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The Montana University Affiliated Rural Institute on Disabilities is one of the sixty-four University Affiliated Programs across the nation. It is an interdisciplinary organization that promotes the full participation in rural life of individuals with disabilities. The Rural Institute accomplishes this goal by developing and disseminating innovations in teaching, research, community supports and policy advocacy.

Through a variety of technical assistance, training, research, information dissemination and service activities, Institute staff work to:

- *discover and develop **inventive approaches** to meet the challenges of living with disability in rural areas;*
- *increase the number and quality of **professionals and providers** in rural areas;*
- *provide **information about rural areas** to the general public, consumers, families, professionals and policy makers; and*
- *increase **access in rural areas** to quality social, educational and health care supports.*

(406) 243-5467 Voice/TT (800) 732-0323 Toll-free (406) 243-2349 FAX
E-mail: muarid@selway.umt.edu



A Guide to Developing Disability Policies on American Indian Reservations

Rural Institute on Disabilities
The University of Montana
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AMERICAN INDIAN DISABILITY LEGISLATION PROJECT ADVISORY PANEL

The advisory panel provides direction and feedback to the AIDL Project, ensuring that there is input over a range of tribes, regions, educational backgrounds and personal experiences.

Michael Blatchford

Navajo
American Indian Disability Advocate,
Tuba City, Arizona

Rod Brod, Ph.D.

Nemaha Algonquian
Professor, Sociology Department,
The University of Montana,
Missoula, Montana

Bobby Brown, B.S.

Navajo
Residential Coordinator,
Chinle Valley School
for Exceptional Children,
Chinle, Arizona

Lewellyn "Rusty" Cantrell, B.S.

Assiniboine Sioux
Director, Assiniboine Sioux
Vocational Rehabilitation Program,
Poplar, Montana

Julie Clay, M.P.H.

Omaha
Research Specialist,
American Indian Rehabilitation
Research and Training Center,
Northern Arizona University,
Flagstaff, Arizona

Sidney Claymore, B.A.

Lakota, Standing Rock Sioux
Director, Tateya Topa Ho,
McLaughlin, South Dakota

Stephen Clincher

Fort Peck Sioux
American Indian Disability Advocate,
Poplar, Montana

Richmond Clow, Ph.D.

Professor
Native American Studies,
The University of Montana,
Missoula, Montana

Jene McCovey, B.A.

Yorok, Tolowa, Hupa
American Indian Disability Advocate,
Arcata, California

Ronald Sam

Athabascan
Rural Independent Living Specialist,
Access Alaska,
Fairbanks, Alaska

Priscilla Sanderson, M.S., C.R.C.

Navajo
Director, American Indian Rehabilitation
Research and Training Center,
Northern Arizona University,
Flagstaff, Arizona

Ryder Studi, B.A., C.R.J.

Cherokee
Instructional Specialist,
Native American Research
and Training Center,
University of Arizona,
Tucson, Arizona

Bob Tate, M.A., J.D.

Senior Policy
Analyst/Program Consultant,
National Education Association,
Washington, D.C.

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Project prepared by: Julie Clay, M.P.H.
Carol Locust, Ph.D.
Tom Seekins, Ph.D.

Study Guide written by: LaDonna Fowler, A.A.S.
Tom Seekins, Ph.D.
Jean Guidry, M.A.
Kathy Dwyer, B.S.
Susan Duffy, B.A., M.A.T.
Susan Brueckmann, B.A.

INTRODUCTION

The American Indian Disability Legislation (AIDL) Project is a three year project whose goal is to develop and test methods for fostering the adoption of disability legislation by American Indian tribes that is consistent with the principles established by the Americans with Disabilities Act (ADA), and is respectful of tribal sovereignty and cultural diversity.

The project consists of three phases:

Phase I: project researchers surveyed 143 tribal governments, representing over 600,000 people, to assess the awareness of disability issues and the status of tribal disability policies. The results of the survey are summarized in Section VI.

Phase II: establishes 5 to 7 Focus Groups, recruited from the tribes who responded to the survey, who will gather to consider disability issues and the ADA in relation to their culture, traditions and belief systems. Each Focus Group will review the survey results and the Titles of the ADA to determine their relevance and appropriateness to their tribe. The Focus Group will then recommend to their tribal councils to adopt the Americans with Disabilities Act directly, change the existing Law to meet the needs of the individual tribe, create unique tribal legislation or not to adopt disability laws.

Phase III: tribes that choose to adopt disability policies will form Disabilities Policy Groups. Their tribal councils will be asked to define the Policy Group's mission and to offer guidance.

AIDL staff members will provide information and assistance throughout the process as tribes work to create disability policies for their reservations and Alaskan Native villages.

Since federal disability legislation does not cover the Indian tribes, you have the right, as sovereign nations, to determine for yourselves how you want to address your tribe's disability issues. How you choose to do this reflects the unique culture, history and resources of your tribe.

WHAT IS THIS GUIDE ALL ABOUT?

The purpose of this guide is two-fold. The first purpose of the American Indian Disability Legislation Project is to gather information and ideas from you, the users of this guide. Our second goal is to share with you a brief overview of some of the federal legislation that ensures equal opportunities for individuals with disabilities. The picture we provide comes from the information, experiences and ideas various tribes reported in our National Survey on Indian Disability Legislation. We hope to bring up some of the issues and barriers which have already confronted some tribes and which might not be immediately apparent to you as you seek your own solutions and make your own legislative decisions about disabilities.

I. YOUR DISABILITY BELIEF , this section asks you to think about your personal beliefs about disability	3
II. PROTECTING THE RIGHTS OF PEOPLE WITH DISABILITIES , this section describes issues around Access, Employment and Transportation	5
III. HOW HAS THE U.S. GOVERNMENT ADDRESSED DISABILITY ISSUES gives a brief overview of federal disability laws	13
IV. DISABILITY LAWS is a brief description of the different federal laws which protect the rights of people with disabilities	14
V. YOUR TRIBE AND DISABILITY LEGISLATION asks you to consider what policies would be appropriate for your tribe	18
VI. AIDL SURVEY RESULTS this section describes the status of disability law and programs as reported by various tribes in our national survey	23
VII. HOW HAVE AMERICAN INDIAN TRIBES ADDRESSED DISABILITY ISSUES notes what some tribes have already done to develop disability policies on their reservations	25
VIII. CONCLUSION	26

These questions are not exhaustive, nor are they the only way to consider the issue. We hope that they will stimulate more questions and dialogue.

DISABILITY BELIEFS

Think about the physical world you live in. If you must use a wheelchair, is it possible for you to get out of your home? Can you get into a tribal meeting? If you are deaf, is it possible for you to participate in tribal meetings? If you are blind, can you get to the meeting? Do you have any difficulties in getting around your community? Does this interfere with your ability to get a job? These are just a few of the issues that people with disabilities must face daily.

As you read the following questions, consider not only your own personal beliefs and thoughts, but also consider what your tribe's tradition suggests or advises.

- Do you believe that Indian people with disabilities should be respected and treated with dignity?
- Do you believe that all people are the same?
- Do you believe, as some traditional people do, that there is "spiritual unwellness"? If so, what causes the unwellness and can it affect people with disabilities?
- Do you believe that Indian people with disabilities should be cared for because it's the traditional or natural way?
- How do you believe Indian people with disabilities want to be treated?
- What are the cultural issues or traditions that should be addressed as a barrier or a resource?

There have always been people with disabilities — people whose ability to walk, talk, hear, see or think is hindered. Until recently in this country, people with disabilities have been excluded from participating in activities of everyday life. In many cases, a lack of understanding and even downright ignorance about disabilities have led to abuse, mistreatment and/or neglect. Even when intentions have been good, people with disabilities have been treated as incapable of making decisions effecting their own lives.

In the U.S., disability describes individuals whose abilities are different than most other people's. These individuals may have an inability or an impaired ability to do certain things which the majority of people take for granted. Activities such as getting around, socializing, taking care of themselves, obtaining an education, communicating with others and getting a job can be very difficult for people with disabilities.

Among American Indian cultures, the concept of disability, as well as beliefs about disabilities and their causes, vary from individual to individual, from tribe to tribe and from region to region.

What does it mean, then, when we speak of disability? As a Navajo vocational rehabilitation counselor once said, it would take a page and a half of words in the traditional Navajo language to capture the meaning of this one English word "disability." Because there are so many ways of looking at disability, we would like to begin by learning your beliefs about disability.

Please note that in this guide we have used the terms "individual with disabilities" and "people with disabilities" and "Indian people with disabilities." We realize that what may be acceptable to one person may not be acceptable to another.

PROTECTING THE RIGHTS OF PEOPLE WITH DISABILITIES

We have already said that people with disabilities have been excluded and that this has often led to mistreatment or neglect. Obviously, this is not the answer. But how should they be treated? What rights do they have?

As you read the following questions, think about how you want to be treated as an Indian person with, or without, a disability.

- Do you feel that you are being treated with respect?
- Do you feel that you are being treated as a part of the community with opportunities to use your gifts and abilities?
- Do you feel that you should be taken care of and not have to worry about working or "doing something"?
- Do you believe that it's your right to participate socially or culturally by going to pow-wows, ceremonies, and gatherings?
- Do you believe that your tribe should address the needs of members with disabilities?

ACCESS

It is estimated that about 14% of the Indian population have disabilities that prevent them from carrying out a major life activity such as working, keeping house or attending school (U.S. Census of Population, 1990). Respondents to the AIDL survey indicated that, on average, only 67% of the public buildings on their reservations are accessible.

For many people with disabilities, there are physical barriers — in their own homes as well as in schools, grocery stores, job sites and community meeting places — that keep them from participating in activities most people take for granted. For others, the barriers may have to do with communication. If a person cannot talk or hear, simple communication by regular telephone is impossible.

1. What are the cultural and traditional issues that should be considered when removing barriers to accessibility?
2. What buildings or facilities are tribal members with disabilities unable to use because of physical barriers?
3. What is your tribe doing to make these buildings and areas physically accessible?

4. What are the major barriers to making your community accessible to people with impairments that restrict their ability to move around?

5. What is your tribe doing to make it easier for members with speech or hearing impairments to participate in community activities?

6. What are the major barriers to making your community accessible to people with speech or hearing impairments?

7. Who should be responsible for removing these barriers?

8. What resources does your tribe need in order to overcome these barriers?

EMPLOYMENT

In general, people with disabilities, whether Indian or non-Indian, are either underemployed or have difficulty obtaining any employment at all. However, Indians and Alaskan Native people have a significantly higher rate of disability than other ethnic groups. Analysis of census data at the American Indian Rehabilitation Research and Training Center at Northern Arizona University indicates that more than one in four (26.9%) Indian people in the labor force have a disability (Schacht, 1993).

For most people with disabilities in the U.S. who do have employment, very few are in well-paying professional positions. In fact, in 1987 workers with disabilities made about 64 cents for every \$1 made by workers without disabilities in comparable jobs. About 30% of people with work disabilities have family incomes below the poverty level (Ficke, 1992).

For American Indians, the picture is more bleak. In 1987 the BIA found that unemployment on reservations varied from 13% among the Jicarilla Apache in New Mexico to 82% on the Rosebud Reservation in South Dakota (BIA, 1987). More recently, in 1994, a study of Section 130 Tribal Vocational Rehabilitation (VR) reports was conducted by the University of Northern Colorado at Greeley. Twelve of 16 responding tribal VR programs reported that the unemployment rate for American Indians living on reservations is estimated to be 40.75%. Rocky Boy Reservation in Montana reported a high of 66% and a low of 22.6% was cited among the Mississippi Choctaw (Nelson & Trevino, 1994).

1. What are the cultural issues or traditions that should be addressed as barriers to or resources to help with the employment of people with disabilities?

2. What are the financial barriers to employing people with disabilities?

3. What other barriers are there?

4. What problems are presented by non-tribal agencies that address employment issues?

5. What would **you** like to see your tribe doing to ensure that members with disabilities can obtain employment?

6. What is **your tribe** doing to help promote employment for members with disabilities?

7. What services (supported employment, transportation assistance, job coach) for employment for people with disabilities comes from outside your tribe?

TRANSPORTATION

For many people with disabilities, getting from one place to another is a constant challenge. Many individuals must rely on friends and family for transportation and do not enjoy the independence that most of us take for granted when we decide to go somewhere.

1. What are the cultural or traditional issues that should be addressed as barriers to transportation for people with disabilities?
2. Are there economic or political barriers to transportation for people with disabilities?
3. What transportation services are available on your reservation?
4. Are people with disabilities able to use these transportation services?

5. What is your tribe doing to make sure that people with disabilities have adequate transportation?

6. What are the major barriers to making transportation on your reservation accessible to people with disabilities?

7. Who should be responsible for removing transportation barriers?

8. What guidelines do you suggest for removing transportation barriers on your reservation?

9. What resources does your tribe need in order to overcome these barriers?

HOW HAS THE U.S. GOVERNMENT ADDRESSED DISABILITY ISSUES?

As American citizens, we have become more aware of these disability issues. People with disabilities have increased their efforts to make sure that no one in this society is discriminated against simply because of a disability. They have passed laws that say that people with disabilities have the right to engage in ordinary life activities — such as entering buildings freely, communicating with others and working — and that their opportunities to do these things should be equal to the opportunities that people without disabilities have.

The U.S. Congress has enacted several laws which guarantee equal rights and opportunities for people with disabilities. Probably the most well-known and widely enforced of these is the Americans with Disabilities Act, or ADA, of 1990. The ADA, however, is not the only law out there. Other laws that protect the civil rights of individuals include the Individuals with Disabilities Education Act (IDEA) and Sections 503 and 504 of the Rehabilitation Act of 1973. These federal laws all were passed in an effort to ensure that individuals with disabilities would have the same opportunities and rights as any other individual.

Although there have been significant improvements as a result of these laws, change continues to be slow and expensive. In fact, these laws have had little or no impact on American Indian reservations. One reason for this is the federal government's respect for tribal sovereignty and the diversity of American Indian nations. Because of this, however, the ADA does not require tribal governments and business owners who reside on reservations, trust lands and Alaska Native villages to do what the ADA requires of every other government and business in the United States. For American Indians with disabilities — indeed, anyone with a disability — who live on tribal land, there are few legal protections unless the individual tribal government has passed such laws.

DISABILITY LAWS

The most important federal disability laws are the Americans with Disabilities Act (ADA), Sections 503 and 504 of the Rehabilitation Act of 1973, and the Individuals with Disabilities Education Act (IDEA). This section briefly reviews these federal laws.

The Americans with Disabilities Act

The most recent, and far-reaching law protecting people with disabilities is the civil rights legislation called the Americans with Disabilities Act. On July 26, 1990, the ADA was passed in an effort to ensure that individuals with disabilities have the same opportunities and rights as any other individual. It is designed to remove barriers which keep people with disabilities from enjoying the same opportunities that people without disabilities have. Earlier federal laws and regulations, such as Section 504 of the Rehabilitation Act, applied only to the federal government and those doing business with it. The ADA, essentially, extends the same guarantees to all businesses and agencies. It consists of five sections, called Titles. Each Title focuses on a different area.

Title I: Employment

Title I of the ADA ensures that individuals with disabilities who are qualified to perform a job are not discriminated against because of their disability. This includes any sort of discrimination that may occur when a person with a disability is applying for a job, working in a job, trying to advance his position or receiving job training. Title I applies to all employers with 15 or more employees. For example, if a person with a disability is applying for a job, the employer cannot use tests on him in a way that will keep him from being hired because of the disability. The employer cannot pay less or deny benefits to a person who is qualified to do a job simply because of the disability. Finally, the employer must make any reasonable accommodations — for example, adding a ramp to the building entrance — that will enable the person with the disability to work, unless the accommodation will cause undue hardship on the operation of the business.

Title II: Public Services

Title II deals with state and local governments, any agencies of these governments, and railroad or other transportation authorities. It says a person cannot be excluded from participating in the activities of these public agencies or denied the benefits of their public services and programs because of a disability. For example, if

a person is eligible to receive services from a public agency, those services must be delivered to that person whether or not he/she has a disability. When a public transportation company buys new equipment or rebuilds old equipment, it must make sure that the equipment can be used by people with disabilities, including those who use wheelchairs. In addition, the facilities and services of these companies must be made accessible to people with disabilities unless doing so would cause an undue financial burden on the company.

Title III: Public Accommodations and Services Provided by Private Companies

Title III says that people with disabilities must have the same opportunities as others to enjoy the goods, services and facilities provided by private companies such as theaters, grocery stores, laundromats, motels, restaurants, libraries, schools, day care programs and any other businesses which provide some sort of service to the public. For example, private companies must make their facilities accessible to people with disabilities unless the cost is too great of a hardship. A company cannot serve people with disabilities in a separate place or provide goods or services that are inferior to those received by people without disabilities.

Title IV: Telecommunications

Title IV ensures that telecommunication services will be provided at no additional cost to individuals who are hearing-impaired or speech-impaired. Telecommunication services make it possible for individuals with hearing or speech impairments to communicate with their communities. This means that telephone companies must provide relay services. A relay service either takes written messages from people with speech impairments and translates them into telephone voice messages, or it provides written translations of voice messages to people with hearing impairments. In addition, public service announcements on television must provide closed captioning. These telecommunication services must be provided to individuals who need them to the same extent and at the same expense as regular telephone or television services.

Title V: Miscellaneous

Title V deals with various provisions not covered in the other sections of the ADA. In particular, it states that the ADA does not in any way lower the standards set by the Rehabilitation Act of 1973. If another law provides greater protection for the rights of people with disabilities, then the ADA cannot limit those rights guaranteed by that law.

Enforcement of the ADA

The ADA states broad expectations about how people with disabilities should be treated. If a person experiences discrimination, he or she is responsible for initiating a complaint. First, the person must try direct negotiation and mediation. Negotiation involves talking directly to the person who has discriminated against you. Mediation involves bringing in a third person who will listen to both sides and help search for a solution. If negotiation and mediation fail, a complaint can be filed with one of the following agencies which have jurisdiction over particular areas:

Title I - Employment Issues	Equal Employment Opportunity Commission (EEOC) (800) 669-EEOC (3302)
Title II - Public Services of Local and State Governments	U.S. Attorney General - U.S. Department of Justice (202) 514-0301
Title II, Parts I & II - Public Transportation Services	U.S. Secretary of Transportation (202) 366-9305
Title III, A & B - Public Accommodations, New Construction or Alterations to Public Accommodations and Commercial Facilities	U.S. Attorney General - U.S. Department of Justice (202) 514-0301
Title III, C - Public Transportation Provided by Private Entities	U.S. Secretary of Transportation (202) 366-9305
Title IV - Telecommunication Services	Federal Communications Commission (FCC) (202) 632-7260

The Rehabilitation Act of 1973

The Rehabilitation Act of 1973 is a federal law that addresses the rights of people with disabilities along with descriptions of various programs that the federal Rehabilitation Services Administration and Vocational Rehabilitation (VR) program provide to people with disabilities. It establishes and funds state systems of vocational rehabilitation. For example, under Title I, Section 130 provides funds specifically to tribes to establish and operate vocational rehabilitation programs to help tribal members with disabilities enter into and maintain employment.

Section 503

Section 503 of the Rehabilitation Act prohibits businesses which receive federal contracts from discriminating against individuals because of their disabilities. It requires these government contractors to take "affirmative action" to employ and advance workers with disabilities. This means that if two people are equally qualified for a job, the one who belongs to a group that traditionally has been discriminated against may be given first consideration for the job.

Section 504

Section 504 of the Rehabilitation Act was the first federal civil-rights law protecting the rights of people with disabilities, but applies only to programs and activities conducted by the federal government or by agencies who receive federal financial assistance. In other words, agencies such as the Bureau of Indian Affairs (BIA), schools, colleges, libraries, Indian Health Services, vocational schools or vocational-rehabilitation agencies must operate their programs so that they are readily accessible to people with disabilities. They may not impose rules that make it impossible for students with disabilities to take part in activities. They must modify their way of teaching in order to meet the needs of students and to enable them to learn. They must provide transportation services which are accessible to students with disabilities. In addition, these agencies cannot discriminate against people with disabilities in their employment practices.

Individuals with Disabilities Education Act

The Individuals with Disabilities Education Act (IDEA) ensures that all children with disabilities will receive a free and appropriate public education. This means that, whenever possible, children will be placed in regular school classrooms and given the special-education services which enable them to participate fully in classrooms alongside their peers without disabilities. Children with disabilities may receive a wide variety of services depending upon their needs: speech therapy, physical therapy, occupational therapy, transportation or one-on-one help from a special-education teacher or aide. The children may be provided with adaptive equipment such as keyboards, switches or standing and sitting devices to help them communicate and interact with others in the classroom.

YOUR TRIBE AND DISABILITY LEGISLATION

This section contains some general questions about equal-opportunity laws. We look at some specific challenges that Indian people with disabilities face and hope to learn how you would like to see them addressed. This section also offers questions that some tribes have already raised and asks questions we hope will be helpful as you consider ways in which your tribe has already addressed challenges that confront the people with disabilities on your reservation.

Since federal disability legislation does not cover the Indian tribes, you have the right, as sovereign nations, to determine for yourselves how you want to address your tribe's disability issues. How you choose to do this reflects the unique culture, history and resources of your tribe.

Federal laws may or may not be appropriate for you. You may wish to adopt federal disability laws as written, or to ignore them completely. You may choose to adopt only certain parts of federal laws, or to adapt them so that they work for your tribe. You may wish to create your own disability laws, or you may choose not to have any. Our interest is in learning what you plan to do as a tribe, to share this information with others and to offer our help in your process, should you want it.

Equal Opportunity Laws: Some Questions to Think About

1. How can your tribe determine what kinds of needs its members have? How should it decide which needs are most important and should be met first?

2. How should disability be defined?

3. Do you think your tribal government should have a law or resolution that prohibits discrimination against and requires equal opportunities for people with disabilities?

4. Is the Americans with Disabilities Act applicable to your tribal situation?

5. In what ways could the Americans with Disabilities Act be useful to your tribe?

6. In what ways might it not be useful?

7. What changes might be made to the Americans with Disabilities Act to make it useful for your tribe?

8. What could your tribe use instead of Americans with Disabilities Act?

9. Using the information gathered about cultural issues and traditions, how can you incorporate this into disability policy?

10. If your tribe decided to adopt a disability resolution or policy, what should it say about:

Accessibility

Employment

Transportation

11. How would your tribe implement an adopted disability resolution or policy on:

Accessibility

Employment

Transportation

12. Who should enforce a disability resolution or policy? How should it be enforced?

13. Are there people, tribal agencies or reservation-based businesses that should not be included in such legislation? Which tribal entity would make this decision?

14. What are the responsibilities of people with disabilities? What roles should people with disabilities play?

15. Can people with disabilities become leaders and advocates? If the tribe's culture or traditions says not, then what other ways exist?

AIDL SURVEY RESULTS

During the winter of 1994-95, the American Indian Disability Legislation Project conducted a survey of American Indian tribes throughout the United States. The purpose of this survey was to discern how aware tribal governments are of disability issues, whether tribal governments have disability policies and whether services are available to tribal members with disabilities. Of the tribes who answered the survey, 143 were randomly selected and their responses are summarized below.

About 37% of these tribes reported that they are familiar with the ADA, Sections 503 and 504 of the Rehabilitation Act, or IDEA. The total enrollment of the selected tribes is 628,759. About 6.5% of these tribes, or 41,237 members, have one or more disabilities. Diabetes and emotional problems were the two most commonly reported problems on these reservations, with tribes reporting that more than 25,000 members have diabetes and more than 18,000 have emotional problems. In addition, tribes reported that nearly 9,000 members are slow to learn; nearly 7,000 members use crutches, walkers, or canes; almost 5,000 use a wheelchair; over 5,000 are deaf or hard of hearing; and over 4,000 have fetal alcohol syndrome or fetal alcohol effect. There are also a large number of tribal members who are blind or have very low vision, have speech or communication difficulties or do not have the use of one or both arms or legs.

Almost all tribes state the belief that it is very important that tribal members with disabilities be treated with respect. Most tribes thought it is important for members with disabilities to participate in their tribal government and in tribal activities, to have access to programs that provide disability-related services and to be employed on the reservation. Although tribes said that all of these issues are important, most were not satisfied with what was being done about them on their reservations.

Typically, the most accessible buildings on reservations were also the most frequently used, including schools, health facilities and community buildings. The least accessible were the least frequently used, in particular, BIA buildings, federal buildings and tribal courts and jails. Most tribes reported that Indian Health Service, Tribal Health Service, home health-care services, special-education services, Senior Citizen Centers and vocational rehabilitation services are available and are part of the tribal structure. Independent living centers, group homes and sheltered workshops are also a part of tribal structure, but only a few exist. Most other services, such as adult day care, respite services and developmental-disabilities services are not part of the tribal structure and are not readily available.

Few of the tribes have budgets for disability services. Thirty-nine percent include \$7,000 to \$8,000 in their budgets for making homes, public buildings and community areas accessible to wheelchairs. About 19% of the tribes include an average of \$12,500 in their budgets for employment services for people with disabilities. About 16% include an average of \$4,000 for public education on disability issues and \$5,000 for staff training on disability issues. About 13% of the tribes included general disability money in their budgets.

HOW HAVE AMERICAN INDIAN TRIBES ADDRESSED DISABILITY ISSUES?

The response of different tribal nations to disability issues, and specifically to being excluded from having to comply with the ADA, has been as varied and diverse as the tribes themselves.

- ◆ Some tribes have asked why they were left out of the jurisdiction of the ADA.
- ◆ At least one tribe has chosen to adopt the ADA as a whole through tribal resolution and is now sorting out what this means for its members.
- ◆ Members of another tribe have chosen to ignore the ADA because they believe that every tribal member is special and that the tribe's mandate is to meet the special needs of all its members.
- ◆ Some tribes have budgeted money to make buildings accessible.
- ◆ One tribe has created its own Office of Special Education to ensure that tribal children with disabilities will have their educational needs met.
- ◆ Members of one tribe have formed their own disability action group to provide support to tribal members with disabilities.

As you can see from the above examples, disability issues are being addressed by individual tribes, each in its own way.

CONCLUSION

Now that you have considered and discussed your beliefs about disability, learned how the Indian tribes and the U.S. government have addressed disability issues, read about the AIDL national survey results, what steps would you like your tribe to take?

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