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## Caregiving in Indian Country: Conversations with Family Caregivers

*The grandfather, a man in his 80s with dementia and other health problems, stays in his bed in the living room before the picture window, looking out on the woods where he has lived all his life. His daughter takes care of him, and other family members and friends come every day to visit him. He feels honored and respected and lives in dignity and peace. Every day after school, his grandson runs into the house and jumps onto the bed excited to tell his grandfather about his day. The family gathers around and listens. The grandfather, though old and unable to take care of himself or others, is the center of the family, as it should be.*

— Story told by an Indian caregiver

### Introduction

Family members provide an estimated 90% of elder care in Indian country. Taking care of an elder is a continuation of a long cultural tradition of extended family and lifelong care for family, and is generally not regarded as being a “burden,” according to research by the National Resource Center on Native American Aging (NRCNAA). As in mainstream communities, Indian family caregivers struggle with the difficulties of caregiving. In those areas where caregiver supports are provided — such as through Title VI-C of the Older Americans Act — services include training on the care of a frail person, support groups, counseling, and respite care. Respite care is the most commonly used caregiver service. Several family caregivers interviewed for this paper report little or no assistance from their tribal leaders.

Lack of knowledge about available services and an inability to access services offered in mainstream communities can result in excessive burdens on family caregivers. Without the availability of and timely access to services, Indian caregivers are susceptible to burnout and

their care recipients are put at risk of institutional placement. Barriers to the provision of long-term care in the home (Home and Community Based Services or HCBS) include lack of funding for services in Indian Country that are provided by tribes to tribal members, a lack of knowledge of how HCBS works, state prohibitions against hiring family members for care, state requirements that place entry or “access” points through non-Indian offices and individuals, a general lack of information among eligibility specialists about income and assets in Indian Country, a shortage of professional caregivers who are native, and lack of transportation to receive services. Other barriers include the impact of drug and alcohol abuse on younger family members, smaller family units because of job-related migration, and the inability of family providers to pass background checks.

### **What Caregivers Need**

To understand caregiving issues for American Indians/Alaskan Natives (AI/AN), it is important to understand two trends, according to Kay Branch, Elder Health Program Coordinator, Alaska Native Tribal Health Consortium:

- 1) AI/AN families want to care for their elders and the elders want to remain in their homes and have family care for them as long as possible.
- 2) There is an out-migration from the reservations to urban areas for jobs, thus reducing the availability of working-age caregivers for elders.

AI/AN caregivers are less likely to voice their difficulties to the same extent as those in the general population, probably because caregiving is seen as part of family life and not as a “burden” (NRCNAA, 2004).

Nonetheless, research shows many Indian caregivers are on the verge of caregiver “burnout”—the inability to effectively continue to care for someone (Colerick, 1986).

“Caregivers need education and training to help them manage the complex health needs of their elders,” according to Dr. Bruce Finke, MD, an Indian Health Service (IHS)/Nashville Area Elder Health Consultant. “They need help with coordinating care and navigating the health system to meet their elders’ needs.”

Indian caregivers are under both financial and emotional distress, according to one community service director in Oklahoma. For instance, some cannot afford the expense of gasoline to take an elder to the doctor, which often involves driving long distances. Not being able to meet simple needs such as medical care makes caregivers feel less successful in their roles.

Focus groups previously conducted with family caregivers of frail elders from five tribes identified the following caregiver concerns: anxiety about managing in-home medical care, problems in dealing with psychosocial aspects of care, strains on family relations, and negative effects on personal health and well-being (Hennessy, 1996). Caregivers said they would like caregiver training and support groups, enhanced care coordination, adult day care services, and respite.

Indian caregivers face a range of problems and emotions in their roles as caregivers for relatives or friends, based on recent telephone conversations with a small number of Indian family caregivers designed to get a sense of their perspectives. These emotions include dissonance between pride, resignation, worry, daily satisfaction, impatience, anger, and guilt. Most were aware of cultural traditions around home caregiving and expressed satisfaction that they were fulfilling an important role. Many reported the need for “someone to talk to,” whether for medical advice or caregiving needs. Some expressed the difficulty of balancing their own personal and medical needs (exercise, not missing appointments) with those of the care recipient.

Most of the interviewed caregivers were taking care of their parents or a grandparent. A few were taking care of a sibling or a friend. Frequently, caregivers reported their roles as “serial,” having cared for other family members or friends prior to their current situation. Many caregivers faced their own health problems, including serious heart disease, diabetes, or physical disabilities such as amputation.

### **Caregiver Viewpoints**

Most caregivers said they were proud or happy to help someone and felt good about it. “She took care of me when I was younger,” a caregiver from Laguna Pueblo explained. “I’m proud of how I deal with myself,” a caregiver in New Mexico said. An Indian caregiver in Oklahoma stated, “I feel like I’m helping somebody.”

Some caregivers expressed sadness at seeing their relative grow frail. One Blackfoot caregiver said that his emotions ran “the whole gamut—in some ways it is sad to see the rapid decline, but I’m also happy and proud we were able to maintain him at home for so long.” Another said he did not feel sad because caregiving had become normal to him. One person admitted to getting angry sometimes and three said caregiving was “overwhelming.” Another Laguna tribal member said, “I’m burned out. But they’re my parents, I’ve gotta take care of them.” “I deal with it the best I can,” another caregiver explained. “It takes a lot from you.”

A small number of the caregivers said they had never expected to be in this role and one said, “I had expected it, but not like this.” A couple had expected to care for their parents, but had never anticipated they would be caring for an aunt or a friend.

A few caregivers reported juggling a job with their caregiving tasks. Others indicated they had either quit a job or turned down job opportunities, left school, relocated, or moved back to the reservation to take care of their family member.

## **Types of Assistance Provided**

The types of assistance provided were fairly similar for all interviewed caregivers: cutting wood, shopping and preparing meals, cleaning house, taking the care recipient to appointments, giving baths, assisting with toileting, and lifting and turning the elder over in bed.

A few reported that these activities sometimes required significant physical strength, because the care recipient was disabled. “The professional home caregivers that come out are usually elders, too, and they’re not strong enough to lift my mother out of her wheelchair either,” said one caregiver, who is himself disabled.

A few caregivers said they receive respite care from other family members so they can do shopping, but many said they “do it all” without assistance from others.

## **Community Services**

The caregivers were asked if they knew what community supports and services were available, what these services were, and if they had used them. Most indicated they were aware of available services, although some were not sure about the availability of specific services. However, some said they were not aware of existing services.

Responses about specific services are below.

**Respite Care.** Respite care—temporary assistance that allows the primary caregiver to take a break or run errands—was generally provided by other family members, although most said it was offered by professional service providers in the community. One person said they would not use respite care if it was available.

**Transportation Services.** These services were sometimes available, but the need to arrange for transport two to three days in advance and sometimes pay for the service meant that many caregivers provided transportation themselves. One caregiver said the Laguna tribe

provides a shuttle for appointments. Another said she did not drive and a third said she did not have a car. Several caregivers indicated skepticism about using transportation services, saying that tribal transportation van schedules conflicted with their own job or home requirements.

**Support Groups.** Most respondents said they would participate in Talking Circles (support groups) if they were available, but a few said they would not have the time. Only one indicated that Talking Circles were already available.

**Adult Day Care.** Some caregivers use adult day care services, but these services are often unavailable in many areas. One caregiver said his parent does not like to go to adult day care, but another said, “My mom would love it.” Reasons given by care recipients for not wanting to go to adult day care included the following: they were too tired, the food was not cooked right, they did not like the van, it was too cold to go out, or other attendees complained too much about their aches and pains.

**Assisted Living.** A few respondents said they would not put their family member in assisted living; other respondents indicated they had already done so, but the family did not like it; others said assisted living was not available; and some did not know if it was even available.

**Home Health.** In some areas, home health care services were not available; others indicated that home health care had been used for a parent. An Oklahoma caregiver said, “The Cherokee Nation offers home health and respite care.”

**Nursing Home Care.** Several respondents said nursing home care was available. One caregiver had a parent in a nursing home and was paying privately for the care. Another said he would like to use a nursing home but did not want to pay for it. One caregiver said a nursing home “would provide better care than we do.”

**Other Services.** Most of the caregivers said they did personal care, housekeeping, and shopping themselves and did not need home modification. One caregiver said he would really like to have personal care services made available. Another said the wait for home modification services is too long.

In Oklahoma, adult day care, home care, medical transport, and other services were provided through the tribe's Program for All-Inclusive Care (PACE) program. PACE is a model of care that provides comprehensive care and services in the community to seniors with long term care needs. However, "income is often a barrier" for participating in PACE, as the elder must need a nursing home level of care to qualify for PACE home care services. "We also live in an area where people ask for help when they could be helping themselves," said another caregiver in Oklahoma.

Many services were only available to those who met low-income eligibility requirements or through a Medicaid waiver program. "It would have been nice to have services without resource eligibility requirements. We were limited by almost every requirement," one caregiver commented.

"Both transportation and CHR (Community Health Representative) service providers need to speed up their processes," one caregiver said. "It takes three to four days for them to get back to you."

### **Community Needs**

Asked what most Indian caregivers in their community need, respondents cited more flexible respite care, personal care without having to qualify for Medicaid, transportation without cost, and adult day care. Several caregivers said they want programs where the family caregiver can be paid for their caregiving time. "That would help a little," one said.

## **Quality of Care**

Surprisingly, several family caregivers said the available services used professional caregivers who themselves seemed too old to provide the services. “The helpers are too old to do personal care,” one said. “The personal care worker herself uses a cane, so I don’t ask her,” another commented.

One caregiver said, “CHR nurses are overworked and can’t always help.” One caregiver said he would use respite care if it could be provided by a “healthy person.” “Most people that the tribe sends are older people, almost as old as the care recipient. They need younger people. The paid people aren’t really trying to help her.”

Most caregivers said they had not received any special training for their caregiving tasks, and many of them stated they did not need any training. Those who would like training mentioned the need for help with dementia care, personal care, medications, and medical procedures. One person said they gained some useful caregiving knowledge when their parent was in a rehabilitation hospital.

Asked if a tribal or community professional had met with them or visited to assist with caregiving, eight caregivers said “no.” One caregiver said her support group had asked the tribal council to come, but the council was too busy.

A few people reported regular visits by a medical care professional for the elder.

## **Caregiver Needs**

Asked what they most wanted, respondents cited appreciation, transportation, and respite care, less red tape, better programs, and getting paid to be a caregiver.

## **What Caregivers Say Tribes Could Offer**

Caregivers also have ideas about what their own tribal leaders could do to help.

**Subsidize caregiver support.**

- *“They should provide education and funding.”*

**Be more involved with elders.**

- *“Tribal leaders need to take more notice of elders and have more programs for them.”*
- *“They need to understand how to take care of older people. A lot of them are young and they haven’t taken care of anybody besides themselves.”*
- *“They should spend a day or two working at the elderly center.”*

**Address elder abuse and other elder issues.**

- *One caregiver said elders need help with financial issues and that family members could not do this because they took advantage of the elder.*

**Provide services such as adult day and respite care.**

- *“Respite care is only available through a waiver program.”*

**Be more involved in health care issues.**

- *“The tribal council is so busy with other issues, health care and elder care often go by the wayside.”*

**Operate tribal elder care programs.**

- *“Very few reservations have their own care programs. There are only three in the state of Montana.”*

These interviews revealed that these Indian family caregivers are doing their best to provide care to family and friends, have a mixture of emotions about their tasks (pride, happiness, sadness, anger), have not received much training on how to be a caregiver, and have not encountered much support from their tribal leaders and providers.

Clearly Indian caregivers can benefit from training on how to take care of an older adult, respite care to give the caregiver a break, and other services to support them. Caregivers can also benefit from services provided to their care recipient, including home health and personal care, meals, homemaker and chore services, transportation, and adult day care.

*This document is available online at [www.chronicdisease.org](http://www.chronicdisease.org), in the Healthy Aging Critical Issue Briefs section. It was written by Dave Baldrige and Nancy Aldrich. William F. Benson was senior editor and project manager. It follows two companion documents prepared in 2009 — “Caregiving in Indian Country: Tribes Support Family Traditions (<http://chronicdisease.org/files/public/CIBIndianCaregiving.pdf>) and “CDC Seeks to Protect Health of Family Caregivers (<http://chronicdisease.org/files/public/CIBHealthofFamilyCaregivers.pdf>) — which summarizes the knowledge of professionals who work with American Indian/Alaskan Natives. After consultation with the Indian Health Service, it was agreed that it would also be useful to create this document, which reflects the views of Indian caregivers themselves. Both documents as a package provide valuable experience and knowledge about AI/AN caregivers.*

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