



**Emerging LTSS Issues in Indian Country:**  
Executive Summary

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

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## Executive Summary

As a population, American Indians and Alaska Natives (AI/ANs) are living longer than previous generations.<sup>1</sup> While this shift in life expectancy indicates some health improvement, AI/ANs still live shorter lives and experience generally worse health outcomes than the overall U.S. population, including higher rates of disability and chronic illnesses occurring at younger ages.<sup>2</sup> These health disparities are of growing concern, particularly in light of recent U.S. Census Bureau estimates that project the number of AI/AN elders aged 65 and over to double by the year 2050.<sup>3</sup> Faced with compounding issues, such as poverty, geographic isolation, and limited access to health care and other health services, AI/AN elders facing a growing need for and access to culturally appropriate long-term supports and services (LTSS).

LTSS are a broad set of services—including health care, personal care, and social services—for the chronically ill, people with disabilities, or elderly individuals who need assistance with activities of daily living.<sup>4</sup> The need for LTSS in Indian Country covers a wide scope of services, ranging from end-of-life care to respite and caregiver support. Currently available research into LTSS issues, concerns, and policies, however, often neglects to include a focus on tribal communities. These papers attempt to address this gap by providing an initial look at three emerging LTSS topics and their related issues within Indian Country: Rebalancing LTSS funding for home- and community-based services (HCBS), Adult Family Homes, and Alzheimer’s and Dementia.

### Rebalancing LTSS Funding for HCBS in Indian Country

HCBS provide promising options to improve access to and quality of LTSS in Indian Country. Recent funding efforts now focus on “rebalancing,” or shifting the majority of LTSS Medicaid spending from institutional care to HCBS in tribal communities. The Money Follows the Person – Tribal Initiative in North Dakota and the Oneida Nation Community Option Program Waiver Program highlight current examples of tribal, state, and federal government efforts to fund needed LTSS programs and supports to enable tribal elders and AI/ANs with disabilities to receive care in the community.

### Adult Family Homes in Indian Country

While LTSS can be provided in a facility, many tribes are working to develop and implement service programs that allow Native elders to remain in their homes and communities while receiving culturally appropriate care and support. Adult family homes (AFHs) provide one option for HCBS in tribal communities. Low start-up and operational costs offer tribes with limited resources or smaller elder populations the possibility of addressing LTSS needs in the community, rather than forcing elders to seek needed long-term care in residential facilities located away from their homes and families. Wide

<sup>1</sup> Indian Health Service. (2015). *Trends in Indian health 2014 edition: General mortality statistics*. Washington, DC: Indian Health Service, p. 143.

<sup>2</sup> <https://www.ihs.gov/newsroom/factsheets/disparities/>

<sup>3</sup> <https://www.census.gov/prod/2014pubs/p25-1140.pdf>

<sup>4</sup> <https://www.cms.gov/Outreach-and-Education/American-Indian-Alaska-Native/AIAN/LTSS-TA-Center/info/ltss-overview.html>

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variations in state requirements for AFH development and operation may impact the type and amount of resources required of a tribe. However, AFHs still offer a viable solution for tribes that want to provide culturally appropriate, affordable, long-term care to elders or others in need of such services in a way that allows tribal members to remain in the community.

## Alzheimer's Disease and Dementia in Indian Country

Unfortunately, not much is known about the prevalence, risks, or incidence of Alzheimer's disease and dementia in Native populations. What is known, however, is that a greater number of AI/ANs are living longer and often face a high risk of developing these diseases. Issues regarding a lack of awareness and education about the disease, the use of culturally inappropriate or ineffective diagnostic tools, and patient-provider relationships often marred by past negative experiences further hamper attempts to address these challenges and assist AI/AN patients in need of care. By increasing Native-specific research, strengthening education and outreach efforts (for community members and providers), and developing more culturally appropriate tools and interventions, it is possible for tribes, health care providers, and policy makers to effectively and proactively address the impact of Alzheimer's and dementia in tribal communities.

These papers not only introduce these issues, but also highlight recommended action steps that tribal leaders, programs, and policy makers can and should take to effectively address emerging concerns and challenges. These recommendations include:

- Establish collaborative stakeholder partnerships between tribal, state, and federal agencies and the funder to increase access to and awareness of resources, such as Medicaid reimbursements.
- Increasing outreach and education efforts to community members and service providers.
- Pursue additional funding streams, particularly those that benefit tribes and states, such as 100% Federal Medical Assistance Percentage.
- Finally, increase research to better understand the current and potential impacts of these LTSS issues as they become more prominent for AI/ANs. This research should focus on these issues as they specifically present in and relate to Native populations. Only then will tribes, providers, and policy makers have the information necessary to develop and implement policies and solutions that effectively address emerging LTSS needs of tribal communities throughout Indian Country.