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People with disabilities on tribal lands: education, health care, vocational rehabilitation, and independent living.

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People with Disabilities on Tribal Lands:

Education, Health Care, Vocational Rehabilitation, and Independent Living

National Council on Disability
August 1, 2003
People with Disabilities on Tribal Lands: Education, Health Care, Vocational Rehabilitation, and Independent Living

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The views contained in this report do not necessarily represent those of the Administration as this and all NCD reports are not subject to the A-19 Executive Branch review process.
LETTER OF TRANSMITTAL

August 1, 2003

The President
The White House
Washington, DC 20500

Dear Mr. President:

The National Council on Disability (NCD) is pleased to submit to you this special report entitled People with Disabilities on Tribal Lands: Education, Health Care, Vocational Rehabilitation, and Independent Living. We are particularly proud of this report because it reflects the results of a project that was developed and guided to completion in conference with American Indian and Alaska Native (AI/AN) representatives of people with disabilities, their families, and tribal community leaders.

NCD has targeted the significant, unmet needs of unserved and underserved people with disabilities, including people from diverse cultures, as a policy priority. While people from diverse cultures constitute a disproportionate share of the disability community, they also have unique needs in addition to those experienced by other people with disabilities. At 22 percent prevalence, according to national research data, American Indians and Alaska Natives have the most disproportionate rate of disabilities of all population groups, compounded by factors such as high poverty and school dropout rates, geographic isolation from state or local district rehabilitation and health care, and limited employment options.

This project examined research on health, rehabilitation, independent living, and education issues that affect people with disabilities living in Indian Country. The report discusses views and perspectives of AI/AN people with disabilities, tribal leaders, and federal agency representatives identified as productive in meeting the needs of people with disabilities residing in tribal lands. This report also assesses and recommends government-to-government (state to sovereign tribal to U.S. government) improvements in relationships needed for effective coordination across existing federally funded projects/programs. In addition, a Toolkit guide providing resource information was developed for use by consumers, tribal communities, and people at state, local, and federal levels.

NCD stands ready to facilitate federal agency dialogue with stakeholders who seek to address jointly the unmet needs of American Indians and Alaska Natives with disabilities in meaningful and culturally sensitive ways. It is only then that we can rest assured that all of our citizens with disabilities have the freedom to fulfill their dreams, access economic independence, and participate meaningfully in their communities.

Sincerely,

Lex Frieden
Chairperson

(This same letter of transmittal was sent to the President Pro Tempore of the Senate and the Speaker of the House of Representatives.)
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Acknowledgments

The National Council on Disability’s (NCD) project, People with Disabilities on Tribal Lands: Education, Health Care, Vocational Rehabilitation, and Independent Living, was formed and guided by the powerful sharing of experiences, knowledge, and hopes of American Indian people with disabilities, their families, and advocates. These individuals strived to create a new perspective about what it means to be an American Indian and Alaska Native with a disability. This new consciousness will serve to transform Indian communities nationally and offer a new hope to so many individuals who for so long have felt invisible and not heard.

NCD expresses its gratitude to the team at Kauffman and Associates, Inc., for drafting this report. Team members include Ann Kauffman, president; Project Director Martina Whelshula; Victor Paternoster; Tim Spellman; Wendy Thompson; and Ara Walline.

Others who supported the development of this work and deserve special acknowledgment are Mike Blatchford, consultant; Desautel Hege Communications; Kathy Langwell and Project HOPE; Robert Shuckahosee, consultant; Frank Ryan, consultant; the Consortium of Administrators for Native American Rehabilitation (CANAR); the American Indian Disability Technical Assistance Center; the American Indian Rehabilitation Research Training Center; the National Congress of American Indians (NCAI); focus group participants at NCAI and CANAR conferences; and Judy Babbit from the City of San Antonio Disability Access Office.

A special acknowledgment goes to those who represent the heart and soul of this effort, our Technical Expert Panel members Mark Azure, Julie Clay, Julia Davis-Wheeler, LaDonna Fowler, Joanne Francis, Joseph Garcia, Cordia LaFontaine, Carol Locust, Danny Lucero, David Miles, Damara Paris, Andrea Siow, H. Sally Smith, Raho Williams, and Alvin Windy Boy. Thank you to Jessie Stewart, age 10, for sharing her story.

In attempts to understand the complex make-up of Indian Country as it addresses the needs of tribal members and descendants with disabilities, tribal program directors shared willingly about the challenges and inspirations experienced in their work. NCD acknowledges these people and the tribes they represent: Jo White, Oglala Nation at Pine Ridge; Arlene Templer, Confederated
Salish and Kootenai Tribes; Rita LaFrance, St. Regis Mohawk; Rhonda Talaswaima, Hopi Nation; Ela Yazzie-King and Paula Seanez, Navajo Nation; Darlene Finley, Three Affiliated Tribes; Linda Pratt, Yakama Nation; Larry Alflen, Pueblo of the Zuni; Steven “Corky” West, Oneida Nation; and Len Whitebear, Cook Inlet Tribal Council.

Federal and regional officials contributed to an increased awareness of practices that promote government-to-government relationships. NCD acknowledges those agencies that offered their insights into the delicate circumstances of improving government-to-government relationships between tribes and federal/state governments. Those agencies who contributed were Indian Health Service, Elder Care; Region X, Rehabilitation Services; BIA, Special Education; Indian Health Service, Public Health; American Indian and Alaska Native Social Security; Administration for Native Americans; and Administration on Aging, Native American Programs.
# Contents

## I. Preface

## II. Executive Summary

Summary of Research Findings ................................................................. 4  
Key Elements of Promising Practices in Indian Country ............................... 6  
Barriers and Challenges to Effective Government-to-Government Relationships ... 7  
Key Findings And Recommendations ............................................................ 9  
Conclusion ........................................................................................................ 12

## III. Research Findings

Overview ........................................................................................................... 13  
Method ................................................................................................................ 14  
Technical Expert Panel ...................................................................................... 15  
Project Strategy ................................................................................................. 15  

### Literature Review

Definition and Description of the American Indian and Alaska Native Population Living in Indian Country Overall, People with Disabilities, and Types of Disabilities ............................................................ 19  
Unique Legal, Environmental, and Economic Factors Affecting Provision of and Access to Appropriate Services for People with Disabilities in Indian Country .................................................. 26  
Barriers to Provision of and Access to Appropriate Services for People with Disabilities in Indian Country .......................................................................................... 36  
Assessing the Effectiveness of Strategies for Reducing Barriers to Provision of and Access to Appropriate Services ................................................................. 47  
Limitations to Understanding Issues of People with Disabilities Living in Indian Country ........................................................................................................... 58  
Federal Responsibility to Address Gaps in Knowledge ...................................... 61

Key Respondent Interviews .............................................................................. 63  
Tribal Interviews ............................................................................................... 64  
Key Elements of Promising Practices .............................................................. 72  
Federal Interviews .......................................................................................... 75
SECTION I

Preface

Among the strategies and decisions that emerged from the National Council on Disability's May 2000 think-tank process was a commitment by people with disabilities from diverse cultures, supporters from national advocacy groups, and the U.S. Congress to (1) investigate different approaches to advancing disability, civil, and human rights and (2) develop an informational toolkit with attention to different cultural needs.

American Indian and Alaska Native (AI/AN) people with disabilities, particularly those who live in Indian country, face unique circumstances and legal environments that require special outreach and consultation in addition to the development of culturally appropriate methods and tools to address their unmet needs for services and support. This project, People with Disabilities on Tribal Lands: Education, Health Care, Vocational Rehabilitation, and Independent Living, was intended to facilitate consultation and input from AI/AN people with disabilities, tribal leaders, and community organizations, to obtain information, and to recommend strategies for improving services to people with disabilities who live in Indian Country. In addition, the project developed a culturally appropriate Toolkit, specifically designed to address the unique political and legal foundations of AI/AN tribal communities. The Toolkit provides background on education, health, vocational rehabilitation, independent living, and other services important to people with disabilities; model approaches; and supporting documentation for improving services and support to people with disabilities living in Indian Country.

"As a child when I moved to a deaf school off tribal lands I couldn't participate in my cultural rituals such as powwows and ceremonies. My life was like a torn piece of paper. When I could reconnect these ceremonies and my ability to be first a Native American and then a deaf person—my life came together again."

—Mark Azure, Intertribal Deaf Council
SECTION II
Executive Summary

"My disabilities are perceived by my American Indian and Alaska Native peers as a part of me. I do not feel as stigmatized as I do in mainstream society. At the same time, powwows and community tribal events are not sign language interpreted. How can I learn my traditions from my people without communication support?"

—Damara Paris, Intertribal Deaf Council

In passing the 1990 Americans with Disabilities Act (ADA), Congress announced its purpose to provide "a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities." This national mandate for the elimination of discrimination ignored the unique circumstances faced by American Indians and Alaska Natives with disabilities living in tribal lands. Caught in a public policy paradox, American Indian and Alaska Native (AI/AN) people with disabilities are stuck between the sometimes conflicting priorities of protecting the sovereignty of tribal governments and ensuring the civil rights guaranteed to all people with disabilities.

AI/AN tribes are sovereign governments and enjoy a unique government-to-government relationship with the United States that is based upon treaties, the U.S. Constitution, federal law, executive orders, and affirming court decisions. In addition to this unique legal status, Indian Country is disproportionately rural, which poses a number of logistical and resource challenges to the provision of and access to social, health, and support services. Historically, American Indians and Alaska Natives tend to have less education, greater unemployment, and higher rates of poverty than people of other racial groups in the United States. Meeting the needs of people with disabilities living in Indian Country requires recognition of the unique legal and socioeconomic environment of tribal communities, as well as an understanding of various AI/AN cultures and history that shape each community. Appropriate consultation and input from tribal leaders and tribal members with disabilities is critical in understanding the depth and complexity of AI/AN cultures. The activities undertaken through this project explored the complex weave of
federal disability laws, tribal sovereignty, tribal cultures, perspectives of AI/AN people with disabilities, and the diverse economic and physical environments in which they find themselves.

The American Indian Disability Legislative Project (AIDLP) reports that only 6 percent of tribal governments surveyed are familiar with major disability legislation, such as ADA or Sections 503 and 504 of the Rehabilitation Act of 1975. The survey responses indicate that only two-thirds of the tribal schools, stores, churches, and other buildings were accessible to people with disabilities. Lack of employment opportunities, transportation, financial resources, and elevated health care costs all add to the numerous inequities faced by people with disabilities living in Indian Country.

This National Council on Disability (NCD) project examined research such as the AIDLP and other studies and reports on health, rehabilitation, independent living, and education issues that impact people with disabilities living in Indian Country. In addition, this report discusses views and perspectives of AI/AN people with disabilities, tribal leaders, and federal agency representatives identified as productive in meeting the needs of people with disabilities residing in tribal lands. Finally, this report assesses and recommends government-to-government (state to sovereign tribal to U.S. government) improvements in relationships needed for effective coordination across existing federally funded projects/programs.

Summary of Research Findings

"Everybody has his or her own unique gifts. It is up to us to find our path. We must show others and teach people to look beyond differences and find good in everyone."

—Andrea Siow, Hopi Nation

According to the 2000 U.S. Census, nearly 2.5 million Americans identify themselves exclusively as "American Indian or Alaska Native." There are 4.1 million people who identify themselves either as Indian only or as Indian in combination with another race. Of this total, approximately 944,433 Indian or Alaska Native people live on federal reservations or on off-reservation trust lands. Thirty-five states have federal reservations within or overlapping state borders. The Federal Government, through the Bureau of Indian Affairs (BIA), officially
recognizes 560 tribes and Alaska Native villages. They are known as “Federally Recognized Tribes.”

Data from the 1997 Survey of Income and Program Participation found that 22 percent of the AI/AN population have one or more disabilities. If we consider the 2.5 million who reported on the 2000 census that they identify themselves exclusively as “American Indian or Alaska Native,” this means that at least 550,000 American Indians and Alaska Natives have disabilities.

Every type of disability that is found in the general population can also be found in the AI/AN population. Several small studies have surveyed tribal communities to identify the most frequent types of disabilities. These studies generally found that the following types of disabilities are most often reported in Indian community surveys: spinal cord injury; diabetes complications; blindness; mobility disability; traumatic brain injury; deafness or hardness of hearing; orthopedic conditions; arthralgia; emotional or mental health concerns; learning disabilities; and alcoholism or drug dependence.

This NCD project sought to bring our understanding of people with disabilities living in tribal lands closer to the community level. The project tapped the knowledge and experience of a Technical Expert Panel (TEP) to begin to identify the major issues related to health, education, vocational rehabilitation, and independent living for people with disabilities in Indian Country. In consultation with the TEP, 10 Indian communities were identified for individual tribal interviews as follows: Confederated Salish and Kootenai Tribes of the Flathead Reservation (MT), Cook Inlet Tribe (AK), Hopi Nation (AZ), Navajo Nation (AZ, NM, UT), Oglala Sioux Tribe (SD), Oneida Nation (WI), The Pueblo of Zuni (NM), St. Regis Mohawk (NY), Three Affiliated Tribes at Fort Berthold (ND), and Yakama Nation (WA).

These tribal interviews uncovered specific strategies and programs implemented at the local community level that have effectively improved access, protections, and services for people with disabilities in tribal communities. Several tribes, such as the Salish and Kootenai Tribes in Montana, the Oglala Sioux Tribe in South Dakota, and the Navajo Nation in the Southwest, have adopted tribe-specific ordinances to establish protections and services for people with disabilities in their communities. The Hopi Nation in Arizona and the St. Regis Mohawk in New York
provide active case management approaches with extensive outreach and grassroots consumer involvement. The Pueblo of Zuni of New Mexico place a high priority on public transportation services as the key to providing assistance and advocacy for people with disabilities. Six key elements emerged as common practices across promising programs. These are summarized below.

**Key Elements of Promising Practices in Indian Country**

"The consumers are the leadership. Learn from the consumer."

—Steven 'Corky' West, Oneida Nation

- **Effective program leadership characteristics**: At the tribal community level, leaders of promising programs commonly embody qualities of passion, perseverance, vision, commitment, change agents, consistency, connection to consumers, and a sense of hope.

- **Responsiveness to the consumer**: Members of program staffs embrace people with disabilities as a part of their teams, developing relationships and shared power in the planning and implementation of services and programs.

- **Innovation in removing barriers**: Breaking down barriers and reshaping tribal communities require personal and collective creativity/inventiveness and risk taking. The reshaping of resources can help to provide a seamless array of supports, programs, and services for people with disabilities.

- **Effective collaboration**: Program staff communication and coordination with other nontribal resources recognize the role of services and resources outside the realm of individual programs or communities and seek to build bridges among separate entities. This also requires personal relationship building.

- **Advocacy strength**: It is important to instill a strong sense of advocacy into the program philosophy and staff approaches to policy and program implementation. The
multiple and disjointed systems that impact people with disabilities require strong self-advocates and supporters to navigate administrative barriers.

- **Support from tribal leadership:** A common ingredient is strong and committed leadership from elected tribal officials, although each tribe interviewed for this report operated differently in its approach to meeting the needs of tribal members with disabilities.

**Barriers and Challenges to Effective Government-to-Government Relationships**

"Sometimes when an elder leaves the home to live in an institutional setting their spirit is just lost. The foundation of the family is gone and the cultural unity of the family suffers. When it is appropriate, day care can help elders and we can see a difference with this personal care. We have a lot of work to do to be recognized and know how to access services like these."

—Raho Williams, Navajo

Federal laws designed to protect people with disabilities are not always enforceable against tribal governments because of the sovereign immunity and sovereign status that tribal governments enjoy. The U.S. Supreme Court has yet to rule on whether or not and to what extent federal disability laws apply to Indian tribes. In the absence of that, different and sometimes conflicting opinions are being developed in lower courts. In addition, the services and resources that should be available to people with disabilities are not always accessible in tribal communities. Chronic underfunding of tribal community programs and a lack of physical infrastructure upgrades create barriers for people with disabilities in these communities. This NCD report identified barriers and challenges that hamper or prevent meaningful government-to-government relationships to develop among tribes and state or federal entities. Such relationships can help governments better address jointly some of the issues related to people with disabilities in Indian Country. Based upon a review of the literature, interviews with tribal officials, and interviews with federal program administrators, the following major barriers were identified:
Disjointed coordination among agencies:

- Fragmentation of services across federal agencies and offices
- Lack of coordination and collaboration among federal, state, and tribal programs
- Federal travel and budget limitations
- Advocacy made difficult by multiple education systems (public, BIA, tribal)

Limited knowledge or understanding about tribal communities:

- Lack of federal staff knowledge and training for federal personnel on the federal trust responsibility to AI/AN people and on tribal sovereignty
- Agency staff fear of the unknown and unfamiliarity with AI/AN populations

Limited enforcement of laws protecting people with disabilities on tribal lands:

- Lack of clarity about legal enforcement options
- Failure to ensure that the national mandate to eliminate discrimination against individuals with disabilities included equal benefits for American Indian and Alaska Natives with disabilities

Limited local tribal planning to protect and support people with disabilities:

- Lack of involvement of tribal leaders and tribal members in the design, development, and implementation of programs
- Limited consumer involvement at all levels of policy development
- Difficulties in tribal/state relationships
- Limited tribal awareness and access to new strategies that can better serve people with disabilities
- Historical distrust of the Federal Government by tribal leaders and members
Key Findings and Recommendations

"You have control. Just ask for what you need."

—Jo White, Quad Squad, Oglala Sioux Tribe

It is important to note that this NCD study found a very active and articulate network of AI/AN people with disabilities who are working through a variety of local and national organizations to bring important resources to their communities and to reshape the way tribal governments address their issues. Examples are numerous, including a one-person sit-in on the steps of a tribal building to force the tribe to construct a ramp sponsored by the Pine Ridge Quad Squad; the development of national research expertise found at the American Indian Rehabilitation Research and Training Center; and the organization of national advocacy groups such as the Intertribal Deaf Council and the American Indian Rehabilitation Rights Organization of Warriors. Through individual self-determination and collective bravery and persistence, changes are occurring in tribal communities. Based in large part on the groundwork performed by the AI/AN disabilities community, this study identified 15 major areas of findings and corresponding specific recommendations to improve government-to-government relationships for the benefit of people with disabilities in tribal communities. Detailed descriptions of these findings and recommendations are provided in subsequent chapters of this report. The following is a summary of the five major categories of recommendations proposed in this report:

Fulfill the federal trust responsibility to AI/AN tribes and the national mandate for the elimination of discrimination against individuals with disabilities:

- **Clarifying application of federal disability laws:** The Department of Justice should provide robust leadership to ensure that the protections of ADA are extended to individuals with disabilities in AI/AN communities, working in close consultation with tribes and AI/AN people with disabilities.

- **Holding federal agencies accountable for information dissemination and service:** Federal agencies must fulfill the federal trust responsibilities to tribes by assertive
efforts to disseminate pertinent information and by developing culturally specific strategies to reach out to tribal communities.

• *Improving coordination and collaboration among programs:* Culturally responsive strategies should be developed among the various federal programs intended to serve people with disabilities to ensure that tribal communities are able to access important services.

Ensure meaningful consultation and involvement of people with disabilities and tribal leaders:

• *Recognizing and valuing tribal and consumer consultation:* Pursuant to the president’s Executive Order on tribal consultation, federal agencies should engage tribes and consumers in meaningful consultation to better address issues related to people with disabilities in tribal communities.

• *Improving state and tribal relationships to better serve people with disabilities:* The Department of Education and other federal agencies supporting state programs and initiatives should provide leadership and encouragement to improve state and tribal relationships regarding services to people with disabilities.

• *Convening national meeting(s) of key stakeholders to better address the needs of people with disabilities in tribal lands.* The federal Departments of Justice, Education, Health and Human Services, Transportation, Housing and Urban Development, and Interior should collaborate with tribal leadership and Indian community consumer groups to convene a national summit to begin to address issues raised in this report and to develop ongoing collaboration.

Provide tribes with better access to federal resources and funded programs:

• *Providing tribal communities access to Independent Living Centers:* The Department of Education should provide a specific set-aside in funds to support independent living centers in tribal communities.
• Increasing access to American Indian Vocational Rehabilitation Services (AIVRS): Funding for AIVRS must be substantially increased to allow for more tribes to participate in this important program and an increase in technical assistance and support to existing programs.

• Expanding home- and community-based services options in tribal communities: The Indian Health Service and Centers for Medicare and Medicaid Services should collaborate to provide necessary training and technical assistance to tribal health care systems to provide home- and community-based services and to decrease unnecessary dependence on institutional care.

Develop cultural competence within federal agencies and increase agencies’ interaction with tribes:

• Expanding cultural competence, training, and orientation: Each of the federal agencies providing services and programs targeting people with disabilities should ensure staff are trained and oriented to understand and engage tribal communities.

• Recruitment and hiring of AI/AN professionals and advocates within the federal system: Specific staff positions to provide liaison between federal programs and tribal communities should be established for federal agencies and programs. In particular, the Social Security Administration should provide a Native American liaison position in each of its federal regional offices for tribal outreach and advocacy.

Include disability issues among tribal priorities and federal initiatives in tribal communities:

• Increasing employment opportunities for people with disabilities in tribal communities: Tribal governments should consider ways to create expanded employment opportunities for people with disabilities in their communities.

• Making all public buildings and public infrastructure in tribal communities accessible to people with disabilities: Federal departments such as Interior,
Transportation, Housing, and Health and Human Services should collaborate with tribal governments to identify funds to retrofit tribal buildings and infrastructure to ensure tribal communities are accessible to people with disabilities.

Conclusion

Effective collaboration among sovereign tribal governments and federal and state programs is key to successfully addressing the issues and needs of tribal members with disabilities and descendants living in Indian Country. AI/AN people with disabilities and advocates must be invited to the table for key conversations regarding application of disability policies, initiatives, and program development and resource allocation. Unless and until this government-to-government collaboration occurs, AI/AN people with disabilities will continue to remain locked out of the protections and services guaranteed to all Americans with disabilities.

Andrea Siow (Hopi Nation), a TEP member, stated, “By getting the word out that people with disabilities are not helpless, we can create awareness and improve things…. It is up to us to find our path…. ” Self-determination is a fundamental and important principle not only for tribal governments, but for individual tribal members with the human need for opportunity, inclusion, support, access, and freedom to chart one’s own course. This nation’s mandate to eliminate discrimination against individuals with disabilities has thus far failed to appropriately address the inclusion of AI/AN communities. For many people with disabilities in tribal communities, the freedom to fulfill their dreams, access economic independence, and meaningfully participate in their tribal community may rest in the willingness of tribal, state, and federal governments to work together. Stakeholders will need to work cooperatively and effectively in ways that respect both the mandates and benefits of ADA and other disability laws, as well as this nation’s time-honored moral and legal obligations to tribal governments.
SECTION III
Research Findings

Overview

The National Council on Disability (NCD) has made a major and continuing commitment to identifying barriers to access, appropriate services, and supports that differentially affect people with disabilities from diverse cultures. This project reflects that commitment and was intended to provide information and products for consumers and to meet the goals set forth for the project. The project goals included addressing key disability policy issues from a multiprogram, cross-agency perspective; offering culturally competent information to tribal communities based on representative input from tribal people with disabilities and tribal leaders; and suggesting practical models to support the empowerment of people with disabilities.

Despite representing a small percentage of the total U.S. population, American Indians and Alaska Natives enjoy a unique legal, historical, and political relationship with the Federal Government. As indigenous peoples, Indian tribes engaged in government-to-government relationships with other sovereign countries before the United States was established. At its formation, the United States recognized the unique relationship with Indian tribes, and this recognition continues today. Meeting the needs of people with disabilities living in Indian Country requires recognition of these unique relationships and cultures and appropriate consultation with and input from tribal leaders and communities to develop effective and useful service approaches. The activities undertaken throughout this project sought to obtain that necessary consultation and input through culturally responsive and appropriate strategies. The result is information presented in both a report and a Toolkit that form a foundation for long-term development of policies and initiatives that can be used to improve access to services and support for this population.

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1 See, e.g., Montoya v. United States, 180 U.S. 261 (1901).
The stated objectives of this project were to

1. Summarize recommendations from relevant research and reports on health, rehabilitation, and education issues that impact independent living and self-determination realities for people with disabilities living in Indian Country.

2. Provide scheduled involvement for representatives of American Indian/Alaska Native (AI/AN) communities, advocates, and key organizations concerned with issues of education, rehabilitation, health, and independent living, as project advisors.

3. Identify and recommend basic factors/elements and key processes that have been productive in getting sovereign governments to develop tribal laws to protect and meet the service needs of people with disabilities who live in Indian Country.

4. Provide a capacity-building toolkit that is user friendly, incorporates principles of cultural competency, and includes as examples for consideration what seems to be working/what has been effective in different tribal settings.

5. Assess and recommend government-to-government (state to sovereign tribal to U.S. government) improvements in relationships needed for effective coordination across existing federally funded projects/programs.

6. Plan to broadly disseminate the project materials among Native people.

Method

This aggressive seven-month project inquired into the needs and issues facing people with disabilities in AI/AN communities as they affect education, health care, vocational rehabilitation, and independent living. A review of relevant literature and research findings was conducted. A 15-member Technical Expert Panel (TEP) was identified and convened for three meetings at different points of the project. The TEP proved to be a solid foundation for this effort, providing ongoing advice and guidance. In addition, a tribal and disability community consultant provided

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2 The TEP members are identified in Appendix A of this report.
input during the course of the project. Headquarters and regional federal officials were identified and interviewed to discern their perspectives on opportunities for and barriers to realizing improved government-to-government relationships with sovereign tribal governments in meeting the service needs of tribal members and descendants with disabilities. Finally, throughout this report and the Toolkit, the term “Indian Country” is used to indicate the federally recognized tribal lands across the United States.

Technical Expert Panel
Individuals representing consumers and advocates within the AI/AN disability community across the country were recommended to serve as members of a national TEP. Tribal leaders were also recruited for the TEP to serve as advisors, particularly in the government-to-government discourse. Members of the TEP functioned in project consultant and advisory roles throughout the course of the research, providing guidance on the direction of the project. The TEP was instrumental in providing input on plans, critical feedback, direction, and redirection of issues this project addressed. In addition, the TEP was utilized to identify sovereign tribal governments to be interviewed as potential case studies.

Project Strategy
The project objectives and tasks were implemented in three major phases. Phase I involved the gathering of preliminary data and information. This phase culminated with the first gathering of the multidisciplinary TEP in July 2002. Phase I also incorporated timelines to organize the project, finalize work plans and schedules, and receive initial project sanction from the TEP. Phase II efforts centered on the collection of data, information, and input. This phase represented the substantive bulk of work for this project. It included finalizing the literature and research reviews, concluding the key respondent interviews, concluding the case studies, and concluding the consumer and tribal leader focus groups. Phase III provided a final feedback loop for the content of the deliverables through the TEP. Each of these three major phases required a strategy that built upon the development of relationships within the AI/AN communities, especially as the strategy relates to tribal members and descendants with disabilities and communication with tribal leadership.
Literature Review

The literature review and synthesis provided a foundation of information for defining key issues and for the design and conduct of the approach to the key respondent interviews and case studies. In addition, the findings were shared with the TEP for review, discussion, and suggestions for revision.

The approach to this task was designed broadly to identify, obtain, and assess published and unpublished information that provided insights into the nature of barriers to access to services in Indian Country, and the factors that may be associated with greater or lesser degrees of difficulties in obtaining supports and services in Indian Country.

Based on the preliminary literature review conducted as background for the initial project proposal, it was anticipated that standard literature search techniques would produce sparse data on barriers to access and on effective strategies for increasing access to services for the population of interest. Consequently, the supplementary activities included:

- Search of Internet Web sites to identify organizations that serve or advocate for people with disabilities who live in Indian Country and to identify background papers, issue papers, data sources, projects, and studies that have addressed the relevant issues for this project.

- Telephone interviews with researchers who have been involved in studies of AI/AN health issues, to identify past and ongoing research projects and findings that may be relevant to this study.

- Telephone interviews with Federal Government employees in agencies that have responsibilities for health, education, vocational rehabilitation, independent living, and other services provided to people in Indian Country, to identify relevant data sources, studies, and initiatives for this study.

- Search of national databases (e.g., National Health Interview Survey, Medicare Current Beneficiary Survey, National Medical Expenditure Survey, Current
Population Survey, 1990 census, and 2000 census) and publications of data summaries from these surveys to obtain estimates of the number of people with disabilities in Indian Country and prevalence of each type of disability.

The first step in the literature survey was to conduct a search of published literature through standard literature sources, including

- Medline
- MedlinePlus: AI/AN Health
- Native Health Research Database
- Native Health History Database
- Education Resources Information Center
- www.disabilityresources.org/Native

These sources enabled identification of relevant published literature, from which a comprehensive bibliography was compiled and organized according to key topic areas. Brief abstracts of each publication were prepared from relevant and available full text. References cited in each publication were also searched to identify additional relevant literature.

Once the published literature bibliography was compiled, the search was expanded to Web sites of national Indian organizations concerned with health and social service issues, as well as organizations specifically focused on serving and advocating on behalf of AI/AN people with disabilities. These organizations included

- National Council of American Indians
- National Indian Health Board
- National Indian Council on Aging
- Association of American Indian Physicians
- American Indian Rehabilitation Research and Training Center (AIRRTC)
• National Center for American Indian and Alaska Native Mental Health Research, University of Colorado Health Sciences Center

• The Native Elder Health Care Resource Center, University of Colorado Health Sciences Center

• Rural Institute on Disabilities and American Indian Disability Technical Assistance Center (AIDTAC), University of Montana

• Native American Research & Training Center, University of Arizona

• Vocational Rehabilitation Service Projects for American Indians with Disabilities (Rehabilitation Services Administration Programs)

In addition, a search of relevant Federal Government Web sites included

• Indian Health Service (IHS)

• Administration for Native Americans

• Administration on Aging

• Department of Education

• Department of Labor

• National Institutes of Health, including National Institute on Aging, National Institute on Alcohol Abuse and Alcoholism, National Institute of Mental Health, National

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3 A search of the U.S. Department of the Interior's Bureau of Indian Affairs Web site was not possible because of the temporary closing due to judicial order. Some BIA data were available at Project HOPE from other project work. During the next stage of this literature review task, contact and interviews with BIA staff were used to obtain additional information on relevant topics.
After all the literature and interview results were synthesized by topic area with key findings highlighted, each topic area was then reviewed for completeness and gaps in information and research. The questions to be addressed in this review included the following:

1. What do we know with reasonable certainty, based on valid and reliable research?
2. What do the research findings suggest, for which supporting evidence is weaker?
3. What important issues, in this area, have not been addressed by any research?
4. What are the reasons that these issues have not been addressed (e.g., lack of appropriate data)?

The review includes a summary of findings from the literature, identification of gaps in the research and findings, and suggestions that could address these gaps in information and research.

**Definition and Description of the American Indian and Alaska Native Population Living in Indian Country Overall, People with Disabilities, and Types of Disabilities**

According to the 2000 U.S. Census, nearly 2.5 million Americans, or 0.9 percent of the U.S. population, identified themselves as American Indians or Alaska Natives. Approximately 4.1 million people or 1.5 percent of the U.S. population identified themselves as AI/AN or AI/AN in combination with another race. Of the people who indicated that they were AI/AN in combination with another race, the majority (66 percent) identified the other race as “White.”
In 1990, the population of AI/AN was approximated at 1.9 million. Although comparison of the 1990 and 2000 census data suggests a 10-year increase in the AI/AN population, the actual magnitude of this increase is unclear because of changes in how the census collects and reports information on race. Specifically, the 1990 census required people to affiliate with only one racial group, and the 2000 census allowed people to identify with multiple racial groups. Comparison of the 1990 AI/AN population estimates to the population who indicated that they were AI/AN in 2000 shows a rate of increase of 26 percent. However, comparison to the total number of people who identify their race as AI/AN only or AI/AN in combination with other races shows a 10-year increase of 110 percent. In contrast, the population of the rest of the United States (all races) increased by only 13 percent during that same period (U.S. Census, 2000).

Population Off and On the Reservation

Although American Indians and Alaska Natives reside in all states of the United States, approximately 42 percent of the AI/AN population (one race only) living both on and off reservations are located in four states: Arizona, California, New Mexico, and Oklahoma. Nearly one-half of the AI/AN population reside in the Western United States, compared with 30 percent who reside in the South, 16 percent who reside in the Midwest, and less than 7 percent who reside in the Northeast.

Defining Indian Country: The Census Bureau distinguishes several types of tribal lands. Federally recognized reservations and off-reservation trust lands are those geographic areas to which the Federal Government has granted sovereignty and whose tribal members are eligible to receive services from the U.S. Department of the Interior’s Bureau of Indian Affairs (BIA). Indian tribes with or without a land base may also be recognized by individual states but not by the U.S. Department of the Interior. In the latter case, the census considered tribal members to be

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4 The number of American Indians reported in 1990 is believed to understate the actual number of Indians residing in the United States. Census takers are believed to have undercounted the number of Indians residing on reservations by more than 12 percent. (Richardson D, Bureau of Labor Statistics Daily Report, December 28, 1999.)

residing in a state-designated American Indian statistical area. In some cases, an American Indian population that resides within a geographic area may function as an organized tribe but not be recognized by either the state or the Federal Government. These distinctions across American Indian lands are important in understanding barriers to access to health and social services that people with disabilities face, because it is only on federally recognized tribal lands that the tribal jurisdiction is granted sovereignty. As such, it is only on federally recognized reservations where the benefits afforded to people with disabilities through the Americans with Disabilities Act (ADA) are not consistently ensured. The matter of this exemption is discussed later in this report.

Approximately 944,433 people resided on federal reservation and off-reservation trust land in 2000. States with the largest population on federally recognized reservations are Arizona, New Mexico, and Washington. These three states are home to nearly one-half of the U.S. populations who live on federal reservations. It is important to note that the number of American Indians and Alaska Natives that are currently living on or near reservations is expected to be somewhat less since these figures include people of all races and ethnicities. In fact, less than one-third of people who identified themselves as AI/AN in the census and one-fifth of people who identified themselves as either AI/AN or AI/AN in combination with another race resided on a federally recognized reservation in 2000.

BIA officially recognizes over 560 tribes. The 10 largest tribal groupings in the United States are the Cherokee, Navajo, Latin American Indian, Choctaw, Sioux, Chippewa, Apache, Blackfeet, Iroquois, and Pueblo. Two-thirds of all people who specified a tribal affiliation on the 2000 census identified themselves as Cherokee either in whole or in combination with another tribal

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6 For example, only 15 percent of the population residing in the Southern Ute Reservation of Colorado in 2000 indicated that they were entirely American Indian or American Indian in combination with another race. Similarly, according to the census, only 35 percent of the population of the Lake Traverse Reservation of South Dakota self-identified themselves as American Indian. The majority of the population on both these reservations identified themselves as “White.”

7 Personal conversation with Jackie Kruszek, Office of Native American Programs, Denver National Program Office, June 20, 2000.
group. One-fourth self-identified with the Navajo Tribe. Among Alaska Natives, the largest tribal
group is the Eskimo.⁸

**Disability Prevalence Among American Indians and Alaska Natives**

It is important to note that statistics vary, depending on the source of data and the definition of
disability. The numbers also vary according to the type and severity of the disabilities included.
There continue to be problems with widely used disability employment and other data in U.S.
Census 2000, including concern about the inadequate collection and analysis of relevant and
reliable statistical data on America’s population with disabilities.

NCD recognizes that findings of the 2000 census, together with those of other compilations
relating to the employment status of Americans with disabilities, are being severely questioned
on methodological and validity grounds. The accuracy of this data is critically important in an era
of evidence-based policy because misleading information can lead to misguided or premature
public policy decisions.

Data from the 1997 Survey of Income and Program Participation (SIPP) indicates that nearly 20
percent of the U.S. population has some level of disability. Twelve percent of the population had
a developmental or other disability of sufficient severity to require the use of a wheelchair, cane,
or crutches and to prevent them from working, or for which they required assistance in
performing activities of daily living or instrumental activities of daily living.⁹ The prevalence of
disabilities has been found to vary significantly by racial and ethnic group. In 1991–1992, nearly
20 percent of Whites and Blacks were estimated to have a disability (defined as the presence of
one or more functional limitations) compared with 15 percent of Hispanics and 10 percent of
Asian and Pacific Islanders. According to the SIPP, rates of disability were highest among
American Indians and Alaska Natives; nearly 22 percent of American Indians, Eskimos, and

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February 2002.

Aleuts were estimated to have a disability. Rates of disability were even higher among the working age population. Nearly 27 percent of American Indians and Alaska Natives between the ages of 16 and 64 were estimated to have a disability in 1991–1992.10

The state-specific estimates from 1990 U.S. Census data on American Indians and Alaska Natives (living both on and off reservations) with a disability reveal that rates of disability vary substantially across states. With few exceptions, rates of disabilities in the AI/AN population tend to be higher in southern states compared with rates in Arizona, New Mexico, and Utah. Among working age AI/AN adults (ages 16 to 64), rates of disability range from a high of over 25 percent in the states of Kentucky, Mississippi, and West Virginia to a low of approximately 12 percent in the states of Alaska, North Dakota, and Wyoming. Rates of disability also vary significantly among the elderly AI/AN population, from a low of 16 percent in Wyoming to a high of nearly 41 percent in Mississippi.

Reservation-specific estimates of disability, for reservations with more than 5,000 persons, are also provided in the 2000 census for the states of California, Arizona, Washington, New Mexico, Montana, and South Dakota. These estimates are based upon a sample of the population. Estimates may therefore be unreliable because of the small number of American Indians and Alaska Natives from any reservation included in the samples. Nevertheless, this data may suggest trends in the prevalence of disability across tribal groups that should be further investigated.

There is a three-fold difference in the proportions of children with disabilities residing in these reservations sampled in the six states listed in the previous paragraph. Approximately 3.4 percent of children living on the Hopi Reservation in Arizona are estimated to have a disability compared with over 10 percent of children in the Tohono O’odham Reservation in Arizona. Rates of disability were not only higher among adults but also varied widely, from a low of 13.5 percent in the Port Madison (WA) Reservation to a high of over 37 percent in the Fort Apache (AZ) and Salt River (AZ) Reservations. Estimated rates of disability among senior citizens living on

reservations are, in many cases, dramatically high. Nearly three-quarters of residents over the age of 65 in the Fort Apache (AZ), Gila River (AZ), Hopi (AZ), Navajo (AZ), and Zuni (NM) reservations are estimated to have a disability.

The extent to which variation in disabilities across reservations is attributable to difference in the proportion of American Indians (as opposed to people of other racial groups) who are living on these reservations is unclear.

**Types of Disabilities**

Information on the types of disabling conditions that are most prevalent on Indian reservations is limited to a small number of studies that either have surveyed organizations serving American Indians and Alaska Natives (e.g., tribal representatives, independent living centers) or have analyzed administrative data. In 1994 the American Indian Disability Legislation Project conducted a survey of 143 AI/AN tribes to obtain information on the accessibility of public buildings, availability of rehabilitation services, and tribal awareness of disability laws. Surveyed tribes were also asked to report on the frequency of disabling conditions. The disabilities most frequently cited by tribes in the continental United States were diabetes (29 percent), emotional disabilities (22 percent), and learning disabilities (11 percent). Among tribes in Alaska, emotional disabilities (31.3 percent), learning disabilities (17 percent), and deafness or hardness of hearing (17 percent) were the most frequently reported disabling conditions.11

Clay (1992) conducted a survey of independent living centers (ILCs) to identify the services that are available to American Indians residing on reservations. According to 42 ILCs that indicated that they served people on reservations or tribal lands, the most frequently observed disabilities among American Indians living on reservations were spinal cord injury, diabetes, blindness,

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mobility disability, traumatic brain injury, deafness, hardness of hearing, orthopedic conditions, and arthralgia. Rates of each of these disabilities were not provided.12

AIRRTC also examined the prevalence of different types of disabilities among American Indians using data from administrative files maintained by the U.S. Department of Education’s Rehabilitation Services Administration (RSA). Since the RSA files contain information on people who have undergone rehabilitation, estimates of the prevalence of disabling conditions may not be representative of the AI/AN population; rather, estimates of disabling conditions derived from this data are likely to reflect the characteristics of people who utilized these services. Nonetheless, this data is useful for purposes of comparing the prevalence of disabling conditions among AI/ANs to that of other racial groups.

AIRRTC analyses found that alcohol abuse or dependence was the most common cause of disability among American Indians and Alaska Natives represented in the 1997 RSA database. Approximately 11 percent of AI/AN clients had a major diagnosis of alcohol abuse compared with only 4 percent of White, nearly 6 percent of Black, and less than 2 percent of Asian clients. Although the prevalence did not vary substantially by race, learning disabilities were found to be the second most frequent major diagnosis (9 percent) among AI/AN clients represented in the RSA database. The frequency of sensory disabilities, however, tended to be slightly lower among American Indians and Alaska Natives than other racial groups. Among AI/AN clients, 1 percent were blind/low vision and 0.8 percent were deaf/hard of hearing compared with 1.9 percent and 1.24 percent, respectively, of the total in the RSA database.13

12 Clay J, A Profile of Independent Living Services for American Indians with Disabilities Living on Reservations, University of Montana Rural Institute, Missoula, MT, 1992.

Unique Legal, Environmental, and Economic Factors Affecting Provision of and Access to Appropriate Services for People with Disabilities in Indian Country

Compared with other U.S. citizens, American Indians and Alaska Natives living in Indian Country have a unique legal status that affects the protections and services available to people with disabilities living on these lands. The definition of Indian Country is derived from 18 U.S.C. Subsection 1151. Although Subsection 1151 is in the criminal code, this section has been applied in civil cases as well. Subsection 1151 provides that “Indian Country” means

(a) all land within the limits of any Indian reservation under the jurisdiction of the United States Government, notwithstanding the issuance of any patent, and, including rights-of-way running through the reservation, (b) all dependent Indian communities within the borders of the United States whether within the original or subsequently acquired territory thereof, and whether within or without the limits of a state, and (c) all Indian allotments, the Indian titles to which have not been extinguished, including rights-of-way running through the same.\(^\text{14}\)

Indian Country, in both civil and criminal matters, is subject to the jurisdiction of tribal governments.\(^\text{15}\)

In addition to the unique legal status of AI/AN residents, Indian Country is disproportionately rural or frontier. This poses a number of logistical and resource challenges to provision of and access to social, health, and support services. Historically, American Indians and Alaska Natives tend to have less education, less employment, and lower incomes than other people in the United States and, thus, tend to have fewer resources to address the needs of people with disabilities.

Environmental Factors

Most of Indian Country is located in rural and frontier areas in the United States, and American Indians and Alaska Natives are more likely than any other racial group to reside in


\(^{15}\) See, e.g., DeCoteau v. District County Court, 420 U.S. 425 (1975).
nonmetropolitan areas. While the challenges of providing services to people with disabilities in rural/frontier areas are not unique to American Indians and Alaska Natives, the substantial majority of people with disabilities in Indian Country are located in rural/frontier areas. People living in rural areas generally experience barriers to accessing health care and other social services; people with disabilities in rural areas face even greater barriers in obtaining the complex medical and related services that they require.

Barriers to health care access and other services in rural areas include lack of resources, long travel distances, and lack of transportation. In addition, people from diverse cultures in rural areas often experience cultural and language barriers to obtaining appropriate health care. They seldom encounter health care and other service providers of the same cultural backgrounds or who have been educated to provide services in a culturally appropriate manner.

NCD has identified a number of challenges in obtaining necessary services faced by people with disabilities from diverse cultures and by people with disabilities in rural areas, including lack of resources and lack of education and training on policy, cultural issues, services, and attitudes. Thus, American Indians and Alaska Natives with disabilities residing in rural Indian Country are dually challenged in their efforts to obtain appropriate services and support.

**Economic Factors**

American Indians and Alaska Natives, particularly those living in Indian Country, face significant economic challenges. National data shows that in 1990, 78 percent of Whites had

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completed high school and 22 percent had completed a college degree; AI/AN rates compared at 65 percent and 9 percent, respectively.\textsuperscript{20} Lower educational levels are associated with reduced income potential, and AI/AN household and family income levels in 1989 were approximately 60 percent of White household and family income.

People who live in Indian Country are more likely than all American Indians and Alaska Natives to be very poor and unemployed. BIA data indicates that in 1999, approximately 50 percent of American Indians and Alaska Natives who were members of a federally recognized tribe living on tribal lands were either unemployed or employed with household incomes below the federal poverty levels.\textsuperscript{21}

Poverty, unemployment, low levels of education, inadequate housing and sanitation, and inadequate funding for federal health and other programs responsible for providing services to American Indians and Alaska Natives in Indian Country are all current problems in Indian Country. These problems contribute to the poor health status of American Indians and Alaska Natives. These problems also contribute to a lack of services to meet health care and social service needs of all people residing in Indian Country, particularly those people with disabilities.

**Understanding Government-to-Government Relationships**

Despite representing a small percentage of the total U.S. population, American Indians and Alaska Natives enjoy a unique legal, historical, and political relationship with the Federal Government. As indigenous peoples, Indian tribes engaged in government-to-government relationships with other sovereign countries before the United States was established.\textsuperscript{22} At its formation, the United States recognized the unique relationship with Indian tribes, and this


\textsuperscript{22} See, e.g., *Montoya v. United States*, 180 U.S. 261 (1901).
recognition continues today. The Federal Government recognizes tribes as “domestic dependant nations.”

To further this government-to-government relationship, in 2000, the Federal Government announced a policy of consultation with tribal governments in Executive Order #13175. The Executive Order requires meaningful consultation with tribal officials on any regulatory policies that have tribal implications. Federal agencies are required to consult with tribes during the development of new policies. When possible, federal agencies must grant tribes the maximum administrative discretion possible. Agencies are required to consult with tribes when developing federal standards. They must also encourage tribes to formulate and implement their own policies and establish standards. This Executive Order was reconfirmed recently by the Honorable Alberto R. Gonzales, Counsel to the President, in a letter to Congressman Frank Pallone dated June 25, 2002. Subsequently, Congressman Frank Pallone issued a letter to advocates of Indian Country quoting Mr. Gonzales and stating his own commitment to Executive Order #13175.

**Legal Factors**

Individuals with disabilities living in Indian Country face a complex legal environment. Long recognized as distinct political entities, Indian tribes enjoy the “inherent powers of a limited sovereignty which has never been extinguished.” Indian tribes are protected from private

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23 *Cherokee Nation v. Georgia*, 33 U.S. 1, 33 (1831).

24 Executive Order #13175 of November 6, 2000.


lawsuits under the doctrine of sovereign immunity. As a result of tribal sovereign immunity to suit, not all federal regulations that apply in Indian Country are enforceable by private parties against tribes.

A tribe is subject to suit by a private party under these laws only when the tribe has expressly waived its sovereign immunity. Thus, individuals with disabilities concerned about their rights and protections guaranteed under the Rehabilitation Act or ADA may face unique barriers when seeking enforcement by a tribal government. Recent decisions in the Eleventh Circuit suggest that while tribes are not specifically excluded from the provisions/requirements and protections of the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1992, enforcement may be limited.

Title I of the Americans with Disabilities Act and Tribes

In passing ADA, Congress announced the purpose as providing “a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities.” Title I of ADA requires that employers with 15 or more employees provide qualified individuals who have a disability with an equal opportunity to benefit from the full range of employment benefits available to others. Title I also restricts discrimination in hiring, promotions, pay, and other privileges of employment. Employers must make reasonable accommodation for the known physical or mental disability of otherwise qualified individuals with disabilities, unless it results

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29 See, e.g., Kiowa Tribe of Oklahoma v. Manufacturing Technologies Inc., 523 U.S. 749 (1998) (holding that, with regard to suits brought by private parties against Indian tribes, “s a matter of federal law, a tribe is subject to suit only where Congress has authorized the suit or the tribe has waived its immunity”).


31 Americans with Disabilities Act, 42 U.S.C. §§ 12101 et seq.

32 See Florida Paraplegic Association, Inc. v. Miccosukee Tribe of Indians of Florida, 166 F.3d 1126 (11th Cir. 1999); Sanderlin v. Seminole Tribe, 243 F.3d 1282 (11th Cir. 2001).

33 42 U.S.C. § 12101(b)(1).
in an undue hardship. While Title I categorically excludes tribal governments as employers under this title, ADA does not exclude qualifying private employers operating in Indian Country.34

Title II of the Americans with Disabilities Act
ADA did not include an explicit exemption for tribal governments under Title II as it did in Title I. On June 22, 1999, the Supreme Court decided a landmark ruling interpreting Title II. In *Olmstead v. L.C.*, the Supreme Court held that Title II of ADA requires states to provide community-based treatment for persons with mental disabilities when the state's treatment professionals determine that such placement is appropriate, the affected persons do not oppose such treatment, and the placement can be reasonably accommodated.35 When considering whether the placement can be reasonably accommodated, it is necessary to consider the resources available to the state and the needs of others with mental disabilities. The practical application of this ruling is that states must help to provide the least restrictive level of care for people with disabilities, moving away from institutionalization and toward home- and community-based care. This ruling could present new opportunities for tribal governments to develop home- and community-based services that are reimbursed by Medicaid or other sources.

Title III of the Americans with Disabilities Act and Tribes
Title III of ADA prohibits discrimination in public accommodations. A case involving public accommodations for people with disabilities at a tribal facility provides some insight. On the basis of Congress' intent to end discrimination and the statute's broad language, the Eleventh Circuit has ruled that Title III of ADA does apply to tribes.36

However, a federal court finding that a statute is applicable to a tribe is not the same as finding a waiver of tribal sovereign immunity.37 While Title III of ADA may apply to tribes, the Eleventh


36 *Florida Paraplegic Association, Inc. v. Miccosukee Tribe of Indians of Florida*, 166 F.3d 1126 (11th Cir. 1999).

Circuit found that the sovereign immunity of tribal governments prohibits private suits for enforcement against tribes in federal courts. In such cases, individuals with disabilities may have a right without a remedy.

Title III does provide for suits brought for enforcement by the U.S. Department of Justice. While this possibility exists, no such action has been brought by the Department of Justice to date. It is also important to note that this ruling of the Eleventh Circuit was not taken to the U.S. Supreme Court.

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

Section 121 of the Rehabilitation Act authorizes RSA to make grants to tribes for the purpose of vocational rehabilitation (VR) services. Tribes accepting these grants, and generally other federal funds, agree to comply with federal law. However, this agreement may not amount to a waiver of sovereign immunity, which protects tribes from suit in federal court.

The Individuals with Disabilities Education Act and Tribes
The purpose of the Individuals with Disabilities Education Act (IDEA) is to ensure that every child has available a free, appropriate public education that meets individual needs. IDEA intends to improve the educational results of children with disabilities. To reach this goal, IDEA requires (1) an Individualized Family Service Plan (IFSP) for infants and toddlers with developmental delays, and (2) an Individualized Education Program (IEP), developed by the

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38 Ibid.


IFSP or IEP team, which includes parents and others as decisionmakers, for each eligible child of school age with a disability.

To assist in meeting needs of children and families in Indian Country and in Department of the Interior-funded schools, IDEA provides a set-aside or percentage of funds from the U.S. Secretary of Education to the Secretary of the Department of the Interior. IDEA funds for infants and toddlers (ages 0–3) are provided directly to tribes by the Department of the Interior. Until the late 1990s, the tribes were not contacted directly by the Department of Education and asked to account for how needs were met for children with disabilities and their families. While IDEA calls for states to provide services to all children of preschool age eligible under IDEA, many children ages 3 to 5 in Indian Country face difficulty in receiving any support from state agencies. Thus, many children often fall through the cracks until they are five years old and can be served by either public or BIA-funded schools.

IDEA provides that the Secretary of the Department of the Interior receive funds from the Secretary of Education to educate children ages 5 to 21 with disabilities on reservations in elementary and secondary schools operated and funded by the Secretary of the Interior. The IDEA also provides an administrative enforcement process that the BIA-funded schools are subject to, based upon their status as a local educational agency. However, IDEA does not waive tribal sovereign immunity because the federal law does not contain the explicit, unequivocal waiver that is necessary. While the U.S. Department of Education has the authority to withhold federal funding when the BIA-funded schools have been out of compliance in meeting children’s needs and in protecting families under IDEA, as well as in failing to improve physical accessibility of BIA facilities, this sanction has not been applied. The investigation for this NCD project revealed concern at the local level regarding adequate federal funding to ensure the BIA’s ability to meet its mandates under IDEA. Advocacy by parents and other groups is critical to protect the rights of Indian children with disabilities, whether in BIA-funded or public schools.


Advocacy Options

The outcomes above may suggest that along with states where tribal lands are located, some tribal governments are failing to meet their responsibility to individuals with disabilities. For many tribes, current funds may be inadequate to address all of the needs of people with disabilities, including improving accessibility in Indian Country. Although, entangled in this complex legal environment, individuals with disabilities living in Indian Country have potential options. A tribe could waive its sovereign immunity to allow suits brought under ADA in federal courts. A more likely scenario might be an increase in the number of tribal governments passing ordinances providing protections similar to those in federal statutes, such as ADA or the Rehabilitation Act. A tribe could thus provide a legal remedy within the existing tribal legal system through a limited waiver of sovereign immunity. Tribal governments have the inherent authority to pass laws, develop programs, and ensure protection and accessibility for people with disabilities under their jurisdiction. A recent survey conducted by the American Disability Legislation Project found that “schools, stores, churches, Bureau of Indian Affairs and other federal buildings, and tribal courts and jail facilities were accessible about two-thirds of the time” (p. 2). Other major tribal facilities, such as health centers and senior citizen buildings, were found to be accessible about 75 percent of the time. Similarly, most major services for people with disabilities were accessible about 71 percent of the time. However, this report also notes that only 13 percent of tribes had a line item in their budget for disability issues. The political power of people with disabilities, their families, and advocates could help to move tribal governments toward adopting such ordinances.

The doctrine of tribal sovereign immunity from suit in federal court does not necessarily support the proposition that the requirements of ADA are inapplicable to tribal governments in all circumstances. In drafting ADA, Congress makes it clear that the act is a “national mandate” to end discrimination. Furthermore, the Act and other comparable legislation suggest that Indian tribes should be the recipients of grants to ensure compliance. If tribes are to meet these federal requirements, increased funds are necessary. Currently, a policy paradox exists in which AI/AN

people with disabilities, caught between the doctrine of tribal sovereign immunity and a national policy to end discrimination, suffer the consequences.

Despite the legal challenges for enforcement of ADA and related legislation in Indian Country, American Indians and Alaska-Natives have a unique relationship with the Federal Government that promises federally provided health, education, and social services. To uphold this promise, the Federal Government could provide appropriate services and support for people with disabilities in Indian Country. Pursuant to trust responsibility of the Federal Government to Indian tribes, federal agencies are responsible for carrying out these guarantees. However, funding for these programs has been inadequate to effectively address the needs of people with disabilities in Indian Country.

In addition, the complex and conflicting structure of federal responsibilities for services provided to American Indians and Alaska Natives results in jurisdictional conflicts, both intra-agency and inter-agency. Such conflicts may lead to a lack of accountability and inadequate or no services provided to people with disabilities in Indian Country. For example, 10 years ago a National Indian Justice Center report suggested that the Department of Education assign to BIA exclusive responsibility for Indian children on reservations that have BIA schools. However, in light of the fact that the overwhelming majority of AI/AN children are educated in public schools, BIA believed it was responsible only for those children enrolled in its programs.44 The authors of the report also note that multiple organizations with roles in developing and delivering services to American Indians and Alaska Natives with disabilities have led to “interagency competition and conflict, jurisdictional confusion, and ‘passing the buck’.45


Barriers to Provision of and Access to Appropriate Services for People with Disabilities in Indian Country

“People have ideas about disabilities but they don’t know what it’s like. They might want to hold you back. I still have all the mechanical knowledge from running heavy equipment but just because I can’t do that anymore, I can still do things like change the transmission on my car by myself.”

—Joseph Garcia, Prairie Band of Potawatomi

General Barriers

In this section, general barriers common to people from diverse cultures and rural people with disabilities are discussed. Then specific barriers that are unique to people with disabilities in Indian Country are described.

While all people with disabilities may face a myriad of challenges in obtaining appropriate services to enable them to function effectively and productively, people who are members of diverse racial and ethnic populations and people with disabilities in rural areas may encounter even greater barriers to necessary supportive services and accommodation than do other people with disabilities. Recognizing the significant difficulties that may face people from diverse cultures who have disabilities and their unique needs, NCD developed a key initiative to address these needs.46

NCD has continued from 1993 to the present to focus attention on the need for special efforts to ensure that people with disabilities from diverse cultures are able to obtain necessary appropriate services and support. In the 1997 Roundtable Report of Findings, NCD noted that “there was consensus that the needs of [people] with disabilities and from [diverse cultures] and people with disabilities living in rural communities warrant ongoing corrective attention in all aspects of the fabric of American public policy” (NCD Roundtable Report, p. 2). In 1999, NCD summarized

findings and recommendations for addressing barriers to access to services and support for people with disabilities from diverse cultures and their families.\textsuperscript{47}

General barriers to access to necessary and appropriate services identified through the NCD meetings on consumers and advocates included:

- Persistent lack of access to appropriate job training and employment opportunities
- Persistent lack of childcare and afterschool programs
- Greater difficulty gaining access to public accommodations (e.g., markets, restaurants) due to lesser compliance with ADA access mandates
- Greater difficulty gaining access to public transportation and greater unwillingness of public transportation personnel to accommodate people with disabilities who are also from diverse cultures
- Lack of culturally competent and culturally appropriate service delivery, including:
  - Lack of people from diverse cultures in the disability service professions, particularly in rural areas
  - Inadequate culturally appropriate outreach to ensure that people are aware of services and resources that are available to them
  - Lack of bilingual speakers, interpreters, and language-appropriate communications materials

The digital divide or limited information technology infrastructure in rural areas poses another barrier to independent living for American Indians and Alaska Natives with disabilities. For

instance, approximately 24 percent of AI/AN households do not have telephones. Less than 30 percent of AI/AN households are equipped with a computer and less than 20 percent have Internet access. In addition to these general barriers to access that are encountered by people with disabilities from diverse cultures, people in rural areas with disabilities also face additional barriers, including long distances to obtain services, lack of transportation and appropriate accommodation to travel to services, greater difficulty obtaining assistive technology or specialized equipment due to lack of commercial establishments with sufficient market demand, and lesser awareness of and/or lack of resources to provide accommodation to facilitate access to services in rural areas.

People with disabilities in Indian Country encounter these general barriers in common with other people from diverse cultures and rural people with disabilities. Since many tribal lands are in remote rural and frontier areas, the barriers that tribal members face may be more extreme on average than those faced by rural people with disabilities generally. Similarly, because the AI/AN population in Indian Country is less than 0.5 percent of the U.S. population, the lack of AI/AN disability service providers is likely to be more severe than for other culturally diverse populations. In addition, for people in Indian Country who speak a native language, appropriate interpreters and language-appropriate communications materials are even less likely to be available.

Over and above these general barriers to access to services, people with disabilities in Indian Country also face a number of additional uniquely difficult and challenging barriers.

**Unique Barriers**

People with disabilities in Indian Country reside in areas that pose special issues for obtaining access to services and accommodation to facilitate their full participation in society. These unique aspects of tribal lands include the following:

- Legislation mandating rights for people with disabilities is not automatically enforceable in Indian Country.

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• Tribal leaders and communities lack awareness and adequate knowledge of programs to meet the needs of people with disabilities in Indian Country.

• A number of federal agencies have interrelated and conflicting responsibilities for provision of health, education, and social services in Indian Country that result in failure and lack of accountability to meet the needs of people with disabilities.

• Chronic underfunding of federal programs serving people in Indian Country results in inadequate and rationed services that do not meet the needs of all people in Indian Country, including those of people with disabilities.

• Indian Country, for the most part, is composed of small, isolated populations with limited resources and capabilities to develop and implement programs and accommodations for people with disabilities.

• Tribes are distinct groups, with different cultures, languages, and resources, and would likely require unique approaches to inform and facilitate changes to meet the needs of people with disabilities in Indian Country.

Disability Legislation in Indian Country

People with disabilities living in Indian Country may not be afforded the benefits and protections of ADA and other legislation affecting rights and services. Because of the unique relationship between tribal governments and the U.S. government, legislation that does not specifically address Indian tribes is generally assumed not to apply to tribal areas. For ADA (and other similar legislation) to apply to tribal lands, the Federal Government likely would need to conduct separate negotiations with each of the more than 500 federally recognized tribes.49 A recent decision in the Eleventh Circuit Court suggests that while tribes are not specifically excluded, there is limited enforcement for ADA compliance. Like federal and state governments, tribes enjoy sovereign immunity from being sued unless the tribe allows for suit or Congress explicitly

provides for suits. Thus, enforcement of ADA in Indian Country would require that the Federal Government bring suit against the tribes or that Congress take explicit action to include tribes within the scope of ADA.

In the absence of legislative action or conduct of separate negotiations between the Federal Government and tribal governments, individuals with disabilities in Indian Country are limited to negotiation and political efforts to persuade tribal governments to adopt policies to ensure rights and provide accommodations.

A 1995 survey conducted by the American Disability Legislation Project found that at least one tribe has chosen to adopt ADA as a whole through tribal resolution and is now sorting out what this means for its members. In addition, AIDLP reported that several tribes had passed resolutions that deal with employment of people with disabilities, one tribe had created an Office of Special Education to ensure that tribal children with disabilities would have their educational needs met, and other tribes had taken steps to begin addressing issues for meeting the needs of people with disabilities. At the same time, the AIDLP survey revealed that only 13 percent of responding tribes had at least one line item in their budget related to disability services; however, the average amount per tribe for these line items was very small (e.g., an average amount of $5,033 for staff training on disability issues and $12,500 for employment services for people with disabilities).

Lack of Awareness/Adequate Knowledge
The AIDLP survey of American Indian tribes indicated that only 37 percent of respondents reported that their tribe was familiar with ADA, the relevant sections of the Rehabilitation Act, or IDEA. Only 6 percent indicated that their tribal governments were very familiar with major disability legislation. None of the Alaska Native respondents stated that their tribal governments were very familiar with major disability legislation. Of American Indian respondents, 74 percent said that they believed that their tribal government would be interested in participating as a focus group for establishing disability legislation within their tribe (NCD Roundtable Report, p. 23).\textsuperscript{50}

\textsuperscript{50} Ibid.
Most respondents to the survey indicated that it was very important that tribal members with disabilities be treated with respect.

**Complex and Interrelated Federal Agency Responsibilities**

A wide variety of federal agencies have some level of responsibility for providing services for people with disabilities in Indian Country. However, it has never been clearly delineated which agencies are specifically accountable for providing specific services. As a result, many services may be provided on a piecemeal basis or not at all, even when there are clear federal responsibilities under law and treaty agreements. The U.S. Department of Health and Human Services’ (HHS) IHS, the U.S. Department of the Interior’s BIA, and the U.S. Department of Education’s Office of Special Education Programs and RSA all have some role in developing and delivering services to AI/AN people with disabilities in Indian Country. However, a 1991 report states, “There are disagreements about who is primarily responsible for providing services to Indian children with disabilities.”51 The authors go on to note that “jurisdictional confusion and ‘passing the buck’... have impeded delivery of services to people with disabilities. This lack of coordination needs to be remedied at federal and state levels to ensure efficient delivery of services....”52 This same study notes that American Indian children received special education from a variety of sources including BIA, Head Start, IHS, and local public school districts. However, less than 30 percent of those in need of special education services received some services and, of those, about one quarter received fewer services than prescribed by their IEP.

**Inadequate Funding of Federal Agencies with Responsibilities for Providing Services to People with Disabilities on Tribal Lands**

Members of federally recognized tribes have access to health services through the federal IHS that provides services to all eligible tribal members. Similarly, BIA is responsible for providing a variety of services that address the needs of people with disabilities (e.g., education and services to school-age children with disabilities). However, chronic underfunding of AI/AN programs by the Federal Government has severely lessened the ability of these federal agencies to meet the needs of the AI/AN population.


52 Ibid., p. 19.
**Funding of Education Programs.** Funding for special education programs for AI/AN children with disabilities is provided from a variety of sources from the U.S. Department of the Interior’s BIA, U.S. Department of Education, and state education departments, depending on the type of school attended. Ninety percent of AI/AN children attend publicly funded schools and 10 percent attend BIA-funded schools, which are run by BIA, contractors, or tribes.

Responsibilities for providing special education and related services to AI/AN children ages 5 to 21 with disabilities reside with the school district in which they are enrolled. Since 90 percent of AI/AN children attend public schools, state and local governments are responsible for funding special education and related services for the vast majority of Indian children with disabilities. All BIA-funded schools that use IDEA allocations from the U.S. Department of Education, whether managed by BIA or tribes, are responsible for carrying out the IDEA requirements by providing special education and related services to eligible children with disabilities who may be among the remaining 10 percent of AI/AN children who attend BIA-funded schools. BIA reports that school administrators believe that funding for staff is still a factor that presents a challenge to fully meeting the requirements.53

**Funding for Health Programs.** IHS estimates that the funding it receives to care for eligible AI/AN people is only about 50 percent of actual need. On a per capita basis, IHS funding has declined by nearly 20 percent since 1987.54 Total U.S. per capita spending for health care was $3,619 in 1998, compared with IHS funding of $1,186 per capita for American Indians who live on or near reservations and use IHS facilities. Total estimated per capita expenditures, paid through all sources of financing including out-of-pocket costs, for the American Indian population were about 58 percent of average U.S. per capita expenditures. For people who reside in Indian Country, however, it is likely that IHS-funded health services constitute the primary or only source of health care available. IHS reports that authorization for referrals to contract health

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services (i.e., services purchased outside the IHS because the needed services are not available directly from IHS) is currently limited to “emergent, saving of life and limb” due to limited funding. 55

IHS direct service or tribally managed health programs may augment financial resources through Medicaid, Medicare, or State Children’s Health Insurance Program reimbursement for services provided to patients who are enrolled in these programs. However, there are many barriers to enrollment in these programs and not all IHS or tribally managed health programs have the information system capabilities or third-party reimbursement experience to effectively obtain the reimbursements that they may be eligible to receive.

While health care is only one component of the services and support needed by people with disabilities living in Indian Country, the relative poor health status and the underfunding of the IHS reflects the general lack of financial resources directed by the Federal Government to meet health, education, vocational rehabilitation, independent living, and other service needs of all people living in Indian Country. People who have disabilities and need appropriate services to permit them to participate fully in society face grave barriers to obtaining these services and support in an environment where the available resources are vastly inadequate to meet basic needs of all tribal members.

_Funding for Vocational Rehabilitation, Independent Living, and Assistive Technology Services._ Federal funding for VR and independent living services is stipulated in the provisions of the Rehabilitation Act of 1973 as amended. Title I, Part C, Section 121 of the Rehabilitation Act establishes competitive grants for the provision of VR services to American Indians with disabilities. Indian tribes located on federal and state reservations are eligible to compete and receive grants under the American Indian Vocational Rehabilitation Services (AIVRS) program. Programs approved under Section 121 may be funded for a period of five years and must provide services that are comparable to those provided by state VR programs. The federal share of costs is equal to 90 percent of the costs of VR services; the remaining 10 percent, or the nonfederal

55 Indian Health Service, _Indian Health Care Services and Eligibility Information_, Rockville, MD (42 CFR 136.23).
share (which may be waived), may be rendered in cash or in kind. The 1998 amendments to the Rehabilitation Act set a reserve for programs funded through Section 121 at an amount greater than 1 percent and no more than 1.5 percent of federal appropriations for state VR grants. Currently, among the more than 560 federally recognized tribes, a limited number of 121 grants have been made available. Only 69 programs are in operation and among this small number, two receive no federal funds for their programs, but the tribes still work to meet needs of people with disabilities. The tribes funding their own programs are Sycuan (which is a consortia) in California and the Eastern Band of Cherokee in Cherokee, North Carolina. 56

Independent living services and centers are funded through Title VII of the Rehabilitation Act. Title VII provides funds that states may use to provide independent living services, develop and maintain state independent living centers, and improve working relations between independent living programs, ILCs, state independent living councils, vocational rehabilitation, supported employment, and other federal and nonfederal programs established or supported through the Rehabilitation Act. Funds to provide independent living services are available through a grant mechanism. Tribal governments may apply to receive a Title VII grant; however, according to Lansing and Yazzie-King, 57 the success of tribal governments in obtaining funding for independent living services through this mechanism may be limited because “tribes must compete for these grants with the majority society, where greater knowledge of the independent living philosophy, the independent living movement, and federal requirements is already in place.” Currently, only one ILC grant has provided a place for service on tribal land anywhere in the United States. Grants are administered through the U.S. Department of Education’s RSA.

The Assistive Technology Act of 1998 provides funds through state assistive technology (AT) programs. There are 56 such federally funded programs, including one in every state,

56 Personal correspondence with Carleen Anderson, Region X: Rehabilitation Services, January 10, 2003.

commonwealth, and territory of the United States.\textsuperscript{58} Funds may be used, in part, to improve access to assistive technology, to increase consumer awareness of technology, and to develop alternative financing mechanisms, such as loan programs, for consumers to purchase assistive technology. Information on the extent to which these state programs meet the AT needs of American Indians with disabilities is unknown.

IHS provides access to only a relatively narrow set of AT devices (e.g., hearing aids, eyeglasses). Funding for assistive technology necessary for independent living must generally be obtained from various other sources. Assistive technology may be covered under Medicare, if the required services fall within the Centers for Medicare and Medicaid (CMS) definition of “durable medical equipment” or by Medicaid if services are deemed to be “medically necessary” and are covered under the different states’ Medicaid plans or their waiver programs. An eligible child with a disability may have access to assistive technology (e.g., computer equipment, listening devices, and communication equipment) to meet needs identified by the IEP team to provide a free appropriate public education under the IDEA educational activities and support his/her opportunities for educational attainment through IDEA. State VR agencies and specifically the AIVRS programs may provide technological equipment including sensory and telecommunications devices; however, data from an evaluation of the AIVRS\textsuperscript{59} suggests that the rehabilitation technology services available through these programs may be limited.\textsuperscript{60} The effectiveness of these programs in assisting American Indians with disabilities to access assistive devices is not known but, based on lack of access to electricity, telephones, and cable, for

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\textsuperscript{60} Of the 54 AIVRS programs included in this evaluation, only seven indicated that they provided rehabilitation technology services to “some” or “most” of their consumers.
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example, in remote/rural areas, it is widely believed that American Indians residing in Indian Country face significant barriers to accessing assistive technology.\footnote{National Council on Disability, “Federal Policy Barriers to Assistive Technology,” May 31, 2000.}

\textit{Limited Tribal Resources to Meet the Needs of People with Disabilities on Tribal lands}  
American Indians and Alaska Natives are among the most impoverished population groups in the United States. This is particularly the case for American Indians and Alaska Natives who live in Indian Country. Most tribal lands have small populations, with high levels of poverty and unemployment. In 1990, for instance, the second largest Indian reservation had a population of less than 12,000 and only 18 reservations had populations of over 5,000.\footnote{Snipp C, “Selected Demographic Characteristics of Indians,” in \textit{American Indian Health: Innovations in Health Care, Promotion, and Policy} (ed. by Rhoades E), The Johns Hopkins University Press, Baltimore, MD, 2000.} The limited population size seldom is sufficient to generate revenues for tribes that would enable them to directly fund any significant level of services to meet the needs of people with disabilities. Services are generally dependent upon a tribe’s ability to develop programs through federal or state funding.

\textit{Diversity Among AI/AN Populations}  
There are over 560 separate federally recognized tribes and each has its own culture, history, health beliefs, and practices. There is also a diversity of languages among the AI/AN population; linguists recognize at least 62 language families among those spoken by American Indians.\footnote{Demalle R and Rhoades E, “The Aboriginal People of America,” in \textit{American Indian Health: Innovations in Health Care, Promotion, and Policy} (ed. by Rhoades E), The Johns Hopkins University Press, Baltimore, MD, 2000.} Community attitudes and cultural beliefs about the causes of disabilities and perceptions differ substantially among tribes, with consequent differences in beliefs about appropriate responses and support that should be offered to people with disabilities.\footnote{National Indian Justice Center, \textit{op cit.}, p. 14.} As a result, designing and implementing culturally competent and culturally appropriate outreach programs and training disability services professionals to offer culturally competent services is not a simple task. There is not a generic approach that can be adopted and used across all tribal lands to address the needs...
of people with disabilities. Programs must be tailored to the specific tribal population through significant input from tribal members. The Tribal Disability Actualization Process illustrates the tailoring of a one-to-one approach that is important when addressing disability policy and services issues with individual tribes. It involves bringing together a wide range of concerned tribal members, using a "self-directed" approach for tribes to develop disability legislation that respects tribal culture and sovereignty. While the model developed by the Tribal Disability Actualization Process is a uniform one, it requires extensive work with individual tribes and community members to produce change in attitudes and effect change in policy. This process is described in more detail below. With over 500 tribes in the United States, implementation of this process across all tribes would require significant resources and time to accomplish substantial change on behalf of people with disabilities in Indian Country.

Assessing the Effectiveness of Strategies for Reducing Barriers to Provision of and Access to Appropriate Services

Although strategies to advance the independent living and self-determination realities of American Indians with disabilities have been initiated, the review of the literature indicates that the effectiveness of most efforts has not been empirically tested. The few studies that report an evaluation component are methodologically weak; small sample sizes and the use of subgroups that are not representative of Indian Country as a whole are among the factors that limit the ability to generalize findings from these studies to the larger population of American Indians and Alaska Natives with disabilities. Evidence on the extent to which initiatives have succeeded in removing barriers to education, health, vocational rehabilitation, and independent living among American Indians residing in Indian Country is primarily anecdotal, with limited information on trends or analyses of patterns across the data that might suggest similarity across findings.

Tribal Disability Actualization Process

Project staff at the University of Montana Rural Institute on Disability AIDTAC designed and evaluated a model to assist tribes in developing disability policy that reflects the tribe's culture

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and values. This model is composed of four primary steps that are designed to increase tribal members' awareness of unmet independent living needs and enhance their understanding of the adequacy or appropriateness of existing tribal disability policies. In the first step of this process, a tribal member willing to advocate and assist in educating the community on disability issues is identified. In the second step, the authorization of the tribal government and support for the actualization process is obtained; typically, this is done through an educational presentation to tribal leaders. Step three consists of focus groups or “talking circles” in which tribal members (as well as invited state and local disability providers) discuss beliefs concerning disability, unmet needs, sovereignty issues, and approaches for establishing disability policy. In the final step in the process, focus group members present to their tribal governments a set of approaches for meeting the needs of people with disabilities through tribal legislation.

A qualitative evaluation of the impact of the Tribal Disability Actualization Process indicates that tribes that participated in this process have in fact engaged in a variety of activities that have resulted in an increased awareness of disability issues within their communities and address barriers to independence within the reservation. Among the outcomes attributed to the Tribal Disability Actualization model are the following: the Oglala Lakota Sioux Tribes in the Pine Ridge Reservation in South Dakota adopted ADA in 1994; in addition to making enhancements to ensure the accessibility of public buildings, tribes located in the Flathead Reservation of Montana adopted a resolution that conformed to the spirit of ADA and made modifications to policies to address hiring and training of people with disabilities; and the Navajo Reservation in the Northeast Arizona and Colorado Plateau initiated activities to arrange for personal assistance training for tribal members.66

Education

A number of strategies have been developed and implemented to increase the availability and effective use of special education and related services for AI/AN children with disabilities. Several IDEA grants have been awarded to train special education teachers to work with AI/AN students. These include the Reaching American Indian Special/Elementary Educators (RAISE) project at Northern Arizona University and two relevant projects at Pennsylvania State University. The RAISE project provides opportunities for students to work directly with Navajo children in local communities and schools and offers experience with culture, language, and traditions. The Pennsylvania State University program provides training in special education and educational administration to AI/AN students and offers them opportunities to conduct research on improving education of AI/AN students with disabilities. Graduates of the program work in special education in AI/AN communities for two years for each year of funding they receive. In addition, the American Indian Higher Education Consortium reports that 34 tribal colleges operate in the United States. BIA reports that 27 tribal colleges receive BIA funding. Some tribal colleges receive grants to train special education personnel at all levels.

Programs are also available to provide education, support, and assistance to parents of AI/AN children with disabilities regarding rights and effective strategies to obtain services for their children. Currently, 106 Parent Training and Information Centers and Community Parent Resource Centers, funded by the U.S. Department of Education, are located throughout the United States. Technical assistance to the centers is provided by the Technical Assistance Alliance for Parent Centers. These centers provide training and information to parents of infants, toddlers, and school-aged children and young adults with disabilities, as well as the professionals who work with families. The assistance provided to parents helps them participate more effectively with school personnel and other professionals to meet the educational needs of children and youth with disabilities. At least two of these centers specialize in assisting AI/AN

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families who have a child with a disability. The National Native American Families Together Parent Center (NNAFT), located in Moscow, Idaho, is directed and staffed by members of tribal communities. NNAFT provides information on the educational rights of children with special needs; communicating with school and medical personnel and other professionals; how to participate in developing and monitoring a child’s educational plan; and disability-specific data on sensory, mental, emotional, or specific learning disabilities. The centers recruit and train community members to provide support and assistance to families of AI/AN children with disabilities.69 The Native American Family Empowerment Center, located in Lac du Flambeau, Wisconsin, is a program of the Great Lakes Intertribal Council. This program seeks to ensure access to services for tribal families with children who have a disability, and other impairments as determined under IDEA. This program works to empower AI/AN families with knowledge to work with schools and state and local health and human services agencies.70 These are two examples of programs with a special emphasis on AI/AN populations. However, it is important to point out that all of the federally funded parent centers across the country are charged to serve all families whose children have disabilities, including families in ethnically diverse populations.71

With regard to testing methods, Faircloth and Tippeconnic (2000) cite examples of school districts that have developed culturally and linguistically appropriate testing methods to distinguish AI/AN children with learning disabilities from those with cultural/linguistic barriers to learning to ensure that referrals for special education and related services are appropriate.

Although a variety of approaches have been designed and implemented to improve services to AI/AN children with disabilities, little data exists providing evidence of the impact of these


strategies on educational outcomes. In addition, since most educational services for AI/AN children with disabilities are provided through state programs (rather than on reservations through BIA-funded and tribally managed programs), the major barriers to appropriate educational services are similar for both AI/AN and non-AI/AN children with disabilities. However, cultural and language differences may create additional barriers for the effectiveness of mainstream services that are provided to AI/AN children.

Vocational Rehabilitation
Available evidence suggests that American Indians with disabilities who complete a program of vocational rehabilitation are likely to experience employment outcomes superior to American Indians who are not rehabilitated. A study that analyzed the employment status of 21 American Indians who participated in VR programs and 40 American Indians who participated in job training programs found that 85 percent of those who completed their VR program were employed following rehabilitation, compared with only 25 percent employment among American Indians, living on and off reservations, who were not rehabilitated. Similarly, 63 percent of American Indians who successfully completed a job training program or were "positively terminated"—meaning they were employed 13 months following the job training program—were employed, compared with only 8 percent employment among the population with training.72

The 64 projects that were supported through the AIVRS program in 2001 served approximately 4,500 persons.73 Estimates suggest that of the consumers served by these AIVRS projects, over 28 percent had a substance abuse problem, 22 percent had an orthopedic disability, 17 percent had a mental or emotional disability, and 15 percent had a learning disability. Interestingly, in interviews with project staff conducted as part of an evaluation of the AIVRS program,

72 Gahungu A and Sherman JM, An Examination of the Relationship Between Consumer Satisfaction and Employment Outcomes for Rehabilitated and Non-Rehabilitated American Indians, American Indian Rehabilitation Research and Training Center, July 18, 2000.

respondents indicated that American Indians/Alaska Natives with physical disabilities were most likely to be in need of but not receive AIVRS services.\textsuperscript{74}

Although estimates were not independently validated, data reported to RSA by tribal VR agencies indicates that nearly 65 percent of American Indians who exited the AIVRS program in 2001 achieved an employment outcome.\textsuperscript{75} In their evaluation of the AIVRS program, which was conducted under contract to RSA, Hopstock et al. noted that in fiscal years 1998 and 1999, only 53 percent of AI/AN consumers who exited state VR programs achieved successful employment outcomes.\textsuperscript{76} During fiscal year 2000, 963 American Indians with disabilities were successfully rehabilitated under AIVRS programs. In addition to the successful rehabilitation, tribal VR programs served 4,178 AI/AN consumers. Thirteen tribes or consortia applied but were not funded in fiscal year 2000 for AIVRS programs. In the 2001 fiscal year, insufficient funds prevented 9 out of 14 tribes or consortia from being funded for AIVRS programs. With the potential to achieve positive results from AIVRS programs, reauthorization with an increase in funding is desperately needed.\textsuperscript{77}

\textit{Vocational Rehabilitation: Native American Technician Program}

The Native American Technician (NAT) program was established by the Florida State Vocational Rehabilitation Agency as a pilot rehabilitation program. The NAT program is

\textsuperscript{74} Hopstock et al., "Evaluation of the American Indian Vocational Rehabilitation Services Program," 2002.


\textsuperscript{76} Hopstock et al., "Evaluation of the American Indian Vocational Rehabilitation Services Program," 2002.

\textsuperscript{77} The Consortia of Administrators for Native American Rehabilitation (CANAR) Legislative Committee developed a set of 11 resolutions for consideration by those who are responsible for reauthorization of the Rehabilitation Act of 1973, as amended. The resolutions were designed to promote the continuing growth of culturally responsive rehabilitation services for American Indians and Alaska Natives with disabilities. The resolutions were edited and finalized with input from CANAR members at the CANAR Annual Conference in Seattle, Washington, on December 11, 2001, and named "The CANAR 11." Retrieved from http://www.nau.edu/ihd/CANAR/legislation.html on January 10, 2003.
premised on the belief that because tribal members are most familiar with their American Indian values and culture, they are also best suited to conduct outreach in their respective communities. Through contractual agreements, the state arranged for Indian members of the community to assist non-Indian counselors in providing VR services to the Indian community. Among their responsibilities, NAT assisted the agency in case management and identified members of their community who were in need of but had not received VR services. Preliminary evidence suggested that the NAT program succeeded in increasing participation of American Indians in the state VR system. However, the program lost funding sometime after 1996. In its place, a pilot program called the Native American Outreach Program was begun in Gainesville, Florida. Outreach counselors from the program attend powwows and tribal gatherings, where they inform American Indians with disabilities of available government programs and funding. Referrals and applications are provided as needed. Further follow-up will be needed to assess the outcomes of this program.

Vocational Rehabilitation: Self-Employment Options

The Jemez/Zia Vocational Rehabilitation Center in New Mexico and the Tanana Chiefs Conference Vocational Rehabilitation Program in Fairbanks, Alaska, are among the programs that are assisting American Indians with disabilities to achieve independence through self-employment. In addition to receiving training in budgeting and marketing, skills that are necessary to operate a small business, the Jemez/Zia program employs tribal people with disabilities to train clients in one of several crafts, such as pottery making or silversmithing. Among the successful outcomes that the Tanana Chiefs VR program seeks is for clients to enter into competitive employment, become self-employed, or engage in subsistence hunting, fishing, and trapping. Subsistence hunting and fishing are respected as culturally appropriate and as an exercise of a person’s right to self-determination. Both the Jemez/Zia and the Tanana Chiefs programs assist clients in purchasing or obtaining supplies and equipment to operate the clients’ businesses. Emerging patterns across anecdotal evidence indicate that these programs are

succeeding in their goal of assisting people with disabilities to move toward economic self-sufficiency; however, empirical evidence of these impacts is unavailable.79

**Independent Living and Transportation in Indian Country**

Recognizing that a weak transportation infrastructure may limit economic opportunities and pose a substantial barrier to accessing essential health and social services, several tribes have developed transportation systems that may be replicated. For instance, with funding from RSA, the tribally controlled Salish Kootenai College (SKC) on the Flathead Reservation of Montana developed a point-to-point transportation system for residents of the reservation with disabilities. The SKC transportation program purchased wheelchair-accessible vans and coordinated access to employment and rehabilitation services as needed by both tribal and nontribal members of the community. An early (six-month) evaluation of this program indicated that ridership was below initial projections. Eligibility limitations and difficulties in advertising availability of services in rural communities were thought to account for this initial low rate of use.80 Current information on the status of this program was not available for this NCD report.

Several tribes have also used funding obtained from a combination of federal and state sources (e.g., the Federal Transit Administration, the HHS’ Administration on Aging, Medicaid) to develop transportation systems that are accessible to people with disabilities. These systems were designed to link tribal members to employment centers and health and human services programs. Among the tribes with such transportation systems, the Chickasaw Nation Transportation System in Oklahoma, the Navajo Transit System in Arizona, and the Shoshone and Arapaho Nation Transit Association in Wyoming operate paratransit vans or vehicles that are fully accessible or

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ADA compliant. Although it may be reasonable to assume that these transportation systems enhanced the independent living opportunities of people with disabilities living in Indian Country, empirical evidence is not available in the literature.

Independent Living and Training Models for Sensitivity

Staff of AIRRTC developed and pilot-tested an independent living training workshop to provide technical assistance to service providers and policymakers on the provision of outreach services culturally appropriate to AI/AN clients with severe disabilities. The purpose of this training module was three-fold: “(1) identify differences among American Indian cultures...(2) create outreach independent living services for American Indians with severe or significant disabilities on and off Indian lands, and (3) identify strategies related to the independent living needs of American Indians.” The training module assists participants in developing “Blue Prints for Action Plans”—strategies for providing outreach to American Indians with disabilities—and identifying resources to implement the plans. Reports of results connected with outreach training at one month, three months, and six months suggested that the 16 program participants were able to identify and/or had taken action toward implementing outreach strategies to assist AI/AN clients with disabilities to achieve their independent living objectives.

Staff of the Northern Arizona University also developed a program to train American Indian community representatives to understand and address the independent living needs of elderly American Indians with visual impairments. Representatives from tribal health departments, senior citizen programs, and other service programs were invited to participate in a five-day workshop in which hands-on training on topics such as the techniques for mobility and daily living, assistive devices, and cultural and rural issues were provided. The 38 trainees were required to practice newly acquired skills with visually impaired volunteers. Following the workshop, an in-service training with tribal members was conducted to address the specific needs


82 Sanderson PL and Clay JA, Strategies on Successful Independent Living Services for American Indians with Disabilities: A Research Dissemination Final Report, American Indian Rehabilitation Research and Training Center, Northern Arizona University.
of the reservations. Evaluation of the workshop was conducted using a pre- and post-test design. The improvement in test scores suggested that the workshop objectives had been met. Study investigators reported that the community representatives who were trained under this one-year program served a total of 211 American Indians with visual impairments.\textsuperscript{83}

**Independent Living and Personal Assistance Services**

Recognizing the need for culturally sensitive personal care services, the Blackfeet tribal council adopted and guaranteed start-up funds for the Blackfeet Personal Care Assistance (PCA) program. The program hires, trains, and arranges for attendants to provide services to tribal members. The program also provides case management services for elderly tribal members with dementia or Alzheimer's disease and has worked to bring independent living apartments to the local community. The Blackfeet PCA program is believed to be among the largest of the personal assistance providers operating in the State of Montana. Most clients are Medicaid-eligible, and funding for program services is obtained largely through Medicaid. Anecdotal evidence suggests that tribal members favorably received the Blackfeet PCA program and that the program has contributed to the local economy through the hiring and training of personal assistants.\textsuperscript{84}

**A Single Independent Living Center in Indian Country**

ASSIST! to Independence is a Native American–operated nonprofit organization that has been very effective in reducing barriers to the provision of, and access to, appropriate services for those tribal members living on reservations. ASSIST! is located on the western edge of the Navajo Reservation in Tuba City, Arizona, and provides services to individuals with disabilities, or chronic health conditions, residing on or near the Navajo, Hopi, and Southern Paiute Reservations. At present, it is the only ILC located in Indian Country.


ASSIST! provides culturally relevant services to cross-disability American Indian consumers and its programs emphasize quality of life and community access through the maximization of independence and the improvement of functional skills. Community members with disabilities created ASSIST! to respond to the need for a more flexible service delivery system, where all services reflect the following independent living principles: (1) it is consumer controlled at the operating policy level with a board of directors that consists of a majority of people with disabilities; (2) the majority of administrative and staff-level personnel are represented by people with disabilities; (3) there is an emphasis on cross-disability consumer services; (4) there is an emphasis on peer role modeling and consumer-controlled service objectives; and (5) the four core services of advocacy, peer mentoring, independent living skills training, information and referral are provided. In addition, ASSIST! has provided services such as home modifications, transportation, attendant care, assessment and evaluation, and AT demonstration/loan.

In 2002, ASSIST! was one of four winners of The Association of Programs for Rural Independent Living’s competition for The Best Center for Independent Living Practices in Rural Independent Living to Emerging Disability Populations. Also, in 2002, ASSIST! was recognized by the National Council on Independent Living as a Best Practice for Assistive Technology Projects.

The main factors contributing to the ability of ASSIST! to successfully reduce barriers to the provision of and access to appropriate services for tribal members living on reservations are (1) dynamic and fluid services allowing for a quick response to needs; (2) understanding, respecting, and immersing in the culture being served; (3) aggressive outreach promoting “wellness” services; (4) extensive networking and collaboration activities; (5) developing relationships with nontraditional disability specialists (senior centers, public health nurses, community health professionals).


representatives, etc.); and (6) maintaining a visible presence in the community (senior functions, health fairs, etc.).

Statistical data, maintained by ASSIST!, exemplifies the positive impact that this organization has had on tribal members with disabilities living on reservations. Between October 1, 2001, and September 30, 2002, ASSIST! opened a case file and conducted ongoing case management for 1,098 individuals with disabilities, of all ages; processed 415 phone and e-mail requests; assisted 784 people who visited the center (721 of whom were American Indian); and conducted 143 off-site visits.

Of the many individuals served by ASSIST! in 2002, roughly 85 percent were referrals received from collaborative efforts developed with community health representatives and public health nurses. The remaining 15 percent were individuals who investigated independent living services on their own. Approximately 70 percent of the ASSIST! budget is devoted to direct consumer services.

Limitations to Understanding Issues of People with Disabilities Living in Indian Country

It is difficult to ascertain the extent to which many programs or initiatives actually impact outcomes since many of the studies or programs identified in the literature, particularly literature on effective strategies for reducing barriers to access, do not include a formal evaluation component. In some cases, failure to evaluate program effectiveness was attributed to lack of funds. In those cases where a formal evaluation appears to have been conducted, small sample sizes, failure to account for confounding factors, and the lack of a control group for comparison make it difficult to determine the actual effect of these initiatives or whether these model programs may be successfully replicated in other tribes or settings.


Much of what is currently known about people with disabilities living in Indian Country—from estimates of the size of the population to information on the impact of barriers to successful education, health, vocational rehabilitation, and independent living outcomes—has been based primarily on anecdotes, individual perceptions, and/or studies with limited statistical validity. The ability to use the information gathered from these studies to identify the unmet needs of American Indians and Alaska Natives with disabilities who reside in Indian Country may be limited by flaws in the methodological or research design and the failure of some studies to understand the characteristics of the AI/AN population.

For instance, data on the size of the AI population with disabilities and the nature or types of disabilities that they experience is among the most basic information for understanding their unmet needs. Yet, the reliability or precision of the estimates that are presently available are affected by discrepancies in the classification of people as American Indians and Alaska Natives, small sample sizes, inconsistent definitions of terms for types of disabilities, and use of nonrepresentative samples to derive these figures. The understanding of trends in the growth of the AI/AN population is significantly affected by changes in the reporting of race and ethnicity that occurred between the 1990 and 2000 censuses and specifically the change from single to multiple race groups. As previously discussed, depending upon whether individuals of multiple races are included, estimates of 10-year growth in the AI/AN population range between 26 percent and 110 percent. This wide variation makes large-scale program planning more challenging.

Information on the characteristics of the American Indian population with disabilities that are derived from national surveys and even those surveys that are commonly used to study disability-related issues (e.g., the National Health Interview Survey, the Medicare Current Beneficiary Survey, SIPP) are often not statistically reliable for analyses of certain populations of people from diverse cultures. The size of the AI/AN population is small relative to that of other groups and the number of American Indians and Alaska Natives with disabilities is an even smaller population segment. If oversampling techniques have not been applied, the margin of error associated with these estimates could be relatively large. This sampling issue is one of the
primary reasons why many studies do not analyze data separately for population segments of people from diverse cultures.

Service records, such as RSA data on VR closures or IHS hospital discharge data, have also been used to gain an understanding of the types of chronic and disabling conditions that are most prevalent among American Indians and Alaska Natives. Although analyses of the characteristics of American Indians and Alaska Natives with disabilities that are conducted with this data may not be affected by small sample sizes, they may have poor external validity. People who utilize these services may not be representative of the target population, and the ability to generalize findings from these studies to the larger AI/AN population may be limited.

Social and environmental factors, such as the high poverty rate and poor living conditions, may also make it more challenging for people studying the American Indian population. As noted by investigators in the Strong Heart Study, the recruitment of American Indians in studies may pose particular difficulty because “[d]ocumented historical events may also affect the spirit of cooperation in government-funded studies of the AI people...”91 Practical considerations such as the lack of street addresses, telephones, and transportation also make it difficult for American Indians with disabilities who are living in Indian Country to participate in health and social services programs or in studies that assess and attempt to address their unmet independent living needs.

Tribal values are likely to affect the adequacy and comprehensiveness of many studies dealing with access to and services for people with disabilities in Indian Country as well as tribal members’ willingness to participate in initiatives to reduce barriers. AI/AN culture, languages, traditions, and beliefs concerning health and disability are distinct across tribes. Studies that “combin[e] groups as separate as Seminole and Sioux into one category called ‘Indian’ seem little different than combining Polish Jews and Scottish Protestants into one category called

Regardless of the intended benefits, a program that fails to incorporate cultural beliefs will have difficulty in obtaining community support. Similarly, a study that is not culturally competent may obtain incomplete or inaccurate information. As one example, the word “disability” is often value-laden. Depending on tribal beliefs and values surrounding the term, American Indians who are asked to self-identify on the basis of disability may be reluctant or refuse to participate in programs that promote independent living objectives, vocational rehabilitation, or special education. Participatory action research methods, such as that used in the Tribal Disability Actualization model, which includes consumers in the design and implementation process, have been recommended as a means to ensure that research is culturally sensitive and findings are both accurate and relevant. \(^93\)

**Federal Responsibility to Address Gaps in Knowledge**

This study begins to scratch the surface of understanding the issues faced by people with disabilities in tribal communities. Federal agencies with significant trust responsibilities to Indian tribes must become much more engaged with and committed to addressing the gaps in research, services, and protections related to this population. Specifically, the U.S. Departments of Education, Interior, Justice, and Health and Human Services have particular interest in better understanding people with disabilities in tribal communities. Although a substantial amount of literature addresses issues relevant to access to and use of services by people with disabilities in Indian Country, the issues discussed above may limit the usefulness of much of the research. This is of particular importance when research-based evidence is sought for planning and developing effective strategies to increase services to people with disabilities in Indian Country.

On the basis of available existing research and data, conclusions may be drawn as follows:

1. A significant number of American Indians and Alaska Natives in Indian Country have disabilities.

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2. Services and accommodations to assist people with disabilities in Indian Country are limited and availability of supports and services varies across Indian Country.

3. Limited legal protections, limited financial resources, and lack of awareness about the needs of and strategies for enhancing opportunities for people with disabilities are major barriers that must be overcome to increase availability of appropriate services in Indian Country.

4. Cultural awareness and competency are important aspects of any strategy to increase knowledge and awareness of the needs of people with disabilities and to design and implement effective programs to meet those needs.

5. The complex federal-state-tribal government relationships and the complicated maze of programs that fund and administer implementation of laws and programs serving people with disabilities pose communication and coordination barriers to improving the provision of services in Indian Country.

The potential for developing effective strategies to increase the availability and use of services to people with disabilities in Indian Country would be enhanced by additional data collection and research in several specific areas, including

- Collection of systematic data on the number of people with disabilities in Indian Country, by type of disability and geographic location

- Identification of the service needs of people with disabilities in Indian Country, by geographic area

- Comprehensive review and documentation of existing programs and current services available in Indian Country, by geographic area

- Estimation of the gap between need and available services, by geographic area

- Identification of promising practices, or what seems to be working effectively, based on outcomes, for education, health, vocational rehabilitation, and independent living
American Indians and Alaska Natives constitute a very diverse set of multiple cultures, traditions, and languages that make it difficult to generalize findings from research in a generic way. As a result, research designed to provide a foundation of knowledge for designing and implementing strategies to increase the availability of services to people with disabilities in Indian Country will require early involvement in planning and decisionmaking, as well as leadership and direction by AI/AN researchers and program managers. In addition, findings from future research will require adaptation and modification to be effective in different tribes.

**Key Respondent Interviews**

"The perspective I think we need to take is a national perspective, which is not just about our own tribe but about all native people."

—LaDonna Fowler, Turtle Mountain Chippewa/Santee Sioux/Assiniboine

The core research strategy in this project was an interview and focus group methodology that provided a free-flow process of information gathering. Open-ended qualitative interviews allowed a flow of feedback to inform and guide the research. The following techniques were used for deepening the inquiry into the issues affecting people with disabilities in Indian Country:

- Tribal and federal key respondent interviews
- Focus group interviews
- Informal talks with professionals and community advocates

Methods for analyzing and interpreting qualitative interviews vary widely. For this report, Technical Expert Panel (TEP) members expressed a desire for a participatory approach toward research. This method appears to be more congruent with AI/AN cultures. The analysis and interpretation of data through a participatory approach with the TEP assisted stakeholders in the construction of a common body of knowledge. The TEP and interviewees served as co-researchers in the project. As new information emerged from the interviews, there was an inquiry into the meaning of the information, what the information suggested, and why. This process generated new questions, thereby deepening the inquiry that served to test the explanations or confirm interpretations. Each phase of the process included gathering, interpreting, testing, and
revising information until a reasonable explanation was developed. Once the analysis was complete, stakeholders collaborated on findings, conclusions, and recommendations. In addition to summarizing the tribal and federal interviews, the following section also highlights promising practices and model approaches identified as examples of improving government-to-government relationships, as well as expanding services for people with disabilities living in Indian Country.

The discussions with key respondents from the 10 tribal communities occurred between September 9, 2002, and January 13, 2003. The 10 tribes were selected from a list of tribes recommended by the TEP. The TEP members were asked to nominate tribes that they believed to be actively engaged in developing programs, services, or tribal laws/ordinances that address the needs of people with disabilities in their communities. On the basis of this preliminary list, tribes were sorted to provide geographical representation across the United States and to reflect diversity in the size (small, medium, large) of the tribes. Finally, only tribes who agreed to participate in this project were interviewed. In alphabetical order, the 10 tribes interviewed were the Confederated Salish and Kootenai Tribes of the Flathead Reservation, Montana; Cook Inlet Tribe of Alaska; Hopi Nation of Arizona; Navajo Nation of Arizona, New Mexico, and Utah; Oglala Sioux Tribe of Pine Ridge, South Dakota; Oneida Nation of Wisconsin; Pueblo of the Zuni, New Mexico; St. Regis Mohawk of New York; Three Affiliated Tribes of North Dakota; and the Yakama Nation of Washington State.

**Tribal Interviews**

As stated earlier, each tribe addresses the unique circumstances of tribal members with disabilities in very different ways. The task was to identify those tribes across the country that demonstrated leadership in creating awareness, developing programs, adopting tribal laws, and meeting the needs of its tribal members and descendants with disabilities. Leaders and advocates in the Indian Country disability movement recommended 16 tribes for a nationwide inquiry about promising practices in leadership as described above. Of the 16 tribes recommended, 10 were randomly selected for follow-up interviews. Letters sent to the tribal leaders of each tribe introduced the research project and requested permission for representatives of their tribal programs to participate in the interview process. Interviews were then scheduled with appropriate program directors.
Discussion guides for interviews touched upon tribal government support through the development of disability laws, support services, major barriers, and promising practices for people with disabilities; access to health care; barriers to health care; children with disabilities who are treated differently; available employment services through the tribe; and what types of information or resources would be helpful to tribes. The tribal program representatives’ interviews provided more than ample information, and wisdom was shared during the brief discussions.

Confederated Salish and Kootenai Tribes

In 1995, the Tribal Council of the Confederated Salish and Kootenai Tribes (CSKT) adopted a resolution in the same spirit as ADA. Under the guidelines set forth by this resolution, the tribe modifies buildings or work environments according to the access needs of tribal members with disabilities. The CSKT have adopted a “one-stop shop” approach to providing services to tribal members with disabilities. At one location, tribal members can access not only VR services, but also, under a Temporary Assistance for Needy Families (TANF) grant, Medicaid, commodities, General Assistance, cash assistance, trust management, Individual Indian Money accounts, childcare, and senior care. Satellite offices in smaller towns help to increase the accessibility of services. By integrating services, the staff and management of these programs are able to make better use of resources, which improves service coordination and delivery of services to tribal members with disabilities.

The promising approach taken by the CSKT entailed networking and developing coordinated services through partnerships within agencies in the tribe as well as with agencies and organizations external to the tribe. The VR director for the CSKT also serves on the state rehabilitation council and the State Independent Living Board. In addition to strong partnerships developed with Salish Kootenai College, she attends conferences to keep abreast of the changes in and developments of programs, funding, grants, and service opportunities.

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**Cook Inlet Tribe**

The Cook Inlet Tribal Council, located in Alaska, has a Section 121 Vocational Rehabilitation Program that serves the Cook Inlet Region. The Cook Inlet Tribal Council faces different challenges than tribes in the lower 48 states, as their lands and jurisdiction are not necessarily "reservation based" but are based on village affiliation, with some Native and village land allotments. The program is in its third year of operation. Participants must have either a tribal or Native village affiliation. In many of the villages there is no economic base and unemployment may exceed 50 percent of the population. Lack of transportation is also an extreme barrier to employment.

Over 70 individuals with disabilities currently receive assistance through the Cook Inlet VR program. To help tribal members with disabilities overcome obstacles, each tribe provides different employment-related services, which range from career guidance and training to a consumer work center on the Internet. The VR program provides services as outlined in the Rehabilitation Act and is in the beginning stages of a school-to-work transition program. The Cook Inlet Tribe is also outlining VR procedures with the state to further collaborative efforts. People with disabilities benefit by the coordination of services offered through Cook Inlet, including assistance with the state’s TANF and other resources.

**Hopi Nation**

The Hopi Nation’s continuum of services for tribal members with disabilities extends from early infant and childhood intervention to adult VR services with their recent award of a Section 121 grant. Grassroots parent advocacy has been at the heart of the Hopi Nation’s service approach. In 1996, the tribes established the Office of Special Needs. Since the Office was formed, partnerships within the community and with national organizations have helped it to grow and become a community resource. These partnerships have allowed the Office of Special Needs to host training and education sessions on topics such as Social Security, fetal alcohol syndrome

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and fetal alcohol effect, parent mentoring, and caregiver training. These trainings provide the Hopi community, including families of children with disabilities, with an increased awareness about issues and resources for Hopi children with disabilities.

The Special Needs Activity Day held each year exemplifies the unique community approach that this program has taken. Since 1996, attendance at the event has grown from a core of interested parents to 600 participants last year. The theme is "Celebrate Diversity—Everyone is Unique." Support for the events, activities, and refreshments is provided in part by a grant from the Arizona Governor’s Council on Developmental Disabilities. In addition, other Hopi community programs and outside agencies volunteer their time to make this event so successful. The Hopi Nation, by creating a central office to assist people with disabilities, has vastly improved the understanding of its community, the awareness of tribal programs, and the access, support network, and services for individuals with disabilities and their families.

Navajo Nation

The Navajo Nation tribal VR program was the first tribal VR program in the country, paving the way for other tribal VR programs in the nation. In the mid-70s, Navajo Nation leaders recognized a serious gap in VR services to tribal members with disabilities. This gap was due, in large part, to the fact that the Navajo Nation spans the corner of three states: Arizona, New Mexico, and Utah. Concern about this gap in services sparked negotiations between the Navajo Nation and surrounding states. Navajo leaders provided strong testimony during the reauthorization of the Rehabilitation Act during the mid-1970s. Because of the Navajo Nation’s unique position in a tri-state area, Navajo leaders felt that their tribe needed to be funded directly rather than having funds funneled through each state office. This made the Navajo Nation the first tribe to receive the funds under the RSA grant, which provided greater access to vocational rehabilitation for tribal members with disabilities. Currently, this program is funded through a five-year grant from the U.S. Department of Education’s RSA.97

Serving Navajo children are 32 schools located on and off the Navajo Reservation. It is estimated that 85 percent of the student population in these schools are Navajo children. The director for

Safe Schools and Healthy Students and former council member of NCD believes that schools need to focus more on career development for Navajos with disabilities.\textsuperscript{98} Students are not typically encouraged to continue with any education beyond high school.

Support to provide individuals with the assistive technology they need has been obtained through a loan to the tribe from the Department of Vocational Rehabilitation. This unique service allows consumers to try out AT equipment on a loan basis to see what works for them. The Navajo Assistive Bank of Loanable Equipment Consortia is an organization composed of professionals from a variety of fields with the goal of assisting people with disabilities. The needs of individuals with disabilities are addressed in tribal regulations that were developed approximately 15 years ago by consumer advocates who gave testimony at an open tribal council meeting on topics such as special education, vocational rehabilitation, employment, and housing. These comments were then used as the basis for current tribal legislation.\textsuperscript{99}

While the effectiveness of many of the Navajo Nation's programs and services for individuals with disabilities has been hampered by barriers caused by jurisdictional overlap, language, and geographic remoteness, the tribal government has worked to offset these barriers and uphold its responsibility to tribal members with disabilities through a unique financial trust fund for programs and service provision. About 10 years ago, a former president of the Navajo Nation oversaw the set-aside of monies obtained from renegotiation of land lease contracts for agencies that provide services to Navajos with disabilities, including border towns. Each year a committee that manages the trust fund reviews proposals from agencies and awards grants from the interest accrued by this trust fund. Grants have been awarded to provide for needs of tribal members with disabilities, which have ranged from creative employment options to improving rehabilitation services and decreasing agency caseload.


\textsuperscript{99} Ibid.
Oglala Sioux Tribe

The Oglala Sioux Tribe passed the Americans with Disabilities Act in 1991.\textsuperscript{100} It is the only tribe thus far to undertake the step of adopting within its own tribal code the entire ADA, thanks in large part to the power of leadership within the tribal council, which included at that time a tribal member with a disability and member of the "Quad Squad," a grassroots advocacy group for people with disabilities. However, tribal interviews report that enforcement of the ADA provisions, particularly with regard to physical infrastructure and parking, is still a problem.

The Oglala Sioux Tribe’s Quad Squad has become an active advocate for people with disabilities. The Quad Squad collaborates with state agencies to help consumers find support services. Although most support services are provided through the state, many people did not know how to obtain them. The Quad Squad helps increase the access that tribal members with disabilities have to resources, assistive technology, and employment by helping and advocating for them. As advocates for people with disabilities, the Quad Squad has worked for safe and accessible sidewalks, crossing lights, housing, transportation, and purchases of wheelchairs and other equipment.

Oneida Nation

Located in Wisconsin, the Oneida Nation has developed a strong employment-centered service program and has had success in finding work placements for many tribal members with disabilities. In 1995, the Job Training Program was developed because tribal members with disabilities were not receiving the kind of assistance they needed from state or other employment programs.\textsuperscript{101} Program enrollment and dropout rates identified this service as one that needed to be addressed from a tribal perspective. The job center was designed as a one-stop service approach that provides mental health, childcare, and other related services in a seamless delivery. Developing employment opportunities through participation in a workforce diversification initiative has helped to reduce employment barriers for tribal members with disabilities. The tribe


\textsuperscript{101} West, Steven "Corky." Oneida Nation. Telephone interview by Martina Whelshula. September 26, 2002.
also supplements funding for its IHS health clinic to provide four doctors and a complete nursing staff.

The next goal that the program has set for itself is extending the reach of its services to include those tribal members who may be reluctant to identify themselves as people with disabilities or to ask for help.

**Pueblo of the Zuni**

The Pueblo of the Zuni, located in Northwest New Mexico, is the largest of 19 pueblos in New Mexico. The population is approximately 11,000 people, of which about 96 percent are enrolled tribal members. The area is remote and isolated and covers about 1,000 square miles.

The tribe has a comprehensive array of services for tribal members with disabilities, which include supported and assisted living services and employment services. Supported living and assisted living services allow tribal members with disabilities to live more independently. Supported living provides one-on-one services on a 24-hour basis. Assisted living provides services for individuals with the ability to live more independently. Employment support, which includes supported employment, vocational rehabilitation, and day habilitation, provides tribal members with disabilities with increased opportunities for employment.

An extensive public transportation program supports people with disabilities as well as other members of the community. Last year the transportation program provided approximately 33,000 trips around the community. Transportation services are funded by multiple sources. The tribe has a Section 5311 grant that assists with administrative monies and capital and recently received approval to provide transportation under the Medicaid program. The transportation program also serves as a mechanism to employ people with disabilities.

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St. Regis Mohawk Tribe

The St. Regis Mohawk tribal government has been active at the local, regional, and national levels in promoting tribal resolutions to address disability issues. The tribe is in the process of implementing tribal codes that pertain to disabilities.

The St. Regis Mohawk Tribe collaborates with the county, state, and federal governments to offer a wide array of services to people with disabilities, ranging from family support programs to vocational rehabilitation. The tribes have a family support program that provides transportation to appointments and grocery shopping, which gives tribal members with disabilities increased mobility. A respite service for parents of children with disabilities provides support to families who have children with disabilities living in the family home. An adult recreation program and an inclusive afterschool recreation program are also available, so that tribal members with disabilities can be active community members.

Members of the staff for the tribal VR program have an excellent working relationship with the state VR program staff. This increases the level of effectiveness for services that can be provided to participants.

Three Affiliated Tribes

The Three Affiliated Tribes report that the tribal government has adopted requirements to protect and serve people with disabilities in their communities. The tribe's legal services department is called upon to help tribal members with disabilities resolve any complaints or appeals. Services and support for people with disabilities are coordinated through the tribes' Social Service Program. Networking and personal attention have been keys to the success of the Three Affiliated Tribes' Social Services Program. The Social Services staff is knowledgeable about the services available through both the tribe and other agencies, thus making them better prepared to help tribal members with disabilities get their needs met.


The Three Affiliated Tribes provide General Assistance and grants to families, including people with disabilities. The Social Services Program will also research other services for which tribal members with disabilities may qualify and provide advocacy for them at tribal, state, and federal levels. The Program has found that assigning one person to follow the client through the entire application process increases the effectiveness of obtaining services. Working in collaboration with county, state, and federal agencies, the Three Affiliated Tribes can better serve clients.

**Yakama Nation**

Services for individuals with disabilities living on the Yakama Reservation are provided through the tribal VR program, the IHS clinic system, the Community Health Representative program, the Veterans' Affairs program, and the Home Health program. In the past, the welfare-to-work program was used to provide transportation services; however, funding is no longer available. There are ongoing attempts through memoranda to educate the tribal council about the needs of tribal members with disabilities, such as providing curb access to public tribal buildings. Diabetes and alcoholism are the disabilities with the greatest impact on the community and where services are currently focused.

The promising approach taken by the Yakama Nation involved education, outreach, and program development. To accomplish this goal, the Yakama Nation hosted a 2002 Regional Disabilities Conference. Area programs had the opportunity to come together, share experiences, and learn from each other. The VR program director believes that ongoing workshop and program opportunities for awareness and collaboration and developing coordinated services between state and tribal programs are essential to strengthening the local services and resources available to tribal members with disabilities.

**Key Elements of Promising Practices**

Leaders and advocates in the Indian Country disability movement recommended tribes that exemplified successful practices that enhanced program and/or service results for people with disabilities. Of the 16 tribes recommended, 10 were selected for follow-up interviews.

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Throughout the interviews with leaders of tribal programs and services, certain themes emerged across the different tribes. The themes of leadership and program qualities appeared to be key elements of success. This rich information can be shared with all tribal communities desiring to improve their tribal community environment for members with disabilities. The following section summarizes key elements for these promising practices identified in tribal communities.

**Leadership Characteristics**
A program leader who embodies the qualities and characteristics of passion, perseverance, vision, commitment, change agents, consistency, and connection and who is seen as an agent of hope can influence greatly the success of a program. Appendix F provides a more detailed description of common qualities and characteristics.

**Responsiveness to the Needs of the Consumer**
Successful programs require staff to know their consumers well. This requires moving beyond the initial identification of consumer needs to the development of personal relationships with consumers in order to truly understand the realities experienced by tribal members with disabilities. These programs tailor their services to the unique needs presented in each tribal community and to each consumer.

**Innovation in Removing Barriers**
"Necessity is the mother of invention" is a phrase that exemplifies the motivation behind many innovative programs throughout Indian Country. The personal diligence and leadership of individuals with disabilities and/or their family members have helped to reshape tribal communities and create more awareness, break down barriers, and push for expanded services and advocacy. Through their advocacy, tribal programs have realigned programs to create seamless services and more comprehensive support.

**Effective Collaboration**
A key factor for a successful program rests in the program's ability to effectively collaborate between agencies, programs, and funding sources. Those programs whose staff have extensive knowledge and awareness of other programs and services were able to develop the most comprehensive and innovative programs. All 10 of these tribes have demonstrated how their
creative collaborations increased the success of their programs in serving tribal members with disabilities.

**Advocacy Strength**

Advocacy is another key program success factor. Advocacy seems to be an inherent process of the work in Indian Country. It is a primary source of support for tribal members with disabilities who do not know how to or cannot advocate for themselves. Advocacy comes in many forms and is multidimensional. It is evident from the many voices of program leaders that it is essential to successfully serve people with disabilities.

**Support from Tribal Leadership**

Every tribal program included in this report noted that tribal leader support was an important factor in the success of the program. However, tribal leader support looked very different from tribe to tribe. Although not all tribes have laws protecting the rights of tribal members with disabilities, some have personnel policies and procedures, while other programs feel supported by their tribal leadership in some way.

**Conclusion**

Combinations of the elements identified from promising practices observed in existing programs seem to be aligned with comments by tribal leader Chief Joseph, Nez Perce: “The earth is the Mother of all people, and all people should have equal rights on it.”

In the development of local policies, processes, and programming to serve and protect the rights of tribal members with disabilities, consideration needs to be given to the power of collaboration and an overarching awareness of local tribal culture. Unless programs are culturally responsive, consumers will not patronize the services offered to assist them. Knowing the consumer through meaningful inclusion in planning and hiring, and risking innovation in program designs to fit consumer needs, rather than attempting to fit consumers to program designs, are critical for success. Combined support from tribal leadership, committed and culturally responsive program staff, and positive results can realize enhanced empowerment for people with disabilities in Indian Country.
**Federal Interviews**

A series of interviews were conducted with federal and regional officials on government-to-government improvements. The selection of federal agency staff who were interviewed for this task was a joint decision, with input from the TEP. Three initial federal contacts were selected and then asked for additional suggestions of other officials to interview. This process led to the use of staff from headquarters and from regional offices in some agencies.

Ten federal interviews were conducted between September 15 and October 16, 2002. Interviewees included individuals who had management or operational responsibilities for AI/AN policies and programs within the following federal agencies: Administration for Native Americans, HHS; Administration on Aging, HHS; BIA, Department of the Interior; Department of Education; Department of Labor; IHS, HHS; and the Social Security Administration, HHS.

Discussion guides were developed and reviewed with the NCD project officer prior to the interviews with tribes and federal and state officials (see Appendix B). The discussion guides were used by the interviewer to focus the discussion, rather than as a formal questionnaire.

**Department of Health and Human Services: Indian Health Service**

IHS' Elder Care Program contributes to policy development and consultation with the tribes on issues affecting elders, including elders with disabilities. 106 IHS held a roundtable on elder issues in April 2002, and much of the discussion and focus of the meeting emphasized the importance of developing stronger linkages between the disability community and elders, since both groups are facing many of the same challenges in obtaining similar services.

IHS is working to develop mechanisms to support tribes in their development of support and programs to meet the needs of elders with disabilities. The approach is one that recognizes that tribal culture and understanding of disabilities are different from that of mainstream culture; tribes must develop culturally appropriate services and programs to meet their unique situations and preferences. The optimal approach is one that creates tribally controlled programs that are planned and developed by each tribe.

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106 Interview with Dr. Bruce Finke, director, Elder Care Program, Indian Health Service, October 17, 2002.
The public health advisor involved with long-term care issues was interviewed for this study. She works closely with the Offices of Tribal Self-Governance and the Office of Treatment Activities. With funding through these offices, tribes have a number of options: they can subcontract, purchase services, and/or provide services directly and pay salaries—such flexibility was touted as one of the strengths of crafting federal policy to match tribal environmental and political realities/needs. Moreover, this flexibility insulates tribes from having to “spend-down,” when such action may not be in the best interest of effective program administration; they can also roll-over funds to the next year if necessary.

As a result of current funding mechanisms, the government-to-government relationship between IHS and tribes is well established. In 1975, the Indian Self Determination Act (P.L. 93-638) provided authority for tribes to contract and administer IHS programs directly. More recently, federal law has allowed for increased flexibility for tribal contractors through a permanent self-governance program. These two federal statutes provide a common point of reference and understanding that affirms the right of each tribe to determine if health services will continue to be provided through IHS or be administered through the tribe. In addition, frequent meetings between various IHS staff and tribes on funding issues and health services programming provide for enhanced interaction. One of the most significant stressors to government-to-government relationship is the unmet level of funding—a persistent undercurrent in almost any federal-tribal interaction.

The trend in CMS is to pay more attention to providing services on the reservation or at home. By fusing a series of resources together, some level of service often can be provided on the reservation. An example of interagency collaboration (and flexibility) that has worked well is the ability to pay family members to provide care at home. In an effort to sidestep internal barriers,

107 Interview with Lehoma Roebuck, public health advisor, Office of Public and Behavioral Health, Indian Health Service, September 27, 2002.


agencies initiate memoranda of understanding. These memoranda of understanding have proven successful in providing additional technical assistance and works to address/solve multiple agency issues at once. Having an interagency team go to council meetings to seek input would be very beneficial in terms of removing barriers.

Department of Education: Rehabilitation Services

The Department of Education’s Office of Special Education and Rehabilitation Services Administration oversees formula and discretionary grant programs that help individuals with physical or mental disabilities obtain employment and live more independently through the provision of such supports as counseling, medical and psychological services, job training, and other individualized services. There are 10 federal regions with responsibility for RSA programs across the country.

Region X staff provide oversight and monitoring of programs in the states of Oregon, Washington, Idaho, and Alaska. In addition, Region X staff provide oversight, mentoring, and technical assistance to AIVRS programs across the country (of which there are only 69, even though there are more than 562 federally recognized tribes). By federal statute, American Indian rehabilitation programs function comparably to the state VR agencies; however, their services are provided to members of tribes who have disabilities and live on or near a reservation. The AIVRS grant application process is a competitive process; however, in keeping with their “community culture,” tribal programs often share successful grant applications with new applicants for use as a template.

In 1996, RSA offered the assistant regional commissioner for Region X the opportunity to develop a technical assistance and mentoring program for all tribal VR projects. RSA provided him with time and a limited amount of money to cover costs to visit tribal VR programs and provide technical assistance and other support. In the first year, with cost containment in mind, he and his wife traveled in their motor home to 11 tribal VR programs in Montana, South Dakota, North Dakota, and Idaho. The agenda was based on two-day monitoring and technical assistance activities at each location.
Technical assistance was provided throughout the monitoring activities and was expanded to include meetings at each site with tribal council members, tribal VR staff, tribal colleges, state VR agencies, and client assistance program staff. The tribal VR agency directors were encouraged to invite state VR program staff and client assistance program staff to participate in two-hour meetings. The state agencies responded in 100 percent of the locations and in most cases it was the first time that state and tribal VR staff had met in the tribal communities and discussed common issues and coordination.

Department of the Interior: Bureau of Indian Affairs, Center for School Improvement – Special Education Programs

BIA’s Office of Indian Education Programs (OIEP) receives funds through the U.S. Department of Education to provide funding for special education services in BIA-funded schools, of which there are 185 in 23 states. In addition, 14 peripheral dormitories receive BIA funding.¹¹⁰

BIA-OIEP awarded contract funds to 13 tribally controlled community colleges and state universities for the specific purpose of providing professional development opportunities for BIA-OIEP personnel and the provision of technical assistance and training to BIA-funded schools. This initiative is funded through the comprehensive system of personnel development requirement under the Individuals with Disabilities Education Act (IDEA) of 1997.

There is a general shortage of “certified” personnel in special education to meet the existing need. Special education is part of the continuum of services for people with disabilities. A primary element of the BIA mission for education is to provide and ensure that special education services are available to tribal school-age children in order to help them achieve academically. Professionals involved in that mission include physical therapists, speech therapists, counselors, and others.

All BIA-funded K−12 schools have schoolwide programs and are expected to provide an inclusive learning environment for all children; a priori planned placement separation between children with special education needs and other children is unacceptable. In accordance with the

¹¹⁰ Interview with Sherry Allison, Ed.D., director, Special Education Programs, Bureau of Indian Affairs, Center for School Improvement, September 27, 2002.
mandates of IDEA, BIA-OIEP submitted a Coordinated Services Plan for Special Education (CSP) to the U.S. Department of Education’s Office of Special Education Programs. The CSP outlines a plan to coordinate services for children with special education needs at the local, regional, and national levels. Providers include vocational rehabilitation, Head Start, and tribal colleges.

Honoring Native American culture and language is an integral part of the school curriculum. BIA-OIEP has identified five general education goals, of which one is “students demonstrate knowledge of language and culture to improve academic achievement.” Toward this end, BIA, through its state plan, requires schools to deliver at least eight two-curriculum units that address culture/language. Conversely, BIA does not require teachers in BIA-operated and/or BIA grant/contract schools to formally demonstrate their degree of cultural sensitivity. BIA-funded schools that are operated by individual tribes can make a determination about such a requirement individually.

**Bureau of Indian Affairs – Division of Human Services**

The Division of Human Services provides General Assistance (GA) to tribal members who are in need. GA is a “secondary” program, available as an interim support program to people who have applied for TANF and are awaiting approval for services. It also provides support for people who are not eligible for TANF (e.g., single people without children). Under contracts/compacts, tribes operate 80–85 percent of the GA programs, with BIA regional offices providing oversight and monitoring. Within BIA, the Individual Indian Money accounts are the primary source of support for people with disabilities who have tribal trust monies. Tribal social workers or agencies evaluate and assess the needs of individuals with disabilities and determine whether they have special needs that require a wheelchair or other special equipment in order to hold a job or to maintain independence. This program is a source of funds to meet those needs and is flexible and specific to the individual’s needs. The regulations have been in place for only a year and time has not been sufficient to assess effectiveness.

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111 Interview with Larry Blair, director, Division of Human Services, Bureau of Indian Affairs, October 14, 2002.
Social Security Administration

The national lead for American Indian/Alaska Native Social Security Programs located in the Denver office was interviewed for this study. This person is involved in a number of activities designed to increase outreach, communication, and understanding of Social Security Administration (SSA) programs for American Indians and Alaska Natives. In March 2000, SSA convened a national meeting to work with the tribes to identify strategies for better delivery of SSA programs to the AI/AN population. The Social Security Disability Insurance (SSDI) program was a major focus of that meeting.

As a result, SSA has developed several ongoing programs to better inform and assist American Indians and Alaska Natives. These initiatives include an interagency agreement with IHS and CMS. This agreement engaged the National Indian Council on Aging in piloting outreach to Indian Nations in New Mexico, Minnesota, and Montana. Results from the Montana Blackfeet Reservation suggest that these outreach efforts are helpful; over 100 people participated and 70 applications were completed on-site. SSA has also prepared a video titled “You and Social Security Disability,” in which AI/AN people explain the SSDI program. The video was made, in part, in response to information that AI/AN people generally do not pursue SSDI enrollment if they receive a notice denying their initial application (regardless of the reason for the denial).

SSA is also developing a training package on Social Security and Medicare/Medicaid programs that will be provided to all SSA regions. This package, the result of the pilots conducted under the interagency agreement, will be useful in training benefit coordinators and community health representatives serving Indian Nations.

Administration on Aging’s Native American Programs

The Administration on Aging (AOA) teams with the National Indian Council on Aging and other Indian organizations to provide training and technical assistance at national and regional meetings/conferences. Regional offices also provide technical assistance and on-site technical assistance every three years. In addition, the central office disseminates technical assistance

112 Interview with Richard Schremp, director, Electronic Service Delivery, American Indian/Alaska Native Social Security Programs, Social Security Administration, Denver Region, October 16, 2002.
briefs on an ongoing basis to tribal grantees. In the near future, AOA intends to fund an Indian contractor to provide technical assistance to Title VI programs.

The Title VI program works very well and a substantial comfort level has been established between federal program staff and the tribes. In part, this is due to the program's flexibility and the fact that AOA has consulted with and involved the tribes in developing the programs. AOA conducts national Listening Sessions with tribes to learn about and to identify areas for change and improvement. For example, tribes are allowed to define “elder” for the purposes of these programs.

In addition, AOA works closely with the National Title VI Association and with the National Association of Area Agencies on Aging to coordinate and collaborate on programs. AOA also administers Title VI, Part C, which provides family caregiver support services (the tribe must have a Part A grant to be eligible for Part C).113 There are 178 Tribal Part C grants. The program permits meals to be delivered to people with disabilities who are not “elders.”

113 Interview with Yvonne Jackson, Administration on Aging, Native American Programs, October 14, 2002.
The major objective of this study was to develop a foundation of knowledge and information upon which to base specific government-to-government recommendations. Specifically, this section is provided (1) to identify barriers to effective federal-tribal government relationships and (2) to develop recommendations for improvements in government-to-government relationships. To accomplish these objectives, input was obtained from AI/AN people with disabilities (through the TEP), tribal leaders, tribal program administrators, and federal agency staff regarding their perceptions of these relationships and on strategies and processes that could be implemented to improve effective working relationships. The comments and recommendations from these interviews were considered and presented to two focus groups to determine if these are appropriate and reflect the concerns in Indian Country. One focus group was held at the National Congress of American Indians annual conference in November 2002 and included tribal leaders and AI/AN people with disabilities. The second focus group was held at the annual meeting of the Consortia of Administrators for Native American Rehabilitation, and included primarily consumers (AI/AN people with disabilities and VR program administrators). Based upon this extensive review by consumers, advocates, program specialists, and leaders in the field, the following government-to-government findings and recommendations are provided.

**Findings: Barriers to Effective Government-to-Government Relationships**

The barriers to effective federal-tribal government-to-government relationships were identified through the tribal and federal interviews. These barriers include

- **Fragmentation of services across federal agencies and offices.** Interviewees cited the fact that while a multitude of services are available, these programs and services are uncoordinated, and people with disabilities, and their advocates, are required to search for assistance with little assistance or advocacy to coordinate services. The complexity of seeking information and completing paperwork to obtain the full range