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Caregiving in Indian Country: Tribes Supporting Family Traditions

Spiritual Message to America: (excerpt)

*We pray that children will honor and respect their Elders—
that is where the wisdom comes from. This respect will not allow forgotten Elders.*

— More than 1,200 Elders from 105 tribes across America contributed to this message,
created at the National Indian Council on Aging's Year 2000 Conference

Introduction

Family members provide an estimated 90% of long-term care in Indian country (IOM, 2008), yet there has been little research about these caregivers, the people they care for, or their need for assistance and support. Taking care of an elder is a continuation of an ancient custom of extended family and lifelong care for family. But that tradition may now be colliding with new realities as more Native people live off their tribe's reservation, have more chronic health problems such as diabetes and obesity, and are less connected with tribal traditions and supports. Those factors are compounded by chronic and persistent poverty among American Indian/Alaskan Native (AI/AN) people. The poverty rate for AI/ANs (25.3%) is double that for the nation as a whole (12.7%), according to 2007 Census data.

In addition, caregiving terminology is often unfamiliar in Indian country, where people often do not identify themselves as "caregivers," do not seek "services," and think of "long-term care" as nursing homes—something to be avoided. Using these poorly understood concepts without explaining them can sometimes become a barrier that keeps families from obtaining the assistance they need.

"Caregiving is a critical issue for the Indian Health System," said Dr. Bruce Finke, MD, an Indian Health Service (IHS)/Nashville Area Elder Health Consultant for the Chronic Care Initiative. "We know that elders prefer to stay at home and in their communities and for most elders that is absolutely the best choice, both for their health and for the health of their family and community. The challenge for Tribal, IHS, and Urban Indian health programs is to identify and develop services that will support frail elders to live with their families, in their communities," Finke said.

Nationwide, caregivers tend to find themselves dealing with anger, resentment, guilt, depression, financial difficulties, isolation, and conflicts with family and work. However, AI/AN caregivers are less likely to voice their difficulties to the same extent as those in the general population (NRCNAA, 2004), probably because caregiving is seen as part of family life and not as a “burden.”

Like all caregivers, AI/AN caregivers do appear to have significant declines in physical and psychological health (such as chronic stress and pain, depression, digestive problems, high cholesterol, and fatigue), coupled with high rates of exposure to traumatic events earlier in life, according to one study in Washington state (Ryser, 2008). The research team found this group of caregivers to be on the verge of “burnout”—the inability to effectively continue to care for someone. Caregiver burnout puts the person receiving caregiving services at risk for entering a hospital or institution (Colerick, 1986). Yet research shows that early community supports can help keep caregivers in that role longer.

“The health system needs to attend to the health of the caregiver, recognizing and treating the symptoms of stress that are often part of caring for a frail and valued elder,” Finke said.

Clearly AI/AN caregivers, like those in the nation as a whole, 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 respite care. This Critical Issue Brief looks at caregiving issues in Indian country and support systems that can maintain this traditional family value.

“Caregivers need education and training to help them manage the complex health needs of their elders,” Finke said. “They need help with coordination of care, to navigate the health system to meet their elders’ needs.”

AI/AN Statistics

More research needs to be done on the aging of the AI/AN population, health concerns, and caregiving issues. “It is very difficult to generalize findings for this population, because they are so diverse” and the study samples are so small and involve unique tribes, explained Dave Baldrige, Executive Director of the American Association for International Aging and former Executive Director of the National Indian Council on Aging. “Research done on Plains tribes caregivers will not apply in Arizona or the Northwest,” he said.

Below are some basic statistics on the AI/AN population, elders, and caregivers:

Aging Population. There are an estimated 264,666 AI/ANs age 65 and older and they represent 6% of the AI/AN population, according to the 2000 Census. It is estimated that the American Indian elder population is growing just over 14% between 1995 and 2030, more than doubling the number of persons likely to need long-term care (Redford, 2002). Half of AI/AN elders live on reservations

(Redford, 2002).

Health Status. Older AI/ANs were less likely to rate their health as excellent or very good (24.2%) than were older whites (40.9%) in 2006, according to the U.S. Administration on Aging.

Chronic Disease. Diabetes and arthritis are the most prevalent chronic diseases among older AI/AN adults (Goins, 2005). In some AI/AN communities, more than half of the elders have diabetes. The AI/AN population also has a disproportionately high prevalence of obesity, according to the U.S. Centers for Disease Control and Prevention (CDC). All of these conditions can lead to functional limitations and the need for assistance.

Functional Limitations. Some studies show that older AI/ANs experience much higher functional disability rates than other U.S. racial groups. Data from the 1992-1996 Medicare Current Beneficiary Survey found that 30% of older AI/ANs had a limitation with at least one activity of daily living compared to 17% of their white counterparts. Another study, using 2000 Census data, indicates that AI/ANs over age 65 reported disability at a rate of 57.6%, compared to 41.9% for all people over 65, although there are regional differences (Moss, 2006).

Cognitive Impairment. Dementia care comprises a large part of elder care in the nation as a whole—an estimated 9.8 million caregivers care for someone with dementia nationwide. The incidence of dementia in the AI/AN population is not known. “We do not even know how many might be suffering from dementing illness, let alone what should be done for them,” according to Mario Garrett, PhD, Professor & Chair of the San Diego State University Gerontology Department.

Alzheimer’s disease as a cause of death in older adults ranks higher in the mainstream culture (the 7th leading cause of death) than in the American Indian population (11th leading cause of death).

Long-Term Care (LTC). The need for long-term care among the AI/AN population age 75 years and older is expected to double over the next two decades (Goins, 2005). A recent survey of tribal leaders found that 62% reported discussions within the past year about developing LTC services, 40% indicated that their tribe has statistics or information on LTC needs of elders, and 29% indicated that their tribe has an agency or office responsible for developing or providing LTC programs (Goins, 2008). The most commonly available tribally operated services were home maintenance/repair, wellness/disease management, home modification, and senior centers. Tribally operated services that were most often reported as having insufficient funding were durable medical equipment, translation service, speech therapy, and financial planning.

Mortality. Mortality among AI/ANs has been similar to the rest of the nation: heart disease, cancer, and stroke were the leading causes of death in 2004. However, Census data for 2005 showed the leading cause of death among AI/ANs were 1) heart disease, 2) cancer 3) unintentional injury, 4) diabetes, and 5) stroke.

Life expectancy. Life expectancy for AI/AN populations is below the national average, although it rose from 64 years in 1972 to 73 years in 1994 (IHS, 2000). A longer life span for AI/ANs also means they are living longer with functional disability (Moss, 2006).

Caregivers. There are few studies on caregivers in Indian country. One study indicated that the average age of an AI/AN caregiver is 50 (Hennessy, 1998). Another study, looking only at North Dakota Indians, found the typical caregiver was somewhere between 45 and 54 years old, female, and taking care of a spouse or mother over the age of 60 who had physical disabilities or cognitive impairment (NRCNAA, 2004). About 16.4% of the general U.S. population is caring for an older adult, compared to 17.6% of the AI/AN population (McGuire, 2008).

Long-Term Care

Many people think of nursing home care as the only form of LTC. There is actually a “continuum of care” that includes home and community care (congregate meals, adult day care, home visitations, and transportation assistance), senior housing, assisted living, and nursing home care. Some Indian communities provide this continuum of care, but there are many gaps, which vary by community, explained Spero Manson, PhD, Professor and Head of American Indian and Alaska Native Programs at the University of Colorado Denver.

LTC provides an array of medical, personal, and social services to support frail elders who need assistance with Activities of Daily Living, commonly known as ADLs. ADLs include bathing, dressing, feeding, toileting, and transferring from bed to chair. Instrumental ADLs (IADLs) include activities such as shopping and meal preparation, housework, transportation, and managing bills and medications. A person often needs assistance with IADLs before they need assistance with ADLs.

The care can be provided in the elder’s home, or in an institution such as a nursing home or assisted living facility. The goal is to provide elders with good quality of life, maximum independence, and dignity. In AI/AN communities, the LTC system strives to include cultural values of the people served. Home and community-based services are preferred by elders and their families over institutional care.

“Frail elders and their caregivers need to have ready access to their care team. They need to know that when the health status of their elder changes, they can get the help they need, when they need it, from the care team that knows that elder,” Finke said.

Long-Term Care in Indian Country

The key to understanding LTC in Indian country is to recognize the role of elders in the family and the community. “Traditionally, Indian culture across the board, like many aborigine cultures, has valued the wisdom, the experience, and the knowledge of its elder citizens,” Baldrige said. “These

values are so deeply inculcated into tribes and tribal communities that it is one of the universal values of Indian country. It is very different than we would see in a mainstream community.”

The term “elder” has a special meaning in Indian communities, because it is related to “that person’s contributions to their community, to their perceived value and wisdom,” Baldrige explained. “There are a lot of cultural implications in an Indian community’s definition of elder, versus the federal definition, which is based on age,” he added.

“Elders are seen as the keepers of tradition and the knowledge of the tribe, they are esteemed in the family and in the larger community, and they hold the tribe together. If you can keep them in the family, then you keep that family tradition going,” explained Yvonne Jackson, Director, Office for American Indian, Alaskan Native and Native Hawaiian Programs at the U.S. Administration on Aging.

American Indians may be reluctant to seek LTC due to cultural barriers, poverty, the belief that the needs of other family members or the community are more important, or the belief that spiritual needs are more important than physical needs (Goins, 2005). There are other barriers to long-term care: lack of funding, a shortage of professional caregivers, and lack of transportation to receive services.

“If the tribe has a lot of LTC services that it delivers and provides, then people are more apt to use those services than those provided outside of the tribal service structure,” explained Turner Goins, PhD, Associate Professor, Department of Community Medicine, University of West Virginia Center on Aging.

“I don’t think much is straight forward in our understanding or the circumstances surrounding the health and well-being of older adults in our communities,” Manson said. “We have this set of conflicts between how important these older adults are to us and our families and our communities. And at the same time, we recognize that they have these enormous needs and we feel responsible for addressing those needs ourselves. And we have a whole set of prejudices about formal systems of care, some of which are warranted, some of which may not be.”

Nursing Homes. The goal of supportive services for elders is to keep them in their home or community as long as is safe and practical. That is even more important in Indian country, where nursing homes are feared and associated with dying. Fortunately, the Medicaid program, which is the largest federal source of funding for nursing home care, has been somewhat moving away from facility-based care toward more home and community-based care. There are few tribal nursing homes—only about a dozen—due to the complexity of state and Medicaid licensing and certification requirements, lack of financing, and the difficulty of hiring sufficient nursing staff in rural or reservation areas (Goins, 2005). More importantly, nursing homes are the least-favored care option for AI/AN elders.

Dementia Care. Dementia care is one of the most time-consuming forms of caregiving. “This is a sad state of affairs in Indian country. ... We have nothing in place for dementia in Indian country,” Garrett said.

However, there are a few AI/AN adult day care centers that provide social and health services for Alzheimer’s and other dementia care.

Financing. LTC services, where available, are financed by Medicaid, Older Americans Act programs, state or tribal programs, or individuals. Research indicates that home health care is the most frequently needed service among AI/ANs. However, 88% of AI/AN communities surveyed by the U.S. Administration on Aging are not able to meet that demand for home health care (Jervis, 2002).

Eligibility for LTC Services

An assessment of an individual is the entry point to older adult services—finding out what services the elder needs and qualifies for. However, assessments can be costly and complex. In addition, the conventional assessment procedures strike many AI/ANs as invasive, personal, and disruptive of family values (Ryser, 2008). The assessments often do not recognize community-specific needs that are part of the traditions of AI/AN cultures.

“The closest we have to needs assessment is the work being performed by the National Resource Center for Native American Aging,” Garrett said. The Center is continuing to refine its tool for assessing the needs of elders. The tool is more relevant to tribes than traditional assessments.

Yet the assessments are important. Reluctance to allow non-Indian social workers into their homes has resulted in many AI/ANs not being assessed for their eligibility for Medicaid home care and other services. “The history and life experiences that many elders have presents a huge barrier when the access is through a white face, particularly if that face is culturally incompetent and cannot even pronounce the name of the tribe correctly,” explained Shelly Zylstra, planning unit director for Northwest Regional Council, an Area Agency on Aging (AAA) in Bellingham, Wash., that works closely with tribes.

Often state or local agency eligibility policies create walls because the AI/AN culture is not understood by mainstream staff. In many Indian cultures, it is considered rude to ask personal questions, especially about bathing and toileting. Some elders do not have a birth date because they tracked their birth by a season, rather than a day. Others do not have a birth or marriage certificate, and do not have paperwork for medical expenses and utility bills, Zylstra said. They may not have a bank account and are reluctant to disclose financial information to a non-Indian.

Questions about “Activities of Daily Living” may miss unique cultural features of various tribes, such as the importance of transportation to cultural events, funerals, naming ceremonies, and other activities. The questionnaires may not be adjusted for the additional effort needed to gather and cook

traditional foods using wood heat. Eligibility criteria often do not address issues such as Tribal Trust Land not being subject to estate recovery, tribal communities that did not pay into Social Security or Medicare, vehicles that are owned but do not run, and the fact that the limited dollars allowed by Medicaid to be put aside for funeral expenses are not sufficient in many AI/AN cultures to cover the tradition of feeding a large number of people for several days. “Elders would never even consider spending this [funeral] money on anything but their funeral, but the money makes it impossible for them to be eligible for [Medicaid] long-term care services,” Zylstra explained.

These cultural issues must be understood and accounted for in eligibility criteria, needs assessments, and service regulations.

Caregiving Issues in Indian Country

To understand caregiving issues in Indian country, 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.

Often there is a push-pull response within families as they debate whether to keep an elder at home. One family member “wants to keep grandma at home because people love her so dearly, she’s central to the family, the family defines and orchestrates itself around her, while another member realizes they need to get grandma into a care setting that addresses her long-term needs,” Manson said.

What does a family gain by keeping an elder at home? Foremost is the sense of family. It is a family role, an honored obligation, Branch explained. There is also comfort in knowing that the elder can remain at home, at the center of the family, and die there with his or her family around, she said.

Indian family caregivers are similar to non-Indian caregivers in many ways, Jackson said. They may provide personal care, assisting the elder with dressing or walking. Or they may provide household assistance with chores, medications, and transportation. “However, the resources available to them are much more limited than for non-Indian caregivers,” Jackson said. Many AI/AN caregivers have to move back to the reservation to provide care to an older adult, giving up their jobs and other benefits of living in an urban environment. The elders are less likely to leave the reservation to go where their children are because they would lose the benefits they receive on the reservation, including health care.

Caregivers provide care at the cost of their own time, money, and health, and often feel unprepared for their tasks, yet they report the satisfaction of keeping a loved one at home.

“Given the poverty in many AI/AN communities and the other kinds of challenges that face many AI/AN families on a day-to-day basis, many of those Native family members do not have resources to provide for their elders,” Manson said. The opportunities and resources to support and protect older adult family members are very stretched, he said. In some cases, the younger family members may be in need

of resources from the older members themselves, Manson explained. “Unfortunately most of the literature and public stereotype is these older adults have large extended networks that provide the care they need,” he said.

Caregiving Needs

Most elders just need someone to be there when they need assistance. In one survey, tribes reported that their elders get the assistance they need “some of the time” (40%), “most of the time” (25%), and “rarely/almost never” (33%) (Redford, 2004). The survey also confirmed that family members are an important source of care for elders. Among the responding communities, family members were available to provide assistance to elders “some of the time” (60%), “most of the time” (22%), and “rarely/almost never” (16%).

Further, the survey confirmed that the informal caregiver system may be stressed. Most (84%) of the responding communities reported that only a “few” family members assist an elder. Most communities reported either that “most” of the family members providing care to elders could use help in providing care (68%) or that “some” family members could use help (26%). Unfortunately, the types of services that responding communities said would be most helpful to caregivers (personal care and respite care) were those that were often reported as unavailable.

Another study of 345 Native communities found a wide variation in the number of potential caregivers compared to the number of potential frail older individuals (Garrett, 2008). Some communities had no potential caregivers and others had 25 or more for each frail older adult. The researchers recommended that tribes with a low ratio of caregivers to older adults consider establishing or enhancing day care centers, case management, and respite care. The authors recommended that tribes should also explore how they can coordinate transportation; develop strategies for employing caregivers from outside of their local area; and expand the Community Health Representative (CHR) system. CHR is an IHS program that promotes the use of paraprofessional tribal health workers to increase basic health education and care in Indian homes and communities.

Another example of the unavailability of caregivers occurs when an Indian elder returns to the reservation late in life. While this places the elder closer to any tribal aging resources, Manson said, it “often puts them at a distance from their children and grandchildren who might otherwise be available to support them, but have not returned to the community of origin.” In addition, tribal resources are stretched “enormously by the demands of the older adults who reside in those communities,” he said.

Interacting with Elders and Families

Central to caregiving issues in Indian country is ensuring that the care is appropriate to the culture of the particular tribe. In the caregiving services world, the term “cultural competency” means that services acknowledge the recipient’s cultural context and traditions. “Many non-Indian people are critical

to providing care at various points in the continuum of care for Alaska Native and American Indian elders, and so that underscores the need to pay attention to cultural competence of those providers,” Manson said.

Sometimes cultural differences are really just about trust, explained Kathy Correa, LNHA, BS, Executive Director, Laguna Rainbow Nursing Center & Elderly Care Center in New Mexico. “We tell the [non-Native] workers ‘when you tell an elder you’re going to do something, then you have to follow through with it’.” She also said, “I tell them, give the elder a lot of respect, come to their level, take any food that is offered. I guarantee that is all it’s going to take, that will foster the relationship and they will trust you.”

Non-Native workers need to understand that talking too much, asking too many questions, and not waiting long enough for an answer may be perceived as rudeness. In contrast to non-minority populations, AI/ANs may find a rushed encounter disrespectful because they may not place a priority on a rigid time structure. A period of silence is okay. It may take several meetings before trust and conversation begin. Storytelling and circular conversation may be used to build trust or describe symptoms. Eye contact, valued in many cultures, may not be appropriate with AI/AN elders, yet total avoidance of eye contact may also be undesirable.

Offended by these behaviors, AI/AN elders may not respond to questions and the interview process may halt before it begins, Zylstra explained.

Ideally, a caregiving program will hire staff that is of the same ethnicity as the care recipient. Reluctance to allow non-Indian social workers into their homes has resulted in many AI/ANs not receiving the personal care or caregiver support that they need.

In Washington State, the Northwest Regional Council used an Indian Health Service (IHS) Elder Care Initiative grant to fund a tribal case aide to go around with the tribal outreach coordinator and do paperwork for the elders. The team would help prepare elders and their families for a visit by the home and community services social worker — who comes with a “very white assessment” form, asking questions that no Indian person would ever ask, such as about toileting, Zylstra said. The tribal outreach coordinator reminds the elder and family that this is what they need to do to receive or continue services. In addition, the Washington Department of Social and Health Services developed a Tribal Handbook for its workers to teach how to interact with Native people. The goal is to teach social and financial workers to ask the right questions to find out if someone is eligible for Medicaid and other services. For example, if the person has multiple cars, it is important to find out if they are non-working cars that would not “count” toward “resources” for Medicaid purposes.

Caregiver Identity

AI/AN families tend not to use the term “caregiver” to describe the care they give to a family member. Ongoing research on AI/AN caregiver resilience is showing that most caregivers see this as part of their duty, part of being “Indian” to look after vulnerable relatives, Garrett said.

According to Jackson, these caregivers just say: “I came to stay with my parents” or “Mom needs help walking, so I help her walk.” AI/AN caregivers do not use concepts like “burden” or “anger” to describe their caregiving roles, although they may express things like being tired or having stress symptoms.

In some instances, the use of the word “caregiver” may carry negative connotations, suggesting that this should be a “paid position” instead of a family honor (Ryser, 2008). Thus, the mainstream approach to providing “services” for “caregivers” is likely to miss its mark altogether.

“AI/ANs are raised to think that the elders will be cared for” by the family, and do not respond to messages about “programs and services.” A program to teach a caregiver how to take care of their elder would be like a program to teach someone in mainstream America how to breathe,” Zylstra said. “Caring for elders is just one of those things you do.”

Caregiver Support

Focus groups 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). The caregivers said they would like caregiver training and support groups, enhanced care coordination, adult day care, and respite.

Caregiver support activities include training on how to take care of a frail person, support groups, counseling, and respite care so the caregiver does something else. Respite care is the most utilized caregiver service in many areas. In-home services, support groups, and counseling may not be comfortable options for many intensely private AI/ANs.

A survey of 68 tribal caregiver programs by the Administration on Aging found that the most frequently reported barriers to implementing caregiver programs were insufficient funding, a lack of staffing, geographic isolation, and programs focused on the needs of the caregiver instead of those of the elder (Ryser, 2008).

Reaching people who do not consider themselves as “caregivers” can also be challenging. That means there is a slower process to get people into programs, Jackson said. “You don’t just put out a notice and your hall fills up with people clamoring for the services.” AI/AN families need to get used to the concept, so it is not something foreign, she said.

Instead of “come to our caregiver support services,” AoA said an outreach message might be:

- Take care of yourself so you can take care of your elder
- Learn how to reduce stress in your life
- Learn how to manage your money
- Come learn how to safely help your Mom out of bed
- Learn caregiving skills

How you get the information out is important. Caregivers in Indian country are more likely to get information through tribal newspapers, and written notices and newsletters. The Rosebud and Cherokee caregiver programs talk about caregiver issues on tribal radio, Jackson noted. The Internet is not a common source of information, except perhaps among younger Indians, she added.

AI/AN caregivers are more responsive to conversational sources of information—provided via home visits, discussions at gatherings, public presentations with written summary material—rather than the methods typically used by the aging services network: radio, television, newspapers, posters, flyers and pamphlets, or information presented in “bureaucratic jargon” (Ryser, 2008).

Mainstream caregiver supports do not draw upon traditional healing practices, support customary food gathering and preparation, or utilize complementary and alternative medicines used by tribal people (Ryser, 2008).

Caregiver Program Funding

The main sources of caregiver support available in Indian country are Medicaid home and community-based care services, Older Americans Act funds, and state and tribal dollars.

Administration on Aging Programs

The Administration on Aging (AoA), an agency of the U.S. Department of Health and Human Services, oversees the Older Americans Act, which is familiar in Indian country for the Title VI Grants for Native Americans program. The grants are for supportive and nutrition services for older AI/ANs and Native Hawaiians. Services might include congregate and home-delivered meals, senior centers, homemaker services, and other assistance that helps to keep elders living at home. Current funding for these programs is about \$26 million, with grants ranging from about \$72,850 to \$135,500 a year. In FY 2007, Title VI grants were awarded to 237 Indian tribal organizations and two Native Hawaiian organizations.

A newer part of the Older Americans Act, Title VI-C, is the Native American Caregiver Support Program (NACSP), added to the Older Americans Act in 2000. Title VI-C provides small grants to tribes to assist families caring for older relatives with chronic illness or disability, as well as for grandparents caring for grandchildren. The \$6 million-per-year program is designed to strengthen the families’ caregiver roles, not replace the tradition of families caring for their elders. AoA currently funds 205 NACSP grants to provide caregiver services, Jackson said. The sums received by any one tribe are fairly small and are distributed based on tribal population. Funding for a single grant in 2005 ranged from

\$16,990 to a high of \$67,990. Tribes are expected to use the funds to offer direct services, including information and assistance, individual counseling, support groups and training, respite, and supplemental services.

Tribes decide the age at which their members are considered elders eligible for services, even if that age is younger than 60. Mainstream Older Americans Act services are only available to people who are 60 and older, which means that an elder who receives services through Title VI on the reservation might not qualify for similar services in town, according to Zylstra.

Respite programs are particularly well utilized. “Respite has been successful from Day One,” Jackson said. “We could spend our entire budget on respite,” she added. Tribes can design programs to meet their needs. Some allow caregivers to use up to \$300 every four months for respite care. Some use vouchers for respite. Some use volunteer respite workers; others allow a family to choose the respite worker, family member, or neighbor. A few programs hire a caregiver assigned by an agency, but most are informal or volunteer caregivers, Jackson explained.

On the other hand, NACSP programs such as support groups have been harder to set up, especially in small communities. “Privacy issues kept people away,” Jackson said. Eventually many Native people do come to the groups and enjoy them. “I didn’t know there was someone else with these same problems,” they might say. “It is nice to get out of the house and talk to someone who understands what I’m going through.”

The Title VI-C NACSP program is not without its problems. Tribes are required to report the number of clients reached with information, access, counseling, caregiver training, respite, and other supportive services activities, Jackson said.

Tribes often find these “outcome evaluations” culturally inappropriate and unrealistic in light of the limited tribal social services staff, according to one research study (Ryser, 2008). Yet, tribes may be reluctant to request or accept training and assistance from local area agencies on aging, which are often not trained in communicating across cultural differences, the researchers found.

The association that represents AAAs also includes Title VI programs among its membership, the National Association of Area Agencies on Aging, includes sessions for Title VI program personnel as part of its annual conference.

Tribes may have difficulty implementing caregiver programs due to staffing limitations, difficulty recruiting participants, geographic isolation, and the difficulty of meeting needs.

AoA Resource Centers. AoA also funds two resource centers on AI/AN aging issues.

- 1) **University of Alaska-Anchorage:** AoA funded the National Resource Center for American Indian, Alaska Native and Native Hawaiian Elders (NRC) at the University of Alaska-Anchorage in 2003. NRC is working to define the clinical, behavioral, and education needs of elders and caregivers; and identify best practices for culturally based Native elder care.

- 2) **University of North Dakota:** The National Resource Center on Native American Aging (NRCNAA) at the University of North Dakota, funded by AoA since 1994, is developing information about family caregivers. As an alternative to conventional needs assessments that do not seem to match the realities of elder care in Indian country, the NRCNAA developed “The Long Term Care Planning Tool Kit” for use by Native communities.

Medicaid Services

The majority of long-term care services not provided by families are paid for through Medicaid nursing home services. The Centers for Medicare & Medicaid Services, an agency of the U.S. Department of Health and Human Services, oversees the Medicaid Home and Community-Based Services (HCBS) Waiver Program. These waivers allow low-income people who are eligible for nursing home admission to instead receive services in their home. There are 264 HCBS waiver programs operating throughout the country. All states except Arizona have at least one HCBS program.

Services available under a Medicaid HCBS waiver include case management, homemaker/home health aide services, personal care services, and adult day health care. But states can also propose to provide caregiver support, education, and training; non-medical transportation; in-home support services; special communication services; minor home modifications; and adult day care when these services will help keep someone out of a nursing home.

Unfortunately, Medicaid reimbursement does not keep up with the cost of providing services, especially in rural areas. Another difficulty is the lack of a well-trained, caring, and competent workforce in many tribal areas. Both of these factors make it difficult to provide services in these areas.

Indian Health Service (IHS)

While IHS is central in providing or coordinating primary health care, the agency does not generally provide long-term care services. Specialty care is provided through Contract Health Services, but the dollars are woefully inadequate, and are not targeted to chronic disease, Manson said. “Some people may be getting services through Medicare or Medicaid, not as an Indian, but as a citizen of the state in which they live,” Manson said. “The number of [professional] caregivers available in caregiving institutions around AI/AN/rural communities is inadequate to meet the needs,” Manson added. “And some are not getting the care they need anywhere.”

IHS has an Elder Care Initiative designed to promote the development of high-quality care for AI/AN elders. The program offers information and referral, technical assistance and education, and advocacy in partnership with tribal, state, federal, and academic programs. In 2008, IHS awarded funds for LTC assessment, planning, and implementation under a \$600,000 Elder Care Initiative Long-Term Care Grant Program.

Some components of IHS services may indirectly benefit caregivers, including public health nurses or medical home visits that educate caregivers about medically complicated elder care, a palliative

plan of care for elders facing a life-threatening illness that may include respite care for the family caregivers, and medical transportation for frail elders.

Tribal Resources

A study conducted by Baldrige and William Benson with Health Benefits ABCs for the National Indian Council on Aging (NICOA) found that the revenues generated by tribal casinos appear to make a significant difference in the availability of long-term care services (Baldrige, 2004). More than half of the tribes in the survey had casinos. Having a full casino was significantly associated with the availability of LTC services.

The NICOA study found that tribes were more likely to use tribal funds for home modifications and home maintenance, transportation, senior centers, and assistive devices than any other sources of funds. More than a quarter of tribes also use tribal funds for congregate and home-delivered meals.

Less than half of the tribes surveyed used the state and federal sources available to fund any given service to elders. Baldrige and Benson concluded that this may indicate that tribes are not fully informed and experienced in tapping major funding streams or that tribal members receive services funded by these sources, but the services are not provided by the tribes.

AI/AN tribes have “an enormous interest around the need for various kinds of services ... they recognize at one level or the other the need to improve the infrastructure for the continuum of care,” Manson said. “NICOA, AoA, and others have done a wonderful job at educating providers, administrators, and local leaders about the need for a more extensive continuum of care. Still, a lot of work needs to be done because of turnover in leadership, and the evolving nature of leadership in these types of communities.”

However, funding is limited and many tribes do not understand how to navigate the systems that control policy and eligibility. Tribes need more education about the sources of information, available data, and funding, Manson continued. They should talk to the experts in Indian country who “have figured out how to represent our institutions to tribal communities and how to broker tribal interests within our own institutions in ways that can benefit both.” He suggested that “CDC could orchestrate a forum to bring these experts together with tribal leaders on an ongoing basis so they can begin a dialogue and find areas of mutual interest and so tribal leaders can use that expertise in developing local resources for themselves.” He envisioned a consortium of AoA, CDC, NICOA, and National Congress of American Indians working on these issues.

Tribal leaders also should work with NICOA and AoA “on how to become critical consumers of research evaluation and the resulting information,” Manson suggested.

“It’s really hard to talk about this population as a whole, especially with services, because some tribes have more resources and can provide tribally delivered LTC services, but others do not,” Goins said. Some tribes also have better relations with their state Medicaid waiver program, she added.

Jackson noted that a CMS-IHS-AoA working group convenes a LTC conference every other year to bring together different tribes “to learn from each other and find out what is out there, to better serve the needs of their communities.”

Other Resources

Other caregiving resources are available from state units on aging and AAAs, the Department of Veterans Affairs (for eligible AI/AN veterans), and federal housing programs (for the housing component of the LTC infrastructure).

As the federal agency that oversees public health, CDC promotes health promotion and disease prevention programs for caregivers. It is working to ensure that caregiver support programs are based on good science.

Looking to the Future

The number of AI/ANs aged 75 years or older who will need long-term care will double in the next 25 years, Census data show (Goins, 2007). Clearly there is a need to develop long-term care policies for AI/ANs. Yet, Congress has not funded health care for AI/ANs at levels that match the rest of the population (Goins, 2007).

Given their higher rates of functional disability—a predictor of the eventual need for long-term care, AI/ANs could benefit from chronic disease management programs and physical activity interventions (Goins, 2007).

Clearly more work needs to be done to ensure adequate services for elders and their family caregivers in Indian country. What elders want is clear: to remain at home and maintain their traditions. To help their elders meet that goal, tribes must understand the needs of an aging population, the demands of caregiving, existing caregiving policies, and ways to access funding to support caregiving programs. That means becoming familiar with complex state and federal policies, and learning how to apply for and win grants and find other sources of funding. In many areas, it may mean starting small, but thinking big.

It also means looking to the model programs or mentors who have already paved the way for successful programs (see “Caregiving in Indian Country: Tribal Success Stories”). It means partnering with other organizations in public health and aging arenas to figure out the best way to utilize local resources. Many of the people interviewed expressed frustration that it took years to get a facility licensed, but they kept at it and learned what needed to be done.

“Some of these changes are fairly straightforward, others are quite complex and difficult to implement. This kind of support for frail elders and their caregivers does not routinely exist in the

mainstream health system and is not supported by current reimbursement structures, including Medicare and Medicaid,” Finke said. “This is not a challenge that the hospitals and clinics of the Indian Health System can or should take on alone. To provide the kind of care frail elders and their caregivers need will require collaboration with community-based services, both Tribal and non-Tribal; Community Health Representatives (CHRs), Community Health Nursing, Home Health and Hospice, and Senior Center programs, both Older Americans Act Title VI and Title III programs will need to be partners,” he said.

“New technologies like home monitoring systems will be part of the solution, but they aren’t the easy fix. The new technologies can extend and enhance support for elders and their caregivers, they won’t replace it,” Finke added.

“Indian Health programs face very real resource limitations and often struggle to provide basic primary care services. The challenges involved in building this absolutely essential support for elders and their caregivers should not be underestimated. But we have to start. We cannot truly honor the elders’ wishes to remain at home and in their communities unless we can build into our health system the kind of support they and their caregivers need,” Finke said.

Tribal governments also could develop their own long-term care policies that reflect the culture and realities of their specific tribe.

One study in Washington state found that, while AI/ANs wanted to take advantage of the AoA caregiver grants, “coordination between western Washington tribal social and health agencies and county area agencies on aging is limited and often non-existent,” making it difficult to work together (Ryser, 2008). Ryser and other researchers from the Center for World Indigenous Studies, working with the University of Washington School of Social Work and the local and regional aging network, suggested that the Older Americans Act itself may be flawed. They said the law gives federal authority to state governments, relegating tribal governments to a “grant recipient role” unable to make policy decisions to tailor caregiver services at the tribal level. They proposed that tribal governments independently establish service and coordinating agencies called Tribal Agencies on Aging that equal the role of the area agencies on aging and have more authority than the current Title VI tribal agencies.

States do have the option of establishing tribal or Indian-based AAAs, which are funded at greater levels than Title VI programs, and several states have elected to do this. There are about seven tribal AAAs throughout the nation, primarily in Arizona, New Mexico, Minnesota, Montana and Washington State.

More studies are needed on caregiving issues that address a broader AI/AN population instead of just one tribe. The studies should examine the need for caregiving, the availability of caregivers, family preferences, and available resources. CDC’s telephone-based survey [the Behavioral Risk Factor Surveillance System (BRFSS)] gathers state level data on chronic care; however, only 67.9% of

AI/ANs on reservations or off-reservation trust lands lived in a household with a telephone (FCC, 2003). Better data on AI/ANs might be provided if the Census added specific questions about ADLs and IADLs on its long form, others suggest (Moss, 2006).

Whatever direction long-term care for the AI/AN population takes, it is sure to reflect the tribal traditions of honoring elders, keeping them at the center of the family, and keeping them at home.

This document was written by Nancy Aldrich. William F. Benson was senior editor and project manager.

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Resources:

Organizations

Administration on Aging, 202-619-0724, www.aoa.gov
Grants for Native Americans program, <http://www.aoa.gov/prof/aoaprogram/natives/native.aspx>
Native American Caregiver Support Program,
www.aoa.gov/prof/aoaprogram/caregiver/careprof/proguidance/resources/docs/FINAL%20NFCSP%20Report%20July22.%202004.pdf
National Resource Center for American Indian, Alaska Native and Native Hawaiian Elders, University of Alaska-Anchorage, <http://elders.uaa.alaska.edu/>
National Resource Center on Native American Aging (NRCNAA), University of North Dakota,
<http://ruralhealth.und.edu/projects/nrcnaa>; needs assessment,
<http://ruralhealth.und.edu/projects/nrcnaa/needsassessment.php>
Agency for Healthcare Research and Quality, 301-427-1364, www.ahrq.gov
Elderly Healthcare, www.ahrq.gov/research/elderix.htm
Addressing Critical Concerns of Healthcare Systems Serving American Indians/Alaska Natives,
www.ahrq.gov/news/ulp/tribal/ulptribal.htm#Contents
American Red Cross Family Caregiver Program, 202-303 5000, www.redcross.org/services/hss/care/family.html
Centers for Medicare & Medicaid Services American Indian/Alaska Native Center, www.cms.hhs.gov/center/ir.asp
Indian Health Service Elder Care Initiative, 413-584-0790, www.ihs.gov/MedicalPrograms/ElderCare/
Medicaid HCBS Waiver Program, www.cms.hhs.gov/MedicaidStWaivProgDemoPGL/
National Indian Council on Aging, 505-292-2001, www.nicoa.org

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American Indian and Alaska Native Roundtable on Long-Term Care: Final Report 2002,
www.nicoa.org/PDFs/2002%20NICOA%20LTC%20Roundtable%20Report.pdf or
www.ihs.gov/medicalprograms/eldercare/Final_LTC_Report_All.doc
Caregiver Assessment: Principles and Strategies for Change (Volume I) and *Caregiver Assessment: Voices and Views from the Field* (Volume II), www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1630
Caregivers Count Too! An Online Toolkit to Help Practitioners Assess the Needs of Family Caregivers,
www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1695

Family Caregiver Support – State Facts at a Glance,
www.aoa.gov/PROF/aoaprof/caregiver/careprof/resources/fcs.pdf
 “Family Caregiver Support of the Rural Elderly,” *The 2006 Report to the Secretary: Rural Health and Human Services Issues*, <http://ruralcommittee.hrsa.gov/NAC06AReport.htm#Family>
Medicaid Home Care for Tribal Health Services: A Tool Kit for Developing New Programs,
www.healthpolicy.ucla.edu/pubs/publication.asp?pubID=79
Native Aging Facts: Informal Caregivers: Challenges in Providing Care, <http://ruralhealth.und.edu/pdf/NA-caregivers.pdf>
 Various caregiving publications, www.niapublications.org/shopdisplayproducts.asp?id=29&cat=Caregiving, call 1-800-222-2225, or e-mail info@niapublications.org

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Caregiving in Indian Country: Tribal Success Stories

Tribes may benefit from the ideas and practices used in successful caregiving efforts for Native Americans already in place elsewhere in the country. Below is a brief description of several success stories from Indian country.

Alaska. The Alaska Commission on Aging provides funds to the Tanana Chiefs Conference, Inc., Fairbanks, to provide outreach to caregivers. Caregiver services include information and assistance, individual counseling, support groups, caregiver training, respite, and other supplemental services to improve caregivers' quality of life while they care for an elder family member.

Cyndi Nation, Home Care Services Director of the Tanana Chiefs Conference, said her tribe uses Older Americans Act Title VI-C (Native American Caregiver Support Program) dollars to bring caregivers to Fairbanks for Talking Circles, where they interact with their peers. "I think they are healing, because people can bring up all kinds of things," Nation explained.

In addition, annual training sessions with about 20 caregivers cover topics such as adult protection, assisted living homes, bathing, end-of-life planning, nursing homes, physical activity, and powers of attorney. The program also offers preventive care information, covering diabetes, exercise, food, heart disease, and other topics, through forums and training.

Caregiver support includes an initial visit in the village, following by a monthly phone call. Caregivers can also ask for help with bathroom modification, incontinence supplies, and cleaning supplies for an elder's room. State dollars also are used for family caregiver support.

"Our villages are very remote and air fare is the most expensive part of the budget," Nation said. The program covers the Interior of Alaska. Home care nurses fly out to do assessments with elders in need, and then do a follow-up assessment in the second year. Available services for elders include chore and respite care by someone living in the community. Unfortunately, their services no longer include personal care, which became too expensive.

The 38 villages covered by the program are small. Hands-on services are provided by someone living in the village. "Even if it is a non-Native person providing care, which is rare, it is someone they know and who knows the culture," Nation said.

In addition to Nation, the staff includes a nurse, a program assistant and a social services coordinator.

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Montana. The Blackfeet Eagle Shield Center in Browning, Mont., developed a Caregivers Program to provide support for family caregivers who reside on the Blackfeet Reservation. A survey revealed that family caregivers felt that non-Indian health care providers did not take the time to talk with them or their elder and were insensitive to their culture. So Eagle Shield Center Director Connie Bremner decided the program should train service providers to interact with Native people. As a result, there is now a network of trained community service providers who are trained to support family caregivers and provide assistance to caregivers to improve the quality of care for elders. They help caregivers identify resources, services, and receive referrals to what they need.

The program offers a caregiver support group, training sessions, health information, a resource directory, and a lending library. Initially, the program had difficulty recruiting caregivers to participate in support groups, because they were reluctant to speak about private matters. The center also developed a training manual for Native caregivers that it plans to copyright and make available for distribution to other tribes around the country in the future.

The center also provides respite workers, which allow many of the caregivers to take some time off from their caregiving responsibilities by becoming volunteers for other community efforts, she said.

The program began with an Administration on Aging demonstration grant to pioneer the Older Americans Act Title VI-C Native American Caregiver Support Program. It received \$100,000 a year for three years. The program now operates on a \$50,000 budget from Title VI-C. Bremner has been successful in generating additional resources for their innovative work for elders. They received a \$100,000 Robert Wood Johnson Foundation Community Health Leader Program award, as well as \$200,000 from the University of Pennsylvania and Glaxo-Smith-Kline pharmaceuticals for a wellness/fitness program. The center's personal care assistance program, begun in 1995, generates over \$1.2 million in Medicaid reimbursements, which cover the salaries for the administrator, an assistant, scheduler, and data technician. The program has trained over 400 individuals to do personal care and employs 120 people. "It is a very welcome program in Indian country in that we take people who have been unemployable, train them, and give them employment. Some have gone on to be nurses," Bremner added.

Many of the care providers and the clients are non-Indian and there has not been any tribal resistance to that. "We don't discriminate," she said.

The Blackfeet center also has a 16-unit independent living apartment building for elders.

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New Mexico. The Laguna Rainbow Corporation, New Laguna, N.M., operates a continuum of long-term care services, including a nursing home, a 40-unit assisted living complex, a senior center with

a wellness clinic, and a gamut of community-based services such as meals, chore and homemaker services, and social activities. The Corporation is owned by the Pueblo of Laguna and located on reservation lands of the Laguna Pueblo in West Central New Mexico. It hopes to get the clinic certified through Medicare and Medicaid, and obtain Medicaid home and community-based waiver dollars to maintain programs.

“I think one of the biggest challenges always is trying to find resources to maintain the programs, and develop new programs,” said Kathy Correa, LNHA, BS, Executive Director, Laguna Rainbow Nursing Center & Elderly Care Center in New Mexico. When Laguna first started, the tribe put in a lot of its own dollars, built the facility, and funded the operation for a number of years. It costs \$225,000/month to operate the nursing facility, and community-based programs run \$350,000/month, Correa said.

Other tribes may lack the financial capacity or the technical support to get these programs started. “I’ve talked to the state department on aging and the area agency on aging and told them that they need to provide technical assistance to help tribes get started, but they don’t have the staff or money to do that,” Correa said. “Some tribes are lucky in that they have casinos and other businesses that bring revenue into the tribe, but a lot of them don’t.” She recommends teaching elders themselves to lobby for what they need. “They were shy at first, but not now,” she added.

A tribally owned 58-bed Medicaid-certified nursing home is staffed and managed by the Laguna Rainbow Corporation. The facility accepts Indians from throughout the country, not just Laguna Pueblo, and people of all ages. To operate efficiently, all the nursing home beds need to be filled. “That is a challenge, because we trying to keep elders at home,” Correa said. At first, the tribe encountered resistance from elders, who did not want a nursing home. “I had to explain that we don’t have tribal physicians and health care providers. If our goal here is to get good care, then we have to do whatever we can to make sure that you get it.”

“Now the elders say, ‘We didn’t even want this place, but now we are glad it is here, because we don’t have to go to Albuquerque, and we can stay here with our own tribe.’ They are even more grateful that we are doing the community-based services, so they can stay at home,” Correa added.

The Laguna programs use non-Native providers. Correa explains to the elders that “it is about the care, not who does it. The goal is good care, so we have to do this.” The program sends along an Indian employee when a non-Native physician goes to an elder’s home.

Future plans include adding a skilled nursing care component and having the nursing home qualify for Medicare, but that would require hiring three RNs, she added. The senior center is currently located in the housing complex, but future plans including building a new center with an adult day care unit. Correa also dreams of having a pilot PACE (Program of All-Inclusive Care for the elderly) demonstration project, which would help keep AI/ANs who are eligible for both Medicare and Medicaid

living in the community instead of going into a nursing home. She also would like to set up a group home with one caregiver in a village.

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New Mexico. In New Mexico, the Zuni Tribe in the western part of the state owns and operates its own Adult Day Services program, which provides 6 hours a day of respite for family caregivers, plus transportation for the elder to and from the facility. The facility is accessible to persons with disabilities, operates with an elder-to-aide ratio of 5:1, and offers socialization, arts and crafts, personal care, grooming, exercise, snacks, meal, bathrooms with showers. The adult day care program has 18 clients, mostly dementia patients. The clients are ages 75-104. Younger elders, ages 55-70, serve as volunteers. The family caregiver is included and consulted for the plan of care, said Karen Leekity, Elderly Services Director, Zuni Senior Center.

The program was launched because care was not available locally, the nearest nursing home was 40 miles away, and elders did not want to go into a nursing home anyway. The adult day care program is a social, not medical, model—aides do not administer medications.

It takes a long time to comply with state licensure and tribal requirements, Leekity said. There was also initial resistance from the community, which did not want a “nursing home.” The adult day care program has a bed in case one of the elders became ill during the day. “It took some community education to explain that this is not a nursing home; it is day services,” Leekity said.

The Zuni Tribe also offers caregiver support through the Native American Caregiver Support Program, respite care is provided by AmeriCorps volunteers who do in-home care for a few hours, and Senior Companions visit frail elders.

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Washington. The Northwest Regional Council, located near Puget Sound, is an area agency on aging (AAA) that goes the extra mile to reach out to Native Americans to ensure access to services and to provide technical assistance for programs on and off the reservation. This focused outreach uses culturally appropriate materials and a culturally relevant approach to make services understandable and effective for older Indians, explained Shelly Zylstra, the council’s planning unit director. The program offers training, support groups, conferences, and consultation as needed. Caregiver support services include caregiver health and family issues information, a caregiver kit, access to a library of information, and fact sheets on caregiving (such as meal tips, safe bathing, and personal hygiene). The AAA also provides “Medicaid Interpreter Services” to assist medical providers who serve Medicaid-eligible, limited-English-speaking clients.

Because the AAA is not a tribal program, it has to work hard to connect with AI/ANs. The approach of the Northwest Regional Council is to build relationships and to have a Tribal Outreach Program “visit” with families, rather than calling them “caregivers” or offering a “service.” The Tribal Outreach Coordinator, who is a Native person, “circuit rides” to visit families and elders in their homes, and engages them in conversations. The discussions are used to screen for needs and offer solutions connecting families with long-term care services. In addition to providing information and assistance, the Tribal Outreach Coordinator offers help in finding culturally appropriate care for elders who need personal care and other assistance in their homes. The Outreach Coordinator acts as a cultural interpreter for service providers and as an advocate for the needs of elders who experience barriers to accessing necessary services. The Outreach Coordinator assists with paperwork, collects necessary documentation, acts as a notary, and communicates problems to service providers, case managers, or social workers. “It is a simple program, and it works,” Zylstra said.

In the AAA region, a large number of Indian elders are eligible for Medicaid Home and Community-Based Service Waivers, which allow the elder to pay anyone, except a spouse, to take care of them. The AAA provides training for the caregiver. It also offers an annual caregiver conference, attended by about 500 people; talking circle/support groups; and support for grandparents raising grandchildren,

But the AAA’s primary service is one-on-one in-home visiting with elders and their caregivers, and referral to services. The AAA does some family reconciliation meetings if needed.

“We just ‘visit’ them. That gets us in the door, and something will come out about their needs. We may drive for hours to sit around having lunch and listening to stories. But that is part of what it is all about.” And when a need is mentioned, the tribal outreach person can say, “Oh I know someone who might be able to help you with that.”

The AAA offers day care services, which are not well utilized because they are off the reservation. There is also a state-funded respite care program, but it has few participants, probably because the caregivers are non-Native, Zylstra said.

Zylstra thought the Northwest Regional Council was probably the only AAA to do this type of outreach to Native people. “It’s a real simple concept: You make a decision that it’s important enough to you that you want to use discretionary funds to fund a position to do nothing but tribal outreach,” she said. “And that’s a decision that not very many AAAs have come to, which is unfortunate because it is a model that works well.”

Older Americans Act Title III-B (supportive services) dollars fund the Tribal Outreach Coordinator’s salary as part of the AAA’s Information & Assistance Program. “We don’t have a special Indian program. We have a special Indian [the outreach coordinator] who helps them get into the regular programs.” Given our ruralness, “we can’t have segregated programs, so we explain that to the people.”

That is a model that I think is appropriate, she added. “We make the mainstream program understand how it has to operate in Indian County, and then we facilitate that.” She also trains other service providers on cultural sensitivity.

Local tribes use their Title VI-C Native American Caregiver Support Program grants to refer Indians to the AAA for services, Zylstra said. One tribe with an excellent caregiver support program hires a caregiver support person. The AAA does the training, while the tribe conducts the recognition ceremonies, a quarterly luncheon for caregivers and elders, and an annual raffle.

“We’re joined at the hip” with our tribes, she said. We help them apply for Title VI and other grants. “Through the years, we’ve worked with tribes all over the U.S. in the same fashion, through word of mouth I get phone calls from other areas,” Zylstra said. It is the tribes from other areas that call, not the AAAs. “Some AAAs are not always interested in listening to what we have to say. It’s a business decision you make to spend your discretionary money in that fashion, and not many choose to go there. For our organization it was a no-brainer.” We’d say, for our demographic, who is the most frail, who has the shortest life expectancy, who is rural ... and in our region Indians are our largest minority group and our largest non-mainstream population.”

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Wisconsin. The Oneida Nation Elderly Services Program, Oneida, Wis., offers respite care, support groups and supportive services, according to Florence Petri, Elderly Services Program Manager. As in many areas, Petri said it is often difficult to get Indians to come to a support group, but usually a small meal or gift will help entice them to come.

Caregiver support is provided with Title VI NACSP funds, plus a small tribal contribution, to cover training and coordination of volunteers. The program has three staff people and serves about 60-80 caregivers. The tribe is also one of the few that owns a nursing home.

A respite care worker is available for up to 8 hours a week to provide relief to the caregiver of an elderly client. Priority is given to clients age 70 and over and disabled individuals who may be at risk of losing their independence at home or going into a nursing home.

The Elderly Services Program is housed in an Elderly Services Complex, consisting of 29 independent living apartments for elders.

In addition, the Oneida Area Faith in Action Coalition, a volunteer-based program, offers transportation, shopping, housekeeping, preparing meals, and respite care.

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