Caregiving in Indian Country

[Announcer] This podcast is presented by the Centers for Disease Control and Prevention. CDC – Safer, healthier people.

Family members provide the vast majority of long-term care for American Indian elders. The key to understanding caregiving in Indian country is to recognize the role of elders in the family and the community. The term "elder" has a special meaning in Indian communities, because it's related to that person's contributions to their community, to their perceived value and wisdom.

Taking care of an elder is a continuation of an ancient custom of extended family and lifelong care for family. But that tradition may be colliding with new realities as more native people live away from their tribe's reservation, have more chronic health problems, such as diabetes and obesity, and are less connected with tribal traditions and supports.

Like almost all older adults, Indian elders prefer to stay at home in their community. The challenge is to develop support services that will allow frail elders to live in their community with their family.

According to the 2000 Census, there are about 265,000 American Indians and Alaskan Natives age 65 and older and they represent six percent of this population. It's estimated that the American Indian elder population will grow by more than 14 percent between 1995 and 2030, thus doubling the number of elders likely to need long-term care.

American Indian and Alaskan Native families tend not to use the term "caregiver" to describe the care they give to a family member. Most caregivers see this as part of their duty, part of being "Indian." These caregivers just say: "I came to stay with my parents" or "Mom needs help walking, so I help her walk."

Nationwide, caregivers often deal with anger, resentment, guilt, depression, financial difficulties, isolation, and conflicts with family and work. However, American Indian and Alaskan Native caregivers are less likely to voice their difficulties compared to the general population. That's probably because caregiving among native people is seen as part of family life and not as a burden.

Nonetheless, these caregivers need education and training to help them manage the complex health needs of their elders. They also need help to navigate the health system to meet their elders' needs.

Elders are not likely to leave the reservation to go where their children are because the reservation is their home, and they may lose the benefits they get from living on the reservation, including health care. Therefore, many American Indian and Alaskan Native caregivers have to move back to the reservation to provide care to an older family member, giving up their jobs and other benefits of living in an urban environment.

While caregivers often say they get satisfaction from their efforts, they usually provide care at the cost of their own time, money, and health, and often feel unprepared for their tasks.

A study of family caregivers from five tribes found they were most concerned about managing in-home medical care, dealing with psychosocial aspects of care, strains on family relations, and the negative effects on their personal health and well-being. The caregivers said they would like caregiver training and support groups, enhanced care coordination, adult day care, and respite care.

Respite care services give the caregiver a break by providing someone else to stay with the care recipient for a brief period of time, or allowing the care recipient to stay a few hours in an adult day care program or a few days in a nursing home. Respite care is the most utilized caregiver service in Indian country.

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

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 their 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.

Whatever direction long-term care for the American Indian and Alaskan Native 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.

For more information about caregiving, please visit www.cdc.gov/aging/caregiving.

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[Announcer] For the most accurate health information, visit www.cdc.gov or call 1-800-CDC-INFO 24-7.