



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

Emerging LTSS Issues in Indian Country: Disability and Housing

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Emerging LTSS in Indian Country: Disability and Housing

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Emerging LTSS in Indian Country: Disability and Housing

Introduction

American Indians and Alaska Natives (AI/ANs), particularly those living on reservations, experience a higher rate of disability than the general American population (Chung-Fan, et al., 2014). In addition, the lack of adequate housing is a problem in tribal communities and is especially problematic for AI/ANs with a disability. This high rate of disability and lack of housing equates to a serious need for long-term services and supports (LTSS) in Indian Country. LTSS are a broad set of services, including health care, personal care and social services, that are delivered over an extended period of time to older adults and people with disabilities who are unable to perform their activities of daily living independently (Centers for Medicare & Medicaid Services (CMS), 2016).

The housing needs of people with disabilities are complex, and the inability to access adequate housing can jeopardize the health and safety of this population. AI/ANs are more likely to live in substandard housing than the general population, which is associated with poor health and increased rates of disability (The Kaiser Family Foundation, 2013; Krieger & Higgins, 2002). The complex relationship between housing, disability, and overall health status is a serious challenge for tribal communities.

The federal Department of Housing and Urban Development (HUD) currently offers several housing assistance programs (HUD, 2017). Many tribal governments have housing authorities that help increase home ownership and affordable housing opportunities for their communities (Ulmer, n.d.; Davis, 2002). However, none of these services are dedicated specifically to AI/ANs with disabilities, and face barriers to implementation in Indian Country.

Tailored housing programs could reduce the far-reaching effects of poverty in tribal communities, improve the basic quality of life for AI/ANs with disabilities, and improve the general health of AI/ANs with and without disabilities (McClure, 2008; Native American Disability Law Center, 2012a & 2012b; Krieger & Higgins, 2002). The research summarized in this brief emphasizes the need for tribes, the federal government, and other stakeholders to come together to address this gap in housing services for AI/ANs with disabilities.

This brief examines the history of housing and disability in Indian Country and the issues AI/ANs with disabilities currently face in their search for housing assistance. The brief also profiles one innovative tribal housing program that address the housing needs of AI/AN communities. Further, it offers recommendations for steps to take to develop accessible housing.

The Legal Status of Indian Tribes

The federal government's relationship with tribes is complicated by centuries of steps and missteps, dating back to the colonial period. At the center of this relationship is the status of federally recognized tribes as sovereign nations within the United States, established in numerous treaties with individual or confederated tribal nations. The sovereign status of federally recognized tribes has been recognized and ratified in the U.S. Constitution, federal treaties with tribes, federal law, and court decisions (Fowler et



al., 2000). Complicating this relationship are years of policy shifts, program development changes, and administrative redirection where the trust responsibility established between tribes and the United States has not been considered. Treaties, which promised tribes benefits and reserved rights including health and housing supports to tribal communities, are irregularly interpreted by policymakers causing barriers to successful implementation and access.

Housing Programs in Indian Country

Substandard housing has been a major issue on tribal reservations since they were created in the 1800s. Progress around housing assistance for AI/AN communities began during the mid-20th century with the 1934 Indian Reorganization Act and the 1937 U.S. Housing Act (USHA) (Davis, 2002; Ulmer, n.d.). Under USHA, the federal government created housing assistance programs for AI/AN tribes (Davis, 2002). The USHA established the Low Rent Public Housing Program to help states remedy unsafe and unsanitary housing conditions for low-income persons and provide local public housing agencies with more responsibility to administer their programs (Ulmer, n.d.).

Federal policy shifted again in the 1960s as tribal self-determination slowly gained momentum, during which time, HUD first formally included tribes in its programs (Davis, 2002; Ulmer, n.d.). Federal housing assistance became even more robust with the passage of the Native American Housing Assistance and Self Determination Act of 1996 (NAHASDA). NAHASDA implements and supports the federal government's trust obligation to provide housing assistance to federally recognized tribes and is a major resource for Indian Housing Authorities (HUD, 2017; Ulmer, n.d.). Under NAHASDA, tribes can design their own housing assistance programs; however, they are no longer eligible for assistance under the USHA (HUD, 2017).

Today, Indian Housing Authorities provide housing assistance on reservations and are crucial to providing housing assistance to many AI/AN community members with disabilities (Dwyer, Fowler, Seekins, Locust, & Clay, 2000; HUD, 2017). Because housing is an important determinant of health and a powerful tool for reducing poverty, Indian Housing Authorities are vital resources for AI/ANs with disabilities, many of whom are in dire need of housing assistance (Krieger & Higgins, 2002; McClure, 2008).

Disability in Indian Country

Several citations in the literature identify that AI/ANs experience higher rates of disability than the general U.S. population (Boccuti, Swoope, & Artiga, 2014; Printup-Harms, 2010). According to the National Council on Disability, 22% of AI/ANs have a disability compared to 20% among the general population. This high rate of disability can indicate a high demand for LTSS, including housing services in tribal communities.



Cultural Preferences and Attitudes Towards Disability

Although the provision of LTSS in the home and community has become mainstream in the United States over the last two decades, and expanded greatly in the last 5 years, care in an individual's home has always been the preferred model in Indian Country. Many AI/ANs with disabilities rely strongly on family and friends as in-home caregivers, who typically do not receive formal training or pay (Printup-Harms, 2010). Nursing homes provide the second most common form of care for AI/ANs with disabilities. However, these facilities are typically far away from tribal communities and may be unavailable to younger AI/ANs with disabilities (Goins et al., 2011).

In-home care is preferred and typical in Indian Country over institutional care. Many AI/ANs with disabilities rely strongly on family and friends as in-home caregivers (Printup-Harms, 2010). Nursing homes provide the second most common form of care for AI/ANs with disabilities. However, these facilities are typically far away from tribal communities and may be unavailable to younger AI/ANs with disabilities (Goins et al., 2011).

Researchers and policy makers often overlook AI/AN cultural considerations and definitions of disability, though many Native cultures' concepts of disability do not resemble the general Western definition (CMS, 2014; Goins et al., 2011). For example, there is no word in the Nez Perce language for *disability* (Fowler et al., 1996). This lack of translation presents a challenge for tribes that attempt to develop disability programs based on traditional Western models.

To provide LTSS for tribal members with disabilities, many AI/AN cultures focus on options that help AI/ANs with disabilities remain in their homes with the support of their families. It is likely that this choice is both culturally and financially based, since a distant long term care facility would prevent family from even visiting their loved one.

Barriers to Housing for AI/ANs with Disabilities

Lack of Information and Awareness

Despite the prevalence of disabilities on tribal reservations, many tribal governments do not have a thorough understanding of federal disability law and policy because it is not a requirement for them as sovereign nations. Since sovereign immunity protects any nation from lawsuits related to federal law, there has been no real reason to fully understand or implement laws which are not applicable and which have tremendous costs associated with compliance. Although implementing the law and understanding it are separate issues, generally when a law requires implementation, tribes seek to master its tenets. It is unlikely that tribes are not implementing disability compliance because they do not support equal access, rather since the law does not apply, they are not familiar with the benefits it could provide to tribal members. In a 2000 survey, very few tribal governments were familiar with major disability legislation, including the Americans with Disabilities Act (ADA), Sections 503 and 504 of the



Rehabilitation Act of 1973, and the Individuals with Disabilities Education Act of 1990 (Fowler et al., 2000). For example:

- only 39% of tribes in the lower 48 states and 4% of tribes in Alaska had a line item in their budgets for LTSS programs that help tribal members make their homes wheelchair accessible, and
- only 20% of tribes in the lower 48 states and 2% of tribes in Alaska had a line item in their budgets to make public buildings and areas accessible (Fowler et al., 2000).

Many individuals in tribal communities, particularly low-income individuals, are unaware of the breadth of housing services available to them (Native American Disability Law Center, 2012a&b). Tribal governments and housing authorities should consider education and outreach in their communities to spread awareness of existing housing services and provide assistance to tribal members who are interested in taking advantage of those services (Native American Disability Law Center, 2012a&b).

Lack of Culturally Relevant Solutions

Housing and disability programs and initiatives are ineffective in Indian Country unless they are culturally relevant. Tribal governments are not obligated to adhere to many federal regulations, including the ADA, which means that tribes may choose not to adhere to federal policies, or they may opt out of federal programs that do not satisfactorily meet their needs in a culturally appropriate way (Fowler et al., 1996 & 2000).

In addition to tribal sovereignty, culturally relevant solutions in Indian Country are necessary to properly address the diversity of AI/AN cultures. Culturally respectful initiatives incorporate community feedback in their planning process to create programs and policies tailored specifically to the individual tribes. This makes it easier to generate community support for the program and increases the program's likelihood to succeed (Dwyer et al., 2000; Fowler et al., 1996; Goins et al., 2011).

Funding for Housing Programs

HUD's Office of Native American Programs

Most Indian Housing Authorities receive funding from federal grant sources. HUD's Office of Native American Programs (ONAP) administers housing and community development programs that benefit AI/AN tribal governments and individuals and works with Indian Housing Authorities. Programs offered through ONAP include:

- the Indian Housing Block Grant,
- the Indian Home Loan Guarantee Program, and
- the Title VI Loan Guarantee Program (HUD, 2017).



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These programs aim to address the federal housing obligation to tribes by increasing the supply of safe, decent, and affordable housing for AI/AN families. In addition, ONAP sponsors training programs for tribal leaders, tribal housing staff, housing professionals, and other stakeholders (HUD, 2017). The programs are helpful resources for AI/ANs with disabilities, tribal leaders, and Indian Housing Authorities interested in addressing housing concerns within their communities. However, none of the three programs specifically address disabilities and housing modifications or solutions to accommodate them (HUD, 2017).

The Indian Housing Block Grant Program provides funding to tribal governments and Indian Housing Authorities looking to provide services in their communities. HUD allocated \$660 million in fiscal year 2016 to 587 tribes in 35 states (HUD, 2016). These funds provide important housing assistance in Indian Country and are an essential funding source for Indian Housing Authorities.

Promising Research

The American Indian Disability Legislation Project

The American Indian Disability Legislation Project (AIDL) is an example of a culturally relevant housing solution for AI/ANs with disabilities. The AIDL sought to develop an understanding of the concept of disabilities among AI/AN tribes and communities and to create a framework for tribes to draft their own disability policies and legislation (Dwyer et al., 2000). After completing case studies with five AI/AN tribes, the AIDL concluded that many tribes would be willing to develop their own programs and legislation in line with the ADA and without direct government intervention if they have the awareness of effective solutions and resources to do so (Dwyer et al., 2000; Fowler et al., 1996). More projects like the AIDL are needed to provide tribes with the resources to develop their own legislation and programs.

Recommendations

There has been little formal research regarding AI/ANs with disabilities and their housing needs. Most literature comes from the late 1990s to mid-2000s. Much of this literature documents the passage of the ADA in 1990 and the NAHASDA in 1996. These federal policies encourage tribal leaders and other stakeholders to think about how disabilities and housing assistance affect Indian Country. Training, toolkits, and effective solutions for accessibility would have a positive impact on providing adequate housing for tribal members with disabilities. Additionally, there is a need for current research about disability legislation and practice in Indian Country and a review of model programs for best practices.

The true rates of AI/ANs with a disability who live in substandard housing is unknown, however with the aging of the AI/AN population and the trend to establish home-based LTSS, accessibility in housing structures will become increasingly important. Additional research is a good first step towards a clearer picture of the housing situation for individuals with a disability in Indian Country. Current literature



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suggests a strong need for increased collaboration between tribal governments, housing authorities, and the federal government to effectively increase housing services for AI/ANs with disabilities. Actions recommended in the literature are summarized here.

- The federal government should establish which agency(ies) are responsible for assisting tribes in developing their own disability laws and policies (Dwyer et al., 2000; Fowler et al., 1996).
- HUD, BIA, and other federal agencies should work with tribes to help them design, develop, and implement disability and long-term care policies that are consistent with specific tribal cultures, traditions, and desires (Chung-Fan et al., n.d.; Fowler et al., 1996; National Council on Disability, 2002).
- The federal government should create federal programs specifically dedicated to addressing disabilities and long-term care in Indian Country (Fowler et al., 2000; Ulmer, n.d.).
- HUD, BIA, tribal governments, and Indian housing Authorities should increase outreach and awareness in Indian Country regarding available housing programs (Native American Disability Law Center, 2012a&b).
- Federal and tribal housing programs should dedicate funding for housing assistance to people with disabilities (Davis, 2002; Native American Disability Law Center, 2012a&b; Ulmer, n.d.).
- Tribal governments should consult with tribal members to determine which specific services and programs their community needs (Fowler et al., 1996; Native American Disability Law Center, 2012a&b).
- HUD should provide trainings for tribal leaders, disability care providers, and housing professionals in tribal communities (Native American Disability Law Center, 2012a&b).



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National American Indian Housing Council

“Because we focus solely on housing in tribal communities, our members and the tribal community at large recognize the NAIHC as a leader on tribal housing advocacy and providing TTA services.”

– Tony Walters, Executive Director, NAIHC

Program Description

The National American Indian Housing Council (NAIHC) was founded in 1974 by tribal housing entities that recognized the need to create a national presence to advocate for tribal housing policies to Congress and to work with federal agencies to support tribal housing entities and initiatives.

Today, the NAIHC promotes and supports Native housing entities in their efforts to provide culturally relevant and affordable housing of good quality on behalf of Native people. NAIHC conducts advocacy in Washington, DC, with Congress and the Executive Branch. NAIHC also provides training and technical assistance (T/TA) to Native housing entities to bolster their programs, help them identify relevant funding, and help them leverage opportunities. This includes T/TA for housing programs that assist AI/ANs with disabilities.

The NAIHC often provides training to its member entities and the tribal housing community on compliance with federal regulations. Because of the diversity of its membership and its small size, the NAIHC does not focus on local or state regulations.

Successful Strategies

NAIHC has seen success in its efforts to build partnerships, acquire funding, and incorporate cultural into their services.

Operation: The NAIHC is an independent, 501(c)(3) corporation

Location: Washington, DC

Contact Information:

Tony Walters
122 C Street, NW.
Washington, DC 20001
(202) 789-1754
twalters@naihc.onmicrosoft.com

Website: <http://naihc.net/>

Community: The NAIHC has 271 members representing 463 tribes and housing organizations





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Partnership

NAIHC's members are tribal housing entities who provide direct housing services in their communities. They also partner with numerous private sector groups in the housing industry to ensure that their services can be effective in tribal communities.

"The NAIHC was created solely to carry out advocacy and TTA activities."

– Tony Walters

Funding

NAIHC uses a mix of membership dues and fundraising for most administrative tasks and operations. The Training and Technical Assistance (TTA) program is funded by grants from the Department of Housing and Urban Development (HUD).

Cultural Considerations

NAIHC's programming is geared towards developing housing projects in tribal communities, which reflects a greater understanding of how tribal governments and their housing entities operate in their communities.

Because it is a national organization, the NAIHC board of directors is broken into geographic regions to ensure that the NAIHC can capture regional issues and best practices and incorporate regional differences into their TTA.

Barriers and Future Considerations

Increased funding would allow NAIHC to provide greater TTA and more opportunities for capacity building in tribal housing programs. Consistent funding is a challenge for the NAIHC, particularly for its TTA, which it funds through HUD grants. Otherwise, NAIHC's biggest challenge is reflecting the specific needs and issues of its members, as tribes across the country vary widely in size, geography, and the socio-economic status of their members.