For example,

> We had a [Black/African-American] client that thought it would be a problem because one of the senior companions that I had assigned was White, and the wife thought, 'I don't know if that's going to work. That might be a problem.' But once it started, the husband didn't even pay attention, having a White companion didn't even bother him (17).

Families' Views of Ethnicity
In fact, providers find that elders' families are sometimes more reluctant to be served by White staff than were elders themselves. The first barrier to convincing Black/African-American family members to use respite services may be getting past a lack of trust based in history. Several Southern providers cite the infamous experiment involving the Tuskegee airmen as an incident that destroyed some persons' trust in research participation and new programs. One generalizes,

> In the rural area, the younger African-Americans are much more mistrustful of Whites than the older population…I think working with the participants is easier, White or Black. It's dealing with the families, because they're promised things. Just for instance, take the Tuskegee experiment. Trying to get them to take part in research programs and such as that…we had to establish a trust…Just for the researchers to go in and say, 'Will you participate in this clinical study?,' they were very hesitant because of history (40).

Although it may not concern elders, past racism is often well-remembered by family members. Lack of trust in White staffers can prevent Black/African-American caregivers from seeking assistance at agencies primarily staffed by Whites, in the opinion of some providers. A northern provider gives an example.

> We had someone in adult day that told me that there's no way their mother would have been there if it wasn't for the ladies of color who work in day care. They would not have sent her…Here we are offering these wonderful services, but just because some of the staff is white, they didn't trust them to come (28).

As a result, some providers have seen racial concerns take precedence over convenience or proximity. In one area, White and Black/African providers worked in adjacent counties. The White provider comments, "Even though I work this county, she works the [next county], the [Black/African-American] individuals felt more comfortable dealing with [the Black/African-American provider] than going directly to myself. And the same with volunteers" (27). Other providers realize the importance of Black/African-American staff members in assuring that Black/African-American families will feel comfortable.

> A few years ago they hired 3 or 4 people who happened to be of color and of this area, and that really opened the doors. That really was eye-opening to us, that because they [Black/African-American staffers] were going out with me and doing the home calls, or they actually knew the families, that the families were so much more trusting to have them come here…And I know we don't want to believe that it's as simple as that, or as much 'color' as that, but that's what happened (28).

Care as Mitigating Factor

Although families' attitudes toward staff members are influenced by ethnicity, providers saw trust as something that could be built despite initial reluctance. One provider explained, "I think we would have less people of color in the program if we didn't have staff of color…But once they're here and the families get to know us and they come in, it's just like we're a big family" (28). A program that meets caregivers' needs and a provider whom they can trust to keep promises can make up for racial differences, according to another provider.

> I'm the only White in the room when I'm in [the rural community], and I feel like they have totally accepted me now to be in that position. The Black community up there is starting to accept me more, because they see that we're going to follow through with what we say (40).

Overall, members of the Black/African-American community express feelings of initial reluctance to accept a White care provider related to mistrust and social mores that have been ingrained for generations. In the same way White recipients are often unwilling to receive care by persons of other ethnicities. However, participation in the respite programs with individuals of diverse backgrounds often facilitated understanding and trust in the multiracial settings.

Hispanic/Latinos—The Need for Cultural Understanding

In order to serve Hispanic/Latino populations, providers often stated that one must be familiar with, if not a part of, the cultures of Central and South America. This understanding is considered essential not only to provide culturally appropriate services, but also to enroll families in the first place.

Outreach Styles

Providers stress the importance of outreach in increasing utilization of respite services among members of the Hispanic/Latino community. Staff members must go out into the community both to educate the population about dementia, and to raise awareness of assistive services. Several providers suggest that outreach, as the first impression families receive of respite services, must be conducted in a manner that inspires trust and implies understanding. In the opinion of one provider, "the importance in doing outreach…[is] to have people who are, number one, of similar cultural backgrounds. That's important so that they feel this other person may understand their experiences, and also because of language barriers" (5). She, like other providers, stresses that families often feel that those with similar backgrounds will be more able to understand their feelings.

The inverse may also be true. Several providers mention that the more business-like approach of traditional outreach programs may alienate Hispanic/Latinos. Instead, outreach workers, regardless of their ethnicity, must understand and know how to work with the cultural norms of older Hispanic/Latinos. That can include taking more time getting to know the family and even relaxing guidelines of professionalism.

> It matters when they send someone that is not culturally in tune, and thinks that knocking on the door, coming in and shaking their hand, which is a really normal Caucasian way of doing things, is going to get them the information they need. [For example], we're all trained not to accept food and not to accept those kinds of things, but I'll tell you, it's a big insult to people if you don't take one of their *bisquitos*. Reciprocity is very important for an older person (45).

A staff member's background can also influence their efficacy as an educator. Some providers have found that educational programs for Hispanic/Latino populations were more successful when presenters were also Hispanic/Latinos.   Hispanic/Latino audiences may be better able to relate to, and thus learn from, caregivers similar to themselves.

> The basic step is to try to know them, the culture. For example, using their own language and using Hispanics for the [educational] program…Because [Hispanics] could

listen to African-American people or White people, and think it only happens to **them**, but [with Hispanic speakers] they realize it can happen in our community too (13).

Communication Techniques

Culturally appropriate outreach is only the first step to gaining the trust of Hispanic/Latino elders and families. The backgrounds of staff members also come into play in the design and provision of services. The most obvious issue involved with serving Spanish speakers is effective communication. Staff members need to be able to speak Spanish well enough to engage Spanish-speaking elders in activities. One provider relates an experience in which a caregiver was reassured by the presence of Spanish-speaking staffers:

> I had a grandmother of a friend of mine that was Spanish-speaking, and that was a major plus to her that she knew that there was a Spanish-speaking staff. So she just didn't worry. She [had been] worried about her grandmother having a heart attack or needing to go to the bathroom and not being able to communicate and being incontinent, being embarrassed (43).

In addition to alleviating practical fears, Hispanic/Latino staff can provide comfort by sounding similar, in a manner in which elders are accustomed. In this respect, the psychological importance of cultural similarity should not be underestimated. "If they [elders] struggle to understand, if the accent is different, color is different, they can't open up as much. That's just the way it is" (13).

Providers can add to the comfort provided by familiar language by employing staff members that appear similar to the elder. One provider finds that same-ethnicity staff people eased elders' transitions into respite care.

> If you can get in your staff, or one or two people in your client population, [people who are] African-American or Hispanic, and you bring a new person in, they see a like face. They see someone like them and it makes the transition into the program much easier (43).

Moreover, some techniques that would be effective for providing comfort to Hispanic/Latino elders would seem inappropriate coming from an Anglo staff member. Some elements of the Hispanic culture would not transfer well, according to a Hispanic/Latino provider.

> In our culture we are so very affectionate. So you know, the love, hugging, the kissing. It can only be received from somebody that is from your culture and that looks like you. I tell them that it is important to have somebody that will mirror that population that you are trying to serve. Otherwise it doesn't fly (48).

Mirroring the Population

Recruiting staff members whose ethnicities mirror those of the target population can also inspire

trust in family members. Another provider deliberately tries to maintain a diverse staff to

preempt the perception of Whites condescending to minority populations.

> We've tried to be purposeful in that, and have diverse staff that also reflects the diversity
> of the clients so that it doesn't look like a bunch of White social workers coming into the
> African-American community. We have a number of staff who are bilingual and that
> does make a difference. I think people probably still see it kind of as outsiders, but
> hopefully [the communities] will become more and more accepting of that (46).

Even within Hispanic/Latino communities, there are background elements that can affect

perceptions of staff members. For one bilingual provider, speaking the same language does not

always prevent judgements based upon perceived ethnic differences. Because she appears

more White than traditionally Hispanic due to a unique background, she admits, "Because my

color of skin and color of eyes are not like them, they are trying to speak with me in English all

the time. So I really need to show them and deal with them over my color of skin or my different

accent in Spanish" (24).

Class differences, brought over by immigrants from their native country, can also influence

feelings about and levels of comfort with staff members and peers. An urban provider describes

an example of class differences in her agency.

> I did have one staff member who was from Colombia and was from a very class-oriented
> society, and was from an upper-class wealthy family, as was one of our clients from
> Colombia…It's an issue here, because I think with our Hispanic group we have some
> very very poor Mexican-Americans…and then we have the other class I'm referring to,
> and we try to deal with issues like that, where those class issues kind of enter into our
> small community here. So the one client will be trying to pay the other client for getting
> her coat for her (46).

Most providers agree that it is difficult to describe Hispanic/Latinos as a single group, as cultural

and linguistic differences could be tied to particular countries and nationalities. This could mean

that a diverse group of elders would not necessarily each be able to relate to a single bilingual

staff member to the same degree.

Working Around Ethnic Differences

Although most providers agree that culturally similar staff members were preferable for

Hispanic/Latino clients, they don't consider ethnic similarity an absolute necessity. In the

opinion of a Hispanic/Latino provider,

> When you care, it doesn't matter if you are purple or you are pink. The people respect you and at the beginning they will see you with a little bit of suspicion. You know, 'Is this person for real or what?' They are going to test you until they realize that you really care and that you really love them (48).

Ethnic similarity would smooth the transition, but mutual respect could occur without it over time. A White provider in a rural area has similar feelings about the language barrier between herself and the clients. She finds that despite ethnic differences, her attempts to learn the Spanish language and culture carry weight with the clients.

> I have not met anyone in the Spanish-speaking population that has not been willing to teach and assist in overcoming the language barrier. They are very happy that we [White staff] are trying to learn their culture and their language, and it makes for an extremely rich environment (44).

A Hispanic/Latino provider affirms the idea that intentions are more important than ethnic similarity.

> Forget the looks, because in the Latino culture you've got every color. Every color you want from the blondest, blue eyed person to the darkest person…So it doesn't matter almost what you look like because if you come out and you look just like a person, and then you don't understand what this person is talking about, forget it. Throw it away. You've got to feel it…you've got to understand (4).

Providers that are familiar with, or a member of, the Hispanic/Latino community and share a common language are the preferred staff members by this cultural group. Recognizing differences within this ethnic group is also important since class stratification and linguistic differences prevent treating all Hispanic/Latino persons like they belong to one homogeneous group.

In summary, it is apparent that members of each cultural group prefer to be served by providers that have looks, language, and values in common with them. However, these preferences can become secondary as families come to appreciate the assistance that respite can bring and understand the genuine caring of the staff.

RESEARCH QUESTION #5: WHAT BARRIERS TO SERVICE USE HAVE BEEN IDENTIFIED FOR THE TARGET POPULATION?

Providers face barriers common to serving dementia families, as well as barriers that are specific to the geographically and ethnic challenges. Difficulties in service delivery can be experienced at both agency and individual levels. Across the three cultural groups under study, there are both shared and unique issues to be addressed.

Agency Level Barriers

At the agency level, funding, cost, staffing, and transportation needs represent a continual struggle for providers to overcome.

Scarce Resources

Although each provider's agency receives grant funding through the ADDGS and other sources, these monies are often enough only to provide base-line services, and then not for the entire population. One rural provider laments the impact of limited funding on timely delivery.

> Lack of funding…is definitely the top one [barrier], and being able to serve people immediately…Sometimes the funding sources…have waiting lists and you can't piggy-back, or once they get off the waiting list they are not able to get all of the services that they would need to stay in their home independently and safely (18).

At times when enough funding is available to serve all who need it, purse strings are still tight when it comes to affording supplies and materials to facilitate activities. This does not always preclude desired activities, but it challenges providers' ingenuity, according to another provider.

> Money is always an issue…We're on a very limited budget, so we have to be very creative. At some times, we'll have a certain activity that we'd like to do, but to buy the materials for that number of people is very limiting (31).

Another provider in an Black/African-American community says that she has enough money to provide basic services, but finds it difficult to have enough money for extra touches.

> Funding is definitely and always an issue…We generally have to be creative in doing fund-raiser type activities to be able to provide adequate supplies and things to them (9).

Developing a stable and adequate funding stream that is necessary for service provision is a universal barrier mentioned by almost every staff member interviewed.

Cost and Affordability

For some caregivers, desire for respite services may not be enough to guarantee utilization. They may have to confront other barriers, such as lack of income or structural issues. Many caregivers do not have the resources to obtain assistance on their own. For example, a provider in a Black/African-American community describes the challenge of setting up home care.

> Once we're referred [families] to [home care agencies], and they come back to us, it's like, "It's too expensive." The financial part of them caring for or getting help to come into their home for a short period of time is really overwhelming to them (10).

Although many programs are able to offer a few free slots to needy families, the need often outpaces the resources to create more slots. A provider has had this problem at her day care agency.

> What we have found the problem to be is, we only have eight slots that are available without cost to the families. And we do not have nursing staff, so we're not eligible for any medical subsidized programs. Therefore, the reason that the people in our community do not utilize our services and we have some vacant slots, is economics. The families cannot afford to pay for the services (38).

In some rural areas that are characterized by low socioeconomic status, providers view non-use as a function of cost. One provider explains,

> In our area, people don't have a lot of money…So when you say adult day program costs $8 or $9 an hour, up here people are flabbergasted. They never made that much money in their lives; they can't possibly understand how anybody can afford it. So it's the affordability of the day service program that keeps folks from utilizing it (21).

An additional barrier is the expectations of families who are unwilling to even make a contribution. Some families are unaware of Medicare payment restrictions, and are dismayed to find that they might have to contribute funds to cover the elder's care. Communicating policy restrictions has been a challenge for one provider.

> You stress it's a voluntary contribution, but you're still saying it's an expectation they can pay. So say they say, "I don't feel like I can afford this." So we lower the fee. We try to work with them but there've been cases where they really don't want to pay anything. They can't understand…it's not completely and totally covered by the government and a lot of families think that Medicare is going to pay for this type of care (11).

In other cases, families have become reliant on the elder's income, and are reluctant to seek services that they think might jeopardize this financial resource. One provider observes, "There is also often a financial incentive to provide care within the family system because the grandparent's Social Security or income becomes important to the household… The minus is that sometimes it is too difficult to manage at home or the care is really marginal" (43). Another provider has encountered situations in which financial need has overshadowed care needs.

> Some people …Some of them, they don't care. To be perfectly honest, granny is a paycheck. [She] is a Social Security check and that's it. And if they don't have to extend too much effort to get something done, then that's okay, but if we're going to have to get up a half hour early to get cleaned up and dressed, "Well, I don't know" (14).

Thus families' ability and willingness to pay for respite services remain barriers in many communities.

Staffing Issues

In addition to the struggle to maintain program funding, many providers also mention difficulties in finding and keeping a sufficient staff. Populations are small, and distances between cities are

often large in rural areas, which can make finding workers particularly difficult. In some places, this can be compounded by demographic shifts in the number of working-age people.

> Finding staffing to go into some of these very isolated areas. We have a very high percentage of older people living in the county and a very few younger people…It does become a challenge to find workers in the very rural areas, and those people need as much help as people that are located in a more urban area (18).

Another reason for current staffing shortage in aides may be a combination of low wages and a booming job market. A provider explains, "A lot of that, of course, has to do with unemployment rates are very, very low, and with a lot of agencies people receive not nearly enough per hour and there are no benefits. So staffing alone has been a great challenge" (22). For in-home respite providers, the job description could have as much impact on the shortage as economics.

> The other barrier for the in-home respite program is the staff. It is so hard to keep home-care aides nowadays…I think it takes a special kind of person to do this…and it is a tough job (28).

Transportation Issues

Transportation is most often seen as a rural challenge; however urban providers mention it as well. It can also be a financial barrier, for both aides and clients. Although providers in many large metropolitan areas did not consider transportation a widespread problem for clients, one agrees that it can be a problem for in-home aides who had to go to several homes.

> Many of the home care aides are from a socioeconomic background where they can't afford a car. They cannot afford a car and so to get to a case that is not located near a subway or bus stop is extremely difficult…I could see it's a barrier to many areas of the country to operating this type of system (11).

Smaller metropolitan areas face even greater obstacles to transporting clients. One provider views her agency's transportation contract as a limiting factor.

> We contract for transportation…That limits the distance we can outreach to, and it also causes us to have to pay more attention to the kind of outdoor activities that we can have in terms of field trips we can have, because that is an added expense each time we put our clients on the bus and take them to activities (38).

Transportation is most difficult for the more remote families.   Rural agencies are often unable to provide transportation widely. Demonstration providers believe that there are many families who might want to use services, but for whom transportation is the central barrier. "We have the county transportation that picks some of them up, but we do have some that are in the far end of the county that it would be kind of hard to get them here for transportation purposes" (34).

Other rural areas lack even a rudimentary countywide transportation system. A provider in one such area laments, "Even though we're rural and transportation is a huge issue out here, we have not had a successful transportation system" (27). Structural barriers like these can prevent even the most motivated potential users from becoming clients.

Other Shared Barriers

At the community level, providers find a pervasive mistrust of institutions and a general lack of awareness about respite services. This lack of knowledge and mistrust includes fear of the government, distrust of bureaucratic procedures, and fear of the medical community.

Mistrust of Institutions
Ethnic minority and immigrant families face special barriers to utilizing services. In rural areas where a recent influx of immigrants from many countries has occurred, some new residents' fears of governmental bureaucracy prevent them from accessing services.

> For some [immigrants]…it's been a great challenge for them to jump through all those hoops to come to this country. So there's a certain sense of mistrust there, because how do they know that the government here isn't like the government in their own mother country? (22).

In urban areas where there may be family members in this country illegally, providers face additional challenges. For undocumented immigrants, fear of the US Immigration and Naturalization Service pervades their attitudes toward government assistance of all kinds. They see service use as contrary to their desire to maintain a low profile. According to one provider, "The people who are undocumented…[are] fearful that somehow the Immigration or the government is going to find out they live at this house or at this address, and that starts the reluctance right there" (3). Another provider attests to the pervasiveness of this fear, even for immigrants who are in the United States legally.

> [Undocumented immigrants] are not allowed to work in this country. So they expand that fear to everybody and everything and every matter…But it's not every family that are undocumented, it's here and there. But they fear the establishment even if they are legal already (24).

The bureaucracy associated with applying for services can be another barrier to utilization. Some caregivers feel intimidated at the mere idea of going to a government building to fill out an application. A provider explains,

> A public office such as the county department or the Social Security office, it's very intimidating. The protocol for how you act to the services and the language is very difficult. So it's kind of intimidating for the client (3).

The application form itself can be equally daunting. The same provider found that the length and extent of the questions can prevent Hispanic/Latinos from receiving the services to which they are entitled.

> You go to apply for SSI for like a 15 page form for Social Security. You go to apply for Medicare with L.A. County, and it's another 20 page form. It's very hard to get through this paperwork…It's very hard to bring documentation like your earnings, your bank account, your rent receipt, your utilities. A lot of times the bills are paid in cash so it's very difficult to get through "the system" (3).

In some cases, Medicare is the only payment option available for a needy elder. The degree of difficulty and the extent of the paperwork and documentation can act as a barrier.

Distrust of Western Medicine

All communities mentioned difficulties with finding competent, trustworthy medical care for dementia issues. However, for the Hispanic/Latino community, this challenge is addressed culturally with a preference for folk remedies or alternative medical treatments over Western techniques. More common among spousal caregivers, use of home remedies and religious devotion often go hand in hand in this community. One provider comments that a combination of religious fervor and tight finances can lead caregivers to use home remedies.

> Our cultural challenge would be the religion, the home remedies…There is a very strong belief that God is going to help me. God is going to answer me and my prayers will share my burden…If they don't have medical, if they can't pay for a medicine for a particular illness such as Alzheimer's, they will cure their person with their own remedies (3).

If they had the means to choose, many older caregivers would still opt for traditional medicine. In fact, another provider has observed that people go out of their way to find the proper ingredients for a medication. "A lot of people will go over the border and buy certain medications because they're not sold here, because they're going to do it the 'right way'" (4).

Other providers feel that the practice of folk medicine has less to do with its benefits than with reluctance to use Western medicine. According to an urban provider, many Hispanic/Latinos are not raised to value preventative care, and are not accustomed to regular doctor visits.

> When I make the schedule for doctors' appointments, sometimes they say to me, "Oh, I am OK. I don't need to go to the doctor, they're just going to say that I'm OK."… So that's another problem I am fighting, because we are not educated to go in for a regular check-up, you know. We just went to the doctor when we felt sick (47).

Lack of funds can perpetuate this phenomenon, and discourage familiarity with the medical system. Another provider adds, "With limited income, it's less likely that you've had preventative medicine throughout your life, it's less likely that you had many interchanges with doctors, so maybe you're not familiar with what might happen in a medical setting" (5). This lack of familiarity with the medical process can lead persons to irrationally fear an adverse diagnosis because of their view of what it represents. A staff member explains Hispanics/Latino's fear of doctors.

> I think they are afraid for the bill, first. And there are other things, like they don't want to face if something is wrong with them…For example, I have a client who has a problem with his prostate, and he says that means that he isn't really going to be a man if they remove the prostate (47).

The Medical Institution

Providers routinely mention difficulties families have in interacting with local physicians. Many staff members report reluctance on the part of family doctors to diagnose Alzheimer's disease or to refer clients on for further testing. Potential clients, without formal diagnoses, are less likely to seek respite services.

In Hispanic/Latino communities, providers report a lack of physician diagnoses or accurate explanations for dementia symptoms. A common problem is the misdiagnosis that dementia is an inevitable part of aging. A staff member complains, "Doctors will tell them there's nothing you can do about it, he's old, this is the sign of aging" (4). Another provider from the same area was quick to add, "And so the families see it as something that's inevitable, and something that they really can't seek help for" (7). Because they do not identify memory problems as Alzheimer's disease, or even if they do, physicians are unlikely to refer families to a dementia-specific portal agency that could point them toward respite. A provider affirms this observation.

> Even the doctors don't recognize what is going on and sometimes they say—most of the time they say—well, yes, your loved one has Alzheimer's without doing any test and they send them home and say, well try for that person to have the best life they can. But they don't say you can call the Alzheimer's Association, you can get some information and some help (13).

Providers indicate that Spanish-speakers are particularly handicapped in this situation by minimal English-language abilities. One staff describes Hispanic/Latinos' difficulties in asking follow-up questions.

> They go to their doctor, and maybe because the doctor doesn't speak their native language, they feel intimidated. So they don't confront the doctor, they don't ask them, and/or the doctor at many times is not educated about dementia, so…they don't go that extra step (7).

Even if they were not satisfied with the diagnosis, providers found many Hispanic/Latinos reluctant to seek a second opinion or visit with a specialist. This can lead to an elder remaining undiagnosed, and not receiving appropriate services. According to the same provider, this is due in part to a desire to maintain a relationship with their long-time physician.

> A lot of these doctors, they're the doctors they've had for 20 or 30 years, and the family is very attached to these doctors, so they don't want to seek the help of a specialized professional and/or receive diagnostic testing. That's a big barrier, because without the doctor working together with the family…a lot of times families go on with their folks being undiagnosed (7).

In rural areas, families face similar challenges. Some rural providers attribute the reluctance on the part of physicians to make a diagnosis to their own lack of understanding about the disease and the diagnosis process. One provider feels that, as doctors' time with elders decreases, so does their ability and inclination to accurately diagnose Alzheimer's disease.

> I don't think dementia is easily evaluated in 20 minutes in a doctor's visit and I think more and more doctor's offices that's all they've got is 20 minutes. I think early dementias are not picked up because folks typically do very well when they get themselves together…and can really cover quite well…I think on one hand the physicians don't have the time and I think sometimes they don't take the time and I also believe they're not well-educated (19).

Other rural providers have found that, even when a positive diagnosis has been made, physicians may not disclose the exact diagnosis to the family. This can be a barrier to service in agencies that require a diagnosis of dementia before an elder can qualify for services. Another provider shared this view.

> Some doctors won't tell families. In order to get on this program, we do have to have a diagnosis from the doctors. And when I've asked for that, the family says, 'Well, the doctor's never said anything like that, but she certainly is having a lot of memory

problems. And we've asked the doctor but he's never told us.' And sure enough, when that diagnosis comes through over the fax, that's exactly what it says, it's Alzheimer's or dementia (21).

Even when willing to both diagnose Alzheimer's disease and inform the family of the situation, physicians may not understand the value in referring elders to respite programs. A provider in rural area described her efforts to obtain referrals from local doctors' offices.

> We have been trying to get these primary-care physicians to refer people to us for a free program…I took packets out to three major physicians in the county, sat down and talked to their nurse managers…and I asked them to please refer eight people, out of ten packets I gave them. Now, you're not going to tell me that all those physicians didn't have at least eight people with dementia that would need some information and referral…I have gotten no names, none, and that was a year ago that we went out and asked them (28).

Providers in Black/African-American communities assert that, by not familiarizing themselves with Alzheimer's care, today's doctors are doing little to remedy this problem. One provider maintains that even when medical care is sought, physicians sometimes perceive dementia as untreatable and recommend nothing. "Educating across the board, and the lack of it, is a real drawback. Having physicians who won't recommend things because it's not going to do any good anyway" (39).

For the Black/African-American community, a more commonly encountered barrier to service use is mistrust of physicians and the medical system. Providers in both urban and rural areas report that some Black/African-American families treat health care providers with suspicion due to past exploitation. One provider sees that past maltreatment has led to residual mistrust.

> It's been a historical fact that African-American people have been exploited. They have participated in events, and have been taken advantage of…There is a big trust issue in this community (26).

A Southern provider cites the specific example of the Tuskegee experiment.

> They [Black/African-Americans] turn down opportunities because they are suspicious that it involves more that what is being presented…The Tuskegee research project is seen as a medical thing. And that research project not only I think affects African-Americans in research, I think it has an effect on African-Americans in medical treatment (39).

Additionally, some providers believe that families are reluctant to use services or trust providers because of past, personal experiences as well. This is common particularly for older persons

who may have been previously treated dismissively by physicians and had their complaints trivialized.

> They haven't had things explained to them where they could understand them in the medical system in the past. Words are used that are not common to them. Full descriptions aren't given because there's an assumption that they wouldn't understand (39).

Lack of Awareness of Respite Services

Providers suggest that another barrier caregivers face is lack of familiarity with services. Some are completely unaware that respite is available. "That's the number one problem that we have in this type of community, and with this type of service, that they're not aware that there are some services out there that are available to the caregiver" (16). This is most often the case with caregivers who work full-time or are overwhelmed by caregiving tasks and have little time to investigate care alternatives.

> [It's hardest to reach] … daughters, or those who work, who's trying to just take care of them, get help during the day or just leave them there at home and try to come home from work, take care of the kids, take care of Mama and really don't stop…to whom no information has been presented because they're so wrapped up in their day-to-day life, working and coming home, taking care of their loved one (10).

This lack of awareness can lead families to find respite services too little, too late. Since some respite programs, particularly day cares, can only take elders who are ambulatory, the advanced condition of elders can also be a barrier to service. A day care provider laments,

> My barriers are I'm really not supposed to serve you unless you're in the early stages. And when we get the call, usually they're in the middle stages, and that's really sad. They went two or three years and didn't call for help. "I thought I could manage it," but they waited too long (17).

A related barrier is caregivers' denial of the true extent of the elder's illness. The gradual progression of the disease makes symptoms easier to ignore.

> Gradual change, change over time is not noticed nearly so much. And also because a lot of times I don't think people really know what to do. A lot of times things are seen as personality, not disease (39).

Even if they have some knowledge of respite, some caregivers face difficulties in accessing care. Without guidance, they can get lost on the way to inquiring about respite. A provider describes an example of how impenetrable the bureaucracy can seem.

> [A caregiver] had been trying to find out what was available for people who had dementia…and she had taken the day off from work, and had been calling continuously since 9:00 that morning before she got to me…Either she always got the wrong person, or the question she asked wasn't phrased so that they could give her an answer. But

the fact of the matter is, she called all day long before she got me, and found out how to just get day care, in-home respite, and that kind of thing (39).

Culturally Specific Barriers

In spite of the many barriers that were common across all cultural groups studied, there are some challenges that are culturally specific.

Rural Families
In rural communities, providers faced a strong desire of families to maintain their independence and a sensitivity to the potential embarrassment that can be caused by dementia-related problem behaviors.

Ethic of Independence
Lack of support from the medical community is one of several factors that might keep families from seeking respite services. Elders and families might be reluctant to inquire due to personal reasons, or language difficulties. Providers mention that in rural areas, where a strong work ethic and independence were highly valued, older persons might not want assistance nor would they feel comfortable asking for help. One provider observes, "These people…were never dependent on anyone else to do things for them…and they find it very difficult to ask for help in any way, any form" (34).

Shame and Embarrassment
Since there is a heightened sense of familiarity in rural communities where everyone knows everyone else, the potential for embarrassment due to dementia symptoms is great. The elder's level of disability and severity of symptoms can influence whether a caregiver will use the services or not. Families of elders who act in a disruptive manner may feel that respite, particularly a day care environment, is not an option for them. This can be frustrating to providers. "Seeing caregivers really stressed out but unwilling to accept the services, saying, 'I don't think he'd like it,' or 'He'd be upset,' or 'His behavior's so bad I wouldn't want to leave him with you'" (23). Others find that while families might try respite, issues surrounding dealing with problem behaviors can cause them to discontinue services.

Black/African-American Clients
Many Black/African-Americans' express a strong preference to keep their elder in the community.

Preference for Family Care

Families sometime view service use as the first step toward institutionalization. One provider sees this attitude in regard to her day care.

> The families are the problem, because they're in denial of what's happening. They want to keep that person as protected as they can keep them, and they do not want to send them into a day care, because when they walk into a day care, it looks like a nursing home to some of them. They say, "I don't want my Mama here, my Mama's not that bad" (17).

Although familial care is highly valued in theory, the bulk of care still falls most commonly to one family member. Ironically, this stress of caregiving without assistance can lead to early placement. Providers have seen this happen due to lack of extended family assistance.

> Most of the time it's lack of support. You've got one family member, usually a daughter or a son, that's doing all the work. When a challenge hits them personally on their jobs or whatever, then everything breaks down for the client…That family member has to make that drastic decision and most of the time I've got to put Mom or Dad in the nursing home because I can't keep them at home. Therefore, I lose them on my attendance (9).

Hispanic/Latino Families

Along with many of the barriers already mentioned, providers who serve Hispanic/Latinos face barriers specific to the diverse national cultures of this population.

Familial Duties

Several providers spoke of caregivers' feelings of familial duty as reasons that they might not seek services. One explains, "They're not really high utilizers of service because they depend on their families to care for them; there's a very inter-woven idea that the family has to care for them" (7). Enmeshed with this belief of family care, seeking services is often seen as complaining about their family duty. According to another provider, many caregivers view it as wrong to complain about doing one's duty, and therefore, wrong to try to find assistance.

> There are very many barriers. One [is] not wanting to complain, thinking that it was wrong. To say "I need help," because they felt that…you suffer in silence. It is your duty, so therefore why complain? (4).

This is especially true for eldest daughters, who, as the culturally appointed caregivers, are more likely to feel personal and societal guilt at not performing these duties. As one provider said,

> It's one of the reasons why Latinos are also not likely to seek help for a while because they assume that the elder daughter [will provide care]…they assume "This is my duty,

this is what I am supposed to do. It would reflect poorly on me if I seek help. I would be a bad person" (5).

Services in Familiar Surroundings

Another reason some Hispanic/Latino caregivers are reluctant to seek services is fear of disapproval and alienation from the population outside of their neighborhood. A provider in Los Angeles finds that families were sometimes unwilling to use services that are not in the immediate vicinity of their home. "Especially in Los Angeles County, there is a huge geographic area, and there are many people who are afraid to venture outside their community because they don't believe that services outside the area will be friendly or accessible" (5). Hispanic/Latino caregivers also do not feel comfortable with some of the programs that help White caregivers, and so are unlikely to seek those services. A provider describes the reluctance to attend support groups. "I think again it's a cultural thing; to go to a [support] group and talk about your problems is not something that they are generally real comfortable with doing" (50).

Language

Language is a clear barrier for both medical professionals and providers. Lack of a common language can prevent families from seeking services, or cause them to discontinue services after a short time. A provider speaks of the need for Spanish-speaking workers. "If you have services, and they're not provided in a culturally sensitive manner with appropriate languages for their loved ones, it's a barrier because they're not able to understand the process" (7). Another factor that is important to keeping Hispanic/Latinos involved in respite is cultural appropriateness. Staff people who are unaware of cultural differences between Hispanic/Latino groups might constitute a barrier to service, according to one provider. "I would say for myself the language barrier has been number one, and then the cultural difference in appropriate communication versus inappropriate communication that's specific to the Spanish [speaking] culture" (43).

The communication barrier can even be more extreme in rural areas. "Probably the biggest issue is the communication…It's pretty hard to help somebody if you can't communicate with them" (22). The situation is compounded by the isolation and often limited resources in small cities and rural areas. A provider serving a community whose minority population has increased rapidly finds it hard to find translators and learn about cultural diversity.

We have a very diverse population in this area; believe it or not, even though we are very rural…It's not like a city where you have 100,000 people in one spot. Because of that, the numbers that we have representing one [ethic] population are much smaller…So it makes it more difficult to find the resources because the population base isn't there to be able to pole other people who can speak languages or know a lot about the culture (18).

Barriers to Service Use

Providers face many common barriers. At the agency or program level, providers need to cultivate stable funding mechanisms, address clients' willingness and ability to afford the costs of the services, hire and retain quality staff, and attend to transportation needs.   Other shared barriers include the pervasive mistrust of the government, difficulty in interacting with the traditional medical community, fear of bureaucratic forms and information seeking, and a general lack of awareness about respite services.

Each community also has barriers specific to their cultures. For rural families, it is the belief in an ethic of independence and self sufficiency as well as the sensitivity to embarrassment due to dementia symptoms. For Black/African-American communities, providers faced a strong preference for family care and a belief that any service use was a step toward institutionalization. Hispanic/Latino communities also promote a strong family care norm and most often do not seek assistance with care, as that is the traditional role of the eldest daughter. The lack of respite services located in Hispanic/Latino neighborhoods, coupled with the cultures' distrust of outside communities, decreases service accessibility. Additionally, Hispanic/Latino families faced communication and language difficulties.

RESEARCH QUESTION #6: HOW HAS SERVICE DELIVERY BEEN MODIFIED TO ADDRESS IDENTIFIED BARRIERS? HAVE THESE EFFORTS BEEN SUCCESSFUL?

Many providers had developed particular program and outreach modifications to address the barriers they had identified. The majority of these solutions are applicable across cultures, while some are culturally specific.   The providers offered concrete suggestions for creating successful strategies for serving diverse populations.

Talking about Respite

Providers found that how one talks about respite services is important. In order to address caregiver concerns about using services, providers need to choose their words carefully. Some providers believe that families need to feel like it is okay to use services.

Providers find that an important first step is approaching caregiving families in a manner that is non-threatening and supportive. One provider often meets with success when she emphasizes that getting assistance does not mean that a caregiver is weak, but instead using respite services can prolong informal caregiving.

> Somewhat it's also giving people permission. Sometimes people need to be told, "You can't do this anymore. This is too hard, it's hurting your health"…Not to point out that they're weak, but that they're really strong but they need to keep that way (23).

Providers also express the need to make caregivers aware that using respite does not mean that they are surrendering their caregiving role. Instead, another provider finds it helpful to work with the family to provide a comprehensive package of care.

> We have had to take the approach…that we are not there to supplant the family. We are there to complement what they're doing, and we try to develop some type of team approach with family members so they realize that we understand that the care that they're providing is excellent (18).

Several other staff members expressed the need to communicate the idea that they are there merely to help the caregiver do her job better, nothing more. In the experience of one provider, when respite is properly explained, caregivers feel less guilty about using it.

> Anybody can give people physical support and take care of them for their actual physical needs…Only the person that's the closest to them can give them the emotional support on an on-going basis…If you're exhausted by the physical, you can't do the emotional. And so to use other sources to help you with the daily care, you can then do your job better (39).

Providers in Black/African-American communities strive to avoid the implication that they're coming in to "take control" of the elder's care. One describes her personable approach to an initial meeting with a family member.

> I try to start a conversation about something they'll relate to. Pick something in their house, or something to talk about, or the baby, or I try to get on a friendly term so that I am not just some lady coming in from out of nowhere to tell you what to do. Under no circumstances would I ever want them to think that I am there to tell them what to do. I am there for them to tell me what they need and then to see if I can do it for them (14).

Since many Hispanic/Latino caregivers feel duty-bound to provide care, and guilty about asking for help, some providers de-emphasize the idea that respite is for the caregiver's benefit. One provider stresses that service use is participation in a research study that will help providers learn more about Alzheimer's disease (4).

Providers saw that caregivers were also reluctant to let outsiders know about their elder's condition, particularly if problematic behaviors were present. One provider found it helpful to discuss the prevalence of dementia in the general population, to demonstrate that no family was alone or should feel ashamed.

> I think the best way is just to tell them, to show them research, and say, "Did you know that so many families are experiencing this?" And whenever they come to the day care where I'm currently working, I let them know, "All these people in this room have dementia. You're not alone, and your wife is not alone," because sometimes they don't want to bring them to a service because they feel they're going to be disruptive of the other people (7).

Creating a Comfortable Respite Environment

Providers also note that the appearance of the respite environment can speak volumes about the care philosophy and how "institutionalized" the care will be. Caregivers should be reassured by the appearance of the care center. Providers mention the importance of a home-like atmosphere to families, particularly families who are adamant about avoiding institutional placement. One provider, who took time decorating her day care, received positive reactions.

> There is no resemblance to any kind of institutional care. We have volunteers who are a part of our services, and they decorate the rooms for the clients. Twice a year they come and look at the rooms to make sure that they are as they should be. And I think this is why the clients that we do have are on-going clients, because the families feel very comfortable in the kind of surroundings that they are in (38).

Familiarity

Because familiarity plays such an important role in rural areas, several providers use their ties to the community to convince families to accept respite service. One quickly learned that a friendlier and less professional approach works better at the start of a relationship with families.

> I save [the] complicated pieces [of information gathering] for later. I will go in and because the communities are so small everyone wants to know who you're related to. That's been very helpful when I say, well my grandfather was the barber in the town, and everybody knew my grandfather, and then all of a sudden there is a comfort level there. So I am already part of the community. It's a community they're familiar with and I am no longer a stranger (18).

Although being a long-standing community member helps increase comfort, providers who do not have that advantage can still make the most of small-town familiarity. Another provider has found that, even though she is not familiar to clients, her volunteers often are.

> One of the things I do on the initial assessment to kind of ease the caregiver's mind and the patient's mind is to say, "You know, I do have a few volunteers who live out in this area," and I would rattle off their names, and I would see if any of them ring a bell. Maybe they know somebody through somebody through somebody else…and we would pair them right away because they have that familiarity. And I would find that those pairings would work so much better (27).

Cultural Similarity

Environments must be comfortable for the elders as well as the caregivers. This may be even more pronounced in the Hispanic/Latino community, but is important to address for all communities. Providers suggest other ways of helping elders feel included that also create an atmosphere that can be fun for all. Several people mention the necessity of serving familiar food. One provider found, "The foods that we served were foods that they were familiar with and so they liked that they were eating rice and beans or something like that" (1). One provider that serves a diverse group of elders has to make a special effort to provide culturally appropriate food, as the food they normally receive for the day care is rather Americanized.

> We try to have more culturally acceptable foods that they like better, on at least some of the days that we have a higher group of people from our Hispanic community. We'll go to local restaurants that serve different foods that they like, and try to have some different meals here other than what we normally get from the Meals-on-Wheels program, which is pretty much geared toward meat and potatoes and vegetables (50).

Celebrating the holidays of many different nations makes Hispanic/Latino elders feel at home, and is also enjoyable to non-Hispanic clients, according to one provider. "Knowing that we had people from different countries and there seems to be a lot of pride in that, and so we would celebrate anytime there was some sort of…independence day, and they really enjoyed that" (1).

A Service, Not a Handout

Another part of caregivers' reluctance to use support services was that they perceived the services as Welfare or a handout. Providers mention that charging the clients a nominal fee for services alleviates much of this resistance. One provider relates the success of this approach.

> A lot of people in this area, because of their pride, want to contribute financially, and we've found that's been kind of nice when people can give what they feel they can afford toward the care that they're receiving. They feel better about the care that they're receiving…So I don't care if it's a dollar, I don't care if it's just 50 cents, as long as they're contributing something (18).

Striking a balance between affordability for the family and payment for service can be a successful strategy for increasing the level of comfort.

Cost and Affordability

A final barrier that providers attempted to address was that of a lack of income. The bureaucracy of the social service system prevents some caregivers from applying for government programs that could help with costs, so some providers work to help clients access the system. A provider explained,

> I will help them fill out the applications. I will try to help them gather their receipts and their papers. Sometimes it's a little difficult because their book system is not…the best, but I try to encourage them on how to do it (3).

For families for whom this is not an option, providers stress the need to use a sliding fee scale that allows needy families to get the care they need. One describes her agency's policy, "Certainly all our services are on a sliding fee scale and if they can't pay today the $10 minimum, then that's fine, we'll bill them for it" (45). Providers realize that a well-designed program of care means little if no one can afford to use it.

> It didn't matter that we had done all the work if that older person would have gone to our partnering agency and could not have paid the minimum. And they couldn't, they would not have gone. So we could have had the best program in the world with [only] one attendee who could afford to pay (45).

Program Responsiveness

Providers report that when they modify their programs to address specific family needs, clients are more likely to begin and continue service use. Some providers find it helpful to set individual programs for clients once their personal needs are known. One provider has been successful by individualizing her approach to each client, which seems to keep them coming back to day care. "What we've done is just be creative all along on an individual basis…We had a lady that didn't want to come, and what they would work out with her is they would set it up where it was a job, and she was actually going to get paid [for helping out at day care], so she was really interested in that" (31). Rural elders who are used to hard work may find productivity more palatable than recreation, and providers can use that to their advantage.

Providers also suggest modifications that they have made to counter elders' resistance to attending day care programs. Providers comment that the manner in which they frame day care services is important to elders' willingness to attend. Sometimes providers' choice of words alone could make a difference. One provider refers to her day care as a "club".

> We refer to the fees as "tuition"…That's the way we let the people think of it. It's more acceptable that way…because most everyone has belonged to [a club], whether it's been a civic club or a social club or a church group…So there really is a different way of thinking when you refer to it as a club (40).

Another provider oriented her day care in the same way, and felt that Black/African-American elders saw it more positively as a result. "You're coming here to socialize, you're not coming to a day care, you're coming to a socialization group where you're going to come and socialize with friends that you've met" (17).

Modifying Activities

Providers also suggest modifications that they have made to counter elders' resistance to attending day care programs. They found that over stimulation could be a problem, and that few programs appealed to all elders, which were both reasons that caregivers might discontinue respite care. One provider mentions that being flexible in the activities that are planned for a given day, and being responsive to the moods of the elders, can prevent over stimulation.

> We may have a certain activity set up that we were going to do…and we need to change. Instead of having a hands-on activity, we may need to change it to an exercise. They may be over stimulated that morning and instead of singing after lunch we might have a movie just to do some calming, so not only on a monthly or weekly basis, but by the day and the hour, what you have might have to change (31).

The kinds of activities for the elders are also important. In general, familiar activities are favorites with day care clients. One provider adjusted her offerings to correspond to the religiosity that is common in Black/African-American culture. "Most African-American elderly people have a very high...spiritual background, so we do have a lot of programs that are geared toward that. We also do Gospel and Bible hour here" (9). An activity that goes hand in hand with a religious orientation is the use of hymns to sooth and entertain elders. Providers see music as an activity that can appeal to elders in all stages of illness. Another provider finds music to be quite popular.

> We play music the whole six hours…so that if we have someone progressing in the disease and they can't really function, they have music. We used to start out with nothing but gospel, but now we play music of the '50's and the '70's, and everybody knows that music because that's their music (17).

Although these activities seem to appeal to the majority of elders, providers cautioned that they still need to think about the needs of each client individually in order to provide the best care for them. As one staff member mentioned, "We deal with each one as an individual and try to meet their needs" (14).

Accommodating Working Caregivers

Providers perceived a special barrier in reaching and serving caregivers who were also employed full-time. Several put forth extra effort to reach these caregivers. One provider has had success reaching working caregivers by doing educational presentations that did not interfere with work schedules.

> We try to do workplace education seminars, and we would go…and do a lunch time program on Alzheimer's disease, because a lot of the people, they're not going to come to a "special program" if they are caregivers. For a lot of them, once they get off work and go home, that's when the caregiving starts…So we can go in to a workplace, do our program [as] a brown-bag lunch where they're not losing any time from their workplace (8).

Once providers reach working caregivers, they also need to adjust services to accommodate tight schedules. Another provider was able to extend her program's hours to facilitate use by working caregivers.

> We have extended hours here because most of our family members if they are daughters or sons, they're still working class people. So we have extended our hours longer than most day care programs. We're open from 7:30 in the morning until 5:30 in the evening. That makes it easier for them to drop their family members off early and to pick them up after work hours (9).

Reinventing Support Groups

A related barrier is caregivers' resistance to attending support groups. Some do not feel comfortable with the concept, and others have a difficult time fitting it into their schedules. Providers have tried several strategies to increase support group attendance, with mixed results. One provider had attributed low attendance to the lack of an alternate caregiver to stay with the elder, and so explored scheduling alternatives. "We're trying to hold our caregiver support group meetings during a time where the caregivers can bring their loved ones to the adult day care program…but we're still having low turn-outs, so we're going to have to rethink

this" (26). Although this idea has not yet played out, the provider sees the need to keep trying until something clicks.

Another provider has seen great increases in attendance since she reworked her support group to include a potluck dinner, which she sees as culturally appropriate for Black/African-American families.

> I deal with low-income and Black people, where family has always been very important, and family in a Black generation is eating. Every Sunday, people come together and eat, and that's what I use. My support groups are support dinners…I use the food to get them here, and then I train them once I get them here…When they can cook for somebody else that can appreciate it, it makes them feel important (17).

Support groups are a service that Hispanic/Latino caregivers as a group appear to be particularly reluctant to utilize. Because providers believe in the importance of sharing for all caregivers, they have developed techniques specific to this community. Like Black/African-American caregivers, Hispanic/Latino caregivers are responsive to linguistic changes in the way "support group" is described. They are more likely to attend and enjoy a group with a title that is more social, and thus less intimidating, according to one provider.

> We find that people tend to go to support groups if it's not called that. If it's called "Ladies' Group" or "Tea Time", it may be the same format, where they're just sharing and talking about their deep issues and venting and supporting each other, but it's not called "Support Group", and you'll get 20 women coming together. Whereas, I think people are a little bit intimidated unless they have that [social] connection (46).

Another provider is able to break the ice at her support group by encouraging caregivers to discuss anything on their minds, not just topics that were related to caregiving. This Hispanic/Latino provider works with the fact that every caregiver in the group had been an immigrant.

> I think I try to blend culture with our support group, and we talk about how we came to the United States, how we feel, and then they start expressing their feelings, and try to have a solution for everybody. I think the communication with them is very important, because they are able to share everything they have some frustration about in being in another country (47).

The atmosphere in which support groups are conducted can also be important to breaking down barriers. Groups held in a non-institutional setting are more comforting and less likely to have a stigma attached, according to one provider.

> Support groups aren't things that are very common within the Latino culture. But because of the one-on-one trust…they have extremely successful support

groups…These people were placed in [groups] in people's back yards, that had no stigma attached to them (5).

Many providers also found that fun is an important element in attracting more people. Music and a party-like atmosphere are important components of a successful program. A staff member who serves both Black/African-Americans and Hispanic/Latinos describes how she has changed her focus to attract Hispanic/Latino caregivers.

> When we do a program for the Latino community, it is more of a festive nature and our other programs seem to be a little more serious, but we did a program last December and it was a dance…We talked about Alzheimer's disease, they ate, played music, and these people paid to come to the program and it was a…holiday party (8).

Another provider agrees, emphasizing the importance of music as an attractor. "You have to be very creative, you must have meals, food, health fair, where the people attend. Music attracts the Latino community" (13).

Addressing Transportation Needs

Another aspect of program responsiveness is to address transportation needs for the service community. Providers found that they needed to employ creativity to find a way to transport clients. One provider is able to get some of her clients rides through another community agency. "There are other social service agencies that provide transportation, so that those clients who live further distances away, and meet the criteria of the [other] agency, they are able to utilize other transportation services to bring them to and from here" (38). Another provider uses a church's van on weekdays, and has realized an added benefit in giving caregivers slightly more respite time as a result.

> We've just now in the last couple of weeks started using another church's van to pick people up on program days. This is just kind of a trial run to test it, but not only does that extend the time that the caregivers have for respite, because we're obviously picking somebody up an hour early so that we're able to pick other people up along the route, so that's extending that time for that caregiver (40).

Empowering Clients

Providers had also identified unclear or incomplete medical diagnoses as a common barrier to use. Empowerment of elders and families was the most common strategy that they used to combat this problem. Rural providers mentioned that many families revered doctors, and accepted their diagnosis without question, even when it lacked specificity. One provider suggests that it is reasonable to get a second opinion. "If their family physician says to them, 'Well it's old age,' then I suggest that they may want a second opinion, and I'll use anecdotal

stories of how somebody thought that's what it was, but in fact [the diagnosis] could change" (21). This tactic often helps families feel justified in seeking answers to their questions.

Like rural residents, Black/African-American elders often did not feel comfortable questioning physicians, and so learned no more than their doctor was willing to volunteer. One provider is trying to change that attitude.

> One thing we're trying to work on is trying to empower the folks to stand up for their own rights…On physician visits I always let them know that doctors are just practicing medicine and if you feel uncomfortable that your doctor has told you, it's okay to ask for a second opinion. It's okay to even look for another doctor. Because a lot of times what I have found in the elderly community, and in the African-American community, if they go to doctors, they tend to take the doctor's word as God's word…It's not to be questioned (26).

Empowering Hispanic/Latino families means educating them about Western medical care. However, addressing the issue of folk remedies requires caution on the part of providers. Providers may want to dispel myths about the effectiveness of traditional remedies, but in a manner that does not belittle cultural beliefs. A provider described her approach in trying to convince families not to rely solely on folk remedies. She finds it helpful to demonstrate basic neurology to dissuade them from believing dementia is a curse.

> The way I did it was use graphs to show them. Like say for example, I showed them a picture of a person who hadn't been affected by Alzheimer's, and somebody who was, and I say, "These times when you see these sudden mood changes, it's because this is happening in their brain, these chemical changes. So it's not that the person is being possessed, it's just that these chemical imbalances are happening in this person's system, and thereby it's contributing to this type of behavior." And then I would say, "And I really think if you look at that aspect of the person with dementia's care, you would be unwise to keep going to these doctors who are promising the instant cure, because it's not going to happen" (7).

However, another provider urges caution in denying the efficacy of traditional medicine.

> We have to understand that we cannot ridicule them, even though the provider may think that medically that's not going to do anything, we have to respect what they believe in. Those are the kinds of things that if we don't respect, then we're not treating that person with the dignity and respect that they need, and they probably are not going to come back (45).

Other Hispanic/Latinos have had bad experiences or are unfamiliar with Western medicine. Although they did not suggest any strategies to assuage these fears, providers do suggest that those agencies who have the means could set up their own clinics where they know care will be

culturally appropriate. For example, Hispanic/Latinos may receive better instruction and feel more comfortable with visiting a Spanish-speaking pharmacy. The same provider finds this effective at her agency.

> The comprehensive array of services is designed to meet those needs of people, so that they don't have to go to, say, a pharmacy. After they visit a bilingual provider here, to go to a monolingual pharmacy out in the community someplace who can't speak to them. So we have our own pharmacy (45).

Culturally Specific Solutions

Though primarily a rural issue, isolation can be a challenge in serving caregivers in general. Rural providers commonly deal with transportation barriers due to the disparate populations in rural areas. Lack of transportation can affect caregivers' abilities to attend support group meetings, as well as their ease of taking elders to day care. Providers have worked on variations of the support group idea to facilitate long-distance meetings. One is beginning a support group by phone.

> A lot of them can't get out and go to support groups on a regular basis, and we're trying to get a buddy caller program started. What we'll do is connect the caregivers to other caregivers in their area so that every month…they can get a support call saying how are things going (20).

Another provider described her experience producing a caregivers' newsletter. Although it took awhile to gain support, she is now finding that many caregivers like it and take an interest in its content.

> Many of them are elderly or they have other family members that they're caring for. We have both groups, children taking care of parents and spouses taking care of spouses, and all with very busy lives…A caregiver newsletter has been very well-received here…Folks are calling me saying, "You know the next time I'd like to see something discussed about activities in the home," or they're dealing with this issue or that issue (21).

The same provider mentions that several day care facilities in her area have developed a program to address the transportation needs that also deals with the difficulties families have in getting elders ready to go out. "The staff will actually go out and help the family get their loved one ready to go to the program…Bathed, and dressed, and out the door, and driven to the day program, again because we don't have the transportation services available for families" (21).

Providers from Hispanic/Latino communities insist that the presence of bilingual staff members is essential for successful service provision. As one provider indicates,

I think definitely the cultural barriers are eased by having bilingual staff or people that at least attempt it…The fact that we provide groups solely in Spanish each day, I think that really makes people feel incorporated into the whole, and like we're investing in everybody and not just trying to mainstream everyone into one type of service (46).

Addressing Barriers

Several themes run through the service modifications that were discussed by providers about clients of different backgrounds. First, almost all caregivers and families benefit from some degree of reassurance that service use does not have to mean relinquishing control of elder care. This is particularly important for providers who work with Black/African-American and Hispanic/Latino families, who often have stronger feelings of familial duty for the provision of care. Second, families of all backgrounds need encouragement from providers to insist on having their questions answered by physicians. Providers view client empowerment as essential to families understanding of dementia and respite care. Due to their clients' lack of familiarity with Western medicine, providers to Hispanic/Latino clients may need to spend more time helping families negotiate the medical system.

Third, all providers' express the need for programs to be responsive to clients' changing needs. This can be accomplished by individualized attention (for rural and Black/African-American clients), or through attention to cultural needs in language, meals, and activities (for Hispanic/Latino elders). Fourth, support groups must be designed to be accessible, and not intimidating, to the target population. This might include long-distance telephone groups in rural areas, or more socially oriented environments to attract Black/African-American and Hispanic/Latino caregivers. Finally, providers to all groups mention the need to work around transportation challenges and financial barriers.

RESEARCH QUESTION #7: HOW HAS STAFF HIRING OR TRAINING BEEN MODIFIED TO ADDRESS THE NEEDS OF THE TARGET POPULATION?

For the most part, the qualities that providers desired in staff members and the ways in which they trained staff were consistent across ethnic lines. Suggestions and caveats offered apply to provision of care for elders with dementia of any ethnicity. A few providers spoke with specificity about serving Black/African-American or Hispanic/Latino clients, and their comments are addressed individually.

Shared Views

Personality

Providers were nearly unanimous in their agreement that it takes an extraordinary individual to excel at assisting individuals with dementia. A naturally caring personality is high on the list of qualities providers consider essential. One describes this personality trait as a prerequisite.

> The primary thing is the caring personality and just knowing how they feel about older people and how they interact with them. There's a lot of skills that you can teach people, but you can't teach somebody to be a caring person. They either are or are not (31).

In addition to empathy, potential staff members need to possess a willingness to become involved with their clients. Providers admit that due to the degenerative nature of Alzheimer's disease, this is sometimes not an easy task.   One provider nevertheless feels that it is necessary to forge a strong bond.

> You have to pick the right staff, and you have to be willing to give of yourself. For years I taught the nurses' aides, 'Be sure and distance yourself. Don't get too close to these people.' That's a joke. If you're really going to be good at what you do, you have to get involved, you have to get your hands dirty (28).

Another quality that providers consider in hiring decisions is a candidate's knowledge of the community. Due to the financial constraints that often come along with work in the social services, providers look for persons who can not only accurately assess programs' needs, but also know where to look to find resources in the local community and beyond. In the words of one provider, "It definitely has to be somebody who has a good knowledge of the community, a good strong background in social work itself or some type of human service field that knows the needs of people: caregivers, people with Alzheimer's, any kind of caregiving issues, and that knows how to be creative in findings resources that are not there, that's willing to go the extra mile to do whatever it takes to try to give families the information they need" (31).

Volunteers

Providers consistently lament that caring, knowledgeable individuals are not easy to find, nor to retain. Finding desirable volunteers to work with dementia patients is especially difficult, because these volunteers often must go through extra training. As one provider mentions, "Some of the challenge is getting volunteers …Especially for the Alzheimer's, to train someone for them to increase their skills in certain things, and what to expect of certain behaviors and attitudes that are displayed by the person that has dementia" (29). In urban areas, logistical problems can combine with personality conflicts to complicate the placement of senior companions. An urban provider finds that,

> Not everybody gets along with everybody. So it's really hard to find the combination that
> the senior companion is satisfied, because she only has to take one bus, and the bus
> stop is near the home of the patient, and that the caregiver [is satisfied], especially if the
> patient is in the early stages where he still has command of his senses to make them
> mutually acceptable [or not] (15).

Finding the right volunteer and making a feasible match with the elder is only the first obstacle.

Providers also express difficulty in retaining staff due to the low financial incentive to be

employed as an aide. A provider argues that staff shortages are due in large part to low rates of

pay for a difficult job.

> Nursing assistants go out and do the hardest job there is in the community. They are
> the link to every one of these clients…and yet they are the lowest paid there is. Like I
> said, I'm not going to get on my soapbox, I could stay on it for half an hour (35).

The day care providers surveyed seem to have more options in staff than do providers of in-

home respite. For example, one day care provider mentions that retirees who already patronize

the senior center make the best volunteers.

> They plan their whole weekly schedule around the [day care shift] because they have
> nothing else to do…The van picks them up at home and brings them to the center…So it
> gives them something to do (32).

Dementia Care Training

In addition to hiring staff persons and identifying volunteers, providers mention several aspects

of dementia care about which they routinely train staff. Many providers mention the importance

of patience and consistent service on the part of the workers. Part of this training consists of

reinforcing common courtesies that enable families to trust in the agency.   A provider lists a few

guidelines, "When you talk to them about what you're going to do, you follow through with it…;

make sure you have the resources to do so; call when you say the you're going to call; if you're

going to be late, let them know that you're going to be late, things like that" (6). Providers also

train their staff members to allow extra patience for dementia patients, whose condition

sometimes prevents delivery of services as promised. Another provider provides an example of

this type of training.

> A prime example is a little old farmer out in the community…You send an aide out there
> for the first time after you have done the assessment…She goes out there and that
> farmer looks at her and says, 'I ain't taking no bath,' totally refusing to take a
> bath…Sometimes an aide maybe had to go there three or four times without doing
> personal care to get in the home and get him used to her. You have to gain the people's
> trust (35).

One factor that helps staff members deal with the clients' specific needs is knowledge about Alzheimer's disease and dementia. Several providers speak about the importance of educating their work staff. "I think the most important thing is providing education to the professional, and equipping them with the tools and resources prior to contact with the client. If the [client] comes to you and you don't know anything, they're very unlikely to go to another professional who might know something" (7). In addition to being able to inform the clients, staff members with some knowledge of dementia will be better able to deal with or even preempt problematic behaviors. A day care provider observes,

> Particularly [with] people with moderate to advanced dementia, a lot of what they're picking up on are more subtle cues or body language and tone of voice, and I think if you have anger in the room or people responding with anger, they pick up on that and get somewhat agitated. But if the staff member is skillful and [can] deal with it and deescalate it, and sort of calms the environment down then it only has temporary negative effects on the room (26).

Although providers cite the need to train staff to expect behavioral changes, most also train them to treat demented elders with respect. One provider is adamant about preserving the dignity of elders.

> My program is teaching. I tell my volunteers, 'Do not ever treat anyone like they're not adults. Do not talk to them like they're a child. Always let them be an adult, because when they lose their dignity, that's when they get hostile' (17).

A related idea is that elders should be addressed as if they are cogent individuals, regardless of their true mental state. The same provider urges her staff to obey a sort of Golden Rule with the patients.

> I also tell them that when you're talking to them, you don't talk to them in the third person, you talk to them one-on-one, conversation between you and them. When you want them to do something, you talk **to** them, not **around** them…You treat them the way you want to be treated, even though they may have this disease (17).

Several providers describe staff supervision and training policies that have worked for them. One recommends setting up a system of rewards for aides who are particularly effective. At her agency, they award "special recognition for the aide that goes that extra mile, [because] you do have special aides that will just continually hang in there" (35). Another provider suggests that agencies hold periodic team meetings in which challenging cases are discussed. In her experience, "We'd bring up this difficult case and what would you suggest, because sometimes other people's suggestions might help, or they may have had the same experience and found the key to helping or breaking that barrier" (4).

Cultural Issues

A few providers within Black/African-American and Hispanic/Latino communities mentioned some staff issues that are specific to their clients' ethnicity.

Black/African-American Cultural Issues

A common focus for providers who work with Black/African-American elders, especially in the South, is showing respect by use of titles. One holds this to be particularly important with the older clients.

> The better I get to know them, if they are younger, then we may use first names. But the older ones, I would never. The patients out in the day care, they are not Mary, they are Ms. Mary or Mr. So-and-so. Everybody here is there to be respectful of these people (14).

Another provider allows her staff to address elders informally only after receiving their permission. "I tell them, 'It's Mr. or Miss. If they tell you it's Juanita, then you call them that. They'll let you know'" (17).

Other areas in which staff persons are trained before working with Black/African-American clients deal with religious and cultural diversity. Because religion plays an important role in the lives of many of her aides, one provider feels the need to caution her staff from imposing on clients who do not share their faith.

> We have to really caution our aides not to put too much religion into what they do unless the client is initiating it in some way or it seems appropriate to the client, because for a lot of our aides, that is their life and that's what they're going to put into their work, and for some of our clients that might not be appropriate (12).

Another provider points out the need for staff training in cultural diversity, even in geographic areas in which staff and clients are often of the same ethnicity.

> I've led some classes on cultural diversity…It can be something that's taught. Nobody is going to come into this being all knowing including people who are right here in the African-American community (8).

Hispanic/Latino Cultural Issues

Providers who speak specifically about staffing for Hispanic/Latino clients put more emphasis on hiring than on training of staff. Several mention the importance of hiring staff persons who will seem familiar and comfortable to the clients. One provider describes her agency's rationale for hiring mostly Hispanic/Latino staff.

> Basically what it comes down to, whenever you would have a client call in for possible services or you'd go to their home, they saw comfort the minute they saw you, the

minute they spoke to you. If they told you that they use this herb or this tea, you knew about it. If they told you they prayed to a saint, you knew about it. If they said they had a holiday coming up, you knew about it. There was no strange ground.

To this provider and others, a staff person's understanding of the Hispanic/Latino culture is a necessary prerequisite onto which other skills can be built.

Staff Hiring and Training Issues

In general, providers within the three cultural groups studied here had similar advice for hiring and training of quality staff members. All providers recognized the importance of recruiting caring and involved staff members. It was also agreed that knowledge of the service community was very important. Providers believed that besides education about Alzheimer's disease, staff members should receive training in the importance of patience and consistency when working with dementia clients. Because of the specific challenges associated with dementia clientele, workers should be taught about the expected behavior changes and the appropriate communication techniques for the care setting. In addition to the aforementioned strategies, the Black/African American providers also include the importance of teaching staff to address the clients respectfully using their title. There is consensus among the Hispanic/Latino respite providers that the most effective staff members are often those hired from the same ethnic community as the service population.

RESEARCH QUESTION #8: WHAT ARE THE KEY COMPONENTS TO SUCCESSFULLY PROVIDE RESPITE SERVICES TO THE TARGET POPULATION?

The providers identified key components that lead to successful service programs. Some factors, such as knowledge of the service community, assist with the development and targeting of services. Other components--developing a relationship built on trust, setting clear expectations, following through--are essential in maintaining clients' perceptions of appropriate service. Providers to rural, Black/African-American, and Hispanic/Latino clients shared their views of the most important factors to serving their community.

Rural Areas

Knowing the Community

Providers who serve mostly-White rural communities stress the need to make community members aware of respite services, and then working to gain their trust. Providers feel that the process begins with attaining knowledge about the characteristics of the specific community. Knowledge of the demographic characteristics of the population that will most likely utilize services enables providers to do selective outreach and tailor programs to match community needs. In more racially homogeneous areas, providers would be interested in such characteristics as level of education and community tenure. One provider describes the cultural characteristics she considers relevant to care.

> To know the community, for one. The history is also important. If people are able to read in that area, what grade level would be a majority of your people. Where did they come from…That kind of stuff, because then you're bringing in cultural [issues] (27).

Once a provider determines the population mixture with which she will be working, she can begin to formulate an idea of the specific services that will be needed. Providers in rural areas emphasize the need to spread awareness of a program's offerings. Because populations are often geographically diffuse, staff members need to go out into the community to do outreach, rather than waiting to be discovered by caregivers in need. One provider suggests,

> Get the information out there in some way or another…because if you don't know about something you're not necessarily going to look for it if you don't know it's there. So you have to go to them and you have to let them know that you're there (20).

Thus, building a citizen base that is aware of a program's existence is one essential key to providing service.

Building and Earning Trust

Perhaps more important to the providers interviewed is what happens once a family begins to receive services. After a caregiver takes the first step of inquiring about respite services, it is up to the provider to build on that initial trust. Providers mention several aspects of earning and maintaining trust. The first is simply listening to families, and making clear the intention to help. According to one provider,

> I think the most important thing is to be there for them. To let them know that you really care and that you're interested in trying to help them to make their lives better. To make their life easier, make the burden a little easier to bear (34).

Part of this supportive role involves striking a balance between educating families about services and allowing them to make their own decisions. Another provider finds that, for services to be effective, families must feel ready for them.

> Being there when it's needed…or when they feel that it's needed. As professionals we sometimes think it's needed now, let's get started. But I found our families don't think that way…and absolutely, it is up to them (19).

Another important part of building trust is creating consistent relationships between providers and families of care recipients. Being honest and keeping one's word is considered essential by many providers. One says that to gain trust,

> It takes calling them back when you're telling them you're going to. If you tell them you're going to do a home visit next week, you be there for that home visit. Standing up to your word I think is the biggest thing that you can do for your community (35).

If families can count on a provider to back up claims with action, they will be satisfied. Continuity in staffing can also help ensure trust, particularly for in-home respite agencies. One provider of in-home care gives an example of the importance of a one-on-one relationship to effective care.

> I just went to this lady's house on Friday…and she said, 'Now will I ever see you again?'…I think the agencies are such that somebody comes in and does an evaluation, you never see them again, and another comes. They [families] have no idea who everybody is who's in and out…I think people just need to know at least one name and number of someone that they know is there (23).

Repeatedly visiting the same communities can be beneficial not only to families but also to providers. With each visit to a community comes greater familiarity, and thus more trust. A provider describes this pattern.

> They have seen you in the community. They know who you are. They know why you're in the community, so when you pull up, the people next door are going to know who you are. That's when it works. When you get to the point that they know who you are and you are there to help them and they believe that's why you're there, you've got it made then (35).

In short, providers from rural service areas agree that an essential element of effective programs include developing relationships with service recipients that revolve around trust, support, and consistency. A successful program is also one whose care providers have

knowledge and insight about the community they serve. Diligent efforts toward outreach are critical, especially given the geographic distance required to contact potential clients.

Black/African-American Communities

Providers who serve primarily Black/African-American clients perceive similar components of successful service, but use different strategies for developing services in their target communities.

Gaining Awareness of Community Resources

The value of knowing the characteristics of the community is more strongly stated by Black/African-American providers than by rural providers. For example, the socioeconomic status of a community has an impact on the funding mechanisms a provider can employ to make services available.   One provider discusses some of the questions that providers should ask themselves and others about their community.

> [Providers] need to be sensitive to language, to cultural preferences, and they have to be aware of the socioeconomic barriers in their community. Is it a wealthy community? Is it a financially impoverished community? What types of benefits are available through the state and the county to help people who are financially challenged? They have to have a full picture of what resources are available in the community (11).

Another provider affirms the need to be aware of community resources. "They need to know the resources that exist within their community, because you need the support of other resources in your community (38).

Knowing Cultural Characteristics

Knowledge of ethnicity and cultural backgrounds was another often cited prerequisite to molding successful care programs. A Southern provider explains, "I think to understand the culture of the people, to understand their background, because what kinds of activities that you have for clients has to do with what is their background" (38). She provides an example of an unusual day care activity, riding a city bus, that illustrates the way in which knowledge of culture can improve a program's responsiveness.

> The idea of riding a city bus may be something that you do not incorporate into some other population, but understanding that coming from a Southern African-American background, the culture is people-oriented, people interactive. So…we provide opportunities to keep them in the community, which is the norm for them, rather than bringing them to a facility and keeping them here for five hours (38).

Knowledge of core community values can act as a base from which to create options that work better for clients. Another provider suggests a steering committee that reflects the ethnic composition of the community as an effective way to uncover these values.

> [A service provider] might have to form a committee of community providers in each of the indigenous communities in their area…[made up of] some members of the aging services network in that community who represent a variety of different cultural and ethnic backgrounds so that there could be input on what's appropriate (11).

Providers also mention the need for individualized knowledge about clients and their families before making a care plan. A physical assessment is obviously necessary, but providers also believe in assessing the knowledge base of caregivers. As one provider put it, "I think it's really important that we put what we know and don't know on the line to give them an opportunity to put what they know and don't know on the line" (39). Family structure and family dynamics can also play a part in managing respite care. Another provider states,

> Family dynamics are something that we do discuss when we get together as providers. Who is involved in the care, who's not involved in the care, how many children, who is the caregiver out of the 13 children…And it does matter if it's a child caregiver, rather than a spouse caregiver. There are different situations that certainly make a difference in how you approach the care situation (37).

Targeting Outreach Efforts
Outreach provides an opportunity to act on the information that providers have gleaned about the community. Providers who serve Black/African-American communities feel that a successful outreach program should have several characteristics. If printed materials are to be used, one provider urges that they be designed appropriately for the culture.

> You need to make sure that whatever outreach materials that you have are culturally sensitive…We recently did our brochure over again. It's a patchwork of different faces, not just showing one race, because for some people they, because they don't know about the disease, they may have a thought that Alzheimer's only affects Whites or Blacks (8).

However, another provider doubts the effectiveness of print media, preferring to talk with families in person. "In terms of African-Americans, word of mouth is a very effective mechanism for recruitment, rather than printing a lot of literature with a whole lot of written stuff that nobody

is going to read" (38). One provider finds that knowledge of the churches that potential clients attend helps her with outreach to Black/African-American populations.

> If we're able to get the pastors and some of the administrative people in the churches to even come out and see our program, introduce the program [to] them, then they can pass that information on to the congregation. The church is one of the major supports for the African-American community (26).

Building Community Trust

Trust building is a component of effective service that goes hand in hand with targeted outreach. Several providers discuss the importance of collaboration with established community leaders in establishing an initial level of trust. A provider elaborates, "When you have a key [community] person who can help you, then nine times out of ten, they have already gained that trust in the community, so they can be like your sponsor who can introduce you to the other folks. And then it can kind of go from there" (26). Having come to the same conclusion, another provider describes an example of an effective "sponsor" in a close-knit Black/African-American community.

> One of the ways they went about doing that, to actually get out into the communities, is they recruited a black sorority that's a real established sorority of older women that are in the area…So it works better if you identify a group or some people in the community itself that can actually do or present what you're trying to get across…You can't just go in by yourself and say, 'I'm here,' because there is some resistance if you're an outsider, whether it's age or race or culture or religion. You have to know how to go in (37).

Another element of successful service is maintaining a relationship of trust between clients and workers. This can be accomplished by being honest with families about the services that may be provided, according to one provider.

> I think by being honest and up-front. You tell them what you can't do as well as what you can do. You give them what help you know about, but you don't promise things that you don't know (39).

In addition to being realistic, providers find it important to give clients and families a high degree of respect. Another provider thinks this is especially true for Black/African-American elders.

> I think it is very important to show these people respect. So many times in their lives, they've not been respected. And I think they appreciate it when you do show them respect, and they deserve it! (14).

Summary

As with the rural providers, Black/African American respite providers echoed the importance of community knowledge as an important component of program success. Understanding the

socio-economic status of the community members was targeted as being of special importance. Along the same lines, program developers should have awareness of the cultural aspects of those they serve, both individually and collectively. Outreach to Black/African American clients is multifaceted, achieved by culturally appropriate written material and through personal interactions. Finally, providers serving Black/African-Americans agree that gaining trust within the community is a key condition to successful programming. One unique way to achieve the trust within this ethnic group is by soliciting the support and collaboration from respected community leaders.

Hispanic/Latino Families

Diverse populations often have unique characteristics that make the development of appropriate services challenging. In many areas of the United States, Hispanic/Latino respite programs have been tailored to assist families caring for elders with dementia more adequately.

Understanding Community Language and Culture
Overwhelmingly, the staff responsible for the initiation and provision of services to Hispanic/Latino families of diverse nationalities report the need to know and understand the community to be served as a key element in effective service delivery. One individual providing care to Hispanic/Latino clients summarizes the need to know the community by saying simply, "Find out about your population…To know the community. To know who needs services and what's here and what's lacking" (3).

More specifically, there is an overwhelming need to address the language barriers present when serving a Hispanic/Latino community. One agency worker says simply, "I think the most important thing is to have a person as a staff person who is from the community and speaks the language" (50). This necessitates not only utilizing bilingual staff, but using appropriate written materials and media advertising. One staff member identifies communication as the foundation of service development:

> Definitely the first thing that you would need in place as far as I could think would be an outreach worker who is fluent, very fluent in both languages. Not only the spoken, but the written because there's a lot of translation in the written word also (44).

Providers also recognize that even within Hispanic/Latino communities there can be diversity that should be addressed. When speaking of the level of Spanish translation required to meet these needs, a provider asks,

> What level is high enough, what level is too high? Do we use Castilian Spanish? That would be ridiculous. But, you know if we use Spanish that is too slangy, will we offend some people? Are we using words that are used in Mexico but not in El Salvador? That's really hard (5).

While it is agreed that common language is important in developing services targeted to this population, understanding the community goes beyond the language issue. Language is a significant, but not the only, element relevant to creating services that Hispanic/Latino recipients will use. The culture needs to be acknowledged holistically in order to understand the family appropriately. For families in a particular community the provider should "know what their culture is and how they handle [issues], how they view illness in the family and who is responsible for their care"(42).

Learning About Community Cultures

Country of origin and length of time in the United States can also impact how services should be rendered, since both influence the acculturation level in a community. One service provider in California summarizes:

> You know, are you dealing with a population who have been in the United States for four generations? That's a very different outreach pattern than you are dealing with [in] a population which is a recent immigrant (5).

The same provider also speaks about the unique origins of families across different Hispanic/Latino communities. She emphasizes the need for accurate assessment of the target population. When speaking about the differences in providing services for Latinos of Mexican descent she states,

> Now if you were working, let's say, in Miami, you might be working with people who are of Cuban descent, or perhaps South American decent. There are language differences, there is a difference in that community's history in the country, there are acculturation differences, and there are socioeconomic differences and educational differences that really, really, really, come into play (5).

One strategy for obtaining staff people with the unique cultural knowledge required to serve the community effectively is by seeking out persons from the community itself. These community individuals may be able to serve as actual staff members or as advisors on boards or committees. A provider explains how both community leaders and caregivers aide in the recruitment and support of new clients.

> [Key leaders] help to reach the Latino community, they give you information how to reach them and I also have caregivers, they bring ideas and activities and they talk to people who have Alzheimer's or memory problems, so what I have is community leaders, caregivers…to help in the committee (13).

Another service provider is able to summarize the significance of culturally appropriate services and staff members by cautioning against "…taking someone from an Hispanic background and an Hispanic culture and popping them into your American idea and saying…fit in" (44).

Another issue, which relates to the ability of an agency to effectively provide services, is the awareness of the socioeconomic status of the clientele. Providers sometimes find that residents of particular areas share a similar income range and standard of living. In many respects, these characteristics can transcend ethnic cultures, providing a common experience for all residents that must be addressed by service providers in order to deliver care effectively. Public financial resources may be available for those that qualify. One provider suggests that knowledge about the community can make a financial difference. "If you are working in the lower income areas, then this population may qualify for in-home supportive services, Medicaid, SSI, things like that" (6).

Raising Awareness and Building Trust
In addition to the development of appropriate services, the ability to reach potential clients can be a serious challenge in some communities. Many providers discuss the importance of finding ways to notify individuals in need of the services. Taking advantage of other institutions that are already established in the community offers service agencies a way to communicate offerings to the targeted group, and helps them gain credibility with the clients. One staff member reports the effectiveness of outreach by identifying the places frequented by potential service recipients.

> …and they did intensive outreach, bringing clients to the door through the Spanish Mexican restaurants and through the Spanish radio and some Spanish newspapers in the areas and the Spanish focused grocery stores and it was amazing (43).

The issue of trust repeatedly occurs as respite providers explain the important elements of successful services. There are several key components in the process of developing trust, one of which is respect. One provider reports that respect is critical to creating a trusting environment, particularly, "…respect for this culture that you are interacting with…That definitely helps establish trust" (44). A trusting relationship does not always occur quickly, but respect can be demonstrated over time. "They are not going to want to put their trust in someone who isn't

showing them that they can be trusted" (44). Another staff member describes the importance of respect and the lack of trust observed in some instances,

> …this is a basic tenet of customer care, is to treat people with dignity. Truly you find so many people who are humble people, and they're treated with such disrespect simply because they look different, their health is poor, they can't speak the language. That's not the case with our organization…(45).

Honesty is another essential antecedent to establishing a trusting relationship with clients. One staff member speaks about honesty in this way, "Just be open and honest with them. Tell them what you can do and what you can't do"(3). Another provider echoes the importance of honesty:

> I think keeping your word. If they come to you, and you tell them that you're going to hook them up with a support group, keeping your promise and giving them that resource (support group) as soon as possible. Or if you don't have access to that, just being honest with them…(7).

As with the other providers, Hispanic/Latino respite providers echoed the importance of community knowledge as an important component of program success. Given the diversity of this population the value of such cultural knowledge of language, beliefs, protocols, and more of each nationality cannot be overstressed. Additionally, the issue of language diversity must be addressed. As with other groups, building relationships based in honesty and respect are also crucial elements in developing successful programs.

Key Strategies

Providers, from all communities, agreed upon certain common requirements for creating quality programs. Each group recognized the importance of developing services that are understanding of and sensitive to the culture and characteristics of the target community. Staff members capable of communicating in the same language as the care recipients are fundamental to the success of culturally diverse respite programs.

In rural areas, providers stressed the importance of building awareness of respite programs among their communities. Relationships with clients need to be built on trust, support, and consistency. Also, providers need to understand their areas as well as the cultural preferences of their community. Similarly, providers within Black/African-American communities also confirm the need to be aware of their communities and the other resources that may be available for

caregivers. These staff members also see the importance of building trust. They suggest working with key community leaders. Additionally, providers in Black/African-American communities stress that cultural appropriateness of materials and personal interactions is vital to these families as well. Providers targeting Hispanic/Latino elders echo analogous sentiments. In addition to needed outreach and community education, building trust, creating clear expectations, consistency in service delivery, these providers stress cultural and language issues. Specifically, providers in Hispanic/Latino communities emphasize the significance of understanding the diversity of both culture and language within this multi-ethnic population.

SUCCESSFULLY DELIVERING RESPITE SERVICES TO DIVERSE POPULATIONS

Demonstration providers have offered the benefit of their experiences in successfully serving diverse populations. Many have noted specific strategies for outreach and service development. Others have explained key cultural issues necessary for understanding the beliefs and needs of their target populations.

The earlier Research Question sections have facilitated a broad discussion of some of the essential service delivery topics providers have identified and addressed. The following section will summarize the important issues by cultural group.

Serving Rural Communities

Providers in rural communities stress the importance of understanding that these areas do have their own geographic culture. In general, rural individuals are relatively isolated and have fewer opportunities for education, medical care, and other services. There is a tendency to rely on oneself, one's family, and one's church. The relationship to family and church are very strong and central within rural communities.

Perhaps because of the size of the communities, there is an enhanced level of familiarity among residents.   Even though rural areas are more homogeneous than many urban areas, discrimination does still exist—sometimes based on race, other times based in "outsiderness". There is a distrust of outsiders, including service staff, service agencies, researchers, and government institutions.

Views of Alzheimer's Disease

Alzheimer's disease is most often seen as mental illness or as normal aging. Families commonly respond with denial, fear, and embarrassment when their elders exhibit dementia symptoms. Specifically, in rural areas there is a lack of general knowledge and understanding of Alzheimer's disease. As there are few informational resources, most families are dependent upon their family doctors for dementia specifics. Unfortunately, rural physicians, especially those who have been practicing for a number of years, have little training in Alzheimer's disease and the possible treatments.

Views of Support Services

Most providers found a general lack of understanding of just what "respite" is and a limited appreciation of the value of dementia-specific services among their clientele. These observations were not limited to rural areas. Providers within rural communities, like their urban and ethnic counterparts, faced the prevalent notion that family care is better than professional or paid care because of the emotional ties of the familial relationship. Families of all cultural groups expressed guilt at using services, embarrassment about the behavioral symptoms of Alzheimer's disease, as well as anxiety and trust issues in letting someone else provide care. Providers also reported that younger caregivers, regardless of their family relationship or ethnicity, were more receptive to service use than older caregivers.

In rural areas and especially with less educated families, providers had to address the stigma that support services are a form of welfare or a public handout. There is also a general distrust of the government and of any service programs that are affiliated with government programs.

Staff Issues

Rural clients prefer staff members of similar ethnic backgrounds and to be familiar members of the community. Religious affiliation and similar gender (i.e., male attendants for male care recipients) are also important in establishing comfortable service provision. However, providers have found that the value of respite to caregivers can outweigh other issues. Once families believe that services are of high quality and beneficial, they are less concerned about the ethnicity and background of the person delivering them.

Retaining good aides is a challenge even in rural areas where other employment opportunities may not be as plentiful. Providers recommend using some form of recognition and reward for those aides that excel.   Team meetings that build team support and allow for aides to provide

input into the care plan were also seen to be helpful in promoting quality care and enhancing staff moral.

Identifying and Addressing Barriers to Service

For those providing services in rural locations, transportation, cost and funding, and agency staffing difficulties are among the most common barriers to service usage. Additionally, lack of physician understanding and referral plus a fear of bureaucracy by the potential clients are frequent dilemmas. Rural residents also have a belief system that values independence.

Many rural barriers can be addressed through innovation and responsiveness to client needs. For example, due to rural families' desire for self-sufficiency, they may view assistance as a relinquishment of their responsibilities, or a government handout. Providers can address this when approaching caregivers by emphasizing that respite care is complementary to, rather than a replacement of, family care. Providers can also attend to the concern that respite is a handout by charging a nominal fee for the services. Additionally, providers can focus on empowering families within their relationships with their physicians in order to address the lack of a diagnosis or medical explanations.

The small size of most rural agencies allows providers to address challenges by individualizing care plans. Program responsiveness (such as matching clients with familiar aides) can be crucial in developing services with which families can be comfortable. Finally, rural providers need to be creative in devising solutions to the barriers bred by isolation. Examples include long-distance support groups and information newsletters, as well as more extensive transportation networks.

Essential Elements of Effective Respite Programs

Providers from rural service areas agree that an essential element of effective programs include developing relationships with service recipients that revolve around trust, support, and consistency. A successful program is also one whose care providers have knowledge and insight about the community they serve. Diligent outreach efforts are critical, especially given the geographic distance required to contact potential clients.

Serving Black/African-American Communities

Black/African-American communities are recognized for their strong sense of extended family and community ties. This community has a greater prevalence of working caregivers, primary caregivers who are more distant relatives, and wider family involvement in caregiving. However, providers note, there is still usually just one person that bears primary responsibility for caregiving, and simply receives input from others.

Black/African-Americans, like their rural White peers, possess great pride in their ability to remain self-sufficient and "take care of their own". They also share a pervasive mistrust of government assistance and the medical system. Spirituality and organized religion also has an important role, both to the Black/African-American community in general, and as a support structure for individual caregivers. The concept of respect among community members is also highly valued, due to past injustices.

Views of Alzheimer's Disease
In Black/African-American communities, providers note that families seem to take the challenge of Alzheimer's disease in stride and are more realistic in dealing with the related care tasks. Additionally, this community shares the mistaken belief that the behavioral systems are signs of "craziness" or other mental illnesses. Other times, families will assume that the dementia symptoms are natural for an older person and thus, deny the need to seek medical attention or other resources.

Views of Support Services
Though no unique views of support services were identified for the Black/African-American community, they do share a general lack of understanding of just what "respite" is and a limited appreciation of the value of dementia-specific services for their elders. Black/African-Americans often believe that family care is better than professional or paid care because of the familial relationship. Like other families, Black/African-Americans feel guilty about using services and embarrassed about the behavior symptoms of Alzheimer's disease, as well as express anxiety about letting someone else provide care. Providers also observe that younger caregivers were more receptive to service use than older caregivers.

This community is also sensitive to the view of support services as a form of welfare or a public handout. However, this was more pronounced among less educated families. There is also a pervasive distrust of the research community and government programs.

Staff Issues

Overall, members of the Black/African-American community express feelings of initial reluctance to accept a White care provider. This reluctance is related to mistrust and social mores that have been ingrained for generations. However, participation in the respite programs with individuals of diverse backgrounds often facilitated understanding and trust in the multiracial settings.

Providers within the Black/African-American communities recognize the importance of recruiting caring and involved staff members who are familiar with the service community. Providers believed that besides education about Alzheimer's disease, staff members should receive training in the importance of patience and consistency when working with dementia clients. Because of the specific challenges associated with dementia clientele, workers should be taught about the expected behavioral changes and the appropriate communication techniques for the care setting. In addition, the Black/African American providers also include the importance of teaching staff to address the clients respectfully as Mister or Misses.

Recognizing and rewarding exemplary work by agency staff and team meetings have been seen to enhance staff retention.

Identifying and Addressing Barriers to Service

Providers within the Black/African American communities face structural barriers to providing services: scarce funding, distrust of government services, and suspicion of the medical research community. Additionally, it is often difficult to locate and educate caregivers due to the pervasive denial or delay in seeking services that takes place.

Providers who serve Black/African-American clientele have found ways to make services more effective for their target populations. Respite services are discussed in terms of supplementing, not replacing, family care. Since Black/African-American families often want to keep care within the family, providers work to provide services in a friendly, home-like manner that does not

suggest institutionalization. Providers rely on familiar activities, often based in music or religion. Programs with social names, like "club", are more likely to be accepted by the community.

Support groups can be better received by combining them with a potluck dinner or luncheon. Providers can also individualize services to better meet caregivers' needs. The prevalence of working caregivers in the Black/African-American community has led some providers to conduct seminars within large workplaces, or to extend day care hours to accommodate busy schedules.

Essential Elements of Effective Respite Programs

Providers within Black/African American neighborhoods stress the importance of understanding their community in developing appropriate services. Understanding the socio-economic status and needs of the community members was targeted as being of special importance. Along the same lines, program developers should have awareness of the cultural aspects of those they serve, both individually and collectively. Specifically, outreach materials and interactions need to be culturally sensitive and tailored to the targeted population. Most important may be the need to gain trust within the community as a key condition to successful programming. A suggested way to achieve the trust within this ethnic group is by soliciting the support and collaboration from respected community leaders.

Serving Hispanic/Latino Communities

Providers within the Hispanic/Latino communities acknowledge the wide diversity within this population of many nationalities. The term "Hispanic/Latino" represents a great variety in cultures, dialects, and etiquette. Of particular importance is for providers to gain a cultural awareness, as well as language knowledge, of the community that they seek to serve. When possible, programs that "mirror" their target population are often most able to adequately provide respite.

Despite the diversity in cultural norms within the Hispanic/Latino community, each nationality places a very strong reliance on the family unit to solve problems and provide care.   Gestures of respect are considered important, and differ by group within the culture. Many clients are monolingual Spanish-speakers with relatively low levels of literacy, which results in isolation from mainstream services, and a greater valuation of one-on-one relationships with service providers.

Views of Alzheimer's Disease

Hispanic/Latinos, like the other groups included in this research, often believe that Alzheimer's disease is a form of mental illness or insanity. Additionally, they may conceive of dementia as a "curse" or a punishment for previous "bad" behavior. Other responses include religious explanations: the caregivers' cross to bear; or the elder's possession by evil spirits. Believing in curses, punishment, and possession leads individuals to seek non-medical cures. Similar to families of other cultures, Hispanic/Latino family members react with denial, fear, and embarrassment.

Views of Support Services

Agency staff in Hispanic/Latino communities mentioned that their clients' perceptions of support services and government programs had been shaped by their experiences in their former country. This results in mistrust of government services in the United States. There is also a stigma that support services are a form of welfare or a public handout in this community. Additionally, as many of these families are monolingual Spanish speakers, this language barrier inhibits their awareness of information and traditional support services as well as their ability to access them.

Like other communities, Hispanic/Latino families have a general lack of understanding of just what "respite" is and a limited appreciation of the value of dementia-specific services. There is also a strong preference for family care over professional or paid care because of the emotional component. Hispanic/Latino families expressed guilt at using services, embarrassment about the behavior symptoms of Alzheimer's disease, as well as anxiety and trust issues in letting someone else provide care. Providers also reported that younger caregivers were more receptive to service use than older caregivers.

Staff Issues

Bicultural staff members enhance the comfort level of Hispanic/Latino families. This refers to a familiarity with the community, the clients' nationalities, and speaking Spanish. There is consensus among the Hispanic/Latino respite providers that the most effective staff members are those hired from the same ethnic community. Most importantly, providers' stress in hiring and training staff members, it is important to recognize the diversity within the Hispanic/Latino community: nationalities, linguistic differences, socio-economic levels, amount of education and degree of acculturation. Additionally, providers agree on the value of recognizing and rewarding

staff members for their skill and expertise. Providers also see merit in regular team meetings to build team support and morale as well as to give all staff members an opportunity to have input.

In general, providers within the three cultural groups under study had similar advice on hiring and training of quality staff members. All providers recognized the importance of recruiting caring and involved staff members with knowledge of the service community. Training should include education about Alzheimer's disease, the importance of patience and consistency when working with dementia clients, difficult behaviors, and respectful communication techniques for the care setting.

Identifying and Addressing Barriers to Service
Providers within the Hispanic/Latino populations identify the strong cultural value of family caregiving, a pervasive mistrust for the government, a preference for folk or home remedies, and difficulties maneuvering through complex bureaucracies as barriers faced by these communities. Additionally, many Hispanic/Latino families do not value Western medical treatments and if they do seek care from a physician, they are often not diagnosed appropriately. In every setting, language represents a significant barrier to service use for this group.

Providers have developed techniques to address resistance to service use that are specific to the Hispanic/Latino culture. At the initial encounter with a family, providers reassure families both that they are not alone in dealing with dementia, and that seeking assistance should not be considered selfish or neglectful of familial duties. Providers also try gently to dispel myths about the effectiveness of folk medicine, without insulting these traditional beliefs. They address other institutional barriers to use, such as mistrust of bureaucracy, by providing assistance with filling out forms and applications, and helping families negotiate the system.

Providers also tailor the services, the materials, and their personal interactions to be appropriate to the Hispanic/Latino cultures. Services must be bilingual, and preferably with bicultural staff members. Providers find it helpful to offer traditional food, and to celebrate national holidays of their clients' home countries. Additionally, providers develop service activities around social themes in non-institutional settings. Support groups are referred to as "clubs" or "tea-time".

Essential Elements of Effective Respite Programs

As with the other providers, Hispanic/Latino respite providers echoed the importance of community knowledge as a key component of program success. Specifically, providers in Hispanic/Latino communities emphasize the significance of understanding the diversity of both culture and language within this population of many nationalities.

Providers targeting Hispanic/Latino elders stress the importance of developing culturally appropriate materials and activities. In addition to needed outreach and community education about Alzheimer's disease and respite services available, building trust, creating clear expectations, consistency in service delivery, are significant. However, language and cultural issues remain core components of a successful program.

IMPLICATIONS FOR SERVICE PROVISION

Providers from the ADDGS project have offered specific and detailed advise for those who wish to develop acceptable and appropriate services for diverse populations. It is clear from the interviews, that each provider has a wealth of experience to share about their service communities. Yet, in spite of the diversity of these populations, several general recommendations can be identified that are pertinent to all families and areas.

General Lessons for Service Delivery

- Become familiar with your service community!
    - Get to know both the culture and language of the community.
    - Become aware of other available resources and services.
    - Understand the issues related to service use, such as socio-economic levels, education, employment status, and other key factors.
    - Understand family structures and caregiving beliefs.
- Develop Appropriate and Responsive Service Programs!
    - Use culturally appropriate materials and activities.
    - Hire and train bicultural staff members (from the community if possible).
    - Individualize care plans when possible.
    - Match hours available to caregiver needs.
    - Create homelike environment with friendly, welcoming staff.
    - Use "socializing" context for support groups.
    - Use "sliding fees" to negate "welfare" stigma.
- Build trusting relationships!
    - Stress honesty in interactions.
    - Create clear expectations for care with clients.
    - Follow through! Follow through! Follow through!

- o Recognize and reward excellent staff members.
- o Hold Team meetings so all staff members can provide input.
- Educate the Community!
  - o Provide information about Alzheimer's disease.
  - o Let families know about the purpose and availability of respite services.
  - o Explain the value of dementia-specific services.
  - o Inform how support services can enhance family care.

Providers also shared issues and advice unique to specific cultural groups. These service aspects, they are quick to add, are second to developing a caring, compassionate service. Understanding the community and building trusting relationships can overcome differences. However, special attention to some of the unique needs of the various cultures can smooth the transition for new service users and ensure greater satisfaction of all users. Providers offered the following lessons.

Lessons for Rural Communities

- Creativity, flexibility, and innovation are needed to address isolation, transportation needs, and lack of resources.
- Respite should be promoted as an support for, not a replacement of, family care.
- Charging a small fee can address the welfare or handout stigma.
- Focus on empowering clients in their relationships with medical professionals.
- Assign familiar aides to families when possible.

Lessons for Black/African-American Communities

- Work with key community leaders to develop trust with residents.
- Address the needs of working caregivers.
- Promote respite as an aid to, not replacement of, family care.
- Create a social atmosphere, preferably with food.
- Match workers and clients by race when possible.

Lessons for Hispanic/Latino Communities

- Develop bicultural expertise in staffing.
  - o Mirror the community, ethnically and culturally when possible.
- Incorporate folk medicine into educational approaches.
- Educate about the medical aspects of Alzheimer's disease.
- Providing familiar food and activities can create more comfortable environments.
- Reassure caregivers that they are not alone.
- Assure caregivers that using respite is not selfish or neglectful.
- Create social, friendly environments for service provision.

ENDNOTE

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[1] Each interviewee is referred to by a numeric code to ensure confidentiality of their responses.