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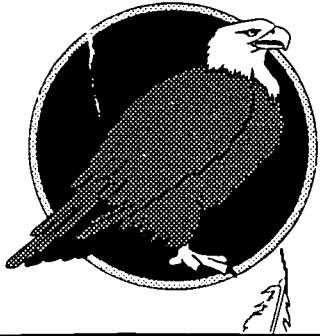
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ABSTRACT

Few studies have reported whether disability laws and regulations such as the Americans with Disabilities Act (ADA) have been implemented among American Indian tribes or whether tribes even view these laws as potentially valuable or culturally relevant. The American Indian Disability Legislation Project aims to develop methods of adopting disability legislation among tribes that are consistent with ADA principles and respect tribal sovereignty and cultural diversity. The first phase of the project involved a national survey of American Indian tribes that examined issues related to disability legislation. Of 685 surveys sent to identified tribes, 143 were returned. The first section of the report discusses results from the 112 surveys returned from tribes in the lower 48 states. A separate analysis was completed for Alaska Native villages and is included in an appendix. The total enrollment of responding tribes from the lower 48 states was 628,759, including an estimated 41,237 tribal members with a disability that substantially limits one or more major life activities. Only 6 percent of respondents indicated that their tribal governments were familiar with major disability legislation. Diabetes, emotional problems, and slow-to-learn were the major disabilities reported among tribal groups. Respondents indicated low satisfaction among disabled tribal members with regard to respect, opportunity, and access to disability-related services. Respondents also reported that only 67 percent of public buildings on reservations were accessible to the disabled; that disability-related tribal services were more accessible than outside services; and that only 13 percent of tribes had a line item in their budget for disability issues. Appendices include data from the Alaska survey, resolutions passed by the National Congress of American Indians in support of the project, and a glossary. Includes many data tables and maps. (LP)

ED 399 122



American Indian Disability Legislation

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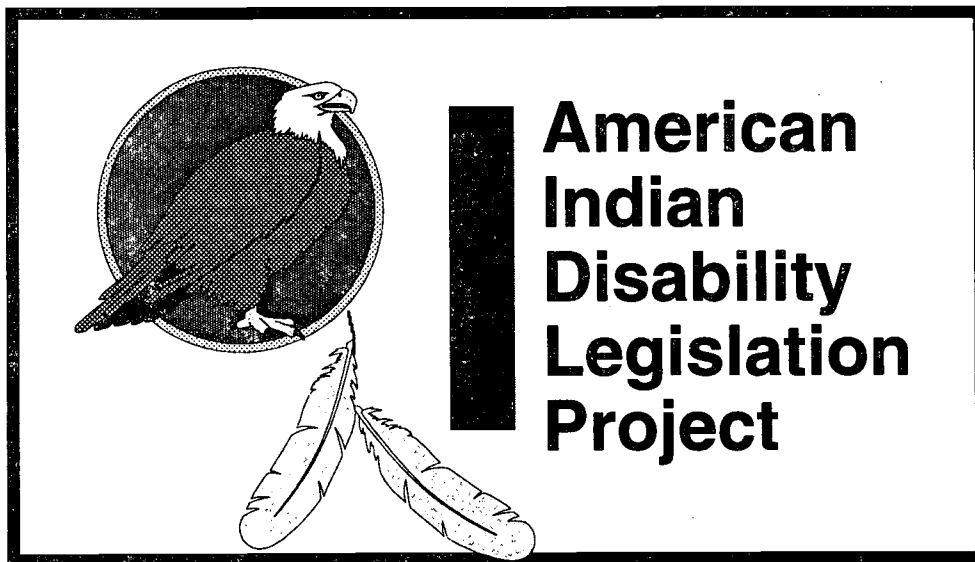
The Montana University Affiliated Rural Institute on Disabilities is an interdisciplinary, university-sponsored organization that promotes the full participation in rural life by individuals of all ages with disabilities. The Rural Institute promotes this goal by developing and disseminating innovations in teaching, research, community services and policy advocacy.

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

- discover and develop state-of-the-art approaches to meet the challenges of living with a disability in rural areas;
- increase the number and quality of disability service professionals and providers in rural areas;
- provide information about rural areas to the public, professionals, and policy makers; and
- help people with disabilities in rural areas access quality social and educational services and health care.

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Findings of a National Survey of Tribal Governments

Rural Institute on Disabilities
The University of Montana
December 1995

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.

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In dedication ...

Farewell, Ditchin Ka'-Thi deh-aaiy
In Memory of Straight-Arrow, Ronald E. Sam, AIDL Project Advisory Panel Member
December 5, 1956 to August 14, 1995

Ron was a friend and a link in the chain of advocates for Indian people with disabilities, especially to the Alaskan Native villagers. Ron made us aware of the barriers faced by Indian people with disabilities in rural Alaska.

Since 1994, Ron served on the Advisory Panel of the American Indian Disability Legislation Project as a representative of Alaskan Natives with disabilities. He was a regular participant in the Rural Institute on Disabilities' national Common Threads Conference where he shared information about ACCESS Alaska, his poetry and his friendship. He was also a member of the Center's National Advisory Board since 1992.

It takes a lot of courage to speak up about disability. Some Indian people with disabilities face a harder time of acceptance because of the culture and the physical barriers that get in the way of living. There are so few Indian people with disabilities willing to speak up on behalf of disability issues. Ron will be missed.

He was a link in the chain, known to his friends as "Straight Arrow". And now that chain is broken with the loss of our friend. Ron contributed to the national struggle for acceptance and equal rights of people with disabilities. We will miss you, Straight Arrow.



Acknowledgement

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We would appreciate your comments on this or any other issues concerning American Indians and disabilities. This document is available in alternative formats from the Rural Institute on Disabilities, 52 Corbin, The University of Montana, Missoula, MT 59812; 406/243-5467 (voice/TTD), 406/243-2448 (AIDL Project) or 406/243-2349 (FAX).

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AMERICAN INDIAN DISABILITY LEGISLATION PROJECT: FINDINGS OF A NATIONAL SURVEY OF TRIBAL GOVERNMENTS

"While many Americans yearn for the romantic days of the past when seemingly noble Indian chiefs provided us with memorable aphorisms regarding the meaning of life, American Indians today do not live in that world. Like other Americans they have to adjust to economic trends, respond to changes in political climate and thought, and act responsibly in relation to others. Indians have survived and that means that they have successfully and consistently adapted themselves and their institutions to new situations."

American Indians, American Justice
Vine Deloria, Jr. and Clifford M. Lytle

The passage of the Americans with Disabilities Act (ADA) has the potential to improve the lives of all people with disabilities residing in the U.S. Yet, American Indians with disabilities living on reservations may not benefit from this law because it specifically excludes Indian tribes from its requirements or may not be enforceable. As noted by Elizabeth Bazan,

"In general, civil rights statutes are often written in comprehensive language and normally are read broadly to accomplish their purposes. On the other hand, when Congress enacts a general federal law, which does not, by its own terms, expressly address Indians or Indian tribes, there is often considerable doubt as to whether such legislation applies to those Indians or Indian tribes. This seeming dilemma flows in large part from the unique relationship between the Indian tribes and the United States, and the rules of statutory construction which result therefrom." (Bazan, 1991).

There are many reasons that tribal governments are excluded from complying with much federal legislation, including the ADA. In general, most tribes are sovereign nations with legal authority and responsibility for their people and lands. The relationship of the various tribal governments to the government of the United States can be most simply understood as one based on negotiated treaties.

"Indian Law has always been heavily intertwined with federal Indian policy, and over the years the law has shifted back and forth with the flow of popular and governmental attitudes toward Indians At the risk of oversimplification, they may be reduced to four. First, the tribes are independent entities with inherent

powers of self-government. Second, the independence of the tribes is subject to exceptionally great powers of Congress to regulate and modify the status of the tribes. Third, the power to deal with an regulate the tribes is wholly federal; the states are excluded unless Congress delegates power to them. Fourth, the federal government has a responsibility for the protection of the tribes and their properties, including protection from encroachments by the states and their citizens." (Canby, 1994).

This means that for the ADA to apply on reservations, a separate negotiation must be conducted with each of the approximately 547 tribes currently recognized by the federal government. While this arrangement clearly allows the tribes to protect their cultures and values, it means that special efforts must be made to extend potentially good ideas to those on reservations who might benefit from them.

There are 1.9 million American Indians and Alaska Natives. About half live on or near one of the 547 state or federally recognized reservations. Most reservations are located in rural or remote areas, and all but two have populations of fewer than 10,000 Indian people (U.S. Census of Population, 1990).

Proportionately, the prevalence of disability among the American Indian population – especially those on reservations – is among the highest of any ethnic group in the country (U.S. Department of Education, 1987). Similarly, studies (e.g., Clay, Seekins & Cowie, 1990) have found that American Indians with disabilities experience both a higher rate and a greater severity of secondary conditions than do other groups. This may be attributed, in part, to American Indians' lack of access to services and information.

American Indian disability advocates also report that service providers (e.g., some Bureau of Indian Affairs and Indian Health Service offices, as well as private providers and businesses) do not have accessible facilities or services. Further, programs that advocate for such access on reservations are extremely rare (Clay, 1992).

Generally, non-Indian disability advocates have promoted access to facilities, services, employment and other social benefits through the passage and enforcement of laws, such as the ADA. Unfortunately, there are few data reported as to whether such laws and regulations exist among the tribes or whether tribes even view these laws as potentially valuable or culturally relevant. The purpose of this survey was to examine issues related to disability legislation among American Indian tribes.

Background

Several national groups were active in the process leading up to the passage and ensuring implementation of the ADA. Importantly, some of these groups included advocates from a broad spectrum of people, including American Indians. Following the passage of the ADA, several of these advocates discussed the exclusion of American Indians from ADA requirements. These discussions led to the development of this project, whose goal is to develop and test methods of fostering the adoption by American Indian tribes of disability legislation that is consistent with principles established by the ADA, and which is also respectful of tribal sovereignty and cultural diversity.

In an effort to garner support for the project's goals, the American Indian Disability Legislation (AIDL) Project's advisory panel (consisting of 13 people representing 11 tribes) solicited endorsement from the National Congress of American Indians (NCAI). NCAI, established in 1944, is the oldest and largest national Indian organization. It endeavors to sustain the rights of Indian people secured under Indian treaties and agreements with the United States, to develop better understanding of Indian people, to preserve Indian cultural values and to otherwise promote the welfare of Indian people. NCAI has a long history of assisting tribes in affecting federal policy.

On two occasions, members of the AIDL research team attended meetings of the NCAI and described the project and survey to its Committee on Health and Human Services. In June of 1994, one staff member and two advisory panel members attended the NCAI mid-year meeting in Buffalo, NY, to petition the assistance of the Health and Education Committee's Health Subcommittee. A resolution supporting the goals of the AIDL Project was submitted and enacted by the full Congress. (see Appendix B – Buffalo Resolution # B-94-038).

The process created an opportunity for project representatives to talk about the AIDL Project and about disability in general, in a continuing effort to educate people about disability issues. Contacts were made with other NCAI subcommittees, including the Education and Veterans subcommittees. Project representatives had numerous opportunities to speak with tribal leaders about the project and about disability. AIDL representatives also met with U.S. Special Advisor to the President for Inter-governmental Affairs Loretta Avent. Avent spoke to the NCAI members about bringing disability issues to the forefront and making the invisible disability community in Indian country visible.

The annual meeting of NCAI was held in November of 1994 in Denver, CO. AIDL's Co-principal Investigator Dr. Carol Locust and Acting Co-principal Investigator/Project Director LaDonna Fowler, with assistance from two Native

American Research and Training Center members, four AIDL advisory panel members, and numerous individuals from the mid-year Buffalo meeting, set up a designated disability-issues meeting room to disseminate information about the project and about disability issues in general.

Meetings were held with the NCAI Veterans and Education subcommittees. A large meeting was held to describe the project, briefly review preliminary results from the AIDL Project's national survey and discuss plans being developed for the future. One issue that was discussed was that portions of the NCAI conference itself were not accessible. This led to a meeting with NCAI President Gaiashkibos and to commitments to make future NCAI conferences more accessible to people with disabilities.

A resolution was also introduced by the Health Subcommittee to the full body of the NCAI to encourage tribes to establish disability legislation and to educate all American Indians and Alaska Native tribal members about disability issues (see Appendix B – Denver Resolution # 94-DEN-HR/H-082). NCAI's advocacy for the AIDL Project and for encouraging tribes to look at legislative protection for Indian people with disabilities provides key support and endorsement nationwide.

Survey Methods

Very little was known about the status of disability policies or programs among Indian nations. Accordingly, the first phase of this project focused on developing and conducting a survey to examine issues relevant to disability legislation among American Indian tribes.

Procedures

A written questionnaire was first drafted by the research team and submitted to the project's advisory panel. Its purpose was to collect information about the demographics of each tribe, to learn whether the tribe had developed written legislation or policy pertaining to disability issues, to discover the availability and accessibility to tribal members of programs that serve people with disabilities and to ascertain the views of tribal leaders about disability issues.

The advisory panel guided the development of the questionnaire to ensure its relevance and its sensitivity to cultural and political issues. After this scrutiny some items were deleted and others were added. To capture a wide range of possible responses, the advisory panel suggested using Likert-type scale questions for a number of the items. When this method proved inadequate, the "consumer concerns"

format was chosen (Seekins & Fawcett, 1987). The questionnaire was subjected to numerous further reviews and extensive discussions by the advisory panel members.

The final version consisted of a brief introduction explaining the goals of the survey, confidentiality and informed-consent statements and a statement of proposed dissemination points (e.g., journals, direct mailings, tribal newspapers, periodicals and national conferences). Respondents were asked a number of background questions, including the tribe's name, address and enrollment. Respondents also were asked a number of personal demographic questions such as their age, gender, educational level, tribal membership status and whether they spoke the tribal language. The remaining questions on the survey are presented and discussed below.

Participants

The number of federally recognized tribes is in a state of flux as various new groups apply for recognition under the Indian Reorganization Act. For this study, we identified 685 tribal organizations.

The identification process began with compiling and comparing lists, including tribal mailing lists from *The Native North American Almanac (NNA Almanac)*, a list from the Bureau of Indian Affairs published in *The Federal Register*, a list provided by the U.S. Department of Health and Human Services Administration for Native Americans and a list from the Native American Research Institute in Norman, OK.

Initially, 547 recognized tribes were compiled. However, the *NNA Almanac* points out that:

"Approximately five hundred Indian communities are officially recognized by the US government through treaty, congressional act, or administrative directive. These communities are entitled to US legal protection of tribal self-government and rights to tribally-owned land. At least 150 non-recognized Indian communities have not signed treaties or have not had regular legal relations with the US government. Other Indian communities, mostly in the eastern states, are not recognized by the federal government but are recognized by state governments. State-recognized tribes have legal protection and legal status within their home states but not with the US government.

"Indian communities have been petitioning for federal recognition as early as the 1820's. In 1978, Congress, because of pressure from numerous non-recognized Indian communities, enacted a law that allowed federally non-recognized Indian tribes to petition for recognition. As early as 1993, about 150 Indian communities were in some state of petitioning the BIA for official

and legal recognition as an Indian tribe. The number of communities appealing recognition continues to grow each year." (p. 355).

In recognition of the diversity of tribes, the questionnaire initially was sent to all tribes identified first by federal recognition, second by state recognition and finally those tribes listed as pending federal recognition. The AIDL advisory panel felt this would accomplish three goals. First, it would help raise the awareness of tribal governments about disability. Second, involving all tribes would reduce the potential for suspicion with which Indians often view research. Third, it would increase the possibility of discovering important views and actions that might be missed in a sample.

Because this study addressed legal and political issues, and in respect for tribal leadership, the initial questionnaire was mailed to the chairperson, chief or president of each tribe or Alaskan Native village identified. A cover letter, reading "Dear Tribal Leader," explained the study, referred to the support of the NCAI and respectfully asked that the tribal leader either complete and return the survey or pass it on to an appropriate designee for return within three weeks in an enclosed, stamped, self-addressed envelope.

The Statistical Package for the Social Sciences (SPSS-X), a statistical computer program, was used to determine which tribes would be included in a random sample. It selected 192 tribes from the list of 384 tribes in the lower 48 states. Similarly, it selected 142 from the list of 224 Alaskan native villages. To ensure the validity of the survey results, the research team set a goal of 60% for sample return rate. The return rate for the sample in the lower 48 states was 58.3% and 22% for the Alaska sample.

Alaska contains 224 native entities comprising tribes, clans, families and villages. This represents 37% of the national total of existing tribal governments. In addition, the entities differ significantly from that of tribes and reservations in the lower 48 states. Including all of Alaska's native entities in a national sample would likely result in significant over-sampling from that state. Therefore, we chose to treat Alaska as a separate group for sampling.

The first mailing was issued in May 1994. A second mailing was sent in September 1994. Early responses to the mailed survey were few, for a number of reasons which soon became evident. First, the development of a culturally sensitive survey took longer than anticipated. This resulted in the survey being distributed in late spring, a time when many tribes hold pow-wows and other ceremonial events and offices often close for the summer. Second, we discovered that the tribal addresses available from several standard sources (Bureau of Indian Affairs, Human Services Administration for Native Americans, American Indian Institute of Norman, OK and the *Native North American Almanac*) were inaccurate or out of date and had to be recreated. Third, because we asked for a rapid return, some respondents felt it was

too late to respond when they finally received the survey. Others had to seek tribal council approval to complete the survey, and this took time. Lastly, there was a reluctance to "complete one more survey" when so many previous surveys had done nothing to help Indian people.

To increase the return rate, we initiated an extensive telephone follow-up procedure. Students from The University of Montana's Indian Studies Program telephoned respondents to ask them to return completed surveys or, if the respondent preferred, to collect the information in a telephone interview. After six weeks of this time- and resource-consuming work, the research team decided that the data collected to date, from 143 tribal respondents (112 from the lower 48 states and 31 from Alaska), would be used as the sample group.

Because of the large number of non-respondents and our limited resources, we chose to focus our telephone work on the sample from the lower 48 states. This increased our return rate for this sample. Unfortunately, the return rate for the Alaska sample remained low. The balance of this report focuses on the sample from the lower 48 states. The results for Alaska are presented in Appendix A.

Data Analysis

For the purposes of this report, only the responses from the sample data are reported. Additional analyses and reports will be conducted on all data.

Results

A total of 685 surveys were sent to the identified tribes. Of these, 192 went to sample tribes selected from the lower 48 states, 141 went to the Alaskan sample tribes and 352 went to tribes not included in the random sample. One hundred twelve (58%) surveys from the lower 48 states and 31 (22%) from Alaska were completed and returned. This report summarizes findings from 29 states of the lower 48 United States.

The total sample enrollment of responding tribes was 628,759. The largest tribe reported 182,000 members and the smallest tribe reported 16 members. Respondents estimated a total of 41,237 tribal members who have a disability or handicap that substantially limits one or more major life activities. This is an average of 448 members with disabilities per reporting tribe. Of the people completing the survey, 70% reported being a tribal member and 34% reported speaking the tribal language. Seventy-four percent of 98 respondents indicated that they believe their

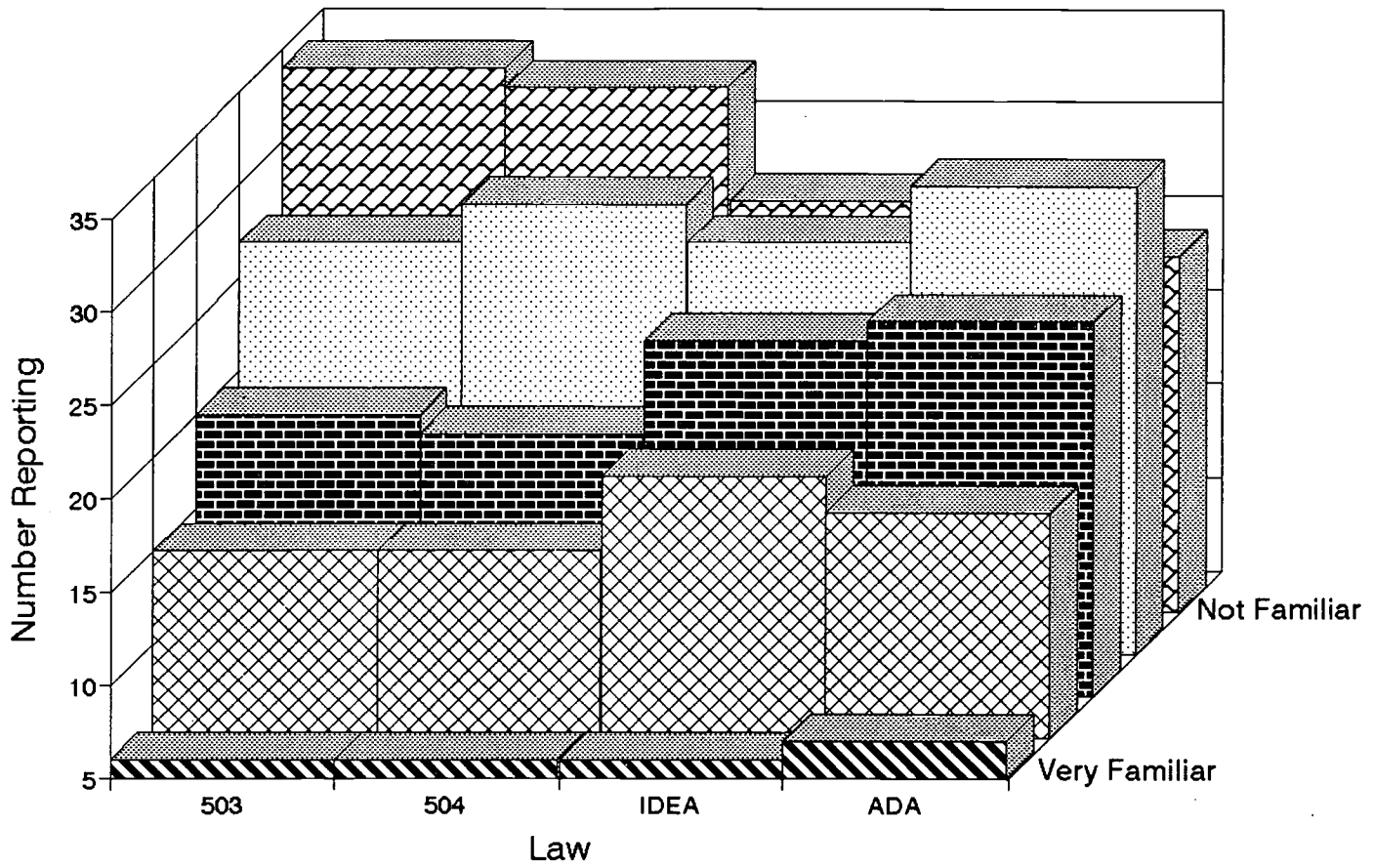
tribal government would be interested in participating as a focus group for establishing disability legislation within their tribe, an activity which is slated for the second phase of the AIDL Project.

Of those responding, 60 (64%) indicated their tribe was chartered under the Indian Reorganization Act (IRA), 20 (21%) said they have a non-IRA government structure and 14 (15%) reported some other governmental status (e.g., currently under constitutional revision). The IRA, enacted by Congress in 1934, provides reservation communities the opportunity to re-organize their tribal governments and adopt new tribal constitutions and tribal charters, and organize tribal business corporations. It offers tribes some freedom from federal bureaucratic control if they organize themselves under constitutions modeled after the U.S. Constitution. It should be noted that the well-known Iroquoian group, the Five Nations of the Haudenosaunee (which means People of the Longhouse), "counseled early American leaders on the virtues of Iroquois-style unity, democracy, and liberty ... The Iroquois were present in body and/or spirit as Americans sought to create a democratic alternative to the British monarchy. At the request of the founding fathers, Iroquois chiefs were present at the debates on the Declaration of Independence in Philadelphia in May and June of 1776 (Champagne, 1994).

Only six (5.9%) of 102 respondents said they thought their tribal government was very familiar with Sections 503 and 504 of the Rehabilitation Act of 1973. Thirty-four (33%) thought their tribal government was not familiar with Section 503 and 33 (32%) thought their tribe was not familiar with Section 504. Of 103 respondents, six (5.8%) said their tribal government was very familiar with the Individuals with Disabilities Education Act (IDEA), while 27 (26%) stated that their tribe was not familiar with the legislation. Finally, seven respondents out of 103 (6.8%) stated that their tribal government was very familiar with the Americans with Disabilities Act and 24 (23%) reported that their tribe was not familiar with the ADA.

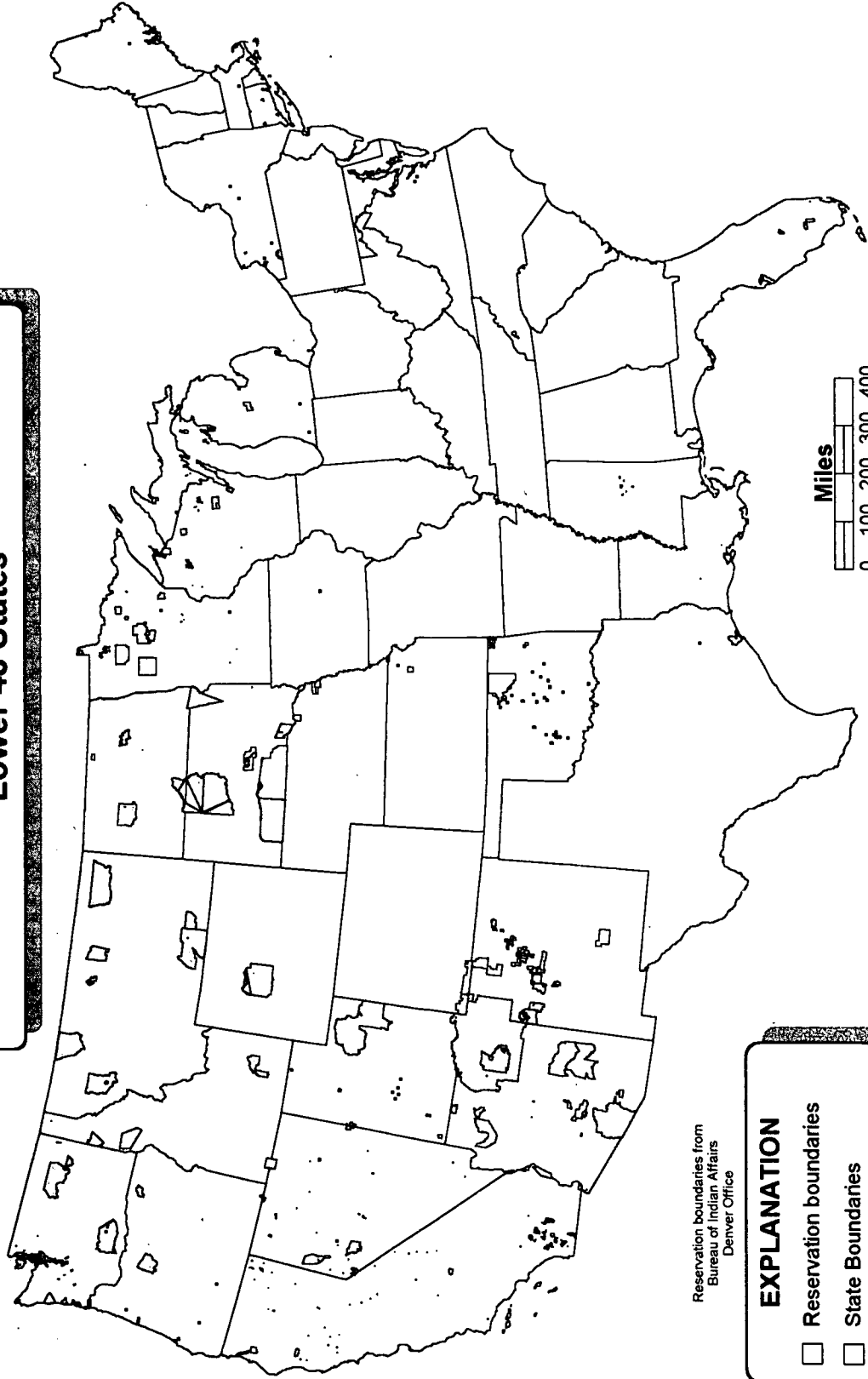
Of those reporting, 13 respondents (9%) indicated that there had been a tribal court case concerning a disability issue. (The research staff currently is contacting these respondents to discover the status of any disability-related court cases.) Eighty-nine respondents (62%) indicated there was no known court case and 25 (17%) said they did not know whether there had ever been such a case.

Familiarity with Disability Law



Reservation Boundaries

Lower 48 States



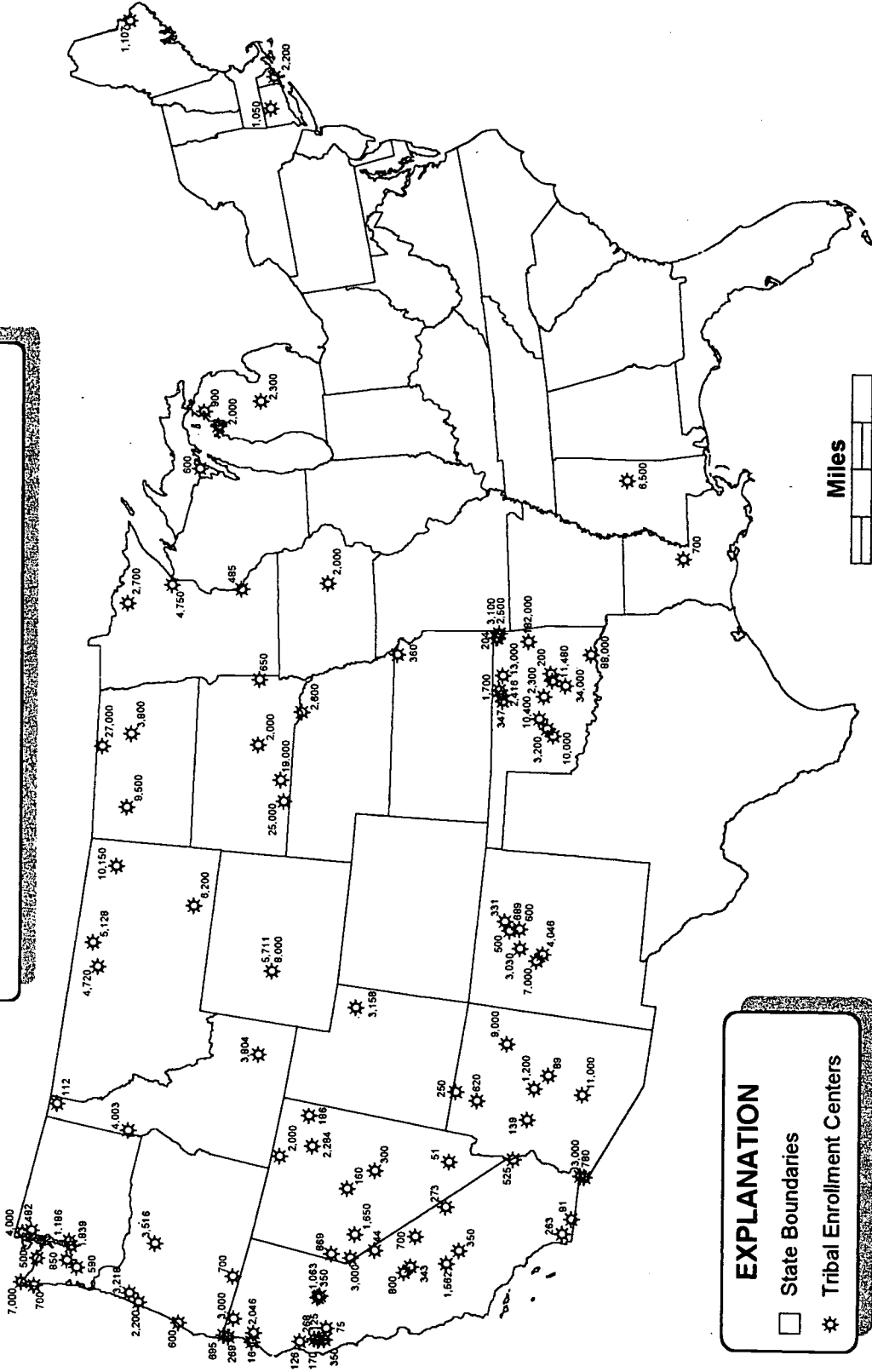
Reservation boundaries from
Bureau of Indian Affairs
Denver Office

EXPLANATION

- Reservation boundaries
- - - State Boundaries



Respondents by Tribe



EXPLANATION

- State Boundaries
- ★ Tribal Enrollment Centers



Table 1 presents respondents' estimate of tribal members with listed specific disabilities. The total number of tribal members with disabilities in Table 1 is higher than the general number respondents estimated when asked independently on the questionnaire. This may reflect the fact that some people have more than one disability and, so, have been counted more than once. This may also indicate that the respondents underestimated the number of tribal members with disabilities on a single question.

**Table 1
Number of Reported Disabilities**

Disability Type	Raw Number	Percent
Are diabetic	24,561	29%
Have emotional problems	18,445	22%
Are slow-to-learn	9,371	11%
Use crutches, walkers or canes	6,917	8%
Use a wheelchair	5,304	6%
Are deaf or hard of hearing	4,807	6%
Are blind or have very low vision	4,678	6%
Have Fetal Alcohol Syndrome (FAS) or Fetal Alcohol Effect (FAE)	4,258	5%
Have a speech or communication difficulty	4,140	5%
Do not have the use of one or both arm(s) or leg(s)	2,366	3%
Total	84,847	100%

As reported by tribes, diabetes is highly prevalent. Complications from diabetes can lead to blindness, loss of limbs, kidney failure and emotional trauma. More funding may be needed to educate American Indians about the prevention and diligent treatment of diabetes.

Tribes reported a high number of members with emotional problems. Early in the development of the survey instrument, the advisory panel discussed what sort of response this item would yield. Many felt the percentage of tribal members with emotional problems would be low. The data, however, indicate otherwise and may suggest a need for more extensive mental health services available to American Indians.

The slow-to-learn rate also appears to be high (11%) as reported by tribes. The phrase was substituted for such terms as mental retardation, learning disabilities, Down syndrome or traumatic brain injury, terms which likely would have led to different interpretations by individual respondents and from tribe to tribe.

Number of Reported Disabilities

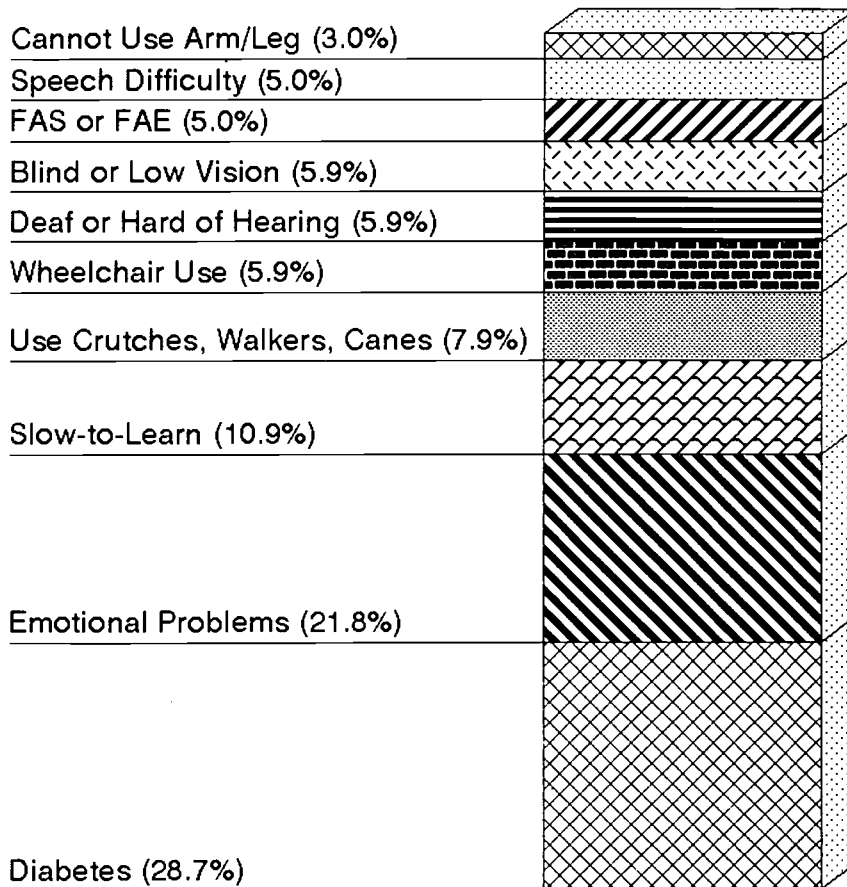


Table 2 presents ratings by respondents of the average importance and average satisfaction with the way a series of issues relating to disability is handled within tribes. While those issues rated as most important by respondents were that tribal members with disabilities be treated with respect, have opportunity to participate in tribal activities and have easy access to disability-related services, respondents also reported low levels of satisfaction in these areas.

Table 2
Importance and Satisfaction on Disability Issues in Percentage

Issue	Average Importance	Average Satisfaction
Are tribal members with disabilities treated with respect?	93%	66%
Do tribal members with disabilities have an opportunity to participate in tribal activities?	91%	58%
Do tribal members with disabilities participate within your tribal government structure (e.g., as council members or program administrators)?	85%	54%
Can tribal members with disabilities easily use programs that provide disabilities-related services?	85%	49%
Are tribal members with disabilities employed on your reservation?	84%	50%
Does your tribal government apply for grant monies that provide services for tribal members with disabilities?	82%	42%
Is there a person designated to manage disability-related issues in order to comply with legislation that affects persons with disabilities?	79%	38%
Are tribal members with disabilities employed off your reservation?	76%	38%
Is there a group within your tribal government whose main purpose is to address disability issues?	76%	35%
Does your tribe have disability legislation or policies?	68%	24%

Importance & Satisfaction on Disability Issues in Percentage

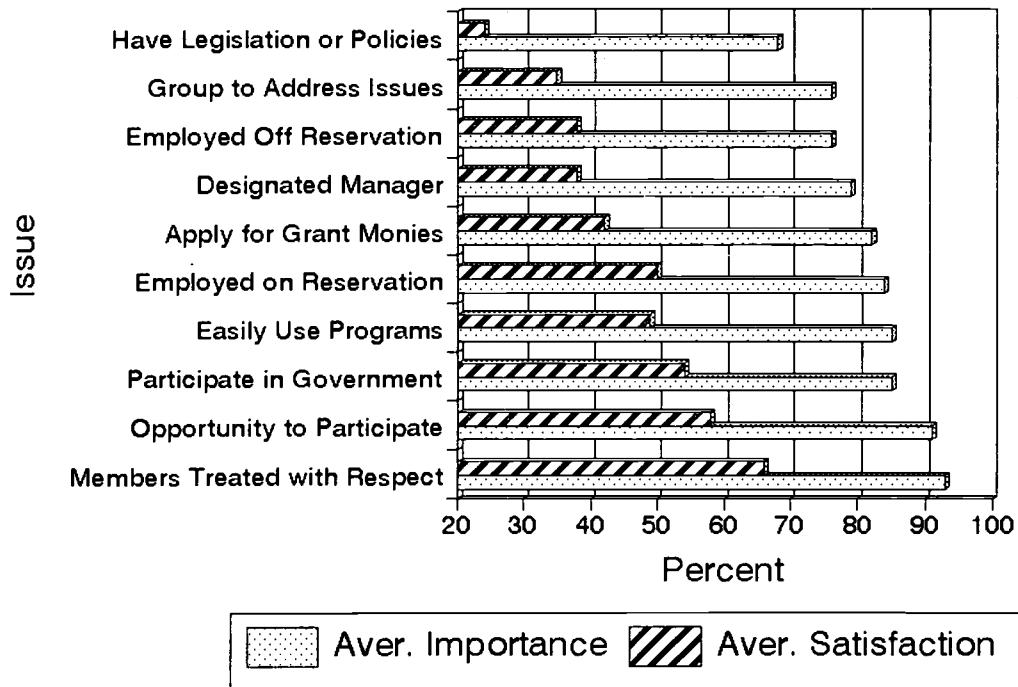


Table 3 presents the average rating of the frequency of use by the general public of a series of buildings and the average degree of accessibility of those varieties of buildings. However, it should be noted that only 32% of respondents reported familiarity with the accessibility standards of the American National Standards Institute.

Table 3
Frequency of Use and Accessibility of Public Buildings
on Reservations in Percentages

Buildings	Frequency of Use	Accessibility
Health facilities	88%	80%
Council building	83%	70%
Community building	81%	70%
Senior citizens building	80%	77%
Schools	77%	68%
Stores	76%	63%
Churches	66%	58%
BIA building	66%	64%
Federal buildings	64%	65%
Tribal court and jail	62%	54%

Buildings reported as having the highest reported frequency of use were health facilities (88%), which had an accessibility rating of 80%. While interpretations of accessibility can be broad, the data show that most individuals with mobility impairments can access health-care facilities.

The council and community buildings' accessibility, on the other hand, were rated much lower. These often-used buildings are important centers for political, social and cultural exchange such as pow-wows, ceremonies, bingo and other activities are held and where tribal members gather. Table 2 notes that participation in tribal-government affairs was rated important to members (85%), surpassed only by the high importance respondents placed on participation in tribal activities (91%) in general. The data seem to suggest that some activities are less available to tribal members with mobility impairments than to non-disabled tribal members.

Senior citizens buildings are also frequently used (80%). While their accessibility rating is only 77%, they appear to be more accessible than community or council buildings. Seniors may, in fact, have more access to these facilities than younger tribal members with mobility impairments.

The least-accessible public buildings on reservations were reported to be federal buildings (65%), BIA buildings (64%) and tribal court and jail buildings (54%). Their frequency of use, however, was also rated low at 64%, 66% and 62% respectively.

The data appear to indicate that BIA and other federal buildings, which are required to comply with Section 504 of the Rehabilitation Act of 1973, have not yet met the standards set down by either Section 504 or the ADA.

Finally, on average, public buildings on reservations are perceived by respondents as accessible only 67% of the time. The combined reporting of disability types (from Table 1) that would have difficulty physically accessing public buildings is 34% of the total number of Indian people with disabilities. This indicates a need for both disability-awareness education and technical assistance in making these facilities more accessible.

Frequency of Use & Accessibility of Public Buildings on Reservations

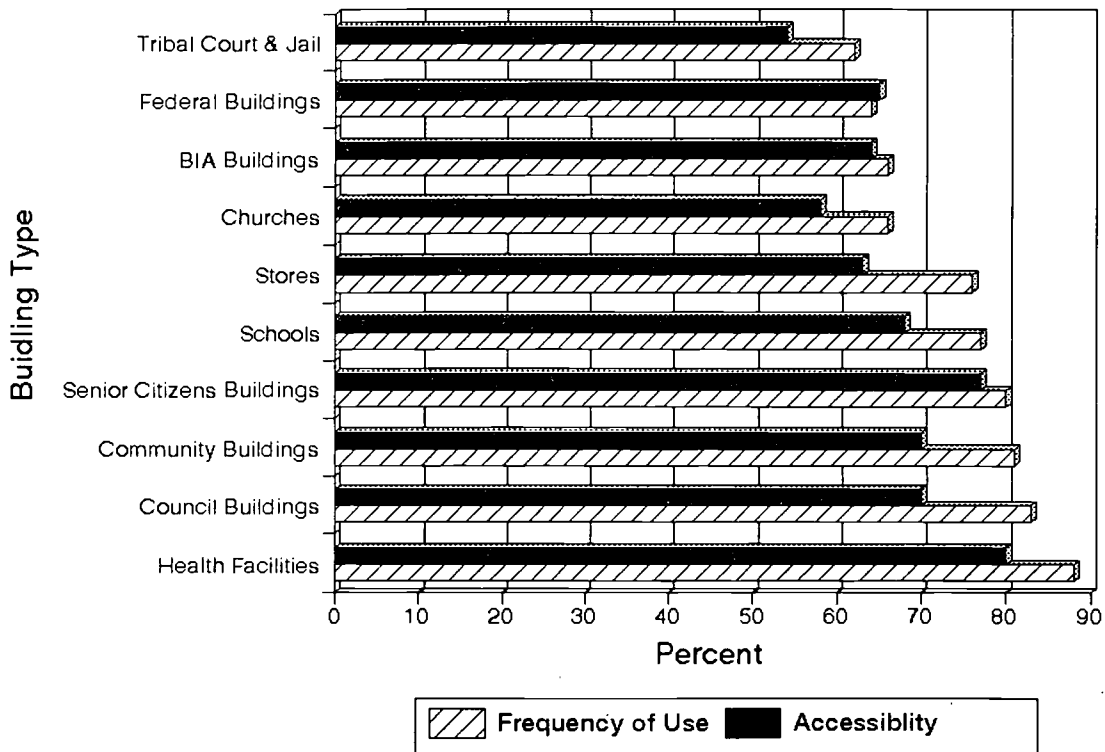


Table 4 presents the percentage of respondents indicating the availability of a range of programs relevant to rehabilitation on their reservation. This table also reports the percentage of available programs that are part of the tribal structure. Health services were most frequently available, followed by special-education services, senior programs and vocational services.

Table 4
Availability of Services Relevant to Rehabilitation in Percentages

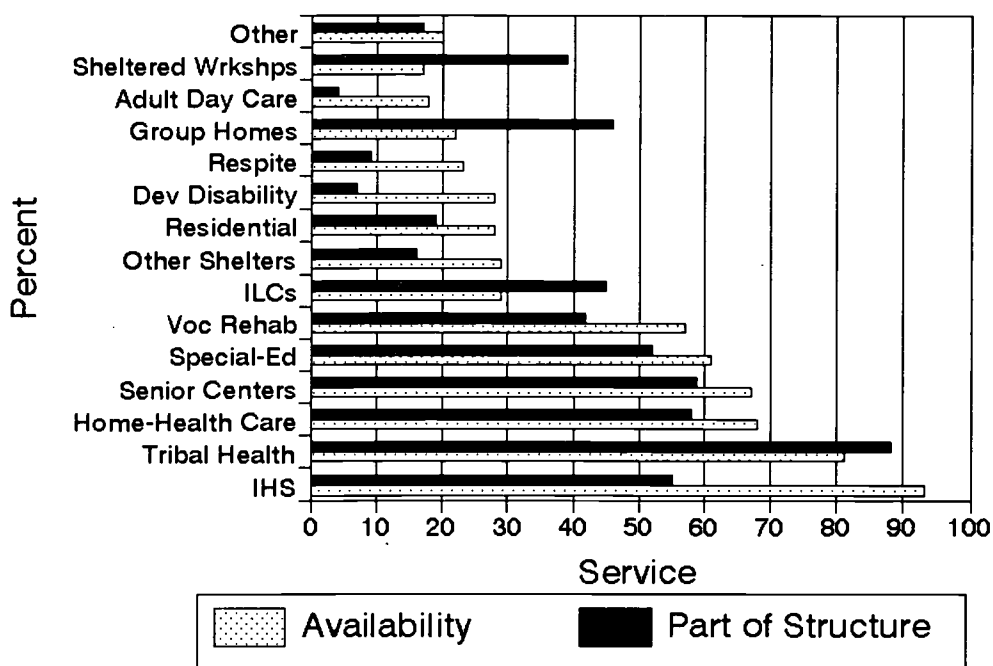
Service	Reporting Availability	Part of Tribal Structure
Indian Health Service	93%	55%
Tribal Health Services	81%	88%
Home-health care services	68%	58%
Senior citizens centers	67%	59%
Special-education services	61%	52%
Vocational Rehabilitation Services	57%	42%
Independent living centers	29%	45%
Other shelters or detention centers	29%	16%
Residential facilities	28%	19%
Developmental disabilities services	28%	7%
Respite services	23%	9%
Group homes	22%	46%
Adult day care	18%	4%
Other (please specify)	18%	14%
Sheltered workshops	17%	39%
Other	2%	3%

Note. An explanation of the services in Table 4 can be found in the glossary in Appendix C.

Services that are not part of the tribal structure are reported as being provided by local, county, state and federal programs. Tribal members apparently are able to obtain general health services such as acute care. Other rehabilitation services such

as independent living, sheltered workshops and respite services are not as readily available. This may cause tribal members to seek services through outreach programs or by traveling a significant distance to their location off the reservation. Lack of transportation or telephone service may bar many people with disabilities from receiving any services at all.

Availability of Services Relevant to Rehabilitation in Percent



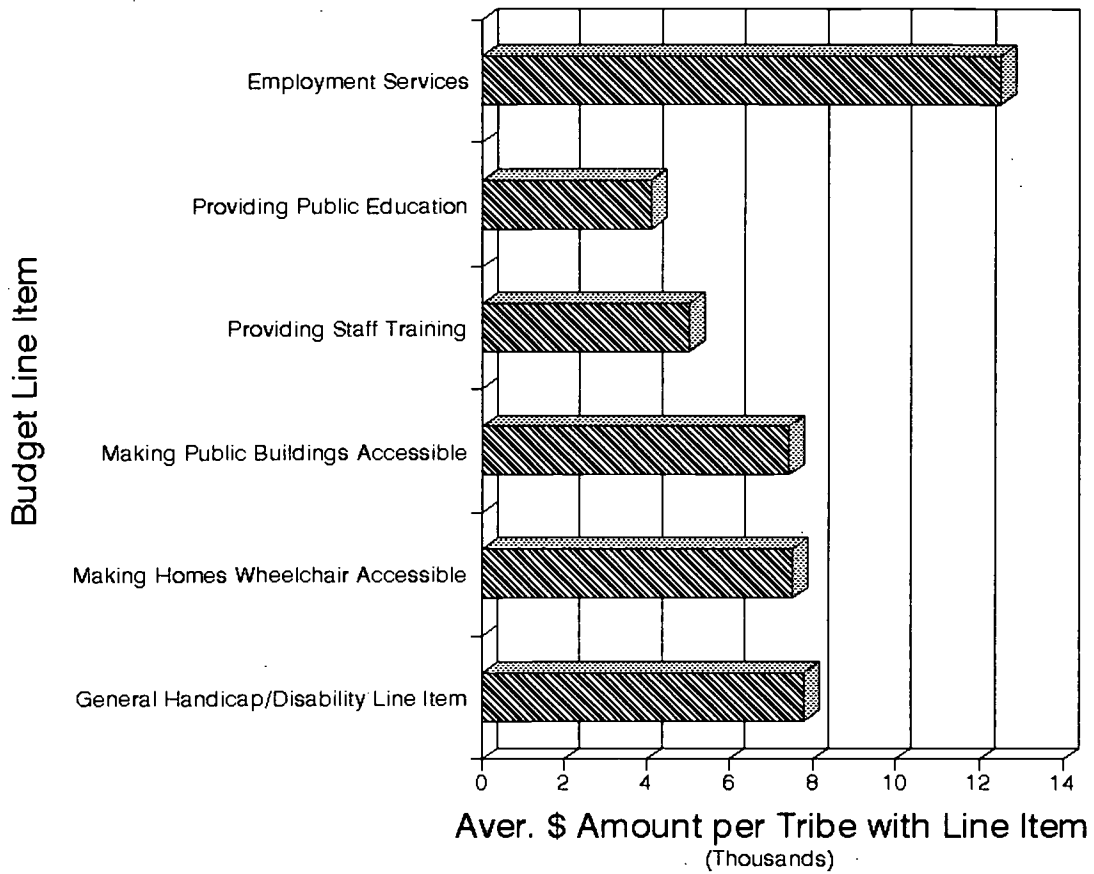
Finally, Table 5 reports the percentage of tribal budgets that have specific line items for a variety of disability services. In addition, the average amount of these line items is presented. Seventy-nine percent of respondents (88) reported budgets for disability services and, of that number, some budgets were relatively higher than the rest, thus skewing the data.

One tribe reported a budget of \$1.2 million for disability services. This amount was not included in calculating the average. Including this "outlying" budget amount would have significantly increased the average and may have given a misleading impression of what most tribes do.

Table 5
Tribal Budgets for Disability Services of Responding Tribes

Budget Line Item	Percent of Tribes with Line Item	Average Amount Per Tribe with Line Item
General handicap/disability line item	13%	\$7,780
Making homes wheelchair accessible	39%	\$7,513
Making public buildings and areas accessible (for example: ceremonial grounds)	37%	\$7,417
Providing staff training on disability issues	20%	\$5,033
Providing public education on disability issues	16%	\$4,100
Employment services for people with disabilities	19%	\$12,500

Tribal Budget of Disability Services



Conclusion

Currently, only about 6% of the respondents indicated their tribal governments were very familiar with major disability legislation, including Sections 503 and 504 of the Rehabilitation Act of 1975, IDEA and the ADA. One tribe of the 143 surveyed has reported adopting the ADA. Several others have said that while they have discussed access and employment issues, they do not have written policy. As such, disability legislation among the tribes remains an unaddressed issue of importance.

This project's goal has been to develop and test methods of encouraging American Indian tribes to adopt disability legislation that is similar in principle and effectiveness to the ADA, and also respects tribal sovereignty and cultural diversity. The conclusions in this report are based on information gathered in pursuit of that goal.

The sample group contained 112 tribes from the mainland United States and 31 Alaskan Native villages. Briefly, our observations include:

1. It is critical in a project addressing issues of importance to American Indians that they be involved and in control. To gain needed tribal support, the project: a. established a 13-member Advisory Panel representing 11 major tribes; b. worked cooperatively with the National Congress of American Indians, obtaining their endorsement; and c. interacted productively with tribal officials nationwide.
2. In 1995, many of the tribal groups knew very little about the disability policies or programs of Indian nations. We based this conclusion on the low rate of return of our mailed surveys. Of 685 surveys mailed, only 112 (less than 18%) were returned from the lower 48 states, and 31 of 224 (13.84%) from Alaska. If there had been more knowledge — and thus more policies and programs — we would expect our survey return rate to be greater. And, as stated above, only about 6% of respondents thought their tribal governments were very familiar with major disability legislation.
3. In 1995, the rate of disability among American Indians was approximately 22.6%. This figure was computed from the total number of tribal members in the sample group, and the total number of people with disabilities in that group, as reported to us on the survey. Cultural or traditional beliefs may influence the way Indian people perceive illness or disability. Some conditions such as arthritis, diabetes and slow-to-learn may not be recognized as disabilities and may have been under-reported.
4. The sample group data suggests that satisfaction among tribal members with disabilities regarding respect, opportunity and accessibility issues in their communities is 45.4%. Although this satisfaction rate is low, only 9% of the tribes reported any tribal court cases concerning disability issues. The conclusion was that either:

- a. tribal members did not know how to access legislation in their behalf, or
- b. there is no recourse, because the tribal governments had no mechanism for protection of people with disabilities.

5. Schools, stores, churches, BIA buildings, federal buildings, and tribal court and jail facilities were accessible about two-thirds of the time (66.9%), that other major tribal facilities such as health centers, council buildings, community buildings and senior citizen buildings were accessible nearly three-fourths of the time (74.2%).

6. Across all service categories, the availability of services to people with disabilities had an average of 71% availability for Indian Health Services, tribal health services, special-education services, vocational rehabilitation services and home health-care services. Other services such as senior citizens centers, residential facilities, independent living centers, sheltered workshops, respite services, developmental disabilities services, group homes, adult day care and other programs were reported available an average of 11% among the tribes. While the majority of the most available services were part of the tribal structure, only about 10% of the other services were tribal services. It appears that if a service is part of the tribal structure, members have a much greater chance of accessing it.

7. Most tribes do not currently recognize the need to provide funds to deal with disability issues. Only 13% of tribes have a line item in their budget for disability issues.

8. Diabetes (29%), emotional problems (22%) and slow-to-learn (11%) are the major categories of disability among tribal members in the lower 48 states. In Alaska, emotional problems ranked first (31.3%), slow-to-learn was second (17%) deaf or hard of hearing was third (15%), and diabetes was fourth (11.6%). It appears that many of those with disabilities may need more attention than currently given.

9. In 1994, most tribes did not appear ready to establish disability legislation. However, 74% of the survey respondents, said they believe their tribal government would be interested in participating as a focus group for establishing disability legislation within their tribe.

It is important to note that the conclusions are based on data from 112 tribes and 31 Alaskan Native villages, and may or may not be applicable to all tribes. However, the process of random selection generally yields representative data. As such the project staff feel that the data is fairly representative of tribal governments and people nationally. Our work with the National Congress of American Indians and directly with many tribes in various parts of the nation indicate that the concerns, percentages, ages, issues and resolutions of disability legislation stated in our data is a fairly accurate reflection of the national picture among tribes.

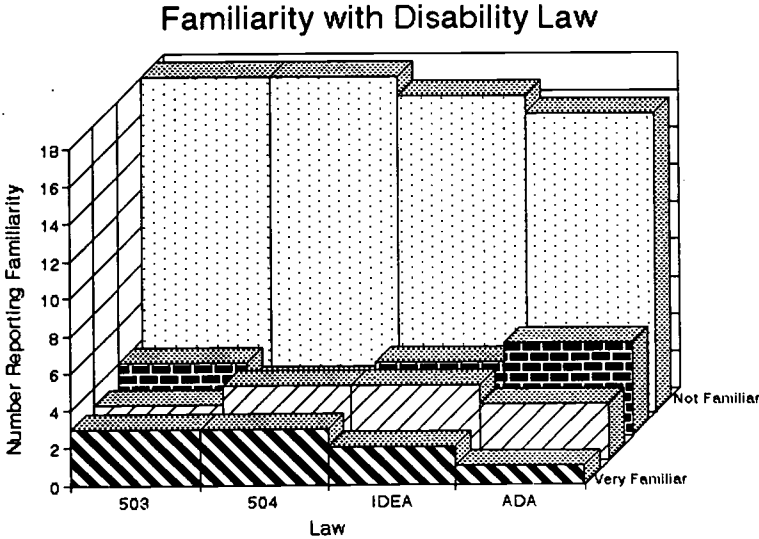
Appendix A

Alaska Data

Alaska contains 224 native entities comprising tribes, clans, families, villages and other groups. This represents 37% of the survey total. Because these entities have significant organizational differences from tribes and reservations in the contiguous U.S., including all of Alaska's native entities in a national sample would likely result in significant over-sampling from that state. Therefore, we chose to treat Alaska as a separate group for sampling.

The total sample enrollment of responding tribes was 10,972. The largest tribe reported 1,894 members and the smallest tribe reported 53 members. Respondents estimated that a total of 701 tribal members have a disability or handicap that substantially limits one or more major life activities. This is an average of 28 members with disabilities per tribal group or village. Of the people completing the survey, 90% reported being a tribal member and 65% reported speaking the tribal language. Fifteen of 26 respondents (58%) indicated that they believe their tribal government would be interested in participating as a focus group for establishing disability legislation within their tribe, an activity the AIDL Project will address in its second phase.

None of the 28 respondents felt that their tribal government was very familiar with Sections 503 and 504 of the Rehabilitation Act of 1973. Eighteen (64%) thought their tribal government was not familiar with the Sections. Of 28 respondents, one (3.6%) said their tribal government was very familiar with the Individuals with Disabilities Education Act (IDEA), while 17 (61%) stated that their tribe was not familiar with the legislation. Finally, four respondents out of 29 (14%) stated that their tribal government was very familiar with the Americans with Disabilities Act and 16 (55%) reported that their tribe was not familiar with the ADA.



Respondents by Alaska Native Villages

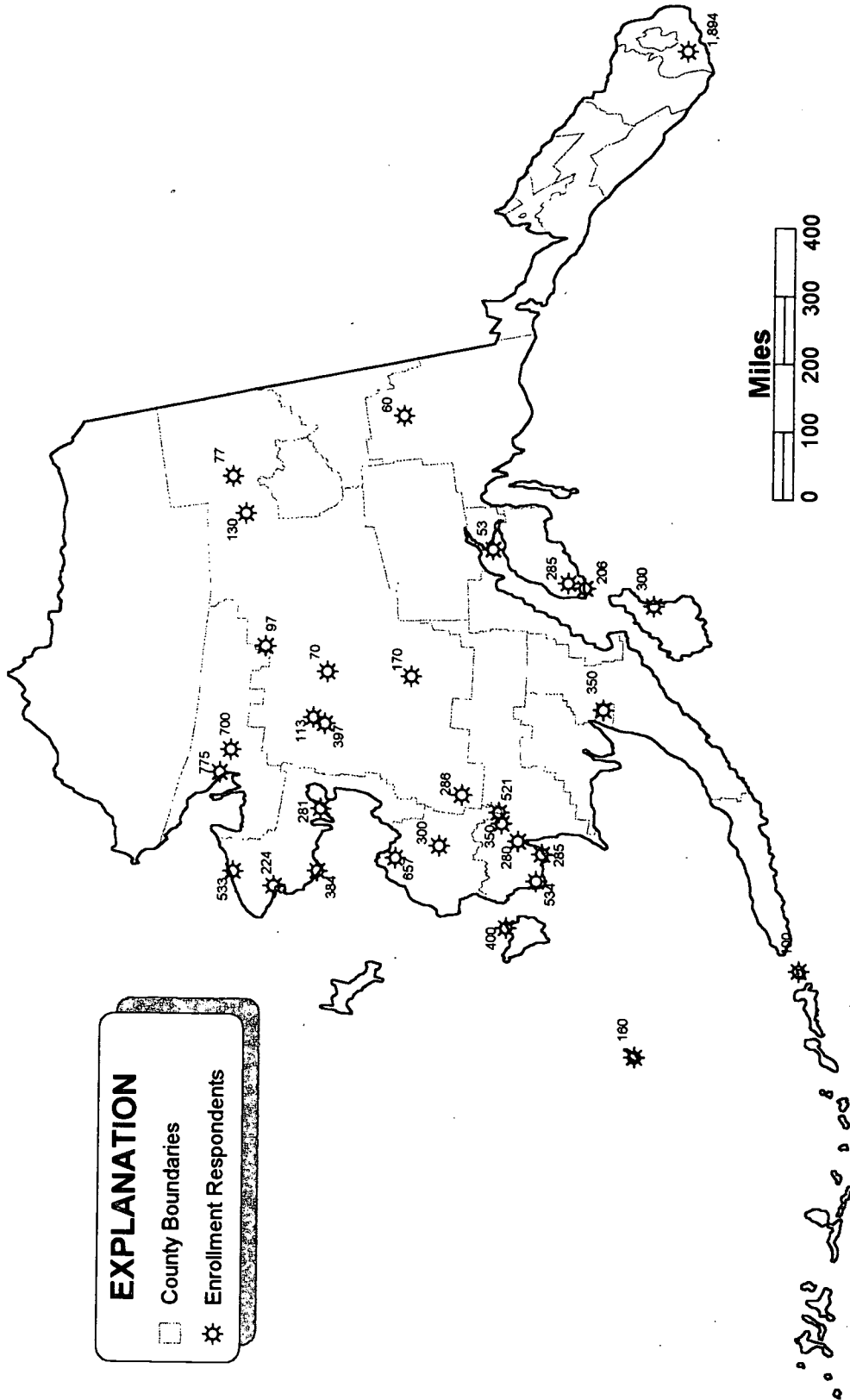


Table A1 presents the estimate of Alaska Native tribal members with a series of specific disabilities.

Table A1
Number of Reported Disabilities

Disability Type	Raw Number	Percent
Have emotional problems	651	31.3%
Are slow-to-learn	358	17%
Are deaf or hard of hearing	312	15%
Are diabetic	241	11.6%
Have Fetal Alcohol Syndrome (FAS) or Fetal Alcohol Effect (FAE)	127	6%
Are blind or have very low vision	115	5.5%
Use crutches, walkers or canes	89	4.3%
Have a speech or communication difficulty	79	4%
Do not have the use of one or both arm(s) or leg(s)	68	3.3%
Use a wheelchair	40	2%
Total	2,080	100%

Alaska's sample reported emotional problems at 31.3%. The data appear to indicate a substantial need for more mental health services.

Slow-to-learn was reported as a disability among Alaskan Native people at 17%. More Alaskan Native people were reported deaf or hard of hearing (15%) than in the lower 48 states (6%). Diabetes rated at 11.6% of Alaskan Native people with disabilities is lower than the 29% reported by respondents from the lower 48 states. Each of these findings demonstrate the need for more services.

Of those responding to this question, 16 (53%) indicated they are chartered under the Indian Reorganization Act (IRA), 5 (16.6%) said they have a non-IRA government structure and 9 (30%) reported some other governmental status (e.g., currently under constitutional revision).

Number of Reported Disabilities

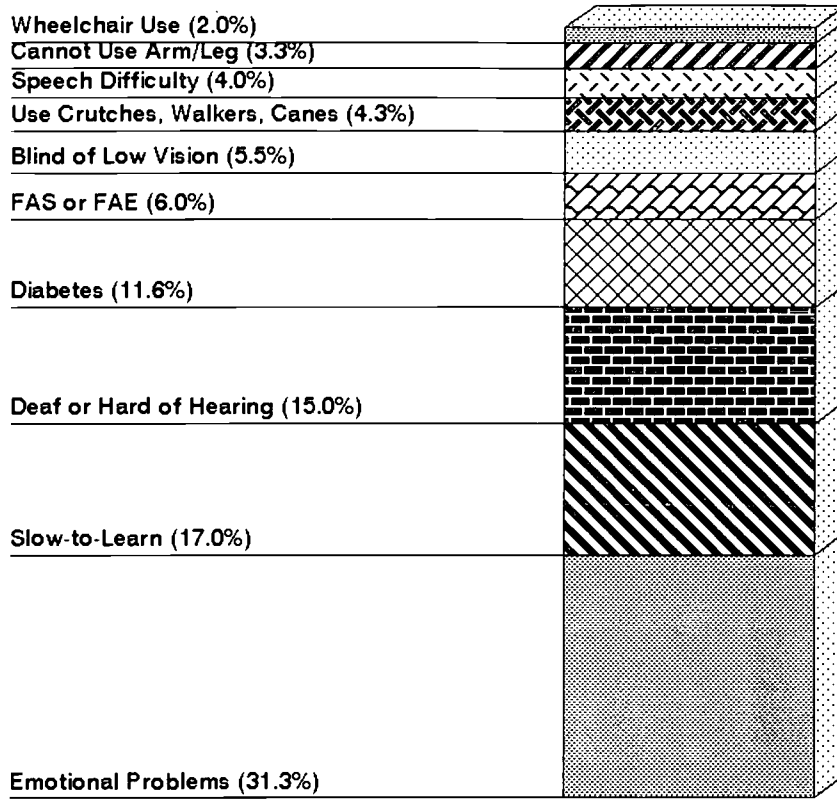


Table A2 presents ratings by respondents of the average importance and average satisfaction with the way a series of issues relating to disability is handled within tribes. While those issues rated as most important were that tribal members with disabilities be treated with respect, have opportunity to participate in tribal activities and have easy access to disability-related services, respondents reported low levels of satisfaction in these areas.

Table A2
Importance and Satisfaction on Disability Issues in Percentage

Issue	Average Importance	Average Satisfaction
Are tribal members with disabilities treated with respect?	88%	74%
Do tribal members with disabilities have an opportunity to participate in tribal activities?	73%	63%
Are tribal members with disabilities employed on your reservation?	59%	44%
Is there a person designated to manage disability-related issues to comply with legislation that affects persons with disabilities?	60%	55%
Can tribal members with disabilities easily use programs that provide disabilities-related services?	50%	60%
Do tribal members with disabilities participate within your tribal government structure (e.g., as council members or program administrators)?	60%	38%
Does your tribal government apply for grant monies that provide services for tribal members with disabilities?	44%	21%
Is there a group within your tribal government whose main purpose is to address disability issues?	42%	30%
Are tribal members with disabilities employed off your reservation?	44%	21%
Does your tribe have disability legislation or policies?	27%	8%

Importance & Satisfaction on Disability Issues in Percentage

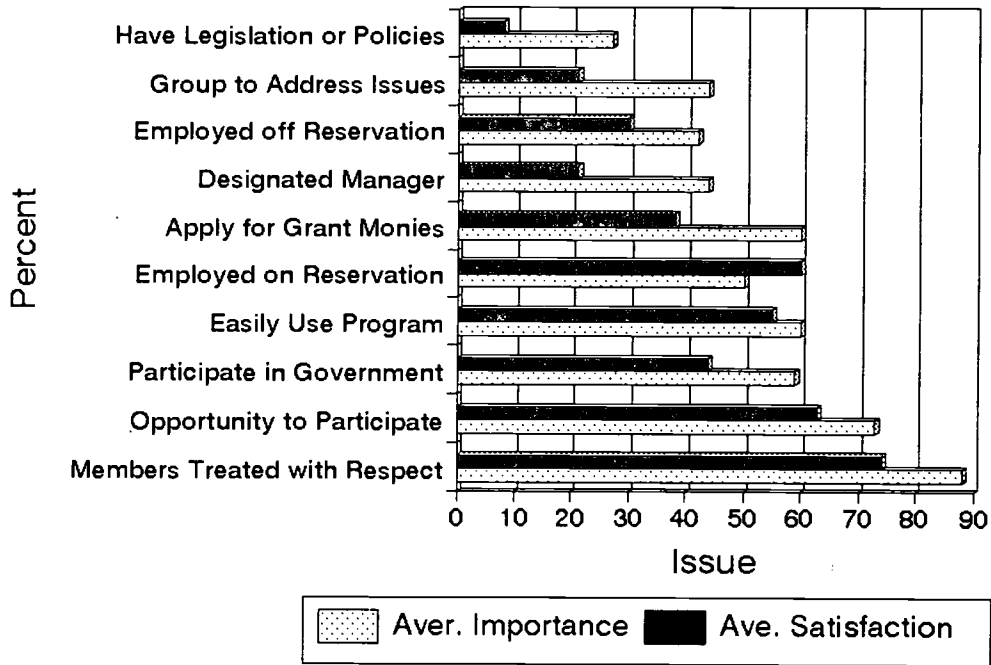


Table A3 presents the average rating of the frequency of use by the general public of a series of buildings and the average accessibility ratings for these kinds of buildings. It should be noted, however, that only 15% of respondents reported familiarity with the accessibility standards of the American National Standards Institute.

Table A3
Frequency of Use and Accessibility of Public Buildings
in Alaska Native Villages in Percentages

Buildings	Frequency of Use	Accessibility
Health facilities	91%	75%
Community building	87%	72%
Schools	87%	91%
Stores	87%	60%
Churches	80%	68%
Council building	77%	62%
Tribal court and jail	31%	42%
Senior citizens building	28%	35%
Federal buildings	19%	23%
BIA building	19%	17%

The highest reported frequency of use was of health facilities (91%) with an accessibility rating at 75%. As stated previously, interpretations of accessibility can be broad. The data, however, show that most individuals with mobility impairments can access health-care facilities most of the time.

Interestingly, the community buildings, schools and stores were used with equal frequency (87%), but schools are perceived as being much more accessible (91%) than the community buildings (72%) or stores (60%).

The council buildings' accessibility, at 62%, also was rated much lower than schools or the community buildings, even though council buildings' use was rated fairly high (77%).

Senior citizens buildings were used only 28% of the time by Alaskan Native people. This may be due to the fact that it is perceived as being accessible only 35% of the time. Only federal and BIA buildings were used less frequently, perhaps because

they, too, are considered accessible at a relatively low rate (23% and 17% respectively).

The data appear to indicate that BIA and other federal buildings in Alaskan Native people areas, which are covered under Section 504 of the Rehabilitation Act of 1973, have not yet met the guidelines set down by Section 504 or by the ADA.

Frequency of Use & Accessibility of Public Buildings in Native Villages

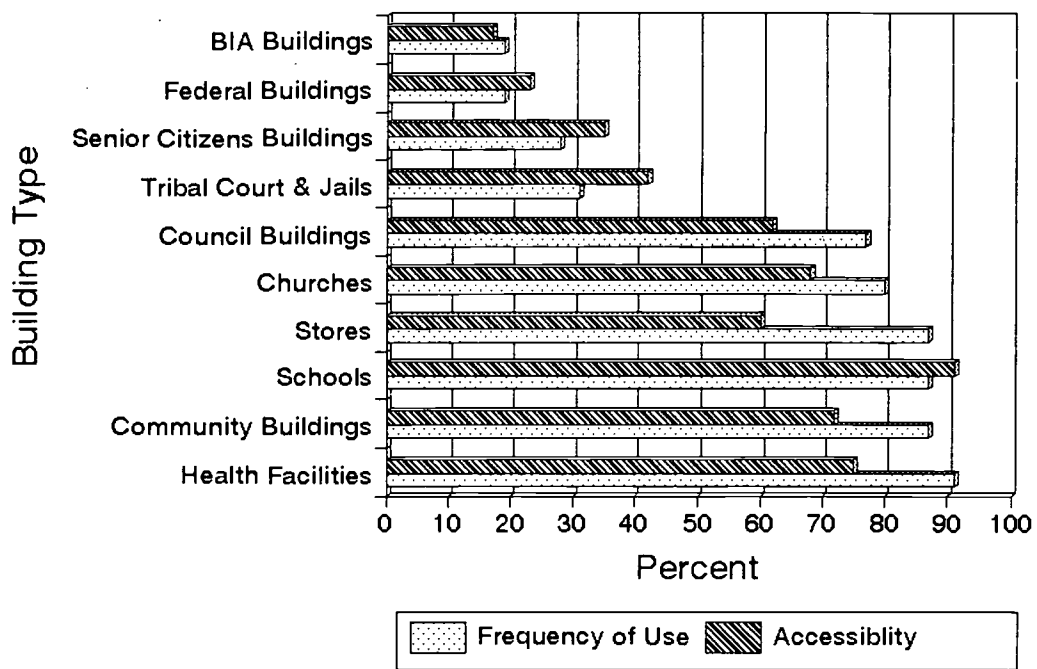


Table A4 presents the percentage of respondents indicating the availability in their tribal community of a range of programs relevant to rehabilitation. This table also reports the percentage of these programs that are part of the tribal structure. Health services were most frequently available, followed by special-education services, senior programs and vocational services.

Table A4
Availability of Services Relevant to Rehabilitation in Percentages

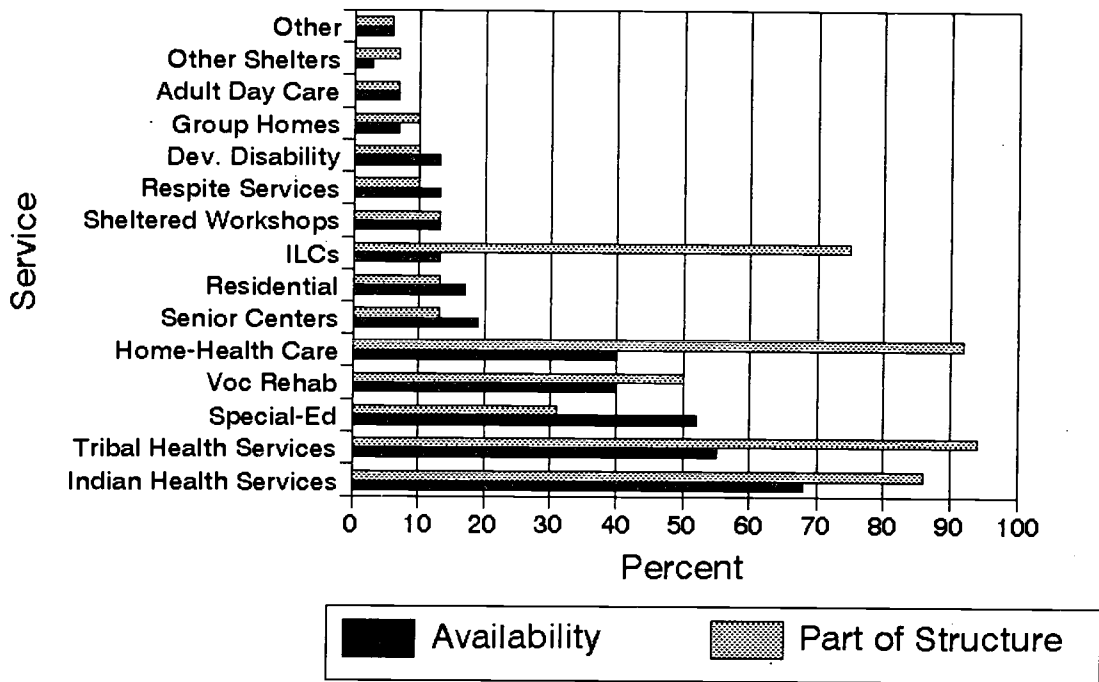
Service	Percent Reporting Availability	Part of Tribal Structure
Indian Health Service	68%	86%
Tribal Health Services	55%	94%
Special-education services	52%	31%
Vocational Rehabilitation Services	40%	50%
Home-health care services	40%	92%
Senior citizens centers	19%	13%
Residential facilities	17%	13%
Independent living centers	13%	75%
Sheltered workshops	13%	13%
Respite services	13%	10%
Developmental disabilities services	13%	10%
Group homes	7%	10%
Adult day care	7%	7%
Other shelters or detention centers	3%	7%
Other (please specify)	3%	3%
Other	3%	3%

Note. An explanation of the services in Table A4 can be found in the glossary in Appendix C.

Across all service categories, the availability of services to Alaskan Native people with disabilities seems to be less than services available to Indian people in the lower 48 states. When services are available, they tend to be provided within the tribal structure rather than by outside agencies.

As with Indian people in the lower 48 states, Alaskan Native people often are forced to seek services through outreach programs or satellite offices, or by traveling a significant distance or go without services.

Availability of Services Relevant to Rehabilitation in Percents



Finally, Table A5 reports the percentage of tribal budgets that have specific line items for a variety of disability services. In addition, the average amount of these line items is presented. These data should be considered cautiously because only 13% respondents reported any budget information at all.

**Table A5
Tribal Budgets for Disability Services**

Budget Line Item	Percent of Tribes Having Line Item	Average Amount per Tribe with Line Item
General handicap/disability line item	0%	0
Making homes wheelchair accessible	4%	0
Making public buildings and areas accessible (for example: ceremonial grounds)	4%	0
Providing staff training on disability issues	2%	\$2,000
Providing public education on disability issues	4%	0
Employment services for people with disabilities	5%	\$1,500

Appendix B



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EXECUTIVE COMMITTEE

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galashkibos
Chippewa

First Vice President
Susan Masten
Yurok

Recording Secretary
S. Diane Kelley
Cherokee

Treasurer
Mary Ann Antone
Tohnon O'odham

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Standing Rock Sioux

Albuquerque Area
Charles J. Dorame
Tesuque Pueblo

Anadarko Area
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Sac & Fox

Billings Area
John Sunchild, Sr.
Chippewa Cree

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Yup'ik

Monneapolis Area
Marge Anderson
Ojibwe

Muskogee Area
Donald E. Giles
Peoria

Northeastern Area
Keller George
Oneida

Phoenix Area
Irene C. Cuch
Northern Ute

Portland Area
Bruce Wynne
Spokane

Sacramento Area
Hank Murphy
Kumeyaay (Mission)

Southeastern Area
A. Bruce Jones
Lumbee

EXECUTIVE DIRECTOR
JoAnn K. Chase, J.D.
Mandan Hidatsa

RESOLUTION # B-94-038

Title: Support For The Project On American Indian Disability Legislation:
Toward The Development Of A Process That Respects Sovereignty and
Cultural Diversity

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 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 welfare of the Indian people, do hereby establish and submit the following resolution:

WHEREAS, the National Congress of American Indians (NCAI) is the oldest and largest national organization established in 1944 and comprised of representatives of and advocates for national, regional, and local Tribal concerns; and

WHEREAS, the health, safety, welfare, education, economic and employment opportunity, and preservation of cultural and natural resources are primary goals and objectives of NCAI; and

WHEREAS, the recent passage of the Americans with Disabilities Act (ADA) has the potential to improve the lives of all citizens with disabilities including American Indians with disabilities living on reservations who may not benefit from this law because it specifically excluded Indian tribes from some of its requirements; and

WHEREAS, traditionally, the applicability of national legislation to tribal governments has been addressed through the courts, creating an adversarial approach which contributes to tension between tribal and other governmental entities; and

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WHEREAS, there is a need to establish disability legislation for American Indian tribes on reservation that is consistent with the principles established by the ADA and is respectful of tribal sovereignty and cultural diversity, and to do so by an alternative method other than the courts and tribes wishing to establish their own ADA legislation that will be respectful of tribal sovereignty and cultural diversity and yet address the issues of the ADA; now

THEREFORE BE IT RESOLVED, that NCAI does hereby endorse the project in its efforts by passing this Resolution of Support.


CERTIFICATION

The foregoing resolution was adopted at the 1994 Mid-Year Conference of the National Congress of American Indians, held at the Hyatt Regency in Buffalo, NY, on June 14-16, 1994 with a quorum present.



gaiashkibos, President

ATTEST:



S. Diane Kelley, Recording Secretary

Adopted by the General Assembly during the 1994 Mid-Year Conference at the Hyatt Regency Hotel in Buffalo, New York.



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Southeastern Area
A. Bruce Jones
Lumbee

EXECUTIVE DIRECTOR
JoAnn K. Chase, J.D.
Mandan Hidatsa

Resolution # 94-DEN-HR/H-082

Title: American Indian Disability Legislation: Americans with Disabilities Act (ADA)

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 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 welfare of the Indian people, do hereby establish and submit the following resolution; and

WHEREAS, the National Congress of American Indians (NCAI) is the oldest and largest national organization established in 1944 and comprised of representatives of and advocates for national, regional, and local Tribal concerns; and

WHEREAS, the health, safety, welfare, education, economic and employment opportunity, and preservation of cultural and natural resources are primary goals and objectives of NCAI; and

WHEREAS, because the United States Congress excluded Indian lands (Federal and State) due to sovereignty issues.

WHEREAS, passage of this resolution would encourage Indian communities (reservations) to pass legislation or resolutions which would provide equal access to all Tribal members; and

WHEREAS, Tribes are excluded from the provisions of the ADA because of the tribes sovereign status, but this legislation does not prevent the tribes from providing equal opportunities to all tribal members: and

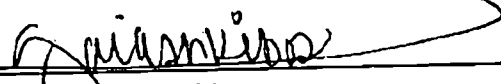
WHEREAS, there is a need to establish disability legislation and educate all American Indian and Alaska Native tribal members that live on reservations that is consistent with the principles established by the ADA and is respectful of tribal sovereignty and cultural diversity; and

WHEREAS, there is an alternative method, other than the courts, for tribes wishing to establish their own ADA legislation that will be respectful of tribal sovereignty and cultural diversity and yet address the issues of the ADA; now

THEREFORE BE IT RESOLVED, that NCAI does hereby recommend to endorsement and encourage the passage of American Indian Disability Legislation as developed by each Tribe.

CERTIFICATION

The foregoing resolution was adopted at the 1994 Annual Convention of the National Congress of American Indians, held at the Sheraton Tech Center Hotel in Denver, Colorado, on November 13-18, 1994 with a quorum present.



gaiashkibos, President

ATTEST:



S. Diane Kelley, Recording Secretary

Appendix C

Glossary

Adult day care: supervised day program for older people which is stimulating and provides social opportunities. Designed to meet the needs of older people who are too frail to participate in senior centers or who need special assistance during the day.

Americans with Disabilities Act (ADA) of 1990: ensures that people with disabilities have the same opportunities and rights as any other individual. Designed to remove barriers which keep people with disabilities from enjoying the same opportunities that people without disabilities have. Consists of five sections which focus on specific areas.

Title I: Employment: ensures that people with disabilities who are qualified to perform a job are not discriminated against because of a disability.

Title II: Public Services: ensures that people with disabilities cannot be excluded from participating in the activities of any local or state government or their agencies, or be denied the benefits of their public services and programs because of a disability.

Title III: Public Accommodations and Services Provided by Private Companies: ensures that people with disabilities have the same opportunities as others to enjoy the goods, services and facilities provided by private companies.

Title IV: Telecommunications: ensures that telecommunication services will be provided to people with disabilities at no additional cost.

Title V: Miscellaneous: deals with various provisions not covered in other sections of the ADA.

Bureau of Indian Affairs (BIA): a federal agency charged with the trust responsibility for tribal land, education and water rights.

Developmental disability: mental or physical disability present since childhood that represents a substantial handicap to the individual.

Developmental disability services: organizations that administer services for people with developmental disabilities, such as educational services, community support, case management, advocacy and health-related services.

Disability: a physical or mental impairment that substantially limits one or more major life activity.

Physical impairment: any physiological disorder or condition, cosmetic disfigurement or loss affecting one or more of the following body systems: neurological, musculoskeletal, specific sense organs, respiratory, cardiovascular.

Mental impairment: any mental or psychological disorder, such as mental retardation, organic brain syndrome, emotional or mental illness and specific learning disabilities.

Group home: a home in a residential neighborhood where 8-12 residents with disabilities live and interact together.

Home health-care: provides skilled care to individuals in their homes. Services may include skilled medical and therapeutic care, skilled nursing care, physical therapy and services of a home health aide.

Independent living: the ability of a person with a severe disability to participate actively in society, to work, to own a home, to raise a family and to participate to the fullest extent possible in activities of daily living.

Independent living center: a community-based program with substantial consumer involvement that provides comprehensive services to assist people with disabilities to increase their self-determination and minimize unnecessary dependence on others. Assistance comes through peer counseling, housing assistance, accessibility modification, job placement assistance, assistance with transportation and prevention services.

Indian Health Service: an agency of the U.S. Public Health Service which operates delivery system designed to provide a broad spectrum of preventative, curative, rehabilitative and environmental services.

Individuals with Disabilities Education Act (IDEA): ensures that all children with disabilities have available to them a free, appropriate public education which emphasizes special-education and related services.

Major life activities: walking, speaking, breathing, performing manual tasks, seeing, hearing, learning, caring for oneself, working.

Other shelters or detention centers: provide temporary and/or emergency housing.

Rehabilitation Act of 1973: a federal law that establishes and funds state systems of vocational rehabilitation.

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 504; prohibits businesses which receive federal contracts from discriminating against individuals because of a disability.

Section 504: applies only to programs and activities conducted by the federal government or by agencies who receive federal financial assistance, such as the Bureau of Indian Affairs, schools, colleges, libraries, Indian Health Services, vocational schools or vocational rehabilitation agencies.

Residential facilities: homes in neighborhoods, owned, staffed and operated by a state agency.

Respite services: provides family caregivers with a break from their care-giving responsibilities. Services are provided either in a facility or in-home and are not available in all communities.

Senior citizen centers: provides older people with social and recreational activities during the day. Designed to serve seniors who function independently in the community and do not require health care.

Sheltered workshops: employment opportunities for individuals with severe and profound disabilities to work under contract. Employees are paid a small wage, not less than 25% of the minimum wage.

Special-education services: Individuals with Disabilities Act entitles children with disabilities to a free, appropriate public education which emphasizes special-education.

Tribal Health Services: tribally-run health facilities that provide health services to enrolled members of federally recognized tribes.

Vocational Rehabilitation Services: authorized by the Rehabilitation Act of 1973 through the U.S. Department of Education. Provides federal funds to help people with disabilities become employed, more independent and integrated into the community. Federal funds are passed to state vocational rehabilitation agencies that provide counseling, job-coach services, job placement and guidance.

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Independence, productivity and community integration

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