



Understanding Disabilities in American Indian & Alaska Native Communities Toolkit Guide



National Council on Disability

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About the Cover

The four symbols on the cover of the Toolkit Guide were chosen to represent the spectrum of disabilities, whether visible or hidden, that may be experienced by people in the American Indian and Alaska Native communities. The universal meaning in each symbol is described in the captions below along with the meanings of the symbol as it is used in this Toolkit specifically.



Access for People Who Are Blind or Visually Impaired

Universally, this symbol identifies areas that are specifically designed to be accessible to or in some cases tailored to the unique abilities of people who are blind or visually impaired. Within the Toolkit, this symbol is used to represent the community of people for whom sight is not a primary sensory tool.



Mobility Access

The wheelchair symbol indicates access for people who have a mobility disability, including people who use wheelchairs. The symbol is most commonly used to indicate an accessible entrance, bathroom, or environment that is sensitive to people with specific mobility access needs. Within the Toolkit, this symbol is simply used to represent the community of people with mobility needs of this kind.



Communication Access for People Who Are Deaf or Hard of Hearing

The signing hands symbol typically indicates that sign language interpretation is provided for a lecture, tour, performance, conference, or other program. Within the Toolkit, the symbol is used to represent the community of people whose primary means of communication is sign language.



Hidden Disabilities

The face beneath face symbol was designed specifically for the Toolkit after the Technical Expert Panel determined that there were currently only universal symbols for disabilities that are seen, leaving out the experiences of people with an unseen disability such as epilepsy, developmental disabilities, alcoholism, mental illness, learning difficulties, diabetes, and others who are not represented by the universal disability symbols. The symbol was inspired by the art of many indigenous cultures that designed faces with multiple overlaid masks. This symbol represents the community of people who have disabilities that are not externally visible but significantly impact an individual's life.

Acknowledgements

Understanding Disabilities in American Indian and Alaska Native Communities Toolkit Guide was developed through the passionate collaboration of many people. The foundation of this project was formed in a powerful sharing of experiences, knowledge, and hopes among consumers and advocates who live with disabilities. These people strived to create a new perspective about what it means to be an American Indian or an Alaska Native with a disability. This new consciousness will serve to transform AI/AN communities nationally and offer a new hope to so many people who for so long have felt invisible with no voice.

Thank you to our project researcher/writer Robin Troup. She contributed greatly to the success of the project.

Special Acknowledgement

The National Council on Disability issues this publication in honor of the late Dr. Geraldine-Drake “Gerrie” Hawkins. Dr. Hawkins served as NCDs Senior Policy Analyst until her death in 2016. We are dedicating this toolkit to her because of her longstanding work, keen interest, and unwavering commitment to making certain that tribal and American Indian issues were included in disability rights efforts. She recognized the intersectionality of so many issues long before intersectionality made its way into the national consciousness.

Technical Expert Panel

Several people representing consumers and advocates within the American Indian and Alaska Native disability communities nationwide were recommended to serve as members of a national Technical Expert Panel. The Technical Expert Panel served as project consultants and advisors, providing guidance to the staff on the direction of the project. The Panel was instrumental in providing critical feedback and direction on the multitude of issues addressed throughout the development of this toolkit. The Technical Expert Panel members are as follows:

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Chapter 1: Introduction to Understanding Disabilities in Indian Country

Treat all men alike. Give them all the same law. Give them all an even chance to live and grow. All men were made by the same Great Spirit Chief. They are all brothers. The Earth is the mother of all people, and all people have equal rights upon it. . . . Let me be a free man, free to travel, free to and talk and act for myself.

*Chief Joseph, Nez Perce
Lincoln Hall speech (1879)*

Chief Joseph understood the basic dignity and rights of all people, and we are still working to realize his vision. In the 1980s, attitudes about people with disabilities began to change with the Social Model of Disability, which states, “People with disabilities are people first.” A disability is not a person’s whole identity. A disability is just one part of the person.

It is understood that AI/AN people with disabilities do not need to be “cured” or “fixed” but do need to be valued and included in all aspects of society. In truth, the effort continues today to ensure that everyone with a disability has equitable access, reasonable accommodations, and the opportunity to fully participate in their community.

AI/AN people with disabilities face unique circumstances and legal environments

that require special outreach, consultation, protections, and services. There is a great desire among AI/AN people with disabilities to work in partnership with sovereign tribal governments and state, local, and nongovernmental entities to make communities and workplaces more accessible, caring, and representative of the beautiful, unique contributions everyone brings to this world.

Who comprises our community and what is the number of federally recognized tribes?

The Federal Government, through the Bureau of Indian Affairs (BIA), officially acknowledges 574 “federally recognized” tribes and Alaska Native villages (U.S. Department of Interior).

What is the size of the American Indian and Alaska Native populations, and where do they live?

There are over 3.7 million Americans who identify exclusively as American Indian or Alaska Native according to the 2020 U.S. Census. Over 9.6 million Americans identify as American Indian or Alaska Native only or in combination with another ethnicity. This is a 159.5 percent increase over the 2010 U.S. Census and comprises 1.8 percent of the total U.S. population (U.S. Census Bureau).

The U.S. Bureau of Labor Statistics reports that most AI/ANs do not reside in AI/AN areas, which are defined as federal or state American Indian reservations or off-reservation trust lands, tribal statistical areas, or Alaska Native village statistical areas. In 2016-18,

- 28% of the AI/AN population resided in AI/AN areas
- 30% of AI/AN area residents were age 55 or older (2019)

What percentages of AI/ANs have a disability and by what age?

Data from the Centers for Disease Control and Prevention found that 30 percent of American Indian or Alaska Native adults have a disability, the highest rate of disability of any ethnicity.

Of the 3.7 million American Indian or Alaska Natives who identify exclusively as AI/AN on the 2020 Census, 1.1 million have a disability (U.S. Census Bureau 2021).

In 2019, the U.S. Census Bureau estimated 2.6 million U.S. households, or 4.3 percent, had at least one child in the home with a disability. In American Indian or Alaska Native homes,

Race	Percentage with Disabilities
American Indian/Alaska Native	30%
Black	25%
White	20%
Native Hawaiian/Pacific Islander	16%
Hispanic	16%
Asian	10%

(Centers for Disease Control and Prevention 2020)

5.9 percent had a child with a disability, the highest disability rate of any ethnic or racial group (Young).

The U.S. Census Bureau's Current Population Survey with a combined 2016 to 2018 average found that younger AI/ANs were more likely to have a disability (16 percent) than the overall population (12 percent). Among AI/ANs 55 and older, 34 percent had a disability, compared with 23 percent for the overall population in the same age range (U.S. Bureau of Labor Statistics 2019).

What Is a Disability?

The term "disability" is defined by the Federal Government in various ways, depending on the context. For the purposes of federal disability nondiscrimination laws (such as the Americans with Disabilities Act (ADA), Section 503 of the Rehabilitation Act of 1973 and Section 188 of the Workforce Innovation and Opportunity Act), the definition of a person with a disability is typically defined as someone who (1) has a physical or mental impairment that substantially

limits one or more “major life activities,” (2) has a record of such an impairment, or (3) is regarded as having such an impairment.

For purposes of Social Security disability benefits, a person with a disability must have a severe disability (or combination of disabilities) that has lasted, or is expected to last, at least 12 months or result in death, and which prevents working at a “substantial gainful activity” level.

State Vocational Rehabilitation (VR) offices define a person with a disability to be eligible for VR services if he or she has a physical or mental impairment that constitutes or results in a “substantial impediment” to employment for the applicant.

U.S. Department of Labor, Office of Disability Employment Policy

While definitions vary, nearly all these definitions rely upon some measure of functional limitation. Assessing the severity of a disability is often done by totaling the number of Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) (NRCNAA 2002).

Activities of Daily Living:

- Feeding
- Walking
- Toileting
- Continence
- Dressing
- Bathing
- Getting in/out of bed or a chair

Instrumental Activities of Daily Living (more complex activities that involve thinking and organizational skills):

- Cleaning and housekeeping
- Doing laundry
- Managing money
- Managing medications
- Preparing meals
- Shopping
- Transportation use
- Use of communication devices such as phones and computers

What Types of Disabilities are Found in Native Communities?

Every type of disability found in the general population is also found in the AI/AN population. Many people have hidden or unseen disabilities, such as emotional or mental health challenges, learning disabilities, substance use disorder, or deafness. People are born with their disability or acquire it early or later in life due to disease, age, or injury. If we live long enough, each of us will experience life with a disability.

Few datasets exist for American Indian people that provide a clear and accurate snapshot of the health status of the AI/AN population. A small study surveyed tribal communities to identify the most frequent types of disabilities in their communities (AIDL 2000). Due to underrepresentation of AI/ANs with disabilities in academic studies, more recent data is not available. However, the results of this small survey are likely still true.

- Diabetes
- Visual impairments, including blindness
- Mobility disability, including Arthralgia

- Hearing impairments, including deafness
- Emotional or mental health issues
- Disabilities affecting learning
- Substance use disorder

The National Resource Center on Native American Aging conducted surveys of older adults and identified the top five chronic conditions of older adults 55 and older. Also, 41.1 percent of Native Elders reported experiencing one or more falls in the past year.

High Blood Pressure	57.5%
Arthritis	45.3%
Diabetes	35.3%
Cataracts	20.0%
Depression	14.1%

(National Resource Center on Native American Aging 2020)

A Minority Health Equity report, by the Centers for Disease Control and Prevention identified the five leading causes of death in male and female Native Americans aged 45 and older:

- Heart disease (#1 in men; #2 in women)
- Cancer (#1 in women; #2 in men)
- Diabetes
- Chronic liver disease
- Chronic lower respiratory disease
- Stroke (2017)

Federal Disability Laws and Tribes

People with disabilities living on tribal lands face a complex legal environment. Tribal lands are subject to the jurisdiction of tribal governments, long recognized as distinct political entities. This

sovereignty may also affect the application of federal regulations to tribes. Federally recognized Indian tribes, as sovereign self-governing nations, are protected from private lawsuits under the doctrine of “sovereign immunity.” Tribes can be sued only if they agree to waive their sovereign immunity for that purpose.

People with disabilities who are concerned about their rights and protections guaranteed under the Rehabilitation Act of 1973 (29 U.S.C. §§ 701 et seq.) or the Americans with Disabilities Act of 1990 (42 U.S.C. §§ 12101 et seq.), may face unique barriers when seeking enforcement or a remedy by a tribal government.

Government-to-Government Relationships

The United States has a unique legal and political relationship with Indian tribes and a special relationship with Alaska Native entities as provided in the Constitution of the United States, treaties, and federal statutes. These relationships extend to the Federal Government’s historic preservation activities, mandating that federal consultation with Native American tribes be meaningful, in good faith, and entered into on a government-to-government basis.

Architectural Barriers Act of 1968 (ABA)

The ABA states that certain federal and federally funded buildings and other facilities are to be designed, constructed, or altered in accordance with standards that ensure accessibility to, and use by, physically handicapped people.

- ABA Regulations in 24 CFR Part 41 do not apply to tribes (U.S. Department of Housing)

Civil Rights Act of 1968

All persons shall be entitled to the full and equal enjoyment of the goods, services, facilities, privileges, advantages, and accommodations of any place of public accommodation without discrimination on the grounds of race, color, religion, or national origin.

- Title II (Public Accommodations) applies to federally recognized tribes, including Tribally Designated Housing Entities (TDHEs)
- Public Accommodations include places of lodging, restaurants, places of entertainment, public gathering spaces, and retail or other establishments that serve customers (U.S. Department of Justice)

Rehabilitation Act of 1973

The Rehabilitation Act prohibits discrimination based on disability in programs conducted by federal agencies, such as federal employment or any programs that receive federal funds. In determining employment discrimination, the Rehabilitation Act uses the same standards as Title I of the ADA.

- Section 121 of the Rehabilitation Act authorizes the Rehabilitation Services Administration to make grants to tribes for the purpose of Vocational Rehabilitation (VR) services. Tribes accepting these grants, and generally other federal funds, agree to comply with federal law. However, this agreement does not amount to a waiver of sovereign immunity, which protects tribes from lawsuits in federal court. As such, people with disabilities may have a right without a remedy.

- Section 504 of the Rehabilitation Act and the U.S. Department of Housing and Urban Development's implementation regulations in 24 CFR Part 8 apply to any recipient of federal financial assistance, including tribes and tribal entities (U.S. Department of Housing).

Fair Housing Act of 1988

The Fair Housing Act prohibits discrimination in housing based on race, color, religion, sex, national origin, familial status, and disability.

- The Federal Fair Housing Act and implementing regulations of NAHASDA in 24 CFR Part 100 do not apply to Indian tribes and the TDHEs of those tribes engaged in NAHASDA-funded activities (U.S. Department of Housing).

Americans with Disabilities Act (ADA) of 1990

The ADA is a civil rights law that prohibits discrimination solely on the basis of disability in employment, public services, and accommodations. Tribal sovereignty makes the ADA largely inapplicable to tribal nations.

Title I of the ADA prohibits discrimination on the basis of disability in employment.

Tribal governments are categorically excluded as employers.

- Title I requires employers with 15 or more employees to provide qualified people with a disability with an equal opportunity to benefit from the full range of employment benefits available to others. It restricts discrimination in hiring, promotions, pay, and other privileges of employment. Employers must make reasonable accommodation for the known

physical or mental limitations of otherwise qualified people with disabilities unless it results in an undue hardship to the employer.

- Private employers operating within reservations are not excluded as employers (Thorton 2019).

Title II of the ADA prohibits discrimination based on disability in state and local government.

Tribal governments are NOT specifically exempt from the provisions of Title II.

- On June 22, 1999, the Supreme Court made a landmark ruling interpreting Title II of the ADA. The decision, *Olmstead v. L.C.* (527 U.S. 581 (1999)), found that Title II of the ADA requires states to provide community-based treatment for persons with mental disabilities when the state's treatment professionals determine that such placement is appropriate, the affected persons do not oppose such treatment, and the placement can be reasonably accommodated.
- Title II of the ADA applies to tribes when receiving federal funds from agencies that have specific ADA regulations. For example, Title II of the ADA applies to Tribal Transit Programs funded by the Federal Transit Administration.
 - The practical application of the Olmstead ruling is that states must help provide the least restrictive level of care for people with disabilities, moving away from institutionalization and toward home- and community-based care.
 - Although Title II is not always applicable to tribes, it could present new opportunities for tribal governments to

partner with states to develop home- and community-based services that are reimbursed by Medicaid or other sources of funding.

Title III of the ADA prohibits discrimination on the basis of disability in public accommodations.

Private people cannot sue a tribal nation for noncompliance (unless the tribe has expressly waived its sovereign immunity). Only the U.S. attorney general can bring a suit against a tribe to enforce the act.

- Public accommodations include places of lodging, restaurants, places of entertainment, public gatherings, etc. are considered public accommodations if they affect interstate commerce.
- In practical terms, tribal nations are immune to private Title III lawsuits (Thorton 2019).
- The only legal remedy available would be for the U.S. Attorney General to compel tribal compliance, which has never happened.

Native American Housing Assistance and Self-Determination Act of 1996 (NAHASDA)

Through the Department of Housing and Urban Development, funding is provided for two housing programs.

- Indian Housing Block Grant, a formula-based grant to provide a range of affordable housing activities on Indian reservations and in Indian areas
- Title VI Loan Guarantee, which provides financing guarantees to Indian tribes for private market loans to develop affordable housing

Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act)

The DD Act assures that people with developmental disabilities and their families participate in:

- The design of and have access to needed community services
- Individualized supports
- Other forms of assistance

The Developmental Disabilities Administration (DDA) partners with state and tribal governments and Indian organizations to deliver services and supports to eligible clients that promote self-determination, independence, productivity, integration, and inclusion in all facets of community life through culturally competent programs.

The Developmental Disabilities Administration is responsible for the implementation of the Act and funds five main programs:

- State Councils on Developmental Disabilities
- Protection and Advocacy Agencies
- University Centers for Excellence in Developmental Disabilities
- Family Support Programs
- Projects of National Significance (Administration for Community Living)

Workforce Innovation and Opportunity Act of 2014 (WIOA)

On July 22, 2014, President Obama signed H.R. 803, the Workforce Innovation and Opportunity Act, commonly referred to as WIOA (pronounced as “wee oh uh”).

- WIOA is designed to help job seekers access employment, education, training, and support services to succeed in the labor market and to match employers with the skilled workers they need to compete in the global economy (U.S. Department of Labor).

WIOA Programs

- Adult and Dislocated Worker Program
 - Funds are allocated to local Job/Career centers for staff salaries, adult employment, and training activities. Priority is given to veterans, recipients of public assistance, low-income individuals, and individuals with basic skills deficiencies.
- Indian and Native American Program
 - Section 166 of WIOA provides grants to Native American programs to support employment and training activities to develop academic, occupational, and literacy skills consistent with the traditional cultural values and beliefs of the people they serve.
- JobCorps
 - A national residential career training program that helps eligible young people ages 16 through 24 to complete their high school education, train for meaningful careers, and obtain employment.
- National Dislocated Worker Grants
 - Section 170 of WIOA provides discretionary grants to state and other eligible applicants to respond to people who are laid off or experience other

significant job loss from such events as relocation of a military spouse or a natural disaster.

- National Farmworker Jobs Program
 - A nationally directed, locally administered program of services for migrant and seasonal farmworkers and their dependents. It provides equitable access to career services, skill development, workforce protections, and housing to some recipients.
- Reentry Employment Opportunities Program
 - Funding for justice-involved youth and young adults and adults who were formerly incarcerated. The purpose is to improve this population's workforce outcomes.
- Wagner-Peyser Employment Service
 - Establishes a national employment service with states to provide employment services and unemployment insurance
- WIOA Youth Program
 - Provides an online learning destination for youth to learn about the workforce system
 - Helps states and local job/career centers develop career pathways with leaders, practitioners, and policy makers
 - Provides summer job opportunities
 - Assists youth who are not enrolled in school or have basic skills deficiencies receive education, training, and services to support their career pathway goals
- YouthBuild

- A community-based pre-apprenticeship program that provides job training and educational opportunities for at-risk youth ages 16 through 24 who have previously dropped out of high school (U.S. Department of Labor)

Supporting Older Americans Act of 2020 (OAA)

OAA was originally authorized in 1965 and provides the organization and delivery of social and nutrition services to older adults and their caregivers. It authorizes a wide array of service programs through a national network of 56 state agencies on aging, 618 area agencies on aging, nearly 20,000 service providers, 281 tribal organizations, and one Native Hawaiian organization representing 400 tribes.

- The OAA also includes community service employment for low-income older Americans; training, research, and demonstration activities in the field of aging; and vulnerable elder rights protection activities
- The 2020 reauthorization aims to remove barriers to the aging network and increase capacity and flexibility in the allocation of services (Administration for Community Living)

Common Barriers

Attitude: Many nondisabled people often see a disability and not the person's gifts, potential, and value. You can help change this! As most tribes recognize, there is power in storytelling to create unity, dismantle barriers, bring healing, and inspire hope. To change attitudes, model respect and kindness and ask others about their experiences.

Lack of Awareness: There is a shortage of information about the number of American Indian/Alaska Natives with disabilities, types of disabilities in Indian communities, and the myriad of opportunities and service programs available to tribal governments to better protect and assist their members with disabilities.

Legal Enforcement Unclear: Federal laws designed to protect people with disabilities are not always enforceable in Indian Country due to the sovereign status of tribes. However, not all enterprises located on tribal lands are exempt from federal laws. Many tribes have adopted their own disability rights ordinances and codes to protect their members with disabilities. The allocation of resources for people with disabilities and enforcement of these ordinances varies by tribe and the jurisdiction that oversees enforcement is most often the tribe and not the Federal Government.

Rural Transportation: Most tribal lands are in remote rural areas of the United States and either lack public transportation systems or have inadequate transportation infrastructure. These conditions make it very difficult for tribal community residents to travel to hospitals, stores, schools, and employment centers. Transportation improvements increase the independence of people with disabilities.

Rural Infrastructure: Tribal communities may not have the infrastructure to support access and accommodation for people with disabilities, such as sidewalks and sidewalk ramps for wheelchair access. Tribal communities may lack access to high-speed Internet or the means to acquire assistive technology for people with disabilities. In 2022, federal infrastructure funds are available to tribes to provide or expand broadband Internet service and improve water systems.

Public Access: Tribal office buildings that serve their community are not always accessible for people with disabilities because some tribes lack the resources to retrofit their buildings to accommodate people with disabilities.

Complex Federal Programs: A variety of federal and state programs provide important resources for people with disabilities on tribal lands, but they can be difficult to navigate. Due to overlapping or conflicting responsibilities of the federal, state, and/or tribal programs, one must be determined and be assertive in accessing information and resources.

State Relationships: Relationships between tribes and states can be strained because of overlapping or conflicting jurisdictions and other issues. States may offer many services and programs that can be helpful for people with disabilities and their families living in Indian Country. It is important to remember that while tribes are sovereign governments, their members are also citizens of the state and of the United States and are entitled to the resources and services of state programs.

Education Systems: The majority of AI/AN children are educated through the public school system of their state. A small number of American Indian/Alaska Native children are educated in tribally operated schools or Bureau of Indian Education (BIE) schools. The Individuals with Disabilities Education Act (IDEA) requires all schools receiving federal funding, including public, grant, BIE, and private schools to provide children with disabilities a free appropriate education based upon the Individualized Education Program of each child. Parents of AI/AN children with disabilities may not be aware of the rights, services, and supports their children are entitled to by IDEA. Every state has

one or more Parent and Community Resource Centers to support parents in advocating for their child’s educational rights under IDEA. (See the “Resources” link in the Education chapter for a list of Parent and Community Resource Centers.)

Employment: Federally recognized Indian tribes are specifically exempt as employers under Title I of the ADA, which prohibits discrimination against qualified people with disabilities in employment and requires that employers make reasonable accommodation for employees with disabilities (42 U.S.C. §§ 12101 et seq.). This exemption is a barrier for Indians with disabilities in Indian Country, particularly in rural areas where tribal governments are the largest employer. Some tribal governments have voluntarily complied with ADA or adopted their own codes to protect people with disabilities from employment discrimination.

Housing: Homes are not generally designed to meet the needs of people with disabilities. There may be limited funding at the tribal level to retrofit tribal or private housing. This housing barrier can mean the difference between a person with disabilities living independently or living under the care of others. Accessibility may mean ramps to doorways, 32-inch-wide doorways, and lower light switches and countertops. At a minimum, every home should be “visitable,” meaning the home can be lived in or visited by people who have difficulty with steps and use canes, wheelchairs, or walkers.

Service Coordination and Advocacy: Tribal communities do not always have a central location where services for people with disabilities are coordinated. Often people have multiple needs, such as housing, employment,

medical care, and advocacy. The lack of centralized coordination results in multiple trips, extra time, expense, and frustration for AI/AN people with disabilities.

Personal Care Assistance: Getting out of bed, bathing, dressing, and leaving the house can present major barriers for some people with disabilities. Yet, the support of a personal care attendant enables AI/ANs with disabilities to participate in their community, including education, social events, and the workforce. Home- and community-based services can facilitate much greater independence for AI/ANs with disabilities.

Historical Trauma and Healing

Historical Trauma in AI/AN Communities

According to a report of the U.S. Department of Health and Human Services Substance Abuse and Mental Health Services Administration (SAMHSA), Native Americans are more likely to experience mental disorders than other racial and ethnic groups in the United States. “Of great concern is the high prevalence of depression, anxiety, substance abuse, violence, and suicide. Other common mental health problems of Native American individuals are psychosomatic symptoms and emotional problems resulting from disturbed interpersonal and family relationships” (SAMHSA, p. 11). According to SAMHSA, failure to address the “historic trauma” and culture of Native Americans in health care and other areas “will only add to the oppression experienced by Native Americans for decades” (ibid, pp. 11- 12). Nonetheless, disentangling socioeconomic

factors, cultural influences, civil rights issues, and the effect of race/ethnicity is difficult for any health condition, particularly mental health disorders.

Vernellia Randall

What Is Historical Trauma?

Historical Trauma is the collective emotional wounding across generations that results from mass cataclysmic events—Historically Traumatic Events (THE). The trauma is held personally and transmitted over generations. Thus, even family members who have not directly experienced the trauma can feel the effects of the event generations later.

Donald Warne

In 1492, the entirety of the current United States was five million and 100 percent indigenous. By 1900, there were 200,000 American Indians in the current U.S. (Warne 2019). American Indians were killed through colonization, warfare, intentional spread of disease, and forced removal from homelands and to boarding schools. Survivors experienced a significant pattern of loss.

- Loss of life
- Loss of population
- Loss of land
- Loss of culture
- Loss of language
- Loss of traditional parenting structures
- Loss of resources

Ongoing wars, the Trail of Tears, boarding schools, bounties paid for dead American Indians,

broken treaties, and the death/disappearance of loved ones leaves a biological-psychological-social response. Today's poverty in Indian Country is rooted in the theft of our land.

The long-term impacts of genocide cause anger and depression and is passed from one generation to the next, which results in stark health disparities. As such, the average age of death in North Dakota is:

- 54.7 years for American Indians
- 75.7 years for Whites (North Dakota Department of Health 2017)

This massive trauma expresses itself today in the form of high rates of substance use disorder, violence, alcoholism, and sexual abuse within Native families and communities. Many accounts suggest that the boarding school generations were permanently scarred by their experiences of physical, mental, and sexual abuse in the school system. When these Native children returned to their homes and families, having lost their culture and identity, and began to have families of their own, they were unable to form healthy bonds and passed on these patterns of abuse to their own children, creating cycles of broken families.

Native Hope

The responses to historical trauma were first documented by Dr. Brave Heart and include:

Survivor guilt; Depression; PTSD; Psychic numbing; Fixation to trauma; Somatic (physical) symptoms; Low self-esteem; Victim identity; Anger; Self-destructive behavior including substance abuse;

Suicidal ideation; Hypervigilant; Intense fear;
Disassociation; Compensatory fantasies;
Poor affect (emotion) tolerance

Culturally Relevant/Healing-Informed Care

She Who Heals

Mother, sing me a song
That will ease my pain,
Mend broken bones,
Bring wholeness again.
Catch my babies
When they are born,
Sing my death song,
Teach me how to mourn.

Show me the Medicine
Of the healing herbs,
The value of spirit,
The way I can serve.

Mother, heal my heart
So that I can see
The gifts of yours
That can live through me.

An American Indian Healing Prayer

(QuotesGram)

The Substance Abuse and Mental Health Administration's handout on Healing-Informed Care for tribal communities outlines the characteristics of indigenous ways of knowing that are important in healing.

Holistic – Interconnectedness underlies all of human experience.

Balance – Because of the interdependencies of all life, achieving and maintaining balance is

important both to the individual and the larger group.

Moral Code – The physical and metaphysical worlds are linked to a moral code.

Respect – Respect of all living things and each other is essential for balance.

Healing has been defined as “transition toward meaning, wholeness, connectedness, and balance (U.S. Health and Human Services 2015, P. 9).

Menominee Example

The Menominee Tribe implements several culturally relevant approaches.

For example, pregnancy is seen as a sacred state of being, and keeping women and babies safe and healthy is considered part of an honorable way of life.

- These values are affirmed by teaching high school students the Menominee Grandfather Teachings (wisdom, love, respect, bravery, honesty, humility, and truth), and providing girls with culturally relevant reproductive health and support services.
- Since these efforts were undertaken, annual births among girls aged 15-17 have dropped from a high of 20 in 2008 to fewer than 5.

Similarly, a local coalition called Maehnow Pemalesen, which means “living in a good way,” has worked to reinforce traditional values among youth and to establish drug-free cultural events, such as an annual sobriety powwow.

- Over the past decade, rates of substance abuse among high school students have declined, including use of marijuana (30%), cigarettes (49%), and alcohol (64%).

Benefits of Culturally Informed Prevention Programs

Cultural Practices	Benefits
Language classes	<ul style="list-style-type: none"> ▪ Informs the cultural worldview, ways of knowing, knowledge systems, values, and practices ▪ Connects tribal members to each other and their culture ▪ Unlocks the worldview, values, and teachings
Smudging (purification)	<ul style="list-style-type: none"> ▪ Provides a feeling of the sacred and safety ▪ Focuses attention and intention ▪ Helps turn thinking from negative to positive
Ceremonies and ritual	<ul style="list-style-type: none"> ▪ Gets tribal members in touch with a sense of spiritual connection ▪ Focuses the mind, heart, and body on healing ▪ Communicates a message of personal responsibility, “You have something to do.” ▪ Reminder that healing is relational and takes place in one’s community
Stories and artwork	<ul style="list-style-type: none"> ▪ Illustrates and clarifies values ▪ Connects people to each other and to place ▪ Conveys culturally specific values, including high expectations, caring, support, and opportunities for participation
Talking circles	<ul style="list-style-type: none"> ▪ Promotes belonging ▪ Provides a safe and healthy way to resolve conflict ▪ Encourages community
Gift giving (generosity)	<ul style="list-style-type: none"> ▪ Demonstrates and solidifies connectedness ▪ Shows respect for the giver and recipient
Visiting	<ul style="list-style-type: none"> ▪ Encourages people to tell their stories and to connect with each other ▪ Helps release internalized pain ▪ May help show the connection between thought and feeling ▪ Helps people get in touch with their purpose
Subsistence/ culture camps	<ul style="list-style-type: none"> ▪ Teaches AI/AN values ▪ Contributes to belonging and a sense of self worth
Respect of elders	<ul style="list-style-type: none"> ▪ Teaches indigenous values ▪ Contributes to belonging and a sense of self worth ▪ Provides support
Fun walks/runs	<ul style="list-style-type: none"> ▪ Addresses the physical component of wellness ▪ Brings the community together

(continued)

Cultural Practices	Benefits
Powwows	<ul style="list-style-type: none"> Connects tribal members to each other and their culture Conveys cultural values, including high expectations, caring, support, and opportunities for participation
Regalia, arts, and craft making	<ul style="list-style-type: none"> Connects tribal members to each other and their culture Provides opportunities for hands-on learners to connect to their culture

(U.S. Health and Human Services 2015, 9)

Examples of Cultural Healing Practices

Cultural healing practices vary from tribe to tribe and village to village. However, there are commonalities among the practices.

Mental Health, Substance Misuse, and Suicide in Indian Country

The statistics on the prevalence of mental illness, substance misuse, and suicide in Indian Country is stark. A 2018 National Survey on Drug Use and Health: American Indians and Alaska Natives conducted by the U.S. Health and Human Services with the Substance Abuse and Mental Health Services Administration found:

- 1 in 11 AI/ANs with a substance use disorder
- 5.3% of AI/ANs older than 18 had both a substance use disorder and a mental illness
- 22.1% of AI/ANs had a mental illness (SAMHSA, slide 17)
- Nearly 25% of Native Americans reported binge drinking in the past month.

The rate of substance dependence or abuse is higher among Native Americans than any other population group in the country. Native Americans have the highest methamphetamine abuse rates, including past month use at more than three times the rate of any other group. They are more likely to report drug abuse in the past

month (17.4%) or year (28.5%) than any other ethnic group (American Addiction Center).

Statistics on the suicide and death rates of young American Indian/Alaska Natives are grim.

- In 2019, suicide was the 2nd leading cause of death for AI/ANs ages of 10–34.
- AI/ANs are 60 percent more likely to experience the feeling that everything is an effort, all or most of the time, as compared to non-Hispanic whites.
- The AI/AN suicide rate is 20 percent higher than the non-Hispanic white population.
- In 2019, the death rate of adolescent AI/AN females, ages 15–19, was five times higher than non-Hispanic white females in the same age group.
- In 2018, the death rate of AI/AN males, ages 15–24, two times that of non-Hispanic white males in the same age group (CDC).

There are many programs in recent years that were developed or adapted based on tribal culture and traditions to address these health and wellness disparities.

The Substance Abuse and Mental Health Services Administration's (SAMHSA) Tribal Training and Technical Assistant Center developed a cultural framework for healing mental health, substance use, and suicide prevention in

Indian Country. The three cornerstones of the framework are:

- *Balance* – Illness is seen as being out of balance; some part of the whole is not in balance with the rest of the whole. To heal, all four aspects of an individual should be considered and should be in balance—mental, emotional, spiritual, and physical.
- *Relational* – All things are interconnected. Health is holistic, but also communal. If an individual is unwell, the family, community, and future generations are affected. By the same token, the effects of a healthy person will also ripple through the community.
- *Strengths-based* – The indigenous worldview assumes that all people have innate strengths they bring when facing adversity. Healing-informed care recognizes this belief and helps people and communities express these strengths.

In the Resources section of this chapter’s toolkit are two publications from SAMHSA that describe many culturally informed programs that reduce substance misuse and promote mental health in American Indian and Alaska Native populations. What follows are summaries of just a few of these prevention programs.

Culturally Informed Programs

The Peacemaker taught us about the Seven Generations. He said, when you sit in council for the welfare of the people, you must not think of yourself or of your family, not even of your generation. He said, make your decisions on behalf of the seven generations

coming, so that they may enjoy what you have today.

*Oren Lyons (Seneca) Faithkeeper,
Onondaga Nation*

American Indian (AI)/Alaska Native (AN) communities represent strength and resilience within a history of attempted genocide, cultural assault, and ongoing systemic oppression. . . . A system of care that includes indigenous community mental health workers in addition to Native psychologists, psychiatrists, and other mental health professionals has great potential in improving overall wellness and restoring balance in Indian Country.

O’Keefe et al. 2021

American Indian and Alaska Native Mental Health Workers

Most tribal members say they prefer to see a Native health provider. AI/AN mental health workers are such a solution because they:

- Hold local tribal understandings of history, culture, health, and wellness
- Increase the number of local mental health practitioners, which removes the barriers that include travel time, wait time, and access to care
- Enable tribes to expand and improve service
- Help people to restore balance, wellness, and connection to the tribe’s resilience

AI/AN mental health workers receive training in evidence-based practices and provide patient navigation, case management, culturally appropriate psychoeducation, and access to local cultural

resources. Although AI/AN beliefs and practices vary by tribe, local cultural resources may include:

- Prayer
- Ceremony
- Storytelling
- Art and movement
- Healing and Talking Circles
- Interactions with a traditional healer
- Daily practices to sustain balance and wellness

(O’Keefe 2021)

Examples of Culturally Informed Adult Programs for Mental Health, Substance Misuse, and Suicide Prevention

Holistic System of Care (HSOC) for Native Americans in Urban Environments

Developed by the Family and Child Guidance Clinic of the Native American Health Center, San Francisco, CA.

- A flexible framework that encourages the combination of evidence-based practices and practice-based evidence, such as:
 - Gathering of Native Americans
 - Positive Indian Parenting
 - Intertribal AI/AN cultural practices
 - Talking circles, sweat lodge ceremonies, traditional healers, prayer, smudging, drumming, and herbs
- Counselors’ aid individuals to develop skills and use healing practices based on their own individual backgrounds, traditions, practices, and stories.

Circles of Care

Circles of Care is a grant provided by the Substance Abuse and Mental Health Services Administration (SAMHSA), and their resources are helpful and available to any tribal or urban Indian community seeking to design, enhance, or expand a comprehensive, holistic, evidence- and community-based, coordinated system of care to support mental health for children, youth, families, and caregivers.

The Circles of Care grant program goals are to:

- Develop a community-based system of care model for children with mental health challenges and their families
- Develop local capacity, infrastructure, and resources to implement the system of care model to improve the mental health and wellness of their tribal community’s children, youth, and families (SAMHSA)

Website: <https://www.samhsa.gov/tribal-ttac/circles-care>

Examples of Culturally Informed Youth Programs for Mental Health, Substance Misuse, and Suicide Prevention

American Indian Life Skills (AILS)

Development is the current version of the former Zuni Life Skills Development program.

1. It is a school-based suicide prevention curriculum that aims to reduce suicide risk factors and increase protective factors among American Indian youth.
2. The curriculum integrates commonly shared Native American beliefs and topics into a life skills program.

3. Recommends places where individual tribal beliefs, practices, culture, and language can be added for customization
4. Students participate in culturally relevant experiential learning exercises on self-esteem, emotions and stress, communication, problem-solving skills, self-destructive behavior, suicide, and personal and community goals.
5. 60 individual sessions, two to three times a week over 20–30 weeks
6. Curriculum is delivered by teachers and tribal community leaders.

Website: <https://sprc.org/resources-programs/american-indian-life-skills-developmentzuni-life-skills-development>

The AILS curriculum is sold on Amazon.com. Enter “American Indian Life Skills” into the Amazon search box or visit: <https://www.amazon.com/American-Indian-Skills-Development-Curriculum/dp/0299149242>

Culture Forward: A Strengths- and Culture-Based Tool to Protect Our Native Youth from Suicide

1. Developed by Casey Family Programs and the Johns Hopkins Center for American Indian Health.
2. Two years were spent:
 - a. listening to Native voices from across Indian Country
 - b. Scanning indigenous literature to gather tribally driven, evidence- and practice-based solutions to prevent youth suicide.
3. Five Core Themes
 - a. Our Networks harness belonging and help keep us safe.

- b. Connection to our lands & elders allows us to thrive.
- c. Traditional knowledge holds the key to health and healing.
- d. Native Youth lead us to reclaim our autonomy and well-being.
- e. Self-determination empowers us to fight.

(Center for American Indian Health)

Website: <https://caih.jhu.edu/programs/cultureforward>

The Healing of the Canoe Project (Squamish Tribe, Port Gamble S’Klallam Tribe)

A substance misuse reduction and suicide prevention program designed for high school students. It is a Culturally Grounded Life Skills for Youth Curriculum. The program uses a Canoe Journey as the metaphor, providing youth the skills needed to:

- Navigate their journey through life without being pulled off course by alcohol or drugs
 - The canoe is a vessel for travel, ceremonies, transportation of food and resources, and subsistence activities.
- Understand how tribal culture, tradition, and values serve as a compass to guide, anchor, and ground tribal youth
- The curriculum is steeped in traditional tribal values and practices.
- Teachings impart knowledge about the community, managing emotions, solving problems, communicating, and is inclusive for LGBTQ/two-spirit peoples.

The curriculum can be customized by tribes and be delivered in a weekend or yearlong program. In 2013, 50 tribes and 19 tribal organizations adapted and implemented the curriculum.

Website: <https://healingofthecanoe.org/>

Curriculum: <https://www.healthynativeyouth.org/curricula/healing-of-the-canoe/>

Family Spirit

A home-visiting mental health promotion and substance abuse prevention intervention for American Indian teenage mothers that aims to increase:

- Parenting competence and reduce risk factors
- Healthy infant and toddler behaviors

Lessons are provided on prenatal care, infant care, breast feeding, child development, family planning, and healthy living. Native paraprofessionals visit the home and build on connection to the community and local culture (Prevention Solutions@Education Development Center).

Website: <https://caih.jhu.edu/programs/family-spirit>

Pandemics and COVID-19

According to the Centers for Disease Control and Prevention (CDC), a pandemic is defined as an event in which a disease is spread across several countries and affects a large number of people. Pandemics are often caused by influenza or a virus as we saw in 2020 with Coronavirus (COVID-19).

Because of health inequities rooted in social determinants of health, such as colonization,

systemic racism, higher rates of poverty, and unequal access to education and health care, the COVID-19 pandemic disproportionately affected American Indian and Alaska Native populations compared to non-Hispanic whites.

- Infection rates were 3.5 times higher
- Hospitalization was 4 times higher
- Higher rates of death and at younger ages (Indian Health Service)

During a pandemic and natural disasters, we all need to follow our tribal, town/city, and state directives. You can also contact your state's Developmental Disability Administration, Disability Council, or Independent Living Council for availability and assistance in obtaining resources.

An Example of a Culturally Relevant Covid-19 Response

The protective factors for health in AI/AN communities were disrupted by COVID-19 due to social isolation and disconnection from seasonal cultural activities, ceremonies, and social gatherings.

Based on needs assessments conducted with tribal partners, the John Hopkins Center for American Indian Health Great Lakes Hub sent holistic wellness boxes to 11 tribal communities in the Midwestern U.S. and Canada in the summer of 2020. The wellness boxes were culturally relevant and based on the needs voiced by indigenous community partners (Aulandez et al.).

The voices of people most affected should be the foremost authority on their own needs and the Holistic Wellness Boxes is one example of respectful bi-directional communication that honored and acted on the needs of AI/AN community members.

Type of Resource	Content of Holistic Wellness Boxes
Resources to bring calm, relieve stress, and strengthen cultural connection	<ul style="list-style-type: none"> ▪ Sage for smudging <ul style="list-style-type: none"> • Traditional practice that provides protective physical and mental health ▪ Ribbon featuring Ojibwe floral designs <ul style="list-style-type: none"> • For use in making traditional crafts ▪ Lavender essential oil (studies have found it to lessen anxiety symptoms and improve sleep). ▪ Ojibwe Elder’s teachings about self-care and dealing with anxiety and stress <ul style="list-style-type: none"> • Available in audio and on printed cards • Cross-generational sharing of knowledge fosters resilience and promotes health ▪ Mental health resource list ▪ Mindfulness exercises <ul style="list-style-type: none"> • Studies show mindfulness correlates to lower stress levels
Resources to nourish body and spirit	<ul style="list-style-type: none"> ▪ Wild rice <ul style="list-style-type: none"> • A diet based on traditional foods is protective against diet-related diseases among AI/AN populations ▪ Recipes using traditional foods <ul style="list-style-type: none"> • To promote nutritional health during a time of food insecurity
Resources to support the mental and physical health of children	<ul style="list-style-type: none"> ▪ Storybook, “<i>Our Smallest Warriors, Our Strongest Medicine: Honoring Our Teachings During Covid 19!</i>” available at https://cih.jhu.edu/programs/our-smallest-warriors-our-strongest-medicine-honoring-our-teachings-during-covid-19 <ul style="list-style-type: none"> • Adapted from <i>My Hero is You: how kids can fight COVID-19!</i> • Adapted by indigenous and non-indigenous allied experts in child development, mental health, and health communication ▪ Minwanjige, Mino-bimaadizi <ul style="list-style-type: none"> • Activity books that integrate the Ojibwe language and culture to educate children about healthy eating ▪ Crayons
Resources to prevent the spread of COVID-19	<ul style="list-style-type: none"> ▪ Cloth mask ▪ Bar soap and/or hand sanitizer

(Aulandez et al.)

Resources About Trauma & Culturally Informed Care

Who	What	Website/Contact Info
Dr. Maria Yellow Horse Brave Heart	An Oglala Lakota member who is recognized as the first person to develop the theory of historical trauma	One hour keynote speech at the conference of the Center for Trauma and Resilience https://www.youtube.com/watch?v=ycQJ8ckwYaU
National Indian Child Welfare Association	Dedicated to the safety, health, and spiritual strength of American Indian and Alaska Native children Holds an annual conference, provides ongoing training, and public policy advocacy	https://www.nicwa.org/
National Native Children’s Trauma Center	Co-facilitates trauma-focused healing for Native children, families, and communities by honoring tribal sovereignty, specific community needs, and the use of traditional healing practices	Website: https://www.nnctc.org/
Native Hope	An AI/AN Youth leadership, education, and advocacy organization	https://www.nativehope.org/

Resources For Mental Health, Substance Misuse, And Suicide Prevention

Who	What	Website/Contact Info
Adolescent Suicide Prevention Program Manual: A Public Health Model for Native American Communities	The manual was based on the principles of community involvement, ownership, the importance of culture and public health approaches.	https://www.sprc.org/sites/default/files/migrate/library/AdolescentSP_ProgramManuaPH_ModelINA_Communities.pdf
American Indian Life Skills (AILS) curriculum	A curriculum to reduce suicide risk factors and increase protective factors among American Indian youth	https://sprc.org/resources-programs/american-indian-life-skills-developmentzuni-life-skills-development The curriculum is also sold on Amazon.com.
Culture Card: A Guide to Build Cultural Awareness (AI/AN)	Four-page flyer with 13 topics such as Tribal sovereignty, cultural customs, spirituality, communication styles, etiquette dos and don’ts, etc.	Published by SAMHSA (Substance Abuse and Mental Health Services Administration) https://store.samhsa.gov/sites/default/files/d7/priv/sma08-4354.pdf

Who	What	Website/Contact Info
Family Spirit	A home-visiting mental health promotion and substance abuse prevention intervention for American Indian teenage mothers	https://caih.jhu.edu/programs/family-spirit
National American Indian and Alaska Native Addiction Technology Transfer Center Network	A National Center on addiction and mental health treatments. Provides training, education, resources, and more.	Native Center for Behavioral Health University of Iowa College of Public Health 145 North Riverside Drive, N410 CPHB Iowa City, IA 52246 (319) 471-2921 native@attcnetwork.org Website: https://attcnetwork.org/centers/content/national-american-indian-and-alaska-native-attc
National American Indian and Alaska Native Mental Health Technology Transfer Center Network	Circles of Care Step-by-Step Implementation Guide	https://mhffcnetwork.org/centers/national-american-indian-and-alaska-native-mhffc/circles-care-resources
National American Indian and Alaska Native Mental Health Technology Transfer Center Network	Mental Health Evidence-Based Practices for American Indian and Alaska Native Schools and Communities (November 2019)	https://mhffcnetwork.org/sites/default/files/2020-02/NAIAN_MHFFC_EnvScan.1.28.2020.pdf
Prevention Solutions @Education Development Center	“Culturally-Informed Programs to Reduce Substance Misuse and Promote Mental Health in American Indian and Alaska Native Populations”	https://preventionsolutions.edc.org/sites/default/files/attachments/Culturally-Informed-Programs-to-Reduce-Substance-Misuse-and-Promote-Mental-Health-in-American-Indian-and-Alaska-Native-Populations_0.pdf
Resource Guide: Promising Programs in Native American Communities	Created by the Montana Healthcare Foundation to help tribes’ plan for implementation of Tier 1 & 2 Medicaid Tribal Health Improvement Programs	http://mthcf.org/wp-content/uploads/THIP-Resource-Guide_WEB.pdf
SAMHSA’s Center for the Application of Prevention Technologies: Cultural Approaches to Prevention	“Culturally-Informed Programs to Reduce Substance Misuse and Promote Mental Health in AI/AN Populations” (March 2018)	https://theathenaforum.org/sites/default/files/public/cultural_approaches_programs_march2018_interactive_1.pdf

Who	What	Website/Contact Info
Substance Abuse and Mental Health Tribal Training and Technical Assistance Center (TTA)	TTA on mental and substance use disorders, suicide prevention, and mental health promotion using the Strategic Cultural Framework	https://www.samhsa.gov/tribal-ttac
Suicide Prevention Resource Center	Manual on Adolescent Suicide Prevention Program for Native American Communities (2011)	https://www.sprc.org/resources-programs/adolescent-suicide-prevention-program-manual

The Understanding Disabilities Toolkit was created to provide people with disabilities, tribes, and allies with information and resources that empower people with disabilities to be full participants in their community and experience meaning, dignity, and control over their lives. What you will find in this book are tools on the journey towards that goal.

Chapter 2: Health Care and Federal Health Insurance Programs



“One of my efforts is to address the stigma associated with disability and not to be afraid, not to be ashamed, but to be free, and to be vocal about what is impacting us, and how do we see a remedy being provided, with our voice being included.”

Dr. Kimberly Yellow Robe, Advocate

Health Care and Federal Health Insurance Programs

Today’s model of health and wellness integrates the mind, body, spirit, and context of the individual. This is similar to many Native American cultures, which emphasize harmony between mind, body, spirit, physical environment, and surrounding community.

Wellness spans a lifetime and a continuum that is unique to each individual’s culture, community, family, social networks, history, and physical environment. Numerous factors can impact a person’s health and wellness, such as:

- Self-care
- Health care management, including medications and pain
- Physical functionality
- Mental health, including historical trauma
- Age
- Attitudes and beliefs
- Sexuality
- Identity
- Employment
- Education
- Social support
- Accessibility accommodations
- Personal assistant services
- Housing
- Transportation
- Location and access to services
- Self-advocacy skills
- Others’ knowledge and sensitivity

Many health and wellness programs exist and can be combined with each other to provide a variety of services most beneficial for the patient. The major health and insurance programs available to AI/AN people are listed below.

Indian Health Services

The U.S. Federal Government provides health care services to AI/AN people through Indian Health Services (IHS), an agency within the Department of Health and Human Services. IHS is the primary health care provider and advocate for AI/AN people. Its goal is to raise their patients' health status as much as possible, but adequate funding has been and continues to be a challenge, resulting in the rationing of services at the local level.

IHS comprises 12 regional Area Offices that administer local Service Units that coordinate health services for tribal beneficiaries. There are over 170 Individual Service Units, and they link the addresses and contact information of each Service Unit facility.

<https://www.ihs.gov/locations/>

The IHS has agreements with approximately 246 tribal organizations to provide some healthcare services while IHS provides other services.

There are no "guaranteed benefits" for IHS patients. Services vary at each IHS/tribal clinic, health station, or hospital. Check with your local IHS or Tribal Health Program to know what services are available. Services can include:

- Outpatient medical services
- Inpatient hospital or specialty services (direct or referral)
- Dental services
- Mental health services

- Pharmacy and laboratory services
- Home nursing visits
- Community health representative visits
- Transportation

IHS Eligibility

Individuals are eligible for IHS services if they are of American Indian and/or Alaska Native (AI/AN) descent and belong to the Indian community served by the IHS program, as evidenced by such factors as:

1. Membership, enrolled or otherwise, in an AI/AN federally recognized tribe or group under federal supervision
2. Residence on tax-exempt land or owning restricted property
3. Actively participates in tribal affairs
4. Any other reasonable factor indicative of Indian descent
5. In case of doubt that an individual applying for care is within the scope of the program, as established in 42 C.F.R. § 136.12(b), and the applicant's condition is such that immediate care and treatment are necessary, services shall be provided pending identification as an Indian beneficiary (Indian Health Service, Indian Health Manual).

Some non-Indians are eligible for IHS services. Please click on the Indian Health Manual link under Healthcare Resources. <https://www.ihs.gov/ihtm/pc/part-2/p2c1/-2-1.2A>

Direct Care

Medical care and dental care provided at an IHS or Tribal Health Program facility is called direct care.

Purchased/Referred Care (PRC)

The PRC Program is for medical/dental care provided away from an IHS or tribal health care facility. PRC is not an entitlement program and an IHS referral does not imply the care will be paid for by IHS. If IHS is requested to pay, then a patient must meet the residency requirements, notification requirements, medical priority, and use of alternate resources (Indian Health Service, Purchased/Referred Care).

With referral situations, the private health care provider or hospital will bill IHS for services to the patient. Due to limited funding, eligibility requirements for PRC are stricter than for services provided at an IHS or Tribal Health Program facility.

- Prior approval from the IHS or tribal clinic is required for each PRC eligible service visit.
- Close coordination with the IHS or tribal clinic is required to effectively utilize PRC services.

Each person who needs and applies for PRC assistance should be aware of the five eligibility requirements:

1. Is of American Indian and/or Alaska Native descent as evidenced by one or more of the factors:
 - a. An individual must be of **Indian descent** and belong to the Indian community, which may be verified by tribal descendancy or census number. An individual must be a member, enrolled or otherwise, or an Indian or Alaska Native tribe or Group under Federal supervision.
 - b. Any other reasonable factor indicative of Indian descent; or
2. An individual resides within his/her tribal Purchased/Referred Care (PRC) delivery area. The tribal PRC delivery area encompasses the reservation, trust land, and the counties that border the reservation. This could include an individual who resides on tax-exempt land or owns restricted property.
 - a. The following individuals also must meet the residency requirements:
 - i. Is an Indian of Canadian or Mexican origin recognized by any Indian tribe or group as a member of an Indian community served by the Indian Health program; or
 - ii. Is a non-Indian woman pregnant with an eligible Indian's child for the duration of her pregnancy through post-partum (usually six weeks); or
 - iii. Is a non-Indian member of an eligible Indian's household and the medical officer in charge of the services necessary to control a public health hazard or an acute infectious disease which constitutes a public health hazard.
 - i. Students who are temporarily absent from his/her PRC delivery area during full-time attendance of boarding school, college, vocational, technical, and other academic education. The coverage ceases 180 days after completing their study.
 - ii. A person who is temporarily absent from his/her PRC delivery area due to travel, employment, etc. Eligibility ceases after 180 days.
 - iii. Children placed in foster care outside of the PRC delivery area by court order.

- iv. Other Indian persons who maintain “close social and economic ties” with the tribe.
3. Notification and authorization of approval for payment. An individual must be authorized by the PRC authorizing official for the payment of services.
 - a. Authorization is based on an IHS provider issuing a referral for medical care being submitted to the PRC program. The referral is reviewed by the Managed Care Committee who will determine the medical priority.
 - b. In cases of emergency based on IHS medical priorities, a 72-hour notification to the PRC program must be made by the individual, provider, hospital, or someone on behalf of the individual.
 - c. Notification is extended to 30 days for older adults and people with disabilities. A person with a disability means the person cannot physically/mentally notify the PRC program.
 4. PRC funds are limited to medical or dental services considered medically necessary and listed within the established area IHS medical/dental priorities. A copy of the area IHS medical/dental priorities is available at local IHS health centers and hospitals. An individual medical need at the time of services must be within the medical priorities being funded at that time.
 5. An individual must apply for and use all alternate resources that are available and accessible, such as Medicare A and B, state Medicaid, state or other federal health programs, private insurance, etc. The IHS facility is also considered a resource,

and therefore, the PRC funds may not be expended for services reasonably accessible and available at IHS facilities (Indian Health Service, Purchased/Referred Care).

In short, the IHS is the “payor of last resort” of persons defined as eligible for PRC, notwithstanding any state or local law or regulation to the contrary.

Medicaid

Medicaid was enacted in 1965 and is a joint federal and state insurance program that provides health coverage to individuals with low incomes or who lack resources. For AI/AN communities, Medicaid can help fill the gap in providing resources that might not be available through the IHS. A tribal clinic or IHS can bill Medicaid for services provided to AI/AN patients who are enrolled in Medicaid. This helps the local Indian clinic expand services.

Medicaid Eligibility

Each state decides eligibility, how providers are paid, and what services are covered under Medicaid. States cannot restrict Medicaid eligibility based on medical condition, type of services needed, or place of residence. Eligibility varies from state to state, with the Federal Government stipulating minimum requirements:

To cover certain groups of individuals:

- Low-income families
- Qualified pregnant women and children
- People with disabilities receiving Supplemental Security Income (SSI)

Some common additional options for coverage are:

- Individuals receiving home- and community-based services

- Children in foster care who are not otherwise eligible (Centers for Medicare and Medicaid Service)

The Affordable Care Act of 2010 created the opportunity for states to expand Medicaid to cover nearly all low-income Americans under age 65.

12 states chose not to expand Medicaid under the Affordable Care Act (ACA), leaving approximately two million people in those states uninsured.

- These states are Alabama, Florida, Georgia, Kansas, Mississippi, North Carolina, South Carolina, South Dakota, Tennessee, Texas, Wisconsin, and Wyoming.
- Wisconsin expanded eligibility under a Medicaid waiver, instead of the ACA, so it does not have an uninsured low-income population as do the other 11 states (Garfield 2021).

Determination of Medicaid Eligibility

In states that expanded Medicaid under the ACA, the enrollment application was simplified, and income eligibility was based on a modified adjusted gross income.

Certain Medicaid eligibility groups do not require a determination of income and coverage may be based on enrollment in another program, such as:

- SSI
- A breast and cervical cancer treatment and prevention program
- Children for whom an adoption assistance agreement is in effect under Title IV-E of the Social Security Act

- Former foster care recipients who meet the requirements are eligible at any income level (Centers for Medicare and Medicaid Service)

Services covered by Medicaid

Medicaid programs have a “defined benefits package” that each enrollee is entitled to receive. To learn what services are available, you can contact your state’s department of Health and Human Services, local IHS clinic, Tribal Health Program facility, or other health care provider.

Health care benefits vary from state to state, and some states might require a nominal co-payment by the patient for certain services. The Federal Government mandates many health care benefits, and there are optional benefits states can provide.

Mandatory Benefits (states must cover with Medicaid):

- Inpatient hospital services
- Outpatient hospital services
- Early and periodic screening, diagnosis, and treatment services: EPSDT*
- Nursing facility services
- Home health services
- Physician services
- Rural health clinic services

*EPSDT program serves as Medicaid’s well-child program and pays regular screening, immunizations, preventative, dental, optical, mental health, developmental, and specialty services, and access to care for diagnosis and treatment.

- Federally qualified health center services
- Laboratory and X-ray services
- Family planning services
- Nurse and midwife services
- Certified Pediatric and Family Nurse Practitioner services
- Freestanding Birth Center services (when licensed or otherwise recognized by the state)
- Transportation to medical care
- Preventative care such as vaccinations and flu shots
- Tobacco cessation counseling for pregnant women
- Other practitioner services
- Private-duty nursing services
- Personal care
- Hospice
- Case management
- Services for individuals aged 65 or older in an institution for mental disease (IMD)
- Services in an intermediate care facility for people with intellectual disabilities
- State plan home and community-based services—1915(i)
- Self-directed personal assistance services—1915(j)
- Community First Option—1915(k)
- Tuberculosis (TB) related services
- Inpatient psychiatric services for individuals under age 21
- Other services approved by the Secretary**
- Health homes for enrollees with chronic conditions—Section 1945

Optional Benefits (states can opt to cover with Medicaid):

- Prescription drugs
- Clinic services
- Physical therapy
- Occupational therapy
- Speech, hearing, and language disorder services
- Respiratory care services
- Other diagnostic, screening, preventative, and rehabilitative services
- Podiatry services
- Optometry services
- Dental services
- Dentures
- Prosthetics
- Eyeglasses
- Chiropractic services

As of June 2019, all 50 states and D.C. have at least one program that provides assistance to older adults living outside of nursing homes, whether it's at home, in adult day care, in adult foster care, or assisted living. Most states offer multiple programs (Paying for Senior Care).

**Includes services furnished in a religious nonmedical health care institution, emergency hospital services by a non-Medicare certified hospital, and critical access hospital (Centers for Medicare & Medicaid Services. Mandatory and Optional Benefits).

How to Enroll in Medicaid?

Federal law mandates that tribal health programs help their community enroll in Medicaid and Children’s Health Insurance Program (CHIP). Many IHS or tribal health clinics have office staff or benefits coordinators who will help you fill out the necessary forms to apply for Medicaid enrollment. You can also go directly to your state’s online portal or to your local, county, or state Medicaid office to apply. Applying online speeds up the approval process.

Many states conduct real-time eligibility determinations for applicants. If a Tribal Health Program has access to their state’s Medicaid eligibility portal, or there’s a state on-site outreach worker with state portal access, patients can get Medicaid and/or CHIP coverage on the spot.

Express Lane Eligibility (ELE)

ELE provides states with important new avenues to ensure that children eligible for Medicaid or CHIP have a fast and simplified process for having their eligibility determined or renewed.

ELE permits states to rely on findings, for things like income, household size, or other factors of eligibility from another program designated as an express lane agency (ELA) to facilitate enrollment in health coverage. Express lane agencies may include:

- Supplemental Nutrition Assistance Program (SNAP)
- School Lunch
- Temporary Assistance for Needy Families (TANF)
- Head Start, National School Lunch Program (NSLP)
- Women, Infants, and Children (WIC)

A state may also use information from state income tax data to identify children in families that might qualify so that families do not have to submit income information (Centers for Medicare and Medicaid Services).

Medicaid Home- and Community-Based Services (HCBS)

To comply with the Supreme Court’s Olmstead ruling, states are required to provide community-based treatment for people with intellectual or developmental disabilities, physical disabilities, and/or mental disabilities when the providers determine that institutional care is inappropriate. The practical effect has been that states must now provide the “least restrictive care” for people with disabilities.

States can apply for waivers to provide home- and community-based services to particular groups. State HCBS Waiver programs must:

- Demonstrate that providing waiver services won’t cost more than providing these services in an institution
- Ensure the protection of people’s health and welfare
- Provide adequate and reasonable provider standards to meet the needs of the target population
- Ensure that services follow an individualized and person-centered plan of care (Centers for Medicare and Medicaid Services, Home and Community-Based Services 1915(c))

Standard home- and community-based services include but are not limited to:

- Case management (i.e., supports and service coordination)

- Homemaker
- Home health aide
- Personal care
- Adult day health services
- Habilitation (both day and residential)
- Respite care
- Other types, such as transitioning individuals from institutional settings into their homes and community (Centers for Medicare and Medicaid Services. Home and Community-Based Services 1915(c))

What Can Tribes Do?

Tribal Health Programs should review their state HCBS plans to see how tribally administered home- and community-based services can be paid through Medicaid reimbursement. HCBS waiver programs may also provide services to foster independence, train family caregivers, and enable the individual to stay at home.

Children’s Health Insurance Program (CHIP)

CHIP provides low-cost health coverage to children in families that earn too much money to qualify for Medicaid. In some states, CHIP covers pregnant women. Each state offers CHIP coverage and works closely with its state Medicaid program (Healthcare.gov).

CHIP Coverage

CHIP benefits are different in each state. But all states are required to provide comprehensive coverage:

- Routine check-ups
- Immunizations

- Doctor visits
- Prescriptions
- Dental and vision care
- Inpatient and outpatient hospital care
- Laboratory and X-ray services
- Emergency services (Healthcare.gov)

Application to CHIP

Each state program has its own rules about who qualifies for CHIP. You can apply any time of year. If you apply for Medicaid coverage to your state agency, you’ll also find out if your children qualify for CHIP (Healthcare.gov).

Two Ways to Apply for CHIP:

1. Call 1-800-318-2596 (TTY: 1-855-889-4325)
2. Online application: <https://www.healthcare.gov/create-account>
3. Fill out an application through the Health Insurance Marketplace®. If it looks like anyone in your household qualifies for Medicaid or CHIP, your information will be sent to your state agency. You will be contacted about enrollment (Healthcare.gov).

Medicare

Medicare is the federal health insurance program for:

- People who are 65 or older
- Certain younger people with disabilities
- People with End-Stage Renal Disease (ESRD); permanent kidney failure requiring dialysis or a transplant (Medicare.gov)

What are the parts of Medicare?

The different parts of Medicare help cover specific services:

- Part A – Hospital Insurance
- Part B – Medical Insurance
- Part C – Medicare Advantage
- Part D – Prescription drug coverage

Medicare Part A (Hospital Insurance)

Part A covers inpatient hospital stays, care in a skilled nursing facility, hospice care, and some home health care.

You usually don't pay a monthly premium for Part A if you or your spouse paid Medicare taxes while working for a certain amount of time. This is sometimes called "premium-free Part A."

If you aren't eligible for premium-free Part A, you may be able to buy Part A. You'll pay up to \$499 each month in 2022. If you paid Medicare taxes for less than 30 quarters, the standard Part A premium is \$499. If you paid Medicare taxes for 30–39 quarters, the standard Part A premium is \$274.

Medicare Part A Coverage

- Inpatient care in a hospital
- Skilled nursing facility care
- Nursing home care (inpatient care in a skilled nursing facility that's not custodial or long-term care)
- Hospice care
- Home health care (Part A)

Medicare Part B (Medical Insurance)

Part B covers certain doctors' services, outpatient care, medical supplies, and preventive services.

Everyone pays a monthly premium for Part B. Your Part B premium will be automatically deducted if you get one of the benefits listed below. If not, you will get a bill.

- Social Security
- Railroad Retirement Board
- Office of Personnel Management

The standard Part B premium amount in 2022 is \$170.10 monthly. Most people pay the standard Part B premium amount. If your modified adjusted gross income as reported on your IRS tax return from two years ago is above a certain amount, you'll pay the standard premium amount and an Income Related Monthly Adjustment Amount (IRMAA). IRMAA is an extra charge added to your premium for an individual earning \$91,000 or more or married couples filing jointly, earning \$182,000 or more (Part B).

Medicare Part B Coverage

- Clinical research
- Ambulance services
- Durable medical equipment (DME)
- Mental health
 - Inpatient
 - Outpatient
 - Partial hospitalization
- Limited outpatient prescription drugs (Part B)

Medicare Part D (prescription drug coverage)

Helps cover the cost of prescription drugs, including many recommended shots or

vaccines. To get Medicare drug coverage, you must join a Medicare-approved plan that offers drug coverage, which includes Medicare drug plans and Medicare Advantage Plans with drug coverage (What's Medicare).

How Does Medicare Work?

There are two options to receive Medicare coverage: Original Medicare and Medicare Advantage.

Original Medicare

Original Medicare includes Medicare Part A (Hospital Insurance) and Medicare Part B (Medical Insurance). You pay for services as you get them. When you get services, you'll pay a deductible at the start of each year, and you usually pay 20 percent of the cost of the Medicare-approved service, called coinsurance. If you want drug coverage, you can add a separate drug plan (Part D). Original Medicare pays for much, but not all, of the cost for covered health care services and supplies (Medicare.gov, What's Medicare). Original Medicare doesn't cover vision, hearing, and dental services.

Medicare Advantage (Part C)

Medicare Advantage is a Medicare-approved plan from a private company that offers an alternative to Original Medicare for your health and drug coverage. These "bundled" plans include Part A, Part B, and usually Part D. Plans may offer some extra benefits that Original Medicare doesn't cover—like vision, hearing, and dental services. Medicare Advantage Plans have yearly contracts with Medicare and must follow Medicare's coverage rules (Medicare.gov, What's Medicare).

How to apply online for just Medicare:

1. If you are within three months of turning 65 or older and not ready to start your monthly Social Security benefits yet, you can use the online retirement application to sign up just for Medicare and wait to apply for your retirement or spouse's benefits later.
2. It takes less than 10 minutes.
3. There are no forms to sign and usually no documentation is required.

Website: <https://secure.ssa.gov/iClaim/rib>

Yes, you can call to apply for Medicare.

Toll-free number: **1-800-MEDICARE**
(1-800-633-4227)

TTY number: **1-877-486-2048**

Veterans Affairs (VA)

A Reimbursement Agreement provides VA Funds for Native Veterans for care from the IHS and many Tribal Health Programs. The VA reimbursement includes direct care service to veterans, including:

- Inpatient hospital
- Outpatient hospital
- Clinic
- Ambulatory surgical
- Outpatient pharmacy services

If you are an eligible AI/AN veteran, you do not need preauthorization to receive care through an IHS facility or a Tribal Health Program (THP) facility that has a reimbursement agreement with

Health Care Resources

Who	What	Contact Info
Indian Healthcare Services—Individual Service Units	Address and contact information of each Service Unit	https://www.ihs.gov/locations/
IHS—Indian Health Manual	Eligibility and services to Indians and others	https://www.ihs.gov/ihm/pc/part-2/p2c1/-2-1.2A
IHS—Purchased Referred Care (PRC)	Requirements of payment requests	https://www.ihs.gov/prc/
Tribes and tribal health care organizations	Medicaid & CHIP enrollment strategies for tribal communities	https://www.medicare.gov/federal-policy-guidance/downloads/cib112816.pdf
Children’s Health Insurance Program (CHIP)	Two ways to apply for enrollment	Call 1-800-318-2596 (TTY: 1-855-889-4325) Complete application at the Health Insurance Marketplace https://www.healthcare.gov/create-account
Medicare coverage	Is my test, item, or service covered by Medicare?	Link is for people with Medicare and for Medicare contractors https://www.medicare.gov/coverage
“Medicare: Securing Today and Tomorrow”	A Medicare informational booklet by the Social Security Administration	https://www.ssa.gov/pubs/EN-05-10043.pdf-page=10
Centers for Medicare and Medicaid Services	“Understanding Medicare Advantage & Medicare Drug Plan (Part C & D) Enrollment Periods”	https://www.medicare.gov/Pubs/pdf/11219-Understanding-Medicare-Part-C-D.pdf
Medicare	Contact information	Website: www.medicare.gov Toll-free number: 1-800-MEDICARE (1-800-633-4227) TTY number: 1-877-486-2048
Indian Health Service and the Memorandum of Understanding with the Veterans’ Administration	Reimbursement Agreement between VA Funds for IHS Care for Native Veterans	https://www.ihs.gov/vaihsmou/
VA Community Care Program	Tribal Health Programs interested in establishing a reimbursement agreement with VA	https://www.va.gov/communitycare/

VA, and you do not have to pay a VA co-payment (U.S. Department of Veterans Affairs).

Tribal Health Programs interested in establishing a reimbursement agreement with VA can learn more about initiation and implementation, eligibility, and enrollment

verification, and submitting claims at the VA through the VA's Community Care program.

VA Community Care Program: <https://www.va.gov/COMMUNITYCARE/programs/veterans/ihs/index.asp>

Chapter 3: Sports & Recreation for People with Disabilities

Introduction

Currently, more than 200 Boys and Girls Clubs of America serve Native communities, supporting youth academic success, providing positive adult role models, offering meal programs, and keeping traditions alive by embedding indigenous cultural components throughout the Club Day. After all, culture is a way of life, and our culture as Native people shows up in our values and beliefs, how we gather, how we eat, how we learn, and so much more. These traditions are so important to pass on to our young people, who will carry our culture forward.

Carla Knapp 2021

Just as the children are active in the indigenous cultural programming at the Boys and Girls Club of America, all American Indian and Alaska Natives can improve their mental and physical health by staying active. Physical activity can help you strengthen your heart, muscles, and bones, improve coordination, and help you feel better about yourself.

Recreational activity is also good for everybody, and the choices of activities for people with disabilities are limitless. Whether

you take up wheelchair basketball or start a new vegetable garden using assistive tools, you'll be rewarded with better physical and mental health, joy, and an enriched quality of life.

The Americans with Disabilities Act requires that community programs be accessible to people with disabilities, and IDEA requires that public school intramural and interscholastic sports programs be available to people with disabilities (Disability Sports, 2001b). As such, adaptive sports and recreation are increasingly available. Most gyms and fitness programs design their activities with modifications to accommodate all skill levels and conditions. Recreational facilities such as movie theaters, museums, hiking trails at state and federal parks, and monuments are required to make trails, information, and activities accessible to all visitors. There are many recreational activities available to people with disabilities.

National Organizations—Sports and Recreation for People with Disabilities

The organizations listed below provide a variety of resources and supports to people and community organizations that empower people with disabilities to live active, creative lives.

Unlimited Recreational Activities for People with Disabilities

Aquatics	Fishing	Jogging
Archery	Fencing	Martial Arts
Arts and Crafts (sewing, weaving, jewelry making, etc.)	Frisbee	Painting
Graphic Arts	Fitness Training	Skiing (Water and Snow)
Aviation	Gardening	Music
Baseball	Golf	Photography
Basketball	Handball	Pottery/Ceramics
Bow hunting	Hiking	Swimming
Bowling	Hockey	Skydiving
Camping	Horseback Riding	Tennis
Cycling	Hunting	Weight training
Dance	Motorcycle Riding	Writing

(CME Toolkit)

Sports: Modifications and Resources

Sport	Modification	Resource
Billiards	This is a great game for wheelchair users. Modified pool cues or a roller attachment at the end of a cue stick allow players with limited hand use to enjoy the sport and be competitive with the best players.	World Disability Billiards and Snooker (WDBS0: https://www.wdbs.info/)
Bowling	Wheelchair bowling is played just as the stand-up version with the exception of special push tools and ball-drop ramps for bowlers with limited arm mobility. Special snap handle balls are available for those who can't get a good grip on the ball	American Wheelchair Bowling Association: https://awba.org/
Camping	Camping is a great way to be close to nature. State and national parks are a good place to start and check whether you need to make reservations. As mandated by the Americans with Disabilities Act, state and national parks generally have accessible accommodations, bathrooms, and level ground. Progress toward accessibility continues but you can find many camp areas that are already inclusive.	U.S. National Park Access Pass https://store.usgs.gov/access-pass

Sport	Modification	Resource
	<p><u>U.S. National Parks</u>. Many have accessible trails and shorelines. Residents of the United States with disabilities can obtain a free Access Pass, a lifetime entrance pass to over 2,000 national parks, monuments, historic sites, recreation areas, and wildlife refuges. The <u>pass</u> also provides a discount on fees for camping, swimming, parking, boat launching, and tours.</p>	
Gardening	<p>With some adaptations (raised beds and special tools, for example), gardening can be barrier-free and fully inclusive.</p> <p>The American Horticultural Therapy Association promotes physical and mental health through gardens and plants.</p>	<p>Video series on adaptive gardening at the Dana and Christopher Reeves Foundation website: https://www.christopherreeve.org/living-with-paralysis/health/staying-active/accessible-gardening</p> <p>American Horticultural Therapy Association: https://www.ahta.org/</p>
Golf	<p>Golf is quite adaptable to the seated player. Custom clubs and special carts, some with single-passenger swivel seats and tires that won't damage the greens, open the game to players who have limited leg function. The Americans with Disabilities Act (ADA) requires all public accommodations, including golf courses, to provide goods and services to people with disabilities as the public. It is advisable to call the golf course ahead of time.</p>	<p>United States Disabled Golfers Association: http://www.usdga.net/</p>
Hand Cycling	<p>Hand cycling uses three-wheel, multi-gear cycles. Hand cranking has become quite popular across the country, and a rider can move the three-wheelers along at a steady 20 mph pace, enough to keep up with bike riders without disabilities. Hand cycling has emerged as an elite competitive sport, too. It's included in the Paralympics and many major marathons, triathlons, and century rides.</p>	<p>There are several variations on hand-powered cycles. For information about bikes see: http://www.freedomryder.com/ https://www.varnahandcycles.com/ Bike-on: https://bike-on.com/</p>
Wheelchair Racing	<p>Wheelchair racing can take place on the track or on the road. The racing wheelchair has three wheels, one small one up front and two larger wheels that the person sits between; it looks like a mini dragster.</p>	<p>A beginner's guide to wheelchair racing, including racing classifications, competitions and more.</p>

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Sport	Modification	Resource
	<p>Almost all running road races from 5K to marathon length have wheelchair divisions.</p> <p>The Summer Paralympics features a wheelchair marathon and numerous track races.</p>	<p>https://www.quantumrehab.com/resources/consumer-article-a-beginners-guide-to-wheelchair-racing.asp</p>
Horseback Riding	<p>Horseback riding is an exhilarating recreation that's doable for many people living with paralysis, using padding or specially made saddles and a mounting ramp. Riding can be fun but also facilitate cognitive as well as sensory and motor development.</p> <p>There are many riding programs across the United States that cater to disabled riders.</p>	<p>Professional Association of Therapeutic Horsemanship International:</p> <p>https://www.pathintl.org/</p>
Sailing	<p>Sailboats can accommodate people with varying degrees of paralysis. There are boats that are quite accessible for the wheelchair sailor (a transfer box helps with the hardest part—getting aboard).</p> <p>A sip 'n puff control has been adapted to a fleet of boats called Martin 16s, originally designed for a person with quadriplegia. These boats are affordable, comfortable, safe, and accessible to anyone.</p> <p>Another accessible boat called an Access Dinghy, which can also be controlled using a joystick, is available for rent at many sailing centers. Sailors are seated low in the boat for added stability. A servo-assist joystick can operate the electric winches and can be controlled by hand, foot, chin, or any moving body part.</p>	<p>There are numerous sailing programs across the country that offer boats and instruction for people with disabilities. Check your local marinas; many programs are listed on the United States Sailing Association (USSA) website: https://www.ussailing.org/</p> <p>Martin 16: https://martin16.com/</p>
Skiing (Alpine)	<p>This is a sport that's been well adapted for people with disabilities, thanks to technology. Depending on one's level of function, there are three ways a person can get from the top of the mountain down the snowy trails to the bottom.</p> <ol style="list-style-type: none"> 1) At the highest end of the tech scale is the mono-ski, best for those with good upper body strength and trunk balance. The skier sits in a molded shell mounted to a frame above a single ski with a shock absorber linking the frame to the ski. Two outriggers are used for balance and turning. Mono-skiing closely resembles stand-up skiing, and the mono-ski self-loads onto the chairlift. 	<p>There are many ski programs for people with disabilities across the United States:</p> <ul style="list-style-type: none"> ▪ National Sports Center for the Disabled: https://nscd.org/ ▪ Breckenridge Outdoor Education Center: https://boec.org/ ▪ National Ability Center: https://discovernac.org/ ▪ Adaptive Sports Foundation: https://www.adaptivesportsfoundation.org/

Sport	Modification	Resource
	<p>2) The biski, a bucket seating system similar to the monoski, sits atop two heavily shaped skis and can be balanced with attached or hand-held outriggers. Bi-skis are used by people who have more significant physical limitations and are tethered or skied from behind by an instructor.</p> <p>3) The sit-ski, akin to a toboggan, works for people with even more significant limitations. Those with some hand function can steer the sit-ski with short ski poles and by leaning. The sit-ski is tethered to an instructor.</p>	<ul style="list-style-type: none"> ▪ Paralympics (Alpine Skiing): https://www.paralympic.org/alpine-skiing
Skiing (cross country)	<p>Cross country sit-skis have molded, or canvas seats, mounted on frames that are simple and lightweight, creating more independence.</p> <p>The frames are attached to two cross country skis for snow skiing or a mountain-board for summer trails.</p> <p>The skier propels along the course using cross country ski poles that have straps to support any limited hand function.</p>	<p>Call your local cross-country ski area to see if it has sit-ski equipment.</p> <p>A good source of information, photos, and videos about sit skiing is available on the state of Massachusetts parks and recreation website.</p> <p>https://www.mass.gov/service-details/accessible-cross-country-skiing</p>
Tennis	<p>Wheelchair tennis is played with the same rules as stand-up tennis, except the wheelchair player is allowed two bounces of the ball.</p>	<p>Tennis is a Summer Paralympic sport. Check out the International Tennis Federation website: https://www.itftennis.com/en/</p>
Water skiing	<p>Water skiing uses sit-skis that are varied in width of 10 to 15 inches, depending on the skier's ability. Some skis have outriggers or short ski tips attached to either side of the sit ski for balance.</p> <p>The tow ropes have a modified handle so people with hand disabilities can hook up to a boat and thrill to the speed and wake-crashing fun of water skiing.</p> <p>Skis are available commercially and many have been added to recreation programs in many communities across the country.</p>	<p>USA Adaptive Water Ski and Wake Sports: https://www.usaadaptivewaterski.org/</p>
	<p>There are water ski tournaments for skiers with mobility limitations and competitions include slalom, tricks, and jumping events.</p>	

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Sport	Modification	Resource
Weight-lifting and body-building	Technically, it is not hard to adapt lifting weights for people with lost function due to paralysis. The activity has clear benefits for fitness, but lifting has also emerged as a very competitive activity at the international level.	<p>Ask your gym about providing adaptive equipment and a trainer for instruction and/or spotting.</p> <p>An article by Devon Palmero offers 10 adaptive disability equipment recommendations: https://www.theptdc.com/articles/disability-fitness</p>
(Wheel) Sportschair basketball	A fast-paced game for athletes with lower limb impairments. During a game, five athletes on the basketball court and seven substitutes on the sidelines. There are four quarters of 10 minutes each unless a game goes into overtime due to a tie at the end of the fourth quarter.	<p>National Wheelchair Basketball Association (NWBA) https://www.nwba.org/ To find NWBA teams: https://www.nwba.org/findateam The Wheelchair Basketball Training Zone is a program of the NWBA, to develop and introduce athletes of all ages and abilities to the sport of wheelchair basketball. https://www.challengedathletes.org/training-zone/ The International Wheelchair Basketball Federation (IWBF) is the governing body for wheelchair basketball around the world. IWBF is a nonprofit organization whose purpose is to provide opportunities for persons with a lower limb disability to play the game of wheelchair basketball. https://iwbf.org/ The Tribal Adaptive Thunderbirds are Indian Country's first sportschair basketball team. While the competitive team is for youth aged 10 to 21, the practices are open to everyone. Practices are held weekly at San Juan College in Farmington, NM. Contact Jason Hotchkiss (970) 306-9951 https://tribaladaptive.com/thunderbirds/</p>

Organization	What They Do	Website
Adaptive Adventures	<p>The world’s largest mobile outdoor adaptive sports provider and nonprofit for children and adults. Core principles:</p> <ol style="list-style-type: none"> 1. We serve anyone in need. No matter your perceived physical limitations or economic barriers, this program can serve you. 2. We’ll come to you. They have worked with rehab hospitals, park districts, community gyms, and other organizations across all 50 states, Canada, and Puerto Rico. 3. We’ll provide what you need. AA provides customized activities, innovative equipment, staff training, and resources to further inclusion for individuals and communities. 	<p>https://adaptiveadventures.org/</p>
American Association of Adapted Sports Programs	<p>Partners with high-quality implementation, growth, and sustainability strategies to programs offering adapted athletics at schools and community organizations. Partner organizations have access to best practices, policy, resources, data, research, educational training programs, equipment kits, rules committees, and technical expertise to successfully implement inclusive adapted athletic programs.</p>	<p>https://adaptedsports.org/</p>
Amputee Coalition	<p>The mission of the Amputee Coalition is to empower people affected by limb loss to achieve their full potential through education, support, and advocacy, and to promote limb loss prevention.</p> <p>Provides information, referrals, a state Resource Map, Support Groups, Peer Support, Youth Camps and more.</p>	<p>https://www.amputee-coalition.org/</p> <p>To contact the Amputee Coalition:</p> <p>https://www.amputee-coalition.org/limb-loss-resource-center/ask-an-information-specialist-2/</p> <p>To locate resources in your state:</p> <p>https://www.amputee-coalition.org/limb-loss-resource-center/resources-by-state/</p>
Art Enables	<p>Art Enables believes that artists with disabilities are vital to a robust arts landscape and should be afforded the opportunity to pursue art as a vocation and career.</p>	<p>https://art-enables.org/</p>

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Organization	What They Do	Website
	<p>Art Enables works with artists who experience a broad range of developmental and cognitive disabilities and mental health challenges, including autism, Down syndrome, traumatic brain injury, schizophrenia, and bipolar disorder, among others.</p> <p>Art Enables’ artists are largely self-taught and tell powerful stories through their artwork.</p>	<p>To become a resident artist at Art Enables: https://art-enables.org/enroll-in-studio</p>
BlazeSports America	<p>Provides adaptive sport, recreation, and physical activity to Georgia’s youth, adults, veterans, and military personnel with physical disabilities and PTSD.</p> <p>Since 2007, BlazeSports has provided training and education to increase the capacity of local service providers across the United States.</p>	<p>https://blazesports.org/</p>
The Boys and Girls Clubs of America (BGCA)	<p>The BGCA provides sports and recreation to AI/AN youth both on and off Native lands.</p> <p>BGCA Native Services offers a broad selection of culturally relevant programs to address the unique needs of Native Youth. Their programs include:</p> <ul style="list-style-type: none"> ▪ All Stars ▪ Be There ▪ Cultural Program Toolbox ▪ Diplomas to Degrees ▪ DIY STEM ▪ Healthy Habits ▪ My Future ▪ Project Learn ▪ SMART Girls ▪ Smart Moves ▪ Teen Dating Violence ▪ T.R.A.I.L. Diabetes Prevention ▪ Workforce Development 	<p>https://www.bgca.org/about-us/local-clubs/native-services</p> <p>Boys and Girls Clubs of America article about Reclaiming our Native Youth: https://www.bgca.org/news-stories/2021/October/reclaiming-our-story-for-native-youth</p>
Disability Arts Online	<p>Led by people with disabilities to advance disability arts and culture. Artists with disabilities have a platform to blog and share thoughts and images describing artistic practice, projects, and how to find inspiration and be creative. Primarily, they publish editorial, blogs, and showcases of art, providing a place where opinion pieces, reviews and interviews can be shared and commented on.</p>	<p>https://disabilityarts.online/ Directory of organizations: https://disabilityarts.online/directory/category/organisation/</p>

Organization	What They Do	Website
Move United	<p>Created in April 2020 from a merger of Disabled Sports USA and Adaptive Sports USA. Move United is an official Affiliate of the U.S. Olympic & Paralympic Committee, a member of the President’s Committee on Employment of People with Disabilities and is endorsed by the President’s Council on Sports, Fitness & Nutrition, the United States Ski and Snowboard Association, the Professional Ski Instructors of America, and the Aerobics and Fitness Association of America.</p> <p>With hundreds of partners, from member organizations, to hospitals, to disability organizations and sports organizations, Move United is leading a movement so that no one is left on the sidelines, and everyone gets in the game.</p>	<p>To find a chapter or adaptive sports team: https://www.moveunitedsport.org/locations/</p> <p>The website provides information on 73 types of sports and adaptive equipment suppliers for a broad range of sports.</p>
National Arts and Disability Center (NADC)	<p>NADC is the national information dissemination, technical assistance, and referral center specializing in the field of arts and disability.</p> <ul style="list-style-type: none"> ▪ Promotes full inclusion of children and adults with disabilities into arts communities 	<p>Its resource directories, annotated bibliographies, related links, and conferences serve to advance artists with disabilities and accessibility to the arts. Website: https://www.semel.ucla.edu/nadc/resource/national-arts-and-disability-center</p> <p>Under the map is a comprehensive list of hundreds of organizations that include people with disabilities in the arts. https://www.semel.ucla.edu/nadc/nadc-resources-map</p>
		<p>NADC, University of California, Los Angeles 11075 Santa Monica Blvd., Suite 200 Los Angeles, CA 90025 Phone: 310-825-5054 Fax: 310-794-1143</p>

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Organization	What They Do	Website
National Center on Health, Physical Activity, and Disability	<p>NCHPAD helps people with disability and other chronic health conditions achieve health benefits through increased participation in all types of physical and social activities, including fitness and aquatic activities, recreational and sports programs, adaptive equipment usage, and more.</p> <p>Provides web-based materials: individualized information, referral, and consultation services to people with disabilities, families, caregivers, policymakers, community members, health care practitioners, and public health professionals.</p>	https://www.nchpad.org/
The National Inclusion Project	<p>Provides recreational programs and provides community organizations the tools and training they need to serve ALL children in their communities.</p> <p>MISSION:</p> <p>To make sure no child has to sit on the sidelines, and that children of all abilities have the chance to play, laugh, and learn TOGETHER.</p> <p>Offers a 16-week online Inclusive Recreation Specialist Course that teaches how to comprehensively adapt to every child’s needs in every activity across all recreational settings.</p>	https://www.inclusionproject.org/
The National Sports Center for the Disabled	<p>NSCD has led the way for 50 years in redefining adaptive outdoor experiences, helping participants reignite a passion for playing and competing in the great outdoors. They have re-invented adaptive equipment, technology, and coaching methods. The National Sports Center for the Disabled is located in Winter Park, CO and offers incredible adaptive outdoor experiences from skiing, hiking, and horseback riding to rafting, archery, camping, and more.</p>	https://nscd.org/
Paralyzed Veterans of America	<p>PVA advocate for:</p> <ul style="list-style-type: none"> ▪ Quality health care ▪ Research and education ▪ Benefits available ▪ Civil rights and opportunities to maximize independence 	https://pva.org/

Organization	What They Do	Website
Project Venture (Previously named The National Indian Youth Leadership Project)	Project Venture operates in 25 states, including Hawaii, and eight Canadian provinces. Started in 1982 as a summer leadership camp, Project Venture now provides year-round programming both in and out of school and is staffed predominantly by Native Americans from various backgrounds.	https://projectventure.org/
Special Olympics	Provides athletic training and competitive outlets to children and adults with intellectual disabilities, empowering them to become physically fit, productive, and respected members of society through sports training and competition. Special Olympics serves 2.5 million people with intellectual disabilities in more than 200 programs in 180 countries.	https://www.specialolympics.org/programs Look for a Special Olympics program in your area or form your own with the assistance of the Special Olympics.
Tribal Adaptive	Uses sports as a tool to improve the health and wellness of Native Americans with disabilities. Encourages other Natives with disabilities to find a path toward a successful, independent life through adaptive sports. Through media and engagement with tribes and urban tribal communities, Tribal Adaptive finds resources and opportunities to access equipment and training to pursue any level of athletic achievement an individual desires.	https://tribaladaptive.com/
United Amputees Services Association Renamed, "The O & P Edge" (Orthopedics and Prosthetics)	Dedicated to helping amputees across the nation live a fulfilling life with dignity and independence. Has a magazine (print and online) and member facilities across the country. Products include: <ul style="list-style-type: none"> ▪ Prosthetics ▪ Orthotics ▪ Footwear & Perorthics ▪ Equipment/Supplies Services include: <ul style="list-style-type: none"> ▪ Accreditation ▪ Central Fabrication ▪ Consulting ▪ Cosmetic Restoration ▪ Networks ▪ Rehabilitation 	https://opedge.com/ Search engine allows you to find orthotics and prosthetics care in your area: https://opedge.com/facilities/

(continued)

Organization	What They Do	Website
World Triathlon	<p>For paratriathlon athletes: ParaTriathlon entails:</p> <ul style="list-style-type: none"> ▪ 750 m swim ▪ 20 km bike (hand bike/tandem) ▪ 5 km run (racing wheelchair) <p>Develops the triathlon community by growing participation at all levels, building a pathway to developing elite performance, evolving events, and building an athlete's profile.</p>	https://www.triathlon.org/paratriathlon

Grant Opportunities to Support Health Programs

Challenged Athletes Foundation (CAF)

provides grants to individual athletes with a permanent physical disability pursuing an active lifestyle through physical fitness or competitive athletics. The individual's permanent disability must impair mobility, affect the neuromuscular system, or impair balance or motor control. CAF uses the International Paralympic Committee's classification structure as a guideline and all qualifying individuals must provide supporting documentation from a medical professional to explain how their physical disability affects their activities of daily living. Hearing impairments and intellectual and developmental disabilities do not qualify for support through CAF.

The website provides specific information about sport expense requests, equipment requests, and athletic prosthetics.

Website: <https://www.challengedathletes.org/programs/grants/>

Kelly Brush Foundation, through the Active Fund, provides grants to purchase adaptive sports equipment for people with paralysis caused by

spinal cord injury. The Kelly Brush Foundation believes in the power of sport and recreation to foster inclusion and overcome the barriers of paralysis. They have helped over 900 people from 48 states purchase handcycles, mono-skis, sport chairs, racing chairs, hockey sleds, and much more.

Website: <https://kellybrushfoundation.org/theactivefund/>

High Fives Foundation has helped countless injured athletes and veterans get back to doing what they love. The Foundation aims to be the leader of education and recovery from life-altering injuries in outdoor action sports. These include spinal cord injuries, traumatic brain injuries, amputation or other mobility-limiting injuries that occurred in an individual's lifetime. Grants provide funding in specific funding categories: living expenses, insurance, health, travel, adaptive equipment, winter equipment, and High Fives' healing network.

Website: <https://highfivesfoundation.org/>

Athletes Helping Athletes provides eligible athletes with a custom-built adaptive bike.

Website: <https://www.roadrunnersports.com/content/aha-home-page>

Chapter 4: Education



“Every time there’s an issue that comes up. You have options. You have rights. And they (parents) really do have a lot of power, but it’s just taking that step, having that courage.”

Tona Treetop, Advocate and parent of a child with a disability

History of Boarding Schools

Throughout our country’s history education has been prioritized for American Indian and Alaska Native (AI/AN) children, and in 1819 the Indian Civilization Act provided \$10,000 to religious groups and individuals who wanted to live with and teach Indian children (Rehnyer).

What ensued was the forced removal of Indian children from their families, tribes, culture, language, and homelands to live in boarding schools sometimes located hundreds of miles away from home. The tyrannical practice continued well into the 1970s. Children at boarding schools endured physical, sexual, and emotional abuse, severe neglect, disappearance, and even death.

Throughout this history, it was believed that Native children needed to be assimilated into mainstream American society. Most off-reservation boarding schools followed the Carlisle Indian Industrial School model, “Kill the Indian, and save the man.”

In 1928, an independent investigation, the Meriam Survey, sharply criticized the conditions of boarding schools and spurred efforts for reform. In 1934, the Indian Reorganization Act was passed to enable tribal nations to take control of boarding and day schools on reservations (History of American Indian Schools, Wikipedia). However, most boarding schools operated off reservation land. It was not until 1978 with the passage of the Indian Child

Welfare Act that Native American parents gained the legal right to deny their children’s placement in off-reservation schools (Northern Plains Reservation AID).

At one time there were as many as 367 government-funded and church-run Indian boarding schools operating in 29 states. In 1926, boarding school enrollment reached:

- 83% of Indian school age children
- 60,889 children (National Native American Boarding School Healing Coalition).

Legacy of Boarding Schools

- 1 in 3 AI/AN children live in poverty today
- 67% AI/AN graduation rate (national average is 80%)
- 53% graduation rate at BIE schools (National Native American Boarding School Healing Coalition, Impact)
- Highest percentage of special education students of any racial/ethnic group in the U.S. (National Center for Education Statistics)

Special Education

- In 2018 18% of AI/AN students aged 3–21 received special education services, the highest of any racial/ethnic group (National Center for Education Statistics 2018)

“American Indian or Alaska Native students ages 6 through 21 were four times as likely to be served under the (IDEA) Part B, [federal special education law], for developmental delay than were students ages 6 through 21 in all other racial/ethnic groups combined” (Individuals with Disabilities Education Act).

The high percentage of special education students and low graduation rates can be attributed to historical trauma induced by boarding schools and many other historical factors. The remainder of this chapter focuses on education laws, practical tips to advocate for your child, and resources to facilitate positive educational outcomes for AI/AN students.

Federal Education and Disability Laws

Introduction – Facts About AI/AN students

AI/AN students comprise one percent of all public elementary and secondary students in the United States or approximately 500,000 students (National Center for Education Statistics).

The vast majority of AI/AN students attend public schools; however, there are 183 Bureau of Indian Education schools operating in 23 states.

- 130 tribally controlled schools
- 53 BIE operated schools
- 2 postsecondary schools are operated by the BIE
 - Haskell Indian Nations University
 - Southwestern Indian Polytechnic Institute

The BIE also funds 33 tribal colleges, universities, tribal technical colleges (NAEP 5).

Federal Education Laws

Every Student Succeeds Act (ESSA) of 2015

The 1965 passage of the Elementary and Secondary Education Act (ESEA) established the goal of “full educational opportunity” for all of

our nation's school aged students. The law was renamed ESSA in its 2015 reauthorization.

The ESSA recognizes the value of cultural preservation and aims "to ensure that Indian students gain knowledge and understanding of Native communities, languages, tribal histories, traditions, and cultures." The law also:

- Established language immersion programs, and
- "Activities that recognize and support the unique cultural and educational needs of Indian children and incorporate appropriately qualified tribal elders and seniors." (NAEP 9)

Federal Disability Laws that Apply to Public Education

There are three laws that protect the rights of public school students with disabilities and their families: the American with Disabilities Act, the Individuals with Disabilities Education Act (IDEA), and Section 504 of the Rehabilitation Act.

Americans with Disabilities Act (ADA) of 1990

The ADA is a civil rights law that prohibits discrimination solely on the basis of disability in employment, public services, and accommodations. Tribal sovereignty makes the ADA largely inapplicable to tribal nations. However, ADA does apply to public schools.

Individuals with Disabilities Education Act (IDEA)

The aim of IDEA is to improve the educational outcomes of children with disabilities by ensuring

that eligible children receive a free, appropriate public education (FAPE) that meets an individual child's needs. IDEA applies to all public schools, tribal and BIE schools, and private schools that receive IDEA funding.

IDEA requires that school districts and tribally controlled and BIE schools provide impartial hearings for parents who disagree with the identification, evaluation, or educational placement of a child with a disability. Part B and C of IDEA guarantees special education and related services are provided to eligible infants, toddler, and youth with disabilities.

- Part B of IDEA provides special education and related services to eligible children/ students aged 3 to 21. A multidisciplinary team determines if a child meets disability criteria within one or more of 13 specific disability categories.
- Part C of IDEA provides early intervention services (birth to 36 months of age) in the areas of physical development, cognitive development, communication, social, emotional development, and adaptive development.

The Rehabilitation Act of 1973

The Rehabilitation Act prohibits discrimination based on disability in federal agencies or in any program that receives federal funds.

- Section 504 of the Rehabilitation Act establishes a student's right to full access and participation to education and all school-related activities and requires schools to provide appropriate services to meet the individual needs of qualified students.

Comparison of ADA, IDEA, and Section 504 of the Rehabilitation Act

Again, the three federal laws that protect students with disabilities are:

ADA = Americans with Disabilities Act

IDEA = Individuals with Disabilities Education Act

504 = Section 504 of the Rehabilitation Act of 1973

The vocabulary below is intended to help readers understand a comparison of the ADA, IDEA, and Section 504 that follows.

Vocabulary

Local education agency	A school district; the Bureau of Indian Education
Special education services	Instruction and related services that help students access the curriculum and school activities
Related services (Can be any one or more)	Adaptive physical education, occupational therapy, physical therapy, music or art therapy, speech and language therapy, audiology, assistive technology, social work, etc.
FAPE “Free Appropriate Public Education”	Free appropriate public education (a legal term that guarantees every student receives a free public education appropriate to the needs of the student)
Procedural safeguards	A set of requirements that schools must follow to protect the rights of children with disabilities and their families.
Identification	The process that determines whether a student has a disability
Inclusion	Inclusion means the full and active participation of people with disabilities in everyday settings
Evaluation	A set of tests and observations used to determine if a student has a disability
Placement	Where and how services are provided to a student with a disability. It can be with the general education population or in a segregated/special education classroom or setting.
Multidisciplinary team	The team is made up of school professionals and parents/guardians—those adults who know the student well. This team decides if the student meets the criteria to receive special education services.
Due process	A formal process to resolve disputes between a school and the parent or guardian about a child’s education. It includes many options, such as mediation, arbitration, and an impartial hearing.

Comparison of ADA, IDEA, and Section 504

What Is Each Type of Law And Its Purpose?

ADA	IDEA	504
The Americans with Disabilities Act is a civil rights law to prohibit discrimination solely based on disability in employment, public services, and accommodations.	The Individuals with Disabilities Education Act provides federal financial assistance to state and local education agencies to guarantee special education and related services to eligible children with disabilities.	Section 504 of the Rehabilitation Act of 1973 is a civil rights law to prohibit discrimination based on disability in programs and activities, public and private, that receive federal financial assistance.

Who Is Protected?

ADA	IDEA	504
Any individual with a disability who (1) has a physical or mental impairment that substantially limits one or more life activities, (2) has a record of such impairment, or (3) is regarded as having such an impairment. Further, the person must be qualified for the program, service, or job.	Children ages 3–21 who are determined by a multidisciplinary team to be eligible within one or more of 13 specific disability categories and who need special education and related services. Categories include autism, deafness, deaf-blindness, hearing impairments, intellectual disability, multiple disabilities, orthopedic impairments, other health impairments, traumatic brain injury, and visual impairments.	Any person who (1) has a physical or mental impairment that substantially limits one or more major life activities, (2) has a record of such an impairment, or (3) is regarded as having such an impairment. Major life activities include walking, seeing, hearing, speaking, breathing, learning, working, caring for oneself, and performing manual tasks.

Is There Funding to Implement Services?

ADA	IDEA	504
No, but limited tax credits may be available for removing architectural or transportation barriers. Also, many federal agencies provide grant funds to support training and to provide technical assistance to public and private institutions.	Yes, IDEA provides federal funds under Parts B and C to assist states and local education agencies in meeting IDEA requirements to serve infants, toddlers, and youth with disabilities.	No. State and local jurisdictions have responsibility. IDEA funds may not be used to serve children found eligible under Section 504.

What Are the Procedural Safeguards?

ADA	IDEA	504
The ADA does not specify procedural safeguards related to special education; it does detail the administrative requirements for complaint procedures and consequences for noncompliance related to both services and employment.	IDEA requires written notice to parents regarding identification, evaluation, and/or placement. Further, written notice must be made prior to any change in placement. The Act delineates the required components of the written process.	Section 504 requires notice to parents regarding identification, evaluation, and/or placements. Written notice is recommended. Notice must be made only before a significant change in placement. Following IDEA procedural safeguards is one way to comply with Section 504 mandates.

What Are The Evaluation and Placement Procedures?

ADA	IDEA	504
The ADA does not specify evaluation and placement procedures; it does specify provision of reasonable accommodations for eligible activities and settings. Reasonable accommodations may include, but are not limited to, redesigning equipment, assigning aides, providing written communication in alternative formats, modifying tests, redesigning services to accessibility locations, altering existing facilities, and building new facilities.	A comprehensive evaluation is required. A multidisciplinary team evaluates the child, and parental consent is required before evaluation. IDEA requires that reevaluations be conducted at least every three years. For evaluation and placement decisions, IDEA requires that more than one single procedure or information source be used; that information from all sources be documented and carefully considered; that the eligibility decision be made by a group of persons who know about the student, the evaluation data, and placement options; and that the placement decision serves the student in the least restrictive environment. An IEP meeting is required before any change in placement.	Unlike IDEA, Section 504 requires only notice, not consent, for evaluation. It is recommended that a district obtain parental consent. Like IDEA evaluation and placement procedures, Section 504 requires that information be obtained from a variety of sources of the area of concern; that all data is documented and considered; and those decisions are made by a group of persons knowledgeable about the student, evaluation data, and placement options. Section 504 requires that students be educated with their peers without disabilities to the maximum extent appropriate. Section 504 does not require a meeting for any change in placement.

What Are the Due Process Procedures?

ADA	IDEA	504
The ADA does not delineate specific due process procedures. People with disabilities have the same remedies that are available under Title VII of the Civil Rights Act of 1964, as amended in 1991. Thus, individuals who are discriminated against may file a complaint with the relevant federal agency or due process in federal court. Enforcement agencies encourage informal mediation and voluntary compliance.	IDEA delineates specific requirements for local education agencies to provide impartial hearings for parents who disagree with the identification, evaluation, or placement of a child.	Section 504 requires local education agencies to provide impartial hearings for parents who disagree with the identification, evaluation, or placement of a student. It requires that parents have an opportunity to participate in the hearing process and to be represented by counsel. Beyond this, due process details are left to the discretion of the local education agency. It is recommended that districts develop policy guidelines and procedures.

(Disability Rights Education & Defense Fund)

Six Principles of the Individuals with Disabilities Education Act (IDEA)

IDEA was enacted by the Federal Government to ensure that all children with disabilities are provided with special education and related services designed to meet a child's "unique needs and prepare them for further education, employment, and independent living" (Saleh).

IDEA is designed around six legal principles of student rights and public school responsibilities. When a parent disagrees with a school about their child's education, the complaint will address one or more the six principles, which are (1) FAPE, (2) Appropriate Evaluation, (3) Individualized Education Plan, (4) Least Restrictive Environment, (5) Parent Participation, and (6) Procedural Safeguards.

(1) **Free Appropriate Public Education (FAPE).**

Each word in the acronym has a specific legal meaning.

- **Free** means that every child with a disability is eligible for special education services at no cost.

- **Appropriate** means that special education services provided are appropriate to that individual student's needs.
- **Public** means the public school system must educate all students regardless of disability.
- **Education** includes special education, general education, and related services.

(2) **Appropriate Evaluation.** A qualified and trained team of evaluators use sound evaluation materials and procedures in a timely and non-discriminatory way to determine whether to recommend a child's eligibility for special education services (Saleh).

(3) **Individualized Education Program**

(IEP). The IEP is a written document that is developed by an IEP team (parents/guardians and special education providers) to establish annual education goals, services, supplementary aides (i.e., assistive technology, auditory screenings, etc.)

and placement of services (i.e., general education classroom or special education classroom).

1. The purpose of the IEP is to discuss how to provide meaningful educational benefits. The intent is to raise student expectations, detail what is appropriate progress, and to plan for transition into postsecondary education, employment, and independent living.

(4) **Least Restrictive Environment (LRE).**

There is a strong emphasis on placement of special education children in a general education setting. The IEP team must explore ways (classroom modifications, supplemental aids and services, alternative instructional methods) to enable a child's participation in a general education classroom (Saleh).

(5) **Parent Participation.** IDEA states that parents are full and equal participants in all aspects of their child's special education program, and therefore participate in placement decisions. When appropriate, the student is also a member of the team.

- At age 14, transition plans must be included in the IEP and require that the student be a member of the IEP team.

(6) **Procedural Safeguards.** These written procedures must be given to parents and students at each IEP meeting. The safeguards ensure parents have access to information pertaining to their child's placement and transition planning, as well as the steps to follow to resolve disagreements regarding the placement of a student.

Part B of IDEA: Special education for children aged 2–21

Part B of IDEA provides federal funding and provisions on how special education and related services are to be provided to eligible children aged 3 to 21. It details the six principles of IDEA and how the Federal Government will monitor and enforce the implementation of IDEA (Center for Parent Information & Resources). In tribally controlled and BIE schools, they enter into a Memorandum of Understanding regarding early intervention and preschool programs (ages 3–5).

The IEP is the cornerstone of IDEA. It is at the annual Individualized Education Program (IEP) meetings that a special education plan for the child is developed for the coming year. The components of an IEP are:

1. **Vision:** The parent and student's vision for the student in the short- and long-term.
2. **Present levels of performance** (e.g., academics, behaviorally)
3. **Goals** (related to the present levels of performance) and sometimes objectives
4. **Reporting progress:** How and when progress will be reported to the parent
5. **Services** to be provided (i.e., special education instruction and/or related service)
6. **Supplementary aids and services** (e.g., nursing services, audiology, training in use of assistive technology)
7. **Modifications** for school personnel (e.g., providing an audio book instead of a paperback)
8. **Hours of services** (by week, month, semester, or year)

9. **Placement** (also called setting) of services
10. **Transition Plan** for students 14 and older (see details below).
11. **Prior written notice** (Every proposal is written down in the IEP, and the team decides whether to accept or reject the proposal and why)
12. **Signature page** of who attended the IEP meeting
 - b. Taking the ASVAB (required test to join a U.S. military service)
 - c. Application to the local community college

Transition Plans: For students 14 and older, it is mandatory to develop a plan for transition to life after high school. The plan must reflect the student's interests and skills. A transition plan requires:

1. The student be invited to the IEP.
2. Annual transition goals that lead to successful post-high school outcomes.
 - a. Postsecondary education or vocational training goals
 - b. Employment goals
 - c. Independent living goals
3. The transition activities/services and person or agency involved in helping the student achieve each goal.
4. Representation by local agencies such as Vocational Rehabilitation to discuss transition goals and available services to support the goals.
5. Measurement and documentation of progress toward annual goals. For example:
 - a. Creating a portfolio that includes the student's resume, work samples, progress reports, work experience, and reviews from supervisors

When Do Special Education Services End?

Upon graduation from high school, students no longer receive services under IDEA and instead are protected from discrimination by the Americans with Disabilities Act of 1990 (ADA) and Section 504 of the Rehabilitation Act of 1973.

How Postsecondary Education Supports Students with Disabilities

Under Section 504 of the Rehabilitation Act of 1973, students are responsible for telling the postsecondary institution they have a disability. They are required to provide documentation to demonstrate the existence of a disability and the need for academic adjustments (often called accommodations) or auxiliary aids and services.

Students are expected to advocate for their needs and to work collaboratively with the postsecondary school's disability coordinator. According to the U.S. Department of Education, the keys to success for students with disabilities include:

1. **Understanding your disability** (strengths, functional limitations, difficulties in the past, what academic adjustments or auxiliary aids and services helped you to overcome challenges)
2. **Accepting responsibility and advocating for yourself** because the institution works directly with the student (not parents of school staff)

3. **Taking advantage of the institution's services**, such as preparatory courses, tutoring, and workshops such as study skills
4. **Learning time management skills**
5. **Acquiring computer skills**
6. **Getting involved on campus**

(Office for Civil Rights)

Post-High School Employment

For youth with disabilities, the transition from school to adulthood is an important time to prepare yourself for future employment and paying living expenses. Support may be needed in the areas of education, vocational training, income support, health insurance coverage, health care, transportation, life skills, housing, etc. (youth.gov).

The resources section lists organizations that assist students with disabilities transition to life after high school graduation.

Tips for IEP Meetings

Arranging an IEP Meeting

A parent advocacy network from Wilton, CT, published a parent handbook, "Bringing Knowledge to the Table," that explains parents' rights for calling/attending IEPs.

1. A parent can ask for an IEP meeting any time
2. IEP Meetings should be held when the parent can attend
3. Call the school immediately if you cannot attend the scheduled IEP. Ask that the meeting be rescheduled at a time you can attend.
4. The written notice of the meeting should state the purpose, date, time, location, and participants of the meeting

5. Notify the school if you intend to bring someone from outside the school (e.g., a friend, relative, advocate, or outside evaluator, someone who has knowledge of your child's needs, someone to take notes while you listen)
6. Ask for an interpreter, if needed

Preparing for an IEP Meeting

1. Request a draft of the proposed IEP and review it before the meeting
2. Request recent evaluations if applicable
3. From the draft IEP, write a list of questions or concerns
4. Contact the school to resolve the questions or concerns before the meeting
5. Get support from other parents or advocacy groups. Look in the Resources Section of this chapter to find support groups in your community. You can also find support groups online or through social media.
6. Think about or write down:
 - a. Your child's strengths, challenges, preferences, learning styles
 - b. What is needed for your child to succeed across curricula and settings.
 - c. Samples of your child's work, art, etc.

Participating in the IEP Meeting

1. If you cannot attend in person, attend online or by phone
2. Remind the school, if necessary, that you will not sign a prepared IEP but wish to be involved in the writing of the IEP
3. Ask questions and share knowledge about your child with the team

4. You may tape-record the meeting
5. Bring another parent, advocate, or note taker to the IEP meeting
6. Know your child's rights and discuss these rights with the team

At the Close of the IEP Meeting

1. Be certain that you understand your child's IEP. If you don't understand the IEP, ask the school to explain.
2. Obtain a copy of the IEP (save all IEPs in a location where you can find them).
3. Signing off on an IEP means you agree with the plan. Do not sign the IEP if it does not meet your child's needs.
4. Request a dispute resolution process if you do not agree with the plan
5. Remember that the IEPs must be reviewed at least once per year

Problem Solving and Procedural Safeguards

At times, parents and schools do not agree on issues affecting a child's education. Public, tribal, BIE schools, or private schools that receive federal funding are required by IDEA to provide procedural safeguards for students and families to solve disputes. The disputes can be resolved by informal or formal approaches (Center for Parent Information and Resources).

Informal Approaches to Dispute Resolution:

1. An IEP Review
 - a. The IEP team meets to discuss the parent's concerns and works toward a solution that is agreeable to all parties,

such as a temporary change in placement to see how the student performs in the temporary setting.

2. A Facilitated IEP meeting
 - a. A neutral facilitator, who is not a member of the IEP team, leads the team through an IEP meeting to find a resolution.

Formal Approaches to Dispute Resolution:

1. Mediation
 - a. A qualified, trained, impartial third person mediator is provided and paid for by the state.
 - b. Both parties volunteer to participate.
 - c. Agreements are provided in writing to both parties.
 - d. Agreements are confidential and cannot be used in future due process hearings or civil law proceedings.
2. Filing a state education agency (SEA) or BIE complaint
 1. The complaint must describe what requirement of IDEA the school has violated (See 6 principles of IDEA).
 2. Complaints can be filed by parents, an organization, or an individual.
 3. The SEA/BIE office must resolve the parents' complaint within 60 calendar days and in writing.
3. Due Process Hearing—considered a legal proceeding, much like a trial
 1. An attorney files a confidential written due process complaint on behalf of the family to the school district or BIE school.

2. The school district/BIE must convene a resolution meeting (hearing) by the timeline outlined in IDEA.
3. Parents and the school present evidence using witnesses, testimony, documents, and legal arguments via their respective attorneys.
4. An impartial hearing officer presides over the due process hearing
5. The hearing officer's decision is final, unless appealed.

(Center for Parent Information and Resources)

Part C of IDEA: Early Intervention— Birth to 36 Months

The first weeks and months of an infant's life can affect a person's entire life, including success in school. Data shows that families across the country often are not informed early enough about the importance of early intervention. Too often children with significant disabilities may be two or three years old before they are referred for assessment and early intervention.

Part C requires each state to implement a public awareness program and "Child Find" activities to find infants and toddlers who may be eligible for early intervention services (Congressional Research Services 2019).

Under Part C of IDEA, the following services must be provided at no cost to families:

- a. Child Find services: Identify, locate, and evaluate all children with disabilities, regardless of the severity of disability
- b. Local school district provides services for children residing on a reservation or within a school district's attendance area

- c. Development and review of an Individual Family Support Plan (IFSP)
- d. Service coordination

Early intervention focuses on helping eligible babies and toddlers learn basic and new skills that typically develop during the first three years of life, such as:

- Physical (reaching, rolling, crawling, walking)
- Cognitive (thinking, learning, solving problems)
- Communication (talking, listening, understanding)
- Social/emotional (playing, feeling secure and happy)
- Self-help (eating, dressing)

The types of early intervention services a family receives depends on the needs of the child and might include:

- * Family training
- * Counseling
- * Home visits
- * Occupational therapy
- * Physical therapy
- * Speech therapy
- * Hearing loss services
- * Health
- * Nutrition
- * Social work
- * Transportation
- * Service coordination
- * Assistive technology & services

(Centers for Disease Control and Prevention)

Natural Environments

All young children tend to thrive when they're in familiar surroundings and with the people and objects that are most dear to them. For young children with disabilities, familiar and reassuring surroundings are an essential part of their early intervention services. The law says:

- "Early intervention services must be provided in natural environments, including the home and community settings in which children without disabilities participate, to the maximum extent that is appropriate" (Sec. 303.12).
- "'Natural environments' are those settings that are natural or normal for the child's same-age peers who have no disabilities" (Sec. 303.18).

Natural environments help a child to model the behavior and skills of family and peers. A child will be more comfortable to practice new skills and for the family to determine what interventions do and do not work for the child (Pacer Center).

Individual Family Service Plan (IFSP)

1. Before Part C services begin, an Individual Family Service Plan (IFSP) is developed. The IFSP is developed by a team, which includes the parents and all providers who work with the child and the family
2. The IFSP describes the child's:
 - a. Present level of development (what the child can do)
 - b. The family's strengths and needs

- c. The specific services to be provided to the child and the family
- d. A plan to transition to public school
(Centers for Disease Control and Prevention)

State policies determine whether early intervention services are free. You may be charged a fee based on what you earn. Some services may be covered by your health insurance, Medicaid, Children's Health Insurance Program, or Indian Health Services (Center for Parent Information and Resources, Overview).

Family and Child Education (FACE): Keeping the Circle Alive

(An Example of an effective early intervention AI/AN model)

FACE celebrated a 30-year anniversary in 2020. FACE operates in BIE schools and is a two-generation model emphasizing family literacy through integrated early childhood and parental involvement. FACE was developed specifically by and for American Indian families. Highly trained, local, indigenous professionals are paired with families from pregnancy through a child's first years of life.

The core beliefs and practices of the FACE model are:

- Parents / primary caregivers are seen as a child's first and most influential teacher
- Parents participate in their child's learning
- Culture and language are supported and celebrated
- Services are provided in the home, at school, and in the community

The activities of the FACE model include:

- Personal visits by indigenous professionals with parents/primary caregivers
- Family circles to form group connections
- Screenings (such as vision and hearing screenings)
- Adult education
- Parent time (Parents learn together)
- Parent and Child Together Time (PACT®)
- Community resources
- Community Advisory Council

AI/AN Organizations Supporting Education

Who	What	Website, Contact Info
American Indian College Fund	Provides college bridge programs, scholarships, and student support services for American Indian students that attend or plan to attend qualified tribal colleges and universities.	American Indian College Fund 8333 Greenwood Blvd. Denver, CO 80221 Phone: 303-426-8900 Tollfree: 800-776-FUND (3863) Website: https://collegefund.org/
American Indian Higher Education Consortium (AIHEC)	Tribal Colleges and Universities (TCUs) operate more than 75 campuses in 16 states—virtually covering Indian Country—and serve students from well more than 250 federally recognized Indian tribes. TCUs vary in enrollment (size), focus (liberal arts, sciences, workforce development/training), location (woodlands, desert, frozen tundra, rural reservation, urban), and student population (predominantly American Indian). However, tribal identity is the core of every TCU, and they all share the mission of tribal self-determination and service to their respective communities.	AIHEC 121 Oronoco Street Alexandria, VA 22314 Phone: 703-838-0400 Fax: 703-838-0388 Website: http://www.aihec.org This web page has a map of TCUs, profiles of the schools, and majors and degrees offered. http://www.aihec.org/who-we-serve/TCUmap.cfm
Benefits.gov	Assistance for Indian Children with Severe Disabilities Provides special education and related services to Native American children with severe disabilities, in accordance with IDEA.	https://www.benefits.gov/benefit/792

Who	What	Website, Contact Info
Bureau of Indian Education (BIE)	<p>Parent Training Centers by State (Bureau of Indian Education, Special Education)</p> <p>This directory shows which states are in each of the six BIE regions. It provides the contact information for each region.</p> <p>Parent Training Center.</p> <p>https://www.bie.edu/sites/default/files/documents/idc-020177.pdf</p>	<p>Bureau of Indian Education (BIE) Division of Performance and Accountability Attn: Marcy Oliver, Education Specialist-Special Education Marcy.Oliver@bie.edu</p> <p>1011 Indian School Rd NW Ste 332 Albuquerque, New Mexico 87104 Fax: 505-563-5453</p> <p>Directory of BIE schools: https://www.bie.edu/schools/directory</p>
BIEs Safeguards and Parental Rights	<p>The procedures BIE and tribally controlled schools are required to follow if there is a dispute between a parent and the school about how special education services are provided to a student.</p>	<p>The written procedures to protect special education students and family rights.</p> <p>https://www.bie.edu/sites/default/files/documents/idc2-087462.pdf</p>
Education for Parents of Indian Children with Special Needs (EPICS) Project	<p>Parent Center that serves 22 tribes in New Mexico.</p> <p>EPICS serves parents of Native American children with disabilities, developmental delays, special health care needs, and Deaf or Hard of Hearing who are in the BIE and NM school systems.</p> <p>EPICS provides comprehensive training on advocacy, leadership, support, and capacity building.</p> <p>Training is provided to educate parents on their rights, responsibilities, and protections as they develop the skills necessary to effectively participate in the planning and decision making relating to Early Intervention, Educational, and Transitional Services to meet their child's specific and unique needs.</p>	<p>EPICS 2201 Buena Vista Dr. SE, Ste 201 Albuquerque, NM 87106 Toll-Free: 888-499-2070 Phone: 505-767-6630 Email: emartin@epicsnm.org Website: https://www.epicsnm.org/</p>
Family and Child Education (FACE)	<p>FACE was initiated in 1990, and currently has programs in 47 Bureau of Indian Education (BIE)-funded schools.</p> <p>A program for children ages 0–8, parents, and primary caretakers. Built on a model that respects American Indian culture and traditions and aims to reform education in three settings—home, school, and community.</p>	<p>FACE Acting Director, Sue Bement sue.bement@bie.edu 952 851-5423 (in Minnesota)</p> <ul style="list-style-type: none"> ▪ FACE Coordinators or School Principals are encouraged to contact her with general questions.

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Who	What	Website, Contact Info
Indian Education Bureaus or Departments at each State's Education Department	The Indian Education Contacts for each State's Education Department as of November 19, 2019, are in the link in the next column.	Indian Education contacts are listed in alphabetical order by state: https://www.parentcenterhub.org/state-indian-education-contacts/
The National Center on Tribal Early Childhood Development	<p>The National Center on Tribal Early Childhood Development assists tribal grantees and administration with implementation of Child Care and Development Fund programs.</p> <p>Targeted technical assistance services support more than 539 Federally recognized tribes, either directly or through tribal consortia.</p> <p>Services include:</p> <ul style="list-style-type: none"> ▪ Toll-free info/referral line ▪ Technical assistance materials ▪ A peer learning and leadership network ▪ National and regional webinars ▪ Technical assistance (in-person and distance learning) ▪ On-site and remote consultations ▪ Collaboration between states, tribes, and local early childhood and school-age care education programs 	Send questions and requests to: ncted@ecetta.info Phone: 877-296-2401 Website: https://childcareta.acf.hhs.gov/sites/default/files/public/nctecd_overview.pdf Tribal Child Care and Development Fund (CCFD) contacts by state: https://childcareta.acf.hhs.gov/sites/default/files/public/tribal_grantee_contact_list_june_2021.pdf
The National Indian Child Care Association	<p>The National Indian Child Care Association is a representative American Indian and Alaska Native organization serving the 268 Tribal CCDF grantees that represent tribal communities across the nation.</p> <p>Tribal childcare and early childhood programs provide our children, families, and communities with high-quality childcare services across Indian Country.</p> <p>They provide education, training, and professional development opportunities to help promote the success of childcare and development professionals supporting tribal children and families.</p>	National Indian Child Care Association PO Box 380 Ramona, OK 74061 To contact online: https://www.nicca.us/contact Website: https://www.nicca.us/ Books for sale for young children written for or by indigenous people: https://www.nicca.us/bookstore

Who	What	Website, Contact Info
National Indian Child Welfare Association	NICWA is dedicated to the well-being of American Indian children and families. Works to address the issues of child abuse and neglect through training, research, public policy, and grassroots community development.	National Indian Child Welfare Association 5100 S Macadam Ave, Suite 300 Portland, OR 97239 Phone: (503) 222-4044 Email: info@nicwa.org Website: https://www.nicwa.org/
National Indian Education Association	NIEA provides a broad range of resources for students, educators, and parents. <i>Digital Access to Native Texts:</i> Links are on the following website. Scroll to mid-page and click on “literacy resources” and scroll down for the link to each book. https://www.niea.org/virtual-resources-for-parents-and-teachers <ul style="list-style-type: none"> ▪ Native Digital Texts for Grades K–4 ▪ Native Digital Texts for Grades 5–12 	Virtual Resources for Schools, Teachers, Parents, and Students On the Indianapolis Public Library digital books platform: Apply for a library card https://libbyapp.com/welcome Digital books: https://www.uniteforliteracy.com/ Reading Rockets <ul style="list-style-type: none"> ▪ Lists books by theme and grade level with an “adventure pack” or lesson plans for hands-on activities that are paired to the list of books. https://www.readingrockets.org/article/reading-adventure-packs-families Native American Children’s Literature Recommended Reading List, K–12 https://www.firstnations.org/wp-content/uploads/2018/11/Revised_Book_Insert_Web_Version_March_2018.pdf <i>Digital Access to Native Texts:</i> Links are on the following website, scroll to mid-page and click on “literacy resources” and scroll down for the link to each book. https://www.niea.org/virtual-resources-for-parents-and-teachers <ul style="list-style-type: none"> ▪ Native Digital Texts for Grades K–4 ▪ Native Digital Texts for Grades 5–12

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Who	What	Website, Contact Info
National Indian Head Start Directors Association (NIHSDA)	NIHSDA strives to preserve and respect indigenous identity while actively providing high-quality advocacy, leadership development, and professional growth opportunities to current and future early care and education leaders.	NIHSDA P.O. Box 6058 Norman, OK 73070 Phone: 405-360-2919 Email: nihsdainfo@nihsda.org Website: https://www.nihsda.org/
National Indian Parent Resource Center (NIPRC)	The mission of the NIPRC is to strengthen our community through support, education, and encouragement for families whose Native American tribal children, ages birth to 26, are experiencing disabilities or learning challenges.	Email: info@nipic.org Phone: 541-244-1822 Facebook: https://www.facebook.com/NationalIndianParentInformationCenter/
National Technical Assistance Center on Transition (in partnership with the Bureau of Indian Education)	Taxonomy for Transition Programming 2.0 A model for planning, organizing, and evaluating transition education services and programs.	https://transitionuniverse.files.wordpress.com/2018/03/tax_trans_prog_0.pdf
Native American Advocacy Program (NAAP)	NAAP serves persons residing on and off the lands of the tribal nations in South Dakota. NAAP provides independent living services for people with disabilities and help to reclaim Lakota Language, culture, and spirituality by promoting education and healthy lifestyles for our youth through culturally based strategies.	Mailing Address: NAAP Box 277 Herrick, SD 57538-0277 Location: 34838 U.S. Hwy 18 Herrick, SD 57538-0277 Phone: 605-775-2147 Fax: 605-775-2148 Website: https://mbullbear.wixsite.com/lakotayouth
Native American Parent Technical Assistance Center (NAPTAC)	NAPTAC is a project within EPICS to provide training and technical assistance to Parent Training Information Centers (PTIs) and Community Parent Resource Centers (CPRCs) nationwide on providing effective, culturally responsive services to Native American families of children and youth with disabilities.	To contact, use online form: https://naptac.org/contact-us/ Website: https://naptac.org/

Who	What	Website, Contact Info
Navajo Nation Office of Special Education and Rehabilitation Services (NNOSERS)	<p>NNOSERS operates three programs. “Growing in Beauty” meets the needs of Navajo children with delays or disabilities from birth to five years of age while honoring the unique culture and language of the Navajo people.</p> <p>Vocational Rehabilitation services are provided to eligible American Indians with disabilities who are interested in going to work. Invite NNOSERS to Transition IEP meetings for youth who will be graduating from high school.</p>	<p>http://www.nnosers.org/ NNOSERS PO Box 1420 Window Rock, AZ 86515 928-871-6338 1-866-341-9918</p>
Partnership with Native Americans (PWNA)	<p>PWNA serves hundreds of tribal communities in nine priority states throughout the Northern Plains and Southwest regions of the U.S.</p> <p>We prioritize underserved, under-resourced and geographically isolated Native communities with limited employment opportunities, addressing immediate relief and working toward long-term solutions.</p>	<p>Website: http://www.nativepartnership.org/site/PageServer?pagename=pwna_home</p> <p>Service areas: MT, ND, SD, NE, CO, UT, NM, AZ, CA (area bordering AZ)</p> <p>http://www.nativepartnership.org/site/PageServer?pagename=pwna_impact_results#service-area</p>
Sacred Circles	<p>Sacred Circles, which was originally called the Intertribal Deaf Council, is a community of Deaf Native Americans that communicates online through Facebook and holds get-togethers.</p> <p>Sacred Circles mission: <i>“To provide education, information & referral, and training about American Indians, Alaska Natives and First Nations Indians who are Deaf, Deaf-Blind, Hard of Hearing and late-deafened to tribal councils, family members and other interested parties in order to improve the social, educational, vocational, health and spiritual well-being of this population.”</i></p>	<p>Executive Director: Teresa Norris executive.director@deafnative.com VP: (971) 239-5697</p> <p>Website: http://www.deafnative.com/ Deaf Native Americans Facebook: https://www.facebook.com/groups/29798247066</p>

Resources For Early Intervention

Who	What	Website, Contact Info
<p>Birth to Five: Watch Me Thrive—Families</p> <p>U.S. Department of Health and Human Services</p> <p>Office of Early Childhood Development</p>	<p>Resources from the <u>Center on the Social and Emotional Foundations of Early Learning</u>.</p> <p>Resources include tools for the family on playtime, developmental milestones, understanding behavior, developing communication, and independent skills in your child.</p>	<p>Website: https://www.acf.hhs.gov/ecd/child-health-development/watch-me-thrive/families/tips-and-resources</p>
<p>CADRE</p>	<p>CADRE was designated by the Office of Special Education Programs in the U.S. Department of Education as the:</p> <ul style="list-style-type: none"> ▪ National Center on Appropriate Dispute Resolution in Special Education on behalf of the Office of Special Education. <p>CADRE delivers high-quality technical assistance, informational support, and other services to state education agencies (Part B), early intervention lead agencies (Part C), federally funded parent centers, local education agencies and early intervention providers, dispute resolution practitioners, family members, and other stakeholders.</p>	<p>CADRE</p> <p>576 Olive St, Suite 300 Eugene, OR 97401</p> <p>Phone: (541) 359-4210 Fax: (458) 215-4957</p> <p>Email: cadre@directionservice.org</p> <p>Website: http://www.cadreworks.org/</p>
<p>Center for Disease Control and Prevention</p>	<p>Information for Parents of Infants and Toddlers (Birth to age three) on:</p> <ul style="list-style-type: none"> ▪ Diseases and conditions ▪ Safety in the home and community ▪ Raising healthy children ▪ A child’s developmental milestones and schedules ▪ Infant vaccination requirements 	<p>Website: https://www.cdc.gov/parents/infants/index.html</p>
<p>Center for Parent Information and Resources (CPIR)</p> <p>c/o Statewide Parent Advocacy Network (SPAN)</p>	<p>CPIR is a “central hub” for information for parents of children with disabilities and has information on early intervention, eligibility, evaluation and assessment, ISFP, timelines, and information on who pays for what services.</p>	<p>Center for Parent Information and Resources (CPIR)</p> <p>c/o Statewide Parent Advocacy Network (SPAN) 35 Halsey St., 4th Floor Newark, NJ 07102</p>

Who	What	Website, Contact Info
		Phone: 973-642-8100 Email: mrodriguez@spanadvocacy.org Website: https://www.parentcenterhub.org/ei-overview/ For information specific to infants and the early intervention system available in each state: https://www.parentcenterhub.org/babies/
Head Start—Early Learning and Knowledge Center (U.S. Department of Health & Human Services)	Head Start helps young children from low-income families prepare to succeed in school through local Head Start Programs and Early Head Start programs. Head Start delivers services to children and families in core areas of early learning, health, and family well-being while engaging parents as partners every step of the way.	Website: https://eclkc.ohs.acf.hhs.gov/ The link below explains how Head Start programs give support to all children who are and are not eligible for services under IDEA. https://eclkc.ohs.acf.hhs.gov/publication/services-children-who-do-not-qualify-idea Head Start Center locator https://eclkc.ohs.acf.hhs.gov/center-locator
Head Start Center for Inclusion	The Head Start Center for Inclusion is committed to supporting early childhood educators to create inclusive learning experiences for all children. The infant and toddler web page offers information on learning opportunities, activity matrices, routines for infants and toddlers, and FAQs.	Head Start for Inclusion 5001 25th Ave NE #201e Seattle, WA 98105 Email: hscenter@uw.edu Phone: 206-221-0569 Website: https://headstartinclusion.org/tip-sheets/infant-and-toddlers/

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Who	What	Website, Contact Info
<p>Pacer Center</p>	<p>Provides guides and activities to foster early literacy and school success.</p> <p>Early Literacy Activities you can do to encourage your child’s early literacy skills:</p> <ul style="list-style-type: none"> ▪ Listening ▪ Speaking ▪ Reading ▪ Writing skills <p>Guide the development of communication from three months to age five.</p> <p>Making the Move from Preschool to Kindergarten:</p> <p>Guidance on how to help your child be successful when transitioning from preschool special education services into elementary school.</p>	<p>PACER Center 8161 Normandale Blvd. Minneapolis, MN 55437</p> <p>Phone: 952-838-9000</p> <p>Website: http://www.pacer.org/</p> <p>Early Literacy Activities: https://www.pacer.org/ec/early-literacy/parents-play-a-key-role.asp</p> <p>Making the Move from Preschool to Kindergarten: https://www.pacer.org/parent/php/PHP-c196.pdf</p>
<p>Parents as Teachers National Center (A FACE Partner; See AI/AN organizations)</p>	<p>Trains staff at affiliate organizations. The focus of the training and certification is:</p> <ul style="list-style-type: none"> ▪ Personal Visits ▪ Group Connections ▪ Resource Networks ▪ Child Screening 	<p>Diane Givens 314-432-4330 ext. 266</p> <p>Email: diane.givens@parentsteachers.org</p> <p>To find a Parents as Teachers affiliate in your community or state: http://ebiz.patnc.org/eBusiness/ProgramLocations.aspx</p>
<p>Zero To Three</p>	<p>Zero to Three resources help you (the parent) tune in to what makes your child tick, and to guide you in thinking about the best way to meet your child’s individual needs. Online resources include:</p> <ul style="list-style-type: none"> ▪ Child development by age and stage ▪ Social emotional development ▪ Positive parenting approaches ▪ Early learning ▪ Play 	<p>For general inquiries: 1255 23rd Street, NW, Suite 350 Washington, D.C. 20037 202-638-1144</p> <p>https://www.zerotothree.org/resources/series/parent-favorites</p>

Who	What	Website, Contact Info
	<ul style="list-style-type: none"> ▪ Sleep ▪ Brain development ▪ Temperament ▪ Discipline ▪ Challenging behavior ▪ Fatherhood 	

Resources For K- 12 Education

Who	What	Website, Contact Info
CADRE	<p>CADRE was designated by the Office of Special Education Programs in the U.S. Department of Education as the:</p> <ul style="list-style-type: none"> ▪ National Center on Appropriate Dispute Resolution in Special Education on behalf of the Office of Special Education. <p>CADRE delivers high-quality technical assistance, informational support, and other services to state education agencies (Part B), early intervention lead agencies (Part C), federally funded parent centers, local education agencies and early intervention providers, dispute resolution practitioners, family members, and other stakeholders.</p>	<p>CADRE 576 Olive St, Suite 300 Eugene, OR 97401 Phone: 541-359-4210 Fax: 458-215-4957 Email: cadre@directionservice.org Website: http://www.cadreworks.org/</p>
Center for Parent Information and Resources (Parent Center Hub)	<p>Each state has at least one parent center that employs advocates who are experts on IDEA who coach families in how to work with their child's school. Advocates can also attend IEPs.</p> <p>The website has an extensive library for all things special education, including birth to 36 months (Part C of IDEA), age 3 to 5, and 5–21 (Part B of IDEA).</p> <p>Library is organized A to Z. Some sample topics are:</p> <ul style="list-style-type: none"> ▪ Accommodations ▪ Assistive Technology ▪ Bullying ▪ Behavior ▪ Dispute resolution ▪ Early childhood 	<p>Center for Parent Information and Resources (Parent Center Hub) Website: https://www.parentcenterhub.org/ Native American resources: https://www.parentcenterhub.org/resourcelibrary/index/n/n1/ Resource library: https://www.parentcenterhub.org/resourcelibrary/</p>

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Who	What	Website, Contact Info
	<ul style="list-style-type: none"> ▪ Inclusion ▪ LRE/Placement ▪ Parent Support and more 	Find your state or region's parent center at: https://www.parentcenterhub.org/find-your-center/
The Federation for Children with Special Needs	This federation provides resources, support, information, and assistance to families of children with special needs.	Phone: 617-236-7210 800-331-0688 Email: info@fcsn.org Website: https://fcsn.org/programs/
Interagency Autism Coordinating Committee	Webinar Series: Transition Aged Youth on the Autism Spectrum <ol style="list-style-type: none"> 1. Making Health Care Transition Work for Youth with Autism: Youth and Parent Perspectives and National Resources 2. Transportation and Mobility Options to Support Post School Transition for Youth with Autism 3. Expanding Career Pathways for Youth and Young Adults on the Autism Spectrum: Employment as a Social Determinant of Health 	https://iacc.hhs.gov/meetings/autism-events/national-autism-coordinator/transition-aged-youth/
Job Accommodation Network	JANs A To Z resources library of Disabilities and Accommodations to assist individuals and organizations comply with the Americans with the Disabilities Act (ADA).	A comprehensive list of disabilities and medical conditions that can be filtered by: <ul style="list-style-type: none"> ▪ Disability ▪ Limitation ▪ Work-related function ▪ Topic ▪ Accommodation https://askjan.org/a-to-z.cfm
National Disability Rights Network	A nonprofit membership organization for the federally mandated Protection and Advocacy Systems & Client Assistance Programs for people with disabilities. Members provide legal services for people with disabilities in all areas of life, including education.	https://www.ndrn.org/ To find a NDRN member in your state: https://www.ndrn.org/about/ndrn-member-agencies/

Who	What	Website, Contact Info
National Parent Teachers Association (PTA)	<p>Special Education Toolkit Resources:</p> <ul style="list-style-type: none"> Tools for families Locating special education services by state National Organization <p>Other PTA Topics include:</p> <ul style="list-style-type: none"> Pre-K to graduation & beyond Understanding federal disability and special needs policy A Parent's Dictionary Guide to Special Education: Helpful Acronyms 	<p>National PTAs special education resources:</p> <p>https://www.pta.org/home/family-resources/Special-Education-Toolkit/Special-Education-Toolkit-Resources</p>
Office of Disability Employment Policy	<p>Employment First is a framework for systems change centered on the premise that all citizens, including people with significant disabilities, are capable of full participation in integrated employment and community life. The website includes videos, webinars, data, and manuals.</p>	<p>Office of Disability Employment Policy 200 Constitution Ave NW Washington, DC 20210 Phone: 1-866-487-2365 https://www.dol.gov/agencies/odep/initiatives/employment-first</p>
Office of Special Education and Rehabilitative Services: U.S. Department of Education	<p>A transition guide to help students, families, and schools plan for a student's life after graduation from high school.</p>	<p>Transition Guide https://sites.ed.gov/idea/files/postsecondary-transition-guide-august-2020.pdf</p>
Parent 2 Parent	<p>Parent 2 Parent matches parents of children with disabilities to other parents who have a child with the same or similar disability or issue so their parents can support each other, share resources, and form connections.</p>	<p>Phone: 484-272-7368 Email: https://www.p2pusa.org/contacts/ Website: http://p2pusa.org/</p>
Project Search	<p>Project Search operates nationwide and is a one-year high school transition program that provides real-life work experience to assist youth with significant disabilities make successful transitions from school to adult life. Utilizes a combination of:</p> <ul style="list-style-type: none"> Classroom instruction Career exploration 	<p>To find a Project Search program in your area: https://projectsearch.us/find-a-program/ To start a Project Search program in your area: https://projectsearch.us/start-a-project-search/</p>

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Who	What	Website, Contact Info
	<ul style="list-style-type: none"> ▪ Hands-on training through worksite rotations in: <ul style="list-style-type: none"> • Health care • Government • business settings <p>Students participate in internships to explore a variety of career paths, to create an employment goal, and acquire employability and marketable work skills during the transition from school to work.</p>	
University Center for Excellence in Developmental Disabilities (UCEDD)	<p>There are 67 UCEDDs—at least one in every U.S. state and territory. Each UCEDD works with people with disabilities, members of their families, state and local government agencies, and community providers in projects that provide training, technical assistance, service, research, and information sharing, with a focus on building the capacity of communities to sustain all their residents.</p> <p>Many UCEDDs have a long history of providing culturally relevant services to the American Indian and Alaska Native community.</p>	<p>Association of University Centers on Disabilities</p> <p>Map to find the UCEDDs in each state:</p> <p>https://www.aucd.org/directory/directory.cfm?program=UCEDD</p>
Wrightslaw	<p>Parents, advocates, educators, and attorneys come to Wrightslaw for accurate, up-to-date information about special education law and advocacy for children with disabilities.</p>	<p>Website:</p> <p>https://www.wrightslaw.com/</p> <p>Wrightslaw has information specific to American Indian Kids with disabilities:</p> <p>https://www.wrightslaw.com/info/ai.index.htm</p>

The 14 Disability Categories In IDEA

Definitions and Resources	
Autism (AU)	
Characteristics	<p>Also called “autism spectrum disorder.” “Considered a form of developmental delay, often people engage in repetitive activities, stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences.”</p> <p>“Sec. 300.8 Child with a Disability.” <i>Individuals with Disabilities Education Act</i>, 25 May 2018, https://sites.ed.gov/idea/regs/b/a/300.8.</p>

Definitions and Resources	
Centers for Disease Control and Prevention Family Resources	https://www.cdc.gov/ncbddd/autism/links.html
The National Autism Center Provides A Parent’s Guide to Evidence-Based Practice and Autism	https://www.nationalautismcenter.org/resources/for-families/
The Autism Society of America Has a database of resources by state	https://autismsociety.org/contact-us/
Autism Now A national autism resource and information center	https://autismnow.org/
The Autism Wandering Awareness Alerts Response and Education (AWAARE) Collaboration Prevents wandering incidents and deaths within the autism community	https://awaare.nationalautismassociation.org/
Organization of Autism Research Published five Life Journey guidebooks that are available online https://researchautism.org/	A Parent’s Guide to Assessment https://researchautism.org/resources/a-parents-guide-to-assessment/ A Guide for Transition to Adulthood https://researchautism.org/resources/a-guide-for-transition-to-adulthood/
Operation Autism Online resources for military families with children with autism spectrum disorder.	https://operationautism.org/
Deaf-Blindness	
Characteristics	<p>“Simultaneous hearing and visual impairments, the combination of which causes such severe communication and other developmental and educational needs that they cannot be accommodated in special education programs solely for children with deafness or children with blindness.”</p> <p>“Sec. 300.8 Child with a Disability.” <i>Individuals with Disabilities Education Act</i>, 25 May 2018, https://sites.ed.gov/idea/regs/b/a/300.8.</p>
Parent Center Hub To find resources and services in your state	https://www.parentcenterhub.org/deafblindness/

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Definitions and Resources	
<p>The American Association of the Deaf-Blind</p> <p>“ . . . national consumer organization of, by, and for deaf-blind Americans and their supporters. The site lists Deaf-Blind Camps, Support Service Providers (SSPs), Technology, FAQs and Factsheets, emergency preparation and National Conferences.”</p>	<p>http://www.aadb.org/index.html</p>
Deafness	
<p>Characteristics</p>	<p>“means a hearing impairment so severe that a child is impaired in processing linguistic information through hearing, with or without amplification, that adversely affects a child’s educational performance.”</p> <p>“Sec. 300.8 Child with a Disability.” <i>Individuals with Disabilities Education Act</i>, 25 May 2018, https://sites.ed.gov/idea/regs/b/a/300.8.</p> <p>For resources, see Hard of Hearing below.</p>
Developmental Delay	
<p>Characteristics</p>	<p>“for children from birth to age three (under IDEA Part C) and children from ages three through nine (under IDEA Part B), the term developmental delay, as defined by each state, means a delay in one or more of the following areas: physical development, cognitive development, communication, social or emotional development, or adaptive [behavioral] development.”</p> <p>“Sec. 300.8 Child with a Disability.” <i>Individuals with Disabilities Education Act</i>, 25 May 2018, https://sites.ed.gov/idea/regs/b/a/300.8.</p>
<p>Parent Center Hub—Information on:</p> <ul style="list-style-type: none"> ▪ Children’s stages of development ▪ Talking with your doctor ▪ Developmental evaluations ▪ Early intervention services ▪ IDEA 	<p>https://www.parentcenterhub.org/dd/</p>
<p>Center for Disease Control and Prevention (CDC)</p> <p>Describes children’s developmental milestones from two months to five years</p>	<p>https://www.cdc.gov/ncbddd/actearly/freematerials.html</p>

Definitions and Resources	
Down Syndrome info from the CDC	https://www.cdc.gov/ncbddd/birthdefects/downsyndrome.html
Fetal Alcohol Syndrome info from the CDC	https://www.cdc.gov/ncbddd/fasd/materials.html
Fragile X Syndrome info from the CDC	https://www.cdc.gov/ncbddd/fxs/freematerials.html
Emotional Disturbance	
Characteristics	<p>“means a condition exhibiting one or more of the following characteristics over a long period of time and to a marked degree that adversely affects a child’s educational performance:</p> <ol style="list-style-type: none"> 1. An inability to learn that cannot be explained by intellectual, sensory, or health factors. 2. An inability to build or maintain satisfactory interpersonal relationships with peers and teachers. 3. Inappropriate types of behavior or feelings under normal circumstances. 4. A general pervasive mood of unhappiness or depression. 5. A tendency to develop physical symptoms or fears associated with personal or school problems. <p>The term includes schizophrenia. The term does not apply to children who are socially maladjusted, unless it is determined that they have an emotional disturbance.” “Sec. 300.8 Child with a Disability.” <i>Individuals with Disabilities Education Act</i>, 25 May 2018, https://sites.ed.gov/idea/regs/b/a/300.8.</p>
Parent Center Hub Learn about mental health characteristics in children, specific conditions, and available resources	https://www.parentcenterhub.org/emotional-disturbance/
Centers for Disease Control and Prevention Information about how to create positive childhood experiences	https://www.cdc.gov/injury/features/prevent-child-abuse/
Anxiety and Depression Association of America	https://adaa.org/
National Institute on Mental Health Information on specific mental disorders	<p>Phone: 866.615.6464. TTY: 1.866.415.8051</p> <p>https://www.nimh.nih.gov/health/publications/children-and-mental-health</p>
National Alliance of Mental Illness	<p>Phone: 800.950.6264 https://www.nami.org/Home</p>

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Definitions and Resources	
Substance Abuse & Mental Health Services Administration (SAMHSA)	1-800-662-HELP (4357) http://www.samhsa.gov/ Treatment locator: https://www.samhsa.gov/find-treatment
Center on Positive Behavioral Interventions and Supports	www.pbis.org
Conduct Disorders	http://www.conductdisorders.com/
Encyclopedia of Mental Disorders	http://www.minddisorders.com/index.html
National Eating Disorders Association	1.800.931.2237 www.nationaleatingdisorders.org
Something Fishy About eating disorders	http://www.something-fishy.org
Hard of Hearing	
Characteristics	“means an impairment in hearing, whether permanent or fluctuating, that adversely affects a child’s educational performance in hearing schools but is not included under the definition of deafness.” “Sec. 300.8 Child with a Disability.” <i>Individuals with Disabilities Education Act</i> , 25 May 2018, https://sites.ed.gov/idea/regs/b/a/300.8 .
The Centers for Disease Control and Prevention Provides information on types of hearing loss, screening and diagnosis, treatments, and free materials for families	https://www.cdc.gov/ncbddd/hearingloss/index.html Parent’s Guide to Hearing Loss: https://www.cdc.gov/ncbddd/hearingloss/parentsguide/index.html
Parent Center Hub Information on types of hearing loss, causes, educational implications and resources	https://www.parentcenterhub.org/hearingloss/
American Society for Deaf Children	1.800.942.2732 https://deafchildren.org/
Beginnings A nonprofit for parents of children who are Deaf or Hard of Hearing	https://ncbegin.org/
Hands and Voices A community of parents of ASL signers, cued speech users, parents of kids with cochlear implants, and people connected through the community of Deafness	https://handsandvoices.org/

Definitions and Resources	
Hearing Loss Association of America	https://www.hearingloss.org/
Laurent Clerc National Deaf Education Center A one-stop center for Deaf resources	202.651.5051 https://clerccenter.gallaudet.edu/national-resources/info/
Medline Plus A program of the U.S. Library of Medicine	https://medlineplus.gov/hearingdisordersanddeafness.html
National Association of the Deaf	https://www.nad.org
Intellectual Disability	
Characteristics	<p>"means significantly subaverage general intellectual functioning, existing concurrently [at the same time] with deficits in adaptive behavior and manifested during the developmental period, that adversely affects a child's educational performance."</p> <p>"Sec. 300.8 Child with a Disability." <i>Individuals with Disabilities Education Act</i>, 25 May 2018, https://sites.ed.gov/idea/regs/b/a/300.8.</p>
Centers Disease Control and Prevention	https://www.cdc.gov/ncbddd/developmentaldisabilities/facts-about-intellectual-disability.html
Parent Center Hub Provides information about the signs, causes, and diagnoses of an intellectual disability, as well as help for babies, toddlers, and school-aged children. They also provide links to several organizations	https://www.parentcenterhub.org/intellectual/
The Arc of the United States	Phone: 800-433-5255 info@thearc.org www.thearc.org Find a local chapter near you: http://www.thearc.org/page.aspx?pid=2437
American Association on Intellectual and Developmental Disabilities Provides an authoritative manual on intellectual disability, including best practice guidelines and supports	Phone: 800-424-3688 http://www.aaid.org/

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Definitions and Resources	
Multiple Disabilities	
Characteristics	<p>“means concomitant [simultaneous] impairments (such as intellectual disability–blindness, intellectual disability–orthopedic impairment, etc.), the combination of which causes such severe educational needs that they cannot be accommodated in a special education program solely for one of the impairments. The term does not include Deaf-Blindness.”</p> <p>“Sec. 300.8 Child with a Disability.” <i>Individuals with Disabilities Education Act</i>, 25 May 2018, https://sites.ed.gov/idea/regs/b/a/300.8.</p>
<p>Parent Center Hub</p> <p>Provides information about how multiple disabilities vary with each individual, causes, evaluation processes and resources</p>	<p>https://www.parentcenterhub.org/multiple/</p>
<p>TASH</p> <p>An organization that advocates for inclusion for people with significant disabilities and support needs</p>	<p>http://tash.org/</p>
<p>The National Lekotek Center Provides information about toys and play activities for children with special needs</p>	<p>http://www.lekotek.org/</p>
<p>March of Dimes</p> <p>Supports moms and babies during pregnancy and afterward with tools, technology, and information</p>	<p>http://www.marchofdimes.com/</p>
<p>Family Connect</p> <p>Provides information about family life when a child has multiple disabilities</p>	<p>https://familyconnect.org/multiple-disabilities/family-and-social-life/family-life/</p>
<p>Perkins Scout and the School for the Blind e-learning</p> <p>Provides information for parents and educators regarding students with blindness and other disabilities</p>	<p>https://www.perkinselearning.org/scout/topics/multiple-disabilities</p>
Orthopedic Impairment	
Characteristics	<p>“means a severe orthopedic impairment that adversely affects a child’s educational performance. The term includes impairments caused by a congenital anomaly, impairments caused by disease (e.g., poliomyelitis, bone tuberculosis), and impairments from other causes (e.g., cerebral palsy, amputations, and fractures or burns that cause contractures).”</p>

Definitions and Resources	
	"Sec. 300.8 Child with a Disability." <i>Individuals with Disabilities Education Act</i> , 25 May 2018, https://sites.ed.gov/idea/regs/b/a/300.8 .
Centers for Disease Control and Prevention Provides information about cerebral palsy	https://www.cdc.gov/ncbddd/cp/index.html
Easter Seals Provides high-quality services to people with special needs to help them live, learn, work, and play	https://www.easterseals.com/our-programs/
Parent Center Hub Provides information about cerebral palsy	https://www.parentcenterhub.org/cp/
United Cerebral Palsy Provides information about cerebral palsy, including state chapters, publications, and resources	https://ucp.org/ 800.872.5827
Cerebral Palsy Foundation Provides information on several topics, such as the definition of Cerebral Palsy, treatments, assistive devices, and more	Cerebral Palsy Foundation 3 Columbus Circle, 15th Floor New York, NY 10019 Phone: 212-520-1686 info@yourcpf.org https://yourcpf.org
Child Neurology Foundation	Child Neurology Foundation 201 Chicago Avenue, Suite 200 Minneapolis, MN 55415 Phone: 612-928-6325 info@childneurologyfoundation.org https://www.childneurologyfoundation.org/
Children's Hemiplegia and Stroke Association (CHASA)	CHASA 4101 West Green Oaks Suite 205, #149 Arlington, TX 76016 Phone: 817-492-4325 info437@chasa.org https://chasa.org

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Definitions and Resources	
CP NOW	<p>CP NOW P.O. Box 8347 Greenville, SC 29604</p> <p>info@cpnowfoundation.org https://cprn.org/</p>
<p>Pathways.org Provides free tools to maximize all children’s motor, sensory, and communication development</p>	<p>Pathways 355 E. Erie Street Chicago, IL 60601</p> <p>Phone: 800-955-CHILD (2445) friends@pathwaysawareness.org https://pathways.org/</p>
Other Health Impairments	
Characteristics	<p>“means having limited strength, vitality, or alertness, including a heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment, that</p> <p>(a) is due to chronic or acute health problems, such as asthma, attention deficit disorder or attention deficit hyperactivity disorder, diabetes, epilepsy, a heart condition, hemophilia, lead poisoning, leukemia, nephritis, rheumatic fever, sickle cell anemia, and Tourette syndrome; and</p> <p>(b) adversely affects a child’s educational performance.”</p> <p>“Sec. 300.8 Child with a Disability.” <i>Individuals with Disabilities Education Act</i>, 25 May 2018, https://sites.ed.gov/idea/regs/b/a/300.8.</p>
<p>Parent Center Hub Provides an overview about specific health impairments that qualify a student for special education services and resources.</p> <p>Some health impairments are:</p> <ul style="list-style-type: none"> ▪ Attention Deficit and Hyperactivity Disorder (ADHD) ▪ Epilepsy ▪ Lead poisoning ▪ Nephritis (Lupus) ▪ Tourette Syndrome 	<p>Other Health Impaired</p> <p>https://www.parentcenterhub.org/ohi/</p> <p>Attention Deficit Disorder and Attention Deficit Hyperactivity Disorder</p> <p>https://www.parentcenterhub.org/adhd/</p> <p>Epilepsy</p> <p>https://www.parentcenterhub.org/epilepsy/</p> <p>Lead Poisoning</p> <p>https://www.parentcenterhub.org/ohi-lead/</p> <p>Nephritis</p> <p>https://www.parentcenterhub.org/ohi-nephritis/</p> <p>Tourette Syndrome</p> <p>https://www.parentcenterhub.org/ohi-tourette/</p>

Definitions and Resources

<p>Attention Deficit / Hyperactivity Disorder</p> <p>Centers for Disease Control and Prevention</p> <p>Institute of Certified ADHD Professionals</p> <p>Attention Deficit Disorder Association</p> <p>HealthyChildren.org</p> <p>A service of the American Academy of Pediatrics that provides numerous articles, information, and resources about ADHD.</p>	<p>https://www.cdc.gov/ncbddd/adhd/materials-multimedia/index.html</p> <p>https://chadd.org/for-parents/overview/</p> <p>Find a support organization in your state:</p> <p>https://chadd.org/organization-directory/</p> <p>301.306.7070</p> <p>1.800.939.1019</p> <p>info@add.org</p> <p>https://add.org/</p> <p>https://healthychildren.org/English/health-issues/conditions/adhd/Pages/default.aspx</p>
<p>Epilepsy</p> <p>Epilepsy Foundation of America</p> <p>Epilepsy Therapy Project</p> <p>Let’s Talk About It!</p> <p>Features videos of people with epilepsy and information for families.</p> <p>The Epilepsy Health Center</p> <p>Webmd.com has detailed, medically based information on epilepsy.</p> <p>Epilepsy Foundation e-Communities</p> <p>Connect with thousands of people electronically for support and information.</p> <p>Parent to Parent</p> <p>Allows parents affected by epilepsy to talk with each other and those in their state.</p>	<p>www.epilepsyfoundation.org/</p> <p>800.332.1000</p> <p>https://www.epilepsy.com/</p> <p>https://talkaboutit.org/</p> <p>https://www.webmd.com/epilepsy/default.htm</p> <p>https://epilepsyfoundation.ning.com/</p> <p>https://www.p2pusa.org/</p>
<p>Lead Poisoning</p> <p>National Lead Information Center (NLIC)</p> <p>Office within the U.S. Environmental Protection Agency.</p> <p>Centers for Disease Control and Prevention</p>	<p>(800) 424-LEAD (5323)</p> <p>https://www.epa.gov/lead</p> <p>State and local programs:</p> <p>https://www.cdc.gov/nceh/lead/</p> <p>Information for parents and caregivers:</p> <p>https://www.cdc.gov/nceh/lead/audience/parents.html</p> <p>A 2015 CDC publication, “Educational Interventions for Children Affected by Lead”:</p> <p>https://www.cdc.gov/nceh/lead/publications/Educational_Interventions_Children_Affected_by_Lead.pdf</p>

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Definitions and Resources	
<p>Nephritis (Inflammation of the kidney due to infection or an autoimmune disease such as Lupus)</p> <p>American Kidney Fund</p> <p>American Society of Pediatric Nephrology</p> <p>National Institute of Diabetes and Digestive and Kidney Diseases</p> <p>National Kidney Foundation</p>	<p>(800) 638-8299</p> <p>https://www.kidneyfund.org/</p> <p>https://www.aspneph.org/</p> <p>https://www.niddk.nih.gov/health-information/kidney-disease?dkrd=hispt0363</p> <p>(800) 622-9010</p> <p>https://www.kidney.org/</p>
<p>Tourette Syndrome</p> <p>Centers for Disease Control and Prevention</p> <p>Provides materials for children, adults, and health care providers.</p> <p>National Tourette Syndrome Association</p> <p>National Institute of Neurological Disorders and Stroke</p> <p>Publishes a Tourette Syndrome Fact Sheet.</p>	<p>https://www.cdc.gov/ncbddd/tourette/freematerials.html</p> <p>https://tourette.org/</p> <p>https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Fact-Sheets/Tourette-Syndrome-Fact-Sheet</p>
Specific Learning Disability	
<p>Characteristics</p>	<p>“means a disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, that may manifest itself in the imperfect ability to listen, think, speak, read, write, spell, or to do mathematical calculations. The term includes such conditions as perceptual disabilities, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia. The term does not include learning problems that are primarily the result of visual, hearing, or motor disabilities; of intellectual disability; of emotional disturbance; or of environmental, cultural, or economic disadvantage.”</p> <p>“Sec. 300.8 Child with a Disability.” <i>Individuals with Disabilities Education Act</i>, 25 May 2018, https://sites.ed.gov/idea/regs/b/a/300.8.</p>
<p>Parent Center Hub</p> <p>Provides information on the definition of learning disabilities, causes, evaluation, and tips and resources for teachers and families.</p>	<p>https://www.parentcenterhub.org/ld/</p>

Definitions and Resources	
Child Mind Institute A Complete guide to dyslexia	https://childmind.org/guide/parents-guide-to-dyslexia/
International Dyslexia Association Provides webinars, conferences, extensive information about dyslexia and resources	https://dyslexiaida.org/ https://dyslexiaida.org/ida-dyslexia-handbook/
American Dyslexia Association	https://www.american-dyslexia-association.com/Dyslexia.html
Dyslexia Resource Provides a dyslexia awareness video series, strategies, partnerships, and state, national, and international resources	https://dyslexiaresource.org/resources/
Smart Kids with Learning Disabilities Provides information about dyscalculia	https://www.smartkidswithld.org/first-steps/what-are-learning-disabilities/dyscalculia-an-overview/
Understood.org 7 Myths about Dyscalculia	https://www.understood.org/articles/en/7-common-myths-about-dyscalculia
Parenting Pod Publishes, "The Complete Dyscalculia Guide for Parents"	https://parentingpod.com/dyscalculia/
LD Online	http://www.ldonline.org/parents
National Center for Learning Disabilities	https://www.understood.org/en
Learning Disabilities Association of America	http://www.ldanatl.org/aboutld/parents/index.asp
Reading Rockets	http://www.readingrockets.org/audience/parents
Speech or Language Impairment	
Characteristics	"means a communication disorder such as stuttering, impaired articulation, a language impairment, or a voice impairment that adversely affects a child's educational performance." "Sec. 300.8 Child with a Disability." <i>Individuals with Disabilities Education Act</i> , 25 May 2018, https://sites.ed.gov/idea/regs/b/a/300.8 .
Centers for Disease Control and Prevention Information about language and speech disorders in children.	https://www.cdc.gov/ncbddd/childdevelopment/language-disorders.html

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Definitions and Resources	
Parent Center Hub Provides definitions, characteristics, causes, tips and resources for parents and teachers	https://www.parentcenterhub.org/speechlanguage/
American Speech-Language-Hearing Association	Phone: 1-800-638-8255 actioncenter@asha.org https://www.asha.org/
Parent Companion Provides information on how to help a child with language delays	https://www.parentcompanion.org/article/resources-to-help-a-child-with-a-language-delay
Cleft Palate-Craniofacial Foundation Provides family resources	Phone: 1-800-242-5338 https://acpa-cpf.org/acpa-family-services/family-resources/
Childhood Apraxia of Speech Association of North America Provides information about apraxia of speech	https://www.apraxia-kids.org/
National Stuttering Foundation	Phone: 1-800-937-8888 info@WeStutter.org https://westutter.org/
The Stuttering Foundation	Phone: 1-800-992-9392 info@stutteringhelp.org https://www.stutteringhelp.org/
Traumatic Brain Injury	
Characteristics	<p>“means an acquired injury to the brain caused by an external physical force, resulting in total or partial functional disability or psychosocial impairment, or both, that adversely affects a child’s educational performance. The term applies to open or closed head injuries resulting in impairments in one or more areas, such as cognition; language; memory; attention; reasoning; abstract thinking; judgment; problem-solving; sensory, perceptual, and motor abilities; psychosocial behavior; physical functions; information processing; and speech.</p> <p>The term does not apply to brain injuries that are congenital or degenerative, or to brain injuries induced by birth trauma.”</p> <p>“Sec. 300.8 Child with a Disability.” <i>Individuals with Disabilities Education Act</i>, 25 May 2018, https://sites.ed.gov/idea/regs/b/a/300.8.</p>

Definitions and Resources	
<p>Parent Center Hub Defines traumatic brain injury; provides resources and tips for educators and parents</p>	<p>https://www.parentcenterhub.org/tbi/</p>
<p><u>Pediatric Brain Foundation (formerly Children’s Neurobiological Solutions)</u> Provides financial support to families with children impacted by neurological disorders, brain cancers, and traumatic brain injuries. They support health care providers and educate the public</p>	<p>Pediatric Brain Foundation 2144 E. Republic Road, Building B, Suite 202 Springfield, MO 65804 Phone: 417-887-4242 info@pediatricbrainfoundation.org https://www.pediatricbrainfoundation.org/</p>
<p>Family Doctor.org Provides basic information on traumatic brain injury</p>	<p>https://familydoctor.org/condition/traumatic-brain-injury/</p>
<p><u>Centers for Disease Control and Prevention</u> Provides information on traumatic brain injury and concussion</p>	<p>https://www.cdc.gov/TraumaticBrainInjury/</p>
<p>Brain Injury Association of America</p>	<p>https://www.biausa.org/</p>
<p>National Resource Center for Traumatic Brain Injury</p>	<p>https://tbi.vcu.edu/</p>
<p>Brainline Provides information about brain injury and PTSD</p>	<p>https://www.brainline.org/</p>
<p>Family Caregiver Alliance</p>	<p>https://www.caregiver.org/</p>
Visual Impairment, Including Blindness	
<p>Characteristics</p>	<p>“means an impairment in vision that, even with correction, adversely affects a child’s educational performance. The term includes both partial sight and blindness.” “Sec. 300.8 Child with a Disability.” <i>Individuals with Disabilities Education Act</i>, 25 May 2018, https://sites.ed.gov/idea/regs/b/a/300.8.</p>
<p>Parent Center Hub Provides information on types of visual impairments, tips for parents and teachers, and resources</p>	<p>https://www.parentcenterhub.org/visualimpairment/</p>

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Definitions and Resources

<p>American Council of the Blind Provides comprehensive information for blind people and their community.</p>	<p>https://www.acb.org/ Phone: 800-424-8666 For parents of a blind child: https://www.acb.org/are-you-parents-blind-child</p>
<p>American Foundation for the Blind</p>	<p>https://www.afb.org/</p>
<p>American Printing House for the Blind</p>	<p>Educational resources: https://www.aph.org/educational-resources/</p>
<p>Family Connect Provides information for after diagnosis, age, education, multiple disabilities, and assistive technology</p>	<p>https://familyconnect.org/parentsitehome.asp</p>
<p>Foundation Fighting Blindness</p>	<p>Phone: 800-683-5555 TTY: 800-683-5551 (TTY) https://www.fightingblindness.org/ Find your local chapter: https://www.fightingblindness.org/find-your-local-chapter</p>
<p>Lighthouse Guild Provides integrated vision and health care services and assistive technology.</p>	<p>Phone: 800-284-4422 https://lighthouseguild.org/</p>
<p>National Braille Association Provides education to those who prepare braille to people with a visual impairment</p>	<p>https://www.nationalbraille.org/</p>
<p>National Braille Press Empowers the blind and visually impaired with programs, materials, and technology to support braille literacy and learning through touch</p>	<p>https://www.nbp.org/ Phone: 888-965-8965</p>
<p>The National Federation of the Blind Provides information about aids and appliances, Braille, closed circuit TVs, guide dog schools, low vision, and technology</p>	<p>https://nfb.org/</p>

Definitions and Resources	
Organizations That Provide Accessible Print Materials for the Visually Impaired	
<p>National Library Service for the Blind and Physically Handicapped, Library of Congress</p> <p>Administers a free national library program that provides braille and recorded materials to people who cannot see or handle regular print materials.</p>	<p>https://www.loc.gov/nls/</p>
<p>Bookshare</p> <p>For people with print disabilities, including visual impairments or blindness. Offers free membership to qualified U.S. students and schools and has more than 539,823 titles available digitally.</p>	<p>https://www.bookshare.org/cms/</p>
<p>Learning Ally</p> <p>For people who cannot read standard print. Offers more than 80,000 digitally recorded textbooks and literature titles for download. Formerly "Recording for the Blind and Dyslexic."</p>	<p>Phone: 800-221-4792</p> <p>https://learningally.org/</p>
<p>The National Center on Accessible Educational Materials at CAST</p> <p>Provides an interactive tool that facilitates the process of decision-making around accessible instructional materials for an individual student.</p>	<p>https://aem.cast.org/acquire/decision-making-accessible-formats#.WOPpYzvYuUk</p>

Parent Resource Centers

Related to Individuals with Disabilities Education Act (IDEA)
Parent Resource and Information Centers
1. Serve parents of children with all types of disabilities (birth to 26 years)
2. At least one Parent Information Center per state
3. Provide resources about IDEA
4. Required to explain dispute resolution procedures, particularly the mediation.
Parent Training and Information Centers listed below by state

(Center for Parent Information and Resources. <https://www.parentcenterhub.org/>)

State	Name	Address	Phone #
AK	Stone Soup Group	307 E. Northern Lights Blvd., Ste 100 Anchorage, AK 99503	877-786-7327
AL	Alabama Parent Education Center	10520 U.S. Highway 231 Wetumpka, AL 36092	866-532-7660
AR	The Center for Exceptional Families	102 Stone Street, Suite A Jonesboro, AR 72401	888-360-9654
AZ	Raising Special Kids	5025 E. Washington St., Ste 204 Phoenix, AZ 85034	800-237-3007 (in AZ only) 602-242-4366
CA	Support for Families of Children with Disabilities	1663 Mission Street, Ste. 700 San Francisco, CA 94110	415-282-7494
CA Region 1	Team of Advocates for Special Kids	100 W. Cerritos Avenue Anaheim, CA 92805	866-828-8275
CA Region 2	Team of Advocates for Special Kids	100 W. Cerritos Avenue Anaheim, CA 92806	866-828-8276
CA Region 3	Exceptional Parents Unlimited	4440 N. 1st Street Fresno, CA 93726	888-774-8981
CA Region 4	Parents Helping Parents Santa Clara	1400 Parkmoor, Suite 100 San Jose, CA 95126	855-727-5775
CA Region 5	Warmline Family Resource Center	2791 24th Street Sacramento, CA 95818	844-455-9517
CO	PEAK Parent Center	917 E. Moreno Ave, Suite 140 Colorado Springs, CO 80903	719-531-9400
CT	Connecticut Parent Advocacy Center	338 Main Street Niantic, CT 06357	800-445-2722 (in CT)
DC	Advocates for Justice and Education	1200 G Street, NW, Suite 725 Washington, DC 20005	888-327-8060
DE	Parent Information Center of Delaware	404 Larch Circle Wilmington, DE 19804	888-547-4412 (DE only)
FL	Parents of the Panhandle Information Network	2196 Main St. Suite L Dunedin, FL 34698	800-825-5736 (in FL)
GA	Parent to Parent of Georgia, Inc.	3070 Presidential Parkway, Suite 130 Atlanta, GA 30340	800-229-2038

State	Name	Address	Phone #
HI	Leadership in Disabilities & Achievement of Hawai'i	245 N. Kukui St., Ste 205 Honolulu, HI 96817	800-533-9684 (in HI)
IA	Access For Special Kids Resource Center	5665 Greendale Rd. Suite D Johnston, IA 50131	800-450-8667
ID	Idaho Parents Unlimited, Inc.	4619 Emerald St., Ste E Boise, ID 83706	800-242-4785 (in ID only)
IL Region 1	Family Resource Center on Disabilities	20 E. Jackson Boulevard, Room 300 Chicago, IL 60604	800-952-4199 (in IL)
IL Region 2	Family Matters	1901 S. 4th Street, Suite 209 Effingham, IL 62401	866-436-7842
IN	IN*SOURCE	1703 S. Ironwood Drive South Bend, IN 46613	800-332-4433 (in IN)
KS	Families Together, Inc.	5611 SW Barrington Court South, Suite 120 Topeka, KS 66614	800-264-6343
KY	Kentucky Special Parent Involvement Network	10301-B Deering Road Louisville, KY 40272	800-525-7746
LA	Louisiana Parent Training and Information Center	201 Evans Road, Building 1, Suite 100 Harahan, LA 70123	800-766-7736
MA	Federation for Children with Special Needs	The Schrafft Center 529 Main Street, Ste 1M3 Boston, MA 02129	800-331-0688 (in MA only)
MD	Parents' Place of Maryland, Inc.	802 Cromwell Park Drive, Suite Q Glen Burnie, MD 21061	800-394-5694
ME	Maine Parent Federation	P.O. Box 2067 Augusta, ME 04338-2067	800-870-7746 (in ME)
MI	Michigan Alliance for Families	1325 S. Washington Avenue Lansing, MI 48910	800-552-4821 (Statewide)
MN	PACER Center, Inc.	8161 Normandale Boulevard Bloomington, MN 55437-1044	888-248-0822 (National)

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State	Name	Address	Phone #
MO	Missouri Parents Act	7421 Mexico Rd, Suite 200 St. Peters, MO 63376	800-743-7634 (V/ TTY)
MS	MS Parent Training and Information Center	2 Old River Place, Suite M Jackson, MS 39202	800-721-7255
MT	Montana PTI	* Guided by South Dakota Parent Connection http://www.sdparent.org/	877-870-1190
NC	ECAC, Inc. (Exceptional Children's Assistance Center)	907 Barra Row, Suites 102/103 Davidson, NC 28036	800-962-6817
ND	Pathfinder Parent Center	1015 S Broadway, Suite 42 Minot, ND 58701	701-837-7500
NE	PTI Nebraska	1941 S. 42nd St., Suite 205 Omaha, NE 68105	800-284-8520 (in NE)
NH	Parent Information Center (PIC)	P.O. Box 2405 Concord, NM 03302-2405	800-947-7005 (in NH)
NJ	Statewide Parent Advocacy Network	35 Halsey Street, 4th Floor Newark, NJ 07102	800-654-7726 (in NJ)
NM	Parents Reaching Out	1920 B Columbia, S.E. Albuquerque, NM 87106	800-524-5176 (in NM)
NV	Nevada PEP	7211 W. Charleston Blvd. Las Vegas, NV 89117	800-216-5188 (in NV)
NY Region 1	Advocates for Children of NY	151 W. 30th Street, 5th Floor New York, NY 10001	866-427-6033
NY Region 1	Include NYC	116 E. 16th Street, 5th Floor New York, NY 10003	212 677-4650
NY Region 1	Long Island Advocacy Center	Herricks Community Ctr. 999 Herricks Road New Hyde Park, NY 11040	516 248-222
NY Region 1	Sinergia	2082 Lexington Ave., 4th Floor New York, NY 10035	866-867-9665
NY Region 2	Starbridge	1650 South Avenue, Suite 200 Rochester, NY 14620	1-800-650-4967 (in NY) 585 546-1700

State	Name	Address	Phone #
OH	Ohio Coalition for the Education of Children with Disabilities	Chase Bank Building 165 W. Center St., Suite 302 Marion, OH 43302-3741	844-382-5452
OK	Oklahoma Parents Center	223 North Broadway, P.O. Box 512 Holdenville, OK 74848	877-553-4332
OR	Family and Community Together (FACT)	2475 SE Ladd Avenue, Suite 430 Portland, OR 97214	888-988-3228
PA	Parent Education and Advocacy Leadership Center (PEAL)	2325 East Carson St., Ste 100A Pittsburg, PA 15203 520 N. Christopher Columbus Blvd, Ste 602 Philadelphia, PA 19123	866-950-1040
PR	APNI, Inc.	P.O. Box 21280 San Juan, PR 00928-1280	
RI	Rhode Island Parent Info Network (RIPIN)	1210 Pontiac Avenue Cranston, RI 02920	800-464-3399 (in RI)
SC	Family Connection of SC	1800 St. Julian Place, Suite 104 Columbia, SC 29204	(800) 578-8750
SD	South Dakota Parent Connection	3701 W. 49th Street, Suite 102 Sioux Falls, SD 57106	800-640-4553 (in SD)
TN	Support and Training for Exceptional Parents, Inc. (STEP)	712 Professional Plaza Greeneville, TN 37745	800-280-7837 (English toll-free in TN only) 800-975-2919 (Spanish toll-free in TN only)
TX 1	Partners Resource Network (PATH)	1090 Longfellow Drive, Suite B Beaumont, TX 77706-4819	800-866-4726 (in TX)
TX 2	Partners Resource Network (TEAM)	4501 Cartwright Rd, Suite 605 Missouri City, TX 77459	877-832-8945 (in TX)
TX 3	Partners Resource Network (PEN)	1001 Main Street, Suite 701 Lubbock TX 79401	877-762-1435 (in TX)
UT	Utah Parent Center	230 West 200 South, Suite 1101 Salt Lake City, UT 84101	800-468-1160 (in UT)

(continued)

State	Name	Address	Phone #
VA	PEATC	8003 Forbes Place, Suite 310 Springfield, VA 22151	800-869-6782
VI	Virgin Islands Parent Training and Information Program	Main Office 63 Cane Carlton Frederiksted, VI 00840	340-772-1200 340-772-1280 http://drcvi.org/
VT	Vermont Family Network	600 Blair Park Road, Suite 240 Williston, VT 05495	800-800-4005 (in VT)
WA	PAVE	6316 S. 12th Street Tacoma, WA 98465-1900	800-572-7368 (V/TTY)
WI	Wisconsin FACETS PTI	600 W. Virginia Street, Suite 501 Milwaukee, WI, 53204	877-374-0511 (Milwaukee)
WV	WV PTI	99 Edmiston Way, Suite 101 Buckhannon, WV 26201	800-281-1436
WY	Parents Helping Parents of WY, Inc	2232 Dell Range Blvd, Suite 20 Cheyenne, WY, 82009	800-660-9742 (in WY)

Chapter 5: Independent Living



“I know there’s a lot of resources out we’re not tapping into because we’re just not seeing them. There’s a disconnect and all of us can be those bridges.”

Dr. Kimberly Yellow Robe, Advocate

Independent Living

Independent Living philosophy emphasizes consumer control, the idea that people with disabilities are the best experts on their own needs, having crucial and valuable perspective to contribute and deserving of equal opportunity to decide how to live, work, and take part in their communities, particularly in reference to services that powerfully affect their day-to-day lives and access to independence.

National Council on Independent Living

Traditionally, independent living was viewed from a rehabilitation model that viewed physical impairments as functional limitations. An Independent Living model focuses on how people with disabilities can navigate community barriers to live an active life of their own choosing.

Continuum of Care

People receive care for a variety of reasons, from short-term medical treatment for an illness to long-term custodial care for a chronic condition. The word continuum suggests a straight line, but the types of care a person may access encircles the person.

A continuum of care includes:

- Medical & non-medical services
- A variety of settings
- Assistance with ADLs/IDLs
- A person’s choices
- Any person at any age
- Disability & chronic needs
- Care coordination
- A range of services

Traditional Rehabilitation And Independent Living Paradigm Comparison (Comparison Of Service Models)

Issue	Rehabilitation	Independent Living
Limitations	Impairments resulting in functional limitations related to walking, seeing, hearing, learning, etc.	Community barriers, including stereotypes, stigma, prejudice, discrimination, expectations, and structural barriers
Label / Role	Patient, victim, sufferer	Person with a disability, advocate, stakeholder
Objectives	Fix deficits to overcome limitations	Systems change to reduce structured inequality; disability awareness minimizes restrictive perceptions.
	Control is vested in professionals	Control is vested in a person(s) with disabilities
Organizational Structure And Response	Knowledge base is advanced degrees Professional counseling Professional therapy	Knowledge base is experiential, focusing on achieving independence Peer support and counseling Independent living skills training
Community And Self-Perceptions Of A Person With A Disability	A person who, as a result of a disability, is unable to participate in a variety of roles due to lack of function	A person identified as having a disability, who, as a result of community perceptions and structural barriers, is restricted from participating in a variety of social roles, including roles related to education, employment, recreation, worship, civic activities, etc.

- Freedom to progress without a goal or to be fixed
- Services that are not covered by Medicare

How Is Care Funded?

Several federal agencies and programs are integrated to provide services and supports to older adults and people of all ages with disabilities.

The Administration of Community Living (ACL)

A federal agency that supports the needs of the aging and disability populations and improves

access to health care and long-term services. ACL has the responsibility in enacting several federal laws that protect and fund programs for older adults and people with disabilities. The laws include:

- Older Americans Act
- Developmental Disabilities Assistance and Bill of Rights Act
- Rehabilitation Act of 1973

ACL funds programs that support American Indians, Alaska Natives and Native Americans in the areas of nutrition, supportive services for older adults, and caregiver services.



Leading Age

Nutrition and supportive services grants include:

- Congregate and home-delivered meals
- Information and referral
- Transportation
- Personal care
- Chores
- Health promotion and disease prevention, and other supportive services

Caregiver services grants include:

- Assisting families in caring for older relatives with chronic illness or disability

- Grandparents caring for grandchildren
- Other necessary services so the people can live independently in their communities

(Administration for Community Living, Services for Native Americans)

The June 2020 Strategic Framework for Action from the ACL has two goals:

1. Growth of Community Integrated Health Networks (CIHNs).
 - a. The network defines roles and responsibilities of network members and who is the lead network entity.

2. Provide information on how to leverage federal and state funds to provide person-centered services and supports in the community.
 - a. Blend and braid funding streams from federal, state, and local levels to broaden the impact and reach of services.
 - i. When federal funds from various sources are braided, they deliver seamless services to individuals, but the funds need to be tracked and reported separately.

(Administration for Community Living, Strategic Framework for Action)

Some Federal Sources of Funds That May be Braided

1. **Medicare:** A federal health insurance program for individuals 65 and older and specific qualifying groups. Pays for medical care and non-medical care to people who are unable to perform basic activities of daily living (ADLs). (Medicare does not pay for long-term care.)
2. **Administration on Aging:** A federal agency that carries out the provisions of the Older Americans Act of 1965. It distributes funds to states for supportive services and programs for older individuals to live independently in their homes and communities.
3. **Medicaid:** A federal health insurance program for people with low incomes and disabilities. Funds are distributed to states. Provides long-term services and support for qualifying individuals. Long-term care can be provided at home, in the community, or in various types of facilities such as nursing homes or assisted living facilities.
4. **Federal Transit Administration:** Provides grants to expand access to transportation for people with disabilities, older adults, and individuals with low income. Section 5311 provides Rural/Tribal Program grants.
 - a. Health and Human Services grant funds spent on transportation can be used for the match requirement for FTA grants.
 - b. Funds can be used for purchasing vehicles, hiring mobility managers, and implementing travel training programs.
5. Several nutrition and food security funds are available.
 - a. **Administration for Community Living**
 - i. Home-Delivered Nutrition Program
 - ii. Congregate Nutrition Program
 - b. **USDA Food and Nutrition Service**
 - i. Supplemental Nutrition Assistance Program (SNAP)
 - ii. Commodity Supplemental Food Program (CSFP)
 - iii. Child and Adult Care Food Program (CACFP)
 - iv. Senior Farmers Market Nutrition Program (SFMNP)
6. **Housing and Urban Development, Rural Housing Service**
7. **Low Income Housing Tax Credit**
 - a. Centers for Independent Living (see below) help many older adults and people with disabilities secure housing through Section 8 vouchers

- b. Support services can be integrated in supportive housing, such as:
- i. Service coordination
 - ii. Wellness nurses
 - iii. Employment services
 - iv. Prevention and wellness programs
 - v. Medical and Behavioral health referrals or services
 - vi. Assistive technology acquisition and training

Centers for Independent Living (CILs)

Centers for Independent Living are designed and operated by people with disabilities to provide independent living services for people with disabilities of all types. CIL programs provide tools, resources, and supports for integrating people with disabilities fully into their communities to promote equal opportunities, self-determination, and respect.

To understand how CILs make community living possible, see the graphic below from the Administration for Community Living.



(Centers for Independent Living)

The Rehabilitation Act, Title VII, Chapter 1 funds independent living programs, and every three years states must submit a “State Independent Plan for Independent Living.” The implementation of the plan is monitored by a statewide independent living council.

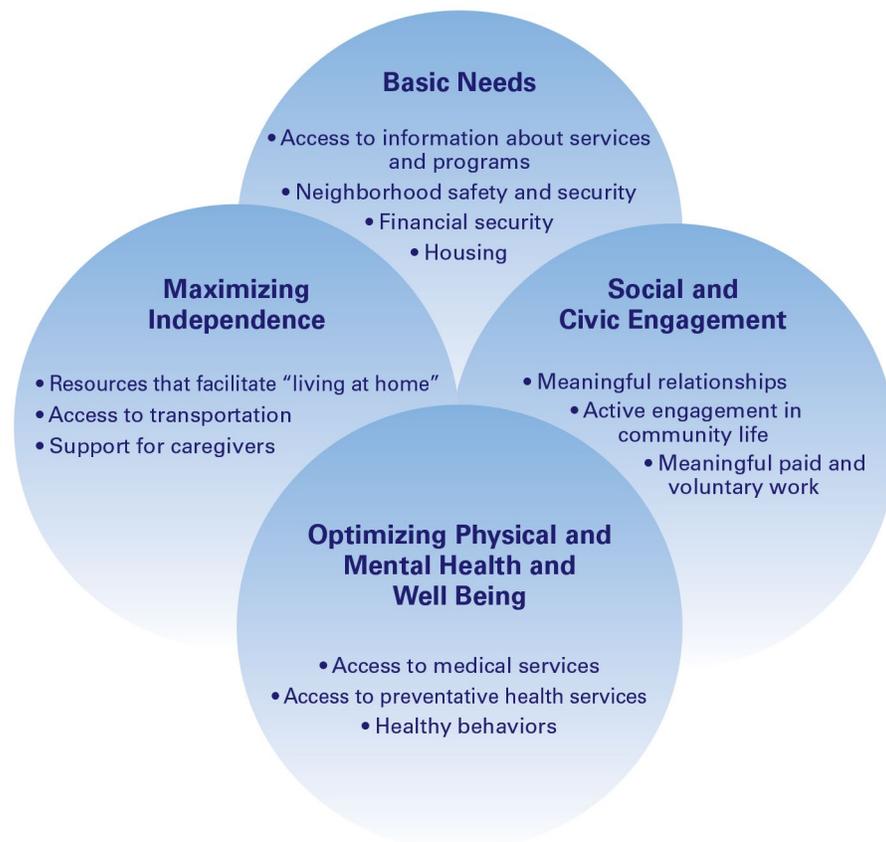
Centers for Independent Living (CILs) are consumer-controlled, community-based, cross-disability, nonresidential private nonprofit agencies that are designed and operated within a local community by people with disabilities and provide an array of independent

living services (Centers for Independent Living).

354 discretionary population-based formula grants fund Centers for Independent Living. At a minimum, the centers must provide core services:

- Information and referral
- Independent Living Skills training
- Peer counseling
- Individual and Systems advocacy

The AdvantAge Initiative Framework: Four Domains of an Aging-Friendly Community



(Oberlink, Mia)

- Services to facilitate transition from nursing homes/other institutions to the community
 - Assist those at risk of entering institutions
 - Facilitate transition of youth to postsecondary life

To find Centers for Independent Living by State and your State Plan for Independent Living, go to: <https://acl.gov/programs/centers-independent-living/list-cils-and-spils>.

The AdvantAge Initiative shows the essential elements of an older adult- and People-with-Disability-Friendly Community.

Tribal Centers for Independent Living

ASSIST! to Independence

Located in Tuba City, AZ, the vision of ASSIST! to Independence is to provide appropriate services to enhance the quality of independent living in a culturally appropriate manner.

Serves individuals who reside on the Navajo Nation, Hopi Reservation, San Juan Southern Paiute Reservation, and individuals living in Navajo, Apache, and Coconino Counties.

Services provided so people can live independently:

- Information and referral—connecting consumers with programs/services
- Independent Living Skills Training—providing one-on-one and group training
- Transition Services—assists consumers move from nursing homes to less restrictive living arrangements, such as a home or apartment
- Assists youth transition to adulthood—assists with transition from rehabilitation setting to the community

- Peer Support—provides peer mentors who are consumers who have been there
- Individual and Systems Advocacy—teach self-determination strategies to address physical and attitudinal barriers in society

Additional Independent Living Services provided:

- Employment
- Work skills education
- Personal assistance
- Socialization and recreation
- Sports, fitness and health promotion
- Home modifications
- Reintegration from nursing home to the community
- Accessing affordable health care
- Obtaining accessible housing
- Transportation
- Traditional healing services
- Durable medical equipment

Website: <https://assistti.org/>

Cherokee Nation Home Health Services, Inc. (CNHHS)

CNHHS is a tribally incorporated, nonprofit home health care agency that is Medicare and Medicaid certified to provide state-licensed home health care services for Medicare and Medicaid beneficiaries.

The services provided are:

- Home health aides who assist with daily activities
- Home-based hospice care
- Personal care to assist with activities of daily living

- Respite support
- Skilled nursing care
- Therapies
- Transportation

Services to assist consumers navigate the health care / independent living systems:

- Client Need Assessments and eligibility for services
- Case management
- Completing Medicaid applications

Medicaid covered services:

- Home modification
- Medical equipment supplies

Pueblo of Zuni’s Long Term Services and Supports Network

Pueblo of Zuni has a wide network of LTSS programs for elders. These programs work

together to provide comprehensive, culturally appropriate care to elders within the community.

Network’s main programs:

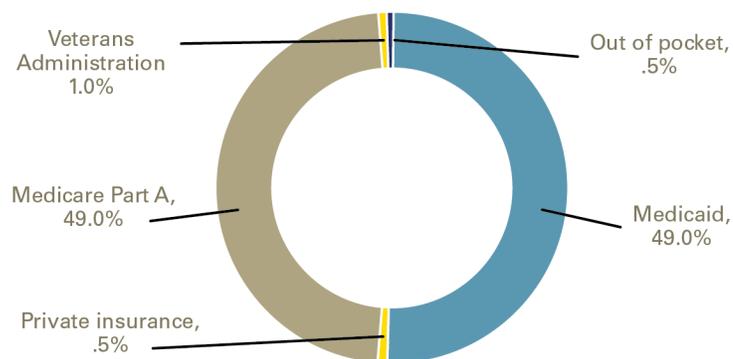
- Adult day care
- A federally qualified home health center
- Zuni IHS hospital’s Elder Care Program

The services provided by the Zuni LTSS Network:

- Adult day care for people with dementia
- Companionship
- Congregate meals
- Disease prevention and health promotion activities
- Household chores
- Home-delivered meals
- Home health aides to assist with daily activities
- Intergenerational activities

Founding

Cherokee Nation Home Health Services Funding Sources



*When clients pay out-of-pocket, rates are slightly lower than they would be for Medicaid.

(Cherokee Nation Home Health Services)

- Outreach and education
- Recreational and social activities
- Skilled nursing care
- Nutrition support
- Transportation
- Support for veterans

Funding

The Zuni Adult Day Care program receives financial support from:

- Title VI Nutrition for the Elderly
- Title V Older Worker Program
- the state of New Mexico

Zuni Home Health receives Medicaid and Medicare reimbursement.

The IHS hospital's Elder Care Program is funded through IHS.

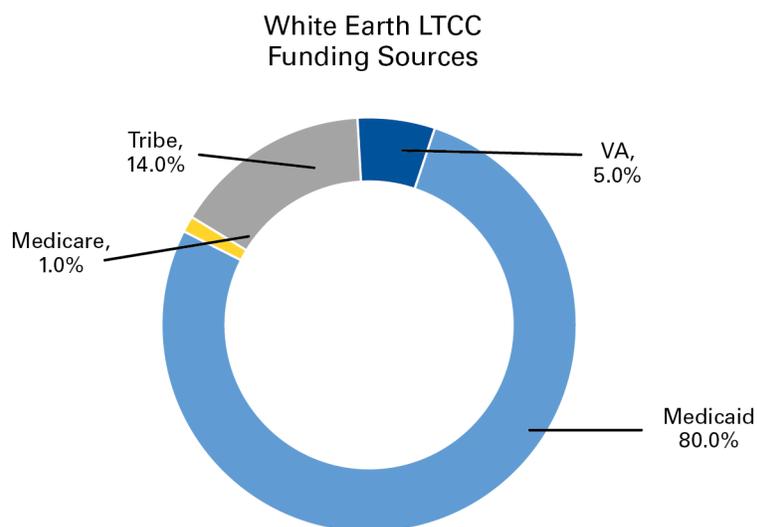
White Earth Long Term Care Consultation Services

The White Earth Band of the Ojibwe formed the Long Term Care Consultation (LTCC) program

in 2005. White Earth contracts with the state of Minnesota and provides case management, eligibility assessments, and home- and community-based services.

Services provided are:

- Adult day care
- Assistive technology
- Caregiver support
- Employment support
- Home-delivered meals
- Home health aides who assist with daily activities
- Household chores
- Home modification
- Medical equipment supplies
- Personal support services
- Respite care
- Skilled nursing care
- Specialist referrals
- Transitional care
- Transportation



Services to assist consumers navigate the health care / independent living systems:

- Client Need Assessments and eligibility for services
- Case management
- Completing Medicaid applications

Funding

White Earth LTCC provides much of its services through several 1915(c) HCBS waivers under Medicaid. The tribe, Medicare, and the Department of Veterans Affairs provide the rest.

Resources to Support Independent Living Initiatives

Who	What	Website/Contact
ADAPT (American Disabled for Attendance Programs Today)	A disability rights advocacy group that trains and organizes local groups to advocate for people with disabilities to receive services in their homes and not be forced to live in institutional settings.	201 S. Cherokee Denver, CO 80223 303-733-9324 https://adapt.org/ Email: adapt@adapt.org
Administration for Community Living, Services for Native Americans	ACL funds a broad range of services for Native Americans: <ul style="list-style-type: none"> ▪ Congregate and home-delivered meals ▪ Information and referral ▪ Transportation ▪ Personal care ▪ Chores ▪ Health promotion and disease prevention ▪ Other services 	https://acl.gov/programs/services-native-americans-oaa-title-vi
American Association of People with Disabilities (AAPD)	AAPD is the nation's largest disability rights organization. Members include people with disabilities, family, friends, and supporters working to promote equal opportunity, economic power, independent living, and political participation of people with disabilities.	The American Association of People with Disabilities (AAPD) 2013 H Street, NW, 5th Floor Washington, DC 20006 800-840-8844 (V/TTY) 202-457-0046 (V/TTY) 866-536-4461 (Fax) https://www.aapd.com/
ANCOR Foundation	Builds and honors exceptional leaders who cultivate inclusive communities for people with intellectual and developmental disabilities.	http://www.ancorfoundation.org/

Who	What	Website/Contact
ASSIST! to Independence	Tribal Center for Independent Living located in Tuba City, AZ	https://assistti.org/
Bazon Center for Mental Health Law	<p>The Bazon Center advocates for the civil rights, full inclusion, and equality of adults and children with mental disabilities.</p> <p>Programs focus on:</p> <ul style="list-style-type: none"> ▪ Education ▪ Mental Health Systems ▪ Criminal Justice ▪ Employment Advocacy ▪ Voting Rights 	<p>http://www.bazon.org/</p> <p>“In the Driver’s Seat: A Guide to Self-Directed Mental Health Care”</p> <p>https://secureservercdn.net/198.71.233.111/d25.2ac.myftpupload.com/wp-content/uploads/2017/01/Drivers-seat.pdf</p>
Benefits CheckUp	Find out what benefits may be available in your area. There are over 2,500 benefit programs available nationwide.	https://www.benefitscheckup.org/
The Center for Self- Determination	<p>The Center for Self-Determination has a national network of trainers, presenters, and consultants.</p> <p>Some of the Center’s specialties include individual budgeting, housing, independent support coordination relationship building, de-institutionalism, systems transformation, CMS Rule compliance, information technology, managed care, Medicaid regulations, employment, inclusive community participation, supported decision-making (alternatives to guardianship), PEER support, etc.</p>	http://www.self-determination.com/
Consortia of Administrators for Native American Rehabilitation	CANAR is the membership organization of the administrators of rehabilitation agencies serving Native Americans and Alaskan Natives.	https://www.csavr.org/canar
Diverse Elders Coalition	Diverse Elders Coalition advocates for policies and programs that improve aging in AI/AN and LGBTQ communities.	https://diverseelders.org/

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Who	What	Website/Contact
Eldercare Locator	A public service of the U.S. Administration for Community Living/Administration on Aging to connect you to services for older adults and their families.	1-800-677-1116 https://eldercare.acl.gov/Public/Index.aspx
Independent Living Research Utilization (ILRU)	ILRU is a national center for information, training, research, and technical assistance in independent living. Directory of Centers for Independent Living and Associations in Alaska	https://www.ilru.org/about-ilru Directory of Centers for Independent Living and Associations in Alaska https://www.ilru.org/projects/cil-net/cil-center-and-association-directory-results/AK
Inter-Tribal Council of Arizona	Provides important links (e.g., Title III reporting forms), manuals, handbooks, and resources on Aging and Adult Services.	https://itcaonline.com/programs/aging/elder-services-news/
Kids Included Together (KIT)	KIT provides training to break down barriers to inclusion so children with disabilities, complex needs, or challenging behaviors have the right to meaningfully participate in their communities.	Kids Included Together 2013 H Street NW, Ste 620 Washington, DC 20006 Phone: 858-225-5680 Fax: 619-758-0949 https://www.kit.org
Long-Term Care.gov	Long-term care is a range of services and support to meet personal care needs. Has a services locator.	https://acl.gov/ltc
National Association of Councils on Developmental Disabilities	A membership association for 56 state and territorial Councils on Developmental Disabilities (DD Councils). DD Councils receive federal funding to support programs that promote self-determination, integration, and inclusion for all people in the U.S. with developmental disabilities.	https://www.nacdd.org/ To find your state's DD Council: https://www.nacdd.org/councils/
National Resource Center for Alaska Native Elders	One of three resource centers for AI/AN and Hawaiian Natives funded by the Administration on Aging. Activity Manual to Honor Alaska Native Cultures and Traditions in Care Facilities Alaska Traditional Kitchen with Chef Flora Deacon Articles, posters, and reports	https://www.uaa.alaska.edu/academics/college-of-health/nrc-alaska-native-elders/ Resources: https://www.uaa.alaska.edu/academics/college-of-health/nrc-alaska-native-elders/resources/index.cshhtml

Who	What	Website/Contact
National Disability Rights Network	The NDRN works in Washington, DC, on behalf of the Protection and Advocacy Systems and Client Assistance Programs. It is the largest provider of legal advocacy services for people with disabilities.	National Disability Rights Network 900 Second Street NE, Ste 211 Washington, DC 20002 Phone: 202-408-9514 TTY: 202-408-9521 Fax: 202-408-9520 https://www.ndrn.org
National Resource Center on Native American Aging	One of three resource centers for AI/AN and Hawaiian Natives funded by the Administration on Aging. NRCNAA provides education, training, and technical assistance in developing community-based solutions to improve the quality of life and delivery of related support services to the Native aging population.	Resources: * Needs Assessment/Survey of Elders (Data can be used for planning and grant applications) https://www.nrcnaa.org/needs-assessment * Native Urban Elder Needs Assessment Survey https://www.nrcnaa.org/urban-needs-assessment * WELL-Balanced (Wise Elders Living Longer) A group exercise and social program https://www.nrcnaa.org/well-balanced * Native Elder Caregiver Curriculum (three-day workshop to help caregivers function more effectively) https://www.nrcnaa.org/native-elder-caregiver-curriculum * Training https://www.nrcnaa.org/training
National Indian Council on Aging	Resources about Long Term Services and Supports. Includes: <ul style="list-style-type: none"> ▪ Advocacy Toolkit ▪ Aging in Place ▪ Caregiver’s Corner ▪ Partners and Community Development ▪ Nutrition ▪ Paying for Your Care ▪ Planning for LTSS ▪ Veterans Administration LTSS 	https://nicoaltsscompass.org/community-resources/

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Who	What	Website/Contact
National Indian Council on Aging	For Tribal Leaders: Thinking About Building a Long Term Care Facility? * 15-page guide	https://nicoaltsscompass.org/wp-content/uploads/2020/12/Nursing-Home-Creation.pdf
Native American Advocacy Program	A program to support Lakotas Transitioning to Culturally Grounded Lifestyles	https://mbullbear.wixsite.com/lakotayouth/independent-living
Native American Disability Law Center	The Native American Disability Law Center is a private nonprofit organization that advocates for the legal rights of Native Americans with disabilities in the four corners area (NM, AZ, UT, CO). Through advocacy and education, we empower Native people with disabilities to lead independent lives in their own communities.	Native American Disability Law Center 905 W. Apache Street Farmington, NM 87401 Phone: 505-566-5880 800-862-7271 Fax: 505-566-5880 https://www.nativedisabilitylaw.org Email: info@disabilitylawcenter.org
Rehabilitation Services Administration	The American Indian Rehabilitation Services program assists tribal governments to develop or increase capacity to provide culturally relevant Vocational Rehabilitation services.	https://rsa.ed.gov/program/aivrs Program Contact: Sonja Turner 400 Maryland Avenue, SW PCP, Room 5049 Washington, DC 20202 Phone: 202-245-7557 Email: sonja.turner@ed.gov August Martin 400 Maryland Avenue, SW PCP, Room 5049 Washington, DC 20202 Phone: 202-245-7410 Email: august.martin@ed.gov
Self Advocates Becoming Empowered (SABE)	The mission of SABE is to ensure that people with disabilities are treated as equals and that they are given the same decisions, choices, rights, responsibilities, and chances to speak up to empower themselves; opportunities to make new friends, and to learn from their mistakes.	https://www.sabeusa.org/

Who	What	Website/Contact
Statewide Independent Living Councils (SILC)	SILCs support the development, implementation, and monitoring of Independent Living services and Centers for Independent Living programs in a state through a State Plan for Independent Living (SPIL).	https://www.ilru.org/projects/silc-net/silc-directory
USAging (Formerly: National Association of Area Agencies on Aging)	U.S. Aging supports the national network of Area Agencies on Aging and advocates for the Title VI Native American Aging Programs that help older adults and people with disabilities.	https://www.usaging.org/

Chapter 6: Vocational Rehabilitation and Employment

“The state (NM DVR) built good relationships with tribal VR staff. The staff has to be willing (to work together).”

Ella Yazzie-King, Advocate

American Indian and Alaska Native Workforce Participation

The employment data on American Indian and Alaska Natives participation in the workforce has been grim for decades. Data from 2016–18 Current Population Survey collected by the U.S. Bureau of Labor Statistics found that in comparison to the overall U.S. population, AI/ANs had:

- Higher unemployment rates
- Lower labor force participation rates
- Higher unemployment rates for AI/ANs who lived in an AI/AN area than for AI/ANs who lived elsewhere
- AI/AN areas are defined as a federal or state American Indian reservation or off-reservation trust land, tribal statistical area, or Alaska Native village statistical area.

- An unemployment rate of 6.6%, considerably higher than the rate of 3.9% for the country as a whole (U.S. Bureau of Labor Statistics 2019)

AI/ANs in 2016–18 were more likely to have a disability (16%) than the overall population (12%). The table below further breaks down rates of disability by age.

In general, people with disabilities are much less likely to participate in the labor force than people without disabilities. In 2016–18, only 22.6 percent of AI/ANs with a disability were either working or looking for work, about a third the rate of AI/ANs with no disability (67.4%) (U.S. Bureau of Labor Statistics 2019).

Employment Protections

Different federal laws have different criteria to determine if a person is deemed to have a disability.

Ages of Persons with a Disability	Percentage of American Indian and Alaska Native with a Disability	Percentage of Total U.S. Population with a Disability
Total, 16 years and older	15.9%	11.8%
16 to 24 years	5.9%	4.0%
25 to 54 years	11.1%	6.2%
55 years and over	34.0%	22.9%

(U.S. Bureau of Labor Statistics 2019)

ADA Definition Of A Disability

Title I of the Americans with Disabilities Act (ADA) categorically excludes tribes as employers (42 U.S.C. § 12111(5)(B)(i)). This exclusion applies to the sovereign status of tribes. Other businesses on the reservation do not necessarily fall under this categorical exclusion. ADA does apply to organizations such as the Indian Education Service and the Bureau of Indian Education.

Under the ADA, an individual is generally deemed to have a disability if he or she suffers from a “physical or mental impairment that substantially limits one or more major life activities.” Working, or being employed, is considered a major life activity for the purpose of determining the existence of a disability. Notably, the definition of “disability” is to be understood broadly, including conditions that are episodic in nature or are in remission (Telework Guidance).

Rehabilitation Act

The Rehabilitation Act prohibits discrimination based on disability in federal employment, programs conducted by federal agencies, and by organizations that receive federal funds. In determining employment discrimination, the Rehabilitation Act uses the same standards as Title I of the ADA.

Employment

Titles I and II of the ADA also specifically address employment issues for people with disabilities. Title I requires employers with 15 or more employees to provide qualified people with disabilities an equal opportunity to benefit from the full range of employment-related opportunities available to others. For example, it prohibits discrimination in recruitment, hiring, promotions, training, pay, social activities, and other privileges of employment.

Title I of the ADA restricts questions that can be asked about an applicant’s disability before a job offer is made, and it requires that employers make reasonable accommodations for the known physical or mental disability of otherwise qualified people with disabilities, unless it results in undue hardship.

State and Local Governmental Requirements

Title II of the ADA covers all activities of state and local governments regardless of the government entity’s size or receipt of federal funding. Title II requires that state and local governments give people with disabilities an equal opportunity to benefit from all their programs, services, and activities (e.g., public education, employment, transportation, recreation, health care, social services, courts, voting, and town meetings).

State and Local Governmental Buildings

State and local governments are required to follow specific architectural standards in new construction and alteration of existing buildings. Governmental programs must be provided in buildings that are accessible and communicate effectively with people who have hearing, vision, or speech disabilities unless such actions would result in undue financial and administrative burdens.

State and local governments are required to make reasonable modifications to policies, practices, and procedures where necessary to avoid discrimination, unless they can demonstrate that doing so would fundamentally alter the nature of the service, program, or activity being provided.

Reasonable Accommodations

The purpose of providing reasonable accommodations is to enable employers to hire or retain qualified job candidates regardless of their disability by eliminating barriers in the workplace (Disability Access Office 2011).

Some types of accommodations include assistive devices, reassignment, modified work schedules, job modifications, relocation, or a change in the physical plant.

Examples of assistive devices often used in the workplace include the teletypewriter (TTY), telephone amplifier, or video relay, often used by Deaf and Hard of Hearing people; wooden blocks to elevate desks and tables for wheelchair users; and large-type computer terminals and Braille printers to assist people with vision impairments (Disability Access Office 2011).

How to File Complaints for Disability Discrimination

The Rehabilitation Act prohibits discrimination based on disability and uses the same standards as Title I of the ADA.

Section 121 of the Rehabilitation Act authorizes the Rehabilitation Services Administration (RSA) to make grants to tribes for the purpose of Vocational Rehabilitation services. Tribes accepting these grants, and generally other federal funds, agree to comply with federal law, which does not equate to a waiver of sovereign immunity.

Sovereign immunity would prevent private parties from seeking redress in federal or state court. However, sovereign immunity may not protect tribes from the federal government enforcing disability legislation. For non-tribal businesses and services, federal law still applies.

Filing a Job Discrimination Complaint

A job discrimination complaint may be filed by mail or in person at the nearest U.S. Equal Employment Opportunity Commission (EEOC) office.

To find the closest EEOC office, call or look online at the EEOC field office map:

Phone: 800-669-4000

TTY/TDD: 800-669-6820

Field Office List and Jurisdiction Map: <https://www.eeoc.gov/field-office>

If you need assistance filing the complaint, tell the EEOC office so arrangements can be made. A few examples of arrangements are a sign

Information Needed to File a Discrimination Complaint

- Name, address, and telephone number of the person who is being treated unfairly
- Name, address, and telephone number of the employer you are filing the complaint against
- A brief description of the event or events that you believe are unfair or harassing
- The dates these events occurred

language interpreter, foreign language interpreter, or print materials in an accessible format.

If you believe you have been treated unfairly or harassed at work by a Federal Government employer, you must follow different procedures. For information on how the process works, you should see the guidelines for Federal Sector Equal Employment Opportunity Complaint Processing.

Federal Sector Equal Employment Opportunity Complaint Processing Guidelines

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<https://www.eeoc.gov/federal-sector/overview-federal-sector-eeo-complaint-process>

A complaint alleging disability discrimination under Title II of the ADA can be filed against a state or local government or a public accommodation (a private business, including a restaurant, doctor's office, retail store, hotel, etc.). A complaint can be filed online using the link below, by mail, or by facsimile.

To file an ADA complaint online:

<https://civilrights.justice.gov/report/>

ADA Complaint form: <https://www.ada.gov/CRT-ReportPDF-Sep2021.pdf>

Fill out the ADA Complaint Form and send it by mail to:

U.S. Department of Justice
Civil Rights Division
950 Pennsylvania Ave., NW
4CON, 9th Floor
Washington, DC 20530

To file an ADA complaint by facsimile, fax the completed ADA complaint form to:

(202) 307-1197

To talk with an ADA specialist, call

Voice: 800-514-0301

TTY: 800-514-1383

Voice: 800-514-0301

TTY: 800-514-0383

Workforce Innovation and Opportunity Act of 2014

On July 22, 2014, President Obama signed into law the Workforce Innovation and Opportunity Act (WIOA) which superseded the Workforce Investment Act of 1998 (WIA).

The purpose of WIOA is to provide a workforce system that is universally accessible, customer centered, and gives emphasis to job-driven training. WIOA is designed to help job seekers access employment, education, training, and support services in order to succeed in the labor market. WIOA matches employers with the skilled workers needed to compete in the global economy (U.S. Department of Labor Laws and Regulations).

The Rehabilitation Act of 1973 was incorporated into WIOA as Title IV and authorizes the formula grant programs of Vocational Rehabilitation, supported employment, and client assistance. The Act includes a focus on rights, advocacy, and protections for people with disabilities (U.S. Department of Labor Laws and Regulations).

Division of Indian and Native American Programs and WIOA

The Division of Indian and Native American Programs (DINAP) Workforce Innovation and Opportunity Act (WIOA) Section 166 grantees and the Department of Labor share a vision of providing quality employment and training services to tribes, tribal organizations, Alaska Native entities, Indian controlled organizations, and Native Hawaiian organizations serving unemployed and low-income Native Americans, Alaska Natives and Native Hawaiians (U.S. Department of Labor, Indian and Native American Programs). In 2021, there were 167 Native American Adult and Youth programs funded by WIOA Section 166. In total, \$54,945,000 was allotted for Adult Programs, and \$13,778,655 for Youth Programs (U.S. Department of Labor, WIOA Section 166).

Job Centers

WIOA requires American Job Centers, also known as Workforce Centers and “one-stop career centers” to provide universal access to basic career services and coordination of individualized training services to eligible participants. One-stop career centers address the needs of employers and the workforce, including co-locating workforce partners at the one-stop career center (The LEAD Center 2016). State and local Department of Vocational Rehabilitation offices are co-located at one-stop career centers.

There are multiple provisions of WIOA, including a requirement that each state submit a four-year Unified State Plan (an action plan), establish a State Workforce Development Board, local workforce development boards, and operate one-stop career centers. The Workforce Development Boards are charged with developing strategies to support career pathways and workforce investment activities such as education, skill development, training, and other supportive services so eligible individuals can gain or retain employment.

WIOA Programs

Individuals who access services through WIOA receive individualized career and training-related services to eligible persons with significant barriers to employment and to assist employers fill their workforce needs with job-seeking individuals.

The LEAD Center 2016

Career Pathways and Partnerships in WIOA

As emphasized in the 2016 WIOA regulations, one-stop career centers (also called workforce centers) are required to collaborate with adult

WIOA Programs

Adult Program (WIOA Title I)

Dislocated Worker Program (WIOA Title I)

Youth Program (WIOA Title I)

Adult Education and Family Literacy Act Program (WIOA Title II)

Wagner-Peyser Act Program (Wagner-Peyser Act, as amended by title III)

Vocational Rehabilitation Program (Title I of the Rehabilitation Act of 1973, as amended by Title IV)

Jobs for Veterans State Grants Program (Authorized under 38, U.S.C. 4100 et. seq.)

Senior Community Service Employment Program (Title V of the Older Americans Act of 1965)

Temporary Assistance for Needy Families Program (TANF)

Employment and Training Programs under the Supplemental and Nutrition Assistance Program (SNAP)

Trade Adjustment Assistance for Workers Program

education, postsecondary education, and other partners to establish career pathway programs. Career pathway programs offer job seekers a clear sequence, or pathway, of education coursework and/or training credentials that are aligned with employer-validated work readiness standards and competencies.

WIOA training funds are eligible to individuals in specific industry sectors identified in their state's "State Unified Plan" due to high demand for employees. Individuals may receive training funds (for example, up to \$9,000 in NM in 2020) if the individual's career pathway is aligned with the state's sector strategy, the individual completes the required career readiness activities (i.e., have a current resume, conducted labor market research on the industry sector of interest, etc.), and enrolls in a state-approved training program. During the career

readiness or development process, individuals learn about:

- Industry sectors
- Careers within an industry sector
- Wages
- Number of job openings
- Daily job tasks
- Local job demand
- Opportunities for advancement
- Industry required credentials
- Education and training requirements (Gioannosa 2018)

Individualized career services must be made available if determined to be appropriate for an individual to obtain or retain employment.

Services at One-Stop Career Centers

- Comprehensive and specialized assessments of the skill levels and services needed by a participant, which may include diagnostic testing, in-depth interviewing, and evaluation to identify employment barriers and appropriate employment goals
- Development of an individual employment plan to identify the employment goals, appropriate achievement objectives, and appropriate combination of services for the participant to achieve his or her employment goals, including information about eligible training providers
- Group counseling
- Individual counseling
- Career planning
- Short-term pre-vocational services including development of learning skills, communication skills, interviewing skills, punctuality, personal maintenance skills, and professional conduct services to prepare individuals for unsubsidized employment or training
- Internships and work experiences that are linked to careers
- Workforce preparation activities
- Financial literacy services
- Out-of-area job search assistance and relocation assistance
- English language acquisition and integrated education and training programs

Eligibility for Adult Program or Dislocated Worker Program

1. U.S. Citizen or otherwise legally entitled to work in the U.S.
2. Age 18 or older
3. Selective Service Registration (males who are 18 or older; born on or after January 1, 1960) unless an exception is justified.

The law mandates that each state/regional WIOA program establish priority populations.

Wagner-Peyser and WIOA

Wagner-Peyser Act of 1933 was amended under WIOA 2014. The Wagner-Peyser Act provides a nationwide system of public employment offices, known as the Employment Service, that brings together individuals seeking employment with employers seeking workers (U.S. Department of Labor, Wagner-Peyser Act Employment Service Results).

Priority Populations (varies by state)

- People who are low-income, recipients of public assistance
- People with basic skills deficient
- People who are unemployed
- People with a disability
- People with a barrier to employment
- Veterans and spouses
- A dislocated worker is an individual who was terminated, laid off, or received a notification of termination or lay off
- It is unlikely the individual will return to the previous employment or occupation
- Has exhausted unemployment compensation or not eligible for unemployment compensation
- A person who lost employment due to permanent closure of a plant, facility, or enterprise, and it was announced 180 days prior to closure
- Was self-employed and due to economic conditions is now considered unemployed
- A person who is no longer supported by another individual (i.e., due to divorce, death, disability)
- A spouse of a member of the armed forces on active duty and whose family income is significantly reduced because of deployment
- A person, including the spouse of a member of the armed forces, who is unemployed or underemployed and experiencing difficulty in obtaining or upgrading employment
- A non-retiree who was discharged/released from service (other than dishonorable) and received a notice of military separation
- The spouse of a member of the armed forces on active duty, and who has experienced a loss of employment as a direct result a change in duty station/location

Pacific Mountain Workforce Development

Vocational Rehabilitation (VR)

Vocational Rehabilitation (VR) is a federally funded program that provides employment and training services in every state, territory, and many American Indian Nations. Vocational

Rehabilitation serves all disability groups, but some states have a separate program called State Services for the Blind that provides specialized services for people with legal blindness (Career One Stop).

Eligibility for Youth Services

- In-school youth, aged 14 to 21, who is attending school, including secondary and postsecondary school
- In-school youth with a disability who meet the low-income definition, which is based on the individual's own income rather than the family's income
- Out-of-school youth with a disability—there is no low-income requirement
- Youth with a basic skills deficit as determined by valid and appropriate assessments, with reasonable accommodations provided for youth with disabilities

(The LEAD Center 2016)

Vocational Rehabilitation (VR) programs vary greatly from state to state and tribe to tribe. Tribal VR programs differ depending on a tribe's cultural and geographical environment. Vocational Rehabilitation is more than job placement or counseling services. It is a comprehensive service uniquely tailored to the local culture and community needs.

The Occupational Outlook Handbook description of Vocational Rehabilitation counselors is, "Rehabilitation counselors help people with physical, mental, developmental, or emotional disabilities to live independently. They work with clients to overcome or manage the personal, social, or psychological effects of disabilities on employment or

independent living" (U.S. Bureau of Labor Statistics 2021).

Tribal Vocational Rehabilitation Programs

American Indian tribes (as described in Section VII of the Rehabilitation Act of 1973 as amended) located on federal and state reservations may apply for American Indian Vocational Rehabilitation Services (AIVRS) discretionary grants through a competitive process with funding for five years, which is administered by the Rehabilitation Services Administration within the U.S. Department of Education.

"According to the 2020 Federal Register's Notice of Applications for American Indian Vocational Rehabilitation Services, the estimated average size of awards will be \$531,000 and the estimated number of awards will be 51" (U.S. Department of Education Office of Special Education and Rehabilitative Services 2020).

Unfortunately, not all tribes have a VR program. States, territories, and the District of Columbia receive funds calculated through a statutory formula based on population and per capita income.

Barriers Created by the Rehabilitation Services Administration

In the 2003 version of this toolkit, the average award to American Indian VR programs was \$350,000. Although the average amount of the VR awards to tribes has increased to \$531,000, the program remains a competitive discretionary grant, and tribes who may have had VR services in the past could lose their VR funding during the next funding cycle, thus creating a lack of

What Does a Rehabilitation Counselor Do?

- Provide individual and group counseling to help consumers adjust to their disability
- Evaluate consumers' abilities, interests, experiences, skills, health, and education
- Develop a treatment plan for consumers in consultation with others
- Arrange for consumers to obtain services such as medical care or career training
- Help employers understand disability laws, resources, and the needs and abilities of people with disabilities
- Help consumers develop their strengths and accommodate their limitations
- Locate resources such as wheelchairs or computer programs that help consumers live and work independently
- Maintain consumer records and monitor consumers' progress
- Advocate for the rights of people with disabilities to live in a community and work in the job of their choice

(U.S. Bureau of Labor Statistics 2021)

continuity in VR services to its tribal members. Tribes that have never had VR funding could be awarded a grant for the first time, which can present start-up and capacity-building challenges. The way VR funds are allotted creates additional barriers for tribes who are attempting to provide a much-needed service to their tribal members with disabilities.

What Services Are Available from Vocational Rehabilitation?

Vocational Rehabilitation is an individualized employment program. Participants may receive diagnosis, an individualized rehabilitation program, counseling and guidance, training, job placement, and services to support job retention. Many applicants are referred by schools, hospitals, welfare agencies, and other

organizations, but an individual may apply directly for services (Career One Stop).

Some people with disabilities enroll in both state Vocational Rehabilitation programs and tribal Vocational Rehabilitation programs, and the needed services are split between the two programs. For example, the tribal Vocational Rehabilitation program may provide career exploration and placement services, while the state Vocational Rehabilitation program provides transportation services to and from the person's job.

How Do You Apply for VR Services?

Contact your local office for the specific process to apply. You will be asked to submit a written application, and eligibility decisions are made within 60 days of application.

Who Is Eligible for VR Services?

To qualify for VR services, an individual must:

- Have a physical or mental impairment that presents a substantial barrier to employment; and be able to benefit from VR services to achieve employment
- Need VR services to prepare for a job, or to get, keep, or regain a job

An “individual with a disability” means any individual who:

- Has a physical or mental impairment that constitutes or results in a substantial impediment to employment for the individual. Some states have added emotional, learning or/and cognitive and “other forms of disability, and can benefit from VR services to achieve an employment outcome
- People who receive Supplemental Security Income (SSI) and/or Social Security Disability Insurance (SSDI) benefits are considered eligible for VR, unless too disabled to benefit

(CareerOneStop)

To find your nearest local office, contact your state’s Vocational Rehabilitation office, or through the American Job Center network, where many Vocational Rehabilitation staff are located.

- State Vocational Rehabilitation Offices: <https://askearn.org/page/108>
 - American Job Center Finder (One Stop Career Center Finder) <https://www.careeronestop.org/LocalHelp/AmericanJobCenters/find-american-job-centers.aspx>
 - American Indian Vocational Rehabilitation Service Projects <http://aivrttac.org/contact/>
- (CareerOneStop)*

Other Disability Employment Programs

The **Ticket to Work Program (TTW)** helps people aged 18–64 who receive Social Security

due to a disability find work and keep their health coverage.

- Ticket to Work Program <https://yourtickettowork.ssa.gov/>
- Phone: (866) YOURTICKET; 866-968-7842
- TDD: (866) TDD2WORK; 866-833-2967

Veterans ReEmployment for help with employment, training, and financial assistance.

Veteran and Military Transition Center <https://www.careeronestop.org/Veterans/default.aspx>

Independent Living Centers (ILCs) provide job coaching, training, and information on disability in the workplace to help people with disabilities maintain their independence. Find your nearest Independent Living Center.

Directory of Independent Living Centers: <https://www.ilru.org/projects/cil-net/cil-center-and-association-directory>

(CareerOneStop)



(First Peoples Fund)

Self-Employment & Entrepreneurship

Self-employment has long been a means of sustenance for tribal members, particularly for those living in rural reservation areas. Many people with disabilities are interested in the opportunity self-employment offers to meet professional, cultural, and financial goals. Starting one's own business can be intimidating, but the Pine Ridge Indian Reservation Case Study described below is a model of how culture can cultivate entrepreneurial initiatives and community development programs.

For entrepreneurs with a disability, the Office of Disability Employment Policy (ODEP) is a federal agency that

encourages and supports self-employment and entrepreneurship among people with disabilities and has helped foster an array of partnerships at the federal, state, and local levels to encourage access to funding and resources to assist people with disabilities interested in alternatives to traditional employment (U.S. Department of Labor Office of Disability Employment Policy, n.d.)

Pine Ridge Entrepreneurship Case Study: Rolling Rez Arts

The bonds that form when artists have the chance to work together is reflected in the strengthening of First Peoples Fund's [FPF] network of nonprofit partners and regional and national funders. At

FPF, we always talk about tightening that weave, and as we weave, our work is growing in the region into what will result in a tightly woven sweetgrass braid.

(Hutter 2017)

The Pine Ridge Indian Reservation offers a case study on how to leverage resources and partnerships to develop entrepreneurs and home-based businesses that channel creativity toward economic and social empowerment.

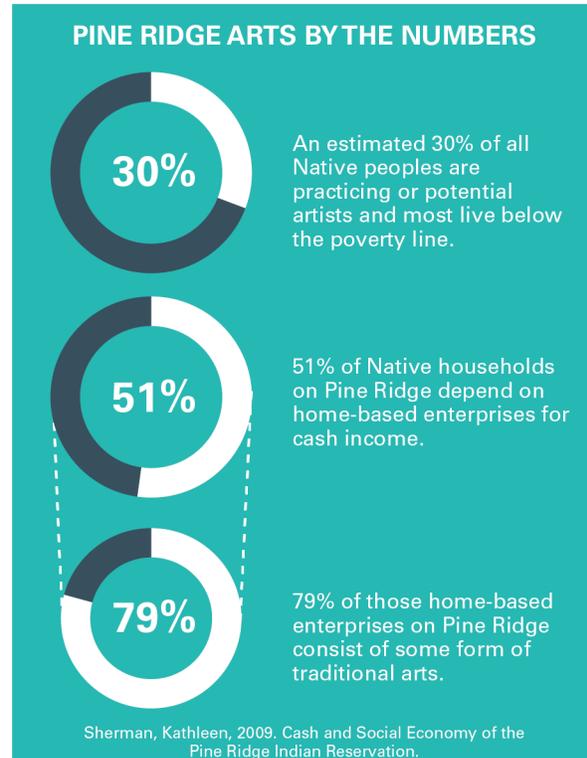
Background on Rolling Rez Arts

A 2013 white paper, *Establishing a Creative Economy: Art as an Economic Engine in Native Communities*, inspired the creation of Rolling Rez Arts. The Pine Ridge Indian Reservation spans nearly 3,500 square miles, and, when the paper was published, 80 percent of the population were unemployed and 98 percent lived below the poverty line. The community largely used an informal trade-and-barter economy. Most had never used a checking or savings account or received a bank loan (Hutter 2017).

Founding of Rolling Rez Arts

To advance the interests of Native artists in remote places and to bring services to the artists, the Rolling Rez Arts bus was fashioned. In 2016, this tricked-out airport shuttle bus began rolling as a mobile artist studio, classroom, bank, and marketplace that traveled across the reservation.

Inside the bus are tables for workshops, computers with design and film editing software, cameras, a cash register, a safe, and air conditioning. In the first year, there were 67



(Oglala Lakota Artspace)

classes to more than 350 people across Pine Ridge and neighboring Cheyenne River and Standing Rock Reservations (Hutter 2017).

First Peoples Fund (FPF) was founded in 1995 with a belief in the “Collective Spirit,” a commitment to honor our humanity, connection, the land, those who came before us, and the spirit of all things. First Peoples Fund secures funding to honor and support First Peoples artists and culture bearers (First Peoples Fund).

First Peoples Fund secured funding from National Endowment for the Arts, ArtPlace America, The Bush Foundation, Northwest Area Foundation, USDA Rural Development, and later The Ford Foundation to create Rolling Rez Arts (Hutter 2017).

Banking Services

Banking Services are provided by Lakota Funds and Lakota Federal Credit Union, established in 2012 as the only federally insured financial institution serving Pine Ridge.

Lakota Funds was established in 1986 and at the time 85 percent of its customers had never used a checking or savings account. In 2017, Lakota Funds had made 900+ loans totaling \$7.2 million and created 1,415 new jobs and 500 new businesses on Pine Ridge (Hutter 2017). The banking services on Rolling Rez Arts are:

- Business loans
- Technical assistance
- Financial management training
- A mobile banking unit so customers in far-flung places have access to personal financial services

Classroom

Rolling Rez Arts is a classroom and contracts with local Native artists to offer:

- FPFs Native Artist Professional Development curriculum
- How to write a business plan
- How to create a budget
- Pricing strategy
- Cultural Capital
- Artist in Business Leadership Programs
- Art classes, ranging from traditional to contemporary, such as ledger art and beadwork to comic illustrations and video editing (Hutter 2017)

Marketplace

Artists can sell their artwork at “buyer’s days” from the bus and across the reservation instead of spending time and gas on driving to retail outlets. Art is also sold online and in the gift shop of the Heritage Center at the Red Cloud Indian School (Hutter 2017).

Ripple Effect of Rolling Rez Arts: Oglala Lakota Artspace

The Oglala Lakota Artspace was funded by ArtPlace America, U.S. Economic Development Administration, The Bush Foundation, Ford Foundation, Hearst Foundation, National Endowment for the Arts, U.S. Department of Agriculture, The Hayes Fund of HRK Foundation, and Margaret A. Cargill Philanthropies (Artspace).

To further promote economic sustainability through the arts, First Peoples Fund and its partners opened the Oglala Lakota Artspace, an 8,500 square foot facility with artist studios and a business incubator. It is located next to the Lakota Prairie Ranch Resort below the Oglala Lakota College campus. The college refers students, provides instructors, and spreads the word across all nine college campuses and reservation districts (Hutter 2017). The coworking space provides business training, networking, and administrative offices. The facility houses:

- Artist studios
- Recording studio
- Film editing studio
- Computer lab
- Classroom space
- Commercial space
- Outdoor market space



- Community gathering space
- Lakota Federal Credit Union storefront
- Garage for Rolling Rez Arts bus
- Homebase for Dances with Words (First Peoples Fund)

The Gig Economy

The gig economy is characterized by employers, usually in the service sector, who typically use short-term contractors or freelance workers, also referred to as contingent workers, instead of hiring employees. Gig economy statistics from a 2021 article on the Fortnuly website explains the impact of the common practice of hiring contingent workers and why it is the “new normal.”

- On average, gig workers earn 58% less than full-time employees. More than half don’t have access to employer-provided benefits, such as health care and retirement

- 74.6% of all contingent workers are white
- More than one-third of U.S. workers (36%) participate in the gig economy, either through primary or secondary jobs.
- 57% of gig economy workers say they work more than 40 hours per week
- The total freelancing income is 5.7% of U.S. gross domestic product (Mitic 2021)
- In 2017, 2% of gig workers were American Indian or Alaskan Native (Steward and Greenberg 2019)

Telecommuting

Many employers have discovered the benefits of allowing employees to work at home through telework (also known as telecommuting).

Telework has allowed employers to attract and retain valuable workers by boosting employee morale and productivity. Technological advancements have also helped increase telework

options by allowing employees to work from home or another approved alternate location.

Not all persons with disabilities need—or want—to work at home, and not all jobs can be performed at home. However, these technological advancements can expand options and opportunities for people with disabilities. Allowing an employee to work at home may be a reasonable accommodation where the person’s disability prevents successful job performance on-site. The consideration of a work-from-home accommodation follows different statutory authority than a request to work from home by employees without disabilities under an agency’s

telework policy. Work from home is viable when the job, or parts of the job, can be performed at home without causing significant difficulty or expense (Telework Guidance).

Reasonable accommodations enhance the opportunity for qualified people with disabilities who may not otherwise be considered for employment for reasons unrelated to actual job requirements. The purpose of providing reasonable accommodations is to enable employers to hire or retain qualified job candidates regardless of their disability by eliminating barriers in the workplace (Leedom and Brynelson 2019).

Resources

Organization	What They Do	Contact Info
American Indian Vocational Rehabilitation Training and Technical Assistance Center (AIVRTTAC)	AIVRTTAC provides education, guidance, and technical assistance (TA) to American Indian Vocational Rehabilitation Services (AIVRS) Programs. We operate on tribal lands in 25 states to help tribal members with disabilities prepare for and obtain gainful employment.	To find your local American Indian Vocational Rehabilitation Program: http://aivrttac.org/contact/ Co-Project Directors: Lee.gaseoma@nau.edu Wayne.dagel@nau.edu Phone: 928 523-5590 Fax: 928 523-9127 Website: https://aivrttac.org/
America Job Center Finder	To find your local One Stop Career Center.	https://www.careeronestop.org/LocalHelp/AmericanJobCenters/find-american-job-centers.aspx
Consortia of Administrators for Native American Rehabilitation (CANAR)	CANAR is a membership organization of the rehabilitation administrators who serve Native Americans and Alaskan Natives living on or near reservations or villages.	(CANAR) Council of State Administrators of Vocational Rehabilitation 1 Research Court, Suite 450 Rockville, MD 20850 Phone: 301-519-8023 Website: https://www.csavr.org/canar

Organization	What They Do	Contact Info
Directory of Independent Living Centers	ILCs provide job coaching, training, and information on disability in the workplace to help people with disabilities maintain their independence.	Find your nearest Independent Living Center: https://www.ilru.org/projects/cil-net/cil-center-and-association-directory
Federal Sector Equal Employment Opportunity (FSEEO)	FSEEO is the office where a complaint alleging disability discrimination under Title II of the ADA can be filed against a state or local government or a public accommodation (a private business, including a restaurant, doctor's office, retail store, hotel, etc.)	Federal Sector Equal Employment Opportunity Complaint Processing Guidelines: https://www.eeoc.gov/federal-sector/overview-federal-sector-eeo-complaint-process To file an ADA complaint online: https://civilrights.justice.gov/report/ To talk with an ADA specialist, call Voice: 800-514-0301 TTY: 800-514-0383
National Association of Multicultural Rehabilitation Concerns (NAMRC)	NAMRC promotes cultural diversity and disability through advocacy for excellence and equity in rehabilitation research, education, and practice.	NAMRC 633 South Washington Street Alexandria, VA 22314 Phone: 703-836-0850 Fax: 703-836-0848 Website: https://www.nationalrehab.org/namrc
National Rehabilitation Association	NRA is a professional membership organization that promotes ethical and collaborative rehabilitation practice. NRA is comprised of counselors, educators, researchers, and provides its members with training, education, and credentialing.	Website: https://www.nationalrehab.org
Office of Native American Affairs Resources	ONAA is an office within the U.S. Small Business Administration. The goal of ONAA is to promote and support Native American entrepreneurs. The ONAA engages in numerous outreach activities including tribal consultations, development and distribution of promotional materials, and attendance and participation in national economic development conferences.	Website: https://www.sba.gov/about-sba/sba-locations/headquarters-offices/office-native-american-affairs

(continued)

Organization	What They Do	Contact Info
RedWind	RedWind is a Native-operated technical assistance firm that helps transform and build strong tribal nations, enterprises, and organizations. RedWind offers a Native American Entrepreneurial Workshop.	Website: https://www.nativesmallbusiness.org/
Rehabilitation Services Administration (RSA)	RSA provides leadership and resources to assist state and other agencies in providing Vocational Rehabilitation and other services to people with disabilities to maximize their employment, independence, and integration into the community and the competitive labor market.	https://www2.ed.gov/about/offices/list/osers/rsa/index.html
Sister Sky, Inc.	Sister Sky, Inc., presents Native Business Development Empowerment Workshops under contract with the Office of Native American Affairs (ONAA). Sister Sky, Inc., is a 100 percent Native American-owned, SBA-certified 8, and an Economically Disadvantaged Woman Owned Small Business (EDWOSB).	Website: https://nativesba.sisterskyinc.com/
State Vocational Rehabilitation Offices (VR)	To find your state VR office.	State Vocational Rehabilitation Offices: https://askearn.org/age/108
Ticket-to-Work	For people aged 18–64 who receive Social Security Disability Insurance.	Ticket to Work Program https://yourtickettowork.ssa.gov/ Phone: (866) YOURTICKET; (866) 968-7842 TDD: (866) TDD2WORK; 866-833-2967
U.S. Department of Education Office of Special Education and Rehabilitative Services (OSERS)	The mission of OSERS is to improve early childhood, educational, and employment outcomes and raise expectations for all people with disabilities, their families, their communities, and the nation.	Office of Special Education and Rehabilitative Services 400 Maryland Ave., SW Washington, DC 20202-7100 Phone: 202-245-7468 Website: https://www2.ed.gov/about/offices/list/osers/index.html?src=oc

Organization	What They Do	Contact Info
U.S. Department of Justice, Civil Rights Division	To file a complaint alleging disability discrimination under the Americans with Disabilities Act.	U.S. Department of Justice Civil Rights Division 950 Pennsylvania Ave., NW 4CON, 9 th Floor Washington, DC 20530 To file a complaint by fax: 202-307-1197 ADA Specialist Phone: 800-514-0301 TTY: 800-514-0383 Guide to Disability Rights Laws website: https://www.ada.gov/cguide.htm Website: https://www.justice.gov/crt/disability-rights-section
U.S. Equal Employment Opportunity Commission (EEOC)	The office where a person can file a job discrimination complaint.	Phone: 800-669-4000 TTY/TDD: 800-669-6820 To find an EEOC Field Office: https://www.eeoc.gov/field-office
Veteran and Military Transition Center	If you are a veteran with a disability, check out Veterans ReEmployment for help with employment, training, and financial assistance.	https://www.careeronestop.org/Veterans/default.aspx

Chapter 7: Assistive Technology



“Devices make me very independent in my personal and professional life. I can verbally state text messages, and texts received are read to me. I can use verbal command to call, check missed calls, and voicemail. I also have a Note Taker with verbal reading capability, and I use it when attending meetings.”

Hoskie Benally



What Is Assistive Technology?

Assistive technology (AT) is any item, piece of equipment, software program, or product system that is used to increase, maintain, or improve the functional capabilities of persons with disabilities.

*Assistive Technology
Industry Association*

Assistive Technology Products can enable people with disabilities to accomplish daily living tasks; assist them in communication, education, work, or recreation activities;

and, in essence, help them achieve greater independence and enhance their quality of life. Assistive Technology devices can help improve physical or mental functioning, overcome a disorder or impairment, help prevent the worsening of a condition, strengthen a physical or mental weakness, and help improve a person’s capacity to learn.

Assistive Technology Services support people with disabilities or their caregivers to help them select, acquire, or use adaptive devices. Such services include functional evaluations, training on devices, product demonstration, and equipment purchasing or leasing.

Category	Types of Assistive Technology
Aids for Daily Living	<p>Self-help aids for use in activities such as eating, bathing, cooking, dressing, toileting, home maintenance, etc.</p> <p><u>Examples:</u> elongated flatware handle, shower bench, long-handled hairbrush and comb, weighted drinking glass, doorknob extension, bed rail, dressing stick, reacher, long-handled shoehorns, button hook, Velcro.</p>
Augmentative or Alternative Communication (AAC)	<p>Electronic and non-electronic devices that provide a means for expressive and receptive communication for people with limited or no speech.</p> <p><u>Examples:</u> picture exchange systems, binders of picture symbols, recorded speech devices, electronic table speech applications (software like ProLoQuo2Go), speech generating devices (also called “durable medical equipment”).</p>
Aids for the Deaf or Hard of Hearing	<p>Aids that facilitate communication between a Deaf or Hard of Hearing person and hearing people.</p> <p><u>Examples:</u> telephone handset amplifiers, hearing aids (compatible with cell phones and television), FM loop systems, infrared systems, open or closed captioning, video remote interpreting, TTYs (text telephones), visual and tactile alerting systems.</p>
Aids for the Blind or Low Vision	<p>Aids vary on need and can include service dogs, electronic mobility aids, or provide reading assistance.</p> <p><u>Examples:</u> magnifiers, Braille or speech output devices, large print screens, closed circuit television for magnifying documents, solar shield documents, wearable artificial intelligence technology that reads text, recognizes faces, and identifies products.</p>
Artificial Intelligence (AI)	<p>AI refers to smart machines or algorithms that can perform cognitive tasks usually made by humans that remove accessibility barriers through different solutions.</p> <p><u>Examples:</u> screen-readers, voice-controlled virtual personal assistants (i.e., Alexa or Siri), transcription apps, text-to-speech applications, apps that normalize speech, apps that map accessible public venues, apps that describes outdoor physical surroundings (Martinez 2021), robotic canes with 3D cameras (National Eye Institute 2021).</p>
Computer Access	<p>Input and output devices that enable people with disabilities to use a computer.</p> <p><u>Examples:</u> braille, headsticks, light pointers, modified keyboards, switches, software like speech recognition software.</p>
Environmental Control Systems	<p>Primarily electronic systems that enable someone with limited mobility to control various appliances, electronic aids, security systems, etc., in their room, home, or other surroundings.</p>
Home/Worksite Modifications	<p>Structural adaptations or fabrications in the home, worksite, or other areas that remove or reduce physical barriers for a person with a disability.</p>

Category	Types of Assistive Technology
	<u>Examples:</u> slip resistant surfaces, sloping walkways, ramps, mechanical stair lifts, grab bars, floor-to-see poles, widened doorways/spaces, walk-in tubs, audio-visual alarms, furniture adaptations, special keyboards.
Prosthetics and Orthotics	Specially fabricated medical supportive devices that fit the patient. They relieve pain and replace, substitute, or augment missing or malfunctioning body parts. There are also prosthetics to assist with cognitive limitations or deficits, including audiotapes or pagers (that function as prompts or reminders). <u>Examples:</u> Artificial limbs splints, braces, gait plates, casts, night bars and heel/arch support.
Seating and Positioning	Equipment that enables a functional seating position to reduce or eliminate the need for human assistance and fatigue. Accommodations to a wheelchair or other seating system to provide greater body stability, trunk/ head support and an upright posture, and reduction of pressure on the skin surface. <u>Examples:</u> Lumbar cushions, contour seats, footrest, standing desk, Trip Trapp chair (grows with the child).
Service Animals	The Americans with Disabilities Act defines a service animal as any guide dog (for people who are blind or have low vision), signal dog (for people who are Deaf or Hard of Hearing), or other animals individually trained to aid a person with a disability.
Wheelchairs/Mobility Aids	Manual and electric wheelchairs, mobile bases for custom chairs, walkers, three-wheel scooters, and other utility vehicles for increasing personal mobility. <u>Examples:</u> Wheelchairs, scooters, power chairs, walkers, canes, crutches.
Vehicle Modifications	Adaptive driving aids, hand controls, wheelchair lifts, modified vans, or other motor vehicles used for personal transportation.

How Do You Choose the Right Assistive Technology?

Most often, the right technology choice is made by the disabled person (or family member) and a team of professionals or consultants trained to match assistive technologies to an individual's specific needs.

An AT team may include family doctors, regular and special education teachers, speech-language pathologists, rehabilitation

engineers, occupational therapists, physical therapists, and other specialists including consulting representatives from companies that manufacture assistive technology (Assistive Technology Industry Association).

Who Pays for Assistive Technology?

Who pays for AT depends on the technology, the use, and the user? Many kinds of AT may cost

What to Ask About Assistive Technology

1. Does this tool address your specific needs and challenges?
2. Does it use your strengths?
3. Is there a simpler tool that would work as effectively?
4. Will it be easy to incorporate into everyday life?
5. Is it portable?
6. Are you willing to use it?
7. How easy is it to learn to use the tool?
8. Will you have support or training in how it works?
9. Will people who support you receive support or training in how it works?
10. Is the tool compatible with the existing technology you use? (For example, will the software work on your mobile device or computer?)
11. How reliable is the device?
12. What technical support is available?
13. For school-aged children, is the tool purchased for school use only, or does your child have access to a comparable tool at home?

Morin

little or nothing, even for very expensive items.
For example:

- School systems pay for special education learning materials as well as technology specified in an Individualized Education Program (IEP).
- Government programs (Social Security, Veterans Affairs, Medicare, or state Medicaid or Worker's Compensation agencies) pay for certain assistive technology if a doctor prescribes it as a necessary medical device.
- Private health insurance pays for certain assistive technology if a doctor prescribes it as a necessary medical or rehabilitative device.
- Rehabilitation and job training programs, whether funded by government or private agencies, may pay for assistive technology and training to help people get and retain jobs.
 - Client Assistance Programs (CAP): Most states have a CAP to advise and inform clients/consumers of all available services and benefits under the Rehabilitation Act of 1973.

- Employers may pay for assistive technology that is a reasonable accommodation to enable an employee to perform essential job tasks (Assistive Technology Industry Association).
- Many State AT Programs provide adaptive telecommunications equipment for Deaf and Hard of Hearing people and others who need adaptive equipment for telecommunications (ADA National Network).

If you are unsure how to get support for the purchase of AT, start with the tribal, state, or federal agency that you are already working with. If you're not working with an agency, go to your state's Assistive Technology Program.

Assistive Technology Alternative Financing Program

The AT Alternative Financing Program (AFP) is an annual competitive grant opportunity offered by the Administration for Community Living. Entities that can apply are state governments, public institutions of higher education, federally recognized tribal organizations, AI/AN tribal governments, and nonprofits. The purpose of the grants is to assist people with disabilities of any age to obtain financial assistance for AT devices and services. Approximately six organizations

Important requirement

Funding sources often *require a statement of medical necessity* for the product or equipment and a prescription from a doctor or other health professional.

are awarded grants each year. Types of AT purchased through AFP:

- Modified vehicles
- Home modifications
- Hearing aids
- Vision aids
- Adapted computers (RESNA)

State Assistive Technology Programs

State AT Programs promote awareness of and access to AT devices and services to people with disabilities for their entire life span. Services are also provided to families or guardians, service providers, other agencies/entities who provide services such as education and employment, and to people with disabilities.

Statewide Assistive Technology Programs offer:

- Information about what devices and services are available and where to obtain them
- Device loan and demonstration, and in some states, borrowing programs to "try out" devices
- Funding resources for purchasing or acquiring assistive technology
- Device exchange and recycling programs (also called reutilization) that provide people with used equipment at little to no cost (RESNA)

Directory of state AT Programs: <https://at3center.net/state-at-programs/>

State Protection and Advocacy Programs (P&A)

The Assistive Technology Act of 1998 provides protection and advocacy services to people of all ages with disabilities in the acquisition, utilization, or maintenance of assistive technology services or devices.

P&As provide information, advocacy, representation, training, technical assistance, and general guidance to increase access to and

provision of assistive technology devices and services.

P&As also provide [legal support](#) to traditionally unserved or underserved populations to help them navigate the legal system to achieve resolution and encourage systems change (Administration for Community Living).

Directory of state P&As: <https://acl.gov/programs/aging-and-disability-networks/state-protection-advocacy-systems>.

Assistive Technology Resources

Who	What	Website or Contact Info
Able Eyes	Able Eyes is a tool that provides virtual walk-through tours of public spaces so people with disabilities can explore accessibility before visiting the space.	https://www.ableeyes.org/
Administration for Community Living	State Protection & Advocacy Systems To find the state directory, scroll down the page to the heading "P&A Programs" In the menu, click on the plus sign next to "Find your P&A Agency"	State Directory: https://acl.gov/programs/aging-and-disability-networks/state-protection-advocacy-systems .
American Indian Vocational Rehabilitation Training and Technical Assistance Center (AIVRTTAC)	AIVRTTAC provides education, guidance, and technical assistance (TA) to American Indian Vocational Rehabilitation Services (AIVRS) Programs On the website are webinars, toolkits, products and tools, and publications.	American Indian VR Training and TA Center PO Box 5630 Flagstaff, AZ 86011-5630 https://aivrttac.org/ Phone: 928-523-5590 Fax: 928-523-9127 Email: aivrttac@nau.edu Co-Project Directors: Lee.gaseoma@nau.edu Wayne.dagel@nau.edu

Who	What	Website or Contact Info
AT3 Center (Assistive Technology Act Technical Assistance and Training Center)	<p>AT3 Center helps increase access to acquisition of AT for people with disabilities across the lifespan.</p> <p>Directory of each State’s AT contact info for:</p> <ul style="list-style-type: none"> ▪ State AT Program ▪ Device loan ▪ Device demo ▪ Device reutilization ▪ Financial loan 	<p>https://at3center.net/</p> <p>State Directory: https://at3center.net/state-at-programs/</p>
The Assistive Technology Network	<p>The Assistive Tech Network’s Community of Practice connects people with disabilities and older adults, AT providers and social service case managers, and AT industry representatives through an innovated social media platform.</p>	<p>https://cidi.gatech.edu/research/assistive-technology/tech-network</p>
Assistive Technology Industry Association	<p>ATIA is a membership organization of AT manufacturers and sellers. It educates the public and conducts research on AT.</p> <p>It hosts webinars for teachers and practitioners.</p>	<p>https://www.atia.org/</p> <p>Assistive Technology Industry Association (ATIA) 330 N. Wabash Ave., Ste 2000 Chicago, IL 60611-4267 Toll-Free: 877-OUR-ATIA (1-877-687-2842) Phone: 312-321-5172 Fax: 312-673-6659 E-mail: info@ATIA.org</p>
Center for Applied Special Technology (CAST)	<p>CAST is “busting barriers” with leading-edge practices to educational design and implementation.</p>	<p>https://www.cast.org/</p> <p>CAST is an early leader in showing how assistive technology creates improved student outcomes.</p> <p>Current & Past CAST projects: https://www.cast.org/our-work/accessibility-inclusive-technology</p>
Closing the Gap	<p>Closing The Gap provides practical, up-to-date information on assistive technology products, procedures, and best practices.</p>	<p>https://www.closingthegap.com/</p>

(continued)

Who	What	Website or Contact Info
Innovations in Special Education Technology (ISET)	ISET is a division of the Council for Exceptional Children (an educator and education researcher membership organization).	https://www.isetcec.org/
Learning Disability Research Foundation (LDRF)	LDRF provides information on AT, tools, and how to incorporate AT in the classroom (digital books, text-to-speech, speech-to-text, organizational tools, and more).	https://www.ldrfa.org/assistive-technology/
Pass It On Center	A national AT Reuse program that coordinates and networks with entities involved in AT reutilization.	https://pioc.gatech.edu/pioc/
Quality Indicators for Assistive Technology Services (QIAT)	<p>QIAT is a grassroots group to promote quality indicators for AT services.</p> <p>QIAT Resource Bank</p> <ul style="list-style-type: none"> ▪ Operating guides and procedures ▪ Educator resources ▪ Tools (inclusive practices and technology) ▪ Data & service planning ▪ Tips for specific devices and software 	https://qiat.org/resources/resources-bank/
Rehabilitation Engineering and Assistive Technology Society of North America (RESNA)	<p>RESNA is a nonprofit professional membership organization.</p> <p>RESNA offers certification, continuing education, and professional development; development of assistive technology standards; research and public policy; and sponsors forums.</p>	<p>https://www.resna.org/</p> <p>RESNA offers a free online tool to find assistive technology professionals near you.</p> <p>https://www.resna.org/Certified-Professionals-Directory</p> <p>Phone: 202-367-1121</p> <p>Email: info@resna.org</p>
Technology in Early Childhood Center (TEC Center)	<p>TEC Center is a research center and professional development provider with expertise in child development and children’s digital media and technology use.</p> <p>Provides professional development to early-childhood educators.</p>	https://www.erikson.edu/professional-development/tec-center/
Trace Research and Development Center	Trace engages in research, development, tech transfer, education, policy, and advocacy.	<p>Look at the Trace web pages: projects, software and tools</p> <p>https://trace.umd.edu/</p>

Who	What	Website or Contact Info
United Cerebral Palsy	UCP connects people and families with resources and services for people with disabilities. There is also a UCP local affiliate locator online.	UCP Resource Guide https://ucp.org/resource-guide/
Veterans Affairs	Veterans Affairs Assistive Technology homepage has information on: <ul style="list-style-type: none"> ▪ AT categories ▪ Device review ▪ Resources ▪ Education ▪ Newsletters 	https://www.prosthetics.va.gov/AssistiveTechnology/index.asp
Web Accessibility Initiative (WAI)	WAI provides strategies, standards, and resources to make the Web accessible to people with disabilities.	https://www.w3.org/WAI/

Guidance and Sources of AT Grants

Who	What	Website or Contact Info
Association of Blind Citizens	The Association of Blind Citizens operates an Assistive Technology Fund to provide funds to cover 50 percent of the retail price of adaptive devices or software.	Assistive Technology Fund: https://blindcitizens.org/assistive-technology-fund/
Bureau of Indian Education	A National Assistive Technology Resource list that includes: <ul style="list-style-type: none"> ▪ National AT Resources ▪ Selected Vendors and Manufacturers ▪ National Equipment Resources/ Foundations ▪ Alternative Financing Programs by state ▪ National Funding Sources ▪ Grants for Assistive Technology 	An undated 30-page list of AT resources and grant and funding sources. https://www.bie.edu/sites/default/files/documents/idc-008209.pdf
Easter Seals	A Guide for Assistive Technology Grants	Fundraising Made Easy: A Guide for Assistive Technology Grants https://www.easterseals.com/explore-resources/living-with-disability/a-step-by-step-funding-plan.html

(continued)

Who	What	Website or Contact Info
Goodwill	Go to the Goodwill locator to find a local center. Some Goodwill Centers participate in Assistive Technology Exchange programs and can help provide AT to their consumers.	https://www.goodwill.org/locator/
Kiwanis Clubs	Their mission is to “make sure kids have what they need to be secure and successful.” Contact your local Kiwanis Club to see if they can help provide assistive technology to a child in need.	Kiwanis Club locator https://www.kiwanis.org/clubs
Knights of Columbus	Global Wheelchair Mission partners with the American Wheelchair Mission to donate wheelchairs.	Global Wheelchair guide sheet. https://www.kofc.org/en/resources/faith-in-action-programs/community/global-wheelchair-mission/10619-wheelchair-guidesheet.pdf
Lion’s Club	The Lion’s Club accepts donations of eyeglasses and hearing aids and recycles them to give to those in need. They also provide medical care and education to combat vision impairment, blindness, and hearing loss. Children’s vision screenings	https://www.lionsclubs.org/en Eyeglasses and hearing aids recycling: https://www.lionsclubs.org/en/explore-our-clubs/eyeglasses-and-hearing-aids-recycling Local Lions Club locator: https://www.lionsclubs.org/en/start-our-approach/club-locator
Multiple Sclerosis Foundation	The MS Foundation’s Assistive Technology Program can help locate, partially fund, or provide full funding for one of a wide range of AT devices.	To learn about the AT Program and access an application: https://msfocus.org/Get-Help/MSF-Programs-Grants/Assistive-Technology-Program
Muscular Dystrophy Association	The Muscular Dystrophy Association provides equipment assistance.	https://www.mda.org/care/resource-list/equipment-assistance Equipment Assistance 1-833-275-6321 (1-833-ASK-MDA1) Email: ResourceCenter@mdausa.org
United Cerebral Palsy Bellows Fund	UCP Bellows Fund provides funds to people with disabilities for assistive technology equipment.	UCP Bellows Fund Grant information https://ucp.org/affiliatepages/bellows-fund/ UCP Resource Guide https://ucp.org/resource-guide/

Chapter 8: Transportation



“A lot of Native communities are rural and not around big cities. So just getting to the places off the reservation to get those services is an arduous process. Transportation is key to independence.”

Mateo TreeTop



Background

Many tribes, located in rural areas with a small population base, lack funding resources to maintain existing roads and address new improvements. Tribal communities need improvements to roads, bridges, highways to adequately connect their communities to other communities, thereby enhancing the opportunity for economic, educational, social, cultural, and community developments. As new economic and community development ventures expand in tribal communities, transportation is becoming a major

planning component for land use, mobility, and accessibility.

San Diego Association of Governments and Southern California Tribal Chairmen’s Association 2018

The spectrum of transportation needs and barriers in Indian Country is as diverse as the land itself. Among the 574 federally recognized tribes, the size, climate, and infrastructure of tribal lands vary, from the urban-centered Oneida Nation in Green Bay, Wisconsin, to the rural-based Cook-Inlet Tribe in the greater Anchorage area of Alaska. Services range from the

dedicated community health care workers who provide transportation services for the Yakama Nation in Washington State to the dispatch-operated fleet of fully accessible vans operated by the Pueblo of the Zuni in New Mexico.

Transportation for tribal members with disabilities living on tribal lands is complicated by the high cost and in some cases physical impossibility of owning, adapting, insuring, and maintaining vehicles for personal use. Without access to a reliable tribal public transportation system, these people must rely on friends and family to meet their health, medical, employment, social, and household needs or go without. An individual's level of independence is often determined to a great extent by community resources, or lack of them, more than by their own physical capabilities.

Barriers to Service

- Remoteness and isolation (distance to services)
- Limited public transportation services
- Lack of accessibility (e.g., roads, providers, accommodations)
- Economic hardship in private transportation ownership (no money for car, insurance, maintenance, other transportation)
- Driver's license (limited drivers, suspension, inaccessibility)
- Limited public transportation operation hours and service area (no evening or weekend transportation)

Assessing Service Needs

The first step to building a strong framework for services for people with disabilities is to know which services are currently available and which are not. The seven questions that follow were developed by AIDTAC to begin this assessment process. Use the questions in a talking circle or group format to bring together community members with diverse perspectives and to come to a full understanding of the spectrum of needs within your specific community. From these shared experiences, new understandings and wisdom may grow to move the process forward.

Transportation Glossary

This transportation glossary will assist you in navigating resources in order to grow and develop your existing transportation framework. A complete glossary can be found on the Small Urban and Rural Center on Mobility website: <https://www.ugpti.org/surcom/resources/transportation-glossary.php?viewAll=1>

Accessibility

The extent to which facilities, including transit vehicles, are barrier-free and can be used by people who have disabilities, including wheelchair users. Accessibility also includes how the transit service is accessed (e.g., access to schedules, dispatch, reservations, and other service information).

Complementary Paratransit Service

A transportation service required by the Americans with Disabilities Act (ADA) of 1990 for those persons with disabilities and others not able to use fixed-route service. Generally, it must operate in the same areas and during the same

Assessing Service Needs

1. What transportation services are available on your reservation?
2. Are people with disabilities able to use these transportation services?
3. What is your tribe doing to make sure that people with disabilities have adequate transportation?
4. What are the cultural or traditional issues that should be addressed as barriers to transportation for people with disabilities?
5. What are the major barriers to making transportation on your reservation accessible to people with disabilities?
6. What resources does your tribe need to overcome these barriers?
7. What guidelines do you suggest for removing transportation barriers on your reservation?

(AIDTAC 10-11)

hours as available fixed-route transportation. The fare is limited to twice the fixed-route fare. Complementary paratransit service may be operated by the fixed-route bus agency or by a completely separate agency. (Note: This is not the same as general paratransit service.)

Coordination

Coordination is a cooperative arrangement between transportation providers and organizations needing transportation services. Coordination models can range in scope from shared use of facilities, training, or maintenance to integrated brokerages or consolidated transportation service providers. The Federal Transit Administration defines transportation coordination as

. . . a process through which representatives of different agencies and client

groups work together to achieve any one or all of the following goals: more cost-effective service delivery; increased capacity to serve unmet needs; improved quality of service; and services which are more easily understood and accessed by riders. Coordination includes joint decision and actions of a group of agencies with formal arrangements to provide for the management of the resources of a distinct system.

Curb-to-Curb Service

A common designation for paratransit services. The transit vehicle picks up and discharges passengers at the curb or driveway in front of their home or destination. In curb-to-curb service, the driver does not assist the passenger along walks or steps to the door of the home or other

destination. The driver does assist the passenger off and on the bus, as needed.

Demand-Response Service

Non-fixed-route service utilizing vans or buses with passengers boarding and alighting at pre-arranged times at any location within the system's service area. Often referred to as Dial-a-Ride, this service allows individual passengers to request transportation from a specific location to another specific location at a particular time. This service may or may not mandate advanced reservations. It does not follow a particular route but travels throughout a designated service area or community, transporting passengers on a door-to-door basis, a curb-to-curb basis, or other specified service provision. The following types of operations fall under this category of transit services (as long as they are not on a scheduled fixed-route basis): many origins to many destinations; many origins to one destination; one origin to many destinations; and one origin to one destination. The vehicle typically may be dispatched to pick up several passengers at different pick-up points before taking them to their respective destinations and may even be interrupted en route to these destinations to pick up additional passengers. (See Paratransit.)

Deviated Fixed Route

Transportation service on a non-exclusive basis which operates along a public way on a standard route at generally fixed times, from which it may deviate in response to a demand for its service or to take a passenger to a destination, after which it returns to its standard route.

Door-to-Door Services

A form of paratransit service which includes passenger assistance between the vehicle and outside door of a person's home or other destination. This is a higher level of service than curb-to-curb, yet not as specialized as door-through-door service.

Fixed Route

Transit services where vehicles run on regular, repetitive, pre-designated, pre-scheduled routes, with no deviation, stopping to pick up and deliver passengers at specific, identified locations. Each fixed-route trip serves the same origins and destinations. Typically, fixed-route service is characterized by printed schedules or timetables, designated bus stops where passengers board and alight, and the use of larger transit vehicles (although the size of the vehicles would be dependent on the number of passengers utilizing the system).

Guaranteed Ride Home

Program that encourages employees to carpool, use transit, bike, or walk to work by guaranteeing them a ride home in case they cannot take the same mode home (e.g., if they need to work late or if an emergency occurs).

Medicaid

Also known as Medical Assistance, this is a health care program for low-income and other "medically needy" persons. It is jointly funded by state and Federal Governments. The Medicaid program pays for transportation to non-emergency medical appointments if the recipient has no other means to travel to the appointment.

Paratransit

Wheelchair-accessible, demand-response transportation service. It can also describe subscription bus services, shared-ride taxis, carpooling and vanpooling. It is much more flexible than conventional fixed-route transit but generally requires reservations or calling for a specific ride. General paratransit service is not required by law and is not subject to the restrictions imposed on complementary paratransit service. The transit agency may limit the service to certain people, or it may be made available to anyone.

Ride Sharing

A form of transportation other than public transit, in which more than one individual shares in the use of a vehicle, such as a van or a car, to make a trip.

Ridesharing Program

A ridesharing program facilitates the formation of carpools and vanpools, usually for work trips. A database is maintained for the ride times, origins, destinations, and driver/rider preferences of users and potential users. Those requesting to join an existing pool or looking for riders are matched by program staff with other appropriate persons. In rural areas, a rideshare program is often used to coordinate Medicaid or volunteer transportation.

Service Route

A hybrid type of transportation between fixed-route and demand-response service. Service routes are established between targeted neighborhoods and service areas riders want to reach. Like deviated fixed routes, service routes are characterized by flexibility and deviation from

fixed-route intervals. However, while deviated fixed routes require advanced reservations, service routes do not. A service route can include both regular, predetermined bus stops and/or allow riders to hail the vehicle and request a drop-off anywhere along the route.

Technical Assistance

Non-financial support to help accomplish program goals, such as hands-on assistance provided to a transit system for the purposes of problem solving, planning, development, expansion, training, consulting, research, or evaluation.

User-Side Subsidy

A type of transit system whereby the passenger purchases tokens or vouchers at designated sale sites and presents the token to a service provider (e.g., taxi company) in exchange for a trip. The price of the token or pass is less than the cost of the trip. The token is then subsidized with federal, state, or local funds, and the taxi operator is reimbursed for the cost of the trip.

Vanpool

A ridesharing service to and from pre-arranged destinations in which a number of people travel together on a regular basis in a van which is designed to carry 7 to 15 passengers (including the driver). Vanpool service operates primarily from rural and outer suburban areas into urban area central business districts or suburban employment centers. Vanpools are typically developed under one of three models: they may be individually owned or leased (owner-operator), employer-operated, or publicly operated (third-party program). A publicly operated, third-party vanpool operation is usually one run by state or

local transit authorities, metropolitan planning organizations, local transportation management associations, or nonprofit transportation entities that are funded under state Departments of Transportation. Vanpools must be in compliance with public transit rules including the Americans with Disabilities Act, be open to the public, and have its availability be made known. The definition of vanpool does not include ridesharing coordination.

Model Approaches

Several tribes have tapped into a variety of state and federal funding sources to provide transportation systems that are fully accessible to people with disabilities and link passengers to employment centers and health and human services programs.

San Carlos Apache Tribe Reservation

Free or Donation-Based Transit for Older Adults and People with Disabilities

The San Carlos Apache Tribe's (SCAT) Reservation in southeastern Arizona sits between the towns of Globe and Safford and in the counties of Graham, Pinal, and Gila and spans 1.8 million acres. The Apache Tribe maintains over 2,400 miles of road ranging from state highway 70, BIA roads, county roads, and tribal roads.

Reservation residents use transit for shopping, commuting, medical purposes, and for family or other personal needs. Residents who are aging, have disabilities, are low-income, or TANF recipients use transit to attend social activities, appointments, and educational and workforce opportunities. For families, children can be transported to childcare facilities if accompanied by a responsible adult.

A past survey identified over 3,000 elders registered with the San Carlos Apache Tribe, and the transit program has dedicated transit staff who works in collaboration with the Older Adult Center. The Transit program allows older adults to ride based on a donation, and many older adults and people with disabilities ride for free.

Challenge: The San Carlos Apache tribe recognized a need within their community for reliable, affordable public transportation as essential to access family, medical, employment, and educational opportunities. Many of the older adults and residents with disabilities were dependent on friends and relatives to provide transportation for their basic needs, thus limiting their independence.

Resolution: Nnee Bich'o Nii ("Helping the People" in Apache) provides transportation services to the general public in the San Carlos Apache Reservation and neighboring cities of Globe and Safford. The mission of Nnee Bich'o Nii Transit Services is to transport all customers in a safe, professional, and courteous manner. By March 2021, Nnee Bich'o Nii Transit Services operated 17 buses on routes that run Monday through Friday with fares ranging from \$1.00 to 3.50 or on a donation basis for older adults and people with disabilities.

How it happened: The program began in 2008 by acquiring three vans from the Arizona Department of Transportation (ADOT) under the Job Access Reverse Commute (JARC) Program. In 2012, SCAT attained two public transit buses under ADOT Rural Transit Programs and the Federal Transit Administration (FTA) Tribal Transit Programs (TTP). In 2019, SCAT received funds from the TTP to purchase additional vans and to replace older vans that had exceeded their useful life (San Carlos Apache Tribe 2021).

Tips from the field

- Utilize a variety of different funding opportunities from state and Federal sources
- Respect tribal culture in structuring transit fees are structured
- Stay true to the mission of the transit system

Oklahoma: Northeast Oklahoma Tribal Transit Consortium, Cherokee Nation and Pelivan Transit

Pelivan Transit was founded in 1985, and 10 tribes in northeastern Oklahoma joined a consortium with Pelivan Transit in 2008 and 2009. A rural public transportation program (5311) was integrated with two tribal transit programs (5311c). One grant created collaboration with the Cherokee Nation, and two other grants funded the Nine Tribes of the Northeast Oklahoma Consortium, consisting of the Eastern Shawnee, Miami, Modoc, Ottawa, Peoria, Quapaw, Seneca-Cayuga, Shawnee, and Wyandotte Tribes of Oklahoma.

Pelivan Transit provides tribal transit services on behalf of the Tribes to seven counties in northeastern Oklahoma. Some of the Pelivan Transit van fleet were purchased by tribes and leased to Pelivan (Pelivan Transit).

In 2019, Pelivan Transit won the “Rural Transportation System of the Year” from the Community Transportation Association of America (CTAA). This award is given to a system which provides service in an urban area with a population of less than 50,000, and the award is based on innovative and creative services in the community,

that is responsive to its customers’ and community needs, among other criteria. (Community Transportation Association of America).

Challenge: Tribal nation members lacked access to safe, reliable, and low-cost transportation to access employment, health care, institutions of higher education, and other vital destinations.

Resolution: The Cherokee Nation Transit program began in 2008 with Ki Bois Area Transit System (KATS) to provide tribal employees and the general public with low-cost transportation to employment sources, also known as a “park-n-ride” commuter-route service, from Stilwell to Tahlequah. In 2009, Pelivan Transit came aboard to begin the Prior to Catoosa route, and since then, the program has expanded to include demand-responsive services and additional commuter-routes through Muskogee County Transit and Cimarron Public Transit (The Cherokee Nation).

Older adults who meet financial eligibility requirements receive free transportation to meal sites, doctor’s appointments, and multiple Indian Health Service clinics.

How it happened: Pelivan Transit of Oklahoma, owned and operated by Grand Gateway Economic Development Association and the Northeast Oklahoma Tribal Transit Consortium, partnered to secure funds for Federal grants. They used a variety of fundraising methods, such as service contracts with the State of Oklahoma and local municipalities, Department of Human Services Temporary Assistance for Needy Families, Medicaid non-emergency transportation, and Older Americans Act nutrition funding. Pelivan also increased revenue by selling advertising space and working with private for-profit businesses, as well as nonprofit foundations.

The tribes take turns purchasing vehicles, then lease these vehicles to Pelivan Transit, which makes all vehicles in its fleet available for Tribal Transit services in its seven-county service territory. Some of the vehicles purchased specifically for Tribal Transit purposes were funded through grants from American Recovery and Reinvestment Act of 2009 (ARRA) stimulus dollars and Section 5311c (National Aging and Disability Transportation Center).

Pelivan operates a six city and surrounding areas demand response curb-to-curb transportation program and Tribal Transit Program through area dispatch centers in cities that are situated in northeastern counties of Craig, Delaware, Mayes, Nowata, Ottawa, northern Tulsa, and Rogers. The Pelivan transit system includes numerous employment routes interconnecting area cities, a trolley loop in Miami, education routes for TANF recipients, and various medical routes for area medical facilities in the region including Indian Health Services and area hospitals (Pelivan Transit).

Arroostook Bank of Micmac Indians and Community Transportation Association of America

On January 16, 2021, I travelled to Arroostook County, Maine, where CTAA is working with the Arroostook Band of Micmac Indians. Arroostook County is the largest county by area in the State of Maine, and the largest county east of the Mississippi. Micmac tribal members live in and around Presque Isle, Maine, as well as in scattered locations throughout Arroostook County. During my visit, I met with Tammy Gagnon, Executive Director of the Arroostook Regional Transportation System (ARTS) in Presque Isle to discuss

Tips from the field

- Coordinate with transit providers, service providers, and for-profit and nonprofit organizations in your community and apply jointly for state and federal agency grants to greatly expand services.
- Conduct ongoing public forums with tribal communities to understand community needs and improve services.
- Consider integrating transportation services with other programs the transportation system supports (e.g., Vocational Rehabilitation, employment and education programs, older adult services, and disability services).

strategies for serving Micmac tribal members. Although ARTS provides demand responsive transit service in many areas of Arroostook County, very few tribal members utilize it. We are working with the tribe and ARTS to develop additional services focused on the specialized needs of tribal members and that would attract more tribal ridership. The project emerged from an earlier Tribal Transit Program planning grant from FTA. Our work there is supported through the Tribal Passenger Transportation Technical Assistance Program (Rukowski).

Sitka Tribe of Alaska Tribal Transportation and Economic Development

The Sitka Tribe of Alaska, located on Baranof Island, started tourism transportation in 1994.

Tips from the field

- Membership in a national transportation association expands access to resources including planning funds, technical assistance, and capacity building.
- Engage in coordination through on-the-ground, face-to-face collaborations to deepen understanding of community needs by local transit providers and association consultants.
- Coordination and development of close working relationships with a variety of partners uncovers solutions tribal transit systems can implement.

Twenty years later, the Center for Community, a nonprofit, provides oversight of the Sitka transportation system and has two main partners:

1. Sitka Tribe of Alaska operates RIDE (a fixed-route service)
2. Southeast Senior Services operates Care-A-Van (ADA-complementary paratransit)

Additional programs have been implemented by the Sitka Tribe and its partners including

1. Free vouchers for fixed-route service to human service agencies
2. Providing grant funding for human service agencies to purchase vehicles, which are relied upon by Sitka transit agencies.

(Tribal Transportation 2022)

With the help of the Community Transportation Association of America in 1997, the Tribe formed a community committee that included tribal organizations, businesses, schools, nonprofits, city officials, and hospitals. They discussed opening a public transportation system, and in 1999 were awarded a U.S. Department of Agriculture (USDA) technical assistant grant that enabled the Tribe to hire a consultant (Tribal Transportation 2022).

The consultant helped the committee to identify existing transportation providers and the community's needs, such as access to employment and medical care. The committee created a management plan and received funding from the Federal Transit Administration (FTA), Job Access and Reverse Commute (JARC), and USDA. Then the Sitka Tribe began operating a fixed-route service.

Tips from the field

- Join a national transportation association, which can facilitate acquisition of a federal grant and subsequently pay for a transportation consultant.
- A partnership between the tribe, community stakeholders, and a consultant can result in development of a management plan centered on economic development and the unique needs of a community.
- An oversight nonprofit, and the tribe as a significant partner, enables further funding and expansion of transportation services.

Transportation Rights of People with Disabilities

It can be confusing understanding how civil rights and disability laws apply to tribal transportation programs and federal funding sources. These explanations speak just to the Federal Transit Administration’s rules. State and private funding may have different rules.

Title VI of the Civil Rights Act of 1964, 42 U.S.C. 2000d et seq. (“Title VI”)

Title VI prohibits discrimination on the basis of race, color, or national origin in any program or activity that receives Federal funds or other Federal financial assistance.

Americans with Disabilities Act (ADA)

The ADA mandates that people with disabilities cannot be denied access to public transportation facilities and services, and that those services must be comparable to those provided to the general public.

- Vehicles operated by public and private transportation providers must be accessible
- ADA paratransit services must be provided and complement the fixed-route services for people who cannot use those fixed-route services

Summary of the Applicability of Federal Transit Administration’s (FTAs) Civil Rights Programs and ADA Compliance for Indian Tribes Receiving FTA Funds

		Program Funds Received		
		Direct recipient of <i>only</i> Tribal Transit Program (5311(c)) funds	Direct recipient of other FTA programs (Rural 5311, Bus Program or Low-no, 5339)	Subrecipient of Rural Formula (5311) funds
Civil Rights / ADA Requirements	Title VI Program	Exempt from program submission	Required	Required and must be submitted to state program for oversight
	DBE Program	Required if awarding contracts exceeding \$250,000 in FTA funds in a Federal Fiscal Year	Required if awarding contracts exceeding \$250,000 in FTA funds in a Federal Fiscal Year	Required if awarding contracts exceeding \$250,000 in FTA funds in a Federal Fiscal Year and must be submitted to state program for oversight
	EEO Program	May be required depending on transit-related staff size and other factors	May be required depending on transit-related staff size and other factors	May be required depending on transit-related staff size and must be submitted to state program for oversight
	ADA Compliance	Required (except Title I, which concerns employment discrimination)	Required	Required

(Civil Rights / ADA 2021)

- ADA paratransit services must be comparable in terms of response times, fares, geographic service area, and hours/days of service
- May not restrict the number of trips an individual can make or prioritize service based on the rider's trip purpose
- Transit providers must assure system-wide accessibility of their demand-responsive services to people with disabilities
- Regulations require only curb-to-curb service, but the grantee may provide a higher level of service (Small Urban and Rural Center on Mobility).

Title II of the ADA applies to state and local government entities and protects qualified people with disabilities from discrimination on the basis of disability in services, programs, and activities provided by state and local government entities. Tribes are NOT specifically exempt from the provision of Title II of the ADA, so the Department of Transportation's ADA regulations DO apply to Indian tribes that receive FTA funding (Civil Rights / ADA 2021).

Disadvantaged Business Enterprise Program (DBE)

The Department of Transportation (DOT) ensures nondiscrimination in the award and administration of DOT-assisted contracts in the department's highway, transit, and airport financial assistance programs. An Indian tribe receiving planning, capital and/or operating assistance exceeding \$250,000 in Federal Transit Administration (FTA) funds in a Federal Fiscal Year (excluding vehicle purchases) must meet the FTAs DBE Program requirements (FTA Civil Rights / ADA 2021).

Equal Employment Opportunity Program (EEO)

The FTAs nondiscrimination statute and supplements employment protections found in Title VII of the Civil Rights Act of 1964 and the Americans with Disabilities Act of 1990. Title VII prohibits discrimination by recipients in employment opportunities based on race, color, religion, sex, and national origin. The ADA prohibits private employers, state and local governments, employment agencies, and labor unions from discriminating against qualified people with disabilities in job application procedures, hiring, firing, advancement, compensation, job training, and other terms, conditions, and privileges of employment (Civil Rights / ADA 2021).

Even though tribes are exempt from ADA's requirements in employment, they must comply with the FTAs nondiscrimination statute if the tribal FTA recipient employs 100 or more transit-related employees and receive capital or operating assistance in excess of \$1 million or planning assistance in excess of \$250,000 in the previous Federal Fiscal Year. Indian tribes do have the authority to include Indian preference in employment on projects located on or near reservations and in any contracts or subcontracts under Tribal Transit Program grants (Civil Rights / ADA 2021).

Federal Transportation Funding

Indian County's economy depends upon transportation infrastructure. Without safe and well-maintained roads, tribes are unable to provide essential services to their citizens. Despite the approximate 11 billion miles traveled on the Tribal Transportation Program system

annually, more than 60 percent of the system is unpaved (Indian Country Today 2021).

Coordinated Transportation

Coordinated transportation involves multiple entities working together to deliver one or more components of a transportation service so they can increase their capacity to provide trips. Coordination activities can include:

- Sharing passenger trips and vehicles
- Joint hiring of mobility manager(s)
- Collaborating on plans, grant applications, vehicle purchasing, or maintenance
- Federal fund braiding
- Co-location of facilities, programs, or services (Transportation Trends 2018)

Federal transportation funds are allocated to the states based on total population, which includes American Indians and Alaska Natives. Developing transportation on tribal lands and Indian reservations involves considerable communications between the tribe and the state Department of Transportation (DOT), local city

governments, and possibly other non-tribal transit providers (Tribal Transportation 2022).

The primary tribal transportation funder is the Federal Transit Administration’s (FTA) Tribal Transit Program (TTP). The TTP was established in 1996 under Section 5311 of the Safe, Accountable, Flexible, Efficient Transportation Equity Act: A Legacy for Users (SAFETEA-LU) and in 2021 was reauthorized in the 2021 Bipartisan Infrastructure Law, or Public Law 117-58. Only Federally recognized tribes are eligible under the Tribal Transit Program and include:

1. Section 5311—Formula Grants for Rural Areas
2. Section 5311(c)(1)(B)—Tribal Transit Formula Grant
3. Section 5310—Enhanced Mobility of Seniors & People with Disabilities
4. Section 5307—Urbanized Area Formula grants
5. Section 5311(j)—Federally recognized tribes providing public transportation on tribal Lands

The Bipartisan Infrastructure Bill Allocations for Federally Recognized Tribes:

Bipartisan Infrastructure Bill		
▪ Tribal Transportation Program	\$	2,966,800,000
▪ Tribal Transportation Facility Bridges (Formula)	\$	825,000,000
▪ Nationally Significant Federal Lands and tribal Projects	\$	275,000,000
▪ Tribal Transportation Facility Bridge (Set-aside)	\$	200,000,000
▪ Tribal High Priority Projects Program	\$	45,000,000
▪ Public Transportation on Indian Reservations (Formula)	\$	183,250,437
▪ Public Transportation on Indian Reservations (Competitive)	\$	45,812,610
Total	\$	1,348,195,863,047

Tribes not federally recognized remain eligible to apply to the state as subrecipients under their state’s apportionment for 5310, 5311, or 5307 funding. Additional FTA funding is available through competitive grants and are announced through notices of funding opportunities (NOFO) at various times throughout the year (Tribal Transportation 2022).

Other Bipartisan Infrastructure Programs Federally Recognized Tribes Are Eligible For Bipartisan Infrastructure Law

Surface Transportation Block Grant	\$72,000,000,000
Enhanced Mobility of Seniors and People with Disabilities	\$2,193,105,343
All Stations Accessibility Program	\$1,750,000,000

The Bipartisan Infrastructure Law includes many more transportation programs that tribes may direct funding for or through the state, such as ferry service for rural communities, bus and bus facilities, railway grants, railroad crossings, highway safety, and more (Building a Better America 2022).

The Bipartisan Infrastructure Bill funded Tribal Transit Program much more than the \$11 billion requested in a 2021 letter by the Congress of American Indians representing 580 AI/AN organizations to the U.S. House of Representatives and U.S. Senate (Infrastructure Legislative proposal).

For comparison purposes, recent funding of the Tribal Transportation Program was as follows:

FY 2016	FY 2017	FY 2018	FY 2019
\$ 465,000,000	\$ 475,000,000	\$ 485,000,000	\$ 495,000,000

Other Sources of Tribal Transportation Funding

Older Americans Act

First passed in 1965, this federal law established a network of services and programs for people who are older that includes transportation and nutrition services and works with public and private agencies that serve the needs of people who are older. The law was reauthorized for FY 2020 through FY 2024 and was renamed the Supporting Older Americans Act of 2020 (Administration for Community Living).

Social Security Act, Title XIX

Established the Medicaid program to provide medical and health related services. It describes the eligibility determination and transportation services offered by Medicaid programs for people with disabilities and older adults with low income, including non-emergency transportation to medical care. Medicaid is administered by each state and provides direct payment to suppliers of services.

Vocational Rehabilitation

The Code of Federal Regulations (C.F.R.) on American Indian Vocational Rehabilitation Services is similar, if not exactly the same, as the C.F.R. for state Vocational Rehabilitation programs. Transportation is defined as any travel and related expenses that are necessary to enable an applicant or eligible individual to participate in a Vocational Rehabilitation

service, including expenses for training in the use of public transportation vehicles and systems. Transportation services are described in an individualized plan for employment and in connection with the provision of any Vocational Rehabilitation service.

Support is also given to entities, such as transportation authorities, designated by the Tribal Vocational Rehabilitation unit to provide services that benefits groups of people with disabilities (34 C.F.R. 2022).

Veterans Administration's (VA) Veteran Transportation Program

VAs Veterans Transportation Program (VTP) offers Veterans many travel solutions to and from their VA health care facilities. This program offers three services at little or no costs to eligible Veterans.

1. Veteran Transportation Service Locations

VTS provides qualifying Veterans with free transportation services to and/or from participating VA medical centers (VAMCs) in a multi-passenger van. If qualifying Veterans do not have access to transportation options of their own, due to financial, medical, or other reasons travel is provided to VA medical facilities or authorized non-VA appointments. VTS also partners with service providers in local communities to serve Veterans' transportation needs. Partners include:

- Local and national nonprofit groups
- Federal, state, and local transportation services

To find Veteran Transportation Services, click on your state to see a listing of VTS sites and Points of Contact in your area. <https://www.va.gov/healthbenefits/vtp/map.asp>

2. Beneficiary Travel

The VA pays a reimbursement for round-trip mileage and other travel expenses to and from approved health care appointments. The application information can be completed orally or in writing and submitted to the Business office or other designee at the VA medical facility responsible for the medical care or services for which travel is required (Vocational Rehabilitation Services).

3. Highly Rural Transportation Grants

This funding is inactive as it expired in July 2020. However, legislation was introduced in 2021 to permanently extend the authority of the Department of Veterans Affairs to make grants for the transportation of highly rural veterans to health care facilities (H.R.3802).

Head Start Transportation

Head Start grants are awarded to public or private nonprofit organizations, including community-based and faith-based organizations and for-profit agencies. Annual discretionary grants are available through the U.S. Department of Health and Human Services (DHHS) Office of Head Start. Grant opportunities are posted on the U.S. Administration for Children and Families (ACF) website and on <http://grants.gov/>.

The funding landscape is continually changing, so tribes and their partners are encouraged to research grant opportunities and learn about state

and local programs that pay for (or reimburse) transportation services for older adults and people with disabilities. Some agencies worth investigating are:

- U.S. Department of Agriculture (USDA) Rural Development

- Administration on Aging
- Center for Independent Living
- Medicaid
- Administration for Native Americans
- Others (see Resources in this chapter)

Resources

Organization	What They Do	Contact Info
Access Board	The Access Board maintains accessibility requirements for the built environment, transit vehicles, telecommunications equipment, and electronic and information technology, providing technical assistance and training on these guidelines and standards and enforcing accessibility standards for federally funded facilities.	The Access Board Office of Compliance and Enforcement 1331 F St NW, Suite 1000 Washington, DC 20004-1111 Email: enforce@access-board.gov Fax: 202-272-0081 Phone: 202-272-0080 Toll free: 800-872-2253 Phone (TTY): 202-272-008 TTY Toll free: 800-993-2822 Online form: https://www.access-board.gov
Administration for Native Americans Office of the Administration for Children & Families	The ANA provides financial assistance and capacity building, gathers and shares data, and advocates for improved policies within Health and Human Services and across the Federal Government.	https://www.acf.hhs.gov/ana ANA funding opportunities: https://www.acf.hhs.gov/ana/grants/funding-opportunities
Administration for Community Living Administration on Aging	The ACL provides funds under the Older Americans Act to provide funds to meet the needs of American Indian elders, including nutrition, information, referrals, and transportation services.	https://acl.gov/about-acl/administration-aging Administration for Community Living 330 C St. SW Washington, DC 20201 Phone: 202-401-4634 To find elder care local resources: 800-677-1116

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Organization	What They Do	Contact Info
American Public Transit Association APTA	A nonprofit international membership association that provides advocacy, technical expertise, consulting services, workforce development programs, conferences, seminars, and hosts 135 subject-matter working committees.	APTA 1300 I Street NW Suite 1200 East Washington, DC 20005 Phone: 202-496-4800 Fax: 202-496-4324 https://www.apta.com/research-technical-resources/public-transportation-links/
Center for Tribal Transportation	The Center for Tribal Transportation provides training, technical assistance, and mentoring to Alaska Native and Native American Transportation Departments	Center for Tribal Transportation 1191 E. White Mountain Blvd. Gilbert, AZ, AZ 85296 Phone: 602-910-8367 Email: becky@tribaltrans.com Website: https://tribaltrans.com/ Facebook page: https://www.facebook.com/theect/
Community Transportation Association of America (CTAA) Tribal Technical Assistance Program	CTAA has a huge website with a lot of information and resources. The program is designed to help Native American tribes enhance economic growth and development by improving transportation services. Technical assistance is limited to planning and may support transit service improvements and expansion, system start-up, facility development, development of marketing plans and materials, transportation coordination, training and other public transit problem-solving activities.	Website: https://ctaa.org/ Tribal Passenger Transportation Technical Assistance Program: https://ctaa.org/rural-tribal-passenger-transportation-technical-assistance/ CTAA -Tribal Technical Assistance Program 1341 G St. NW, 10th Floor Washington, DC 20005 Tel: 1-800-891-0590 Fax: 202-737-9197 Charles Rutkowski x719 or Kelly Shawn x718

Organization	What They Do	Contact Info
Easterseals, Inc	Easterseals Project Action Consulting Provides training on <ul style="list-style-type: none"> ▪ ADA transportation requirements ▪ Transit management training ▪ Paratransit management certification and instruction 	1101 Vermont Ave NW, Ste 510 Washington, D.C. 20005 Toll-free: 844-227-3772 Office: 202-347-3066 TTY: 202-347-7385 Email: espaconsulting@easterseals.com Website: https://www.projectaction.com/
FTA Enhanced Mobility of Seniors & Individuals with Disabilities—Section 5310	Enhanced Mobility of Seniors & Individuals with Disabilities—Section 5310	https://www.transit.dot.gov/funding/grants/enhanced-mobility-seniors-individuals-disabilities-section-5310
FTA Formula Grants for Rural Areas—5311	Formula Grants for Rural Areas—5311 provides capital, planning, and operating assistance to states to support public transportation in rural areas with populations of less than 50,000, where many residents often rely on public transit to reach their destinations. The program also provides funding for state and national training and technical assistance through the Rural Transportation Assistance Program.	https://www.transit.dot.gov/rural-formula-grants-5311
FTA Grants Programs	Competitive and Formula Grants are listed	https://www.transit.dot.gov/grants
FTA Notice of Funding Opportunity (NOFO) <ul style="list-style-type: none"> ▪ Low or No Emission and Grants Buses and Bus Facilities Competitive Programs	Low or No Emission and Grants for Buses and Bus Facilities Competitive Programs FY2022	https://www.transit.dot.gov/notices-funding/low-or-no-emission-and-grants-buses-and-bus-facilities-competitive-programs-fy2022 Website: https://www.transit.dot.gov/bus-program

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Organization	What They Do	Contact Info
FTA Notice of Funding Opportunity (NOFO) Tribal Transit Competitive program	Tribal Transit Competitive program FY2022, Notice of Funding Opportunity	https://www.transit.dot.gov/notices-funding/public-transportation-indian-reservations-program-fy-2022-notice-funding
FTA Public Transportation on Indian Reservations: Tribal Transit Competitive Program	On February 22, 2022, the FTA announced the availability of \$8.75 million in Fiscal Year 2022 competitive grant funding to support transit services for American Indian and Alaska Native tribes in rural areas.	https://www.transit.dot.gov/tribal-transit Webinar dated March 24, 2022. Links on the above website to the recording, presentation, and transcript.
FTA Regional Tribal Offices and Liaisons	Region 1 (CT, MA, ME, NH, RI, VT) Region 2 (NY, NJ) Region 3 (DE, DC, MD, PA, VA, WV) Region 4 (AL, FL, GA, KY, MS, NC, SC, TN, Puerto Rico, U.S. Virgin Islands) Region 5 (IL, IN, MN, MI, OH, WI) Region 6 (AR, LA, NM, OK, TX) Region 7 (IA, KS, MO, NE) Region 8 (CO, MT ND, SD, UT, WY) Region 9 (AZ, CA, HI, NV, American Samoa, Guam, Mariana Islands) Region 10 (AK, WA, ID, OR)	Addresses and phone numbers of the regional offices: https://www.transit.dot.gov/about/regional-offices/regional-offices FTAs Regional Tribal Liaisons https://www.transit.dot.gov/funding/grants/federal-transit-administrations-regional-tribal-liaisons
FTA Coordination Council on Access and Mobility (CCAM) Transportation Coordination Guidance And Access and Mobility Federal Fund Braiding Guide	The CCAM promotes activities to coordinate the efforts of 80 federal agencies that fund transportation services for older adults, people with disabilities, and people of low income. Coordinated transportation involves multiple entities working together to deliver one or more components of transportation services to increase capacity and provide more trips.s	https://www.transit.dot.gov/coordinating-council-access-and-mobility https://www.transit.dot.gov/ccam/about/transportation-coordination Guide from the Coordinating Council on Access and Mobility Federal Fund Braiding https://www.transit.dot.gov/sites/fta.dot.gov/files/2021-04/ccam-federal-fund-braiding-guide-june-2020.pdf

Organization	What They Do	Contact Info
FTA Transit Workforce Development Technical Assistance Center (TWC)	The TWC supports public transit agencies' workforce development needs for all modes of public transit across urban, tribal, and rural entities.	Workforce Development Initiative https://www.transit.dot.gov/research-innovation/workforce-development-initiative
FTA Transportation Technical Assistance Coordination Library (TACL)	The TACL provides a sustainable methodology and platform for access and findability of rural and tribal transit coordination resources across a diverse range of transportation technical assistance centers and the FTA. <ul style="list-style-type: none"> ▪ NADTC ▪ N-CATT ▪ NCMM ▪ National RTAP ▪ SUMC ▪ TWC 	TACL website: https://transportation-tacl.org/ National Aging and Disability Transportation Center (NADTC): https://www.nadtc.org/coordination/
FTA Tribal Transit Program Formula Grants 5311(c)(1)(B)	The Public Transportation on Indian Reservations Program (Tribal Transit Program) for Fiscal Years (FY) 2022-2026. Five percent of Rural Formula (Section 5311) funding is available for the Public Transportation on Indian Reservations program. 20 percent of the Public Transportation on Indian Reservations funds must be distributed on a competitive basis, while the remainder must be apportioned by formula. There is no local match required under the formula program.	https://www.transit.dot.gov/funding/grants/tribal-transit-formula-grants-5311c1b
FTA Urbanized Area Formula Grants 5307	Urbanized Area Formula Grants 5307	https://www.transit.dot.gov/funding/grants/urbanized-area-formula-grants-5307
National Aging and Disability Transportation Center (NADTC)	The NADTC promotes the availability and accessibility of transportation options that meet the needs of older adults and people with disabilities and caregivers.	Website: https://www.nadtc.org/ Phone: 866-983-3222 Blog about Section 5307, 5310, and 5311: Using Non-OT Federal Funds for Local Match: https://www.nadtc.org/news/blog/section-5307-5310-and-5311-using-non-dot-funds-for-local-match/

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Organization	What They Do	Contact Info
National Center for Applied Transit Technology (N-CATT)	The N-CATT provides small urban, rural, and tribal transit agencies with practical resources for replicable technological solutions and innovations.	https://n-catt.org/ Phone: 888-891-0590
National Center for Mobility Management (NCMM)	The NCMM operates in a consortium with The American Public Transportation Association, The Community Transportation Association of America, and Easterseals Inc. NCMM promotes customer-centered mobility strategies that advance good health, economic vitality, self-sufficiency, and community.	https://nationalcenterformobilitymanagement.org/
National Rural Transit Assistance Program	National RTAP creates rural and tribal transit solutions through technical assistance, collaboration, and free training and transit industry materials.	https://www.nationalrtap.org/ Phone: 888-589-6821
National Transit Database (NTD) of the Federal Transit Administration	The NTD is used to apportion funding for transportation grants. Tribes enter data at least annually into the database.	https://www.transit.dot.gov/ntd Email: NTDhelp@dot.gov Phone: 877-561-7466 (IT Support only) Business Hours: 8:00am–7:00pm ET, M–F
National Transit Institute (NTI)	The NTI is located at Rutgers University and provides training, education, and clearinghouse services to enhance skills and performance in public transportation	NTI 120 Albany Street Tower Two, Suite 250 New Brunswick, NJ 08901-2163 https://www.ntionline.com/
Shared-Use Mobility Center (SUMC)	The SUMC connects public and private sectors, pilots programs, and provides technical expertise so all people share in equitable, affordable, and environmentally sound mobility across the U.S.	https://sharedusemobilitycenter.org/
Transportation Research Board (TRB)	The TRB provides leadership in transportation improvements and innovation based on research and evidence-based practices.	Transportation Research Board (TRB) 2001 500 Fifth St., N.W. Washington, D.C. 20001 Tel: 202-334-2934 Email: mytrb@nas.edu Website: https://www.nationalacademies.org/trb/transportation-research-board

Organization	What They Do	Contact Info
U.S. Department of the Interior Bureau of Indian Affairs		
Regional Directors for Indian Services	BIAs Regional directors staff transportation specialists in the 12 regions of the country.	
Alaska Regional Office		Bureau of Indian Affairs Regional Director—Mr. Eugene R. Peltola Jr. 3601 C Street Suite 1200 Anchorage, AK 99503-5947 Telephone: 907-271-4085 Toll Free: 800-645-8465 Fax: -907-271-1349 Website: https://www.bia.gov/regional-offices/alaska
Eastern Regional Office		Bureau of Indian Affairs 545 Marriott Drive Suite 700 Nashville, TN 37214 Telephone: 615-564-6500 Telefax: 615-564-6701 Email: eastern.inquiries@bia.gov Website: https://www.bia.gov/regional-offices/eastern
Eastern Oklahoma Regional Office		Bureau of Indian Affairs P.O. Box 8002 Muskogee, OK 74402-8002 Physical Address: Eastern Oklahoma Regional Office Bureau of Indian Affairs 3100 W. Peak Boulevard Muskogee, OK 74401 Telephone: 918-781-4600 Telefax: 918-781-4604 Website: https://www.bia.gov/regional-offices/eastern-oklahoma

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Organization	What They Do	Contact Info
Great Plains Regional Office		Bureau of Indian Affairs 115 4th Avenue Southeast Suite 400 Aberdeen, SD 57401 Hours: 7:45 A.M.–4:30 P.M. CST Phone: 605-226-7343 Fax: 605-226-7446 Website: https://www.bia.gov/regional-offices/great-plains
Midwest Regional Office		Bureau of Indian Affairs Department of the Interior Norman Pointe II Building 5600 W. American Blvd., Suite 500 Bloomington, MN 55437 Telephone: 612-725-4500 Telefax: 612-713-4401 Website: https://www.bia.gov/regional-offices/midwest
Navajo Regional Office		Bureau of Indian Affairs P.O. Box 1060 Gallup, NM 87305 Physical Address: Navajo Regional Office Bureau of Indian Affairs 301 West Hill Street Gallup, NM 87301 Telephone: 505-863-8314 Telefax: 505-863-8324 Website: https://www.bia.gov/regional-offices/navajo
Northwest Regional Office		Northwest Regional Office Bureau of Indian Affairs 911 Northeast 11th Avenue Portland, Oregon 97232-4169 Telephone: 503-231-6702 Telefax: 503-231-2201 Website: https://www.bia.gov/regional-offices/northwest

Organization	What They Do	Contact Info
Pacific Regional Office		Bureau of Indian Affairs Regional Director: Amy Dutschke 2800 Cottage Way Sacramento, CA 95825 Telephone: 916-978-6000 Telefax: 916-978-6099 Website: https://www.bia.gov/regional-offices/pacific
Rocky Mountain Regional Office		Bureau of Indian Affairs 2021 4th Avenue North Billings, MT 59101 Telephone: 406-247-7943 Telefax: 406-247-7976 Website: https://www.bia.gov/regional-offices/rocky-mountain
Southern Plains Regional Office		Bureau of Indian Affairs WCD Office Complex P.O. Box 368 (Physical: 1 Mile North on Hwy 281) Anadarko, OK 73005 Telephone: 405-247-6673 Telefax: 405-247-5611 Website: https://www.bia.gov/regional-offices/southern-plains
Southwest Regional Office		Bureau of Indian Affairs 1001 Indian School Road, NW Albuquerque, NM 87104 Telephone: 505-563-3103 Telefax: 505-563-3101 Website: https://www.bia.gov/regional-offices/southwest

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Organization	What They Do	Contact Info
Western Regional Office		Bureau of Indian Affairs 2600 N. Central Avenue, 4th Floor Mailroom Phoenix, AZ 85001 Telephone: 602-379-6600 Telefax: 602-379-4139 Website: https://www.bia.gov/regional-offices/western
Veterans Administration Veterans Transportation Service	The VTS provides qualifying Veterans with free transportation services to and/or from participating VA medical centers (VAMCs) in a multi-passenger van.	To find Veteran Transportation Services, click on your state to see a listing of VTS sites and Points of Contact in your area. https://www.va.gov/healthbenefits/vtp/map.asp
White House Bipartisan Infrastructure Bill	A Guidebook to the Bipartisan Infrastructure Law for state, local, tribal, and territorial governments, and other partners.	https://www.whitehouse.gov/wp-content/uploads/2022/01/BUILDING-A-BETTER-AMERICA_FINAL.pdf

Chapter 9: Accessible Housing & Facilities

Where American Indians and Alaska Natives Live and Disability Rates

A 2016-18 survey by the U.S. Bureau of Labor Statistics found just a little over one quarter (28 percent) of American Indians and Alaska Natives (AI/ANs) resided in reservations or land trusts. The AI/ANs residing in AI/AN areas tend to be older, with 30 percent over the age of 55 (The U.S. Bureau of Labor Statistics 2019). Rates of disability increases with age, and in 2016, 50 percent of American Indian and Alaska Native elders aged 65 and older had one or more disabilities (Administration for Community Living). Disabilities rates vary by tribal community. For example, on the Navajo Nation, 30 percent of Navajos between the ages of 21 and 54 have a disability, but 70 percent over the age of 64 have a disability (The Native American Disability Law Center 2011).

If one calculates 30 percent of 9.6 million native people, there are an estimated 2,880,000 AI/ANs with disabilities, and approximately 864,000 live in reservations or land trusts. Even though many American Indians and Alaska Natives grow up outside their tribal homelands or leave to pursue educational and economic opportunities, tribal members often return to their reservations to visit family or for other reasons.

Given the high rates of disabilities and health disparities in the AI/AN population, it is a priority that tribal buildings, businesses, and homes are accessible to both residents and visitors with disabilities.

Tribal Housing Challenges

To remain independent, many AI/ANs with disabilities living on tribal lands require their homes, work environment, and other tribal facilities be accessible to actively participate in family and tribal life. Unfortunately, the confluence of poor housing conditions, limited housing funds, and lack of awareness about universal design create barriers to providing accessible homes and public buildings on reservations or trust lands.

Barriers to Service

- Costs of building modifications
- Limited program funding
- Administrative backlog
- Limited awareness of universal design

AI/AN Housing Problems in Tribal Areas 2013–2015 Household Survey

Individual Housing Problems	AI/AN Tribal Areas	Total U.S. Annual Housing Survey
Facilities Problems	% Problem	% Problem
▪ Plumbing	5.6 %	1.3 %
▪ Kitchen	6.6 %	1.7 %
▪ Electrical	1.1 %	1.4 %
▪ Heating	12.0 %	0.1 %
One Condition Problem*	8.1 %	0.8 %
More than one Condition Problem*	23 %	5 %
Overcrowded	15.9 %	2.2 %
Cost Burden	37.5 %	36.1 %
One or more physical problems	34 %	7 %
One or more identified housing problem of any kind	57 %	40 %

(Pindus 2017)

*Condition problems include structural deficiencies; leaks from outdoors; leaks from indoors (broken pipes or water heaters, backed up plumbing or water from another unit); holes in the floors; holes or open cracks in the walls or ceiling; peeling paint or plaster one foot or larger (Pindus 2017).

AI/AN Housing Study

The U.S. Department of Housing and Urban Development conducted the largest study to date of AI/AN housing conditions and policies between 2011 and 2016. The study found a prevalence of housing problems (Pindus 2017).

These survey statistics show that more than half of existing tribal homes are in need of repair; additionally, the households of older adults who are frail or with disabilities need home modifications, such as safety features like grab bars in bathrooms, entrance ramps, and 36-inch wide doorways to accommodate a wheelchair. (Pindus 2017). A 2011 survey on the Navajo Nation found that none of its public offices were accessible to people with disabilities.

Accessibility Challenges on the Navajo Nation

In 2021, the Navajo Nation's official enrollment grew to 399,494 according to the Navajo Office of Vital Records and Identification, making it the most populous tribal nation in the United States (Romero 2021). As such, it is estimated that well over 100,000 Navajo members have disabilities.

In 2011, 2,000 Navajos participated in surveys and focus groups to assess accessibility of 15 Navajo Nation public offices in five communities. It was revealed that "Navajos with disabilities are more likely to miss needed assistance or lack benefits because they literally could not get in the door of the Navajo office that was responsible for serving them" (The Native American Disability Law Center 2011). The study also found that none

Facilities	Accessibility Issues
Parking lots	<ol style="list-style-type: none"> 1. Insufficient space for lowering a wheelchair ramp. 2. Pathways to the entrance of builds had obstructions 3. Curb cuts and crosswalks were not visibly marked or painted.
Entrance doors and doors within offices	<ol style="list-style-type: none"> 1. Doorknobs are rounded and difficult to grasp, essentially making it difficult to impossible for an individual to enter the building.
Public telephones	<ol style="list-style-type: none"> 1. Available public telephones were not within reach of a person using a wheelchair 2. Public telephones did not have text capability or volume controls for Deaf or Hard of Hearing people.
Water Fountains	<ol style="list-style-type: none"> 1. Too high for wheelchair users.
Restrooms	<ol style="list-style-type: none"> 1. Sinks, dispensers, disposal units, and mirrors were out of reach or unusable for wheelchair users.
Conference/waiting rooms	<ol style="list-style-type: none"> 1. Waiting rooms did not have enough room for people using wheelchairs 2. Meeting places were inaccessible and unusable by persons with disabilities.
Ramps and steps	<ol style="list-style-type: none"> 1. Ramps were too steep 2. Surfaces were made with materials that would be slippery when wet.
Elevators	<ol style="list-style-type: none"> 1. Controls were not within reach of people using wheelchairs 2. Controls were not marked with Braille for people with visual impairments

(The Native American Disability Law Center 2011)

of the 15 offices evaluated were fully accessible and that “. . . lack of access to public buildings [is] one of the top five issues facing the Navajo community” (The Native American Disability Law Center 2011). The accessibility issues identified by the survey were widespread.

Navajo Nation Legislation Protecting the Rights of People with Disabilities

Despite the lack of accessibility of public offices, the Navajo Nation has a long history of enacting legislation to address the needs of people with disabilities. In 1979, an Affirmative Action Plan was enacted and spoke

of employment for Navajos with disabilities and access in public, private, governmental buildings on the Navajo Reservation. Additionally, it established a 10-member Navajo Advisory Council on Disabilities. This law and subsequent laws did not include verbiage regarding compliance or legal remedies for noncompliance (Benally 2021).

In 2014, President Shelly issued an executive order that mandated tribal departments, chapter houses, enterprise buildings, and private businesses review their policies (Shebala 2014). The mandate required that policies state that people with disabilities be provided services,

reasonable accommodations, and accessibility to all facilities within the reservation (Benally 2021).

In 2018, The Navajo Nation Civil Rights for Individuals with Disabilities was enacted and gave people with disabilities the right to sue and receive legal and equitable outcomes if the individual felt discriminated against. The law is similar to the Americans with Disabilities Act of 1990 and protects against discrimination in the areas of housing, employment, training, social services, medical services, and participation in cultural, social, political, and economic activities (Benally 2021).

By the summer of 2021, some of the accessibility improvements recommended in the 2011 study had been made, such as adding signage, ramps, and concrete slabs

for wheelchairs. However, accessibility improvements occurred gradually rather than systematically by creating and following a master plan. Lack of accountability and awareness about the needs and rights of Navajos with disabilities persists (Benally 2021).

The Basics of Universal Design

Universal Design is a method of designing environments, services, and products . . . that are usable by the highest number of people, including:

- Small children and grandparents
- People with temporary or permanent disabilities

7 Principles of Universal Design

1. **Equitable use.** The design is useful and marketable to people with diverse abilities
2. **Flexibility in use.** The design accommodates a wide range of individual preferences and abilities.
3. **Simple and intuitive.** Use of the design is easy to understand, regardless of the user's experience, knowledge, language skills, or current concentration level.
4. **Perceptible information.** The design communicates necessary information effectively to the user regardless of ambient (environmental) conditions or the user's sensory abilities.
5. **Tolerance for error.** The design minimizes hazards and negative, accidental, or unintended consequences.
6. **Low physical effort.** The design can be used efficiently, comfortably, and with a minimum of fatigue.
7. **Size and space for approach and use.** Appropriate size and space is provided for approach, reach, manipulation, and use regardless of the user's body size, posture, or mobility.

(National Disability Authority)

Examples of Universal Design Features

(Compliant with federal disability legislation requirements)

1. **Front entrance.** At least one no-step entrance with 36-inch door.
2. **Lever Door Handles.** Lever door handles on all doors and plumbing fixtures.
3. **Electric Controls.** Location of Electrical controls between 48 and 15 inches above the finished floor.
4. **Accessible Route** to the public right-of-way streets and sidewalks.
5. **36-Inch Doors.** Minimum 32-inch-wide interior doors.
6. **36-Inch Hallways.** Minimum 36-inch-wide hallways.
7. **Bathrooms.** All bathroom walls should be reinforced around the toilet and shower/tub for future installation of grab bars.

(Universal Housing Design)

- People wishing to remain in their homes as they age
- First responders, furniture and appliance movers
- Visitors with mobility problems
- And many others . . . (City of San Antonio. Universal Housing Design)

The goal of Universal Design is to remove barriers for all users and follows seven principles.

Even though the Americans with Disabilities Act categorically excludes tribes from the law, it is a best practice to apply the principles of Universal Design to the built environment.

Visitability

“Visitability” is a term that refers to single-family or owner-occupied housing designed in such a way that it can be lived in or visited by

people who have trouble with steps or who use wheelchairs or walkers (Visitability).

Remodeling a home for accessibility costs \$4,380 on average and typically will cost between \$773 and \$7,988 (Home Advisor). It is important to note that actual construction costs will vary by locality, and there will be savings

Three Basic Requirements of a Visitable Home

1. one zero-step entrance
2. doors with 36 inches of clear passage space
3. one bathroom on the main floor you can get into in a wheelchair

(Visitability)

Visitability Comparative Costs: New Construction Vs. Retrofitting

New Construction		Retrofitting	
One zero-step entrance on a concrete slab:	\$ 0	Typical cost of widening one interior door:	\$700
Five doors at \$2 more per door than narrower doors:	\$10	Retrofit an entrance without steps:	\$3,300
One zero-step entrance over a basement:	\$250		
	<i>TOTAL:</i>		
	\$10 (slab)		
	\$260 (basement or crawl space)		

(Visitability)

from the integration of universal design at the time of construction versus later modification.

Assessing Needs

The first step to building a strong framework for services for people with disabilities is to know which services are currently available and which

are not. The following eight questions were developed by the American Indian Disability Technical Assistance Center (AIDTAC) to assess accessibility barriers.

Use the questions in a talking circle or group format to bring together community members with diverse perspectives so you can understand

Checklist to Evaluate Accessibility Barriers in Tribal Communities

1. What does your tribe or tribally designated housing entity (TDHE) do to provide accessible housing for members with disabilities?
2. Does your tribe or TDHE comply with Section 504 of the Rehabilitation Act?
3. Does your tribe or TDHE retrofit existing houses when someone needs a bathroom modified or ramp built?
4. What is your tribe or TDHE doing to make sure that people with disabilities have adequate accessible housing?
5. What cultural or traditional issues may be barriers to providing accessible housing for people with disabilities?
6. What are the major barriers to making more homes accessible on your reservation?
7. What resources does your tribe need in order to overcome these barriers?
8. What guidelines do you suggest for improving housing options for members with disabilities on your reservation?

(American Indian Disability Technical Assistance Center)

the spectrum of needs within your specific community.

The graphic from the Center of Universal Design in North Carolina State University

below provides features and their benefits of the basic principles of universal design and a visitable home.

UNIVERSAL DESIGN Features in Housing

The following list of characteristics are elements, features, ideas or concepts that contribute to or can be components of universal housing. This list is intended as a guide. The features described are those we might look for in universal housing but not all are expected to be included in any given home.

Some are finite recommendations, some are lists of options, and some are scope statements identifying how many particular features must or should be included. Obviously, the more universal design characteristics or features included, the more usable the house.

A key component of universal design is the market appeal it adds to the home because the universal features are integrated into the overall design. Done well, universal design becomes a virtually invisible element.

This list contains structural and non-structural features. Structural features, indicated by ✖, should be considered for new homes and major renovations. Non-structural features, indicated by O, are less expensive and easier to incorporate into a finished home.

CHARACTERISTICS	BENEFITS
Entrances	
Stepless Entrances	
✖ It is best to make all home entrances stepless.	Easier to move furniture and appliances in and out.
✖ More than one stepless entrance is preferred	Great for baby strollers and bicycles.
✖ At least one stepless entrance is essential; if only one, not through a garage or from a patio or raised deck.	Easier to bring in groceries and packages.
Site Design Methods for Integrated Stepless Entrances	
✖ Level bridges to uphill point.	Safer in wet or icy condtions.
✖ Driveway and garage elevated to floor level so vehicles do the climbing.	Easier to clear snow, ice and leaves.
✖ Earth berm and bridge with sloping walk.	Easier than steps to repair and maintain.
✖ Site grading and earth work (with foundation waterproofing) and sloping walks at 1:20 maximum slope.	Slope of route is shallow making travel from parking to door easier.
✖ Avoid ramps. If ramps are used, integrate into the design.	

Housing Legislation and Funding

More than two hundred years of disastrous federal policies have resulted in the alarming disintegration of reservation conditions and shocking impoverishment of Native people (Kunesh 2021). In 1975, Congress enacted The Indian Self-Determination and Education Assistance Act (ISDEAA), making self-determination the focus of future government action and reversing a 30-year effort by the Federal Government to sever treaty relationships with and obligations to Indian tribes (Kunesh 2021).

Housing was one of the first programs over which tribes assumed control under the ISDEAA (Kunesh 2021). In 1996, Congress passed The Native American Housing Assistance and Self-Determination Act (NAHASDA), which is the dominant structure for federal housing assistance in Indian Country (Pindus 2017). See NAHASDA's objectives, activities, and eligibility below.

In 2012, complementary legislation was enacted, The Helping Expedite and Advance

Responsible Tribal Homeownership (HEARTH), which is designed to enhance tribal governance over tribal lands and promote the efficient leasing of those lands for housing and business purposes (Kunesh 2021). Under The HEARTH Act, tribes submit Tribal Leasing Regulations to the Secretary of the Interior, and upon approval are authorized to negotiate and enter into surface leases in the areas of:

- Business
- Agriculture
- Wind and solar
- Wind Energy Evaluation
- Residential
- Public, religious, educational, or recreation (U.S. Department of the Interior Indian Affairs, Hearth Act Leasing)

NAHASDA expired in 2013, but congress has continued annual funding, increasing it to \$1 billion a year. As of this writing, the reauthorization bill was passed by the

NAHASDA Objectives

1. Assist and promote safe, healthy, and affordable housing activities for occupancy by low-income Indian families on Indian reservations and in other Indian areas.
2. Better access to private mortgage markets for Indian tribes and their members.
3. Coordinate housing activities between Indian tribes and their members with federal, state, and local activities.
4. Integrate infrastructure resources for Indian tribes with housing developments.
5. Promote private capital markets in Indian Country.

(Pindus 2017)

NAHASDA Activities

1. **Indian Housing Assistance:** Includes modernization, operating assistance, rent, and utility subsidies for housing.
2. **Housing Development:** Includes property acquisition, new construction of affordable housing, reconstruction, rehabilitation, site improvements, development of utilities and utility services, demolition and other rehabilitation and construction activities.
3. **Housing Services:** Includes housing counseling, establishment and support of resident management organizations, energy auditing, and other services to assist owners, tenants, contractors, and other entities.
4. **Housing Management Services:** Includes work specifications, loan processing, inspections, tenant selection, management of tenant-based rental assistance, operation, and management, and maintenance of affordable housing projects/units.
5. **Model Activities:** Activities not explicitly stated within the goals of NAHASDA. Includes construction of community buildings, day care centers, job training centers, and maintenance storage buildings.
6. **Administration and Planning:** Can spend up to 20 percent on administration and planning.

(Pindus 2017)

NAHASDA Eligibility

1. **Low-income Indian families** whose income does not exceed 80 percent of the median income for the area.
2. **Non-low-income Indian families** whose income exceeds 80 percent of the area median and under certain circumstances specified by NAHASDA.
3. **Non-Indian families** whose housing needs cannot be met without assistance and that the grant recipient agrees the family's presence is essential to the well-being of the Indian families living in the tribal area.

(Pindus 2017)

U.S. Senate Committee on Indian Affairs and next will go to the full senate, then U.S. House of Representatives (Crouse 2022). The 2021 bill would reauthorize NAHASDA through 2032 and would provide an assistant secretary for

the Office of Native American Programs within Housing and Urban Development rather than a deputy assistant secretary (National Low Income Housing Coalition 2021).

4 Programs Funded by NAHASDA

Indian Housing Block Grant (IHBG)

A formula-based grant program. Tribes use IHBG resources for direct housing investment and to leverage a larger pool of resources for housing improvement in their service areas (Pindus 2017). Eligible activities are housing assistance, development, services, management, and model approaches (U.S. Housing and Urban Development, n.d.).

https://www.hud.gov/program_offices/public_indian_housing/ih/grants/ihbg

Section 184 Indian Home Loan Guarantee Program

Created in 1992 to increase Native access to homeownership by providing a guarantee to lenders on mortgage loans made to Native borrowers, including American Indian and Alaska Native families, Alaska Villages, tribes, or Tribally Designated Housing Entities. The loans can be used, both on and off native lands, for new construction, rehabilitation, purchase of an existing home, or refinance (U.S. Housing and Urban Development, n.d.).

https://www.hud.gov/program_offices/public_indian_housing/ih/homeownership/184

Indian Community Development Block Grant (ICDBG)

An annual competitive single-purpose grant for developing Indian and Alaska Native communities via housing rehabilitation, land acquisition, construction of community facilities and infrastructure, and economic development activities to benefit people with low and moderate incomes (U.S. Housing and Urban Development).

https://www.hud.gov/program_offices/public_indian_housing/ih/grants/icdbg

Title VI Loan Guarantee Program

Assists Indian Housing Block Grant recipients (borrowers) who want to finance eligible affordable housing activities but are unable to secure financing without the assistance of a federal guarantee (U.S. Housing and Urban Development, n.d.).

https://www.hud.gov/program_offices/public_indian_housing/ih/homeownership/titlevi

BIAs Housing Improvement Program (HIP)

The Bureau of Indian Affairs established the Housing Improvement Program (HIP), an

emergency housing assistance grant program for Indians who occupied substandard reservation homes acquired outside of the 1937 Housing Act programs (Pierson 2020).

Who Is Eligible for BIAs HIP

A program participant must be a member of a federally recognized tribe who lives in an approved tribal service area and has:

1. A household annual income that does not exceed 125 percent of poverty income guidelines
2. Substandard housing
3. Not received assistance after October 1, 1986, for repairs, renovation, replacement, housing, or down payment assistance
4. A home that was not acquired through a federal housing program, such as the Housing Act of 1937 or NAHASDA
5. No alternative housing assistance
6. Met ownership requirements or has a leasehold extending 25 years beyond the grant date

(Pierson 2020)

How do I apply BIAs HIP?

Individual tribal members apply by filing an application form, together with documentary evidence of membership, household income, and land tenure.

1. Applications are ranked by the HIP Servicing Office according to need
2. The Servicing Office determines what work should be done on the home and coordinates with the IHS with regard to funding for sanitation facilities
3. The Servicing Office selects contractors and manages the project
4. Funds are allocated based on information provided by tribes to their regional BIA offices based on a competitive process that takes into account the number of members who meet age, income, disability, and family-size criteria

(Pierson 2020)

Section 202 Supportive Housing for the Elderly

Capital advances for new construction, rehabilitation, or acquisition of housing for occupancy for at least 40 years by older adults with very low income.

Who Is Eligible?

Private nonprofit organizations and nonprofit consumer cooperatives are the only eligible applicants under this program. Neither a public body nor an instrumentality of a public body is eligible to participate in the program.

Section 202 has rarely been used in Indian Country because tribal governments and TDHEs are not eligible applicants.

- Several tribes in recent years have, however, teamed up with nonprofits to meet the needs of tribal elders. In order to access the program, a tribe must grant a long-term lease to a nonprofit developer/applicant.

How do I apply?

By the Housing and Economic Recovery Act of 2008, Congress delegated the authority to review applications for 202 funding to state housing finance agencies. For Indian Country projects, applications are made by a nonprofit entity, with the tribe's support. For more information, visit the HUD website.

https://www.hud.gov/program_offices/housing/mfh/progdesc/eld202

(Pierson 2020)

The Bureau of Indian Affairs Housing Improvement Program provides grants to repair, renovate, replace, or provide housing for the neediest Indian families. HIP grants may be for interim improvements (up to \$2,500), repairs and renovation (up to \$35,000), or replacement of housing (sufficient for a "modest dwelling") (Pierson 2020).

Bureau of Indian Affairs Low-Income Housing Tax Credit Program (LIHTC)

LIHTC is a dollar-for-dollar credit against the federal income tax liability of the owner

(developer or investor) of a low-income housing development (Hopi Tribal Housing Authority). Under Section 42 of the IRS code, states are responsible for developing "Qualified Allocation Plans" and determining which projects receive awards. States administer the Low-Income Housing Tax Credit program. Tribes can raise the equity they need for building projects through the LIHTC program, which lowers the amount a tribe will need to contribute to the project. It does not need to repay this equity but must follow all regulations for the 15-year compliance program (Kapp 2015).

Section 811 Supportive Housing for Persons with Disabilities

Section 811 of the National Affordable Housing Act of 1990 offers

- (i) Interest-free capital advances and rental assistance to private nonprofit organizations to finance acquisition, construction, rehabilitation, and/or operation of rental housing that provides supportive services for persons with disabilities, and
- (ii) Project rental assistance, through state housing finance agencies, to sponsors who operate housing with community-based supportive services for people with disabilities.

Eligible housing includes group homes, independent living facilities, multifamily housing, condominium housing and cooperative housing.

Services must address the individual needs of people with disabilities, provide them with opportunities for optimal independent living and participation in normal daily activities, and facilitate access to the community at large and to suitable employment opportunities.

A capital advance does not have to be repaid as long as the housing remains available for people with very low income and disabilities for at least 40 years.

Under the rental assistance program, state housing finance agencies enter into rental assistance contracts with project sponsors, which may include tribes, which cover the difference between the HUD-approved operating costs of the project and the tenants' contribution toward rent, usually 30 percent of adjusted income. The initial term of the project rental assistance contract is five years and can be renewed if funds are available.

The program is limited to very low-income households whose income does not exceed 50 percent of the area median income.

- For purposes of program eligibility, a “person with disabilities” is someone determined to have a physical, mental, or emotional impairment, which (1) is expected to be of long-continued and indefinite duration, (2) substantially impedes his or her ability to live independently, and (3) is of such a nature that such ability could be improved by more suitable housing conditions.
- A person with a developmental disability, as defined in section 102(7) of the Developmental Disabilities Assistance and Bill of Rights Act, also qualifies if certain conditions are met. Capital advances may be made only to private nonprofit organizations, which could include nonprofits serving tribal communities.

Tribes may qualify as project sponsors for the purposes of applying for rental assistance provided they meet the project sponsor criteria established by the state housing finance agency. To learn more, visit the HUD website or your state housing finance agency.

https://www.hud.gov/program_offices/housing/mfh/progdesc/disab811

(Pierson 2020)

Tribal HUD-Veterans Affairs Supportive Housing Program (HUD-VASH)

The VA and HUD established HUD-VASH to serve homeless veterans and their immediate families.

- The VA provides case management and eligibility screening services
- HUD allocates permanent housing subsidies from its “Housing Choice” program

The funding has been historically small, and the future of the Tribal HUD-VASH program is uncertain. To learn more, click on the link to the HUD-VASH Resource Guide for Permanent Housing and Clinical Care: <https://files.hudexchange.info/resources/documents/HUD-VASHResourceGuide.pdf>

(Pierson 2020)

Section 4 Funding—Capacity Building for Community Development and Affordable Housing

The Section 4 program was originally authorized under Section 4 of the HUD Demonstration Act of 1993 (Pub. L. 103-120, 107 Stat. 1148, 42 U.S.C. 9816 note), as amended. The program enhances the capacity and ability of community development corporations (CDCs) and community housing development organizations (CHDOs) to carry out community development

and affordable housing activities that benefit people with low income. (HUD).

Model Approaches

To meet the housing and accessibility needs of people with disabilities, partnerships between tribal councils, tribal programs, nonprofit organizations, and financial institutions are essential.

Several barriers to providing safe, sanitary, and affordable housing were described by the Tribally Designated Housing Entities in the largest study of tribal Housing, published in 2017.

Section 4 Eligible Applicants

The competition for Section 4 funding is limited to three types of nonprofit organizations:

1. Enterprise Community Partners, Inc.
2. Local Initiatives Support Corporation (LISC)
3. Habitat for Humanity International

(HUD)

Section 4 Activities

1. Training, education, support, and advice to enhance the technical and administrative capabilities of CDCs and CHDOs, including:
 - a. Fair housing planning
 - b. Continuum-of-care homeless assistance, assessing area needs, and consulting broadly within the community
 - c. Cooperative planning
2. Loans, grants, development assistance, predevelopment assistance, and financial assistance to CDCs and CHDOs to carry out affordable housing for people with low and moderate incomes.
3. Other activities such as home investment partnerships, homeless programs, and housing opportunities for people with AIDS.

(HUD)

Barriers to Safe & Affordable Housing (% of TDHEs who reported the barrier)

- Developing Infrastructure (70%)
- Availability of Labor (39%)
- Lack of Funds (34%)
- Acquiring or Assembling Land (30%)
- Other Challenges such as risk of flooding, water shortages, aging of existing infrastructure (% not provided)

(Pindus 2017)

Blackfeet Housing Partners to Maximize Resources

Blackfeet Housing offers an emergency repair program for older adults, veterans, and people who have a disability. Funds are capped at \$500

for each participating household, but respondents say this amount is insufficient to make any substantial repairs. Blackfeet Housing is working with the U.S. Department of Agriculture and the Bureau of Indian Affairs' Home Improvement

Program to pool resources. This partnership would allow for up to \$20,000 to be spent on needed repairs (Pindus 2017).

Choctaw Nation Interagency Approach Reduces Service Gaps

The Choctaw Nation of Oklahoma developed a client-centered, interagency approach to service delivery that seeks to meet clients' needs and reduce any service gaps. The collaboration includes several tribal departments and programs—housing, community health representatives, community-based home visitors, Temporary Assistance for Needy Families, transportation services, domestic violence, Food Distribution Program on Indian Reservations, adult protective services, and emergency services. This interagency cooperation includes the State of Oklahoma and municipalities located within the Choctaw Nation service area. This collaborative approach to service delivery helps to identify clients' needs and reduce gaps in services (Pindus 2017).

The Saint Regis Mohawk Tribe and Section 4

The Saint Regis Mohawk Tribe, located near the Canadian border of New York, did not have a permanent source of housing for its 16,000 members. The Saint Regis Mohawk Health Service officials underscored the need for supportive housing for veterans and older adults with disabilities on the reservation.

Resolution

The Sunrise Acres' Complex included 41 units that mainly housed older adults in an independent living environment with general support services. The Saint Regis Mohawk Health

Service officials identified 29 tribe members who would specifically benefit from living in supportive housing.

Through a variety of funding sources, partnerships, and Section 4 funding, the tribe expanded its Sunrise Acres Complex to include Supportive Housing (SASH) with an additional 18 homes. 12 homes were for older adults with disabilities and six homes for Native American veterans, including four homes designated for homeless veterans.

How it Happened

The Akwesasne Housing Authority's (AHA) support services referral program hosts quarterly "Support to Elders Program (STEP)" meetings with program service providers to discuss the issues and current needs of the community.

"From those meetings, it came to light that there were seniors who needed more supportive services than what was currently offered. The Sunrise Acres' 41 units mainly housed seniors in an independent living environment with general support services. They wanted to offer more options for supportive services for seniors as they age in place," said Theresa Cole, special projects coordinator.

Section 4 funding set the process in motion and was an invaluable resource. The AHA was able to secure additional funding for their Supportive Housing Project through the New York State Homes and Community Renewal, Homeless Housing Assistance Program, and the Empire State Supportive Housing Initiative.

Recently, The AHA was awarded the Indian Housing Block Grant for 2020 to expand the Sunrise Acres complex, which will include an additional 20 independent living homes for older adults (Norwood).

Confederated Tribes of Warm Springs Reservation and the U.S. Department of Agriculture (USDA) Rural Development Investments

For half a century, Marilyn Wagner raised her children, grandchildren, and great-grandchildren in a home on the Confederated Tribes of Warm Springs Reservation in Central Oregon. Due to her limited income, she could no longer keep up with the aging home's growing maintenance needs.

- An unusable sink and leaky kitchen plumbing
- Dry rot in the bathroom floor
- Collapsing woodstove chimney
- Ceiling tile around the woodstove's chimney sagged and leaked (2019)

Resolution

Through a partnership with the USDA, Warm Springs Tribal Credit Enterprise helped Ms. Wagner to complete an application for a home repair grant. USDA awarded her a \$6,840 grant to replace plumbing, the bathroom floor, ceiling tile, an entry door, and a new chimney.

The repairs were completed just as Ms. Wagner made the final payment on her home mortgage. The Warm Springs Tribal Credit Enterprise and USDA Rural Development program are continuing to work together to help more tribal elders repair their homes on the Reservation (USDA Rural Development and Innovation Center 2019).

How it Happened

Wagner contacted the Warm Springs Tribal Credit Enterprise for a loan to cover the cost of the badly needed home repairs. She was delighted to learn she qualified for a grant from

USDA Rural Development. These grants are available to older adults with very low income aged 62 or older to enable them to remove health and safety hazards from their homes because they cannot repay a repair loan (USDA Rural Development and Innovation Center 2019).

Tips from the field

- Reach out to other organizations and tribal programs. Help is available, but you might have to find opportunities and build on them.
- Develop a voice in the Tribal Council and relevant boards. Tribal governance can respond to the needs of people with disabilities if they know what you need.

Five FAQs to Ask about Accessible Homes and Workplaces

Frequently Asked Questions

1. Whom do I contact first for help in making my home or workplace accessible?
2. What legislation impacts housing for tribal members with disabilities, and how do I file a complaint if the laws are not being honored?
3. Where do I learn more about universal design?
4. Whom can I contact for technical assistance, training needs, networking opportunities, and information on housing?
5. What types of funding are available for tribal accessible-housing programs, and how do I apply?

1. Whom do I contact first for help in making my home or workplace accessible?

Start by contacting your tribal housing authority and/or Tribally Designated Housing Entity (TDHE). The TDHE is designated by the tribe to develop a five-year plan of action and an annual plan detailing the resources the tribe will use to meet the needs of its residents with low income.

The TDHE is the primary contact point for federal funds for housing and construction. The TDHE is given funds by either a formula or block grant. In 2020, nearly 600 tribes were eligible to participate in the NAHSADSA program, totaling \$826 million (National Association of Housing and Redevelopment Officials).

The TDHE sets its housing and construction priorities, such as building ramps, constructing Independent Living Centers, or modifying existing buildings. The TDHE determines the plan, design, construction, and maintenance of affordable housing on Indian reservations and Native communities (U.S. Housing and Urban Development, Office of Policy Development and Research).

Many tribes have a partnership between the Vocational Rehabilitation Office, the tribal housing authority, and the tribal council to identify workplace modification needs for tribal members with disabilities who train for employment with tribal employers or employers outside of tribal communities. Independent Living Centers can also be an important source of information regarding housing and accessibility issues (see Independent Living chapter).

2. What legislation impacts housing for tribal members with disabilities, and how do I file a complaint if the laws are not being honored?

See an earlier section of this chapter on Housing Legislation and Funding. Other laws to be knowledgeable about are Section 504 of the Rehabilitation Act, the Architectural Barriers Act, the Americans with Disabilities Act (Titles I, II, and III), and the Fair Housing Act.

Section 504 of the Rehabilitation Act

Prohibits discrimination against a person with a disability by programs receiving Federal financial assistance. The law specifically references “Indian Tribe” as a program that has an agreement with the state to provide Vocational Rehabilitation services (Yazzie 2021).

The act requires that new construction and newly altered facilities built with federal funds be accessible. Each federal agency providing funds is responsible for enforcing the Act, and complaints must be directed to the federal agency with authorization for the particular project in question (Makoa 2002).

The Architectural Barriers Act

Requires buildings and facilities be accessible if, since 1968, they were “designed, built, or altered with certain federal funds, or if they are leased for occupancy by federal agencies” (U.S. Access Board, 2022).

Accessibility standards cover walks, ramps, curb ramps, entrances, elevators, and restrooms and are described in the Uniform Federal Accessibility Standards. Complaints may be filed with the Access Board (U.S. Access Board, 2022). See the Resources section of this chapter.

Americans with Disabilities Act (ADA)

Tribes are categorically excluded from compliance with Title I of the ADA, which prohibits discrimination on the basis of disability in employment. Title II of the ADA prohibits discrimination based on disability in any public program, service, or activity by any “public entity” defined to include state, and local, but not tribal governments. The Eleventh Circuit Court of Appeals has held that tribes are subject to Title III, relating to public accommodations, but that only the United States, and not private parties, can bring suit to enforce the Act (Pierson 2020).

Fair Housing Act

Prohibits discrimination based on disability in the sale, rental, or financing of housing, and it requires certain architectural accessibility requirements in new multifamily housing. Complaints may be filed with HUD (Makoa 2002).

3. Where do I learn more about universal design?

A great place to start is the City of San Antonio Disability Access Office, which includes a web page on Universal Design, and publications such as an Accessibility Manual, Disability Etiquette Handbook, and Design Guidelines and Construction Standards that are compliant with TX law and the principles of Universal design. Their specific links are found in the Resources section of this chapter. <https://www.sanantonio.gov/dao>

4. Whom can I contact for technical assistance, training needs, networking opportunities, and information on housing?

Start with the National American Indian Housing Council (NAIHC). It is a national membership

organization that promotes, supports, and upholds tribal housing agencies in their self-determined goal to provide culturally relevant and quality affordable housing for native people. More contact information is provided in the Resources section of this chapter.

<https://naihc.net>

There are regional Indian Housing Associations with offices in Alaska, Michigan, California, Washington, Oklahoma, Montana, Tennessee, New Mexico, and Washington DC. The names and contact information for each is listed in the Resources section of this chapter.

The Resources section of this chapter lists many more national public and private organizations with a variety of customers. Some serve American Indian and Alaska Native communities, and others serve rural communities and others serve every state.

5. What types of funding are available for tribal accessible-housing programs, and how do I apply?

The U.S. Department of Housing and Urban Development (HUD) and the Bureau of Indian Affairs (BIA) are the two federal agencies responsible for much of the funding for tribal housing, and a good place to begin. See the Legislative and Funding section of this chapter as well as the Resources section.

HUD offers assistance and loan programs specifically for Native American tribes, organizations, and (sometimes) individuals. HUD offers basic information on homebuying, fair housing, and housing counseling. The HUD Office of Native American Programs offers grant assistance through four main programs; two programs are focused on tribal communities and two are focused on individuals. The Code

Talk Website administered by HUD is also an excellent resource for program information.
<https://www.hud.gov/codetalk>

The Bureau of Indian Affairs (BIA) is the oldest agency in the U.S. Department of the Interior. Established in 1824, it is responsible for the administration and management of 55 million surface acres and 57 million acres of subsurface

mineral estates held in trust by the United States for American Indians, Indian tribes, and Alaska Natives. BIAs mission is “ . . . to enhance the quality of life, to promote economic opportunity, and to carry out the responsibility to protect and improve the trust assets of American Indians, Indian tribes, and Alaska Natives.”

Resources

Organization	What	Contact
1st Tribal Lending	First Tribal Lending assists Tribal members residing anywhere in the United States who may qualify for a Section 184 Home Loan.	1st Tribal Lending dba Mid America Mortgage, Inc. (NMLS 150009) Nate Schmidt, Loan Officer (NMLS 400277) 5010 S. Broadband lane, Suite 110 Sioux Falls, SD 57108 Phone: 605-271-3531 Toll-free: 855-288-3123 Fax: 866-376-5903 Website: www.hud184loans.com
Access Board	The Access Board is an independent federal agency devoted to accessibility for people with disabilities. It develops and maintains accessibility criteria for the built environment, transit vehicles, telecommunications equipment, and electronic and information technology.	U.S. Access Board Office of Compliance and Enforcement 1331 F Street NW, Suite 1000 Washington, DC 20004-1111 Email: enforce@access-board.gov Fax: 202-272-0081 Phone (Voice): 202-272-0080 Toll free: 800-872-2253 Phone (TTY): 202-272-0082 Toll free: 800-993-2822 Online form: https://www.access-board.gov/enforcement/complaint.html

Organization	What	Contact
Association of Alaska Housing Authorities (AAHA)	A regional Indian housing authority located in Alaska.	AAHA Statewide Office Colleen Dushkin— Administrator 4300 Boniface Pkwy. Anchorage, AK 99504 Phone: 907-330-8398 Fax: 907-338-4904 fax Email: cdushkin@aahaak.org Website: https://www.aahaak.org/
Bureau of Indian Affairs	The BIA is responsible for the administration and management of 55 million surface acres and 57 million acres of subsurface minerals estates held in trust by the United States for American Indians, Indian tribes, and Alaska Natives.	Bureau of Indian Affairs Office of Public Affairs 1849 C Street, NW-MS-4542-MIB Washington, DC 20240-0001 Phone: 202-208-3711 Fax: 202-501-1516 Website: https://www.bia.gov/
City of San Antonio Disability Access Office	The resources on the City of San Antonio Disability Access Office include: <ul style="list-style-type: none"> ▪ Universal Design ▪ Accessibility Manual ▪ Disability Equity Handbook ▪ Design Guidelines and Construction Standards (compliant with TX laws, but a good reference nonetheless) 	<i>Universal Design</i> https://www.sanantonio.gov/DAO/ADADesign/UniversalHousingDesign <i>Accessibility Manual</i> https://www.sanantonio.gov/DAO/Publications-and-Maps/AccessibilityManual <i>Disability Equity Handbook</i> https://www.sanantonio.gov/DAO/Publications-and-Maps/Disability-Etiquette-Handbook <i>Design Guidelines and Construction Standards (compliant with TX statutes and Universal Design)</i> https://www.sanantonio.gov/Portals/0/Files/NHSD/OurSA/2020%20Guidelines%20for%20New%20Construction.pdf?ver=2019-12-19-135230-023
Department of Housing and Urban Development (to file a complaint)	To file a complaint under the Fair Housing and Equal Opportunity Housing and Urban Development	Website: https://www.hud.gov/i_want_to/file_a_fair_housing_discrimination_complaint

(continued)

Organization	What	Contact
	<p>To file a complaint, you can call, complete a form and mail it, or write a letter that includes:</p> <ul style="list-style-type: none"> ▪ Your name, address, and the person your complaint is about ▪ The address of the house or apartment you were trying to rent or buy ▪ The date the incident occurred ▪ A short description of what happened 	<p>Toll-free: 1-800-669-9777</p> <p>Print a form and mail it to:</p> <p>https://www.hud.gov/program_offices/administration/hudclips/forms/hud9</p> <p>Office of Fair Housing and Equal Opportunity</p> <p>Department of Housing and Urban Development Room 5204 451 Seventh St. SW Washington, DC 20410-2000</p>
<p>Great Lakes Regional Housing Association</p>	<p>A regional housing authority located in MI and serving the Great Lakes area.</p>	<p>Great Lakes Regional Housing Association Kevin Fitzgibbons 3095 S. Towering Pines Street Brimley, MI 49715</p> <p>Phone: 847-894-1113</p> <p>Email: kf438@yahoo.com</p> <p>Website: https://www.gliha.org/welcome</p>
<p>Home Innovation Research Labs</p>	<p>Home Innovation Research Labs is an independent subsidiary of the National Association of Home Builders. It publishes hundreds of technical assistance resources including reports, building standards, how-to brochures, research, books, and a monthly blog.</p>	<p>Home Innovation Research Labs 400 Prince George's Blvd. Upper Marlboro, MD 20774</p> <p>Phone: 301-249-4000</p> <p>Tollfree: 800-638-8556</p> <p>Fax: 301-430-6180</p> <p>Website: https://www.homeinnovation.com/</p>
<p>Housing Assistance Council (HAC)</p>	<p>HAC is a national nonprofit that supports affordable housing throughout rural America, particularly the poorest of the poor. Provides below-market financing for affordable housing and community development, technical assistance, training, research and information, and policy information.</p>	<p>Housing Assistance Council National Office 1025 Vermont Avenue NW, Suite 606 Washington, DC 20005</p> <p>Phone: 202-842-8600</p> <p>Fax: 202-347-3441</p> <p>Email: hac@ruralhome.org</p>

Organization	What	Contact
HUD Exchange	<p>Information about Section 4: Capacity Building for Community Development and Affordable Housing</p> <p>Information on HUD-VASH to provide permanent housing and clinical care to homeless Veterans.</p>	<p>https://www.hudexchange.info/programs/section-4-capacity-building/</p> <p>Enterprise Community Partners, Inc. 70 Corporate Center 11000 Broken Land Pkwy, Ste 700 Columbia, MD 21044</p> <p>Local Initiatives Support Corporation (LISC) 501 Seventh Avenue, 7th Floor New York, NY 10018</p> <p>Habitat for Humanity International 121 Habitat Street Americus, GA 31709</p> <p>HUD-VASH Resource Guide for Permanent Housing and Clinical Care: https://www.hudexchange.info/resource/2011/hud-vash-resource-guide-for-permanent-housing-and-clinical-care/</p>
National American Indian Housing Council (NAIHC)	<p>A national membership organization promoting and supporting tribal housing agencies.</p>	<p>NAIHC 900 2nd Street NE, Suite 305 Washington, DC 20002 Phone: 202-789-1754 Toll-free: 800-284-9165 Fax: 202-789-1758 https://naihc.net/ 2020 Indian Housing Development Handbook: https://naihc.net/wp-content/uploads/2019/12/Indian-Housing-Development-Handbook-2020-Single-Page.pdf</p>
National Low Income Housing Coalition (NLIHC)	<p>NLIHC educates, organizes, and advocates to preserve existing federally assisted homes and housing resources, expand the supply of low-income housing, and establish housing stability as the primary purpose of federal low-income housing policy.</p>	<p>National Low Income Housing Coalition 1000 Vermont Ave NW, Ste 500 Washington, DC 20005 Phone: 202-662-1530 Fax: 202-393-1973 info@nlihc.org Website: www.nlihc.org</p>

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Organization	What	Contact
NeighborWorks America	NeighborWorks America works through public and private partnerships and is a network of organizations representing all 50 states to support organizations that provide communities with affordable housing, financial counseling, training, and more.	<p>NeighborWorks America 999 N. Capitol Street NE, Ste 900 Washington, DC, 20002</p> <p>Phone: 202-760-4000 Fax: 202-376-2600</p> <p>Email general questions to: editor@nw.org Email training questions to training@nw.org or call 800 438-5547</p> <p>Website: https://www.neighborworks.org/Home.aspx</p>
Nevada-California Indian Housing Association	A regional Indian housing authority serving Nevada and California.	<p>NV-CA Indian Housing Assoc. Phil Bush—Chair Modoc-Lassen IHA 401 Peninsula Drive, Suite 6 Lake Almanor, CA 96137</p> <p>Phone: 530-596-4127 Fax: 530-596-4137</p> <p>Email: modoclasseniha@thegrid.net Website: http://www.nevcal.org/</p>
Northwest Indian Housing Association	A regional Indian housing authority located in Washington state.	<p>NW Indian Housing Association Laurie Ann Cloud—Chairwoman Nez Perce PO Box 603 Anacortes, WA 98221</p> <p>PH: 208-843-2229 E: lauriec@nezperce.org Website: http://www.nwiha.org/</p>
Rebuilding Together	Rebuilding Together makes essential repairs to help our neighbors stay in their homes. Local affiliates are rooted in the community and work with local leaders and community residents. They also help communities recover from natural disasters.	<p>Rebuilding Together National Headquarters 999 N. Capitol St. NE, Ste 330 Washington, DC 20002</p> <p>Phone: 202-518-3100</p> <p>General Inquiries: communications@rebuildingtogether.org To find a local affiliate: https://rebuildingtogether.org/find-your-local-affiliate</p>

Organization	What	Contact
<p>Rural Housing Service National Office U.S. Department of Agriculture</p>	<p>USDA's Rural Housing Service offers a variety of programs to build or improve housing and essential community facilities in rural areas. They offer loans, grants, and loan guarantees for single- and multifamily housing, childcare centers, fire and police stations, hospitals, libraries, nursing homes, schools, first responder vehicles and equipment, housing for farm laborers, and much more.</p> <p>USDA's Rural Housing Service provides technical assistance loans and grants in partnership with nonprofit organizations, Indian tribes, state and Federal Government agencies, and local communities.</p>	<p>USDA's Rural Housing Service National Office 1400 Independence Ave SW, Rm 5014, STOP 0701 Washington, DC 20250-0701</p> <p>Phone: 202-692-0268; Customer Inquiries: 800-414-1226</p> <p>USDA's Rural Housing Service https://www.rd.usda.gov/about-rd/agencies/rural-housing-service</p> <p>To locate your field office: https://www.farmers.gov/service-center-locator</p>
<p>Southern Plains Indian Housing Association</p>	<p>A regional Indian housing authority located in Oklahoma.</p>	<p>Southern Plains Indian Housing Association Renee Sweet—President Chickasaw Nation Division of Housing PO Box 788 Ada, OK 74821</p> <p>Phone: 580-421-8880 ext. 48812 Email: renne.sweet@chickasaw.net Website: https://spiha.org/default.aspx</p>
<p>Southwest Tribal Housing Alliance</p>	<p>A regional Indian housing authority located in New Mexico.</p>	<p>Southwest Tribal Housing Alliance Floyd Tortalita—President Pueblo of Acoma Housing Authority PO Box 620 Acoma, NM 87034</p> <p>Phone: 505-552-7528 Email: ftortalita@acomahousing.org Website: https://www.swtha.org/</p>

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Organization	What	Contact
Sustainable Native Communities Collaborative (SNCC)	SNCC provides culturally and environmentally sustainable development with American Indian, First Nations, and indigenous communities worldwide. Services include planning, architectural design, technical assistance, and research.	Sustainable Native Communities Collaborative www.sustainablenativecommunities.org Reach out to SNCC at: https://www.sustainablenativecommunities.org/contact A “Healthy Housing Roadmap” for housing development: http://roadmap.sustainablenativecommunities.org/
United Native American Housing Association	A regional Indian housing authority located in Montana.	United Native American Housing Association Jason Adams—Chairman Salish & Kootenai Housing Authority PO Box 38 Pablo, MT 59855 Phone: 406-675-4491 Website: http://unaha.org/
United Southern and Eastern Tribes	A regional Indian housing authority located in Tennessee.	United Southern and Eastern Tribes Kirk Francis, SR—President Penobscot Indian Nation 711 Stewarts Ferry Pike Nashville, TN 37214 Phone: 615-872-7900 Fax: 615-872-7417 Website: https://www.usetinc.org/
U.S. Department of Housing and Urban Development	HUD offers assistance and loan programs specifically for Native American tribes, organizations, and (sometimes) individuals. HUD offers basic information on homebuying, fair housing, and housing counseling. The HUD Office of Native American Programs offers grant assistance through four main programs; two programs are focused on tribal communities and two are focused on individuals.	HUD Office of Public and Indian Housing (PIH); HUD Office of Native American Programs (ONAP) 451 7th Street SW Washington, DC 20410 Phone: 202-708-1112 Fax: 202-708-1455 The Code Talk website administered by HUD is also an excellent resource for program information. https://www.hud.gov/codetalk

Organization	What	Contact
U.S. Department of Housing and Urban Development Indian Housing Block Grant (IHBG)	A formula-based grant program. Tribes use IHBG resources for housing assistance, development, services, management, and funding model approaches.	https://www.hud.gov/program_offices/public_indian_housing/ih/grants/ihbg
U.S. Department of Housing and Urban Development Indian Community Development Block Grant (ICDBG)	Indian Community Development Block Grant is an annual competitive single-purpose grant for developing Indian and Alaska Native communities via housing rehabilitation, land acquisition, construction of community facilities and infrastructure, and economic development activities to benefit people with low and moderate incomes.	https://www.hud.gov/program_offices/public_indian_housing/ih/grants/icdbg
U. S. Department of Housing and Urban Development Low Income Housing Tax Credit (LIHTC)	LIHTC issues approximately \$8 billion annually in tax credits for the acquisition, rehabilitation, or new construction of rental housing targeted to lower-income households.	https://www.huduser.gov/portal/datasets/lihtc.html List of LIHTC allocating agencies https://lihtc.huduser.gov/agency_list.htm
U.S. Department of Housing and Urban Development Section 184 Indian Home Loan Guarantee Program	Section 184 Indian Home Loan Guarantee Program increases AI/ANs access to homeownership by providing a guarantee to lenders on mortgage loans. Loans can be used, both on and off Native lands, for new construction, rehabilitation, purchase of an existing home, or refinance.	https://www.hud.gov/program_offices/public_indian_housing/ih/homeownership/184

Organization	What	Contact
U.S. Department of Housing and Urban Development Section 202 Supportive Housing for the Elderly Program	HUDs Section 202 provides interest-free capital advances to private, nonprofit sponsors to finance the development of supportive housing for older adults. The capital advance does not have to be repaid as long as the project serves older adults with very low income for 40 years.	https://www.hud.gov/program_offices/housing/mfh/progdesc/eld202
U.S. Department of Housing and Urban Development Section 811 Supportive Housing for Persons with Disabilities	Section 811 Supportive Housing for Persons with Disabilities provides interest-free capital advances and operating subsidies to nonprofit developers of affordable housing for people with disabilities; and provides project rental assistance to state housing agencies.	https://www.hud.gov/program_offices/housing/mfh/progdesc/disab811 Section 811's Portal https://www.hud.gov/program_offices/housing/mfh/grants/section811ptl
U.S. Department of Housing and Urban Development Title VI Loan Guarantee Program	Title VI Loan Guarantee Program Assists Indian Housing Block Grant recipients (borrowers) who want to finance eligible affordable housing activities but are unable to secure financing without the assistance of a federal guarantee.	https://www.hud.gov/program_offices/public_indian_housing/ih/homeownership/titlevi
U.S. Department of Interior. Indian Affairs. Housing Improvement Program (HIP)	HIP is a home repair, renovation, replacement, and new housing grant program.	https://www.bia.gov/bia/ois/dhs/housing-improvement-program
Visitability The website is hosted by the National Council on Independent Living.	Provides resources and information about visitability.	https://visitability.org/ To contact visitability: https://visitability.org/contact/

Chapter 10: Key Elements of Effective Programs



“Often, people think we’re a culture that needs rescuing, and we’re not. We’re a people who are very resilient, very strong, and we want to be partners in creating systems that are effective and matter. We don’t want to be served; we want to be part of building service structures.”

Dr. Crystal Hernandez, Advocate and parent of a child with a disability

A 2021 panel of experts who work in programs that support AIAN people with disabilities described the elements of effective AIAN programs listed below.

Responsiveness to the Needs of the Consumer

Successful programs require staff to know all their consumers well. The staff move beyond a consumer’s needs to build authentic personal relationships with consumers. Staff try to understand the realities experienced by tribal members with disabilities. In turn, the staff can

influence program structures and tailor services around the unique needs of each consumer and each tribal community. These are person-centered programs.

Innovation in Removing Barriers

“Necessity is the mother of invention” describes how tribal programs came to innovate. They partner with other entities, advocates, people with disabilities, and their families. They are responsive and collectively remove barriers, realign, and expand programs to seamlessly serve the community.

Effective Collaboration

A program's capacity to effectively collaborate between agencies, programs, and funding sources means establishing trust, building relationships, educating, learning, and listening to all partners in service of tribal members with disabilities.

Advocacy Strength

To be an advocate is to believe in the rights of people with disabilities and their inclusion in all aspects of a barrier-free society. Advocates work to change laws, politics, programs, and attitudes through training, testimony, and action. People with disabilities are self-advocates and essential voices in understanding how to serve their interests. Advocacy is necessary for tribal members with disabilities who don't know how or can't advocate for themselves.

Support from Tribal Leadership

Leaders of tribal programs serving AI/AN people with disabilities credit their success to support

from tribal governmental leaders. The ways tribal governments have supported their tribal members with disabilities include enacting disability rights' laws, policies, and procedures, issuing funds, establishing disability councils or taskforces, and continuously educating the community about inclusion and the rights of people with disabilities.

Conclusion

Despite substantial barriers, tribal members with disabilities can enjoy restored health, spiritual well-being, and inclusion in all aspects of society. It requires hopeful and persistent leadership to forge a collaborative and integrated system of culturally relevant, person-centered programs, policies, procedures, educational initiatives, and more. By implementing the key elements of promising programs and the leadership model described by Freeman, strength and wholeness can be the lived experience of the entire tribal community.

Chapter 11: Advocating Change

“We need more inclusion of people with disabilities in the decision-making process in all the programs that affect our lives, housing, health care, Vocational Rehabilitation.”

Joseph Ray



Introduction

While the word “advocacy” may not be used in many Native cultures, it has deep roots within Native communities as kinship care. The structure of kinship care is the long and proud tradition of taking care of your relatives, elders, and community and of creating a community support system (Generations United & National Indian Child Welfare Association, 2020).

Self-advocacy is viewed as a civil rights movement, so every person has control over their own life, and people with disabilities are treated the same as everyone else.

Self-advocacy beliefs and values:

- Being a person first
- Being able to make our own decisions
- Believing in my value as a person

- Having other people believe in you as a person
(Minnesota Department of Administration)

Self-advocacy is a lifelong personal pursuit of control over one’s own circumstances. It is the act of advocating for what one wants, for how one desires to live, for how one wants to be treated, within one’s family, community, and services, and it does not end with one concession or victory.

Bonnie Shoultz, 2002

There are three commonly recognized types of advocacy:

- Self-advocacy is an individual’s ability to effectively communicate, convey, negotiate, or assert his or her own interests, desires, needs, and rights.

- Individual advocacy is when a person speaks out and advocates for a vulnerable person, such as a friend, family member, neighbor, or coworker with a disability. There are also paid advocates who are employed by a support agency.
- Systems change advocacy focuses on changing policies, laws, or rules that impact how others live their lives (West Virginia University Center for Excellence in Disabilities).

Allyship and Advocacy

An ally is someone who is associated with another person or marginalized group for a common cause or purpose. According to the Centers for Disease Control and Prevention, a person can become a disability A.L.L.Y. in their community and promote inclusion for all by implementing the A.L.L.Y. acronym.

A – Acknowledge and respect individual experiences and abilities

L – Learn about different disability types

L – Leverage your influence to promote accessibility and inclusion

Y – Yield the floor to people with disabilities to help identify and eliminate barriers

(Centers for Disease Control and Prevention)

A common refrain from people with disabilities is, “Nothing about me without me.” As an ally and advocate, it’s important to remember that all people need support, advice, and encouragement in their daily lives. Advocates have an ethical obligation to represent the desires and needs of the person they represent. Your role is to support the person to exercise his or her rights by assisting to voice concerns, access

information, resolve issues, identify available support options, and to share with the person the joy of community.

Self-Advocacy

Kindred care is a feature of nearly all American Indian and Alaska Native cultures. Kindred care means tribal members take care of relatives, elders, and the community. The extended family structures and supportive community systems empower kindred care. Advocacy is a form of kindred care. When you advocate to bring about change to help yourself or others, you are demonstrating a form of kindred care (Generations United 2020).

Even in the 21st century, the need for advocacy endures and will likely never end. As Native people, we must continue to fight for self-determination and against oppression.

Tribes differ greatly in their awareness of and attitudes about tribal members with disabilities, as does their capacity and willingness to address the needs of tribal members with disabilities. It is very important that consumers speak up about services offered by tribes, tribal programs, and county, state, and federal agencies.

Jo White, of the Pine Ridge Quad Squad, teaches self-advocacy by telling consumers that if there are no access ramps into a building for you, and they don’t provide access after you have requested them, then you plant yourself on the steps of that building and make them carry you into the building. You keep doing that, she says, and they will finally get tired of carrying you and build you a ramp.

Four Steps to Self-Advocacy

To effectively advocate for yourself, it’s important to invest time in developing an effective strategy. The four steps that will help you be successful

are research, preparation, influencing, and following up.

Step 1: Research

Do your homework and have information about the issue so you can effectively persuade others to do what's right.

A. *Learn Everything About the Issue*

Be familiar and knowledgeable about all aspects of the issue to give you confidence and able to counter opposing arguments.

B. *Have Detailed Goals*

Make specific, achievable goals. Remember small victories can lead to big changes.

C. *Develop Solutions*

Offer solutions to address the issues you are advocating for.

D. *Identify Stakeholders*

Identify the people, organizations, and tribal leaders who can help bring the change you want to make. Know their feelings about the issue. Are they opposed, neutral, or in agreement? Next, create a network of people who are in agreement with your position and contact them for help and information as needed.

Step 2: Preparation

The second step is to develop a plan of what to communicate and how. You can communicate in face-to-face meetings, by telephone, in online meeting platforms such as Zoom and Teams, by a slide presentation, by social media, emails, letter writing, webinars, and town halls.

Practice what to say and ask others for feedback. This will build confidence and help

you create a convincing argument. To develop an effective and memorable message, be:

A. *Clear, Concrete, and Concise*

Be as clear and as brief as possible.

Condense both the issue and solution into a one- or two-page letter, one or two slides, or a couple minutes of speech.

B. *Use Your Own Experience*

To increase your audience's understanding of the issue, use your own experience to show how you were affected. This personal touch can be very powerful.

C. *Adjust Your Content for Specific Audiences and Formats*

The focus of your message will be determined by your intent (your ask) and the audience. For example, advocating for a policy change before a tribal council will be quite different than a face-to-face meeting with a service provider where you are advocating for a specific resource.

Step 3: Influencing

To influence decision makers to adopt your solution, model effective communication.

A. *Be an Active Listener*

Listen. Be respectful and attentive when other people speak.

B. *Ask Questions*

When advocating, always ask questions of both your allies and your opponents. It will help you understand other people's perspectives and may help you see a different solution.

C. *Document Your Interactions*

Keep notes (in writing or make a video) of meetings and phone calls so you have accurate documentation of what happened. Be sure to include the date, time, who you spoke with or was in attendance, and what was said.

Step 4: Following Up

Advocacy is a process, remember change remember change does not happen overnight. Consistency and timely follow-up are essential to successful advocacy.

A. *Perseverance*

You should persist with reaching out and following up. It may take many attempts and longer than you thought it would, but your efforts will help raise awareness and bring about change.

B. *Allies*

Allies are the people who support you. Use your allies to think of new ways to communicate about the issue you want addressed.

Advocacy Burnout

Resistance is NOT a one-lane highway. Maybe your lane is protesting; maybe your lane is organizing; maybe your lane is counseling; maybe your lane is art activism; maybe your lane is surviving the day. Do NOT feel guilty for not occupying every lane. We need all of them.

Lindsey Young

Advocacy burnout is an emotional, physical, and mental state of cumulative stress brought

on by severe exhaustion. It can lead to a lack of interest in activities that were once meaningful. When encountering disinterested leaders or discrimination, it may feel like advocating is an uphill battle and a thankless job. To protect your overall well-being, self-care is important.

To avoid advocacy burnout, Jennifer Brown describes several strategies in her blog, “*How Advocates for Inclusion Keep from Burning Out*” (Brown 2020).

Strategies to Avoid Advocacy Burnout

1. **Voice your inner distress**

Give yourself permission to vent your frustrations. Write about the situation in a journal. Talk with someone you are close to. Say it out loud to yourself.

2. **Disentangle your sense of self from work**

Reframe your work as merely one part of yourself, rather than an all-consuming identity or lifestyle. Examine the ratio between how much energy is spent on advocacy versus energy spent in other areas. Reflect on whether these divisions are balanced. To ensure your advocacy work can be sustained, devote time to other things, such as family, the community, celebrations, hobbies, and other responsibilities or interests.

3. **Learn to say no, even when you want to say yes**

If you are passionate about making the world more equitable, you may feel compelled to agree to attend every committee meeting, webinar, appointment, and side project. This is a quick route to burnout. Let go of the guilt that you are not

doing enough because there's no shame in saying no sometimes or asking others to help. It's important to pace yourself and manage your mental health.

4. **Work incrementally and celebrate small victories**

Establish small, achievable goals and rewards and celebrate these victories. Try listing three recent successes (however minor) and use these moments as fuel for motivation.

5. **Reconnect with your support network and lean on your loved ones**

Chances are the more isolated you feel, the more likely it is you will feel overwhelmed and hopeless. To care for yourself, reach out to your circle of loved ones, give up some of your advocacy work, delegate the work to

others, and reconnect with the human side of your work to reignite a sense of purpose.

Systems Change Advocacy

Systems change advocacy is the process of making positive changes in our society that improves the quality of life for people with disabilities. Systems change advocacy influences:

- The creation of new laws or changes to current law
- The priorities and plans of government and nongovernment agencies
- The policies and procedures that relate to services or systems (The Public Advocate, 2019)

There are systems change advocates employed by organizations that serve the disability community. These professional

What Do Systems Change Advocates Do?

A systems advocate is a person who advocates for the needs and rights of a group of people (people with a disability).

A systems advocate would work or advocate to change laws. For example, an advocate might work for a law that allows ALL people with very low-incomes to receive subsidized housing.

A systems advocate needs to be aware of tribal, neighborhood, city, county, state, and federal processes where decisions are being made.

A systems advocate should be in contact with many people, so they can affect the decision makers at all levels.

A systems advocate should participate in public hearings, advisory committees, public forums during governmental meetings, and any setting where public policy is being debated.

Writing letters to public officials in support of legislation that will positively affect the group as a whole is a common form of systems change advocacy.

advocates seek to bridge the gap between the disabled community and elected officials by educating both about issues of importance and how the disabled community could be impacted. The major components of an advocacy program include organizing, advocating, and educating.

For example, the Navajo Nation has an Advisory Council on Disability. In 2021, the Navajo Nation held the 12th Annual Disability Conference with the theme of “We Walk in Beauty, Beyond Our Disability.” The conference aired on KTNN radio and some sessions can be found on YouTube. The conference held sessions on:

- Updates of legal rights of people with disabilities at federal, state, and Navajo Nation level
- Navajo Nation Advisory Council on Disability initiatives
- Educational presentations

Tribal Leadership Advocacy

As sovereign nations, tribal nations have different avenues of advocacy. Tribal leaders will be successful advocates and create inclusive policies and laws when they have a solid understanding of the issues faced by AI/AN people with disabilities.

Guidelines for Writing a Resolution

To achieve the goal of building inclusive and equitable communities, it often begins with the passage of tribal policy through resolutions. Each tribe and Indian organization has its procedures set out for the creation and approval of resolutions. This section provides general guidelines on how to develop and present a resolution, including sample resolutions approved by the National Congress of American Indians.

Purpose of Submitting a Resolution

The purpose of writing a resolution is to provide a formal procedure so members of the tribal governing body can give input concerning policy and activities. A resolution is a means of expressing an opinion on a pressing matter or of recommending that some action be taken by the tribal governing body or other agency.

Useful types of resolutions include the following:

- A request that the tribal governing body develop protections and accommodations for tribal members with disabilities
- A request that the tribal governing body establishes a new program or activity or reconsider a current tribal program or activity
- A request that the tribal governing body change its operating procedures

When drafting and sponsoring a resolution, the wording must be carefully crafted and accurately defined. The resolution should be clear, concise, and specific. Sponsors should expect to introduce resolutions from the floor and to make impromptu defenses of the document throughout the session. Review existing tribal resolutions and follow that format.

Resolution Format

Resolutions may originate from tribal government leaders, community advocates, or organization members.

The resolution format needs to include the resolution number, title, date, a “whereas” section that clearly defines the problem and possible resolution, certification by the tribe or organization leaders, a “refer to” designation, and

Resolutions Components

Resolution Number: Supplied by the organization's secretary

Title: Should reflect the action for which the resolution calls.

Date: Date submitted

Whereas: Statements should clearly define the problem and state a solution is possible. There should be 3–4 "Whereas" statements to maintain focus. Use the tribal governing body "Whereas" template if one exists.

Resolve: Each "resolved" portion of the resolution requests action by the tribal governing body.

Certification: This section signifies the resolution was formally adopted by the tribal governing body.

Refer to: Each tribe's governing body has a referral process. Check with the designated secretary or tribal governing body.

Author/Contact Person: This section indicates the individual who drafted the resolution and can be contacted for clarification

the contact information for the person filing the resolution form. These components are detailed in the descriptions that follow.

Sample resolutions follow.

The National Congress of American Indians Resolution # MSP-15-012

Title: Support Expansion of Employment Services to American Indians/Alaska Natives with Disabilities

WHEREAS, we, the members of the National Congress of American Indians of the United States, invoking the divine blessing of the Creator upon our efforts and purposes, in order to preserve for ourselves and our descendants the inherent sovereign rights of our Indian nations, rights secured under Indian treaties

and agreements with the United States, and all other rights and benefits to which we are entitled under the laws and Constitution of the United States, to enlighten the public toward a better understanding of the Indian people, to preserve Indian cultural values, and otherwise promote the health, safety and welfare of the Indian people, do hereby establish and submit the following resolution; and

WHEREAS, the National Congress of American Indians (NCAI) was established in 1944 and is the oldest and largest national organization of American Indian and Alaska Native tribal governments; and

WHEREAS, there are nearly 1 million American Indians and Alaska Natives (AI/AN) who live with disabilities and nearly 600,000

of this population are of working age and that represents the highest rate of disability among any other demographic group; and

WHEREAS, the NCAI recognizes that AI/ANs with disabilities were not being well served by the states' Vocational Rehabilitation (VR) services and that this is mainly due to the lack of culturally-centered services, because much like with the Veteran population, tribal people find it difficult to seek services in the traditional VR setting; and

WHEREAS, tribal governments asserted their sovereignty and called for the establishment of tribal vocational rehabilitation programs called American Indian Vocational Rehabilitation Services (AIVRS) funded by the U.S. Department of Education, Rehabilitation Services Administration (RSA) work by using culturally centered services to assist AI/ANs with disabilities find and obtain meaningful employment and consistently have a nearly 60% placement rate; and

WHEREAS, while progress has been made to increase the number of AIVRS programs serving Indian Country, there remains a significant gap in available programs versus the number of AI/ANs with disabilities needing culturally-centered services and of the 600,000 working age AI/ANs with a disability, AIVRS programs are currently serving less than 10,000; and

WHEREAS, this vulnerable part of our people are literally in crises and are crying out for the hope and the dignity of being able to care for themselves and their families by attaining meaningful employment and loss of hope for those with disabilities who cannot find employment contributes to the alarming suicide rates in Indian Country, finding ways to instill hope in them is paramount.

NOW THEREFORE BE IT RESOLVED, that the NCAI supports that the American Indian Vocational Rehabilitation Services programs continue providing culturally-centered services to their people and increase the number served and that the programs have demonstrated that culture and language are the keys in providing quality services; and

BE IT FURTHER RESOLVED, that the NCAI urges Congress and federal agencies to support direct permanent funding for AIVRS programs in addition to legislation and federal policies that increases the tribal set-aside for AIVRS programs to 5%; and

BE IT FURTHER RESOLVED, that the NCAI supports legislation and federal policies that establish Tribally-Controlled Satellite Services to meet the needs of Indian Country; and

BE IT FINALLY RESOLVED, that the NCAI urges Congress and federal agencies, including the U.S. Department of Education, to ensure that programs serving AI/ANs with a disability are administered and operated by tribally-controlled organizations that provide services in a culturally-centered manner, so as to improve the opportunities and resources for those living with disabilities, and that they may freely strive to realize their full potential; and

BE IT FURTHER RESOLVED, that the NCAI recognizes and supports the mission of the Consortia of Administrators of Native American Rehabilitation (CANAR) to empower American Indians and Alaskan Natives with disabilities through education and advocacy, and their work in bringing technical assistance training and capacity building to AIVRS programs; and

BE IT FURTHER RESOLVED, that this resolution shall be the policy of NCAI until it is withdrawn or modified by subsequent resolution.

Certification

The foregoing resolution was adopted by the General Assembly at the 2015 Midyear Session of the National Congress of American Indians, held at the St. Paul River Centre, St. Paul, MN, June 28 to July 1, 2015, with a quorum present.

Brian Cladoosby, President

ATTEST: Aaron Payment, Recording Secretary

The National Congress of American Indians Resolution # ABQ-10-088

Title: Urge Congress and US Federal Agencies to Support Native Parents of Children with a Disability through Tribally-Driven Organizations and Service Providers

WHEREAS, we, the members of the National Congress of American Indians of the United States, invoking the divine blessing of the Creator upon our efforts and purposes, in order to preserve for ourselves and our descendants the inherent sovereign rights of our Indian nations, rights secured under Indian treaties and agreements with the United States, and all other rights and benefits to which we are entitled under the laws and Constitution of the United States, to enlighten the public toward a better understanding of the Indian people, to preserve Indian cultural values, and otherwise promote the health, safety and welfare of the Indian people, do hereby establish and submit the following resolution; and

WHEREAS, the National Congress of American Indians (NCAI) was established in 1944 and is the oldest and largest national organization of American Indian and Alaska Native tribal governments; and

WHEREAS, at 28%, American Indians/Alaska Natives (AI/AN) have the highest ratio of disability than any other race and have a tremendous need to access culturally-appropriate services; and

WHEREAS, the NCAI has a longstanding policy to support the unique needs of AI/ANs living with a disability, and that Native parents of children with a disability need this support as they work with public/tribal/government school systems to provide educational opportunities that are essential in order for their children to become independent and self-sufficient; and

WHEREAS, the NCAI recognizes that for too long services have been provided to AI/ANs by non-Indian organizations that lack the cultural understanding to effectively work with Native peoples, and the NCAI also has a longstanding policy to support the need for full exercise of tribal self-determination and self-governance in caring for the needs of our own people collectively through the services of tribally driven organizations and service providers; and

WHEREAS, the NCAI recognizes that by supporting programs serving AI/ANs to be administered and operated by tribally-driven organizations it alleviates the unfortunate, but inevitable, culture clashes that often arise when differing value systems and management methods collide.

NOW THEREFORE BE IT RESOLVED, that the NCAI urges Congress and federal agencies that authorize, and award grants meant to serve tribal communities and AI/AN parents of children with a disability to take action in respect for the principles of self-determination and self-governance by ensuring that these grant recipients are tribally-driven organizations and/or service providers; and

BE IT FURTHER RESOLVED, that the NCAI urges Congress and federal agencies, including the U.S. Department of Education and the U.S. Department of Health and Human Services, to ensure that programs serving AI/AN parents

of children with a disability are administered and operated by tribally-driven organizations that provide services in a culturally appropriate manner, so as to improve the opportunities and resources for those living with disabilities, and that they may freely strive to realize their full potential; and

BE IT FINALLY RESOLVED, that the NCAI urges federal agencies to exercise their fiduciary responsibility and seek to recruit and retain qualified AI/AN candidates to direct and carry out the day to day delivery of services to AI/AN parents of children with disabilities within the auspices of a tribally-driven organization; and

BE IT FINALLY RESOLVED, that NCAI urges tribal nations to support tribally driven programs and organizations that seek to serve AI/AN parents of children with a disability; and

BE IT FINALLY RESOLVED, that this resolution shall be the policy of NCAI until it is withdrawn or modified by subsequent resolution.

Certification

The foregoing resolution was adopted by the General Assembly at the 2010 Annual Convention of the National Congress of American Indians, held at the Albuquerque Convention Center in Albuquerque, NM, on November 14–19, 2010, with a quorum present.

Jefferson Keel, President

ATTEST: Mathew Wesaw, Recording Secretary

The National Congress of American Indians Resolution # ATL-14-060

Title: NICOA Elders Request Long Term Care Funding

WHEREAS, we, the members of the National Congress of American Indians of the

United States, invoking the divine blessing of the Creator upon our efforts and purposes, in order to preserve for ourselves and our descendants the inherent sovereign rights of our Indian nations, rights secured under Indian treaties and agreements with the United States, and all other rights and benefits to which we are entitled under the laws and Constitution of the United States, to enlighten the public toward a better understanding of the Indian people, to preserve Indian cultural values, and otherwise promote the health, safety and welfare of the Indian people, do hereby establish and submit the following resolution; and

WHEREAS, National Indian Council on Aging, Inc. (NICOA) was established in 1976 by Tribal Leaders to advocate for improved comprehensive health, social services, and economic wellbeing for American Indian and Alaska Native Elders. NICOA, submits to the National Congress of American Indians (NCAI) this resolution passed by its members at their biennial meeting on September 5, 2014; and

WHEREAS, as the American Indian/Alaska Native Elder population increases, the urgent need for long term care services and supports also increases. According to the Administration on Aging, the number of AI/AN people age 65 and older is projected to increase by nearly 75% between 2010 and 2020. The Centers for Disease Control and Prevention found that Native people overall were 50.3% more likely to have a disability, when compared with the national average. Overall AI/AN populations experience some of the highest rates of chronic disease and disability in the U.S; and

WHEREAS, a 2010 survey by R. Tuner Goins, Ph.D. found that out of 566 tribes only 15 percent

of tribes had nursing home services and 16 percent had assisted living services; and

WHEREAS, The Affordable Care Act and its dual legislation, the Indian Healthcare Improvement Act grants the Indian Health Service (IHS) specific authorities for provision of long term care; and

WHEREAS, the aforementioned legislation only authorizes IHS to provide services but does not mandate any new funding specific to long-term care. The Indian Health Service does provide care but has been underfunded for decades. A 2005 GAO report titled "Indian Health Service: Health Care Services Are Not Always Available to Native Americans" highlighted the ongoing problems of long wait times, lack of adequate facilities and rationing of care due to lack of funding; and

WHEREAS, adequate appropriations are needed to address this impending health crisis.

NOW THEREFORE BE IT RESOLVED, that NCAI does hereby call on the Obama administration to request and for Congress to authorize and appropriate adequate funding for the provision of long term care services and supports in addition to home and community based services for American Indian and Alaska Natives; and

BE IT FURTHER RESOLVED, that this resolution shall be the policy of NCAI until it is withdrawn or modified by subsequent resolution.

Certification

The foregoing resolution was adopted by the General Assembly at the 2014 Annual Session of the National Congress of American Indians, held at the Hyatt Regency Atlanta, October 26-31, 2014 in Atlanta, Georgia, with a quorum present.

Resolution No. _____

SAMPLE RESOLUTION OF THE GOVERNING BODY OF

A RESOLUTION TO SUPPORT THE ESTABLISHMENT OF NEEDED ACCESSIBILITY TO NATIVE AMERICANS WITH DISABILITIES

BE IT RESOLVED BY THE COUNCIL OF THE _____ THAT THERE IS A NEED TO PROVIDE ACCESSIBILITY TO NATIVE AMERICANS WITH DISABILITIES:

WHEREAS, the _____ respect the lives of all of our people and recognize that our people are the most important tribal resource; and

WHEREAS, the _____, utilizing the authority vested in them pursuant to the Tribal Constitution, has authority to protect the health, security, and general welfare of the _____; and

WHEREAS, the _____ recognize the need for tribal facilities, including recreational areas, powwow grounds, and other tribal areas that are operated and maintained by the _____ to be in compliance with the spirit of the American with Disabilities Act of 1990, Public Law 101-336 (104 Stat. 327) (ADA); and

WHEREAS, the _____ recognize that no individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, and accommodations of any place of tribal accommodation; and

WHEREAS, the _____ further recognize that the objective of the ADA is to provide mobility for Americans with disabilities and to enable them to lead normal and productive lives; and

WHEREAS, the _____ are aware that an estimated __ percent of the Native American population have disabilities and are denied social and economic enjoyment taken for granted by others who have no disabilities, e.g., employment and recreational activities, and

WHEREAS, the _____ are also aware that respondents to a recent survey of the American Indian Disability Legislation indicated that approximately 67 percent of the public buildings on the various Indian reservations are accessible, leaving one-third of the public buildings inaccessible; and

WHEREAS, the _____ have identified a need to develop a tribal policy implementing the ADA in our present facilities, as well as any future (new or reconstructed) facilities; and

NOW, THEREFORE, BE IT RESOLVED, that the _____ recognize that our people with disabilities are entitled to accessibility to our tribal facilities, recreational sites, powwow grounds, and other areas.

BE IT FURTHER RESOLVED, that the _____ are committed to developing a tribal policy to address and comply with ADA.

AND BE IT FURTHER RESOLVED, that there shall be an established committee to assist in the review process addressing the application of appropriate ADA accessibility guidelines.

AND BE IT FURTHER RESOLVED, that the _____ shall direct the Tribal Division of _____ and _____, and any other tribal department whose involvement will be necessary to address and meet the guidelines of the ADA and to participate in said committee to ensure compliance.

Certification

The foregoing resolution was adopted by the Tribal Council on the ____ day of _____. _____, with a vote of ____ for, _____ opposed, and _____ not voting, pursuant to authority vested in _____ by _____ as amended.

Chair, Tribal Council

ATTEST:

Executive Secretary

*Thanks to the Confederated Salish and Kootenai Tribes for use of their tribal resolution to improve the overall quality of life for tribal members with disabilities.

Resources

Organization	What They Do	Contact Information
National Association of Councils on Developmental Disabilities (NACDD)	This is the national association of the 56 councils on developmental disabilities in the U.S. and its territories. Federal funds support DD Councils to provide programs that promote self-determination, integration, and inclusion for all people with developmental disabilities.	NACDD 1825 K Street, Suite 600 Washington, DC 20006 Phone: 202-506-5813 https://www.nacdd.org/
National Congress of American Indians (NCAI)	The oldest and largest representative American Indian and Alaska Native organization serving the broad interests of tribal governments and communities.	NCAI 1516 P Street NW Washington, DC 20005 Phone: 202-466-7767 Fax: 202-466-7797 https://www.ncai.org/
National Disability Rights Network (NDRN)	NDRN is the nonprofit membership organization for the federally mandated Protection and Advocacy (P&A) Systems and the Client Assistance Programs (CAP) for people with disabilities.	NDRN 820 First Street, NE, Ste 740 Washington, DC 20002 Phone: 202-408-9514 Fax: 202-408-9520 TDD/TTY: 202-408-9521 https://www.ndrn.org/ To find your state P&A/CAP: https://www.ndrn.org/about/ndrn-member-agencies/
Native American Disability Law Center (NADLC)	NADLC provides advocacy, referral information, and educational resources to all Native Americans with a disability living anywhere in the Four Corners area who feels that they have been: <ul style="list-style-type: none"> ▪ discriminated against because of their disability ▪ abused or neglected ▪ wrongly denied a service 	NADLC 905 W. Apache Street Farmington, NM 87401 Phone: 505-566-5880 Fax: 505-566-5889 https://www.nativedisabilitylaw.org/
University Centers for Excellence in Developmental Disabilities (UCEDD)	UCEDDs work with people with disabilities, members of their families, state and local government agencies, and community providers in projects that provide training, technical assistance, service, research, and information sharing, with a focus on building the capacity of communities to sustain all their residents.	To find your local UCEDD: https://www.aucd.org/directory/directory.cfm?program=UCEDD

Disability Etiquette Handbook

People with disabilities are people first. They are not their conditions or diseases. Lack of awareness about disabilities can lead to unintended stereotypes and discrimination. How we view and communicate with and about people with disabilities shape our relationships. This guiding principle is the same in American Indian and Alaska Native communities as it is in the general population. American Indian and Alaska Native people with disabilities want to be dealt with as people.

This handbook is for anyone—with or without a disability—who wants to interact more effectively with people with disabilities. This section contains information and awareness-building resources to assist in developing effective and respectful communication practices within our Native communities. This resource can be particularly useful to new program staff who have not worked in the area of disabilities before and to help orient tribal leaders and other community program staff who want to better understand how to work effectively for people with disabilities in tribal communities. The AI/AN consumers who served on the Technical Expert Panel that designed this Toolkit believed very strongly that a brief guide was needed to help tribal programs and tribal leaders understand fundamental dos and don'ts.

From the San Antonio Disability Etiquette 2011 publication:

Distinction Between Disability and Handicap

A Disability is a condition caused by an accident, trauma, genetics or disease which may limit a person's mobility, hearing, vision, speech or mental function. Some people with disabilities have one or more disabilities.

A Handicap is a physical or attitudinal constraint that is imposed upon a person, regardless of whether that person has a disability. Webster's Ninth New Collegiate Dictionary defines handicap as "to put at a disadvantage".

Example: Some people with disabilities use wheelchairs. Stairs, narrow doorways and curbs are handicaps imposed upon people with disabilities who use wheelchairs.

People with disabilities have all manner of disabling conditions:

- mobility impairments
- blindness and vision impairments
- deaf and hard of hearing
- speech and language impairments
- cognitive and learning impairments

The information provided below this paragraph and to the end of the chapter is directly quoted from the United Spinal Association, Disability Etiquette 2015 publication:

The Basics

Ask Before You Help

Interact with the person as a person first! Just because someone has a disability, don't assume he or she needs help. Adults with disabilities want to be treated and viewed as independent. Offer assistance only if the person appears to need it and ask how you may help before you act.

Be Sensitive About Physical Contact

Some people with disabilities depend on their arms for balance. Grabbing them—even if your intention is to assist—could knock them off balance. Avoid patting a person on the head or touching his wheelchair, scooter, or cane. People with disabilities consider their equipment part of their personal space.

Think Before You Speak

Always speak directly to the person with a disability, not to his companion, aide, or sign language interpreter. Don't apologize if you use an expression such as "I gotta run" or "See you later" that relates to the person's disability. These expressions are part of everyday language, and it is likely the apology will be more offensive than the expression.

Don't Make Assumptions

People with disabilities are the best judge of what they can or cannot do. Don't make decisions for them about participating in any activity.

Terminology Tips

Put People First

Refer to the individual first, then to his or her disability, when it is relevant and appropriate. Say "person with disability" rather than "disabled person" or use the following formula:

Name or Title of a Person	+	Verb	+	Assistive Device or Disability
Professor, student, person		<ul style="list-style-type: none"> ▪ Has ▪ Uses ▪ Utilizes etc. 		Wheelchair, autism, development delay, etc.

The following terms should be avoided in a disability context, because they have negative meanings:

- invalid
- wheelchair-bound
- defect
- handicapped
- victim
- suffers from
- crippled
- a patient

Don't portray people with disabilities as overly courageous, brave, special, or superhuman. This implies that it is unusual for people with disabilities to have talents or skills.

Avoid using the term "normal" to describe people who don't have disabilities. It is better to say "people without disabilities" or "typical," if necessary to make comparisons.

People Who Use Wheelchairs or Other Mobility Devices

People who use wheelchairs have different disabilities and varying abilities. Some can use their arms and hands. Some can get out of their wheelchairs and even walk for short distances.

People who use wheelchairs are individuals, not equipment. Don't lean over someone who uses a wheelchair to shake another person's hand or ask a wheelchair user to hold coats. Setting your drink on the desktop attached to someone's wheelchair is a definite no-no.

- Don't push or touch a person's wheelchair; it's part of their personal space. If you help someone down a curb without waiting for instructions, you may dump them out of the chair. You may detach the chair's parts if you lift it by the handles or the footrest.
- Keep the ramps and wheelchair-accessible doors to your building unlocked and unblocked. Under the ADA, displays should not be in front of entrances, wastebaskets should not be in the middle of aisles, and boxes should not be stored on ramps.
- Be aware of a person's reach limits. Place as many items as possible within their grasp. And make sure that there is a clear path of travel to shelves and display racks. When talking to a person using a wheelchair, grab your own chair and sit at their level. If that's not possible, stand at a slight distance so that they aren't straining their neck to make eye contact with you.
- If the service counter at your place of business is too high for a person using a wheelchair to see over, step around it to provide service. Have a clipboard handy if filling in forms or providing signatures is expected. A business may also want to make sure employees are prepared to angle down or detach a keypad so a person using a wheelchair can sign their electronic signature after making a credit card purchase.
- If your building has different routes through it, be sure that signs direct people to the accessible routes around the facility. People who use canes or crutches also need to know the easiest way to get around a place, but stairs may be easier for them than a ramp. Ensure that security guards and receptionists can answer questions about the most accessible way around the building and grounds, including the location of elevators.
- People who use canes or crutches need their arms to balance themselves, so never grab them. People who have limited mobility may lean on a door for support as they open it. Pushing the door open from behind or unexpectedly opening the door may cause them to fall. Even pulling out or pushing in a chair may present a problem. Always ask before offering help.
- If you offer a seat to a person who has limited mobility, keep in mind that chairs with arms or with higher seats are easier for some people to use.
- Falls are a big problem for people who have limited mobility. Be sure to set out adequate warning signs after washing floors. Also put out mats on rainy or snowy days to keep the floors as dry as possible. (Make sure they don't bunch up and make the floor impassable.)
- People who do not have a visible disability may have needs related to their mobility. For example, a person with a respiratory or

heart condition may have trouble walking long distances or walking quickly. Be sure that your museum, hotel, or department store has ample benches for people to sit and rest on.

- Some people have limited use of their hands, wrists, or arms. Be prepared to offer assistance with reaching, grasping or lifting objects, opening doors and display cases, and operating vending machines and other equipment.

People Who Are Blind

People who are blind know how to orient themselves and get around on the street. They are competent to travel unassisted and they may use a cane or a guide dog. A person may have a visual disability that is not obvious. Be prepared to offer assistance—for example in reading—when asked.

- Identify yourself before you make physical contact with a person who is blind. Tell them your name and your role if it's appropriate, such as security guard, usher, case worker, receptionist, or fellow student. And be sure to introduce them to others who are in the group so that they're not excluded.
 - If a new customer or employee is blind or has low vision, offer them a tour of your facility.
 - If you have changed your facility (e.g., rearranged the furniture), notify your customers who are blind of the changes.
 - People who are blind may need their arms for balance, so offer your arm—don't take theirs—if they need to be guided. (It is, however, appropriate to guide a blind person's hand to a banister or the back of a chair to help direct them to a stairway or a seat.)
- If the person has a guide dog, walk on the side opposite the dog. As you are walking, describe the setting, noting any obstacles, such as stairs ("up" or "down") or a big crack in the sidewalk. Other hazards include revolving doors, half-opened filing cabinets or doors, and objects protruding from the wall at head level, such as hanging plants or lamps. If you are going to give a warning, be specific. Hollering, "Look out!" does not tell the person if they should stop, run, duck or jump.
 - If you are giving directions, give specific, nonvisual information. Rather than say, "Go to your right when you reach the office supplies," which assumes the person knows where the office supplies are, say, "Walk forward to the end of this aisle and make a full right."
 - If you need to leave a person who is blind, inform them you are leaving and ask if they need anything before you leave.
 - Don't touch the person's cane or guide dog. The dog is working and needs to concentrate. The cane is part of the individual's personal space. If the person puts the cane down, don't move it. Let them know if it's in the way.
 - Offer to read written information—such as the menu, merchandise labels, or bank statements—to customers who are blind. Count out change so that they know which bills are which.
 - If you serve food to a person who is blind, let them know where it is on the plate

according to a clock orientation (12 o'clock is furthest from them, 6 o'clock is nearest). Remove garnishes and anything that is not edible from the plate. Some patrons may ask you to cut their food; this can be done in the restaurant's kitchen before the meal is served.

People With Low Vision

A person who has low vision may need written material in large print. A clear font with appropriate spacing is just as important as the type size. Labels and signs should be clearly lettered in contrasting colors. It is easiest for most people with low vision to read bold white letters on black background. Avoid using all uppercase letters because it is more difficult for people with low vision to distinguish the end of a sentence.

- Good lighting is important, but it shouldn't be too bright. In fact, very shiny paper or walls can produce a glare that disturbs people's eyes.
- Keep walkways clear of obstructions. If people with low vision regularly use your facility as customers or employees, inform them about any physical changes, such as rearranged furniture, equipment, or other items that have been moved.

The Deaf or Hard of Hearing

American sign language (ASL) is an entirely different language from English, with a syntax all its own. Lip reading is difficult for Deaf people if their first language is ASL because the majority of sounds in English are formed inside the mouth, and it's hard to lipread a second language.

People who have hearing loss, however, communicate in English. They use some hearing but may rely on amplification and/or seeing the speaker's lips to communicate effectively.

There is a range of communication preferences and styles among people with hearing loss that cannot be explained in this brief space. It is helpful to note that the majority of people who incurred a hearing loss as adults do not communicate with sign language, do use English, and may be candidates for writing and assistive listening devices to help improve communication. People with cochlear implants, like other people with hearing loss, will usually inform you what works best for them.

- When the exchange of information is complex (e.g., during a job interview or doctor's visit or when reporting a crime) the most effective way to communicate with a native signer is through a qualified sign language interpreter. For a simple interaction (e.g., ordering in a restaurant or registering for a hotel room) writing back and forth is usually okay.
- Follow the person's cues to find out if she prefers sign language, gesturing, writing or speaking. If you have trouble understanding the speech of a Deaf or Hard of Hearing person, let her know.
- When using a sign language interpreter, look directly at the Deaf person, and maintain eye contact to be polite. Talk directly to the person ("What would you like?"), rather than to the interpreter ("Ask her what she'd like:").
- Deaf people need to be included in the decision-making process for issues that affect them; don't decide for them.

- Before speaking to a Deaf or Hard of Hearing person, make sure that you get her attention. Depending on the situation, you can extend your arm and wave your hand, tap her on the shoulder, or flicker the lights.
- Rephrase, rather than repeat, sentences that the person does not understand.
- When talking, face the person. A quiet, well-lit room is most conducive to effective communication. If you are in front of the light source (e.g., a window) with your back to it, the glare may obscure your face and make it difficult for the Hard of Hearing person to lip read.
- Speak clearly. Most people who have a hearing loss count on watching people's lips as they speak to help them understand. Avoid chewing gum, smoking, or obscuring your mouth with your hand while speaking.
- There is no need to shout. If the person uses a hearing aid, it will be calibrated to normal voice levels; your shout will just distort the words.
- Deaf people and some who have hearing loss or speech disabilities make and receive telephone calls with the assistance of various technologies including a TTY (short for teletypewriter) or a Video Relay Service (VRS). VRS enables a person who is Deaf or Hard of Hearing to make and receive telephone calls through a communications assistant who is a qualified American Sign Language Interpreter. For many people who are Deaf or Hard of Hearing, VRS is closer to "functionally equivalent" telephone services than any other form

of relay service. For American Sign Language users, VRS conversations flow more smoothly, naturally, and faster than communicating by typing.

- When a TTY user calls a business that does not have a TTY, she places the call through her state's relay service. Likewise, a business that does not have a TTY can reach a customer who is a TTY user through the relay service. If you receive a relay call, the operator will identify it as such. Please do not hang up; this is the way that Deaf people are able to place an order at your pizza parlor, call your store to find out what hours you are open, or make a reservation at your restaurant.

People With Speech Disabilities

A person who has had a stroke, is Deaf, uses a voice prosthesis, or has a stammer or other type of speech disability may be difficult to understand.

- Give the person your full attention. Don't interrupt or finish the person's sentences. If you have trouble understanding, don't nod. Just ask them to repeat. In most cases the person won't mind and will appreciate your effort to hear what they have to say.
- If you are not sure whether you have understood, you can repeat for verification.
- If, after trying, you still cannot understand the person, ask them to write it down or to suggest another way of facilitating communication.
- A quiet environment makes communication easier.

- Don't tease or laugh at a person with a speech disability. The ability to communicate effectively and to be taken seriously is important to all of us.

Persons of Short Stature

There are 200 diagnosed types of growth-related disorders that can cause dwarfism and that result in the person being 4 feet 10 inches or less in height. For an adult, being treated as cute and childlike can be a tough obstacle.

- Be aware of having necessary items within the person's reach to the maximum extent possible.
- Be aware that people of short stature count on being able to use equipment that is at their height. Be sensitive about not using lower telephones, bank counters, and urinals if they are in limited supply.
- As with people who have other disabilities, never pet or kiss a person of short stature on the head.
- Communication can be easier when people are at the same level. People of short stature have different preferences. You might kneel to be at the person's level; stand back so you can make eye contact without the person straining her neck (this can be hard to do in a crowded room); or sit in a chair. Act natural and follow the person's cues.

People With Cerebral Palsy

As a result of injury to the central nervous system, people with cerebral palsy (CP) have difficulty controlling their muscles.

- Many people with CP have slurred speech and involuntary body movements. Your impulse may be to discount what they have to say, based on their appearance. Monitor your responses and interact with the person as you would with anyone else.
- A person who may appear to be drunk, sick, or have a medical emergency might in fact have CP or another disability. Get the facts before acting on your first impression, whether the situation is business, social, or law enforcement.

People With Tourette Syndrome

People with Tourette syndrome may make vocalizations or gestures such as tics that they cannot control. A small percentage of people with Tourette syndrome involuntarily say ethnic slurs or obscene words. An employee or other person with Tourette syndrome will benefit from the understanding and acceptance of coworkers and others.

- If a person with Tourette makes vocalizations during a conversation, simply wait for her to finish and then calmly continue.
- The more the person tries to contain these urges, the more the urges build up. It may be helpful for a person with Tourette to have the option to leave the meeting or conversation temporarily to release the build-up in a private place.

People Who Look Different

A different issue confronts people who may not be limited in their life activities, but who are treated as if they have a disability because of their appearance. People with facial

differences, such as cleft lip or palate, cranio-facial disfigurement, or a skin condition; people who are above or below the average height or weight; people who may display visible effects of medication, such as a tremor—in short, people who look different—have the frequent experience of finding people staring at them, looking away, or looking through them as if they are invisible.

- If the situation is appropriate, strike up a conversation and include the person in whatever is going on.

People With Hidden Disabilities

Not all disabilities are apparent. A person may make a request or act in a way that seems strange to you. That request or behavior may be disability-related.

For example, you may give seemingly simple verbal directions to someone, but the person asks you to write the information down. They may have a disability that makes written communication easier for them. Or a person may ask to sit, rather than stand, in line. This person may be fatigued from a condition such as cancer or may be feeling the effects of medication.

Even though these disabilities are hidden, they are real. Please respect the person's needs and requests whenever possible.

People With Epilepsy or Seizure Disorders

Epilepsy is a neurological condition characterized by seizures that happen when the electrical system of the brain malfunctions. The seizures may be convulsive or the person may appear to be in a trance. During complex partial seizures, the person may walk or make other movements while he is, in effect, unconscious.

- If a person has a seizure, you cannot do anything to stop it. If he has fallen, be sure his head is protected and wait for the seizure to end.
- When a seizure has ended, the person may feel disoriented and embarrassed. Try to ensure that he has privacy to collect himself.
- Be aware that strobe lights can trigger seizures in some people.

People With Multiple Chemical Sensitivity (MCS) and Respiratory Disabilities

People with MCS and respiratory disabilities such as asthma or emphysema react to toxins in the air. Stale air, fumes from cleaning products, perfume, carpeting, air freshener, or even the fumes from magic markers can trigger a severe reaction.

- Try to avoid spray-cleaning tables, windows, or other surfaces while people are in your place of business. If you must use a spray product, spray or pour it closely into the cloth, not into the air. Use less-toxic products when possible. Request that staff that have contact with the public go easy on fragranced body-care products like cologne, hair spray, hand lotion, and aftershave.
- Maintaining good ventilation and indoor air quality will not only benefit your customers who have MCS and respiratory disabilities, it will also help you and all of your employees stay healthier.
- Secondhand smoke can be particularly harmful to people with MCS or respiratory disabilities. Follow and enforce no-smoking

regulations, including in restrooms and stairwells. Discourage smokers from congregating at the entrance to your business. If appropriate, designate a separate smoking area where the door is kept closed and the air ventilates to the outside.

People With HIV & AIDS

People with human immunodeficiency virus (HIV) or Autoimmune Deficiency Syndrome (AIDS) have impaired immune systems, so their bodies have trouble fighting off infections.

- You can't catch HIV from casual contact such as shaking hands, so don't be afraid of touching or being touched by a person with AIDS.
- A person with HIV or AIDS, however, is at significant risk of picking up an airborne infection. Be conscious of not putting someone else at risk. If you have a respiratory infection or any other easily transmittable illness, be considerate of all your customers and employees and stay home, if possible.
- Many people with AIDS feel stigmatized. By simply greeting or shaking the person's hand, you are letting them know that they are accepted.

A word about confidentiality: You may really care, or you may just be curious about a person with a disability who is in crisis, suddenly ill, or misses work for unexplained reasons. In spite of your concern, please respect the privacy of a person with a disability. Allow them to discuss their situation if and when they feel comfortable doing so.

People with Psychiatric Disabilities or Mental Illness

People with psychiatric disabilities may at times have difficulty coping with the tasks and interactions of daily life. Their disorder may interfere with their ability to feel, think, or relate to others. Most people with psychiatric disabilities are not violent. One of the main obstacles they face is the attitudes that people have about them. Because it is a hidden disability, chances are you will not even realize that the person has a mental health condition.

- Stress can affect the person's ability to function. Try to keep the pressure of the situation to a minimum.
- People who have psychiatric disabilities have varying personalities and different ways of coping with their disability. Some may have trouble picking up on social cues; others may be super sensitive. One person may be very high energy, while someone else may appear sluggish. Treat each person as an individual. Ask what will make them most comfortable and respect their needs to the maximum extent possible.
- In a crisis, stay calm and be supportive as you would with anyone. Ask how you can help and find out if there is a support person who can be sent for. If appropriate, you might ask if the person has medication that they need to take.

People With Intellectual Disabilities

An intellectual disability is a developmental disability that affects a person's intellectual functioning, such as reasoning, learning, problem-solving, and adaptive behavior. Adaptive

behavior limitations impact areas of daily living skills, such as travel, shopping, following directions, and reading environmental and social cues.

- Speak to the person as you would any other adult. Use simple language, not baby talk.
- Use clear, concise, short sentences with simple language. Do not give more than one direction in a sentence. Be prepared to repeat yourself or use other words if they do not respond.
- Be patient and allow time for the person with an intellectual disability to process the information before responding.
- People with intellectual disabilities may be anxious to please or to agree with what you say. Be sure they know they can refuse to do something or say they don't know what you mean. This is especially important in certain situations such as law enforcement or health care.
- Keep in mind that noisy environments or ones with many distractions may make it difficult for them to focus on a task or direction, especially when first learning how to do something.
- Do not assume that a person with an intellectual disability cannot learn. They may only need a little more time and attention to transfer what is learned in one situation to another.
- Clear signage and pictograms identifying different areas of a facility may increase their ability to navigate through a building.
- Remember people with intellectual disabilities can and do live and work

independently and productively in the community. They want to be treated with respect and accorded their human dignity.

People with Learning Disabilities

Learning disabilities are lifelong disorders that interfere with a person's ability to receive, express, or process information. Although they have certain limitations, most people with learning disabilities have average or above-average intelligence. You may not realize that the person has a learning disability because he functions so well. Or you may be confused about why such a high-functioning person has problems in one aspect of their work.

- People with dyslexia or other reading disabilities have trouble reading written information. Give them verbal explanations and allow extra time for reading.
- Don't be surprised if you tell someone very simple instructions and they request that you write them down. Because spoken information gets "scrambled" as they listen, a person who has a learning disability such as auditory processing disorder may need information demonstrated or in writing.
- Ask the person how you can best relay information. Be direct in your communication. A person with a learning disability may have trouble grasping subtleties.
- It may be easier for the person to function in a quiet environment without distractions, such as a radio playing, people moving around, or loudly patterned curtains.

People with Traumatic (or Acquired) Brain Injury

People with traumatic brain injury have had damage to the brain usually as the result of trauma, such as an accident or stroke.

- Some of the factors that affect people with learning disabilities also apply to people with traumatic brain injury. People with brain injury may have a loss of muscle control or mobility that is not obvious. For example, a person may not be able to sign her name, even though she can move her hand.
- A person with a brain injury may have poor impulse control. The person may make inappropriate comments and may not understand social cues or “get” indications that she has offended someone. In her frustration to understand or to get her own ideas across, she may seem pushy. All of these behaviors arise as a result of the injury.
- A person with a brain injury may be unable to follow directions due to poor short-term memory or poor directional orientation. She may ask to be accompanied, or she may use a guide dog for orientation, although she does not appear to be mobility impaired.
- If you are not sure that the person understands you, ask if she would like you to write down what you were saying.
- The person may have trouble concentrating or organizing her thoughts, especially in an overstimulating environment like a crowded movie theater or transportation terminal. Be patient. You might suggest going somewhere with fewer distractions.

People Who Use Service Animals

Some people who are Deaf, blind or have low vision, or who have traumatic brain injury, seizure disorder, or a range of other disabilities may use a service animal to assist them with daily living.

- While you may inquire whether an animal is a service animal, the person may not have information identifying it as such. This means that in general, you will need to modify a “no animals” policy to allow the person to enter with her service animal. Barring a direct threat to health and safety, this requirement of the ADA is generally thought to take precedence over any health codes, such as those for restaurants, and personal preferences, such as those of taxi drivers, prohibiting pets.
- Service animals are generally highly trained and well behaved. You may ask the person to remove the animal if she does not have the animal under her control. Do not touch the service animal without permission. The animal may be adorable, but it is on the job.

Service Animal Resources

The Delta Society
580 Naches Avenue SW, Suite 101
Renton, WA 98055-2297

Phone: (425) 226-7357

Fax: (425) 235-1076

E-mail: info@deltasociety.org

The Delta Society is the leading international resource for the human-animal bond. The Delta Society has been the force to validate the important role of animals for people’s health and

well-being by promoting the results of research to the media and health and human services organizations.

Canine Companions for Independence

National Headquarters & Northwest Regional Center

2965 Dutton Avenue
PO Box 446
Santa Rosa, CA 95402-0446
Phone: (707) 577-1700
TDD: (707) 577-1756
E-mail: info@caninecompanions.org

Dogs for the Deaf

10175 Wheeler Road Central Point, OR 97502
Voice/TDD: (541) 826-9220
Fax: (541) 826-6696
E-mail: info@dogstothedeaf.org

Dogs for the Deaf's mission is to rescue and professionally train dogs to assist people and enhance their lives. Hearing dogs are chosen from adoption shelters, where they might otherwise be euthanized if no homes are found for them. By using shelter dogs, Dogs for the Deaf is able to help alleviate some of the unwanted dog population by rescuing these dogs, training them, and placing them in loving homes where they can provide an important service. The dogs are usually mixed breeds, small to medium in size, and up to 24 months of age. The trainers look for dogs that are friendly, energetic, healthy, and intelligent. Each dog is individually evaluated by a Dogs for the Deaf trainer. Those passing the aptitude tests are brought back to the facility for a thorough medical evaluation and needed vaccinations. All

dogs are spayed or neutered and then begin the intensive four to six months of training.

Emergency Evacuation Procedures for People with Disabilities

People with disabilities must be considered in any facility's evacuation plan.

- Compile a voluntary list of people with disabilities who are regulars at your facility, such as employees, students, or residents. While you are compiling this list, let people know that even though they may not consider themselves to have a disability, they should be included if they may need help during an emergency. For example, this might apply to someone whose asthma may be triggered by stress or smoke. Keep the list updated to include people who are living with temporary disabilities, such as a pregnant woman or someone with a broken leg.
- Interview each individual on the list to plan the most effective way to assist them in case of an emergency. For example, a person with a cognitive disability may get confused and need assistance in following directions.
- Also develop a plan, including a voluntary sign-in, for an emergency that may affect people who are not attached to the facility, such as customers, theatergoers, patients, or other members of the public.
- Practice the evacuation procedures and keep your plans up to date.

Autistic People

There are several important points to consider when meeting the needs of autistic people that can help them be safe, included, respected,

and equal participants in all kinds of activities. Remember that the things listed here are access needs and not conveniences or luxuries. Each autistic person is different and may need more or less or different accommodations.

- Please use respectful language, including considering identity-first (autistic) vs. person-first (person with autism) language. Many in the autistic community strongly prefer identity-first language and should have their wishes respected. Respectful language also means not using functioning (high vs. low functioning) labels to describe people.
- Do not insist on eye contact. Eye contact can be very distracting or even uncomfortable and threatening to many autistic people.
- It is important to understand that autistic people communicate in many different ways, from spoken words to typing to gestures and sounds. Meaningful interaction with autistic people must involve respecting their manner of communication. Make sure to allow for sufficient processing time when having a conversation with or asking questions of an autistic person. Offering a text-based way to communicate (text, instant message, etc.) is a good alternative for people who may be uncomfortable with oral speech in some or all settings.
- Bear in mind that an autistic person's tone of voice, body language, or facial expressions may not match what they intend to communicate. Do not expect an autistic person to read nonverbal communication. When necessary, be clear and direct.
- Large groups can be overstimulating or overwhelming for many autistic people. It

can be difficult for autistic people to time their responses or understand the social nuances of large groups. Small groups in quiet rooms can be a good option for meaningful autistic participation.

- Some autistic people have difficulty understanding auditory information, especially when there is background noise. It is helpful to minimize nonessential sensory input to create a safer sensory environment and facilitate autistic communication. These can be things as simple as closing doors to shut out background noise or finding environments to meet that are quiet.
- To accommodate sensory needs, refrain from wearing perfumes or scented toiletries. Loud noises should be avoided. Lighting is important as well. Fluorescent lighting can cause severe sensory processing issues, so natural light or soft, incandescent lighting is better. Ask before using flash photography as it can cause sensory overload, as well as seizures in the third of autistic people who have seizures and/or epilepsy.

It can be helpful to make sure your agenda or plans are concrete and presented in advance, then adhered to. Sudden changes and transitions are difficult for many autistic people.

(Contributed by the Autistic Self Advocacy Network, <http://autisticadvocacy.org/>)

Conflict Management

Sometimes conflicts arise between people with disabilities and the places they visit for work, recreation, health care, or education. These conflicts are usually the result of misunderstanding or a lack of information.

Sometimes conflicts develop between people with disabilities who have conflicting needs. For example, a person who has a hearing loss cannot hear the proceedings with the window open, but a person with Multiple Chemical Sensitivity needs the window open for fresh air; someone who uses a service dog may run into a conflict with a person who has an anxiety disorder and an extreme fear of dogs.

All of these situations call for flexibility, patience, creativity, and open communication—a willingness to listen to the other person’s perspective and to learn is need.

Sometimes good faith efforts are not enough, and parties have difficulty working out their differences. In these cases, consider using the services of a skilled mediator.

A Final Word

People with disabilities are individuals with families, jobs, hobbies, likes and dislikes, and problems and joys. While the disability is an integral part of who they are, it alone does not define them. Don’t make them into disability heroes or victims. Treat them as individuals.

Glossary of Acceptable Terms

Labels Not to Use	People First Language
The handicapped or the disabled	People with disabilities
The mentally retarded or he’s retarded	People with an intellectual disability
The autistic child	People with autism
She’s a Down; she’s mongoloid	She has down syndrome
Birth defect	Has a congenital disability
Epileptic	A person with epilepsy
Wheelchair-bound or confined to a wheelchair	Uses a wheelchair or mobility chair, or is a wheelchair user
She is developmentally delayed	She has a developmental disability
He’s crippled or lame	He has a physical disability
She’s a dwarf or midget	She has a short stature; she is a little person
Mute	Communicates with her eyes/device
Is learning disabled	Has a learning disability
Afflicted with, suffers from, victim of	Person who has
She’s emotionally disturbed; she’s crazy	She has an emotional disability
Normal and/or healthy	A person without a disability
Quadriplegic, paraplegic, etc.	He has quadriplegia, paraplegia, etc.
She’s in Special Ed	She receives Special Ed services
Handicapped parking, hotel room, etc.	Accessible parking, hotel room, etc.
Client, consumer, recipient, etc. (e.g., when a person is making a purchase at a store)	Customer

References

- 1 U.S. Bureau of Labor Statistics. "American Indians and Alaska Natives in the U.S. Labor Force." Nov. 2019, <https://www.bls.gov/opub/mlr/2019/article/american-indians-and-alaska-natives-in-the-u-s-labor-force.htm>. Accessed 6 Oct. 2021.
- 2 U.S. Census Bureau. "Race and Ethnicity in the United States: 2010 Census and 2020 Census." 12 Aug. 2021, <https://www.census.gov/library/visualizations/interactive/race-and-ethnicity-in-the-united-state-2010-and-2020-census.html>. Accessed 5 Oct. 2021.
- 3 U.S. Department of Health and Human Services, Centers for Disease Control and Prevention. "Adults with Disabilities: Ethnicity and Race." 16 Sept. 2020, <https://www.cdc.gov/ncbddd/disabilityandhealth/materials/infographic-disabilities-ethnicity-race.html>. Accessed 2 July 2021.
- 4 U.S. Department of the Interior, Indian Affairs. "About Us." <https://www.bia.gov/about-us#:~:text=There%20are%20574%20federally%20recognized,Villages%20in%20the%20United%20States>. Accessed July 2, 2021.
- 5 Young, Natalie A. E. "Childhood Disability in the United States: 2019." *American Community Survey Briefs*, U.S. Department of Commerce, Mar. 2021, <https://www.census.gov/content/dam/Census/library/publications/2021/acs/acsbr-006.pdf>. Accessed 1 July 2021.
- 6 "Functional Limitations and the Future Needs for Long Term Care." University of North Dakota, National Resource Center on Native American Aging, 2002, <https://www.nrcnaa.org/pdf/02-1.pdf>. Accessed 2 July 2021.
- 7 U.S. Department of Labor, Office of Disability Employment Policy. "Frequently Asked Questions—General." <https://www.dol.gov/agencies/odep/publications/faqs/general>. Accessed 19 February 2022.
- 8 *American Indian Disability Legislation Project*. University of Montana, Rural Institute on Disabilities, Research and Training Center on Disability in Rural Communities, 2000.
- 9 "Functional Limitations and the Future Needs for Long Term Care." University of North Dakota, Center for Rural Health, National Resource Center on Native American Aging, 2002, <https://www.nrcnaa.org/pdf/02-1.pdf>. Accessed 2 July 2021.
- 10 "Needs Assessment, Identifying Our Needs: A Survey of Elders VII." University of North Dakota, Center for Rural Health, National Resource Center on Native American Aging, 2020, <https://www.nrcnaa.org/needs-assessment>. Accessed 19 Feb. 2022.
- 11 U.S. Department of Health and Human Services, The Centers for Disease Control and Prevention. "Leading Causes of Death—Females—Non-Hispanic American Indian or Alaska Native—United States, 2017." <https://www.cdc.gov/women/lcod/2017/nonhispanic-native/index.htm>. Accessed 19 Feb. 2022.
- 12 ———, ———. "Leading Causes of Death—Males—Non-Hispanic American Indian or Alaska Native—United States, 2017." <https://www.cdc.gov/healthequity/lcod/men/2017/nonhispanic-native/> - anchor_1571150018. Accessed 19 Feb. 2022.
- 13 Thornton, Joshua, et al. "How does the ADA Apply to Tribal Nations and What Resources are Available Within Region 8?" Rocky Mountain ADA Center, June 2019, <https://rockymountainada.org/resources/research/how-does-ada-apply-tribal-nations-and-what-resources-are-available-within-region>. Accessed 22 Feb. 2022.

- 14 U.S. Department of Health and Human Services, Administration for Community Living. "The Developmental Disabilities Assistance and Bill of Rights Act of 2000." 25 Mar. 2021, <https://acl.gov/about-acl/authorizing-statutes/developmental-disabilities-assistance-and-bill-rights-act-2000>. Accessed 19 Feb. 2022.
- 15 ———, ———. "Older Americans Act." 8 July 2021, <https://acl.gov/about-acl/authorizing-statutes/older-americans-act>. Accessed 20 Feb. 2022.
- 16 U.S. Department of Housing and Urban Development, Office of Public and Indian Housing. "Notice PIH-2014-08." 30 Apr. 2014, <https://www.hud.gov/sites/documents/PIH2014-08.PDF>. Accessed 22 Feb. 2022.
- 17 U.S. Department of Justice. "Title II of the Civil Rights Act (Public Accommodations)." 27 Jan. 2022, <https://www.justice.gov/crt/title-ii-civil-rights-act-public-accommodations>. Accessed 22 Feb. 2022.
- 18 U.S. Department of Labor, Employment and Training Administration. "Workforce Innovation and Opportunity Act." <https://www.dol.gov/agencies/eta/wioa>. Accessed 22 Feb. 2022.
- 19 Brave Heart, Maria Yellow Horse. "The Return to the Sacred Path: Reflections on the Development of Historical Trauma." 2001, https://www.ihs.gov/sites/telebehavioral/themes/responsive2017/display_objects/documents/slides/historicaltrauma/hreturnsacredpath0513.pdf. Accessed 14 Oct. 2021.
- 20 North Dakota Department of Health, Division of Vital Statistics. "North Dakota 2017 Health Disparities Report." https://www.health.nd.gov/sites/www/files/documents/Files/HSC/HEO/Health_Equity_Report.pdf. Accessed 10 Mar. 2022.
- 21 Randall, Vernellia R. "Background: Disparity, Discrimination and Diversity in Health Care." *The Role of Governmental and Private Health Care Programs and Initiatives*, U.S. Commission on Civil Rights, Sept. 1999, https://archive.org/stream/healthcarechalle00unse/healthcarechalle00unse_djvu.txt. Accessed 27 Dec. 2002.
- 22 Vol. 1 of *The Health Care Challenge: Acknowledging Disparity, Confronting Discrimination, and Ensuring Equality*.
- 23 "Strengthening Our Native Communities: How Understanding Adverse Childhood Experiences Can Help." *ACEs Toolkit*. Association of American Indian Physicians, <https://www.aaip.org/programs/aces-toolkit/>. Accessed 10 Mar. 2022.
- 24 "Understanding the Destruction: Native American Life Today." Native Hope, <https://pages.nativehope.org/native-american-life-today>. Accessed 5 Nov. 2021
- 25 "American Quotes Native Prayer." QuotesGram, <https://quotesgram.com/american-quotes-native-prayer/>. Accessed 11 Mar. 2022.
- 26 U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration. "Tribal TTA Center Healing-Informed Care Handout." 11 Sept. 2015, <https://www.samhsa.gov/sites/default/files/tribal-tta-healing-informed-care-handout.pdf>. Accessed 25 Oct. 2021.
- 27 "Alcohol and Drug Abuse Among Native Americans." American Addiction Centers, 7 Jan. 2022, <https://americanaddictioncenters.org/rehab-guide/addiction-statistics/native-americans>. Accessed 15 Mar. 2022.
- 28 "Culturally-Informed Programs to Reduce Substance Misuse and Promote Mental Health in American Indian and Alaska Native Populations." Prevention Solutions@Education Development Center, Mar. 2018, https://preventionsolutions.edc.org/sites/default/files/attachments/Culturally-Informed-Programs-to-Reduce-Substance-Misuse-and-Promote-Mental-Health-in-American-Indian-and-Alaska-Native-Populations_0.pdf. Accessed 17 Mar. 2022.
- 29 *Culture Forward: A Strengths and Culture Based Tool to Protect our Native Youth from Suicide*. Johns Hopkins, Center for American Indian Health, 16 Apr. 2021, <https://caih.jhu.edu/programs/cultureforward>. Accessed 17 Mar. 2022.
- 30 O'Keefe, V. M. et al. "Increasing Culturally Responsive Care and Mental Health Equity with Indigenous Community Mental Health Workers." *Psychological Services*, vol. 18, no. 1, Feb. 2021, pp. 84–92, <https://doi.org/10.1037/ser0000358>. Accessed 14 Mar. 2022.
- 31 U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Injury Prevention and Control. "WISQARS™ Web-Based—Injury Statistics Query and Reporting System." 2 Dec. 2021, <https://www.cdc.gov/injury/wisqars/index.html>. Accessed 15 Mar. 2022.

- 32 ———, Substance Abuse and Mental Health Services Administration. “2018 National Survey on Drug Use and Health: American Indians and Alaska Natives.” *PowerPoint*, slide 7, <https://www.samhsa.gov/data/release/2018-national-survey-drug-use-and-health-nsduh-releases>. Accessed 15 Mar. 2022.
- 33 ———, ———, Tribal Training and Technical Assistance Center. “Circles of Care.” 6 July 2021, <https://www.samhsa.gov/tribal-ttac/circles-care>. Accessed 17 Mar. 2022.
- 34 Aulandez, Kevalin M. et.al. “Cultural Sources of Strength and Resilience: A Case Study of Holistic Wellness Boxes for COVID-19 Response in Indigenous Communities.” *Frontiers in Sociology*, 22 Feb. 2021, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8022692/>. Accessed 28 Feb. 2022.
- 35 U.S. Department of Health and Human Services, Indian Health Service. “Coronavirus (COVID-19).” 10 Mar. 2022, <https://www.ihs.gov/coronavirus/>. Accessed 11 Mar. 2022.
- 36 U.S. Department of Health and Human Services, Indian Health Service. “Eligibility for Services.” *Indian Health Manual*, <https://www.ihs.gov/ihtm/pc/part-2/p2c1/-2-1.2A>. Accessed 23 Feb. 2022.
- 37 ———, ———. “Purchased/Referred Care (PRC).” <https://www.ihs.gov/prc/>. Accessed 23 Feb. 2022.
- 38 Garfield, Rachel, et al. “The Coverage Gap: Uninsured Poor Adults in States That Do Not Expand Medicaid.” *Kaiser Family Foundation*, 21 Jan. 2021, <https://www.kff.org/medicaid/issue-brief/the-coverage-gap-uninsured-poor-adults-in-states-that-do-not-expand-medicaid/>. Accessed 23 Feb. 2022.
- 39 “Medicaid Home Care Benefits for the Aging.” *Paying for Senior Care*, 14 Aug. 2020, <https://www.payingforseniorecare.com/medicaid-waivers/home-care>. Accessed 23 Feb. 2022.
- 40 U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services. “Eligibility.” <https://www.medicare.gov/medicaid/eligibility/index.html>. Accessed 23 Feb. 2022.
- 41 ———, ———. “Express Lane Eligibility.” 6 Aug. 2021, <https://www.medicare.gov/medicaid/enrollment-strategies/express-lane-eligibility-medicare-and-chip-coverage/index.html>. Accessed 24 Feb. 2022.
- 42 ———, ———. “Home and Community-Based Services 1915 (c).” <https://www.medicare.gov/medicaid/home-community-based-services/home-community-based-services-authorities/home-community-based-services-1915c/index.html>. Accessed 24 Feb. 2022.
- 43 ———, ———. “Mandatory and Optional Benefits.” <https://www.medicare.gov/medicaid/benefits/mandatory-optional-medicare-benefits/index.html>. Accessed 18 Oct. 2021.
- 44 “The Children’s Health Insurance Program (CHIP).” *Healthcare.gov*, <https://www.healthcare.gov/medicaid-chip/childrens-health-insurance-program/>. Accessed 24 Feb. 2022.
- 45 “What Part A Covers.” *Medicare.gov.*, <https://www.medicare.gov/what-medicare-covers/what-part-a-covers>. Accessed 24 Feb. 2022.
- 46 “What Part B Covers.” *Medicare.gov.*, <https://www.medicare.gov/what-medicare-covers/what-part-b-covers>. Accessed 24 Feb. 2022.
- 47 “What’s Medicare?” *Medicare.gov.*, <https://www.medicare.gov/what-medicare-covers/your-medicare-coverage-choices/whats-medicare>. Accessed 24 Feb. 2022.
- 48 U.S. Department of Health and Human Services, Indian Health Service, VA HIS MOU. “Reimbursement Agreement Provides VA Funds for IHS Care for Native Veterans.” <https://www.ihs.gov/vaihsmou/>. Accessed 4 Nov. 2021.
- 49 U.S. Department of Veterans Affairs, Indian Health Service. “Indian Health Service/Tribal Health Program/Urban Indian Organization (I/T/U).” <https://www.va.gov/COMMUNITYCARE/programs/veterans/ihs/index.asp>. Accessed 4 Nov. 2021.
- 50 Knapp, Carla. “Reclaiming Our Story for Native Youth.” *Boys and Girls Clubs of America*, 4 Oct. 2021, <https://www.bgca.org/news-stories/2021/October/reclaiming-our-story-for-native-youth>. Accessed 12 Oct. 2021.
- 51 “Recreational Activities for People with Disabilities.” *CME Toolkit*. Prime Education, 2014, <https://cmetoolkit.com/wp-content/uploads/Recreational-Activities-for-People-with-Disabilities.pdf>. Accessed 21 Mar. 2022.
- 52 “History and Culture: Boarding Schools.” *Northern Plains Reservation AID*, http://www.nativepartnership.org/site/PageServer?pagename=airc_hist_boardingschools. Accessed 5 Oct. 2021.

- 53 "History of American Indian Schools." *Wikipedia*, https://en.wikipedia.org/wiki/American_Indian_boarding_schools. Accessed 5 Oct. 2021.
- 54 "Impact of Historical Trauma." The National Native American Boarding School Healing Coalition, <https://boardingschoolhealing.org/education/impact-of-historical-trauma/>. Accessed 23 Mar. 2022.
- 55 Rehyner, Jon. "1819–2013: A History of American Indian Education." 3 Dec. 2013, <https://www.edweek.org/leadership/1819-2013-a-history-of-american-indian-education/2013/12>. Slide 1. Accessed 23 Mar. 2022.
- 56 U.S. Department of Education, Institution of Education Sciences, National Center for Education Statistics, National Assessment of Educational Progress (NAEP). "National Indian Education Study 2019." 2021, <https://nces.ed.gov/nationsreportcard/subject/publications/studies/pdf/2021018.pdf>. Accessed 23 Mar. 2022.
- 57 ———, ———, ———. "Status and Trends in the Education of Racial and Ethnic Groups 2018." May 2021, <https://nces.ed.gov/pubs2019/2019038.pdf>. Accessed 23 Mar. 2022.
- 58 ———, Office of Special Education and Rehabilitative Services, Office of Special Education Programs. "2020 Annual Report to Congress on the Individuals with Disabilities Education Act (IDEA)." 25 Jan. 2022, <https://sites.ed.gov/idea/2020-annual-report-congress-idea/>. Accessed 23 Mar. 2022.
- 59 "U.S. Indian Boarding School History." The National Native American Boarding School Healing Coalition, 21 Mar. 2022, <https://boardingschoolhealing.org/>. Accessed 23 Mar. 2022.
- 60 "A Comparison of ADA, IDEA, and Section 504." Disability Rights Education & Defense Fund, <https://dredf.org/legal-advocacy/laws/a-comparison-of-ada-idea-and-section-504/>. Accessed 13 Oct. 2021.
- 61 U.S. Department of Education, Institution of Education Sciences, National Center for Education Statistics, National Assessment of Educational Progress. "National Indian Education Study 2019." 2021, <https://nces.ed.gov/nationsreportcard/subject/publications/studies/pdf/2021018.pdf>. Accessed 23 Mar. 2022.
- 62 ———, ———, ———. "Status and Trends in the Education of Racial and Ethnic Groups 2018." May 2021, <https://nces.ed.gov/pubs2019/2019038.pdf>. Accessed 23 Mar. 2022.
- 63 Saleh, Matthew J. D. "Your Child's Rights: 6 Principles of IDEA." Smart Kids with Learning Disabilities, <https://www.smartkidswithld.org/getting-help/know-your-childs-rights/your-childs-rights-6-principles-of-idea/>. Accessed 24 Mar. 2022.
- 64 U.S. Department of Education, Office for Civil Rights. "Employment and Postsecondary Education: Transitioning from School to Employment." <https://youth.gov/youth-topics/employment-and-postsecondary-education>. Accessed 24 June 2021.
- 65 ———, ———. "Transition of Students with Disabilities to Postsecondary Education: A Guide for Educators." March 2011, <https://www2.ed.gov/about/offices/list/ocr/transitionguide.html>. Accessed 24 June 2021.
- 66 Connecticut, Special Education Network of Wilton. "Tips for Parents." <https://spednet.org/tips/>. Accessed 12 September 2022.
- 67 "Five Options 1-2-3." Center for Parent Information and Resources, Oct. 2019, <https://www.parentcenterhub.org/disputes-overview/>. Accessed 17 June 2021.
- 68 "Part B of IDEA: Services for School-Aged Children." Center for Parent Information and Resources, Oct. 2018, <https://www.parentcenterhub.org/partb/>. Accessed 24 Mar. 2022.
- 69 *Guidelines*, Family and Child Education, June 2020, <https://www.faceresources.org/>. Accessed 26 Aug. 2021.
- 70 "Overview of Early Intervention." Center for Parent Information and Resources, 1 Sept. 2017, <https://www.parentcenterhub.org/ei-overview/>. Accessed 18 June 2021.
- 71 United States, Congress, Congressional Research Services. "The Individuals with Disabilities Education Act (IDEA), Part C: Early Intervention for Infants and Toddlers with Disabilities." 9 Aug. 2019, <https://sgp.fas.org/crs/misc/R43631.pdf>. Accessed 26 Aug. 2021.
- 72 U.S. Department of Health and Human Service, Centers for Disease Control and Prevention. "Individuals with Disabilities Education Act (IDEA) Services." <https://www.cdc.gov/ncbddd/cp/treatment.html>. Accessed 30 June 2021.
- 73 "About Independent Living." National Council on Independent Living, <https://ncil.org/about/aboutil/>. Accessed 28 Mar. 2022.

- 74 “Provider Types.” Leading Age, <https://leadingage.org/provider-types>. Accessed 28 Mar. 2022.
- 75 U.S. Department of Health and Human Services, Administration for Community Living. “Services for Native Americans (OAA Title VI).” 19 Oct. 2020, <https://acl.gov/programs/services-native-americans-oaa-title-vi>. Accessed 28 Mar. 2022.
- 76 ———, ———. “Strategic Framework for Action: State Opportunities to Integrate Services and Improve Outcomes for Older Adults and People with Disabilities.” June 2020, https://acl.gov/sites/default/files/programs/2020-06/ACL_Strategic_Framework_for_Action_v1_June_2020_final_508_v2.pdf. Accessed 29 Mar. 2022.
- 77 Oberlink, Mia. “What Is the AdvantAge Initiative?” The AdvantAge Initiative. <https://apps.vnsny.org/advantage/advantage.html>. Accessed 31 Aug. 2022
- 78 U.S. Department of Health and Human Services, Administration for Community Living. “Centers for Independent Living Make Community Living Possible.” 1 Mar. 2022, <https://acl.gov/sites/default/files/news/2018-08/ILProgramsIG.FinalWeb.pdf>. Accessed 28 Mar. 2022.
- 79 U.S. Centers for Medicare and Medicaid. “Cherokee Nation Home Health Services.” CMS.gov., 1 Dec. 2021, <https://www.cms.gov/Outreach-and-Education/American-Indian-Alaska-Native/AIAN/LTSS-TA-Center/program-examples/cherokee-nation-oklahoma>. Accessed 29 Mar. 2022.
- 80 ———. “Pueblo of Zuni’s LTSS Network.” CMS.gov., 1 Dec. 2021, <https://www.cms.gov/Outreach-and-Education/American-Indian-Alaska-Native/AIAN/LTSS-TA-Center/program-examples/pueblo-of-zuni>. Accessed 29 Mar. 2022.
- 81 ———. “White Earth Long Term Care Consultation Services.” CMS.gov., 1 Dec. 2021, <https://www.cms.gov/Outreach-and-Education/American-Indian-Alaska-Native/AIAN/LTSS-TA-Center/program-examples/white-earth-ojibwe-mn>. Accessed 29 Mar. 2022.
- 82 U.S. Bureau of Labor Statistics. “American Indians and Alaska Natives in the U.S. labor force.” *Monthly Labor Review*, Nov. 2019, <https://www.bls.gov/opub/mlr/2019/article/american-indians-and-alaska-natives-in-the-u-s-labor-force.htm>. Accessed 18 Oct. 2021.
- 83 San Antonio, Department of Public Works, Disability Access Office. Jan. 2011, <https://www.sanantonio.gov/Portals/0/Files/DAO/DisabilityEtiquetteHandbook.pdf>. Accessed 20 Oct. 2021.
- 84 U.S. Office of Personnel Management. “Telework Guide.” <https://www.telework.gov/>. Accessed 12 September 2022.
- 85 Gioannosa, Jennifer. “WIOA Career Pathways Programs.” Educational Data Systems, 26 July 2018, <https://www.edsisolutions.com/blog/wioa-implementation-how-career-pathways-brochures-can-help-free-templates>. Accessed 20 Oct. 2021.
- 86 “Summary Description from a Disability Perspective: FINAL RULE Implementing Title I of the Workforce Innovation and Opportunity Act (Workforce Development Systems).” The LEAD Center, 19 Aug. 2016, <https://www.nationaldisabilityinstitute.org/wp-content/uploads/2018/12/wioa-title-1-final-rule-summary.pdf>. Accessed 19 Oct. 2021.
- 87 U.S. Department of Labor Employment and Training Administration. “Indian and Native American Programs.” <https://www.dol.gov/agencies/eta/dinap>. Accessed 20 Oct. 2021.
- 88 ———. “Laws and Regulations.” <https://www.dol.gov/agencies/eta/disability/laws>. Accessed 20 Oct. 2021.
- 89 ———. “Wagner-Peyser Act Employment Service Results.” <https://www.dol.gov/agencies/eta/performance/results/wagner-peyser>. Accessed 20 Oct. 2021.
- 90 ———. “WIOA Section 166 Adult and Youth Funding for Native Americans PY 2021 Funding Allotments.” https://wdr.doleta.gov/directives/attach/TEGL/TEGL_22-20_Attachment_1.pdf. Accessed 20 Oct. 2021.
- 91 “WIOA Adult & Dislocated Worker Program Eligibility Policy #5000.” Pacific Mountain Workforce Development, 7 July 2016, https://pacmtn.org/wp-content/uploads/2018/02/5000-Adult_DW-Eligibility-2.pdf. Accessed 20 Oct. 2021.
- 92 U.S. Bureau of Labor Statistics “What Rehabilitation Counselors Do.” *Occupational Outlook Handbook*, 8 Sept. 2021, <https://www.bls.gov/ooh/community-and-social-service/rehabilitation-counselors.htm-tab-2>. Accessed 18 Oct. 2021.

- 93 U.S. Department of Labor. "Vocational Rehabilitation." CareerOneStop, <https://www.careeronestop.org/ResourcesFor/WorkersWithDisabilities/vocational-rehabilitation.aspx>. Accessed 20 Oct. 2021.
- 94 U.S. Department of Labor. "Vocational Rehabilitation." CareerOneStop, <https://www.careeronestop.org/ResourcesFor/WorkersWithDisabilities/vocational-rehabilitation.aspx>. Accessed 20 Oct. 2021.
- 95 Hutter, Victoria. "Fostering and Supporting Access to the Arts." *NEA Arts*, no. 3, 2017, https://www.arts.gov/sites/default/files/nea_arts/NEAArts_No3_2017.pdf. Accessed 21 March 2022.
- 96 "Oglala Lakota Artspace." Artspace, 30 Mar. 2018, https://www.artspace.org/sites/default/files/downloads/OglalaLakotaArtspace_6pgr_v5_30Mar18.pdf. Accessed 14 Apr. 2022.
- 97 "What We Do." First Peoples Fund, <https://www.firstpeoplesfund.org/what-we-do>. Accessed 14 Apr. 2022.
- 98 U.S. Department of Labor, Office of Disability Employment Policy. "Self-Employment & Entrepreneurship." <https://www.dol.gov/agencies/odep/program-areas/employers/self-employment-entrepreneurship>. Accessed 25 Sept. 2021.
- 99 Leedom, Conor, and Axley Brynelson. "EEOC Addresses Telework as Reasonable Accommodation." *HR Daily Advisor*, 11 Dec. 2020, <https://hrdailyadvisor.blr.com/2020/12/11/eec-addresses-telework-as-reasonable-accommodation/>. Accessed Sept. 2021.
- 100 Mitic, I. "Gig Economy Statistics: The New Normal in the Workplace." *Fortunly*, 16 Aug. 2021, <https://fortunly.com/statistics/gig-economy-statistics/> - gref. Accessed 20 Oct. 2021.
- 101 Steward, Shelly, and Hilary Greenberg. "New Interactive Data Tools Added to Gig Economy Data Hub." *Gig Economy Data Hub*, 17 June 2019, <https://www.gigeconomydata.org/blog/new-interactive-data-tools-added-gig-economy-data-hub>. Accessed 25 Oct. 2021.
- 102 U.S. Office of Personnel Management. "Telework Guide." <https://www.telework.gov/>. Accessed 12 September 2022.
- 103 Martinez, Carole. "Artificial Intelligence and Accessibility: Examples of a Technology That Serves People with Disabilities." 5 Mar. 2021, <https://www.inclusivecitymaker.com/artificial-intelligence-accessibility-examples-technology-serves-people-disabilities/>. Accessed 11 Oct. 2021.
- 104 U.S. Department of Health and Human Services, National Institutes of Health, National Eye Institute. "NIH-funded Modern 'White Cane' Brings Navigation Assistance to the 21st Century." 8 Sept. 2021. <https://www.nei.nih.gov/about/news-and-events/news/nih-funded-modern-white-cane-brings-navigation-assistance-21st-century>. Accessed 11 Oct. 2021.
- 105 "What is AT?" Assistive Technology Industry Association, <https://www.atia.org/home/at-resources/what-is-at/>. Accessed 30 Mar. 2022.
- 106 Morin, Amanda. "Checklist: What to Consider When Looking at Assistive Technology." *Understood*, <https://www.understood.org/en/articles/checklist-what-to-consider-when-looking-at-assistive-technology>. Accessed 30 Mar. 2022.
- 107 "What is AT?" Assistive Technology Industry Association, <https://www.atia.org/home/at-resources/what-is-at/>. Accessed 30 Mar. 2022.
- 108 "Consumer and Public Information." The Rehabilitation Engineering and Assistive Technology Society of North America, <https://www.resna.org/About/Consumer-and-Public-Information>. Accessed 28 June 2021.
- 109 "What Funding Assistance is Available for Individuals with Disabilities to Purchase Assistive Devices, Ramps, etc.?" ADA National Network, March 2022, <https://adata.org/faq/what-funding-assistance-available-individuals-disabilities-purchase-assistive-devices-ramps-etc>. Accessed 30 Mar. 2022.
- 110 "What is AT?" Assistive Technology Industry Association, <https://www.atia.org/home/at-resources/what-is-at/>. Accessed 30 Mar. 2022.
- 111 "Consumer and Public Information." The Rehabilitation Engineering and Assistive Technology Society of North America, <https://www.resna.org/About/Consumer-and-Public-Information>. Accessed 28 June 2021.
- 112 U.S. Department of Health and Human Services, Administration for Community Living.
- 113 "P&A Programs" <https://acl.gov/programs/pa-programs> Accessed 12 September 2022.

- 114 *Intraregional Tribal Transportation Strategy*. San Diego Association of Governments / Southern California Tribal Chairmen's Association, Jan. 2018, https://www.sandag.org/uploads/publicationid/publicationid_4480_23377.pdf. Accessed 28 Oct. 2021.
- 115 *Understanding Disabilities in American Indian and Alaska Native Communities Toolkit Guide*. The University of Montana, Rural Institute on Disabilities, American Indian Disability Technical Assistance Center, 2003. <https://ncd.gov/publications/2003/aug12003>. Accessed 22 Oct. 2021. The Resource book is no longer available.
- 116 North Dakota State University, Upper Great Plains Transportation Institute, Small Urban and Rural Center on Mobility, <https://www.ugpti.org/surcom/resources/transportation-glossary.php?viewAll=1>. Accessed 28 Sept. 2021.
- 117 "Apache Transportation." San Carlos Apache Tribe Nnee Bich'o Nii Services, 2021, <http://scat-tanf.org/transit/>. Accessed 25 Oct. 2021.
- 118 The Cherokee Nation, Department of Transportation & Infrastructure. "Cherokee Nation Transit." <https://transit.cherokee.org/>. Accessed 23 Aug. 2021.
- 119 *Crossing Great Divides: A Guide to Elder Mobility Resources and Solutions in Indian Country*. National Aging and Disability Transportation Center, <https://www.nadtc.org/resources-publications/resource/crossing-great-divides-a-guide-to-elder-mobility-resources-and-solutions-in-indian-country/>. Accessed 1 Oct. 2021.
- 120 Pelivan Transit. "The Pelivan Story." <https://www.pelivantransit.org/the-pelivan-story>. Accessed 23 Aug. 2021.
- 121 "Rural Transportation System of the Year." Community Transportation Association of America, <https://ctaa.org/system-of-the-year/>. Accessed 1 Oct. 2021.
- 122 "Tribal Transit in Maine." *Community Transportation Reader*, Community Transportation Association of America, <https://ctaa.org/aroostook-band-of-micmac-indians/>. Accessed 21 Apr. 2022.
- 123 U.S. Department of Transportation, Federal Transit Administration, National Rural Transit Assistance Program. "Tribal Transportation Issues and Successful Models." Mar. 2022, https://irp.cdn-website.com/270961f6/files/uploaded/NRTAP_Tribal_Transportation_Issues_and_Successful_Models_Tech_Brief_Published_March_2022.pdf. Accessed 21 Apr. 2022.
- 124 North Dakota State University, Upper Great Plains Transportation Institute, Small Urban and Rural Center on Mobility, <https://www.ugpti.org/surcom/resources/transportation-glossary.php?viewAll=1>. Accessed. 28 Sept. 2021.
- 125 U.S. Department of Transportation, Federal Transit Administration. "FTA Civil Rights / ADA Programs and Requirements for Indian Tribes Fact Sheet." 28 Sept. 2021, https://www.transit.dot.gov/sites/fta.dot.gov/files/2021-09/Civil-Rights-ADA-Reqs-for-Tribes-Fact-Sheet_0.pdf. Accessed 21 Apr. 2022.
- 126 "American Indian Vocational Rehabilitation Services." *Code of Federal Regulations*, 34 C.F.R., Subtitle B, Ch. III, Part 371, 20 Apr. 2022, <https://www.ecfr.gov/current/title-34/subtitle-B/chapter-III/part-371>. Accessed 23 Apr. 2022.
- 127 "Beneficiary Travel and Special Mode Transportation." *Code of Federal Regulations*, 38 C.F.R., Ch. I, Part 70, 11 Apr. 2022. <https://www.ecfr.gov/current/title-38/chapter-I/part-70/subpart-A>. Accessed 23 Apr. 2022.
- 128 "Bipartisan Bill Renews Effort to Strengthen Tribal Transportation Infrastructure." *Indian Country Today*, 24 Feb. 2021, <https://indiancountrytoday.com/the-press-pool/bipartisan-bill-renews-effort-to-strengthen-tribal-transportation-infrastructure>. Accessed 22 Apr. 2022.
- 129 "RE: Infrastructure Legislative Proposal." National Congress of American Indians et. al., 13 Apr. 2021, https://ncai.org/NCAI_Indian_Country_Infrastructure_Letter_FINAL_Update.pdf. Accessed 25 Oct. 2021.
- 130 United States, Congress. "H.R.3802: To Make Permanent the Authority of the Secretary of Veterans Affairs to Make Grants for the Transportation of Highly Rural Veterans to Medical Care." *Congress.gov*, 7 July 2021. <https://www.congress.gov/bill/117th-congress/house-bill/3802?s=1&r=50>. Accessed 23 Apr. 2022.
- 131 ———, Federal Transit Administration, National Aging and Disability Transportation Center. "2018 Transportation Trends: Non-Emergency Medical Transportation Brokerages and Benefits of Coordination." July 2019, <https://www.nadtc.org/wp-content/uploads/NADTC-Topic-Spotlight-NEMT-Brokerages-and-Benefits-for-web-7-22-2019-1-1.pdf>. Accessed 23 Apr. 2022.

- 132 ———, ———, National Rural Transit Assistance Program. “Tribal Transportation Issues and Successful Models.” Mar. 2022, <https://irp.cdn-website.com/270961f6/files/uploaded/NRTAP Tribal Transportation Issues and Successful Models Tech Brief Published March 2022.pdf>. Accessed 21 Apr. 2022.
- 133 ———, ———, ———. “Head Start Program: Transportation in Rural Areas.” Mar. 2020, <https://www.transit.dot.gov/sites/fta.dot.gov/files/docs/regulations-and-programs/ccam/about/147016/head-start-program-transportation-rural-areas.pdf>. Accessed 23 Apr. 2022.
- 134 ———, The White House. *Building a Better America: A Guidebook to the Bipartisan Infrastructure Law for State, Local, Tribal, and Territorial Governments, and Other Partners*. 31 Jan. 2022. https://www.whitehouse.gov/wp-content/uploads/2022/01/BUILDING-A-BETTER-AMERICA_FINAL.pdf. Accessed 22 Apr. 2022.
- 135 U.S. Department of Health and Human Services, Administration for Community Living. “Older Americans Act.” <https://acl.gov/about-acl/authorizing-statutes/older-americans-act>. Accessed 19 Aug. 2021.
- 136 Benally, Hoskie. “17th Annual Indian Disability Summit—Session Two.” *YouTube*, <https://youtu.be/6MAGhtFjtB0>. Accessed 28 July 2021.
- 137 ———. Chair of the Navajo Advisory Council on Disabilities 46:22. Native American Disabilities Law Center, 15 Apr. 2021.
- 138 and Governmental Liaison with the Native American Disability Law Center. Personal Interview. 3 Aug. 2021.
- 139 “Open Doors: Accessibility of Public Buildings on the Navajo Nation.” The Native American Disability Law Center, 2011, <https://www.nativedisabilitylaw.org/resources/item/183-opening-doors-accessibility-of-public-buildings-on-the-navajo-nation>.
- 140 Pindus, Nancy et.al. “Housing Needs of American Indians and Alaska Natives in Tribal Areas: A Report from the Assessment of American Indian, Alaska Native, and Native Hawaiian Housing Needs.” U.S. Department of Housing and Urban Development, Office of Policy Development and Research, 19 Jan. 2017, <https://www.huduser.gov/portal/publications/HNAIHousingNeeds.html>. Accessed 5 Oct. 2021.
- 141 Romero, Simon. “Navajo Nation Becomes Largest Tribe in U.S. After Pandemic Enrollment Surge.” *The New York Times*, 21 May 2021, <https://www.nytimes.com/2021/05/21/us/navajo-chokeee-population.html>.
- 142 Shebala, Marley. “Making Public Buildings on Navajo Reservation Accessible to the Disabled.” Marley Shebala’s Notebook: Keeping an Eye on Navajo Government, 2014, <http://www.dineresourcesandinfocenter.org/making-public-buildings-on-navajo-reservation-accessible-to-the-disabled/>.
- 143 U.S. Census Bureau. “Race and Ethnicity in the United States: 2010 Census and 2020 Census.” 12 Aug. 2021, <https://www.census.gov/library/visualizations/interactive/race-and-ethnicity-in-the-united-state-2010-and-2020-census.html>. Accessed 5 Oct. 2021.
- 144 U.S. Department of Health and Human Services, Administration for Community Living and the Administration on Aging. “Profile of American Indians and Alaska Natives Age 65 and Older.” 2017, <https://acl.gov/sites/default/files/Aging and Disability in America/2017OAPProfileAIAN508.pdf>. Accessed 15 Apr. 2022.
- 145 ———, Centers for Disease Control and Prevention. “Adults with Disabilities: Ethnicity and Race.” 16 Sept. 2020. <https://www.cdc.gov/ncbddd/disabilityandhealth/materials/infographic-disabilities-ethnicity-race.html>. Accessed 2 July 2021.
- 146 Villarroela, Maria A., et.al. “Health of American Indian and Alaska Native Adults, by Urbanization Level: United States, 2014–18.” Centers for Disease Control and Prevention, National Center for Health Statistics, Data Brief, no. 372, Aug. 2020, <https://www.cdc.gov/nchs/products/databriefs/db372.htm> - ref2. Accessed 2022.
- 147 City of San Antonio. “Universal Housing Design.” <https://www.sanantonio.gov/DAO/ADADesign/UniversalHousingDesign>. Accessed 26 July 2021.
- 148 City of San Antonio Neighborhood and Housing Services Department. “Design Guidelines and Construction Standards for New, Single-Family Affordable Housing Developments.” Dec. 2019, <https://www.sanantonio.gov/Portals/0/Files/NHSD/OurSA/2020 Guidelines for New Construction.pdf?ver=2019-12-19-135230-023>. Accessed 26 July 2021.
- 149 “The 7 Principles.” National Disability Authority, Centre for Excellence in Universal Design. <https://universaldesign.ie/what-is-universal-design/the-7-principles/>. Accessed 18 Apr. 2022.

- 150 Center for Universal Design. "Universal Design In Housing." *Center for Universal Design NCSU - Home*, North Carolina State University, Jan. 2006, <https://projects.ncsu.edu/ncsu/design/cud/>.
- 151 "How Much Does It Cost to Remodel for Disability Accommodation?" Home Advisor, <https://www.homeadvisor.com/cost/environmental-safety/remodel-for-disability-accommodation/>. Accessed 22 July 2021.
- 152 *Understanding Disabilities in American Indian and Alaska Native Communities Toolkit Guide*. The University of Montana, Rural Institute on Disabilities, American Indian Disability Technical Assistance Center, 2003. <https://ncd.gov/publications/2003/aug12003>. Accessed 22 Oct. 2021. The Resource book is no longer available.
- 153 "Visitability: Basic Access to Homes." Visitability, <https://visitability.org/>. Accessed 6 July 2021.
- 154 Crouse, Tripp J. "Senate Committee on Indian Affairs Passes Senate NAHASDA Reauthorization Out of Committee." KNBA 90.3 FM, 21 Feb. 2022, <https://www.knba.org/news/2022-02-21/senate-committee-on-indian-affairs-passes-senate-nahasda-reauthorization-out-of-committee>. Accessed 19 Apr. 2022.
- 155 Kunesh, Patrice H. "The Significance of Belonging for Indigenous Peoples: The Power of Place and People—Creating a Vision for Community in Indian Country Through Self-Governance and Self-Determination." *Journal of Affordable Housing & Community Development Law*, vol. 30, no. 1., 2021, https://www.americanbar.org/content/dam/aba/publications/journal_of_affordable_housing/affordablehousing-may21.pdf. Accessed 20 Apr. 2022.
- 156 "NAHASDA Reauthorization Reintroduced in Senate." National Low Income Housing Coalition, 2021, <https://nlihc.org/resource/nahasda-reauthorization-reintroduced-senate>.
- 157 Pierson, Brian. "2020 Indian Housing Development Handbook." National American Indian Housing Council, <https://naihc.net/wp-content/uploads/2019/12/Indian-Housing-Development-Handbook-2020-Single-Page.pdf>. Accessed 19 Apr. 2020.
- 158 Pindus, Nancy et.al. "Housing Needs of American Indians and Alaska Natives in Tribal Areas: A Report from the Assessment of American Indian, Alaska Native, and Native Hawaiian Housing Needs." U.S. Department of Housing and Urban Development, Office of Policy Development and Research, 19 Jan. 2017, <https://www.huduser.gov/portal/publications/HNAIHousingNeeds.html>. Accessed 5 Oct. 2021.
- 159 "Programs." Hopi Tribal Housing Authority, <https://htha.org/programs>. Accessed 20 Apr. 2022.
- 160 U.S. Department of Housing and Urban Development. "Section 4 Capacity Building for Community Development and Affordable Housing Program." HUD Exchange, <https://www.hudexchange.info/programs/section-4-capacity-building/>. Accessed 20 Apr. 2022.
- 161 ———, Office of Policy Development and Research. "Assessment of American Indian, Alaska Native and Native Hawaiian Housing Needs: Briefing on Study Findings." 2017, <https://www.huduser.gov/portal/sites/default/files/pdf/Final-Presentation.pdf>.
- 162 U.S. Department of the Interior, Indian Affairs. "Hearth Act Leasing." <https://www.bia.gov/service/hearth-leasing> - :~:text=The Helping Expedite and Advance,415. Accessed 20 Apr. 2022.
- 163 Kapp, Beth. "Karuk Tribe Wins Low Income Housing Tax Credit Award to Build 30 New Homes." Travois, 18 June 2015. <https://travois.com/articles/karuk-tribe-wins-low-income-housing-tax-credit-award-build-30-new-homes/>. Accessed 21 Apr. 2022.
- 164 Norwood, Adrienne. "Section 4 Funding Supports Housing for Seniors and Native American Veterans." Enterprise Blog, 28 Feb. 2020, <https://www.enterprisecommunity.org/blog/section-4-funding-supports-housing-seniors-and-native-american-veterans>. Accessed 23 July 2021.
- 165 Pindus, Nancy et.al. "Housing Needs of American Indians and Alaska Natives in Tribal Areas: A Report from the Assessment of American Indian, Alaska Native, and Native Hawaiian Housing Needs." U.S. Department of Housing and Urban Development, Office of Policy Development and Research. 19 Jan. 2017. <https://www.huduser.gov/portal/publications/HNAIHousingNeeds.html>. Accessed 5 Oct. 2021.
- 166 U.S. Department of Agriculture, Rural Development and Innovation Center. "USDA Rural Development Investments Benefitting American Indian/Alaska Native Communities." 2019, https://www.rd.usda.gov/files/508_RD_TribalReport_2019.pdf.

- 167 "Architectural Barriers Act (ABA) of 1968." U.S. Access Board, <https://www.access-board.gov/law/aba.html>. Accessed 4 Oct. 2002.
- 168 Pierson, Brian. "2020 Indian Housing Development Handbook." National American Indian Housing Council, <https://naihc.net/wp-content/uploads/2019/12/Indian-Housing-Development-Handbook-2020-Single-Page.pdf>. Accessed 19 Apr. 2020.
- 169 U.S. Department of Housing and Urban Development, Office of Policy Development and Research. "Assessment of American Indian, Alaska Native and Native Hawaiian Housing Needs: Briefing on Study Findings." 2017, <https://www.huduser.gov/portal/sites/default/files/pdf/Final-Presentation.pdf>.
- 170 "What is NAHASDA?" National Association of Housing and Redevelopment Officials, https://www.nahro.org/wp-content/uploads/2020/04/NAHASDA_One-Page.pdf. Accessed 26 July 2021.
- 171 Yazzie, Annette. "17th Annual Indian Disability Summit—Session Two." *YouTube*, 46:22, Native American Disabilities Law Center, 15 Apr. 2021, <https://youtu.be/6MAGhtFjtB0>. Accessed 26 July 2021.
- 172 *American Indian and Alaska Native Grandfamilies: Helping Children Thrive Through Connection to Family and Cultural Identity*. Generations United and National Indian Child Welfare Association, 2020, <https://www.nicwa.org/wpcontent/uploads/2020/07/AIAN-Toolkit-WEB.pdf>, Accessed 7 September 2022.
- 173 Minnesota Department of Administration, Governor's Council on Developmental Disabilities. "Parallels in Time: A History of Developmental Disabilities." <https://mn.gov/mnddc/parallels/seven/7c/1.html>. Accessed 22 Feb. 2022.
- 174 Shoultz, Bonnie. "More Thoughts on Self-Advocacy: The Movement, the Group, and the Individual." Syracuse University, The Center on Human Policy, 2002, <https://thechp.syr.edu/more-thoughts-on-self-advocacy-the-movement-the-group-and-the-individual/>. Accessed 22 Feb. 2022.
- 175 "Types of Advocacy." West Virginia University Center for Excellence in Disabilities, <https://cedwvu.org/resources/types-of-advocacy/>. Accessed 22 Feb. 2022.
- 176 U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, the Division of Human Development and Disability. "Become a Disability A.L.L.Y. in Your Community and Promote Inclusion." 26 July 2021. <https://www.cdc.gov/ncbddd/humandevelopment/become-a-disability-ALLY.html>. Accessed 22 Feb. 2022.
- 177 Brown, Jennifer. "How Advocates for Inclusion Keep from Burning Out." *Berrett-Koehler Publishers Blog*, 2 Sept. 2020, <https://ideas.bkconnection.com/how-advocates-for-inclusion-keep-from-burning-out>.
- 178 Young, Lindsey [@Lindss_tastic]. *Twitter*, 30 May 2020, https://twitter.com/lindss_tastic/status/1266763433560756225?lang=en. Accessed 9 Nov. 2021.
- 179 "What is systemic advocacy?" Office of the Public Advocate, Accessed 7 September 2022, <https://www.justice.qld.gov.au/public-advocate/about-the-public-advocate/what-is-systemic-advocacy>. Accessed 5 Nov. 2021.
- 180 "System Change Advocacy." Community Access Center, <https://ilcac.org/system-change-advocacy/>. Accessed 13 Apr. 2022.
- 181 *Disability Etiquette*. United Spinal Association, 2015, <https://www.unitedspinal.org/pdf/DisabilityEtiquette.pdf>. Accessed 29 Mar. 2022.
- 182 San Antonio, Department of Public Works, Disability Access Office. *Disability Etiquette Handbook*. Jan. 2011, <https://www.sanantonio.gov/Portals/0/Files/DAO/DisabilityEtiquetteHandbook.pdf>. Accessed Mar. 2022.



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