

Long-Term Services and Supports in Indian Country: Issues Affecting American Indians and Alaska Native Consumers with Disabilities

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Executive Summary

Throughout the United States, American Indians and Alaska Natives (AI/ANs), particularly those living on reservations, experience higher rates of disability and health conditions than other racial or ethnic groups (Agency for Healthcare and Research and Quality, 2003; University of Montana, 1995). And while rates of disability increase with age, more than 25 percent of those who need care are 64 years old or younger (U.S. Census Bureau, 2012). For those with disabilities who require assistance with daily living activities, AI/AN communities often lack access to the necessary resources. Greater research on this topic as well as increased financial, social, and political support are needed to improve information, outreach, and outcomes of long-term services and supports programs that can effectively serve the needs of AI/ANs with disabilities in tribal communities. Initial steps toward such improvements can and should include increased collaboration, communication, and programmatic and service flexibility.

Introduction and Methodology

This report highlights the status and experiences of AI/AN people with disabilities and the issues they face seeking long-term services and supports in Indian Country. It summarizes and discusses data collected from academic articles, government publications, organizational materials, and other online information sources. The report contains a brief overview of three tribally-operated programs providing long term services and supports (LTSS) for people with disabilities, as well as a discussion of findings which suggest methods to improve the research into, and the development of services for, tribal members with disabilities.

In short, this report aims to:

- Discuss perspectives of disability within an indigenous framework,
- Provide an overview of the status of people with disabilities in Indian Country, including an examination of prevalence and incidence rates, causes, and implications for tribal communities;
- Examine issues of tribal sovereignty, program and service funding, and family caregiver needs; and
- Offer a discussion of best practices and findings from the literature regarding ways to improve the provision of effective LTSS for AI/ANs with disabilities throughout Indian Country.

Background

The unique legal status of Indian tribes

American Indians and Alaska Natives have a unique relationship with the federal government that is unlike any other population in the United States. Treaties were negotiated with sovereign Indian nations beginning in the colonial period and continuing after the

establishment of the U.S. into the late 1800s. This long-established special political relationship with AI/ANs is based upon the AI/AN tribal status as sovereign¹ nations, and is recognized and ratified in the U.S. Constitution, treaties, federal law, court decisions and numerous executive orders. It is a unique government-to-government relationship, based upon the cession of millions of acres of land in exchange for certain promises, benefits, and reserved rights.

The federal obligation to provide health services to American Indians and Alaska Natives is based upon this unique historical government-to-government relationship. The Snyder Act of 1921² was authorized by Congress for the “relief of distress and conservation of health and for the employment of physicians” for Indian people throughout the U.S. Later, the Indian Health Service (IHS) was established under the U.S. Public Health Service to carry out the federal responsibility to provide health care to AI/AN people under the Transfer Act³ in 1955. Subsequent federal statutes have expanded and clarified the underlying authority of the Snyder Act and opened doors to a broader range of health delivery systems, reimbursements, and initiatives. Most significant were the Indian Self-Determination Act of 1975⁴, which authorized tribes to administer their own health programs, and the Indian Health Care Improvement Act of 1976⁵, which, among other advances, expanded revenues by authorizing IHS and its tribal contractors to bill Medicare and Medicaid for services provided to eligible beneficiaries. The Center for Medicare and Medicaid Services (CMS) oversees the policies implementing Medicare, Medicaid, Children’s Health Insurance (CHIP) and new authorities under the Affordable Care Act⁶ (ACA) that serve AI/AN communities.

Over 2 million AI/AN people from 566 federally recognized tribes and 34 urban Indian communities are served by health programs funded by the IHS. The IHS-funded health system is significantly challenged given the limited funds appropriated annually, geographic access barriers faced by many remote communities, and poor living conditions of the majority of the population. While steady progress has been achieved since 1955, the health status of AI/AN populations still lags far behind that of other populations, exacerbated by poverty, poor nutrition, lack of exercise, obesity, substance abuse, violence, and injuries. In fact, according to the *IHS Trends in Indian Health 2002-2003*, comparison of death rates among AI/AN populations and that of the general population in the U.S. show that AI/AN alcoholism death rates are 524% greater, diabetes mellitus rates are 193% greater, tuberculosis rates are 750% greater, and unintentional injury rates are 153% greater. The 10 leading causes of death for AI/AN populations of all ages cited by IHS (2009) are: (1) diseases of the heart; (2) malignant neoplasms; (3) unintentional injuries; (4) diabetes mellitus; (5) chronic liver disease/cirrhosis; (6) cerebrovascular disease; (7) chronic lower respiratory diseases; (8) suicide; (9)

¹ **Tribal sovereignty** in the United States is the inherent authority of indigenous tribes to govern themselves within the borders of the United States. The federal government recognizes tribal nations as "domestic dependent nations" and has established a number of laws attempting to clarify the relationship between federal, state, and tribal governments.

² U.S. Code, Title 25, Sec. 13

³ H.R. 303. Public Law 568

⁴ 25 USC 450. Public Law 93-638

⁵ 25 USC 1601. Public Law 94-437

⁶ H.R. 3590. Public Law 111-148

pneumonia/influenza; and (10) homicide. The AI/AN age-adjusted mortality rate remains among the highest in the nation at 1,027.1 deaths per 100,000 population, as compared to 832.7 for all races in the U.S. The majority of these leading causes of death for the AI/AN population are preventable.

While AI/ANs' health care is often viewed as a prepaid right negotiated by treaty and affirmed by federal law, its funding is discretionary and relies upon annual Congressional appropriations which fall far short of the need. Reimbursement for services through Medicare, Medicaid, CHIP and new insurance markets offered under the ACA provide much needed financial support to Indian health care systems.

Long-Term Services and Supports and American Indians/Alaska Natives with Disabilities

The federal government recognizes 566 American Indian and Alaska Native tribes and villages within the United States. The 5.2 million people counted in these groups comprise roughly 2%(1.7%, specifically) of the U.S. population (Norris, Vines, & Hoeffel, 2012). Despite such small numbers, American Indians and Alaskan Natives (AI/AN) experience a disproportionate rate of disability that some estimates place as much as six times higher than any other group in the United States (Ma, Coyle, Wares, & Cornell, 1999). Current national data shows that the rate of disabilities among AI/AN non-institutionalized populations is close to 23% (U.S. Census Bureau, 2012; Smith-Kaprosy, Martin, & Whitman, 2012). By comparison, the disability rate for the general population is approximately 18% (Brault, 2012). These numbers are further compounded by high poverty rates, geographic isolation, limited employment options, and a cultural heterogeneity that mandates an individual service approach for every tribe (National Council on Disability [NCD], 2003). It is this population of AI/ANs with disabilities, who make up a significant portion of Native consumers in need of long-term services and supports, on which this report focuses.

Long Term Care (LTC) is defined as a spectrum of on-going health and social services required by an individual with a health condition that limits their capacity to care for themselves due to physical, cognitive, or mental disability. **Long Term Services and Supports (LTSS)** are defined as services provided to individuals in need of LTC to assist with activities of daily living, or ADLs (e.g., personal care, dressing, bathing and other daily living activities); instrumental activities of daily living, or IADLs (e.g., medication management, financial assistance, transportation, housework and other activities considered instrumental to daily living), or both.⁷ Also, it is important to note that LTSS services include residential care in facilities and non-institutional placement, like home and community-based care options which provide both health care-related and non-health-care-related services. This is not to be confused with **managed LTSS**,

⁷ The need for long-term services and support is generally defined based on functional limitations (need for assistance with or supervision in ADLs and IADLs) regardless of cause, age of the person, where the person is receiving assistance, whether the assistance is human or mechanical, and whether the assistance is paid or unpaid.

which is contracted care with state Medicaid programs that ensure delivery of quality, standard, predefined LTSS services in exchange for capitated payments.

There is no single, definitive, list of services that defines an LTSS program. Rather, any service provided to an individual by a program that serves in a daily or instrumental capacity can be LTSS. However, a program receiving funds from Medicaid is required to provide specific services in order to qualify to receive funding.

Typical LTSS services provide medical, personal, and social support such as assistance with eating and meal preparation, bathing, driving, house care, financial assistance, and counseling services (Goins, Bogart, and Roubideaux, 2010). These services can be provided within institutional or home- or community-based settings. Goins et al. (2010) report that for AI/ANs with disabilities, more human services than health services tend to be readily available and offered by tribes, with nutrition/congregate meals, transportation, and home delivered meal programs most often provided. Conversely, financial planning, speech therapy, and adult day care are the least common. The services most likely to be tribally operated include home maintenance and repair, home modification, and wellness and disease management.

Disability in Indian Country

Indigenous perspectives of “disability”

Researchers and policy makers often overlook the cultural heritages, circumstances, attitudes, and expectations that influence perception of disability (Hasnain, 2004; Marshall & Largo, 1999). Variations in identity and perspectives of disability can have considerable repercussions on the development, implementation, and reception of services to AI/ANs with disabilities. Each tribe will have their own perspective on disability. Frankland, Turnbull, Wehmeyer, & Blackmountain (2004) note that the Diné (Navajo) people do not historically recognize disability as a medically-bound condition. In fact, terms such as *learning disabilities* and *autism* have only recently been translated into the Navajo language. As a result, most commonly used disability models, while helpful when framing disability and service provision, often fail to account for variations in cultural perspective of minority communities (Nikora, Karapu, Hickey, & Te Awekotuku, 2004).

In its survey examining the cultural relevance and implementation of federal disability law in tribal communities, the University of Montana’s Rural Institute (1995) concluded that cultural or traditional influences may impact whether an AI/AN individual identifies as a person with a disability. Such variations in identity could not only affect the accuracy of reported rates of disability in tribal communities, but also the rates at which AI/ANs with disabilities actively seek out LTSS services. Individuals who do not perceive themselves as having a disability may not be aware that they may possibly qualify for LTSS programs that could help them live more independently.

One of the observations made in the literature by Cohen et al. (2012) focuses on the cultural context within which the term “disability” is conceptualized by many AI/ANs. As the authors point out:

...the concept of disability in some AI/AN communities may focus on whether the individual is living in harmony or whether the individual is able to fill his/her role in family and community rather than an individual's impairment. Although the term 'disability' is now more commonly used in AI/AN communities, its meaning may differ from community to community (p. 25).

Research continually stresses the importance of recognizing the heterogeneity of Native communities and how they understand and talk about issues that may fall within the purview of what non-Native culture traditionally interprets and defines as a disability. How disability services are presented has an impact on the receipt of these services within the community. LTSS is commonly viewed as services provided to the elderly or individuals with disability. It is a less common view that young people are eligible for LTSS or that LTSS services may not meet the needs for every individual with disability.

Incidence, prevalence, and causes

A survey of independent living centers referenced by the National Council on Disability (2003) noted that the most frequently observed disabilities among American Indians living on reservations included spinal cord injury, diabetes, blindness, mobility disability, traumatic brain injury, deafness, hardness of hearing, orthopedic conditions, and arthralgia.

AI/ANs have one of the highest levels of disability of any racial group in the United States (Goins et al., 2010; Cohen et al., 2012). A report by the Social Security Administration, drawing on data and definitions from the 2005-2009 American Community Survey, estimates that the rate of disability among the AI/AN population is approximately 23% as compared to 18% for the national average (Smith-Kaprosy et al., 2012; Brault, 2012). Research further indicates that AI/ANs with disabilities generally have higher rates and greater severity of secondary conditions than other racial and ethnic groups (University of Montana, 1995; Aldrich, 2009). This suggests that AI/ANs with disabilities experience greater need for more complex care and potentially more limitations with activities of daily living than the general population (Goins, Turner, Spencer, Roubideaux, & Manson, 2005).

Beyond what qualifies as a disability, the literature points to other causes contributing to the prevalence of disability rates found across AI/AN populations. The 1997-2000 Behavioral Risk Factor Surveillance System (BRFSS), which looks at health-status indicators and health-risk behaviors, found that AI/ANs were more likely to report having poor health, obesity, and diabetes than other racial groups (Denny, Holtzman, & Cobb, 2003). Barnes, Adams, and Powell-Griner (2010) similarly found higher rates for diabetes, heart disease, and chronic liver disease and cirrhosis for the AI/AN population than for all other racial and ethnic groups, as well as higher mortality rates from tuberculosis, chronic liver disease and cirrhosis, accidents, diabetes, pneumonia, suicide, and homicide in 2005. Many of the aforementioned conditions indicate that many AI/AN communities experience risk factors and chronic conditions that often lead to a greater incidence of disability later in life at disproportionately high rates compared to the general population.

The BRFSS also reported that AI/AN respondents were more likely to engage in health-risk and health-adverse behaviors, such as smoking, lack of physical activity, binge drinking, and drinking and driving (Denny et al., 2003). It is thought that the rate of fetal alcohol syndrome and the growing rate of diabetes (at an increase of 46% between 1990 and 1998) in the AI/AN community, particularly among younger people, also contribute to the rate of disability (Cohen et al., 2012). Poor health outcomes are no surprise in Indian Country, but it seems that the legacy of these health issues, and what they may mean for AI/AN communities, is not always taken into account.

Beyond physical ailments, research also suggests that other demographics have a similar impact on disability rates in Indian Country. In their comparison of disability rates among older AI/ANs and other races, Goins, Moss, Buchwald, and Guralnik (2007) found that lower levels of education attainment, employment, marriage, and household income increased the likelihood of reporting a functional limitation. In addition, “being female increased the odds of having a mobility disability by 10%” (Goins et. al, 2007, p. 694). These figures mirror data for the general population of people with disabilities: recent census data indicate that more women than men live with a disability in the United States, and that people with disabilities are less likely to be employed, experience higher rates of poverty, and earn less income than people living without disabilities (Brault, 2012).

Although the tendency is to discuss this issue and how it affects adults, particularly the elderly in Indian Country, the impact of disabilities among AI/ANs can often be seen earlier. Okoro et al. (2007) note that the onset of disability occurs at much younger ages among Native populations. As Cohen et al. (2010) point out:

Among children 5 to 15 years old, the disability rate is 5.7% for non-Hispanic Whites, but 7.0% for Black children and 7.7% for AI/AN children. Although the disability rate is 16.2% for non-Hispanic Whites of working age (16-64), it is 26.4% for Blacks and 27.0% for AI/AN (p. 10).

Although it is important to understand the aging AI/AN population with regard to rates of disability in Indian Country, this does not adequately capture the fact that more and more young AI/AN people are experiencing disabling conditions long before they reach the age where they might be considered elderly. Redford (2002) points out that as AI/ANs develop disabilities at earlier ages, the potential demand of long term services and supports in Indian Country rapidly increases. These individuals require LTSS provisions earlier and over a longer period of time. And as these individuals age, additional services may be required to adequately respond to LTSS needs that evolve over the course of one’s lifespan. Factors such as these make managing disabilities and health care needs through the implementation of effective and appropriate LTSS programming even more imperative for many AI/AN communities.

Implications and impact

The implications of these prevalence figures are significant. While the lifespan of the AI/AN population is lower than the national average, life expectancy has been growing. For instance, the 2000 Census demonstrated that the AI/AN elder population has

increased since 1995 (Aldrich, 2009). By the year 2020 the AI/AN population aged 55 or older is expected to be 1,319,000 (Goins & Pilkerton, 2010). This means that many AI/ANs will end up living longer with functional disabilities. Research evidence suggests that older AI/ANs experience much higher functional disability rates than other U.S. racial groups. According to Census data, AI/ANs over 65 years of age reported disability at a rate of 57.6%, compared to 41.9% the general population of the same age (Aldrich, 2009). Should these projected growth estimates hold true, they could potentially more than double the number of people in Indian Country in need of long-term care.

Preexisting infrastructure barriers and service gaps further compound issues faced by many AI/ANs with disabilities. People with disabilities living in Indian Country are additionally hampered by “cultural barriers, geographic isolation, inadequate sewage disposal, and low income” (Office of Minority Health, n.d., “Health”; NCD, 2003). Tribal communities often lack employment or day programs for adults living with developmental disabilities, and there is a dearth of transportation available for people who cannot drive themselves (Cohen et al., 2012). While examining tribal service accessibility, researchers at the University of Montana (1995) found that acute care and general health services were often available, but services that fall under the umbrella of LTSS, such as rehabilitative services (either institutional or home-based) and respite care were not widely available. Transportation and communication also serve as key factors in terms of access, particularly in rural areas such as reservations. Many LTSS services are located off the reservation, and a lack of telephone access for many living on reservations often prevent access to and remote engagement in LTSS programs (University of Montana, 1995). This is an important point, as disabilities can often be isolative not only physically, but also mentally. Barriers to access thus pose additional hurdles that must be overcome.

Urban Indians

Prior to the 1950s, most AI/AN resided on reservations, in nearby rural towns, or in tribal jurisdictional areas. In the era of the 1950s and 1960s, the federal government’s policy included termination of tribes and relocation of Indian families into some of the largest cities in America. This philosophy produced the Bureau of Indian Affairs (BIA) Relocation/Employment Assistance Program, which enticed Indian families living on impoverished Indian reservations to relocate to various cities across the country (i.e., San Francisco, Los Angeles, Chicago, Salt Lake, Phoenix, etc.) BIA Relocation offered job training and placement, and many Indian families saw it as a way to escape poverty on the reservation. Health care was usually provided for only six months through the private sector, unless the family was relocated to a city near a reservation with an IHS facility service area such as Rapid City, Phoenix, or Albuquerque. The 1977 American Indian and Policy Review Commission found that in the 1950s and 1960s the BIA relocated more than 160,000 AI/ANs to selected urban centers across the country.

Today, 78% of all AI/ANs identified in the 2010 census reside off-reservation.⁸ In 2004, the first comprehensive national study on urban Indian health revealed a community in crisis. The study

⁸ U.S. Census Bureau, 2010 Census Redistricting Data (Public Law 94-171) Summary File, Table P1.

found that urban Indians had multiple health risks. When compared to the general population, urban Indians also experienced higher death rates due to alcohol-related causes, chronic liver disease and cirrhosis, diabetes, and accidents.

The findings of this study were later republished in 2006 in a peer-reviewed article in the *American Journal of Public Health* (Castor et al.). American Indians and Alaska Natives living in cities face poverty, unemployment, disability and inadequate education at rates far above those of other Americans. These and other risk factors have contributed to a health crisis in this population despite an ongoing effort to eliminate health care disparities across all races and ethnicities.

In their report, Castor, Smyser, & Taulii (2006) found that the urban Indian death rate due to accidents is 38% higher; diabetes is 54% higher; chronic liver disease and cirrhosis is 126% higher, and alcohol-related deaths is 178% higher than rate of the general population. Diabetes can double to quadruple an American Indian or Alaska Native adult's risk of developing cardiovascular disease (CVD), a condition that was virtually unheard of as recently as 40 years ago. Now it is the leading cause of death. However, urban cities are more likely to offer public accommodations for people with disabilities than may be found in rural remote reservation communities where roads, sidewalks, public buildings, transportation, and handicap restrooms may still lack compliance with the Americans with Disabilities Act (ADA) requirements.

Issues Influencing LTSS for AI/ANs with Disabilities

The intersection of tribal sovereignty and federal policy

Various federal laws have been implemented to protect the rights of people with disabilities within the United States over the past four decades. These laws protect access to free and quality education (the Individuals with Disabilities Act⁹), access voting opportunities (the Voting Accessibility for the Elderly and Handicapped Act of 1984¹⁰), and freedom from discrimination (the Rehabilitation Act of 1973¹¹). The most significant and often-cited piece of legislation, however, is the Americans with Disabilities Act (ADA) of 1990 (P.L. 101-336). The ADA provides protections and prohibits discrimination based on disability in four core areas:

- **Title I: Employment** (including hiring practices and provision of reasonable accommodation in a work setting)
- **Title II: Public Services** (including state and local government activities and public transportation)
- **Title III: Public Accommodations** (including privately owned services)

⁹ P.L. 94-142

¹⁰ P.L. 98-435

¹¹ P.L. 93-112

- **Title IV: Telecommunications** (including provision of telecommunication relay services)
- **Title V: Miscellaneous** (including supplemental regulations not explicitly covered in other parts of the Act. Among other things, it protects individuals with disabilities from retaliation or coercion [U.S. Department of Justice, 2009]).

Congress retains the plenary powers to regulate tribal governments. Tribal governments are not subdivisions of state governments. Tribes do not fall under state law, unless explicitly authorized by federal law. This complex legal environment, the rural remoteness of many tribes, the sovereign immunity of tribal governments from any suits brought under ADA, and the limited funding available to tribes to modernize public infrastructure suggests some reasons why some tribal governments have been slow to implement the provisions of the ADA.

For example, Title I provisions of the ADA require employers to provide fair labor practices to those with disabilities and “excludes tribal government as employers under this title” (NCD 2003, p. 31). Title I does not, however, exclude *private employers* located in Indian Country. Similarly, Title II regulates participation in programs and services run by state and local governments. As it does *not* explicitly mention tribal governments as included or exempt, many consider it inapplicable to tribal governments. Title III regarding the provision of appropriate public accommodations for people with disabilities *does* apply to tribal governments. However, the Eleventh Circuit court ruled that private lawsuits could not be brought against tribes in the federal court system, thus limiting the right of individuals with disabilities from bringing suit against a tribal government. Meanwhile, a provision exists that allows the Department of Justice to bring a suit against a tribal government, though such a suit has yet to take place (NCD, 2003).

This should not be taken as a sign that AI/AN tribes do not want to comply with the ADA or similar pieces of disability rights legislation. Many tribes are in fact very interested in implementing the provisions offered by such laws for their tribal members. For example, the Confederated Salish and Kootenai Tribes passed a resolution that adopts the spirit of the ADA, while the Oglala Lakota Nation adopted the ADA outright (RTC Rural, 1999; NCD, 2003). However, like many others in Indian Country, they have faced challenges with regard to funding to be able to adequately implement the different requirements of the law. As NCD (2003) notes, many tribal communities have small populations spread out over vast tracts of land and lack the necessary revenue streams to help support programing such as LTSS for people with disabilities.

Barriers to LTSS for People with Disabilities in Indian Country

Tribal communities face a wide range of challenges that impact their ability to develop and implement policies and LTSS programs that address the needs of tribal members with disabilities. Challenging factors faced by tribes can be environmental or economic and are often compounded by legal issues and poor understanding of government-to-government relationships. The impact of these factors, however, is considerable.

- Most of Indian Country is in rural areas, though most AI/AN peoples live in urban areas. This makes access to medical and other services difficult for AI/ANs with disabilities

living in rural areas due to a lack of resources, long travel distances, lack of public transportation, and language barriers.

- Poor health status and lack of services (particularly for people with disabilities) can be attributed to high levels of poverty and unemployment, low levels of education, insufficient housing and sanitation, and scant funding for federal health or other programs responsible for providing services to AI/ANs in Indian Country.
- Tribal government infrastructure, roads, sidewalks, public buildings, restrooms, and housing may not meet the public accommodations requirements of the ADA. This may increase the likelihood of institutionalization and reduce opportunities for independent living or even home-based LTSS.

AI/ANs with disabilities living in Indian Country face unique challenges influenced by the inherent nature and location of their communities.

Funding for services

With regard to funding for LTSS in Indian Country, there are several resources for individuals, families, and communities to draw from to create a patchwork approach to long-term service provision. For instance, the Administration on Aging (AoA) manages the Older Americans Act, which provides for the Title VI Grants for Native Americans program. The grants primarily support nutrition programs for older AI/ANs and Native Hawaiians and serves as a common funding source for human services for many older AI/ANs (Goins et al., 2010). Other services covered under the Act include home-delivered meals, senior centers, homemaker services, and other assistance designed to help elders live independently outside of an institution or residential facility (Aldrich, 2009).

Beyond the AoA, the Centers for Medicare & Medicaid Services (CMS) manages the Medicaid Home and Community-Based Services (HCBS) Waiver Program. This program allows individuals who are eligible for nursing home care and are at certain income levels to receive services in their home rather than in a facility. As Aldrich (2009) notes, “Services available under a Medicaid HCBS waiver include case management, homemaker/home health aide services, personal care services, and adult day health care” (p. 13). Goins et al. (2010) similarly found that Medicaid most often provided funding for long-term health services in AI/AN communities.

Though it often serves as the major source of LTSS funding, respondents to a survey conducted by Goins et al. (2010) indicated that fewer than half of elder and/or tribal members with disabilities were enrolled in Medicare, while 63% indicated that fewer than half were enrolled in Medicaid (p. 1345). Older tribal members often lacked of awareness or knowledge of the programs or mistrusted state and federal government (Goins et al., 2010). Aldrich (2009), however, notes that Medicaid-provided reimbursement for LTSS cannot keep pace with the cost of service provision. This is particularly salient in rural communities, which make up the majority of Indian Country. Further complicating matters is a current deficit of trained home health care workers in tribal areas. Therefore, it is an issue of lacking resources both in terms of personnel and funding.

Tribes may also have a hand in providing LTSS in their communities: A 2004 National Indian Council on Aging study (Aldrich, 2009) found that profits from tribal casinos have a profound influence on whether or not tribes provide long-term care supports and services to their tribal members. The study further noted that tribes had a tendency to use the money to pay for “home modifications and home maintenance, transportation, senior centers, and assistive devices” (Aldrich, 2009, p. 14).

Other funding sources include the IHS, which contributes to LTSS in Indian Country in the form of primary care, health disparity reduction programs (such as the Improving Patient Care program), and targeted condition resource and information provision (such as the IHS Division of Diabetes Treatment and Prevention). The passage of the Patient Protection and Affordable Care Act¹² (also known as the Affordable Care Act) enhanced the duties, responsibilities and authorities of the IHS Director. The Act also permanently reauthorized the Indian Health Care Improvement Act, permitting (though not appropriating) funding for assisted living services, home and community based services, hospice care, and long-term care and convenient care services. IHS and tribally-operated long-term care programs are also permitted to share staff and facilities (National Indian Health Board, 2010).

Tribes can also receive social service program funding from the Bureau of Indian Affairs’ (BIA) Division of Human Services, which seeks to improve the quality of life for AI/ANs throughout Indian Country and protect children, elderly and people with disabilities from abuse and neglect (Bureau of Indian Affairs, 2014). In order to obtain BIA funding, tribes must submit an end-of-year Financial Assistance and Social Service Report (FASSR) to their regional Office Self Governance (OSG) and to the office of Indian Energy and Economic Development each fiscal year. The Division of Human Services uses the FASSR to determine the amount of funds distributed during the following fiscal year (Bureau of Indian Affairs, 2010). Potential funds could also be sought through the Native American House Assistance and Self-Determination Act (NAHASDA), which provides U.S. Department of Housing and Urban Development (HUD) block grant funding to improve affordable housing activities in tribal communities (HUD, 2014). HUD-sponsored funding programs such as the Indian Community Development Block Grant and the Resident Opportunities and Self-Sufficiency program can offer tribes and tribally designated housing entities avenues through which programs that focus on independent living and accessible housing can be developed (HUD, 2009).

Community-based caregiving

Research suggests that some 90% of elder care in Indian Country is provided not by an organization or program, but by a family member (Aldrich, 2009; Ryser, Korn, & Berridge, 2008). Ryser et al. (2008) provide additional descriptions of the typical caregiver for an older AI/AN family member. According to their research, the average caregiver in AI/AN communities is often:

- 50 years of age

¹² P.L. 111-148

- Performs at least 4 hours of direct care a day
- The daughter of a family member
- Working a separate job at least half-time
- Simultaneously raising children and grandchildren (p.12).

Since caregivers are generally family members or close friends, the services they perform are usually unpaid. They are also often costly, including uncompensated labor, fuel and car maintenance, food, housing, sundries, and other out-of-pocket expenses (Ryser et al., 2008).

Similar to the impact on perceptions of disability, culture and traditional views influence the significance of the caregiver role within the family structure. Aldrich (2009) highlights the long cultural tradition of lifelong care for family. Rather than being regarded as a burden, caring for an elder family member's well-being is given great importance (Aldrich, 2009; Brown & Gibbons, 2008). Ryser et al. (2008) also note that some tribal communities do not use or recognize the meaning of the term "caregiver" and may, in fact, consider it an inappropriate label for an historical family practice, as it carries the connotation of formal work rather than custom-directed responsibility.

However, this trend is beginning to shift due to a variety of factors, such as the push and pull of migration for younger people leading them to leave the reservation in search of greater opportunities. Another confounding factor in the provision of LTSS in Indian Country is the increase in chronic health problems among AI/AN populations that often leads to an increasing need for LTSS. When combined with a declining familial support system, many AI/ANs face uncertain and often undesirable prospects with regard to receiving culturally appropriate long-term care. The literature overwhelmingly demonstrates that the preference of many AI/ANs is to stay with their families and within their communities to receive care, which has traditionally been the way that AI/AN communities have handled long-term care (Aldrich, 2009).

Program Examples: Serving AI/ANs with Disabilities

The programs described below serve as a small select sample of the tribally operated programs and organizations that serve the needs of AI/ANs with disabilities. Information on program operations and activities comes from research into program outreach and promotional materials (including program websites), the National Council on Disability (2003), and the National Association of Chronic Disease Directors (Aldrich, 2009). These programs may help serve as a model for other tribal communities seeking to develop and implement programs and services designed to meet the needs of the population of LTSS consumers—be they tribal members with disabilities, tribal elders, or both.

The Native American Advocacy Program (Rosebud Sioux)

Established in 1992, the Native American Advocacy Program (NAAP) serves two purposes for tribal communities. First, it provides culturally-based programs and interventions designed to help tribal youth and at-risk youth build a cultural identity. Second, it helps Native peoples with disabilities live an independent lifestyle. Though chartered by the Rosebud Sioux Tribe, the organization serves tribal members living on and off any of the nine tribal nations in South Dakota.

NAAP offers a range of independent living services for AI/ANs with disabilities throughout the state, including:

- Information and referrals related to accessible housing, accessible transportation, employment, personal assistance services, and assistive technology access;
- Independent living skills training such as food preparation, communication, and budget management;
- Advocacy to teach individuals with disabilities the skills needed in order to advocate on their own behalf or to advocate for systemic change;
- Peer support (i.e., peer counseling) for individuals with disabilities, their family or caregiver networks; and
- Home modification services that allow individuals with disabilities to remain in their home through property renovation (e.g., ramp installation or bathroom modification) or implementation of adaptive device technology (e.g., doorbell indicators or telecommunication devices).

NAAP also works within the state to increase public awareness of disability issues and accessibility needs at community and educational events. The group has been able to establish partnerships with other organizations to help its consumer base. For example, in 2011 NAAP partnered with Hope Haven International Ministries to provide refurbished wheelchairs for tribal members with disabilities.

The Office of Special Education and Rehabilitation Services (Navajo Nation)

With offices in Window Rock, AZ, as well as Gallup, NM, the Navajo Nation Office of Special Education and Rehabilitation Services (OSERS) provides vocational and independent living support for members of the Navajo Nation living with disabilities. This particular program is housed within the tribe's Division of Diné Education and provides services ranging from early childhood intervention (birth to three years of age) to independent living support for elderly tribal members.

The main components of the OSERS service platform are comprised of independent living support services and vocational rehabilitation services. Independent living services are provided

by ASSIST! To Independence, a Native-owned, community-based nonprofit that provides community support including assistive technology information and access, advocacy, and education and information sharing services. Vocational rehabilitation services assist tribal members with disabilities seeking to obtain or maintain employment. The services may include skills training, OT/PT services, counseling services, or Native healing services.

Additional funding and advocacy for tribally based disability programs and services comes from the Navajo Nation Advisory Council on the Handi-Capable (NNACHC) and the Navajo Nation Trust Fund for Handicapped Services. Prior tribal council approval allows Indian Trust Funds—administered by the Division of Diné Education—to be used for disability advocacy and support services expansion and improvement for people with disabilities living on Navajo lands. Trust Funds also provided the foundation for the NNACH. NNACH members receive Council appointment from tribal leadership and are tasked with numerous responsibilities, including:

- advocating for equal access to employment, education, independent living and other services for tribal members with disabilities;
- providing educational outreach and training about the needs of tribal members with disabilities to the community (including schools and other tribal programs);
- keeping informed about relevant legislative and funding issues at all levels of government; and
- advising the Navajo Nation on matters pertaining to tribal members with disabilities.

Vocational Rehabilitation and Transportation Programs (Confederated Salish and Kootenai Tribes)

As previously mentioned, the Confederated Salish and Kootenai Tribes in western Montana passed a resolution adopting the spirit of the Americans with Disabilities Act to establish protections and services for people with disabilities in their communities. Subsequently, LTSS program designers in the community first worked to increase awareness and understanding of disabilities and disability services when creating and implementing services. Through increased outreach and education efforts, the tribe improved community awareness of LTSS services and coordination efforts across programs. These efforts resulted in a strengthened vocational rehabilitation program that serves the entire reservation, with satellite offices in the cities of Mission, Polson, and Ronan. Consumers can receive support and assistance with employment training and job placement, educational support (including learning disability assessment), food stamp and commodity services, and child care support. Transportation services have also been integrated into the tribe's programs where possible, with additional support sought through collaborative efforts with partner agencies such as the Missoula Rural Transportation Department.

A Summary of Findings

The need for assessment, collaboration, and service coordination

Planning the financing of care to an American Indian and Alaska Native population that is living longer, but with greater prevalence of disabilities, is both financially and emotionally straining. Families and tribal communities often struggle to support the wide range of medical, personal, and social services needed to help individuals with disabilities live full and independent lives (Aldrich, 2009). The Agency for Healthcare and Research and Quality (AHRQ) calls for the creation of a system designed to properly identify and then coordinate American Indian long-term care needs (AHRQ, 2003). Research has identified many of the barriers preventing AI/AN with disabilities from accessing LTSS in their tribal communities: lack of infrastructure, limited funding, limited staffing, geographic isolation, failure to understand consumer perspectives of needs and disabilities, and a failure to engage tribal leadership and support (AHRQ, 2003; NCD, 2003; Ryser et al., 2008; Aldrich, 2009; Goins et al., 2010).

Moving towards implementation of effective LTSS for AI/ANs with disabilities calls for additional solutions. These include:

- **Communication, awareness and understanding of LTSS** among consumers, tribes, states and other agencies. This will help stakeholders better understand relevant community health issues, allowing for improved, targeted, policy and program decisions. In addition, including consumers in discussions of LTSS program design and implementation offers American Indian communities greater opportunities to design programs that best meets their unique needs (AHRQ, 2003).
- **Increasing access to resources through partnership and collaboration among existing systems.** Given the scarcity of adequate funding to cover the costs for LTSS in Indian Country, there is a greater need for collaboration among existing service providers and funding entities to work together to provide a more substantive safety net of services. This is particularly salient given the growing rate of disability among AI/ANs, combined with the longer life expectancy of the population, that likely signals an increase in need for LTSS moving forward (Aldrich, 2009).
- **Improving the quality of services through training and flexibility in service provision** to avoid breaks in the service streamline from agency, to caregiver, to family members. Obstructions between service agencies are responsible for lack of support for AI/AN caregivers, and impairment of services to recipients. Tribes, counties, and states should strive to provide regular in-service training explaining state and federal policies and practices; develop and engage tribal-specific long-term care policies and practices that reflect cultural, social, and economic realities; define and support assistance options for caregivers; and increase flexibility in the delivery of support services to tribal members and their caregivers (Ryser, 2008).

The need for additional research

Goins et al. (2007) point to the need for better comprehension of disability among American Indian and Alaska Native communities:

More information on the nature and extent of disabilities among [AI/ANs] would enhance the ability of advocates to document their needs and raise public awareness. Likewise, policy makers could enact prevention strategies and make comprehensive rehabilitative and long-term care services available to this population (p. 690).

Additional research in this area is needed. Research efforts for this literature review found data that, while rich, lacks the necessary sample size to make conclusions applicable across regions. As Goins et al. (2005) note in their own research, the examination of one tribe does not measure the variance in Native population, culture, and health status (p. 654). Such information requires research specific to the population of AI/ANs with disabilities by tribe and region including examinations of incidence and prevalence rates, program needs, and other data specific unique to a particular tribal area or community.

Finally, as time passes, new research is required in order to maintain the accuracy and validity of available data. Research used for program descriptions contained in this review is already between 5 and 10 years old. The rapidly changing nature of funding and resource availability necessitates continual and current research efforts in order to provide an accurate account of disability status as well as LTSS programs and activities across Indian Country.

The need for additional action

Current literature contains several points of action in which tribal communities, federal policy makers and state officials can engage in order to increase the participation of, and services to, AI/ANs with disabilities. The summary of findings from the literature is organized by government level; however, many of these actions and interventions can be implemented across other, if not all, types and levels of administration.

At the federal level

- CMS, IHS and ACL jointly support a national study on AI/AN people with disabilities;
- Amend the Older Americans Act to include financial support for intergovernmental agencies providing tribal and state representation;
- Create and fund an intergovernmental effort dedicated to disabilities and long-term care in tribal communities;
- Create and pass legislation that clarifies, defines, and provides guidelines regarding caregiver qualifications and services; and
- Create a forum that includes insight and input from subject matter experts and tribal leaders that allows for discussion and development of local resources of tribal communities (Ryser et al., 2008).

At the state level

- Consult with tribes on a regular basis to answer questions and gather input on current LTSS and disability policy and practices;
- Enact policy authorizing the creation of an intergovernmental LTSS agency that includes a budget and designated representatives;
- Utilize culturally relevant forms of communication (e.g., open public discussions, tribal forums, provision of clearly written summary materials at gatherings) when reaching out to tribal communities;
- Conduct regular staff trainings to develop levels of professional, multi-cultural best practices across state management systems, improving service quality and cross-cultural communication skills; and
- Form partnerships with tribal communities and assist in the facilitation of tribal and non-tribal community-based service collaboration to encourage and assist in the incorporation of and access to new and assistive technologies (Ryser et al., 2008; Aldrich, 2009).

At the tribal level

- Develop disability and long-term care policy that appropriately reflects the culture, traditions, and realities of the specific tribe;
- Hold regular trainings to explain and compare state and federal policy with tribal policy and practices;
- Consult with tribal members with disabilities and their families to determine the types of services and resources needed and the settings in which people prefer to receive them;
- Engage in community and programmatic outreach and educational efforts to promote awareness, respect, and acceptance of the needs of and issues affecting people with disabilities;
- Develop health living intervention programs and prevention strategies to improve the overall health outcomes of older tribal members and tribal members living with disabilities (Aldrich, 2009; Ryser et al., 2008; Cohen et al., 2012; Crawford, 2003; Goins et al., 2007).

It is imperative that researchers, policy analysts, tribal and state government officials, and service providers take the time to address the unique needs of Native peoples with disabilities. This will ensure the development of LTSS programs that are both effective and culturally appropriate for consumers across all ages and for specific communities and conditions. Not to do so runs the risk of continuing a pattern of discrimination and exclusion experienced by an already vulnerable population.

References

- Agency for Healthcare and Research and Quality (AHRQ). (2003). *Improving long-term care for American Indians in Region VIII: A workshop for tribal and state health officials*. Retrieved May 1, 2014, from AHRQ Archive at <http://archive.ahrq.gov/news/ulp/amindltc/ulpailtc.htm>
- Aldrich, N. (2009). *Caregiving in Indian Country: Tribes supporting family traditions*. Retrieved April 24, 2014, from the National Association of Chronic Disease at http://c.ymcdn.com/sites/www.chronicdisease.org/resource/resmgr/healthy_aging_critical_issues_brief/ha_cib_indiancaregiving.pdf
- American Indian Disability Technical Assistance Center (AIDTAC). (2006). *Agencies and organizations committed to improving employment opportunities and vocational rehabilitation outcomes for American Indians and Alaska Natives with disabilities*. Retrieved March 25, 2014, from www.adrc-tae.acl.gov/tiki-download_file.php?fileId=26753
- Barnes, P., Adams, P., & Powell-Griner, E. (2010). Health characteristics of the American Indian or Alaska Native Adult Population: United States, 2004-2008. *National health statistics report, 20*. Retrieved April 20, 2014, from the Centers for Disease Control and Prevention at <http://www.cdc.gov/nchs/data/nhsr/nhsr020.pdf>
- Brault, M. (2012). *Americans with disabilities 2010: Household economic studies*. Retrieved May 4, 2014, from the U.S. Census Bureau Current Population Reports: <http://www.census.gov/prod/2012pubs/p70-131.pdf>
- Brown, C., & Gibbons, J. (2008). Taking care of our elders: an initial study of an assisted-living facility for American Indians. *Journal of Applied Gerontology, 27*(4), 523-531.
- Bureau of Indian Affairs. (2014). *Mission Statement*. Retrieved June 11, 2014, from the Division of Human Services website: <http://www.bia.gov/WhoWeAre/BIA/OIS/HumanServices/index.htm>
- Bureau of Indian Affairs. (2010, December 28). Guidance: FY/CY 2011 welfare assistance distribution methodology. Memorandum retrieved June 11, 2014, from <http://www.bia.gov/cs/groups/xois/documents/collection/idc013196.pdf>
- Castor ML, Smyser MS, Taulii MM, et al. (2006). A Nationwide Population-Based Study Identifying Health Disparities Between American Indians/Alaska Natives and the General Populations Living in Select Urban Counties. *American Journal of Public Health, 96*(8), 1478-84.
- Cohen, L., Solomon, T., Joe, J., Haring, R., Randall, L., DeRoins, D., & Villavicencio, J. (2012). *2012 Native American developmental disabilities needs assessment*. Retrieved April 23, 2014, from the Association from University Centers on Disabilities: http://www.aucd.org/docs/publications/native_am_needs_assmt_sm.pdf
- Crawford, N. (2003). Knocking down access barriers: Psychologists are working to step up services to people with disabilities in rural areas. *Rural Psychologist, 34*(3), 64.

- Denny, C., Holtzman, D., & Cobb, N. (2003). Surveillance for health behaviors of American Indians and Alaska Natives: Findings from the behavioral risk factor surveillance system, 1997-2000. *MMWR*, 52(SS07), 1-13.
- Goins, R., Bogart, A., & Roubideaux, Y. (2010). Service provider perceptions of long-term care access in American Indian and Alaska Native communities. *Journal of Health Care for the Poor and Underserved*, 21(4), 1340-1353.
- Goins, R., Moss, M., Buchwald, D., & Guralnik, J. (2007). Disability among older American Indians and Alaska Natives: An analysis of the 2000 census public use microdata sample. *Gerontologist*, 47(5), 690-696.
- Goins, T., & Pilkerton, C. (2010). Comorbidity among older American Indians: The Native elder care study. *Journal of Cross Cultural Gerontology*, 25, 343-354.
- Goins, R., Turner, S., Spencer, M., Roubideaux, Y., & Manson, S. (2005). Differences in functional disability of rural American Indian and white older adults with comorbid diabetes. *Research on Aging*, 27, 643-658.
- Hasnain, R. (2004). The reality of life after high school transition: A joint effort of the young adult and his family. *TASH Connections*, 30(11), 25-26.
- Indian Self-Determination and Education Assistance Act of 1975, Pub. L. No. 93-638, 88 Stat. 2206 (codified in scattered sections of 5 U.S.C. and 25 U.S.C.).
- Kauffman & Associates, Inc. (n.d.). *Zuni elder services: Adult day care program*. Retrieved May 8, 2014, from <http://www.kauffmaninc.com/LTSS/Documents/Presentations/Zuni%20Elder%20Day%20Health%20Programs.pdf>
- Ma, G., Coyle, C., Wares, D., & Cornell, D. (1999). Assessment of services to American Indians with Disabilities. *Journal of Rehabilitation*, 65(3), 11-16.
- Marshall, C., & Largo, Jr., H. (1999). Disability and rehabilitation: A context for understanding the American Indian experience. *Lancet*, 354, 758-760.
- National Council on Disability. (2003). *People with disabilities on tribal lands: Education, health care, vocational rehabilitation, and independent living*. Retrieved March 23, 2014, from http://www.ncd.gov/rawmedia_repository/329c5323_6bb3_403c_a146_495780db5d39?document.pdf
- National Indian Health Board. (2010). *Summary of the Indian Health Care Improvement Act and Indian specific provisions in the Patient Protection and Affordable Care Act*. Retrieved June 10, 2014, from http://www.nihb.org/docs/05042010/Tab%203_3_Rev%20Summary%20of%20IHCA%20and%20OPACA_April%20%2028%202010.pdf
- Nikora, L., Karapu, R., Hickey, H., & Te Awekotuku, N. (2004). *Disabled Māori and disability support options*. Hamilton: Māori & Psychology Research Unit, University of Waikato.

Norris, T., Vines, P., & Hoeffel, E. (2012). *The American Indian and Alaska Native population: 2010*. Retrieved May 6, 2014, from the U.S. Census website:
<http://www.census.gov/prod/cen2010/briefs/c2010br-10.pdf>

Office of Minority Health. (n.d.). *American Indian/Alaska Native profile*. Retrieved February 10, 2014, from:
<http://minorityhealth.hhs.gov/templates/browse.aspx?lvl=2&lvlID=52#sthash.m6X60Dy2.dpuf>

Okoro, C., Denny, C., McGuire, L., Balluz, L., Goins, R., & Mokdad, A. (2007). Disability among older American Indians and Alaska Natives: Disparities in prevalence, health-risk behaviors, obesity, and chronic conditions. *Ethnicity & Disease, 17*, 682-692.

Redford, L. (2002). Long term care in Indian Country: Important considerations in developing long term care services. In B., Y. Jackson, L. Roebuck, and D. Baldrige Finke (Eds.), *American Indian and Alaska Native roundtable on long-term care: Final report 2002*. Spokane, WA: Kauffman & Associates, Inc.

RTC Rural. (1999). *Rural disability and rehabilitation research progress report #2: American Indian disability legislation research*. Retrieved May 3, 2014, from the National Clearinghouse of Rehabilitation Training Materials:
<http://library.ncrtm.org/pdf/674.061.pdf?t=pdf&n=674.061.pdf>

Ryser, R., Korn, L., & Berridge, C. (2008). *American Indian caregiver policy study: An analysis with findings of the barriers to federally funded and state and tribally administered caregiver programs in the state of Washington*. Retrieved May 2, 2014, from the Center for Traditional Medicine:
http://www.centerfortraditionalmedicine.org/uploads/2/3/7/5/23750643/caregiver_policy_study.pdf

Smith-Kaprosy, N., Martin, P., & Whitman, K. (2012). An overview of American Indians and Alaska Natives in the context of social security and supplemental security income. *Social Security Bulletin, 72*(4). Retrieved April 16, 2014, from the Social Security Administration website: <http://www.ssa.gov/policy/docs/ssb/v72n4/v72n4p1.pdf>

University of Montana Rural Institute. (1995). *American Indian disability legislation project: Findings of a national survey of tribal governments*. Retrieved March 28, 2014, from <http://files.eric.ed.gov/fulltext/ED399122.pdf>

U.S. American Indian Policy Review Commission. (1977). *Submitted to Congress, May 17, 1977*. Retrieved May 7, 2014, from the University of Illinois Urbana-Champaign website:
<https://archive.org/details/finalreport01unit>

U.S. Census. (2012). *Selected population profile in the United States: American Indian and Alaska Native alone or in combination with one or more other races*. Retrieved April 12, 2014, from http://factfinder2.census.gov/bkmk/table/1.0/en/ACS/12_1YR/S0201//popgroup~009

U.S. Code, Title 18: 1151. Retrieved on June 18, 2014 from Cornell University Law School website: <http://www.law.cornell.edu/uscode/text/18/1151>

U.S. Department of Health and Human Services. (2009). *Trends in Indian Health 2002-2003 Edition*. Retrieved from August 5, 2014, from the Indian Health Service, Division of Program Statistics website: [http://www.ihs.gov/dps/files/Trends_02-03_Entire%20Book%20\(508\).pdf](http://www.ihs.gov/dps/files/Trends_02-03_Entire%20Book%20(508).pdf)

U.S. Department of Justice. (2009). *A guide to disability rights law*. Retrieved on May 3, 2014, from the Information and Technical Assistance on the Americans with Disabilities Act website: <http://www.ada.gov/cguide.pdf>

U.S. Department of Housing and Urban Development. (2014). *NAHASDA*. Retrieved June 11, 2014, from: http://portal.hud.gov/hudportal/HUD?src=/program_offices/public_indian_housing/ih/codetail/nahasda

U.S. Department of Housing and Urban Development. (2009). *Native American programs-Indian community development block grant program*. Retrieved June 11, 2014, from the Community Planning & Development website: <http://www.hud.gov/offices/cpd/communitydevelopment/programs/indiancdbg.cfm>