


A Field Guide for Community Work Incentives Coordinators:

**How to Improve Services to
Native American Social Security
Beneficiaries with Disabilities
in Tribal and Urban Areas**



It takes far more than simple personal resolve to become the director of one's own course in life. Please remember that we who are Indians living with disabilities operate as trapeze artists living our lives on a tightrope. Each day we struggle to maintain our balance, survive, and hopefully thrive. It is indeed our fondest wish to be contributing members of our families, our tribes, and society as a whole."

- Cinda Hughes, legislative associate for the
National Congress of American Indians (2006)

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Beneficiaries with Disabilities in Tribal and Urban Areas**

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Acculturation is a good word for indigenous people who walk in two worlds. ... Many times the two worlds can be blended to create a third world; that being a compilation of skills and knowledge that far exceeds demands of a single culture."

- Dr. Carol Locust, AIDTAC consultant (2006a)

Table of Contents

- Introduction 2
- 1: American Indians, Alaska Natives and
Native Hawaiians: Degrees of Acculturation 3
- 2: Health in Native Communities and the Concept of Disability..... 7
- 3: Impact of Tribal Sovereignty on Disability Programs..... 10
- 4: Cross-Cultural Outreach in Native Communities 14
- 5: Tribal Members as Cultural Liaisons..... 18
- 6: Holding a Talking Circle 23
- References: 25
- Appendix I: Technical Support and Resources 27
- Appendix II: Tribal and Local Newspapers 28
- Appendix III: Outreach Checklist..... 29

Introduction

“Our challenge is to suspend whatever romantic or stereotypic notions we may come with in favor of just being respectful and open to learning.”

- Marsha Katz, *The Rural Institute* (n.d.)

Serving American Indians, Alaska Natives, and Native Hawaiians with disabilities in both tribal communities and urban areas is a challenging yet critical aspect of the Social Security Administration’s Work Incentives Planning and Assistance Program. Integral to providing fair and equitable services is opening doors to employment and informing Social Security Administration beneficiaries about potential changes in benefits. The goal is to encourage the pursuit of a rewarding and full life, including the possibility of employment, and to help SSA beneficiaries with disabilities navigate their way through difficult decisions and paperwork. It may sound straightforward; truth be told, it can be challenging and potentially frustrating to work in a new or different culture, to communicate effectively and with care.

This monograph is the product of Technical Assistance on Native American Culture (TANAC) training materials distributed to disability program service providers in the past two years. The federal government’s TANAC project, overseen by the American Indian Disability Technical Assistance Center (AIDTAC), developed Issues Briefs and held teleconferences to assist Community Work Incentives Coordinators (CWICs) in the field. This guide compiles and advances the key points of TANAC materials through research, interviews, and expert voices on indigenous communities and cultures in the United States. The goal is to better assist disability program service providers and improve services. This publication

offers guidance on outreach techniques specifically for Native Americans¹ with disabilities, highlighting the value of cultural liaisons to facilitate effective interaction. Community Work Incentives Coordinators may enter the field with little or no experience in Native cultures. With patience and gentle persistence, trust can be built and efforts rewarded.

This guide includes statistical and historical information on the diversity of indigenous peoples in the United States and their varying degrees of acculturation, as well as an introduction to tribal sovereignty and how it affects accessibility for people with disabilities. A section on achieving cultural competency follows. Finally, the monograph outlines steps for effective outreach, including how to hold a Talking Circle and work with tribal liaisons to build on efforts. Appendices include technical resources and support, media contacts, and an outreach checklist.

It is our sincere hope that this project will assist CWICs in the field with information about American Indian, Alaska Native, and Native Hawaiian communities. The material herein draws from the knowledge and experience of experts who have worked with Native American communities and people with disabilities for many years – some of whom are Native and have disabilities themselves. Keep this publication as a resource for your toolbox, and don’t hesitate to contact AIDTAC with questions or for more information.

¹ For the purposes of this guide, Native American is a general term encompassing the three groups of people indigenous to the lands of the United States – American Indians, Alaska Natives, and Native Hawaiians.

Chapter 1

American Indians, Alaska Natives, and Native Hawaiians: Degrees of Acculturation

American Indians, Alaska Natives, and Native Hawaiians comprise extraordinarily diverse cultures and social systems. All are indigenous to the land on which they live and belong to a group that at some point in recent history was forced to assimilate into white European culture in the United States. Assimilation, however, has meant forcing people to take a foreign and unfamiliar identity. On the other hand, the term acculturation has come to mean learning to blend into another culture as necessary, acquiring the skills and tools to function – to survive and even flourish in the other world, but maintaining a meaningful life in a Native culture and knowing how to operate in it, as well.

American Indians and Alaska Natives are 1.5 percent of the total population in the United States, according to the U.S. Census Bureau (2003). Native Hawaiians and other Pacific Islanders comprise 0.3 percent of the total population, the agency reported in 2005. The following sections describe the American Indian and Alaska Native populations, as well as levels of acculturation and issues specific to rural and urban areas. There is also a section on Native Hawaiians.

Overview of American Indians and Alaska Natives

The U.S. Census Bureau (2003) estimates that 4.4 million American Indians and Alaska Natives live in the United States, including those in combination with other races. Of these, 3.1 million claim membership to a tribe. There are an impressive 562 different federally recognized tribes. Their rich and storied cultural fabric includes at least 250 languages and many variations on society and spirituality, community and customs,

sacred sites and ceremonies. Tribes that share the same language may speak different dialects. So, despite attempts in popular culture to stereotype what it means to be Indian, a little time spent with Native Americans of different backgrounds quickly demonstrates otherwise, revealing a diverse spectrum of cultures, lifestyles, and concerns.

The history and cultures of many Indian peoples are more than facts and dates. They are beliefs and emotions, ways of thinking, ways of doing. History and culture are known through spoken words, the objects we used and the creations of the people.”

*- From the book “Native Universe: Voices of Indian America”
McMaster, G. & Trafzer, C.*

Though culturally diverse, American Indian and Alaska Native tribes share common ground. A significant similarity is their sacred relationship with the natural world. In most tribes, human beings are considered an interdependent part of the earth, and a respect for the world’s living beings, natural features, and resources emphasizes balance and harmony with all living things. Spirituality flows from this worldview – not a separate religion as such, but a way of life.

This relationship between humans, animals, and the earth is found often in Native storytelling and the arts, with as many variations as there are tribes.

It is important to get to know a tribal culture in its own right. Gary Flom, project coordinator for the WIPA Project at the Montana Center on Disabilities in Billings, remarked on the value of this in a TANAC Teleconference (2006a): “Each and every one of the reservations is a complete, separate entity unto itself just as any other country. ... I highly encourage that you really get to know something about the people before you go onto the reservation.”

The strength of an individual’s cultural ties depends on the overall extent of personal or familial involvement in tribal or Native activities as well as place of residence. Varying degrees of acculturation among American

Indians and Alaska Natives make it impossible to generalize about a level of acculturation or distance from the mainstream culture.

Today, the majority of American Indians and Alaska Natives – 66 percent – live in cities or urban areas, making it more challenging for them to connect with others of the same tribe or heritage, except where community meeting places or cultural bases sprout up to meet the need. The other 44 percent live in rural areas on American Indian reservations or in Alaska Native villages.

Regardless of urban or rural residence, Native Americans struggle with ranking at the bottom of almost every social statistical indicator and average one of the highest rates of unemployment, the lowest levels of educational achievement, the lowest per capita income, and the poorest housing and transportation in the country (Fugleberg, 2006).

Who is American Indian and Alaska Native?

Overview

The most important aspect of defining what it means to be an American Indian or Alaska Native is self-identification (Clay & Fugleberg, 2005). Beyond that, tribal qualifications differ typically by blood quantum. The Bureau of Indian Affairs also bases their definition on blood quantum, requiring one-fourth Native blood. Some tribes follow fractions of heritage, others call for a Native ancestor. Other federal agencies have different rules, complicating the matter of who qualifies for what services. The Census Bureau relies on self-identification. The Department of Education calls for tribal registration.

Largest American Indian Tribes

About 1.5 percent of the U.S. population is American Indian or Alaska Native. The following American Indian tribes have more than 50,000 members:

Cherokee (largest with population of 697,400)

Navajo

Choctaw

Blackfeet

Chippewa

Muscogee (Creek)

Apache

Lumbee

Source: U.S. Census Bureau, 2003

About 16 percent of the inhabitants of Alaska today are Alaska Native. Language, culture, and geographic location factor into distinct Alaska Native groups, according to Carol Barnhardt, an associate professor of education at the University of Alaska (2001). Eskimo, Indian, and Aleut are three main groups that communicate with four language families and about 20 distinct languages. "Alaska Native people often identify themselves with a tiered description: as Alaska Native, as belonging to a particular linguistic/cultural group ... and as being a member of a particular region, village and/or family. In some areas, further clan distinctions are made," she writes. Since 1971, they also identify with a village or region divided up by the Alaska Native Claims Settlement Act, which effectively made Alaska Natives shareholders in business enterprises.

Alaska Native Tribal Groups

The following Alaska Native tribal groups have more than 5,000 members:

Tlingit (largest with 17,200 members)

Alaskan Athabaskan

Eskimo

Yup'ik

Source: U.S. Census Bureau, 2003

Aside from tribes acknowledged by the U.S. government, there are many others in the United States who consider themselves unique Native American cultures and are attempting to gain official status with the benefits it can bring. In addition, more than 45 tribes are recognized only by states, which have different rules determining ethnic heritage (Locust & Beck, 2007).

The United States has 619 American Indian reservations and Alaska Native villages that are mainly in rural areas (Clay & Fugleberg, 2005). The Navajo Nation is the largest reservation, encompassing 16 million acres in Arizona, New Mexico, and Utah. Smaller American Indian reservations range from 100 to 1,000 acres. Each local tribal government has the authority to manage its reservation as a sovereign government, which will be explored further. A detailed map of U.S. Indian Reservations is on the National Park Service website at <http://www.nps.gov/history/nagpra/DOCUMENTS/ResMAP.HTM>.

American Indian reservations tend to be located in outlying areas, and Alaska Native villages are considerably more remote. AIDTAC has pointed out that the Center for Independent Living with the largest service area in the United States, Access Alaska, is nearly a half million square miles and contains 100 Alaska Native bush villages lacking any access by road (Clay & Fugleberg, 2005). For a clear picture, the Environmental Protection Agency offers a complete map of Alaska Native Tribal Villages online at <http://yosemite.epa.gov/R10/OEA.NSF/data+&+maps/Tribal+Areas+-+Alaska>

Rural Roadblocks for American Indians and Alaska Natives with Disabilities

Native Americans with disabilities who live in rural or frontier areas often find it difficult to access health care and social services. Resources may be limited and transportation unreliable. A lack of training on federal policy and cultural issues coupled with differing perspectives complicate matters, according to the National Council on Disability (2003). Poverty and substandard housing overshadow Indian Country. More than a third of American Indian households on reservations use wood for fuel (Fugleberg, 2006).

Life in rural Indian Country can be harsh. Many people live in rural or extremely remote areas with frontier-like conditions, a lack of services, and little infrastructure. It can be very difficult to find transportation or, for a person with a disability, physical assistance. This is especially true in Alaska Native villages reachable only by boat or plane. Jim Beck, executive director for Access Alaska, Inc., says his service area is the largest in the country with almost 440,000 square miles (Fugleberg, 2006). Family and friends provide help to people with physical limitations, but living conditions affect everyone. "For a Native American with a disability living on a reservation, the main issue is survival," reports AIDTAC Director Julie Clay (1992).

Territory on the reservation is inaccessible and people with disabilities are not visible out in public very often, described Michael Blatchford, Navajo, an AIDTAC board member, and executive director of Assist! to

Independence in Tuba City, Arizona, in a TANAC Teleconference (2006b). Communities have not worked on solutions to the lack of public access, he says

Challenges Faced by Natives in Urban Areas

In urban areas, challenges for people with disabilities also include limited accessibility and opportunity. In addition, distance from the culture of origin can feed a sense of isolation. Blatchford (Clay & Fugleberg, 2006a) explains the type of encounter CWICs can expect in both rural and urban areas, and how to handle it:

A lot of our people with disabilities are on Social Security. A lot are very skeptical about benefits specialists offering to help them get jobs. A lot are afraid of saying something wrong, something that will cause them to lose their benefits. It is important to deal with the cultural issues, so don't ignore the cultural issues. Work with the person ... and explain to them (you) are not there to take their Social Security away.

Since 1990, scales have tipped so the majority of American Indians and Alaska Natives live in cities, where many similar problems exist (U.S. Census Bureau, 2003). It wasn't until the 1950s that American Indians and Alaska Natives began to leave reservations in significant numbers for the hope of a better life, the product of enticements by the BIA Relocation Program.

According to David Gipp (2006), president of United Tribes Technical College in Bismarck, N.D., the controversial Relocation Program promised more than it delivered, and it left Native Americans and their offspring in many ways void of the rich cultural history and strong family and social networks of the reservation. He writes:

These relocates were recruited by the BIA and promised jobs, housing, counseling, and guidance, as well as community and social resources. Unfortunately, many of these promises were not kept, not everyone finds a job, and those that did found themselves in a lower economic status than they were on their reservations.

The significant migration of American Indians and Alaska Natives to urban areas has not resolved socioeconomic problems or health disparities. In Dr. James Dixon's report (2006) for a TANAC project on outreach in urban areas, he cites the groundbreaking research on Natives in urban areas by the Seattle Indian Health Board's Urban Indian Health Institute. The 2004 study showed the same health disparities as on the reservation.²

The National Council of Urban Indian Health (n.d.) has criticized the U.S. government for not holding up their end of the trust arrangement with indigenous peoples: "Although economic conditions in Indian Country have improved over the years, AI/ANs still lag behind the general population in terms of social, economic and educational attainment levels. ... The widespread indifference and ignorance of policy makers regarding Urban Indian health is – and has been – instrumental to these dismal health rates."

American Indian and Alaska Native Population: 10 Largest Places		
United States City	Population	% of Population
New York, New York	87,241	1.1
Los Angeles, California	53,092	1.4
Phoenix, Arizona.....	35,093	2.7
Tulsa, Oklahoma	30,227	7.7
Oklahoma City, Oklahoma	29,001	5.7
Anchorage, Alaska.....	26,995	0.4
Albuquerque, New Mexico	22,047	4.9
Chicago, Illinois.....	20,898.....	0.7
Tucson, Arizona	15,358.....	3.2
San Antonio, Texas.....	15,224.....	1.3

Source: U.S. Census Bureau, 2000

Native Hawaiians

An estimated 959,603 U.S. residents are Native Hawaiian or in combination with other races, according to the U.S. Census Bureau in 2005. Hawaii has 282,500 Native Hawaiians or Pacific Islanders, more than any other state and 23 percent of the total

population in the state. Native Hawaiians do not live on reservations or exist as sovereign nations as do federally recognized American Indian tribes, but the State of Hawaii offers some select land holdings for development by Native Hawaiians, though demand is far greater than supply.

Native Hawaiians may hail from Hawaii, Guam, Samoa, or other Pacific Islands. The existence of specific tribes or family bands of Native Hawaiians has been fading in part as ancestral roots blend with other Native Hawaiians, but this also is due to centuries of influence and oppression of outsiders (Locust, 2006a). Still, Native Hawaiians often maintain traditional family names.

Phillip Ana, Native Hawaiian and outreach director at Hawaii Center for Independent Living, says history changed the lifestyles of the Native Hawaiian people (2006a). "Before contact with the outside world, there was a very different way of life. It was simple and everyone contributed to the community. ... Each individual Native Hawaiian has adapted to societal changes differently," he says.

Overview of the United States in Hawaii

Hawaii had been an independent monarchy until 1893 when it was overthrown by U.S. business interests, although at the time it was designed to appear as though the population of Hawaii ousted their queen. In reality, the United States had found in the Hawaiian Islands both strategic and economic value, and in 1898, Hawaii was taken as a U.S. territory. It was designated the 50th state in 1959. Many Native Hawaiians still feel that claims to traditional lands remain unresolved.

Source: Adapted from Stromnes-Elias (2007c)

² The UIHI report is available online at <http://www.uihi.org/reports/2004HealthStatusReport.pdf>

Chapter 2

Health in Native Communities and the Concept of Disability

The lives of those with disabilities may be seen as one measure of our society's humanity. If our rights are valued, then all civilization is enhanced."

*- Cinda Hughes,
legislative associate of
National Congress of
American Indians (2006)*

Significant healthcare disparities plague American Indians and Alaska Natives throughout the United States. The troubling inequalities bring home the fact that Natives suffer an increased risk of almost every health condition, according to a 2003 report by the National Council on Disability

status, according to an Indian Health Service Report in 2005. "Lower life expectancy and the disproportionate disease burden exist perhaps because of inadequate education, disproportionate poverty, discrimination in the delivery of health services, and cultural differences. These are broad quality of life issues rooted in economic adversity and poor social conditions," the report said.

The appalling state of health care and increased risk of life-threatening conditions for Native Americans was outlined in a 2004 report by the U.S. Commission on Civil Rights: "Today, in Indian Country, health-related problems and the lack of adequate health care are the enemy."

(NCD). Native Hawaiians also suffer from health problems and an elevated rate of disability. In addition, Native American cultures may view disabilities in unique ways, affecting how they perceive WIPA programs and services.

Health Conditions for American Indians and Alaska Natives

Twenty-two percent of American Indians and Alaska Natives have disabilities, the highest rate of all population groups in the country, according to the NCD (2003). High poverty and school dropout rates, geographic isolation from rehabilitation or health care, and limited employment options exacerbate the challenges for many individuals, including those with disabilities, according to the report. It is worth noting that since the arrival of European colonists, health deterioration has been a major factor in the decline and decimation of Native peoples who lacked immunity to diseases brought by white settlers.

Compared with other U.S. citizens, American Indian and Alaska Native people have long suffered a lower health

American Indians and Alaska Natives Face Harsher Mortality Rates

- American Indians and Alaska Natives face higher mortality rates throughout the lifespan and a shorter life expectancy (Indian Health Service, 2005).
- According to the U.S. Commission on Civil Rights (2004), American Indians and Alaska Natives also are more likely to die from the following illnesses and events:
 - 8 times more likely to die from alcoholism than the rest of the United States, including white and minority populations
 - 7 times more likely to die from tuberculosis
 - 4 times more likely to die from diabetes
 - 3 times more likely to die from accidents
 - 50 percent more likely to die from pneumonia or influenza

Higher poverty rates and limited access to healthcare both contribute to the increased rates of disability and health problems for American Indians and Alaska Natives.

Almost half of low-income Natives are uninsured. The Indian Health Service only reaches half of the uninsured patients, which means many Natives do not receive adequate or any health care, according to The Henry J. Kaiser Family Foundation (2004).

Michael Blatchford describes the reality of life on the reservation for a person with a disability, pointing out that the struggle is for basic survival (2006a): “Most people living on the Rez are in basic survival mode, lacking transportation, telephone access, and in most cases, running water and electricity. ... People want to be able to stay in their home, to get in and out of the house safely, to get to the outhouse safely ... to be warm and have a means to haul water.”

The fact that having a disability leads to an unpredictable life is common for many Native Americans with disabilities, says Cinda Hughes, a member of the Kiowa Tribe and legislative associate with the National Congress of American Indians in Washington, D.C. (TANAC, 2006b). She reinforced the perspective by describing a possible day in the life of a Native person with a disability:

We navigate our lives like trapeze artists on tightrope, many of us with no net to catch us should we fall. We live with constant uncertainties: Will someone actually show up to help with bathing and dressing for the day? Will the doctor be able to see me today? Will I ever find a job? Which of my co-workers may I approach to help me in the restroom today? Even though the concept of “disability” is new to many of our Indian communities, the ideals of independence and mobility are not.

Concept of Disability in American Indian and Alaska Native Traditions

There is no word for disability in most traditional American Indian cultures, a point on which AIDTAC has reflected in several publications. This lack of a parallel for the Western concept of disability results in a dissonance between cultures in how to live with disabilities. Julie Clay and Alan Fugleberg (2006a) write that the American Indian concept does not look at physical characteristics but considers disability to be disharmony of spirit. “In addition, the cultures and

traditional beliefs of the many tribes vary significantly, each with a unique set of creation stories, religious doctrines, and sacred taboos,” they write. The body, mind, and spirit must strike a balance to achieve health and wellness; if there is disharmony in any aspect of the human being, the whole person is affected, says Clay, Omaha tribal member and AIDTAC director. She hastens to add: “Just because a person may have a physical or mental disability, however, does not mean one is in disharmony or in a state of unwellness. But if there is disharmony in one’s environment or reactions to certain events, then a state of unwellness is present.”

Traditional Views on Disability

Julie Clay, an expert on disability and independent living in Native communities, points to Dr. Carol Locust’s work from 1985 as perhaps most illustrative of general Native American cultural concepts of disability. According to Clay, Locust identified 10 spiritual beliefs common to most Indian tribes that serve as a good basis for understanding the Native perspective on disability.

1. American Indians have a belief in a Supreme Creator. In this belief system there are lesser beings, also.
2. Man is a three-fold being made up of a body, mind, and spirit.
3. Plants and animals, like humans, are part of the spirit world. The spirit world exists side-by-side, intermingling with the physical world.
4. The spirit existed before it came into a physical body and will exist after the body dies.
5. Illness affects the mind and spirit as well as the body.
6. Wellness is harmony in body, mind, or spirit.
7. Unwellness is disharmony in body, mind, or spirit.
8. Natural unwellness is caused by the violation of a sacred or tribal taboo.
9. Unnatural unwellness is caused by witchcraft.
10. Each of us is responsible for our own wellness.

Source: Clay & Fugleberg, 2006a

Oscar Frank, Jr. (2006), a member of the Tlingit Tribe who is a job coach with the Fairbanks Resource Agency in Fairbanks, Alaska, writes that elders once described a person with a disability with a word translating as “poor thing.” Frank says the intent of the phrase was positive: “We need to help the tribe; we need to help the family.

We don't know why this person came into the world this way, but we need to do all we can to help the family provide food, clothing, and do what we can to help this person." Frank also recalls that before outreach and education bore influence on Alaska Native villages, many people thought a disability meant the family was being punished for something bad done in the past.

After his serious injury that led to a permanent disability, Michael Blatchford was sent to a medicine man for traditional treatment. He recalled the visit in a TANAC teleconference (TANAC, 2006b): "The medicine man told me the reason I was the way I was and why it happened is because I had touched dead people. And that comes from being a paramedic, and saving lives, things like that. Apparently I didn't have the right traditional healing method that would have kept me from getting this way. There's that stigma."

An open heart and mind will help WIPA program CWICs in their understanding of other cultural views on disability. Native Americans are indigenous to the country and have traditional belief systems that can vary among tribes and different groups (Clay & Fugleberg, 2006a).

Native Hawaiians and Health

Health risks such as diabetes and asthma contribute to an increased risk of disability for Native Hawaiians, who experience a disability rate of almost one in five. Poor health can be attributed to cultural barriers, limited access to health care, poor nutrition and lifestyles, according to Dr. Weol Soon Kim-Rupnow, project director of the National Technical Assistance Center Asian American and Pacific Islanders in Hawaii, in a TANAC Teleconference (2006b).

These developments were born of the influence of European colonists, according to Papa Ola Lokahi (n.d.), a nonprofit organization working to improve health and wellness in Hawaii. Outside influences challenged the Native Hawaiian way of life until it collapsed, leaving people vulnerable to physical, emotional, and spiritual illnesses:

The traditional Hawaiian subsistence way of life was a physically active lifestyle with a simple nutritious diet that maintained a robust and healthy

population. In addition ... Hawaii was free of most diseases and scourges that affected other parts of the world. Unfortunately, this isolation also meant that Hawaiians did not have the antibodies to fight diseases.

Of grave concern for Native Hawaiians is cardiovascular disease; they are 44 percent more likely to die from heart disease and 31 percent more likely to die from stroke than other U.S. races. Risk factors for cardiovascular disease, including obesity and smoking, occur more in Native Hawaiians, according to the Hawaii State Department of Health (2000).

Increased Health Risks for Native Hawaiians

- Native Hawaiians were 2.5 times more likely to be diagnosed with diabetes than non-Hispanic white residents of Hawaii of similar age.
- Native Hawaiians had an asthma rate almost twice the rate for all other races in Hawaii.
- Native Hawaiians had a smoking rate of 30.9 percent compared with 19.7 percent of Hawaii residents overall.
- Native Hawaiian infant mortality was almost 60 percent higher than non-Hispanic whites.

Source: Centers for Disease Control, 2004

Concept of Disability in Native Hawaiian Communities

Disability among Native Hawaiians is not seen as a hindrance to a person's lifestyle, but rather as an opportunity to grow and succeed in new and different ways, according to Philip Ana, a consultant on Hawaiian issues and outreach director for the Hawaii Center for Independent Living (2006a). A disability teaches an individual to compensate by strengthening other personal qualities. Ana offers an example:

When a child is born with a disability, the parents look at some traditional ways they can strengthen the child physically to compensate for physical loss in limbs and in eye sight. Exercise in running on the beach, burying limbs in the sand are some traditional ways practiced by Native Hawaiians. ... The parents ... are harder on this child to succeed.

Chapter 3

Impact of Tribal Sovereignty on Disability Programs

The power to govern carries responsibility. By very definition, sovereignty can encourage tribes to build better access to employment, services, and opportunities. Tribes are uniquely situated to create their own plans to accommodate people with disabilities in their communities in ways that work within their cultures.”

- Katja Stromnes-Elias (2007b)

There is a dominating historical experience shared by present-day American Indians, Alaska Natives, and Native Hawaiians. All endured having their land forcibly taken and cultural identities threatened by white settlers. The three groups experienced this in different ways and at different times, however, so relationships with the U.S. government have developed differently. The following section will shed light on how Native people relate and negotiate with the United States and how this interaction affects people with disabilities, including a look at tribal infrastructure and disability programs.

Background on Tribal Sovereignty

In the early 1800s, after nearly 300 years of treaties made and broken by representatives of European nations and the more recent U.S. government, the U.S. Supreme Court called American Indian tribes separate nations free from state laws or regulation. Near the end of the century, however, the federal government stopped making treaties and began requiring American Indians to assimilate and give up their languages and cultures. Children were forced into boarding schools, and land was marked for ownership. A TANAC Issues Brief discusses the consequences (Stromnes-Elias, 2007b):

Tribal lands were divided and allotted to individual American Indians; what was left was sold off mainly to non-Natives. Assimilation served its purpose; it tore apart American Indian families and communities. It also compounded the deep mistrust resulting from years of treaty-breaking on the part of the U.S. government.

“During this time period, Indians only had a few choices. They could assimilate into mainstream culture

or suffer the consequences,” writes Tawa Witko, a Sicangu Lakota tribal member and clinical psychologist (2006a). In the course of the 20th century, American Indians lived through many changes in status that eventually developed into the sovereignty that was backed by the passage of the Indian Self-Determination Act in 1975. In addition, since 2000, the federal government has required consultation and collaboration with tribes in developing federal laws that have tribal implications. Tribes are encouraged to make their own laws in step with federal policies.

Government to Government: Native Americans and the United States

Federally recognized American Indian tribes have a unique relationship with the U.S. government in terms of sovereignty. They have the responsibility to make and enforce laws, regulate businesses, and tax tribal members on reservation and trust lands.

American Indian tribes negotiate directly with the U.S. government. This government-to-government relationship sidesteps state governments, which have no authority. The federal government regulates tribes; sovereignty is dynamic and ultimately at regulatory oversight.

For the most part, Alaska Natives do not have the same relationship with the United States. There is one Alaska reservation, and the Alaska Native Claims Settlement Act of 1971 determined Alaska Native land rights by dividing 44 million acres into regional and village economic development corporations. Alaska Natives are shareholders. Native claims for much of Alaska were relinquished to obtain holdings in the corporations and about \$962.5 million.

In general, according to a report by The Economics Resource Group, Inc. and The Institute of Social and Economic Research, governance is more complicated for indigenous peoples in Alaska than for American Indians in the lower 48 states. The report synthesized the differences in 1999: “The institutions that matter most on Indian lands in the lower forty-eight are either tribal or federal, and relations between them, while sometimes tense, tend to be well specified. In contrast, complexity, ambiguity, and the multi-layering of institutions are central characteristics of the Alaska Natives situation.”

Alaska Native self-governance is a subject of ongoing debate, and the economic report made recommendations based on the 1999 Alaska Natives Commission report. It urges the implementation of self-governance for Alaska Natives, and points to productive examples of villages or sub-regional areas where Alaska Natives have worked toward sovereignty. The report summarized the developments:

The movement for tribal self-governance has produced a remarkable array of new governing strategies and institutions. From village-regional relations in the Northwest Arctic region to municipal-tribal government consolidation in Quinhagak to tribal consortia in the Yukon Flats and elsewhere, a number of Native communities are inventing solutions to their problems. Their efforts contain important lessons for all of rural Alaska and provide a number of self-governance options for Alaska Natives to consider.

Native Hawaiians do not have sovereignty or self-government as do American Indian tribes. A sovereignty movement in Hawaii has kept alive the Akaka Bill in Congress for several years, but it has not passed. The bill would lead to Native Hawaiians gaining federal recognition and self-governing status similar to American Indians.

Regardless of sovereign status, information in this publication about barriers to services for people with disabilities as well as outreach suggestions can be applied to all Native groups – American Indians, Alaska Natives, and Native Hawaiians – and the communities in which they live.

Tribal Sovereignty: Q & A with Dr. David Beck

A basic overview of tribal sovereignty and its implications for people with disabilities on tribal lands can assist CWICs in the field. The following information about sovereignty is adapted from Dr. David Beck’s paper on tribal sovereignty for AIDTAC in 2007. Dr. Beck is a professor of Native American Studies at the University of Montana.

Q: What is tribal sovereignty?

A: American Indian tribes have a special status within the federal system of the United States based both on their prior control of all the land and resources of this country and on the constitutional, congressional, and judicial rights recognized by the United States. They have a political status in this country unlike any other group of people, based on the treaty clause of the U.S. Constitution. As a result, American Indian individuals are members of tribal nations and citizens of the United States, having some rights and responsibilities that differ from other Americans and some that are the same. The complex relationships are constantly evolving. Tribes with federal recognition have the greatest powers of self-governance, but degrees of sovereignty vary widely from tribe to tribe based on their constitutions as well as their history. Unrecognized tribes, and their members, in some cases have rights deriving from being Indian and in other cases lack those rights. And state-recognized tribes have rights derived from the relationship as defined jointly by the tribe and the state. Some of the latter arrangements predate U.S. nationhood.

Q: What is the trust relationship?

A: In its most basic terms, the trust relationship posits that the United States has a responsibility for the survival and welfare of the people whose land and resources were dispossessed in order to build what by the 20th century was the wealthiest nation in the world. One example, the Indian Health Service, is supported under this trust doctrine as a responsibility that the U.S. has assumed to ensure the health of Native Americans, as part of the exchange to gain access to their best lands and the resources on those lands.

Q: Are there limitations on tribal sovereignty?

A: Congress has restricted both tribal and federal jurisdiction in Indian country. With exceptions, Indian nations have no control over international relations. Since the late 19th century, the United States has claimed jurisdiction over specifically defined “major crimes” such as felonies. Tribes have broad civil jurisdiction over other domestic matters, but only when their authority has not been restricted by Congress; as a rule, tribes lack that jurisdiction unless they specifically claim it. To complicate matters, many Indian reservations were physically or politically diminished or disbanded by various policies in the 19th and 20th centuries; in many cases non-Indians have become the primary land-controllers, either by ownership or lease of Indian lands.

Q. How does sovereignty affect the coverage area of CWICs?

A: The only way to know the extent of sovereignty in a specific tribal community is to understand the community individually. Service providers should grasp what tribal sovereignty means in general terms and then look at the specific conditions. Develop relationships with community members in a respectful manner; demonstrate your openness to learning the intricacies of the historical development of the community

Tribal Lands Lack ADA Protections

Tribal sovereignty is significant to people with disabilities living on reservations or tribal lands where the Americans with Disabilities Act (ADA) is not enforceable. The ADA was passed in 1990 to protect the rights of people with disabilities and implement equal access to jobs, facilities, transportation, and telecommunications. Yet American Indian sovereignty shields tribes from private lawsuits on ADA grounds, removing the incentive to make following the law a priority.

The National Council on Disability expressed concern about barriers to accessibility and employment in Indian Country (2003). Poor coordination by agencies, a lack of understanding of diverse tribal communities, and limited local tribal planning to protect and support

people with disabilities are problems and, according to the NCD, “the services and resources that should be available to people with disabilities are not always accessible in tribal communities. Chronic under-funding of tribal community programs and a lack of physical infrastructure upgrades create barriers for people with disabilities in these communities.”

American Indian tribes have moved away from traditional ways of handling social issues that need attention, says Dr. Vine Deloria Jr., American Indian political scientist and activist (American Indian Policy Center Spring Forum, 1996). He suggests tribal governments engage elders in helping address community issues. Disability rights would be one arena where elders could be called on for wisdom.

Disability Survey and Tribal Efforts Prompt Action

The American Indian Disability Legislation Project, conducted by the University of Montana Affiliated Rural Institute and sponsored by the National Institute on Disabilities and Rehabilitation Research, surveyed tribes in 1994 to determine what was being done for the benefit of people with disabilities. At the time, only about six percent of respondents were very familiar with disability legislation such as the ADA (Fowler, L., Seekins, T., Dwyer, K., Brod, R. & Locust, C., 2000).

The analysis also finds that the same disability issues that tribes considered important received low levels of satisfaction in terms of how well the tribes were addressing those issues. The survey exposed a gap between tribal governments and the issues faced by people with disabilities. It also prompted case studies of five tribes that proceeded to work through the Tribal Disability Actualization Process (TDAP) and develop their own disability legislation (Dwyer, K., Fowler, L., Seekins, T., Clay, J., & Locust, C., 2000). The TDAP was developed to inspire local analysis leading to positive change with tribal authorization for people with disabilities in Native communities.

The process worked. It “generated recommendations that led to changes in tribal governments’ practices and policies,” writes LaDonna Fowler in her 1996 report on the case studies. In fact, the Pine Ridge Oglala Lakota Tribe of South Dakota adopted the ADA as a whole, and the Confederated Salish and Kootenai Tribes of Montana passed a resolution similar to the ADA. The process prompted other tribal governments to change their perspectives and laws regarding tribal members with disabilities.

Note: The American Indian Disability Legislation (AIDL) project was funded by grant #H133G30031-94 from the NIDRR, U.S. Department of Education.

Engaging Sovereign Tribal Communities

There are two federal agencies common in tribal areas that are critical to understanding tribal worlds, according to Dr. Carol Locust (2006a). The Bureau of Indian Affairs is the federal agency that oversees tribal affairs. The Indian Health Service is the federal provider of health services. Each American Indian tribe has an elected tribal government that manages the reservation community, and each Native cultural group has its own customs and politics.

Sovereignty preserves the tribal right to self-govern. Each tribe has the choice to establish disability standards. The National Institute on Disability and Rehabilitation Research (1995) highlights the opportunity within the dilemma: “While this arrangement clearly allows the tribes to protect their culture and values, it means that special efforts must be made to extend potentially good ideas to those on reservations who might benefit from them.”

Taking time to get to know a community can help pave the way for an open conversation about improving

access and employment opportunities for Social Security Administration beneficiaries with disabilities. Marsha Katz (n.d.), project director at The Rural Institute, advises that taking time is a key component in building relationships. “Building relationships, showing respect for the culture, and earning trust are necessities if one is to partner successfully with Indian communities. Our challenge is to suspend whatever romantic or stereotypic notions we may come with, in favor of just being respectful and open to learning,” she writes.

Patience, persistence, and follow-through have helped CWICs get the message out in a culturally effective way on reservations. Try not to focus on the difficulties, but turn challenges into hope; the more a community acknowledges and addresses disability, the better the conditions will be for everyone in the area. Collaboration among tribes and state and federal governmental programs is in part the key to helping people with disabilities live secure and full lives on tribal lands. Respect and consideration for all members of the community is, after all, the hallmark of the Native spirit.

Chapter 4

Cross-Cultural Outreach in Native Communities

“This is another key to effective outreach: the ability to listen and making adaptations.”
Michael Blatchford, (2006b)

SSA beneficiaries with disabilities in Native areas benefit immeasurably from culturally competent service providers (Clay & Fugleberg, 2006a). Without cultural understanding on the part of the service worker, chances will be slim that an individual with a disability will feel fully informed about their options.

A culturally skilled service provider, on the other hand, will apply strategies and techniques that match cultural values (Marshall, Johnson, and Lonetree, n.d.). Community Work Incentives Coordinators have expertise built from training and experience. A willingness to become culturally aware will complete their toolbox and improve the likelihood of productive and rewarding interactions. One way to increase cultural understanding is to consider outreach to be filled with teaching moments. Both positive and negative experiences on the surface can be considered more deeply in the context

Comparison of AI/AN and Euro-American Values and Communication Styles

In the following charts, traditional American Indian and Alaska Native (AI/AN) values and communication styles are compared with Anglo (or mainstream) values and communication styles. The tables are adapted from several TANAC publications and references. Consider the differences relative to your own observations. Spending time in Native communities is the best way to keep the differences – while worthy of attention – in perspective.

Traditional AI/AN Values	European American Values
Cooperation, sharing, humility	Competition, possession, accomplishment
Group harmony	Individual achievement
Living in the present	Working, planning, saving for the future
Sense of time relative, flexible; enjoy present	World is built around clock; time is money
Seek harmony with nature for health	Control and organize nature for health
Deep sense of humor about life	Light humor and jokes
Work for survival; it has its place	Work for its own sake, as an ethic
Extended family orientation	Nuclear family orientation

Traditional AI/AN Communication Styles	European American Communication Styles
Non-interference, silence is valued	Giving advice, directing a conversation
Storytelling as a teaching tool	Direct criticism, immediate feedback
Emotional control, contemplation	Action, direct questioning, confrontation
Patience, group consensus for decision	Rapid responses and quick decision-making
Eye contact can be a sign of aggression	Eye contact a sign of respect
Light handshake, if at all	Firm handshake a common greeting
Behave according to what feels right	Behave based on logical argument

of culture to the benefit of the CWIC, who may be on unfamiliar ground but learning.

This section offers an overview of cross-cultural considerations related to social protocol and customs of American Indians, Alaska Natives, and Native Hawaiians, and how to build trust. Typically, protocol and expectations relate to cultural background no matter where a person lives, but degrees of acculturation can vary widely in rural and urban areas. Dr. Carol Locust (2006a) writes: "Education, time off-reservation, employment, and outside religions have impacted greatly on indigenous cultures, traditions, diversity, and acculturation."

Cultures Form Social Protocols

Cultural values shared by Native Americans may include the perspective that the dominant culture in the United States lives quite differently and, as noted by the expert on American Indian health-related beliefs Dr. B. Josea Kramer (1992), that "mainstream attitudes are intolerably rude, such as getting right down to business; addressing strangers in loud, confident tones; and frequently interrupting speakers. These attitudes increase social distance and decrease confidence in non-Indian professionals."

A chart comparing cultural values is a fascinating way to consider different cultures and ways of life (see Table on page 14), but the question of how the information can be used is more difficult. Dr. Carol Locust, TANAC project consultant (2006a), offers tips for CWICs in bridging the gap to Native cultures. The following list is adapted from her guidelines to avoid social blunders. In general, she suggests seeking out an elder in a group for guidance. "If the request is made in sincerity, with a true request for knowledge, it will not be termed offensive," she writes. The following is applicable to all Native American groups:

Good manners: Talk friend to friend, not as service provider to client. Be human. Follow the tribal way of self-identification (tribe/clan/village) by substituting parallel settings.

Hand clasp: Some cultures clasp hands gently with slightly firm pressure, no shake. Others may have adopted the hard handshake. Use the soft hand clasp to

avoid being offensive.

Eye contact: Brief eye contact in the first few minutes is important, but extended eye contact is rude and even considered harmful. Head and eyes looking downward is respectful.

Interacting with others: Try not to call attention to yourself. Speak softly, smile, and don't disagree, but say things like "there are other ways of looking at it," or "perhaps we can come to a compromise." The Moccasin Telegraph in the community will get the message to people with disabilities and their families that you are a good person.

Understanding rationale: When you don't get the responses from people you think would be in their best interest, there is usually a good reason. Native loyalty is to the family, clan, and tribe. Unity of the group is binding and dictates responses and responsibilities. One cannot expect commitments contrary to loyalties to the community or responsibilities.

Time is relative: Try to be flexible with times; lateness of an indigenous person may be a factor of culture, transportation, childcare, but is seldom an expression of defiance.

Notes on Alaska Native Culture

The importance of elders in Native cultures and communities is especially strong in Alaska Native villages. Interaction among all generations is important, according to Oscar Frank, Jr., (2006) consultant for AIDTAC, member of the Tlingit Tribe, and job coach with the Fairbanks Resource Agency in Alaska. Elders help facilitate and keep traditions alive. "Elders are one of the first important links when coming to a village for the first time," Frank writes. He advises CWICs to make contact with elders or tribal administrators in a service area, keep family members in the loop, and talk in a straightforward and honest way.

It is difficult for those outside Alaska to comprehend the severe and remote nature of life in many outlying villages, and 58 percent of Alaska Natives live in rural areas, according to the Alaska Native Policy Center (2004). Frank adds that for "many bush villages, there is no road access, only airplanes. People travel by snow

machines in the winter, and boats in the summer allow river access. Winter months can be very cold – 51 below zero in Fairbanks – and people stay in” (Clay & Fugleberg, 2006a). Frank suggests taking into account brutally cold winters and extraordinarily high fuel costs when gauging SSA beneficiaries’ options of finding work or transportation. Coupled with this, “unemployment is over 60 percent and there are almost no jobs,” he adds (2006).

Observations Specific to Native Hawaiian Culture

Aloha Eguchi-Dixon (2006a), AIDTAC Native Hawaiian consultant, says there is a considerable awareness and participation in Hawaii’s wide-ranging ethnic population in order to preserve the Native cultural heritage. “Hawaiian cultural values and traditions embodied in such words as “aloha” (love), “ ‘ohana” (family), and “aloha ‘aina” (love of the land) are understood and respected widely throughout society. Conversely, there is a deep appreciation among the (Native Hawaiians) for other ethnic traditions and cultures.”

In addition, Cavin Castaneda (2007), outreach specialist for Medicaid and Social Security Work Incentives Education, says the expectation in Native Hawaiian communities is rapport and relationship-building. Offer yourself as a compassionate spirit who is welcoming, caring, and understanding in all interactions, in what is known as the Aloha Spirit, he says. “First and foremost, the Aloha Spirit is a simple and universal disposition. It’s culturally sensitive to be conscious of embracing and extending an “Aloha Spirit” when reaching out to Native Hawaiians as well as all living beings.”

One note on the pleasant and open spirit of Native Hawaiian communities: Philip Ana, outreach director for Hawaiian Center for Independent Living, commented in a TANAC Teleconference (2006d) that Native Hawaiians do not always ask for what they need, potentially leading to passive frustration. “They are typically a group of people who tolerate their circumstances, to the point of being angry. They usually work with what they have, but I think there are times when they get angry,” he says. To that end, Ana says he is always careful to

Forming Social Bonds in Native Communities

Cavin Castaneda, outreach specialist for Medicaid and Social Security Work Incentives Education, offers tips on outreach to Native Hawaiians, including:

- Get to know the person and family before other issues are addressed.
- Start by asking simple questions.
- Families want to see you as a human being just like them.
- Be compassionate by listening to their needs and what is important to the family.
- Show the feeling that you care about their success.
- Make a conscious effort not to be rushed and hurried; show your humanity.

Source: Castaneda, 2007

make sure the client and family members are aware of how the issues at hand can fit with their traditional culture, to ease trust and help meet needs. “Because of a dominant family structure, and extended family, I also recognize that independence may begin in the home first, and second in the community,” he says. Ana (2006a) expands on this when he writes: “Members of the family often have a great deal of influence over the decisions/choices made by a person with disabilities. This often results in receiving services that meet the family’s needs and not necessarily the disabled person’s needs. This will always be a delicate issue for an outreach worker. Change is often slow and requires understanding.”

Align with other outreach services to help gauge how WIPA programs will be received and open doors to meeting respected people in the community. “Do not promise what you cannot deliver,” Ana says. “It is important that you have a reputation of being a good (outreach provider); one who will follow up on concerns or problems with the services that were provided.”

Guidelines for Respecting Native Cultures

The following is adapted from AIDTAC Native Hawaiian consultant Aloha Eguchi-Dixon's guide to Native Hawaiian culture (2006). The edited list is applicable to appropriate behavior in all indigenous cultures.

- Be polite, gentle, and well-mannered.
- Attend community gatherings or social activities.
- Listen more than speak; if you are not sure, ask.
- Don't question reasons you don't understand; they may have religious significance.
- Don't ask religious questions. People will share as they wish.
- Ask a Native liaison as to appropriate way to ask personal questions.
- Greet with a hello and gentle handshake.
- Don't stare or initiate hugs or touching; avoid finger-pointing.
- Treat everyone in the family with kindness.
- Avoid gossip and do not act on rumors.
- Don't interrupt; intelligence is measured by ability to learn through observation.
- Follow through on what you say you will do.
- Ask before taking any photographs.
- You may encounter resentment or prejudice, which may be a test of your character; try not to be sensitive or defensive.

Source: Eguchi-Dixon excerpted the guidelines in part from "Cultural Sensitivity" published by Black Mesa Indigenous Support in Flagstaff, Arizona, located online at http://www.blackmesais.org/cultural_sen.html

Building Confidence out of Historical Mistrust

According to a 2003 report by the U.S. Commission on Civil Rights, resources for Native American programs and services are disproportionately lower than for other populations:

In exchange for land and in compensation for forced removal from their original homelands, the government promised through laws, treaties, and pledges to support and protect Native Americans. However, funding for programs associated with those promises has fallen short, and Native

peoples continue to suffer the consequences of a discriminatory history. ... Native Americans continue to rank at or near the bottom of nearly every social, health, and economic indicator.

CWICs may encounter distrust at different levels in the community's government and social structures, both directly and indirectly. Mistrust is a consequence of broken promises, and for Native Americans, it is based in the reality of centuries of betrayals on the part of the U.S. government (Stromnes-Elias, 2007c).

CWICs should be aware that mistrust is not personal; it is a sign that more time should be taken to build trust. It will take time to earn the trust of SSA beneficiaries who may be in a vulnerable position financially or have had negative experiences in the past with social services or government agencies. Trust and respect are attainable in rural and urban areas. Julie Clay (1992), AIDTAC director and a Native American with a disability, explains that Native people generally respect those with knowledge and experience who express needs and ideas in culturally appropriate ways. In addition, some basic principals will help:

1. Explore this guide, spend time on the chapters on cultural awareness and outreach.
2. Find a cultural or tribal "liaison" to introduce you to the community.
3. Use the outreach checklist at the back of the guide as you get to know members of a community and first meet with SSA beneficiaries.
4. Consider holding a Talking Circle.
5. Follow through on what you say you will do.

Chapter 5

Tribal Members as Cultural Liaisons

I want to let all the (CWICs) know not to be overly concerned about going on to reservations and working with people. There is a process you must follow and steps to honor their culture and traditions, but the people will welcome you, and there is a huge need for the services.”

Gary Flom, project coordinator for the WIPA Project at the Montana Center on Disabilities in Billings (TANAC Teleconference 2006a)

Successful outreach does not follow a formula. Conducting outreach in American Indian, Alaska Native, and Native Hawaiian communities is a creative journey that rewards with successes and surprises. There are, however, strategies that have been shown to be useful when working with Native Americans. The following chapter is designed to help you make contacts, join community gatherings, and talk in a way people can understand. It also explores incorporating family members and elders. The section on media offers effective ways to use newspapers and radio.

Find a Tribal Liaison

To ease the outreach process, get to know a person who can serve as a cultural liaison and guide you through the process of reaching out to SSA beneficiaries with disabilities. Research has shown that engaging tribal leaders in your work will be extremely valuable (Siegel, et al., 2005). The following steps will help you engage an elder, tribal leader, or other respected community member. (Stromnes-Elias, 2007a).

1. Ask a community leader, such as the tribal health board director or tribal council president, for a meeting. He or she may meet with you, or they may refer you on to other respected community members they think would serve you better.
2. Arrange a face-to-face meeting at a location of the person's choice.
3. Listen carefully. Show interest in their knowledge and viewpoints. Learn as much as you can about the area, customs and protocol. Follow their lead in social customs such as handshakes.

Once you have a tribal contact and had the chance to tell them about WIPA services, ask for help arranging a gathering of community members to explain the program. If the liaison is a service provider, ask to join a community visit (Katz, Scalpcane, Clay, and Fugleberg; 2007).

Tribal Liaison Offers Wisdom to CWICs

Quintin Kingfisher is the Tribal Vocational Rehabilitation Director in Lame Deer, Montana. He has provided support as an American Indian tribal liaison to WIPA Project Coordinator and CWIC Gary Flom, who appreciates Kingfisher's expertise, insights, and assistance in conducting outreach to American Indians (G. Flom, personal communication, August 24, 2007).

The support is mutual, Kingfisher says. He has benefited from knowing about WIPA programs in helping SSA beneficiaries with disabilities make informed decisions. "It has been a good thing for everybody involved," he says (Q. Kingfisher, personal communication, August 28, 2007).

Kingfisher emphasizes cultural competence in bringing a CWIC a long way in a tribal area. In order to get established in the community as a person worthy of trust, it is important to get in touch with tribal leaders and make appropriate contacts to learn about the culture, he says. "If we can be the go-between, if someone is going to come and interview and talk to some of our consumers, it would be appropriate for us to run interference on that and to say, 'This is how we should frame it.' Because there will be lots of different perceptions."

He points out that there are often unnecessary drops in service in tribal areas, so the importance of follow-through cannot be overemphasized. Also, it is important to explain government systems in clear terms. There may be a fear, as well, of losing benefits. "People don't understand the system that well, and their view of money is very different from mainstream America," Kingfisher says. "The system doesn't realize we have always been transitional people, we still need to pay bills, we still need to be as self sufficient as we can, and we want to try and help culturally as a family."

Kingfisher says that partnerships between tribal groups and the federal government can help improve the situation for SSA beneficiaries with disabilities.

"We need to teach each other. There is no ADA, but we can capture the spirit of ADA and glean useful things; glean things that are going to help and not hurt," he suggests. "And I think, as a tribal advocate, my message is: 'If we're going to put people to work who have a disability, then give us the support we need to take them off the rolls.'"

Partnering with Other Programs and Services

Linking to other programs and services will help establish tribal contacts, build relationships, and improve trust. It also opens the door to collaboration for the benefit of the people who are served.³ Partnering is part of the five steps to outreach Michael Blatchford (2006b) provides based on the work he does on the Navajo Reservation:

1. Define outreach specifically as it relates to your organization.
2. Define the target group or population you want to reach out to.
3. Establish partnerships with established community resources. Listen!
4. Maintain a presence within the community and provide ongoing follow-up.
5. Adapt your methods to respect the culture.

Effective interaction between disability programs and tribal communities will occur and be sustained by the networking that goes on between agencies involved in both. Based on guidelines by an AIDTAC Issues Brief on outreach (Katz et al., 2007), here's how to work with the partnerships you've established:

- Find a Native American community program with a natural connection to people with disabilities, such as tribal vocational rehabilitation, tribal health, Indian Health Service, a public health representative, tribal employment, a branch office of state rehabilitation, or a Center for Independent Living.
- Urban Indian Centers are useful in highly populated areas. If there isn't one, try community colleges or universities for student groups.
- Seek contacts on boards for local or state disability groups.

Connecting with other community resources has another benefit. The partnerships will help get the word out about WIPA programs to the people in need of services. Kimberly Irwin, Rosebud Sioux and SSA Regional Public Affairs Specialist on American Indian Outreach in San Francisco, suggested in a TANAC Teleconference

³ On the TANAC website, there is a useful history of the successful development of federal benefits training with a team of service providers on Montana's seven reservations provided by Gary Flom. To read the history, see the teleconference materials for TANAC Teleconference on Thursday, Sept. 21, 2006, called Model Programs to Increase Trained Tribal Members as Liaisons between Their Tribes and BPAO Programs and located online at http://www.nativeamericancwic.org/TeleInfoPage_2006_09_21.html

working with Public Benefits Assistance and Outreach in tribal communities to streamline the outreach and ensure that it's culturally appropriate ("Trained Tribal Members," 2007a). Another possibility is to subcontract tribal members in outreach efforts, an approach Mary Lundy Meruvia, Program Director for the Mississippi Band of Choctaw Indians' Vocational Rehabilitation Services Program and Office for Independent Living Services, finds successful in her work.

Also, when working with other agencies, concentrate on open communication and defining limits in order to avoid conflicts of interest. According to a TANAC Issues Brief (Stromnes-Elias, 2007d): "Make it clear how WIPA programs fit into the community without overlapping other services. ... Territorial issues may arise, but communication and follow-up can help resolve disagreements. CWIC Cassie Stoesser in Pierre, South Dakota, suggests taking time to explain how the work of CWICs only enhances what others are doing."

As you start connecting with tribal communities or urban community centers for Indians, think about holding a gathering called "Talking Circle." The next chapter of this guide will explore Talking Circles and how to hold one.

A Familiar Face in an Unfamiliar Setting

Attend community functions in your service area as often as possible. Make a regular stop in town, check bulletin boards in the local market, and attend special community celebrations. Find a place to sit down and work, perhaps the waiting room of Indian Health Service facilities. Go to powwows. When possible, set up a booth or join another service provider at community events.

Cinda Hughes (2006), legislative associate for the National Congress of American Indians, says spending time with people in the community – at tribal powwows and other cultural events, for example – is one of the most effective and important aspects of outreach. "It takes time and effort to learn about a different culture. ... After two or three visits, (CWICs) should notice more interest in learning about their program," she says.

Practicing User-Friendly Language

Listening is the first rule of good communication. Listen with care in Native communities. Learn what is expected by practicing the power of observation, a common and respected practice in many Native cultures. The power of listening is described by Covering Kids and Families (2006): “When community members tell their stories, you are being honored with their ‘truths,’ so you should listen quietly and carefully. Do not interrupt to ask questions or talk over them. The latter is a contemporary communication pattern. If you are working with traditional people ... you should wait until they are finished before you respond.”

In addition, Dr. Carol Locust (2006b) developed a guide on user-friendly communication; its emphasis is to simplify and slow down. The following tips are adapted from the guide.

1. Use simple explanations for complex words. Go slow, draw diagrams, and use words that are in the local vocabulary. Start general, be specific, speak personally.
2. Avoid acronyms. Say the full name and explain it.
3. Explain specific benefits of each program. Allow time for questions.
4. Explain bureaucratic jargon in simple terms. Some words to explain: access, chronic, criteria, eligibility, impairment, impediment, integrated, recipients, substantial, etc.
5. Pause often. Use silence to allow time to process. Give 15 seconds before asking a question again in another way.
6. Smile. Avoid prolonged eye contact or crossing the arms.

When asking questions, be sensitive to cultural issues. If it means changing your approach, you will get better data and provide better services in the long run, Michael Blatchford says in his guide on outreach (2006b). There is no Navajo word for disability, which provides a good example of how to talk around unfamiliar or bureaucratic English words. Blatchford writes: “Nine times out of ten, if we ask someone what their disability is, they will say they do not have one. But if we ask what they have difficulty with or how their

health is, they might respond. ... It is then our job to translate this information into a format that fits our record-keeping categories.”

Slowing Down, Taking Time

The following is taken from Dr. Carol Locust’s guide on user-friendly language (2006b).

- Rate of speech is important for user-friendly communication. Our brains store languages in linguistic “trees.” If our brain is functioning in a tree containing a tribal language, such as Hopi, it may take that little linguistic squirrel several seconds of quiet time to run from the Hopi tree to the English tree, climb up, and locate a word and its meaning. Slowing your rate of speech gives the squirrel more time to find the right tree and the right word.
- Don’t rush into your work mode too quickly when a Native client comes into your office. Give your client ten to fifteen seconds (more if you have time) of silence in which to become accustomed to you, your office, the atmosphere. Shuffle papers, look for something in a desk drawer, etc. Smile a lot, and after the silence comment on the weather, a ball game, something common to both of you. Then proceed with business.

In general, slower speech and simpler words will be more effective in cross-cultural communication. Learn to be comfortable with silence. When possible, use real-life examples to simplify an explanation. Sharing your own personal stories can make communication and understanding more interesting. Finally, frame messages as choices. SSA beneficiaries will be more receptive and invested when they have the information they need to make their own decisions.

Design printed materials so they are small enough to tuck into a pocket or purse, and avoid using all capital letters, says Linda Burhansstipanov (personal communication, February 24, 2007), executive director and president of Native American Cancer Research. Also, bring any supplies you may need when going out.

Language Barriers

Generally, two situations call for accommodating other languages by employing Native speakers or interpreters, or by translating materials:

1. If anyone involved in the discussion has difficulty with English.
2. If the CWIC would like to show respect to tribes where the native language is still taught to younger generations. Discuss the matter with a cultural liaison.

Incorporating Family in Outreach

For people with disabilities in mainstream culture, the individual's right to make choices is the priority. This emphasis changes in American Indian and Alaska Native cultures, where "decisions are made by the family through consensus after options are presented. The choices being made do not only affect the person with a disability, but the entire family and ultimately the entire community," writes Blatchford (2006a). "It is extremely important when you do work with beneficiaries on the reservations that you work not only with the beneficiary but with their family ... family is the essence in the Native American community," Gary Flom said in a TANAC Teleconference (2006a).

In Native Hawaiian cultures, as well, the strength of family is very important to people with disabilities, says Philip Ana, AIDTAC Hawaiian consultant (2006a). Support for the person with a disability comes in all forms; in turn, he or she is responsible to the family. This can result in services that meet the needs of the family first. "This will always be a delicate issue for an outreach worker," Ana says. "Change is often slow and requires understanding." Independence might not be the most valuable goal for the disabled person, so seek to meet the beneficiary on their terms, welcoming the role of the family – and extended family members – in that person's life. Set up an informal brainstorming session with significant family members in the place of their choice. Finally, if you'd like to offer gifts to Native families or others, Dr. James Dixon (2006), AIDTAC rehabilitation consultant, suggests asking your tribal liaison or community leaders for ideas. Tobacco, cedar, white

sage, firewood, and food may be good choices. Also, anytime a meeting is conducted with American Indians, Gary Flom presents a gift to both the person who gives the opening remarks and the medicine man – an elk skin bag with a neck loop (personal communication, August 23, 2007). "It's just a small token of appreciation but very appropriate for the occasion," he says.

Importance of Elders

Respect and trust of the older generation is fundamental in American Indian and Alaska Native cultures. Tribal elders hold status as sources of cultural wisdom, leadership, and community awareness. The community will see it as a sign of respect if you go to them.

Look for elder organizations, or find elders to talk with at language classes, meals programs, craft and health groups, or elder councils. Tribal leaders will know of respected elders who may be willing to get to know the WIPA program and lend credibility. Include elders when possible. Enjoy the chance to learn from their stories, and respect that the community relies on them for cultural direction. They will influence whether you and CWIC offerings can be beneficial and introduced into the community.

Newspapers as Outreach Tools

Newspapers are a relatively easy and effective way to get the message out to a community each time you are planning a visit. Local community and tribal newspapers appreciate direct contact. Simply sending a news release probably won't attract attention. Make the effort to call the newspaper's editor or a local news reporter and ask to meet with them about the WIPA program. Your information will get in the newspaper, and it may even attract a feature article.

How to go about getting contacts at a local paper in your service area? AIDTAC offers the following information (Katz et al., 2007):

Make the extra effort to ensure that your organization stands out among competing organizations. ... Tribal and local newspapers are in business to report the news and publicize events in their communities. We suggest that you capitalize on these opportunities to have stories or news releases about outreach activities published in the weekly newspapers in your service area.

Brian Longie, an employment trainer at the Phoenix Indian Center, uses newspapers to conduct outreach. Longie said in a TANAC Teleconference (2007) that he sent a pamphlet to tribes and also published in a newspaper. "So, it wasn't just word of mouth ... and that's what helped build up our clientele."

In addition, many tribal communities have radio stations that serve as the connecting voice for community members in outlying areas. On the Pine Ridge Reservation in South Dakota, for example, KILI Radio keeps a constant grip on the community with its informational bulletins on local events and news. It also incorporates voices from all aspects of the community, plays out tribal council disputes, and offers Native music as well as live performances such as drum groups.

Kimberly Irwin, Rosebud Sioux Tribal member and SSA Regional Public Affairs Specialist on American Indian Outreach in San Francisco, recommends radio as an outreach tool throughout Indian Country. "You can fax in your message to the radio and they can interpret that for you in the tribal language, whatever radio station

they are coming from. I send in my pieces ... and they will even allow us to come in when we are there to talk a little bit on the radio, and if it's going to be in a tribal language, then they will just say what we have to say for us in the tribal language," she said in a TANAC Teleconference in 2007.

At the end of the day, successful outreach is born of an open mind, patience, and consistency. Building trust is a key in Native communities. Be available and follow through on commitments. Invest in learning about the community and working in a culturally appropriate manner. Katz et al. (2007) offer what they call the most important advice of all in two general principles:

1. Ask the experts. Native American people are the best experts on themselves and their culture. Let them know you need their help to act appropriately and respectfully in their community. Ask them to please be patient with you and teach you. In the beginning, listen more than you talk.
2. Don't give up. If at first you feel like you've failed or not accomplished what you thought you wanted to accomplish ... don't stop. Keep coming back to the community, ideally on a regular basis. People need to know that your first visit isn't your only one. ... A person who receives helpful WIPA services will tell others, and before you know it you will have people waiting to see you every time you visit, and calling you regularly on the phone.

Chapter 6

Holding a Talking Circle

The Talking Circle is a valuable part of outreach in American Indian, Alaska Native, and Native Hawaiian communities. It is a tool to help CWICs learn how to better work with Native SSA beneficiaries and their families. It is useful in both tribal and urban service areas as a part of the Tribal Disability Actualization Process (TDAP) and Disability Actualization Process (DAP), respectively.

The Talking Circle will bridge the gap between cultures and hasten the level of trust. It is not designed to present WIPA programs. Instead, the Talking Circle is a gathering for the CWIC to hear concerns and suggestions from community or tribal members, to gain insight into appropriate conduct, and to improve services to American Indians, Alaska Natives, and Native Hawaiians with disabilities (Katz et al., 2007). The CWIC may also answer questions.

What is a Talking Circle?

Numerous tribes have long used Talking Circles as a

traditional way to resolve conflicts and make important decisions. Not every Native culture has used Talking Circles as a matter of course, but it is recommended as an appropriate and effective way to build cultural awareness and to improve an outsider's ability to function and communicate in a Native culture. The Talking Circle invites input from all with an interest and promotes consensus by using "practical methods that promote positive results" (Clay & Fugleberg, 2006b). Remember to respect tribal sovereignty and cultural values when working with any Native group. Here is a sketch of steps for a Talking Circle adapted from a TANAC Issues Brief (Clay & Fugleberg, 2006b):

1. A CWIC identifies a tribal contact person, such as a tribal social service program director or urban Indian center director.
2. A welcome letter is sent to the tribal contact explaining the purpose of the meeting.
3. The contact person seeks tribal council approval when appropriate.
4. Relevant materials to facilitate the meeting are sent to the contact.
5. The contact is responsible for organizing the Talking Circle, including inviting key participants, advertising the event, and providing copies of materials for the meeting.
6. The Talking Circle, generally a two-day workshop format, is held for CWICs to learn about culture, customs, traditions, and socioeconomic issues.
7. The CWIC shares information about important SSA program terms and concepts, followed by a general participant discussion and a question and answer period.

You may have concerns about being culturally respectful during a traditional meeting. Talk with a cultural liaison or community leader or elder about customs or taboos you would need to know about before the meeting. Let the group know that you are not completely familiar with their culture, and invite them to bring to your attention anything you do that could be interpreted as disrespectful (Clay & Fugleberg, 2006b).

The Difference Between TDAP and DAP

TDAP and DAP were born when AIDTAC designed a unique training method to help outside groups get to know a Native community and then form action plans to make life better, more accessible, and more productive for people with disabilities.

1. They are basically the same method but in different places.
2. They are both about meeting local needs with culturally relevant services. Both use the Talking Circle.
3. The TDAP brings together tribal officials and members to discuss disability and the importance of culturally relevant services, building capacity to identify issues faced by tribal members with disabilities.
4. The DAP does the same but in an urban area. It brings together urban tribal members and state and tribal VR staff.

Source: Clay & Fugleberg, 2006b

Talking Circle Q & A

Dr. James Dixon is a human services consultant focused on American Indians and Alaska Natives with disabilities. He was recently invited by Disabled People's International (DPI) to represent the indigenous people of the United States with disabilities in their quest for equal rights at the World Assembly held in Seoul, South Korea. He subcontracted with AIDTAC from 2003-2006 to plan and conduct workshops in major urban cities with high American Indian and Alaska Native populations to encourage agencies to reach out to the AI/AN population and make them aware of the programs and services that are available to them, and provide cultural orientation. Here, he answers questions about the process:

Q: Why did you use a Talking Circle approach?

A: The Talking Circle or Talking Stick was commonly used in tribal council circles to establish who had the authority to speak. The tribal chief or elder would initially hold the "Talking Stick" and start the discussion. No one is to interrupt or cause disharmony when someone is speaking. Then, he passes the Talking Stick to whoever desired to speak. Whenever anyone speaks while holding the Talking Stick, they are to speak only the truth from their heart and mind. All in the circle must listen attentively. There is great wisdom in this traditional method of conducting meetings or councils. Each person, one at a time, is allowed the opportunity to share feelings and thoughts from their heart on the topic.

Q: What was it like?

A: Teaching and implementing this traditional approach was an interesting and rewarding experience. It provided orientation and sensitivity to the Native culture. It also was a unique method of exposing non-Native participants to some Native traditional ways.

Q: How did you prepare for it?

A: It is important to provide preliminary information including goals and objectives to the participants prior to the workshop, such as a mailing. It is important for them to know the history, significance and symbolism represented in the Talking Circle. This creates a special

interest and curiosity. Also, chairs in the room need to be arranged in a circle.

Q: How might a Talking Circle help bridge the gap between cultures?

A: Using the Talking Circle, the CWICs will demonstrate their interest and sensitivity to the Native culture, thus helping to bridge the gap.

Q: How does a Talking Circle encourage everyone to speak?

A: As non-Native individuals understand and experience the Talking Circle, they will feel comfortable and recognize the wisdom of this traditional approach. It allows each person in the circle in a structured manner to express thoughts and feelings from the heart and mind.

Q: How does a Talking Circle encourage honesty?

A: When the history and tradition of the Talking Circle is shared with non-Native individuals, they will know and understand that as each member of the circle speaks there is no judgment or criticism of the words spoken. Each member must listen attentively to the person speaking. It is understood that what they say is from the heart and true to them.

Q: What can a Talking Circle teach us about listening in everyday life?

A: When the history and tradition of the Talking Circle is understood and applied, it can teach all involved in the experience the value of speaking from the heart and mind and to listen attentively. Applying this traditional Native approach will assist us all in our daily communication and relationships with others.

Q: Could someone use the "rules" of a Talking Circle in day-to-day outreach efforts?

A: Yes, definitely! Persons new to the traditions of Native cultures can benefit from understanding the value of the Talking Circle by applying the principles of this approach in their daily contact with Native people, i.e., listening respectfully to the person speaking and, when the opportunity is presented, responding by speaking truthfully from the heart.

Source: J. Dixon, personal communication, August 16, 2007

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Appendix I:

Technical Support and Resources

For help with questions or support related to WIPA programs, contact:

Julie Clay, AIDTAC Director

The University of Montana Rural Institute:
Center for Excellence in Disability Education, Research and Services
52 Corbin Hall, The University of Montana
Missoula, MT 59812-7056
Telephone: 406-243-5764
Email: jclay@ruralinstitute.umt.edu

Materials related to production of this monograph are available on the TANAC website:
www.nativeamericancwic.org

More information about disability and American Indians and Alaska Natives:

- American Indian Disability Technical Assistance Center at **www.aidtac.ruralinstitute.umt.edu**
- Research and Training Center on Rural Rehabilitation (RTC: Rural) at **www.rtc.ruralinstitute.umt.edu**

More information about disability and Native Hawaiians:

- National Technical Assistance Center—Asian Americans and Pacific Islanders (NTAC—AAPI) website at **www.ntac.hawaii.edu**.
- Rehabilitation and Research Training Center at the University of Hawaii at Manoa **www.rrtc.hawaii.edu**.

Resources

AIDTAC'S list of National Organizations provides useful outreach contacts:

www.rtc.ruralinstitute.umt.edu/Indian/ResourceBook/National%20Organizations.pdf

Consortia for Administrators for Native American Rehabilitation (CANAR) has contact information for tribal rehabilitation programs: **www.canar.org**

The Indian Health Service maintains an online list of Community Health Representatives:

www.ihs.gov/NonMedicalPrograms/chr/peer.cfm.

The National Congress of American Indians offers a tribal directory:

www.ncai.org/Tribal_Directory.3.0.html

- The National Council on Disability has a useful review of Native outreach techniques **www.ncd.gov/newsroom/advisory/cultural/cdi_litreview.htm**
- Urban areas often have an American Indian Community Center or an Intertribal Council that would serve as a starting point or bridge for outreach. Some are listed on the Internet **www.nativeculturelinks.com/organizations.html** and **www.urbanindian.info/centers.htm**

Appendix II:

Tribal and Local Newspapers

- The National Newspaper Association, located at the University of Missouri – Columbia, is a good place to learn about a state’s newspaper or press association to find out about media contacts in your service area.

For more information contact:

National Newspaper Association
P.O. Box 7540
Columbia, MO 65205-7540
Telephone: (800) 829-4662
Website: www.nna.org

- Native Web, an organization whose purpose is dedicated to using telecommunications including computer technology and the Internet to disseminate information from and about indigenous nations, peoples, and organizations around the world, maintains a web page with contact information for a number of Native American and tribal publications: www.nativeweb.org/resources/newspapers_-_native_indigenous
- The Native American Journalists Association and its members form a network of Native American journalists, media partners, and friends:

Native American Journalists Association
University of Oklahoma
Gaylord College
395 W. Lindsey
Norman, OK 73019-0001
(405) 436-3744
Email: info@naja.com
Website: www.naja.org

- Following is a list of tribal and local newspapers that report news in Native American communities and maintain Web pages. Or check with your state newspaper / press association for a list of member newspapers.

Alaska Star (Eagle River, AK): www.alaskastar.com

The Nome Nugget (Nome, AK): www.nomenugget.com

Chickasaw Times (Ada, OK): www.chickasaw.net

Charkoosta News (Pablo, MT): www.charkoosta.com

Hawai'i Island Journal (Honolulu, HI): hawaiiislandjournal.com

Lake County Leader (Polson, MT): www.leaderadvertiser.com

Lakota Journal (Rapid City, SD): www.lakotajournal.com

Navajo Times (Window Rock, AZ): www.navajotimes.com

Navajo/Hopi Observer (Flagstaff, AZ): www.navajohopiobserver.com

OCB Tracker (Glendora, CA): www.ocbtracker.com

Red Lake Net News (Red Lake, MN): www.rlenn.com

Sho-Ban News Online (Fort Hall, ID): www.shobannews.com

The Seminole Tribune (Hollywood, FL): www.seminoletribe.com/tribune

Indian Country Today (national): www.indiancountry.com

Native Times News (national): www.nativetimes.com

Reznet (national): www.reznet.org

Appendix III – Outreach Checklist

Practical considerations for outreach in Native areas (Katz et al., 2007):

- Have a toll-free number available, so people outside the local calling area can afford to contact you.
- In advance of your visits to the community, don't hesitate to send a notice to the tribal and local papers, radio, or TV station. Include information about WIPA services along with the time and place of your meeting, or where beneficiaries and their families or friends can meet with you in person.
- Developing a relationship with a community and establishing your credibility as a CWIC will be easier if you maintain a presence in the community. Attend community events like powwows, basketball games, health fairs, etc.
- In many tribal communities there is someone in the health/IHS program who assists people in applying for Medicaid. These are people you want to go out of your way to meet and partner with as they also often help people with SSI/SSDI issues.
- Before your first gathering, ask your contact person if he/she or an elder might talk with you about common etiquette or protocol. They also can explain any ceremonies or rituals that typically occur before or during community meetings.
- In many tribal communities or urban Indian centers, at the beginning of a meeting or community gathering, it is customary to have a respected person offer a welcome and blessing. A community member can arrange this.
- Don't plan on only those registered for a gathering to show up. Sometimes more, sometimes less, and some will come and go as schedules and transportation allow.
- If at all possible, make sure refreshments are provided.
- If you plan to do a Power Point presentation, take along your own LCD projector, a power strip, extension cord, and a screen or white paper and tape. Also take along newsprint pads, markers and any other materials you think you'll need.
- Don't expect most people or communities to have Internet access and email. It is common in Native American communities for one third of the population to not have phones, let alone computers.

