A Qualitative Review of the Native American Caregivers Support Program: The Successes, Barriers, and Training Needs

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A QUALITATIVE REVIEW OF THE NATIVE AMERICAN CAREGIVERS SUPPORT PROGRAM:
THE SUCCESSES, BARRIERS, AND TRAINING NEEDS

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"The opinions presented in this paper are those of the authors and not necessarily those of the Administration on Aging"
ABSTRACT
Caregiving is accepted as a natural part of life and is recognized as an inherent responsibility within the American Indian/Alaskan Native community. A qualitative analysis was conducted employing constant comparative method to explain the current status of the Native American Caregiver Support Program (NACSP) funded by Title VI-C grants. The NACSP (Title VI-C) of the Older Americans Act (OAA) is administered by the Department of Health and Human Services (DHHS), Administration on Aging (AoA). The NACSP allows each tribal organization to develop a program to deliver supportive services that are tailored to the needs of their caregiver's while providing five basic types of services: information, assistance, counseling, respite, and supplemental services. This study was guided by four objectives: 1) To understand the successes and barriers that Tribal organizations have faced in the design, administration, and implementation of their Caregiver Support Program; 2) To determine if the Native American Caregiver Program, supported by Title VI-C grants, is operating according to the legislative intent; 3) To discover the degree to which the five required components are being fulfilled; and 4) To ascertain training and technical assistance needs. Consistently revealed throughout the interviews was the interplay of key factors. Instrumental in providing services to caregivers was a shared understanding among the funding agency, grantees, and consumers of the supportive services. Moreover, the level of understanding also affected trust, training, and other resources. These factors were crucial in determining the success of individual programs as well as the difficulties experienced by other programs.

INTRODUCTION
Caregiving is accepted as a natural part of life and is acknowledged as an innate responsibility within the American Indian/Alaska Native (AI/AN) community. The elder is revered as a well-respected individual within the Tribal community. Moreover, the family unit has been found to be considered the primary source of assistance to include "supportive, housing, economic, and religious/spiritual services" (Jervis, Jackson, & Manson, 2002, p.308). Typically, AI/AN individuals do not outwardly express negative feelings related to their care giving responsibilities, but this does not discount the need to support caregivers of the elderly (Kramer, 1995). Caregivers often deny their own needs while attending to the needs of the care recipient. The denial of caregiver strain is regularly observed in a variety of cultural groups including in AI/AN populations (Plowfield, Raymond, & Blevins, 2000). The term "caregiver immersion" has been coined to describe when caregivers become involved in the act of caregiving to the point that they do not care for their own personal needs (Plowfield et al., 2000). Past research indicates that increased caregiver strain may lead to a higher mortality rate for the caregiver, increased rates of depression, and a greater likelihood of reporting other physiological impairments (Plowfield et al., 2000; Schulz & Beach, 1999). The physical health problems associated with caregiving range from injuries due to heavy and frequent lifting to lower immune response due to chronic stress (Livingston et al., 1996 as cited in Plowfield et al., 2000; Kiecolt-Glaser et al., 1991 as cited in Plowfield et al., 2000). Additionally, challenges faced by AI/AN caregivers are made more difficult due to socioeconomic obstacles, geographical barriers, informational barriers, and limited culturally relevant programs and services.

In response to the growing concerns of the state of long-term care, Congress established the Native American Caregiver Support Program (NACSP) in 2000 to address the needs of caregivers (OAA, 2000). This program is designed to provide services to family caregivers who care for the elderly and grandparents who are the primary caregiver of their grandchildren. The NACSP (Title VI-C) of the Older Americans Act (OAA) is administered by the Department of Health and Human Services (DHHS), Administration on Aging (AoA). The NACSP permits each Tribal organization to develop a program to deliver supportive services tailored to the needs of their caregivers while providing five basic types of services: information, assistance, counseling, respite, and supplemental services. This study will focus on the 176 Tribes awarded the formula grant in 2002 and 2003 to establish a multidimensional Caregivers Support Program. The benefit for reviewing the current status of the Caregivers Support Program is that technical assistance, additional training, and further explanations and clarifications of federal policy can be made to improve program management service provision.

METHODS
A qualitative analysis was conducted employing the constant comparative method to illustrate the current status of the NACSP funded by Title VI-C monies. This methodology is based in grounded theory and allows emerging theories and concepts to develop (Strauss & Corbin, 1990).

This study was guided by four objectives:
• Understand the successes and barriers Tribal organizations have faced in the design, administration, and implementation of their Caregivers Support Program.
• Determine if the Native American Caregivers Program supported by Title VI-C grants is operating according to the legislative intent.
• Determine the degree to which the five required components are being fulfilled
• Ascertain training and technical assistance needs.

All Title VI-C program directors (n=176) were contacted via telephone in June 2003. Only those program directors who were available at the time or who would reschedule a call were interviewed. A convenience sample of 56 directors of 68 different Tribal programs participated in the assessment. Several program directors that were interviewed administered up to seven programs located on different reservations. Interviews were conducted until theoretical saturation was achieved and dominant themes emerged. Tribes throughout the United States were represented in the sample. Three trained interviewers administered the survey. Training consisted of one mock interview with a well-informed staff member. This session was tape recorded for future reference.

The interview guide was adapted from an unpublished survey used to assess State caregiver support programs (Feinberg, n.d.). The instrument used in the structured interviews was modified to use more appropriate language for our target group, additional questions were added to inquire about areas not included in the original survey, and questions were tailored to be open-ended. The revised instrument was piloted and changes were made after the interview. Each interview took approximately twenty minutes to complete and informed consent was obtained from each participant before the interview began. Additionally, 22 of the 56 interviews were tape recorded with the permission of the respondent.

The interview was organized by eleven subject areas: success, barriers, training needs, assessing the caregiver, educational materials, support groups, counseling, respite difficulties, grandparents raising grandchildren respite problems, supplemental services, and evaluating the program. Each area represented one facet of the legislative requirements for the NACSP. Respondents were encouraged to elaborate on any topic brought up during the interview. Within each subject area dominant themes emerged.

The authors' interpretation was corroborated utilizing two methods. First, experts in the field were consulted about the federal regulations imposed by the Title VI-C program and individuals that are well versed in AI/AN culture. Second, to determine the validity of this study, consultation with Tribal members attending a presentation at a professional conference occurred. Comment cards were distributed before the presentation and attendees were instructed to write their suggestions, comments, and questions on the cards. Both oral and written comments made after the presentation were used to check the accuracy of the authors' interpretation of the findings.

RESULTS.

The ability to provide respite services is a new endeavor on most reservations. Several program directors expressed that respite is an unmet need that had not been previously identified within the reservation communities. Most said that they were “surprised” at the extraordinary demand for respite services. Consequently, respite has been the most requested component of the NACSP. Program directors consistently referred to the relief they were able to provide for family caregivers. For example, one program director stated: “...some of the people that I give respite care for have come back and said it's been really relief-full for them and they could take the time they need to get away so they don’t get burnt out.”

Support groups were also frequently revealed as one of the greatest successes by many program directors. However, others suggested that the caregivers were uncomfortable in a support group setting. The wariness of the family caregivers impeded several programs from providing this service. One program recognized a guarded feeling early among the caregivers during the support group sessions and took action to make the caregivers feel more comfortable. They developed a confidentiality oath for each member to sign. Once the members of the group signed the agreement, the support groups provided the caregivers a safe place to communicate their feelings.
Coordination is occurring between both Tribal and State agencies to provide training, counseling, supplies, and additional sources of funding to expand services. Initiating these partnerships created links throughout the community to establish a continuum of services: "If you know what's out there...and you work within that circle it's often easier...you're not trying to reinvent the wheel, you are part of that original wheel." Some of the most successful caregivers programs are actively seeking partnerships and are coordinating with other agencies to provide services: "...we work together to try to find resources or provide help, provide that care". The coordination is not limited to agencies. Program directors expressed their pride obtaining community ownership of their program: "what I guess I am very proud of is the fact that we're networking within the community and that way there would be ownership within that community of this program and it's gonna work then."

Several program directors were proud of the initial development of the NACSP: “The greatest success for our program has been...just the organization of putting it together this first six months. We’ve signed up about twenty-four participants.” Additionally, the concept of providing supportive services for the caregivers was innovative and most grantees had to develop an infrastructure to support the services mandated by the grant. Tribal organizations have developed policies, recruited participants, and have provided training for staff members.

The need for clarity of the program guidelines was expressed as the greatest barrier when administering the NASCP. Many felt unsure about which services were appropriate to provide using the funds made available by the grant. A general feeling of confusion and a degree of discomfort with moving ahead with caregiver services was verbalized: “I feel they [guidelines] could have been more enhanced...because this being such a new endeavor for everybody...it was pretty much poke as you go along.”

Prior to establishing the NACSP, the Tribal elders had been the sole clients for services provided by the senior programs. Misunderstandings between elders, caregivers, and providers initially occurred about who the client should be for this program. Participants also alluded to unclear guidelines, which prevented some programs from providing services. Explicit guidelines were requested during many interviews.

Both a lack of administrative and provider staff was voiced as a barrier to implementing the NACSP. The inability to fill program director positions was cited as a barrier and also stifled the initiation of the program within those Tribes that have yet to provide services. Of those programs that were providing services, the program directors indicated the need for an assistant: “I’m the only...full time staff...so I’m not able to reach and go as I want...and so I believe that will help the outreach.”

Stifled communication between grantees, grantor, and caregivers is perceived as a barrier for some program directors. Communication with the grantor also seems to stem from the lack of guidelines and understanding about the program. Grantees also requested information about the other Tribes that were awarded the same grant. They expressed the need to connect with other grantees in order to share ideas and best practices. Furthermore, communicating the purpose of the program to caregivers was also perceived as a barrier. One response indicates that they sought out other support programs. They want to know what other Tribes have tried, what has been successful, and what has not worked. This reflects both the lack of understanding about the program and the caregiver not identifying themselves as caregivers.

All program directors identified numerous training needs. The most frequently identified need was training about the program itself. Respondents suggest that there is an immense need to educate grantees how to administer the program. Past interactions with the grantor were characterized as peculiar: “…I feel like I sent this off into the great void and…I didn’t really hear much and I haven’t heard much and I have been operating on faith that everything is okay.” One response specifically wanted information about the goals and objectives of the Caregiver Support program directly from the grantor to share among program directors and their staff.

A broad array of general caregiving training was requested from the most basic concepts to training about emotional issues. Consistent themes presented by the participants included: what is caregiving, personal care skills, safety issues, and caregiver burnout. Some responses indicated that they did not know what qualifies as caregiving, what are the needs of a caregiver, and survival skills. One response requested training specific to alcoholism and...
handling emergency situations: “We have a lot of alcoholism on the reservation, a lot of alcoholism…”

For the most part existing educational materials were viewed as not culturally relevant to the AI/AN caregiver. The issue of relevant educational materials is pervasive through the native culture: “That’s always an issue and it’s so much an issue that sometimes I even forget to mention it. We’re generally used to taking materials and then having to adapt them once they get here.” Existing materials were almost always modified to address the specific needs of the caregiver. Modifications ranged from adding pictures of AI/ANs or translating into the local language. Other informal changes were made to previously existing literature such as verbal addendums and notations placed at the bottom of a brochure. Culturally appropriate videos that explained caregiver skills are in high demand amongst the Tribal communities. The available videos do not consider the dissimilar living conditions compared to the general population: “…tapes in a native setting about native[s] in native homes so that people aren’t walking into a bathroom with a big marble sink and nice lights and running water and a bathtub and a shower and a little porcelain duck soap dish. That is NEVER gonna exist in the villages.” One respondent indicated that she used no printed educational materials and solely relied on verbal communication to educate caregivers.

A few program directors did not view cultural appropriateness as a problem. They described their client base as being fairly assimilated: “I don’t think that we found that any of our folks have found that problematic… I think they could be a bit more culturally appropriate, but we haven’t noticed it as a barrier.” Typically, those program directors also resided in a less rural geographic region.

The convening of support groups varied greatly between Tribes. There were many Tribes that have a successful support group for their caregivers. The emerging themes throughout the successful groups always included a social event for the caregiver. This event varied to some extent, but always provided an activity for the caregiver that did not involve the elder. Examples of events were crafts, beading, hay rides, nature spirit ceremony, and potluck dinners. In addition to the activity, a light meal was always served. These group meetings were “disguised” under another title such as a “social hour”. The caregivers in an informal setting shared ideas, thoughts, and concerns about their personal situation when it is comfortable for them to do so. Other groups spontaneously developed once the caregivers in the community met each other.

Conversely, many programs articulated that it has been difficult to provide this service. Some indicated that caregivers continue to be reluctant to attend a group meeting: “We initially wanted to. That’s one of the things that we wanted to jump right into doing, but there was…some sort of reluctance to develop…a support group.” Others suggested that administrative and staffing barriers have prevented them from providing these services: “Well, money buys time…you know that the more money the more staff dedicated towards doing that [support groups].” Some programs did not hold support groups. Many respondents stressed that lack of time was a major factor in the decision not to have support groups: “…that is one of the things we would like to do is actually have a care giving support group up here…but sometimes it’s hard to fit 30 hours of stuff in a 24 hour day.” Furthermore, having support groups on some of the reservations was not realistic “…it’s probably not practical I mean you already got problems with everybody knowing everybody, everybody related to everybody it probably will never happen.”

Respite is the service provided most often by the NACSP. Respite services are most often provided either within the caregiver’s home or the elder’s home. However, some programs are offering adult day care and institutional based respite services. Many programs are placing limits on their respite services. These programs place either a financial cap or time limit on how much respite services they will provide. Others, especially those coordinating with State programs have a stipend for respite services. The most common barrier to providing respite services was reported to be funding. Responses signify that additional funding is needed to provide respite services to fulfill the demand. The requests for respite care seems to have far exceeded the current funding level. Other problems brought to light by the program directors were the lack of qualified respite workers on the reservations. This problem was further described when queried about training needs. The responses from the extremely rural reservations explained that the geographic location created a barrier for respite workers: “…a lot of time for the special care it’s a two hour one way trip to take them into town so it is a lot of transportation needs.”
Although respite services are provided, program directors reported that, some elders and caregivers did not want respite services. One response proposes that administrative barriers to receive respite services are too inconvenient: "...they think it's just too much paperwork. Too much hassle. They would rather pull one of their relatives in and they'll watch them while they come in or they'll just bring them with them." One response suggests that the caregivers do not understand the program well enough to request respite services. Elders are also refusing respite workers because they are unsure about the program and do not want strangers in their house. Some respondents specified that elder's particularly did not want non-Indian respite workers.

DISCUSSION

Findings suggest that the establishment of a caregiver support infrastructure in a native context accentuates the challenges faced by other program administrators attempting to implement a similar program. Consistently revealed throughout the interviews was the interplay of key factors that were crucial in determining the success of individual programs as well as the breakdown of other programs. Instrumental in providing services to caregivers was a shared understanding among the funding agency, grantees, and consumers of the supportive services. Moreover, the level of understanding also affected the level of trust, training, and other resources. The Relations Model demonstrates the relationships crucial to the administration and implementation of the NACSP (See figure 1). This model is consistent with the American Indian concept of "relation" in that we cannot know where we started without knowing where we are in relation to everything else (Garrett, 1996, p.155).

Understanding in the framework of these findings implies a mutual understanding of the intent and delivery of services through the NACSP. In this model understanding encompasses service provision. The level of understanding has a direct influence on service provision and is also directly affected by trust, training, and resources. When queried about individual barriers, many program directors referred to the lack of understanding the basic guidelines of the program. This obstacle carried over into requested training needs. It must be noted that the amount of understanding varied greatly between programs and this observed variability is due, in part, to the lack of administrative guidelines and training from the grantor.

Although trust issues were not explicitly stated, they were implied throughout the interviews. Trust was apparent throughout those programs, including between caregivers, elders, agency, and program directors. These issues have influenced service provision. Trust became an issue in three major areas: 1) particularly in the delivery of respite services; 2) providing educational materials; and 3) support groups. While, on the face of it, it appears as if trust may be an issue for many this is their first encounter with this type of service provider. One might conclude that the hesitancy voiced by the elders is not a lack of trust, but may also be due to the unfamiliarity of the service.

Many programs indicated that caregivers were unwilling to attend support groups. The size of most reservation communities is very small, which has added another dimension to the concept of trust. Most program directors indicated that the communities were too small for individuals to feel comfortable in a group setting. Further investigation revealed that since "everyone knows everyone," individuals did not necessarily trust other members of the support group to retain confidentiality of the meetings.

Training is crucial in the understanding and administration of any program, particularly in a program such as this. The concepts of training and understanding are linked; you must have one to have the other. This effect was demonstrated in this study. Many grantees recognized that additional training about the program was essential. These grantees also indicated that the largest obstacle to implementing this program was the lack of training. This would suggest that some of the difficulties program directors are experiencing may be due to the minimal training. The extent of understanding not only stems from knowing the program guidelines, but also from well-trained staff members informed about the needs of caregivers and skills for addressing those needs.

Resources are those items that have the potential to inhibit or accelerate the distribution of services. The utilization and allocation of resources has also had an effect on service provision under the authority of this program. Resources for this discussion are defined as funding, staffing, and time. The level of funding was frequently cited as
preventing the allocation of staff and time for the caregivers program. Most program directors also indicated that their time is not solely dedicated to the Caregivers Support Program. This program is competing for the director's time with up to seven other grant programs.

The program directors appreciate the broad nature of the OAA and have encouraged Tribal organizations to tailor their programs to fit the individual needs of their caregivers. The ongoing struggle between legislative oversight and allowing enough flexibility to meet local needs is a constant battle. The successes and barriers revealed by this analysis may not necessarily be unique to the group sampled. These results have identified some important steps to consider in implementing a new program.
REFERENCES


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