



Department of Health & Human Services, Centers for Medicare & Medicaid Services

# **Emerging LTSS Issues in Indian Country: Caregiver Training in Indian Country**

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## Glossary

Term	Definition <sup>1</sup>
Activities of daily living	Basic activities a person must perform during a normal day to remain independent, which include daily actions such as getting in and out of bed, dressing, bathing, eating, walking, and using the bathroom
Long-term services and supports (LTSS)	A set of health care, personal care, and social services delivered over an extended period to persons who are unable to perform their activities of daily living independently; LTSS may be provided in a variety of settings or in the person's own home
Long-term care	Services that help people with personal or health care needs and activities of daily living over an extended period; long-term care is an older term that has generally been replaced with LTSS
Informal caregiver	Typically, a family member or friend who provides care without receiving payment or formal training to an individual who is unable to perform their activities of daily living independently
Caregiver burden	The physical, psychological, social, and emotional challenges and stresses associated with caregiving and experienced by the person providing care for another

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<sup>1</sup> Definitions are from the CMS.gov website <https://www.cms.gov/apps/glossary/>



### Introduction

In Indian Country, family members provide approximately 90% of long-term care to older adults and people with a disability, which is 10% more than the general U.S. population (Institute of Medicine, 2008). These family caregivers provide a wide array of services and activities which allow their loved ones to continue to live in their homes and communities. Long Term Services and Supports (LTSS) are a set of health care, personal care, and social services delivered over an extended period to persons who are unable to perform their activities of daily living independently (Centers for Medicare & Medicaid Services (CMS), 2016). The remote nature of Indian Country, combined with an increasing aging population and high levels of chronic disease and disability, equates to complex LTSS needs and an enormous need for caregivers in Native communities.

Most caregivers in Indian Country are considered informal caregivers, as they do not receive payment and have little to no training (Schure & Goins, 2015). American Indian and Alaska Native (AI/AN) caregivers handle complex and physically challenging tasks, including medication management assistance with ambulation and transfer, and assistance to manage the many aspects of serious health conditions, including Alzheimer's and other dementias and diabetes. (Scarton, et al., 2014). The literature suggests that there is an interest in and demand for caregiver training in Indian Country. It also suggests that with training, caregivers experience less stress and depression, demonstrate improved competence when faced with challenging caregiver tasks, and provide higher quality care.

The literature on caregiver training in Indian Country is scarce, but, the increasing aging population and chronic disease rates in Indian Country are well documented. More research is needed to examine the gaps in knowledge and understanding of caregiver burden in Indian Country to create effective and culturally appropriate trainings for AI/AN caregivers. This brief provides an overview of the existing literature on caregiver training in Indian Country.

The brief:

- Provides an overview of the need for caregiver training in Indian Country,
- Examines the benefits of caregiver training,
- Assesses evaluated caregiver training programs and their implications for Indian Country,
- Outlines funding for caregiver training in Indian Country, and
- Provides recommendations, and
- Profiles one innovative program that provides caregiver training in Indian Country.



### The Need for Caregiver Training in Indian Country

#### Health Status, Demographics, and Culture

Several complex factors related to health status, culture, and geography contribute to the high need for LTSS and caregiving in Indian Country. These factors include a rapidly aging population, high rates of chronic disease, rurality, and a cultural preference for in-home care. In terms of the aging population, the number of AI/AN people aged 65 and older is rapidly increasing, and is likely to double by 2060 (Administration for Community Living (ACL), 2015).

AI/ANs also face disproportionately high levels of chronic disease, including cancer, diabetes, heart disease, and stroke (Centers for Disease Control and Prevention (CDC), 2014, 2010 & 2016). The CDC reports that as of 2010, AI/ANs have the highest rate of diabetes of any other racial or ethnic group in the United States, and are more than 2.4 times as likely as white adults to be diagnosed with diabetes (CDC, 2010). Further, AI/ANs have the highest rate of disability of any ethnic group in the United States. According to the National Council on Disability, 22% of AI/ANs have a disability compared to 20% among the general population (National Council on Disability, 2003).

Additionally, AI/ANs tend to have a cultural preference for in-home care. Institutional care for tribal elders and people with disabilities is generally not culturally accepted and elders rarely thrive when taken from their communities (Baldrige, Aldrich & Benson, 2009; Hennessy & John, 1996). Native cultures emphasize respect for elders and an obligation to provide care (National Indian Council on Aging, 2013; Jervis, Boland & Fickenschler, 2010). In addition, the majority of tribal communities and reservations are in rural or frontier areas, where institutional care and access to formal LTSS is a challenge. These factors result in heavy reliance upon informal caregiving in AI/AN communities and few opportunities for training and support.

#### Caregiver Burden and Interest in Caregiver Training

Caring for individuals with complex chronic conditions, like diabetes, cancer, or Alzheimer's and other dementias, is incredibly demanding and complex, especially for caregivers who do not have any training. Several studies that assessed the needs of AI/AN caregivers found that the stress related to managing these complicated conditions is a serious source of caregiver burden for AI/AN caregivers (Cordova, et al., 2016; Hennessy & John, 1996; Scarton, et al., 2014). For example, a 2016 article that assessed a 2012 survey of Hopi tribal members found that 49% of the survey respondents who identified as caregivers reported stress as their greatest challenge with caregiving (Cordova, et al., 2016).

Similarly, a 1996 study that analyzed data from focus groups of caregivers for frail elders from five different tribes found that these caregivers felt high levels of stress and caregiver burden related to the in-home care they provided for elders with serious health conditions (Hennessy & John, 1996). Specifically, the caregivers experienced anxiety about handling high-tech medical equipment and



managing medication, especially for care recipients with diabetes. Although dated, this study is one of the few that assess AI/AN caregivers' needs and desired services (Hennessy & John, 1996).

In both studies, the AI/AN caregivers identified caregiver training as a desired service that would reduce stress and caregiver burden. For the 2012 study of Hopi caregivers, the survey respondents most often requested caregiver training, specifically training on patient care, to improve their caregiving (Cordova, et al., 2016). Participants in the 1996 focus group study also identified caregiver training as a service that could improve their caregiving and reduce their burden (Hennessy & John, 1996). Focus group participants from the 1996 study further identified the following topics they felt unsure about and need training on:

- practical information about the care recipient's condition, their condition's expected course, and their condition's care requirements;
- in-home medical care management techniques,
- and preventive health maintenance (Hennessy & John, 1996).

Although not explored in the literature, caregivers often need training on the transferring and ambulation of care recipients, especially of older adults. During an interview with the Inter Tribal Council of Arizona, Inc., Area Agency on Aging (ITCA-AAA), staff explained that caregivers in the communities they serve frequently need training on how to safely transfer elders (ITCA-AAA, personal communication, April 17, 2017). ITCA-AAA staff added that caregivers also need training on how to properly use gait belts, which are an important tool for safe patient transfer (ITCA-AAA, personal communication, April 17, 2017). A gait belt is a wide belt with handles that caregivers can fasten around the waist of a care recipient with mobility issues to safely move them from a wheelchair to a standing position, in and out of vehicles, or to walk from place to place (Chao & Henshaw, 2009). Although a primary concern for caregivers, there is nothing in the literature that examines how to best teach safe transfer and assistance with ambulation in AI/AN communities. This is especially important in rural homes which may be in poor repair, and that may have numerous falls hazards. Safe transportation of frail individuals requires safely transferring them from a wheel chair into a vehicle. This gap also highlights the need to evaluate how caregiver training programs address needs specific to AI/AN communities.

### **Evaluation of Caregiver Training Programs**

Very little to no literature assesses the effectiveness of caregiver training programs among AI/AN communities. However, assessments of two different caregiver training interventions in other communities have been adapted for use in Native communities: the Savvy Caregiver Program (SCP) and the Resources for Enhancing Alzheimer's Caregiver Health (REACH) program. These programs, their available resources and the bulk of the literature focus on caregiving for individuals with Alzheimer's and dementia, which suggests that these conditions are particularly challenging for caregivers. However, it



also indicates a gap in the literature on the myriad of other challenging health conditions with which caregivers in Indian Country are confronted.

### The Savvy Caregiver Program

SCP is an evidence-based training program for individuals caring for a family member with Alzheimer's or other dementias. SCP, which has been adapted for use in different settings, including in Indian Country, was initially developed by the University of Minnesota (Hepburn, et al. 2007; 2003). It is a psychoeducational, 12-hour training that is ideally delivered in 2-hour sessions over a 6-week period through training manuals and supplemental videos (Hepburn, et al. 2007). The program is broken into separate sections that focus on knowledge of Alzheimer's and dementia, caregiver skills, and how to better manage stress related to caregiving (Hepburn, et al. 2007).

SCP has been evaluated in both rural and urban settings (Hepburn, et al. 2003; 2007; Smith & Bell, 2005). The rural evaluations are of particular interest, considering the remote locations of most tribal communities. A 2003 article documenting SCP program field testing in several different states, including rural Minnesota, reported positive results (Hepburn, et al. 2003). The authors found that SCP program participants experienced lower stress related to caregiving and increased competence and mastery of caregiving skills (Hepburn, et al. 2003). Similarly, a 2005 evaluation of SCP in rural Colorado found that, after 6 months, caregivers who participated in SCP reported lower rates of depression and increased use of support groups to help manage their stress (Smith & Bell, 2005).

The success of SCP in a variety of settings marks it as a highly adaptable and promising practice option for tribal communities. The National Indian Council on Aging (NICOA) adapted SCP for use in Indian Country under the name Savvy Caregiver in Indian Country; however, NICOA's version has not yet been evaluated (NICOA, 2013).

### Resources for Enhancing Alzheimer's Caregiver Health

Another caregiver training program that has been evaluated in a variety of settings and adapted for use in Indian Country is the REACH program. REACH is a caregiver training intervention that has been used and proven successful by several programs, including the U.S. Department of Veterans Affairs (VA). The REACH VA program includes four sessions with a certified REACH VA program coach who provides education on patient safety, coping with challenging patient problems, stress management, mood management, and problem solving (U.S. Department of Veteran Affairs, 2017). A 2014 study that assesses the implementation of REACH VA reported overwhelmingly positive results for caregivers (Nichols, et al. 2014). The authors found that caregivers who participated in REACH VA experienced improvements in several areas, including, "significant decreases in burden, depression, anxiety, and [a] number of troubling patient behaviors" (Nichols, et al. 2014).

The University of Tennessee Health Science Center Caregiver Center has since developed the REACH VA program for use in Indian Country through the REACH into Indian Country program (The University of



Tennessee Health Science Center, 2016). Like REACH VA, REACH into Indian Country focuses on handling difficult patient problems and behaviors and reducing caregiver stress (The University of Tennessee Health Science Center, 2016). Given the positive results of REACH VA, REACH into Indian Country holds great promise for AI/AN caregivers. The program has received funding to serve a greater number of AI/AN caregivers, and the University of Tennessee and Indian Health Service established a Memorandum of Understanding (MOU) to make the training materials widely available in Indian Country (The University of Tennessee Health Science Center, 2016).

### Funding for Caregiver Training in Indian Country

Obtaining funding for caregiver training in Indian Country is a challenge. Tribal communities have many competing health and human service needs, and caregiver training does not always make the list of funding priorities. In addition, the reporting requirements and paperwork associated with funding for caregiver training are a noted burden for tribal health and human services staff (ITCA-AAA, personal communication, April 17, 2017). Funding for caregiver training is available through the following sources.

- **Older Americans Act Title III-E funding (National Family Caregiver Support Program):**

The federal government provides grants to states for caregiver support programs, including caregiver training, through the National Family Caregiver Support Program, which is funded through Title III E of the OAA (ACL, 2016b). This funding, commonly referred to as Title III-E or Family Caregiver funding, is provided to states and is available to tribes by contracting with their Area Agencies on Aging (AAAs) (National Association of Area Agencies on Aging, 2016). AI/AN tribes are eligible for this funding, however funds are very limited and competitive to receive.

- **OAA Title VI funding (Services for Native Americans):**

Federally recognized AI/AN tribes can also receive funding for caregiver training through the Services for Native Americans program, which is funded through OAA Title VI funding (ACL, 2016b). Funding amounts are based on the number of the AI/ANs and Native Hawaiians, age 60 and older, who reside in a tribe or tribal organization's service area (ACL, 2016b). AI/AN and Native Hawaiian communities must be able to provide services to at least 50 individuals age 60 and older (ACL, 2017). Under Title VI, there are two parts, A (for meals and supportive services) and C (for caregiver services). Tribes must apply for Part A to be eligible for Part C. These funds are offered in three year cycles and between procurement periods are not available to new grantees

- **Tribal Support:**

Some tribes can provide funds for caregiver training. However, as noted above, competing health and human service needs of tribal communities can make this challenging.



- **State Funding:**

Some states are also able to provide funding for caregiver support, including caregiver training in tribal communities. However, state funding is limited. In addition, the paperwork required by states to receive training can be burdensome. For example, Arizona provides funding for caregiver training to tribal communities through the Family Caregiver Support Program. However, ITCA-AAA staff explained that the reporting requirements for the state are different than those required by Title III and Title VI. The limited caregiver staff in tribal communities may not have the time to adhere to and complete the reporting requirements, so they may choose forgo the state funding (ITCA-AAA, personal communication, April 17, 2017).

### Recommendations

The demand for caregiving in Indian Country equates to a high need for caregiver training for AI/AN caregivers. While challenges exist related to the accessibility of and funding for caregiver training in tribal communities, the cultural preference for in-home care, tribal communities' great respect for elders, and AI/AN caregivers' interest in caregiver training present opportunities for caregiver training initiatives. Overall, more research is needed that evaluates current caregiver training initiatives in Indian Country and determines the needs of AI/AN caregivers. Based on information gained from the literature and interviews, the following recommendations may help programs and tribal communities improve and increase caregiver training in Indian Country.

- Recommend that state reporting requirements for their caregiver training funding reduce reporting conflicts with Title III and Title VI requirements (ITCA-AAA, personal communication, April 17, 2017).
- Develop and include a culturally appropriate stress reduction skills component in caregiver training initiatives (Hepburn, et al. 2007; Cordova, et al., 2016; Hennessy & John, 1996; Scarton, et al., 2014).
- Expand available caregiver training components beyond Alzheimer's and dementia to include other health conditions, particularly diabetes (Hennessy & John, 1996).
- Utilize available caregiver training resources that have been tailored for use in Indian Country, including Savvy Caregiver in Indian Country and REACH into Indian Country (NICOA, 2017; The University of Tennessee Health Science Center, 2016).
- Educate tribal programs and communities on available funding sources for caregiver training.
- Assure that all training developed includes information about the safe transfer of elders and others who cannot ambulate or transfer independently (ITCA-AAA, personal communication, April 17, 2017).



## Program Profile: Inter Tribal Council of Arizona, Inc., Area Agency on Aging

“We are constantly working with the tribes to make sure that the service is working for them.”

– Laurai Atcitty, AAA Director

### Program Description

The Inter Tribal Council of Arizona, Inc., Area Agency on Aging (ITCA-AAA) provides an array of supportive services, including caregiver training to elders and their families, in 21 of the 22 tribes in Arizona. Overall, the ITCA-AAA serves about 10,000 elders in Arizona. The ITCA-AAA administers Title III and Title VI programs to tribal governments across Arizona.

The program provides in-person trainings to Native caregivers throughout the state on a variety of topics, including how to transfer elders, manage medication, manage stress, and care for individuals with Alzheimer’s and other dementias. The ITCA-AAA also provides technical assistance to assist tribes with caregiver support program development.

### Partnerships and Contracts

The ITCA-AAA partners and contracts with an array of organizations, including Foundations for Senior Living, other Area Agencies on Aging, AARP, and Banner Alzheimer’s Institute, to provide caregiving training to tribal communities across Arizona. ITCA-AAA partnered with Foundations for Senior Living to conduct an in-person training for caregivers on direct care. The ITCA-AAA also collaborated with the Gila River Indian community, which is offering its facilities for the in-person training. These types of partnerships are common and allow ITCA-AAA to conserve funding and serve many caregivers.

### Funding

Most of ITCA-AAA’s funding for caregiver training comes from Title III and Title VI funds. As an AAA, ITCA-AAA receives Title III funding for caregiver support for five tribes and Title VI for four tribes. Their

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**Community:** ITCA-AAA serves 21 of the 22 tribes in Arizona and approximately 10,000 elders.





## LTSS Research: Caregiver Training in Indian Country

### Program Profile

many partnerships include in-kind investments of time and experience to assist ITCA-AAA to establish best practice models and expand their ability to serve.

### Challenges

The caregiver training reporting requirements for funding present a serious challenge for the tribal communities that ITCA-AAA serves. The state reporting requirements are stringent and are not aligned with requirements for either Title III or Title VI of the federal Older Americans Act. Even though the tribes in Arizona need more funding for caregiver training, they do not always have the capacity to handle the reporting, particularly for the state, and decide to do without state funding as a result.

ITCA-AAA staff suggest that states reduce stringent reporting requirements to facilitate greater utilization of available caregiver training funds. This may be a concern specific to Arizona, however as states establish their own caregiver requirements, advocates should look to existing data requirements to determine if they are sufficient to meet their needs.

### Cultural Considerations

Given the diversity of the tribal communities in Arizona, ITCA-AAA works closely with the different tribal communities they serve to ensure that various aspects of programming, from intake forms to event spaces, are culturally appropriate. Hosting caregiver trainings at tribal facilities is one way that ITCA-AAA encourages tribal engagement, and assures that the diverse and unique cultural requirements for their trainings are met.

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“The reporting requirements are the biggest hurdle for us, because we definitely know there’s a great amount of need among the unpaid caregivers in the tribal communities.”

– Laurai Atcitty



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