



Native American Developmental Disabilities Needs Assessment



Authors

Leslie Cohen, JD, Sonoran UCEDD Director
Teshia Solomon, PhD, Native American Research and Training Center Co-Director
Jennie Joe, PhD, Native American Research and Training Center Co-Director
Rodney Haring, PhD, Faculty, NARTC and Family and Community Medicine, University of Arizona
Leslie Randall, RN, MPH, NARTC Faculty Fellow
DeeAnn DeRoins, MD, NARTC Faculty Fellow
Mildred Manuel, Health and Human Services Special Needs Manager, Tohono O'odham Nation
Jacy Farkas, MA, Sonoran UCEDD
Jazmin Villavicencio, Public Health Student, University of Arizona

Funder

This report was funded by the Administration on Intellectual and Developmental Disabilities through technical assistance contract # HHSP23320082917YC. The contents of this document do not necessarily reflect the views or policies of the Administration on Intellectual and Developmental Disabilities, Administration for Children and Families, US Department of Health and Human Services, or the US Government.

Publication and Design

Association of University Centers on Disabilities
1100 Wayne Avenue, Suite 1000, Silver Spring, MD 20910 www.aucd.org
George S. Jesien, PhD, Executive Director

Contents

Executive Summary	5
I. Introduction and Background	9
II. Methods	13
III. Key Findings	16
IV. Recommendations	22
References	25

Figures and Tables

Figure 1. Estimated percentage of different disabilities served by the respondents' Native American Vocational Rehabilitation program as reported at the 2011 CANAR Conference.	14
Figure 2. Percentage of Nez Perce tribal members indicating an acquaintance with people with DD.	14
Figure 3. Percentage of survey respondents at the 2011 American Indian Health and Wellness Fair indicating acquaintance with people with DD.	15
Table 1: Number and Type of Individual Key Informants	15
Table 2: Familiarity with DD Network Agencies	18
Table 3: Community Needs to Make Life Better for People with DD and their Families	20
Appendix A: Native American and Developmental Disabilities Articles and/or Websites	27
Appendix B: American Indians/Alaskan Natives and Disability Organizations	33
Appendix C: Native American Developmental Disabilities Needs Assessment: Survey Instrument & Interview Format	37
Appendix D: Survey Comments to AIDD Commissioner	45

Executive Summary

The Sonoran University Center for Excellence in Developmental Disabilities (UCEDD) at the University of Arizona in conjunction with the Native American Research and Training Center (NARTC) performed a needs assessment of selected American Indians and Alaska Natives (AI/AN) in the spring and summer of 2011. The purpose of the project is to provide Commissioner Sharon Lewis, Administration on Intellectual and Developmental Disabilities (AIDD), with a snapshot of the AI/AN experience with DD in selected Tribal and urban American Indian communities. Specifically, the report provides information about the availability of services and support for individuals with developmental disabilities (DD) and their families, the needs of DD tribal members and their families, and tribal members' familiarity and contact with the DD Network agencies.

Communities Participating

The Project had access to Native American populations through its association with Native American researchers from NARTC at the University of Arizona. Recognizing that there are 565 Federally-recognized AI/AN communities in the US, each with distinct cultural characteristics, language, government structures, and social and political issues, the needs assessment surveyed selected tribes in rural and urban areas (Seneca Nation, Nez Perce Nation, Midwest/Kansas, Tohono O'odham Nation, and the Tucson and Greater Phoenix Metropolitan areas) as well as gathered information from a broad range of informants attending Native American conferences. In addition, all communities were chosen based on already existing relationships with NARTC fellows and staff.

Methods: The Sonoran UCEDD and NARTC used a multi-faceted approach including surveys, interviews, and a public meeting, all focusing on four areas of inquiry: community strengths and challenges for individuals with DD and their families, familiarity with the DD network agencies in their state, where individuals with DD and their families get services and supports, and the greatest community need or information the respondent would like the AIDD Commissioner to know. The information was gathered from the following sources:

- Written surveys: AI/AN respondents completed surveys at three different conferences/meetings (n=323)
- Key informant interviews: AI/AN individual service providers, school personnel, and family/individuals with DD in four distinct communities were interviewed (n=24)
- Community meeting: Individuals from the Tohono O'odham Nation attended a community meeting where project staff conducted a training on person-centered practices and where community members responded with their observations about on the lives of individuals with DD in their community (n=13)

Key Findings

The key findings based on the needs assessment are:

- AI/AN community strengths for people with DD include their family relationships (both immediate and the broader extended and community family) and tribal service agency staff who care, are tenacious, and know their communities.
- AI/AN communities face difficult challenges in trying to provide community services and supports for individuals with DD and their families. Transportation is often not available to DD services located off-reservation and there are few tribes providing DD services and supports themselves. Issues of poverty, drug and alcohol use, mental health, and lack of jobs in many AI/AN communities make it more difficult for people with DD to live inclusive community lives.

- Most AI/AN people with DD and their families access services locally from their tribal health clinic, tribal early childhood programs, schools, or tribal vocational rehabilitation. Accessing State DD agency and other state services is not easy for AI/AN people living outside metropolitan areas.
- AI/AN communities for the most part do not have a high degree of knowledge or connection to the DD Network, but are interested in finding out more about the network and having more contact with the Network.
- AI/AN individuals with DD and their families want service systems to respect their culture and customs and provide information, training and services that are relevant and appropriate.

Recommendations

As a result of the key findings for increasing DD Network effectiveness in Native American communities:

1. Increase connections to people with DD and their families in AI/AN communities by forging relationships with respected community collaborators. As part of this needs assessment, we spoke with trusted individuals—elders, health workers, advocates, teachers—in every community. They were the “go to” people in their community who knew every family with a DD member and all the services and supports available within their area. Most of them had little relationship to the DD Network programs, but were open to knowing more and forging those connections. To be successful in partnering with these communities, relationships with these individuals, community health representatives, tribal social workers, early education providers, and teachers is necessary.
2. Increase the availability of information about AI/AN individuals with DD for all agencies working with AI/AN communities. Many of the agencies and services in AI/AN communities may be health or social service oriented, rather than specifically developmental disabilities focused. There may be a variety of tribal, state and federal agencies touching the lives of people with DD and their families on a regular basis. An understanding of DD and the issues faced by AI/AN families is also important for these non-disability specific entities and agencies interacting with AI/AN families with DD in the same way understanding AI/AN culture and custom is important to disability agencies. At a federal level, agency collaborations can be a start to infusing information about DD into agency initiatives and at the state and tribe level creating effective partnerships between disability and AI/AN agencies and organizations to increase the sharing of information.
3. Ensure connections to people with DD and their families in AI/AN communities are sustainable through capacity building. We heard from many AI/AN participants in the project that their knowledge of the DD Network agency was based on a onetime event, project or other contact. With limited funding it is often difficult to keep up a presence and connection in a remote community. To effectively partner with AI/AN communities, DD agencies must help in building capacity within those communities. This reflects AI/AN communities desire to develop their own service models.
4. Promote education and training on DD through tribal colleges/University Native American Programs. There are many two-year tribal colleges throughout Indian Country. Partnership projects between tribal colleges and UCEDDs, similar to UCEDD partnerships with minority serving institutions, could go a long way in building the capacity of American Indian Nations to provide support for individuals with DD. Initiatives to develop curriculum, distance learning, and knowledge exchange are needed.
5. Build a national one-stop resource for information on AI/AN and DD. There is no national one-stop center providing information for AI/AN communities about the issues for Native Americans with DD. There are pockets of disability related national resources addressing AI/AN issues and DD (see appendix B to this report), but no comprehensive resource for training, information, or technical assistance. Clearly, for individuals, groups, and agencies working with AI/AN individuals with DD and their families, having culturally relevant, up-to-date resources and information in one place would be enormously helpful.
6. Promote connections that are based on mutual respect and understanding of the culture, laws and customs of a population. AI/AN respondents stressed the importance of people working in the DD field learning about their culture in order to be able to provide the services and supports needed. Education and training as well as just “listening” to AI/AN people.
7. Promote connections that are based on AI/AN community needs. Our data collection pointed to important community needs for community-based services and supports, more information and training, and better family support. Though clearly not generalizable to all AI/AN communities, these are likely to be important issues to many AI/AN communities. It is crucial that programs and projects in these areas are geared to the specific needs, customs, and cultures of each of the communities served.

I. Introduction and Background

The Sonoran University Center for Excellence in Developmental Disabilities (UCEDD) at the University of Arizona in conjunction with the Native American Research and Training Center (NARTC) performed a needs assessment of selected American Indians and Alaska Natives (AI/AN) in the spring and summer of 2011 pursuant to a sub-contract with the Association of University Centers on Disabilities (AUCD) funded by the Administration on Intellectual and Developmental Disabilities (AIDD). Recognizing that there are 565 federally-recognized AI/AN communities in the US, each with distinct cultural characteristics, language, government structures, and social and political issues, the needs assessment surveyed selected tribes in rural and urban areas as well as gathered information from a broader range of informants attending Native American conferences. A national sample allowed for the identification of conditions and issues of importance to begin to develop a national agenda for serving AI/AN families and individuals with Developmental Disabilities (DD).

The purpose of the project is to provide AIDD and the Administration on Native Americans with a snapshot of the AI/AN experience with DD in selected Tribal and urban Indian communities and more specifically to provide information about the availability of services and support for individuals with DD and their families, the needs of DD tribal members and their families, and their familiarity and contact with the DD Network agencies.

Access to Native American Populations

The Sonoran UCEDD and NARTC are housed within the Department of Family and Community Medicine at the University of Arizona. The Sonoran UCEDD has partnered with NARTC to ensure its projects, publications and trainings are culturally appropriate and relevant. Jennie Joe, PhD, MPH (retired) (Navajo) and Teshia Solomon, PhD

(Choctaw), Co-Directors of NARTC, are affiliated UCEDD faculty. NARTC was established in 1983 by the University of Arizona Board of Regents to serve as a national resource for Native American communities and has a rich history of working in chronic diseases and disabilities. The overall mission of NARTC is to conduct health related research and training projects that will help improve the quality of life for Native Americans. The NARTC Faculty Fellows and staff have significant relationships with the tribes participating in this needs assessment through either their own tribal membership or work and are known to tribal members working in the health, education, and social service systems. Leslie Cohen, JD, Sonoran UCEDD Director, has extensive experience with DD Network programs as Director of the Arizona P&A and as a long standing DD Planning Council (DDPC) member and former committee chair.

Characteristics of AI/AN Communities/Organizations Involved in Project

The tribes and communities were chosen to represent both rural and urban areas as well as geographic diversity. In addition, all communities were chosen based on already existing relationships with NARTC fellows and staff¹. The communities participating in this project were:

- Seneca Nation has a total enrolled population of 7,800 members and is located in western New York. The area is generally rural, with several residential areas. Seneca Nation is the largest of six Tribal nations which comprise the Iroquois Confederacy.
- Nez Perce (NiMiiPuu) Nation is located in North Central Idaho with total enrollment of 3,363. The reservation encompasses 1,195 square miles with rolling plateaus dissected by deeply

¹ We did not select the Navajo Nation despite its size and the proximity and staff relationships there because the Navajos have the only Protection and Advocacy System located on the reservation and have also been studied and assessed more than most other tribes. We've attached in Appendix A a short bibliography of Navajo-related research on disability related issues.

cut canyons and forested mountainous terrain. The NiMiiPuu Health is the main service agency with direct health care, mental health and alcohol treatment, community and outreach programs, maternal child health, WIC, and Nutrition Programs.

- **Mid-West Communities:** Interviews were conducted with tribal members in two rural Native American reservations in Kansas and one urban community. Kansas City has a population of 8,000 -10,000 AI tribal members, and statewide Kansas has an AI/AN population of approximately 28,500. Interviews were conducted with tribal members, educators, and social service providers in two rural Kansas Native American communities and the urban Indian population of metropolitan Kansas City, which includes areas of both Kansas and Missouri. Rural services are limited and available primarily through Head Start and schools, both public and tribal. Tertiary pediatric care centers are 100 miles from the reservations.
- **Arizona Reservation and Urban Communities:** Tohono O'odham Nation (TON) includes approximately 28,000 members occupying 2.8 million acres of tribal lands in rural Southwestern Arizona. The Tohono O'odham Nation is the second largest reservation in Arizona in population and geographical size and uses both the IHS and tribal systems. The Tucson Indian Center serves the urban AI community providing various services including culturally appropriate social, economic, education, and wellness programs. The Salt River Pima-Maricopa Indian Community (8,700 members) is the closest reservation to Phoenix with its borders contiguous to Scottsdale, Arizona. The Ft. McDowell Yavapai Indian Nation and Ak-Chin Nation are also very close to the Phoenix metropolitan area. The Phoenix and Tucson metropolitan areas are home to approximately 125,000 American Indians. (2000 US Census as cited in National Indian Child Welfare Association, 2005)
- **The Consortia of Administrators of Native American Rehabilitation (CANAR) Conference**

brings together administrators of AI/AN rehabilitation programs from across the country serving individuals with developmental and other disabilities. These participants represent 85 tribal vocational rehabilitation programs in 26 states.

Review of Current AI/AN DD Research, Service Systems, and Resources

Few aggregate datasets exist for American Indian people that provide a clear and accurate picture of the health status of these distinct populations distributed throughout the country. There are more than 4.5 million AI/AN in the United States, about 1/2 of who are women and about 1.3 million are under age 18. Racial misclassification is a well-recognized problem specifically for AI/AN living in urban areas. Some studies fail to ask for racial classification and others fail to report findings due to small sample size. Few national datasets have sample sizes large enough to draw meaningful conclusions and when they do, studies that reflect urban AI/AN issues may not be representative of specific tribal communities issues and vice versa. American Indians and Alaska Natives are an extremely diverse group of people. Each of the 565 tribes is sovereign and has its own unique customs and beliefs. (Urban Indian Health Institute, 2009)

AI/ANs have the highest rate of disability of any racial and ethnic population in the United States. Twenty-two percent of the AI/AN population has one or more disabilities (approximately 550,000 individuals), which is the highest rate of disabilities when compared with all other races/ethnicities surveyed in the United States. (McNeil, 2001) Among children 5 to 15 years old, the disability rate is 5.7% for non-Hispanic Whites, but 7.0% for Black children and 7.7% for AI/AN children. Although the disability rate is 16.2% for non-Hispanic Whites of working age (16 to 64), it is 26.4% for Blacks and 27.0% for AI/AN. (US Census Bureau, 2009)

Specific Developmental Disabilities

The main cause of preventable intellectual disabilities in the US is prenatal alcohol use. Fetal Alcohol Spectrum Disorders (FASD) prevalence rates for Native Americans range from 1.0 to 8.97 per 1000 births. (Beckett, 2011) "Native Americans have higher rates of alcohol use, frequency of use, and increased rates of fetal alcohol syndrome, compared with other ethnic groups" (Szlemko, Wood, & Thurman, 2006). AI/AN have the second highest rates of intellectual and learning disabilities, only surpassed by African Americans. (Zhang & Katsiyannis, 2002) "From 1981 to 1986, the CDC Birth Defects Monitoring Program reported that American Indians had the highest rates of hydrocephalus, atrial septal defect, valve stenosis, and atresia, cleft palate without cleft lip, cleft lip without cleft palate, rectal atresia and stenosis, fetal alcohol syndrome, and autosomal abnormalities, excluding Down's Syndrome, among 18 major congenital defects being monitored" (Brenneman, 1997).

It should be noted however, that there is little data on prevalence rates for many specific developmental disabilities in the AI/AN community. In many of the studies, the sample size from the AI/AN community has been too small to include the population as a separate category. For example, the Autism and Developmental Disabilities Monitoring (ADDM) Network Study, does not separate out prevalence rates for AI/AN children (2007).

Children with Special Health Care Needs

The National Survey of Children with Special Health Care Needs found Native American Indian/Alaska Native children have the highest prevalence of special health care needs at 16.6% compared to 14.2% of non-Hispanic White Children. Conditions such as diabetes are on the rise in AI/AN populations as well. From 1990 to 1998, the total number of young AI/AN with diagnosed diabetes increased by 71% (4534 to 7736); prevalence increased by 46% (6.4 per 1000 to 9.3 per 1000 population). Increases in prevalence were greater among adolescents and among young

men. Diabetes should be considered a major public health problem among young AI/AN. (Acton et al., 2002)

Children in Special Education

AI/AN Students are slightly over-represented in the special education population in relation to their percentage of the population. (US Department of Education, 2000) The majority of AI/AN children are educated through the public school systems in each state, while other children attend tribally-operated schools or schools run by the Federal Bureau of Indian Education (BIE).

According to National Association of State Directors of Special Education, 21% of AI/AN students educated in the BIE operated and/or funded schools are enrolled in special education compared to 13% of all US public school students (Muller & Markowitz, 2005). "Challenges related to disability are compounded by the fact that 58% of BIA [Bureau of Indian Affairs]-educated students have limited English proficiency (LEP) as compared with 8% of public school students and approximately 80% of BIA-educated students are eligible to receive free or reduced-price lunches as compared with 40% of public school students" (Muller & Markowitz, 2005, p. 4).

Other information sources for data on Native American populations and disability can be found in Appendix A.

Resources Nationally for Native Americans with Disabilities

There are several national organizations providing resources and technical assistance to Native Americans with disabilities and their tribes on a variety of health, education, employment, and family support issues. In addition, these organizations have valuable information for use by the DD Network in providing culturally appropriate services and supports to AI/AN communities. We have included a list of organizations developed by the Waisman Center UCEDD at University of Wisconsin in Appendix

B. It is worth noting here that The American Indian Disability Technical Assistance Center (AIDTAC) at the University of Montana, Rural Institute UCEDD provided training and technical assistance on the intersection of American Indian and disability issues under a US Department of Education grant which has now ended, but their website includes resources produced under that grant which are still available. In addition, the National Indian Parent Information Center program provides information on disability issues to Native children with disabilities, their family members, and the professionals who work with them and supports a national Native American Parent Information and Training Center. The US Department of Health and Human Services/Administration for Children and Families' Administration for Native Americans has a wide variety of initiatives and resources targeting health issues in Native American communities.

DD Network Resources

Many DD Network agencies engage in activities including providing services, supports, training, and advocacy assistance in partnership with Native American communities and to AI/AN individuals with DD and their families. A comprehensive survey of DD Network programs and activities in relation to Native American individuals, families, and communities was beyond the scope of the current project. Rather, the current project assessed where people with DD in the targeted Native American communities receive their services and supports and how familiar these communities were with the DD Network agencies in their state. That being said, there are a number of examples of additional work various DD Network organizations have undertaken in this area:

- Native American Resource Guide for New Mexico (University of New Mexico Center for Development and Disability UCEDD and New Mexico DDPC)
- Capacity Building for American Indians Project, providing technical assistance to tribes applying to become vocational rehabilitation agencies (Northern Arizona University – Institute for

- Human Development, Arizona UCEDD)
- Expanding the Circle: Respecting the Past, Preparing for the Future curriculum training, a transition curriculum for American Indian youth (University of Minnesota Institute on Community Integration UCEDD)
- Exploring strategies to develop housing/ programs for 18-year-olds transitioning out of foster care, including those with Fetal Alcohol Spectrum Disorder (Alaska Governor's Council on Disabilities and Special Education)
- Utilizing a contracted Native American Community Liaison as “cultural broker” (Oklahoma Disability Law Center, Inc.)
- Legal Options Manual (Arizona Center for Disability Law, Arizona DDPC, and Native American Disability Law Center)
- The Utah Indian Children's Program (ICP) strives to provide responsive, family-centered and community based services for Native American children with known or suspected disabilities. (Utah State University Center for Persons with Disabilities UCEDD)
- Family Village: Native American Resources (University of Wisconsin-Madison Waisman Center UCEDD)
- The Technical Assistance on Native American Culture project for the Social Security Administration's Community Work Incentive Coordinators (University of Montana – Rural Institute UCEDD)

Disability as a Construct in Native American Communities

There is no “one size fits all” in how disability is viewed in AI/AN communities or how AI/AN individuals with DD and their families access services and supports. Whether someone lives on or off the reservation; in an urban or rural community; the extent to which the AI/AN individual retains customs, traditions, and language; and the size and complexity of the particular tribal government and its infrastructure all go into determining the relationship a Native American individual and community has to disability and disability related services and supports.

AI/ANs with DD may receive services through the Indian Health Service hospitals and clinics, local tribal health clinics and social service agencies, BIE and tribal schools, and tribal vocational rehabilitation agencies. Since Indian people are also citizens of the states in which they reside, local government agencies and entities have the responsibility to serve AI/AN populations that reside in their cities, counties, and states as well.

II. Methods

The Sonoran UCEDD and NARTC used a multi-faceted approach to collect the data and information presented in this report. The process began by a review of the current data available on AI/ANs with DD and resources available nationally. Native American researchers on the team provided input on procedures for engaging Native American communities, methods for surveying and interviewing tribal members, and likely key informants in Native American Communities. UCEDD staff provided training to the Native American NARTC fellows on developmental disabilities, services, and supports and the DD Network in each state. As an initial activity, the project tabled at the AI Disability Summit in Phoenix, Arizona in April 2011. Attended by over 150 individuals from more than a dozen sovereign nations (primarily located in Arizona), project staff obtained initial feedback from attendees which assisted us in developing the project survey and interview format. The questions developed for the surveys, the format of the key informant interview, and the format of the community meeting and training targeted four areas of inquiry:

- Community strengths and challenges for individuals with DD and their families
- Familiarity with the DD network agencies in their state
- Where individuals with DD and their families get services and supports
- Greatest community needs or information respondent would like the AIDD Commissioner to know

The information was gathered from the following sources:

- Written surveys: AI/AN respondents completed surveys at three different conferences or meetings (n=323)
- Key informant interviews: AI/AN individual service providers, school personnel, and family/individuals with DD in four distinct communities were interviewed (n=24)
- Community meeting and training: Individuals from the Tohono O'odham Nation attended a community meeting where project staff presented training on person-centered practices. Community members responded with their observations about the lives of individuals with DD in their community. (n=13)

Survey Sample and Administration

The project utilized the same survey with minor changes for each audience; a copy of the basic survey and interview format is attached at Appendix C. For example, when administered to the Nez Perce tribal members, tribal affiliation was not requested because all respondents were likely to be Nez Perce. At the CANAR conference, participants were asked to estimate DD and other disability caseload percentages in order to determine if those surveyed had experience with providing services to people with DD. Where surveys were state-specific (Nez Perce and Tucson Wellness Day Event), DD Network agencies were mentioned by name; at CANAR they were not. All surveys touched on the four targeted inquiries above. At all venues, Native American representatives from the project administered the survey instrument. At the survey sites, incentives were used as “giveaways” to those participating. These included items such as pens or raffles to win gift cards or an iPod shuffle®. At the national CANAR conference, a table was set up to provide information on the project to interested participants. A request was submitted to and approved by the Nez Perce Tribal Council for the administration of the survey both in-person and on-line. At the American Indian Health and Wellness Fair in Tucson, project staff had information on the project for participants as well as

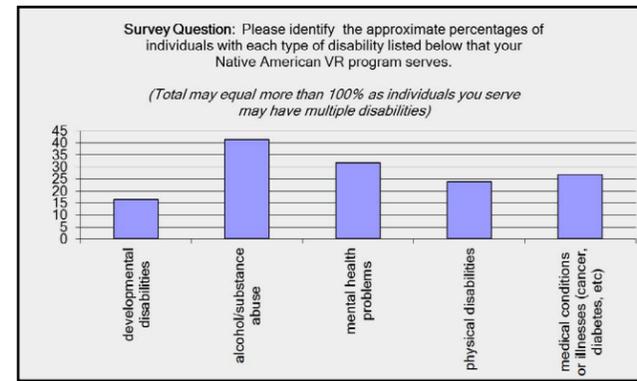
disability resource lists for Southern Arizona. Since none of the surveys were administered in a DD-specific conference yet a high number of respondents noted interest, experience and personal connection to DD, it can be inferred that AI/ANs with a personal connection to DD were more likely to take the time to fill out the survey.

CANAR Conference

Project staff attended the June 2011 Consortia of Administrators for Native American Rehabilitation (CANAR) conference which brought together key representatives from multiple reservation and off-reservation areas. CANAR, www.canar.org, is an organization whose mission includes the collaboration and cooperation among administrators of rehabilitation projects serving Native American persons with disabilities to increase the quality of services, resulting in positive outcomes for Native American persons with disabilities. The national conference brings together multiple organizations and tribes to learn and collaborate in the best interests of Native peoples, communities, and the multiple departments and agencies that serve Native consumers.

Of the approximately 250 conference, participants 123 individuals filled out the survey. Almost all of these individuals worked with one or more tribal vocational rehabilitation programs either in a direct service, administration or consultative capacity. Of these individuals, 62 filled out the tribal affiliation question, with 41 noting a specific tribal membership (38 different tribes). Respondents were asked to estimate the percentage of different disabilities served by their vocational rehabilitation program (they were not restricted to 100% total) with the following results in Figure 1.

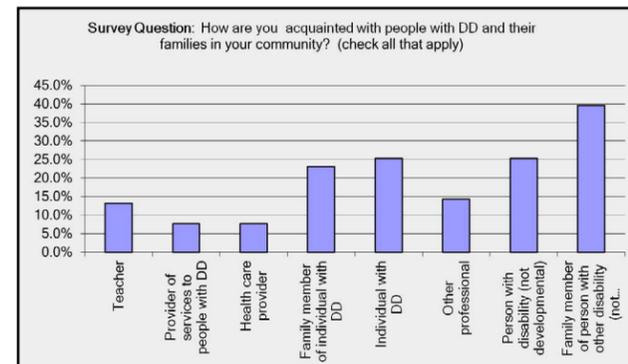
Figure 1. Estimated percentage of different disabilities served by the respondents' Native American Vocational Rehabilitation program as reported at the 2011 CANAR Conference.



Spring General Council Meeting of the Nez Perce Tribe

113 Nez Perce tribal members filled out the survey, either electronically or in hard copy provided, at the Spring General Council Meeting of the Tribe in May 2011. Respondents were asked how they were acquainted with people with DD, as represented in Figure 2.

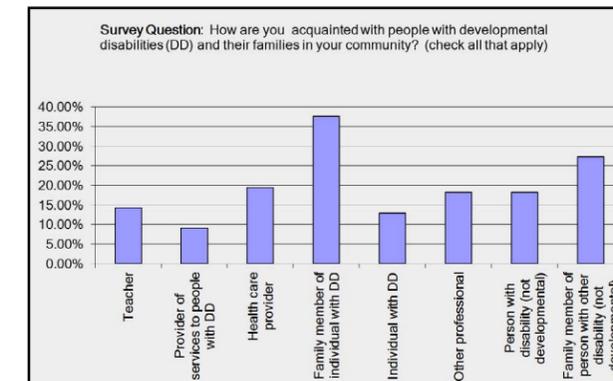
Figure 2. Percentage of Nez Perce tribal members indicating an acquaintance with people with DD.



American Indian Health and Wellness Fair Tucson Indian Center

The American Indian Health and Wellness Fair in Tucson, Arizona, in August 2011, was sponsored by the Tucson Indian Center and were attended by over 200 AI/ANs. This yearly event draws AI/AN individuals from the Tucson area and surrounding reservations (Pascua Yaqui and Tohono O'odham Nation) seeking information, services, and supports with a wide range of government agencies, health, and service providers in attendance. 87 individuals filled out the survey. Only 47 of those respondents identified their tribal affiliation with the highest numbers coming from the two closest reservations: Tohono O'odham Nation (n=18) and the Pascua Yaqui Nation (n=11). Respondents were asked how they were acquainted with people with DD; see Figure 3.

Figure 3. Percentage of survey respondents at the 2011 American Indian Health and Wellness Fair indicating acquaintance with people with DD.



Interviews of Key Informants

Twenty-four individuals were interviewed representing four different Native American communities with representation from thirteen distinct tribes. Key informants were selected based on one or more of the following factors: (a) their standing and knowledge within the tribe (some were elders, recognized tribal advocates, or long time social service tribal workers); (b) contact/experience/personal connection with families and individuals

with DD; and (c) specific AI/AN disability agency personnel. All key informant interviews began by reviewing the informant's experience with people with DD to evaluate whether informants were responding based on their knowledge of people with DD in their communities. All key informants had experience working with AI/AN people with DD in their communities or were family members or individuals with DD. Interview questions were similar to the survey questions and a copy of the standard interview format is attached as Appendix C. Key informants were interviewed in their home or office and were offered a small gift card for their participation, although some did not accept the card. Most interviews lasted between forty-five and ninety minutes. See Table 1 for the list of individual key informants.

Table 1: Number and Type of Individual Key Informants

Key Informants (n=24)	Number of identifying individuals*
Tribal Early Childhood, Head Start personnel	2
Tribal social services or health clinic personnel	5
School personnel (primarily special education, but includes counselors and administrators)	6
Independent Living Specialist/advocate	6
Family Member	4
Person with DD	1
Employment service provider/VR	2
Urban	7
Rural	17

*Note: 24 individuals were interviewed, however some Key Informants identified with multiple roles.

Community Meeting and Training with Tohono O’odham Nation

In July 2011, project staff held a community meeting and training in Sells, Arizona, on the Tohono O’odham Nation (TON). The meeting was organized and facilitated by the TON Health and Human Services, Division of Special Needs Manager. Thirteen tribal members attended, almost all who worked for TON’s senior, health, or disability services. Approximately 5-6 individuals identified as having family members with a developmental disability during the course of the community meeting. Jacy Farkas, MA, from the Sonoran UCEDD, led the group in a person-centered thinking/planning session. During this session we received feedback on the issues people with DD are faced with on the TON. Participants were provided a meal. We briefly described the current project and asked for feedback on the DD Network and the questions on the survey: (a) Where do people go to get help? (b) What works well in their communities for AI/AN with DD and their families? (c) What are the challenges for AI/AN with DD and their families? (d) What is the one thing that would make life better for people with DD in the community?

Limitations with the Methodology

The planning time for the project and actual time frame for obtaining data for the project were limited to seven months. Because of this we needed to rely on obtaining information at conferences scheduled during the relevant time period and interviewing key informants who were available during the specific time frame set for interviews. Because of this, we were unable to include as many individuals with DD and family members as we would have liked. A broader assessment planned over a longer period of time would reach more individuals with DD, their family members, and AI/AN service providers. The limitation inherent in asking people if they are familiar with DD Network agencies by name is discussed below in key findings. Given these limitations, the project was successful in obtaining a wide range of input during the relevant time period

III. Key Findings

The key findings from the surveys, interviews, and community meetings are categorized below under the four main areas of enquiry.

Community Strengths and Challenges for AI/AN Individuals with DD and their Families

All individuals taking the survey or participating in the interviews/meetings were asked about the strengths of their communities for individuals with DD and their families and the challenges AI/AN with DD and their families face in those communities. In interviews and the public meeting, this was an open-ended question. In the survey, respondents were given a choice of different strengths and challenges with the option to write in their own. The results were remarkably consistent among the surveys, interviews, and community meeting with some small variations.

Community Strengths

Almost all respondents saw families and family relationships as the primary strength in their community for people with DD. In interviews, the family was more likely to be seen in the context of the larger community (in the survey, family and community were separate categories, with family ranked number one in all surveys and community ranked in the top five of all surveys) and interviewees expressed “compassion,” “empathy,” and “acceptance” as family/community values. The majority of persons interviewed were providers of service in their AI/AN communities and also expressed their agency or school’s “willingness to do what it takes,” “tenacity,” and “knowledge of the community and where to get what people need” as a real strength of their communities. In relation to tribal agency staff: “they know what it is like; our staff can walk the walk and talk the talk...many of our staff...has a family member with DD, or has been part of our program in the past.” The tribe itself and tribal resources were also noted as strengths, though most strongly in

interviews with members of a more resource-rich tribe. Respondents most often listed the following specific types of tribal or reservation entities as strengths in their communities: early childhood and Head Start, schools, tribal health clinics, and tribal vocational rehabilitation programs.

Community Challenges

Not surprisingly, transportation to services located in cities and the related issue of lack of services in the AI/AN community were the two greatest challenges for AI/AN with DD and their families cited in all data collection methods. Transportation was listed in the top three most highly related challenges for all surveys and was noted in all interviews except for four in the urban areas. Lack of services and need for better support systems for families was also a universal challenge, again noted in all surveys as one of the top three challenges and noted in every interview. There was a good deal of overlap (particularly in the interviews/community meetings) between community challenges and what respondents expressed as the greatest need of their community and/or the one thing respondents wanted to have the AIDD Commissioner know. Further discussion of community challenges is discussed as part of the section below on “information respondents would like the AIDD Commissioner to know about the greatest community needs.”

Other commonly cited community challenges include:

Drug/alcohol use and Fetal Alcohol Spectrum Disorder

This was expressed as a twofold problem: providing services and supports for children and adults with FASD and how to address youth and adult drinking and substance abuse. The following comments characterized participants’ frustrations about this issue.

- “FAS itself is a challenge to find services. (Tribal attorneys often have to fight for disability services.”
- “[Our problems] have to do with mental health, lack of self-esteem, drinking to treat these problems without resources to address these issues.”
- “There are decreasing state resources and increasing kids’ needs, especially from drugs and alcohol.”
- “A young man was a concern to the community. He’s DD caused by abuse of drugs and inhalants when really young. His health issues caused him to be disabled and nonfunctional.”
- “How do we eradicate the mixed drug/alcohol use in pregnancy leading to all the developmental delay and disabilities we see?”

Lack of Jobs and Meaningful Day Activities for Adults with DD

Needs assessment participants noted the lack of opportunity once youth graduate or leave high school. Although many nations have tribal vocational rehabilitation agencies, participants felt there was still little for adults with DD in their community.

“Supports for person [are needed] - often there is no family members- they become 19 and are lost.”

“I had two students that graduated that are still unemployed. They just babysit. They have both been out of school 2 and 5 years each. That is sad.”

Familiarity with the DD Network Agencies in their State

Individuals participating in this assessment were asked about their familiarity with the DD Network agencies in their state (P&A, UCEDD, and DDPC)². We understood the limitations in asking

2 Because the Sonoran UCEDD staff participated in the TON community meeting as trainers, we have not included the data from the 13 community participants for this question. All other data collection was performed by non-DD network personnel.

Table 2: Familiarity with DD Network Agencies

DD Network	TOTAL	CANAR	Nez Perce Survey	American Indian Health and Wellness Day	Interviews (n=24)	% of Interviewees from Urban areas
P&A: never heard of	36.3%	18.3%	47.2%	45.3%	37.5%	0%
P&A: heard of, familiar with, referred to, or participated in	63.7%	87.5%	57.5%	57%	62.5%	46%
DDPC: never heard of	45%	32.2%	46.3%	62.4%	41.6%	0%
DDPC: heard of, familiar with, referred to, or participated in	55%	70.4%	56.5%	42.4%	58.3%	46%
UCEDD: never heard of	67.9%	60.8%	69.5%	75%	66.6%	6% (one person)
UCEDD: heard of, familiar with, referred to, or participated in	32.1%	40.8%	33.4%	26.2%	33.3%	75%

* It was unclear from the context whether five people interviewed were confusing the DD service agency with the DDPC; we counted all five as being familiar with the DDPC.

the question in so far as many if not most people surveyed or interviewed are more likely to know the name of an individual who helps them or a local clinic or social service agency than the name of a statewide agency that may be providing the training, services, supports, or information indirectly to that individual. The answers to “where do individuals with DD and their families get services and supports in your community?” bore this out. Overwhelmingly, respondents answered with the name of the local tribal health clinic, followed by the school system and early childhood centers or Head Start (see section below). When asked about their familiarity with the DD Network agencies in each state, responses resulted, for the most part, in a very low rate of recognition or knowledge about the agencies (see Table 2).

Most of the AI/AN individuals who responded affirmatively to having some familiarity with a particular agency within the DD Network had “heard of the agency,” but had very little personal contact. Of those who had greatest contact with the agencies, the most common area was school-based advocacy

by the P&A. Others knew the DD network agencies through attendance at disability related meetings, conferences or other events.

There was no indication of a regular presence by the DD Network agencies in the AI/AN communities surveyed; there was some indication that agency contact with the AI/AN population was limited or sporadic. One individual mentioned that someone from their community had been on the DDPC in their state several years ago, but they “didn’t know what happened since then.” Another stated that someone had dropped off brochures for one of the DD Network agencies at one time: “the information packets that were sent; saw them at a (FAIR) and went to their booth.” Another: “No information available even for those working in the clinic, no presentations, no trainings, no information given out. They should be visible at health fairs. And we know people that need the services. They need to have more outreach to the community.” As might be expected, there was a greater familiarity with the DD Network from respondents in urban areas and respondents who worked in tribal VR. The narrative

comments were interesting in that they expressed AI/AN interest in having greater connection to the DD Network programs.

Many respondents indicated the need for more information about the DD Network programs. They “want more information,” wondered if a lack of knowledge was “part of my ignorance?” and “don’t know?” Although respondents may have not heard of the DD Network program or had limited knowledge of the program, they were open to learning more. When the work of the DD Network programs was described, respondents in interviews expressed interest in getting in touch with the programs and knowing more about them. One interviewee commented: “Get information about these agencies (DD Network) out to people living on AI tribal lands. If social workers and case managers don’t know about them, families don’t. Need information and resources!”

Where Individuals with DD and their Families get Services and Supports

Respondents were asked to list where people with DD in their community received services and supports³. The following categories of services were listed and respondents were asked to provide the name of the organization or place:

- Health care
- Early Intervention services
- Early Childhood services
- School based services
- Therapies
- Vocational help
- Advocacy or legal help
- Information on Developmental Disabilities
- Home modification
- Other

The data indicate that the AI/AN population participating in this project is most likely to access DD services and supports through their local tribal

³ We did not ask this question on the CANAR survey because respondents were from so many different reservations that names of specific organizations or places would be too difficult to categorize for purposes of this project.

health center. The tribal clinic serves as a hub for both health care and referral to other services. The clinic frequently has personnel who help individuals and families applying for state or federal benefits. Many tribal health centers have Community Health Representatives who serve as the main liaison for families seeking assistance.

For early childhood services, AI/AN children with DD are most likely to attend a tribal early childhood program in their community. School age children receive DD related services and supports through the local schools and adults may receive vocational assistance through a tribal or state vocational rehabilitation program. Legal or advocacy assistance was cited as being provided by State Legal Services (Legal Aid) more than any other source⁴. In areas where there is a strong Independent Living Center presence (OAHIO Independent Living Center in New York and Arizona Bridge to Independent Living in Phoenix) respondents included the ILC as sources of advocacy and other assistance. There were few specific resources listed for general information on DD except what might be available at the tribal health center or tribal vocational rehabilitation program. In fact, the question of where people go for information on DD came up with the greatest number of “don’t know” responses of any question on the surveys. When asked during interviews, respondents stated that families sought such services in the nearest metropolitan area or that specialized DD services were generally unavailable.

Information Respondents Would Like the AIDD Commissioner to Know About the Greatest Community Needs

AI/AN participants were asked as part of the written survey to identify the one thing that would make life better for individuals with DD and their families in their community. This information was also gathered as part of the interview process and community meeting, along with an additional question: “Is there any additional information you would like to share with the AIDD Commissioner

⁴ In New York, Legal Services is the P&A provider.

about your community?” A compilation of responses to this question is included as Appendix D. The data collected in the surveys, interviews, and meeting were remarkably similar. Respondents in the interview process focused strongly on respecting culture as an important need and something that was important for the Commissioner to know.

The top categories listed that would make life better for people with DD and their families from the conference sample were:

1. Family/Community/Tribal support – supporting families within their communities
2. Services and resources, particularly AI/AN based services
3. Awareness, respect, and acceptance – both for AI/AN culture and customs in accessing state services and for AI/AN people with DD
4. Information, education, and training for families and tribal personnel about people with DD

Results from the surveys are categorized in Table 3, with additional qualitative detail from the interviews below.

Table 3: Community Needs to Make Life Better for People with DD and their Families

Category	CANAR Survey (n=123)		Nez Perce Nation (n=113)		AI Health and Wellness Fair (n=87)	
	Number	%	Number	%	Number	%
Information/education and training	17	11%	33	29%	12	25%
Jobs (and job training)	9	6%	4	3%	2	4%
Services (other than job training or education)	13	9%	28	24%	7	14%
Resources (more funding, better services and supports)	25	17%	12	10%	3	6%
Family/Community/ Tribal support	26	17%	9	8%	13	27%
Education (school)	6	4%	6	5%	2	4%
Transportation	15	10%	2	2%		
Housing	9	6%	5	4%		
Awareness, respect, and acceptance	22	15%	13	11%	8	17%
Don't know	2	1%	2	2%	3	6%
Other	6	4%	1	1%	2	4%
TOTAL RESPONSE*	150		115		52	
Skipped question	23		34		40	

* Total responses may be more or less than total surveyed because some people responded with more than one top issue and others skipped this question.

Family/Community/Tribal support

Family/Community/Tribal support represented the most widely noted item to improve quality of life for AI/AN individuals with DD. Respondents noted the following as important needs: “home support,” “help and understanding for families,” and “family and peer support groups.” “Support” also included improved information for families and more or better services in the community. There is some overlap with this category and “More Resources/Services” in the comments, however, there was enough of a distinct categorization of family/community/tribal support as a separate construct to highlight it here. As one respondent stated,

“It seems like with the very difficult cases there is not enough support for people who would like to keep their children home. The caregivers provided do not seem to have the training to give the type of care that is needed. The parents need to play a big role and many times they do not have the tools to provide the care and they often feel like

they are alone. The parents of these children need training from the beginning to know how to provide the best care.”

More Services/resources/AI/AN-based Services

Respondents cited both the “need for increased access to services off reservation” and “more resources in general on reservation” (e.g., increased funding, expansion of programs and services, and increasing attention to rural areas). Several respondents mentioned the need for further **development of tribal directed services and improved AI/AN infrastructure to provide DD services**. Responses included: “Make it easier for tribal communities to become their own direct service providers” and “The (Nation) depends too much on outside agencies and we need to continue developing our own infrastructure to help in this area.” One interviewee mentioned that the model for AI/AN vocational services was a model for development of DD services. Another suggested more Native American Independent Living Centers as a positive step in providing services to AI/AN individuals with DD.

During the interviews, the lack of services particularly for adults was noted. Children receive assistance through early intervention, early childhood programs, and the schools, but respondents indicated they believed adults have little assistance. Responses indicated there is limited accessible housing, jobs are scarce, and for the most part there is limited or no day programming. Respondents believed tribal VR programs provide some assistance, but more is needed. In one community, people with psychiatric disabilities and people with DD attend the one available day program together. In another, tribal social services personnel were urged to place an individual in a congregate setting over an hour away because of the lack of appropriate services nearer to home. As one respondent put it:

“I think lack of services results in a lifetime of dependency on others and poverty due to the lack of employment and education. They become potential victims in society, have hazardous

living conditions, and a life of nothingness if these services are not provided.”

Lastly, as indicated above in the “challenges” section, transportation remains a concern and was frequently cited by individuals as the “one greatest need”. This has been a concern in remote and rural areas across the country and was also evidenced as part of this needs assessment. Transportation remains an issue and was noted by many with a small dimension in variance to include: “better transportation,” “more transportation,” and “employment transportation.”

Awareness, Respect, and Acceptance

The importance of respecting and understanding Native culture in the DD service context was cited by many AI/ANs interviewed or attending the community meeting. Concerns were stated that **DD services, supports, and programs have to be responsive to the Native culture and customs in order to be effective**. In the interviews, several respondents gave instances where the requirements of a state DD system made it more difficult for AI/AN individuals and their families living in remote areas to obtain assistance:

“There is a rule. They [State DD agency] call three times and if you don't answer or call right back, they close your case.”

“We've been trying since January to get him [her son age 30] services, but the [DD agency] keeps calling my cell and when I'm at work I can't talk... I have been shifted around from place to place, telling me to go here go there.”

Training in AI/AN cultures for DD service and school personnel was recommended. As one individual stated, “It's not all in the book, and knowing the individual and listening to Native consumers and families are a way of learning what's not taught in school or through reading.”

This category also included awareness, respect, and acceptance of AI/AN people with DD. This was titled by one participant as “awareness to the community.” They included: “there needs to be a societal attitude

change,” “more awareness of the programs available,” and the “acceptance and understanding of what DD is on a family and community scale.” There “needs to be more acceptance among community members” and that “acceptance” along with “respect for all including those with DD” was important to respondents.

Information, Education, and Training

The AI/AN communities participating in this project expressed that they need and want information and training on all aspects of developmental disabilities. This included: “educational awareness programs for the tribe,” more community education (in general); and the continued education about DD barriers that may exist in the communities. “Parents of children with DD need better training from the beginning to know how to provide the best care,” said one respondent. The respondents listed education needs on how to access services, what kinds of services and supports are best, advocacy, supporting individuals in the community, and creating opportunities for individuals with DD.

Other Issues

The problems of AI/AN alcohol and substance abuse, poverty, and mental health were raised throughout our needs assessment and are prominent in the literature. In all of the areas above – services, resources, family support, education, and awareness – consideration of the multi-generational effects of alcohol and substance abuse, poverty, and attendant mental health problems must be woven into any strategy for DD individuals and their families.

In addition, obesity and attendant secondary conditions such as diabetes affect AI/AN communities at much higher rates. Although respondents in our assessment did not focus on preventative care, wellness, exercise, or nutrition as the most pressing problems for families with DD, these issues must be addressed as part of an overall strategy to increase community inclusion and opportunity for AI/ANs with DD.

IV. Recommendations

On the basis of the above findings, we would make the following recommendations for consideration in future programmatic areas for AIDD, the DD Network, and agencies interacting with AI/ANs with DD and their families.

1. **Increase DD Network and DD Agency connections to people with DD and their families in AI/AN communities by forging relationships with respected community collaborators.** As part of this needs assessment, we spoke with trusted individuals – elders, health workers, advocates, teachers—in every community. They were the “go to” people in their community who knew every family with a member with DD and all the services and supports available within their area. They weren’t for the most part people who were situated in a disability related occupational role. Although larger AI/AN communities may have a more comprehensive social service system with specific staff addressing people with disabilities, in most smaller communities that is not the case. It is much more likely that a health worker at the local clinic or a respected community elder is the main contact for people with DD to access services and supports and to assist with advocacy efforts. This necessitates a different approach for community engagement by disability organizations both in terms of who to connect with and how to most effectively work with the community. Many DD specific agencies or organizations that are not located in AI/AN communities are not familiar with those communities including what the “lived lives” of people with DD look like. Most of these trusted individuals in AI/AN communities have had little contact with the DD agency world and are approaching assisting families in a framework that is less DD-specific in service and practice. Most of the respondents we spoke with had little relationship to the DD Network programs, but were open to knowing more and forging those connections. To be successful in partnering with

these communities, relationships with these individuals, community health representatives, tribal social workers, early education providers, and teachers is necessary. Examples of ways to forge successful partnerships include:

- The utilization of a “cultural broker” is one example of a method for a non-AI/AN disability agency to reach out to a new community. The “cultural broker” is a AI/AN community member who is trusted and has ties with the community, either through the broker’s own membership in the tribe or previous relationship with the tribe. This trusted individual serves as a bridge between the DD agency and the AI/AN community in developing information sharing and projects which are both relevant to the community and welcome to community members. The Oklahoma Disability Law Center has utilized this model by hiring an AI/AN individual with ties to many Oklahoma native communities to build relationships and to determine priorities for engagement in those communities. This individual may be a staff member of the DD agency or someone contracted with the agency.
 - Identification of an AI/AN community advocate for people with DD and developing a relationship by responding to a stated need in the community for information. The Center for Interdisciplinary Learning and Leadership, University of Oklahoma UCEDD, has utilized this strategy by building relationships with Community Health Representatives (CHR) for AI/AN communities and then providing requested materials and information for the CHR to distribute to families with DD in their communities. Building on this relationship, The Oklahoma UCEDD is able to utilize the CHR relations and infrastructure to grow its engagement in AI/AN communities.
2. **Increase the availability of information about AI/AN individuals with DD for all agencies working with AI/AN communities.**
 3. **Ensure connections to people with DD and their families in AI/AN communities have sustainability through capacity building.** We heard from many AI/AN participants in the project that their knowledge of the DD Network or other DD agency was based on a onetime event, project, or other contact. With limited funding it is often difficult to keep up a presence and connection in a remote community. The strategy for long term sustainability for DD Network agencies working with AI/AN communities is to help in building capacity within those communities. This reflects AI/AN communities desire to develop their own service models and to control their own services and supports.
 - There are some models for tribal provision of services in vocational rehabilitation which

As indicated above, many of the agencies and services in AI/AN communities may be health or social service oriented, rather than specifically developmental disabilities focused. There may be a variety of tribal and federal agencies touching the lives of people with DD and their families on a regular basis. For example, people with DD and their families may have contact with their Nation’s tribal government, the Indian Health Service, Bureau of Indian Affairs, Bureau of Indian Education, US Department of Housing and Urban Development housing programs, and/or the US Department of Justice on a frequent basis. There may also be State social service and health agencies on or near AI/AN communities which families access for assistance. An understanding of DD and the issues faced by AI/AN families is also important for these non-disability specific entities and agencies interacting with AI/AN families with DD in the same way understanding AI/AN culture and custom is important to disability agencies. At a federal level, agency collaborations can be a start to infusing information about DD into agency initiatives and at the state and tribe level creating effective partnerships between disability and AI/AN agencies and organizations to increase the sharing of information.

have been successful and from which we can learn. Many AI/AN nations have their own tribal vocational rehabilitation programs (Section 121 of the Rehabilitation Act of 1973), and have received technical assistance in developing their applications and programs through Rehab Act Grants (Arizona UCEDD at Northern Arizona University). The national organization Consortium on Administrators of Native American Rehabilitation Programs (CANAR) provides technical assistance and training to these tribal programs as well.

- Many larger AI/AN Nations run their own tribally-directed behavioral health services through intergovernmental agreements with the State. For example, in Arizona, Tribal Regional Behavioral Health Authorities serve the same role for AI/AN communities as other state funded regional behavioral health entities. The National Indian Child Welfare Association has also been very active in providing technical assistance to tribes on developing mental health services. Consultation in capacity building strategies for tribes in providing services and supports for individuals with DD would be a first step in tribally-directed services and supports. State and federal support for projects which support this capacity building and explore how communities can begin to provide their own directed DD services and supports are needed.
4. Promote education and training on DD through tribal colleges/University Native American Programs. There are many two-year tribal colleges throughout Indian Country. Partnership projects between tribal colleges and UCEDDs, similar to partnerships between UCEDDs and minority serving institutions, could go a long way in building the capacity of American Indian Nations to provide support for individuals with DD. Initiatives to develop curriculum, distance learning, and knowledge exchange are needed. In addition, a wide variety of programs and centers at universities in states with significant American

Indian populations are active in creating a pipeline for AI/AN students in health sciences, engineering, and other fields. Closer connections between these university pipeline initiatives in AI/AN communities and UCEDDs could help to create trainee opportunities for AI/AN students within UCEDDs and longer range connections to AI/AN communities through these students.

5. Building a national one-stop resource for information on AI/AN and DD. There is no national one-stop center providing information for AI/AN communities about the issues for Native Americans with DD. The American Indian Disability Technical Assistance Center (AIDTAC) at the University of Montana Rural Institute UCEDD, under a Department of Education, Rehabilitation Services Administration grant, addressed broad disability issues of employment, transportation, health, independent living, voter participation, and education until funding was discontinued in 2008. There are pockets of disability related national resources addressing AI/AN issues and DD (see appendix B to this report), but no comprehensive resource for training, information, or technical assistance. Clearly, for individuals, groups, and agencies working with AI/AN individuals with DD and their families, having culturally relevant, up-to-date resources and information in one place would be enormously helpful.
6. Promote connections that are based on mutual respect and understanding of the culture, laws, and customs of a population. AI/AN respondents stressed the importance of people working in the DD field learning about their culture in order to be able to provide the services and supports needed. Just listening to AI/AN people is as important as formal education and training. Many AI/AN communities may not see disability in the same way as the dominant culture. For example, the concept of disability in some AI/AN communities may focus on whether the individual is living in harmony or whether the individual is able to fill his/her

role in family and community rather than an individual's impairment. Although the term 'disability' is now more commonly used in AI/AN communities, its meaning may differ from community to community. Understanding this is important to building connections and developing collaborations. Technical assistance and training for individuals working with AI/AN communities on the culture, law, and customs is crucial to building trusting and effective partnerships.

7. Promote connections that are based on AI/AN community needs. Our data collection pointed to important community needs for community based services and supports, more information and training, and better family support. Though clearly not generalizable to all AI/AN communities, these are likely to be important issues to many AI/AN communities. It is crucial that programs and projects in these areas are geared to the specific needs, customs, and cultures of each of the communities served. Many DD Network agencies as well as other DD agencies and organizations may have priorities that are not in sync with the needs of AI/AN communities or priorities that must be adapted to have relevance to those communities. It is important that materials, trainings, and projects have input from AI/AN communities to ensure they are accessible and applicable to the community.

References

- Acton, K.J., Burrows, N.R., Moore, K., Querec, L., Geiss, L.S. & Engelgau, M.M. (2002). Indian Health Service, Rockville, MD, USA. *Am J Public Health*, 92(9), 1485-90. Erratum in: *Am J Public Health* 2002 Nov; 92(11):1709.
- Autism Developmental Disabilities Monitoring [ADDM] Network. (2007). Prevalence of the Autism Spectrum Disorders in multiple areas of the United States, 2000 and 2002. Center of Disease Control and Prevention. Retrieved from <http://www.cdc.gov/ncbddd/autism/documents/autismcommunityreport.pdf>
- Beckett, C. (2011). Fetal Alcohol Spectrum Disorders: A Native American Journey to Prevention. *Family & Community Health*, 34(3), 242-245.
- Brenneman, G. (1997). Chronic and disabling conditions among American Indian and Alaskan Native Children and Youth. *Families, Systems & Health*, 15(3), 263-274.
- McNeil, J. (2001). Americans with Disabilities 1997. Current Population Reports: US Census Bureau.
- Muller, E., & Markowitz, J. (2005). American Indian and Alaska Native Students with Disabilities. National Association of State Directors of Special Education, Inc. Retrieved from http://www.projectforum.org/docs/AI_AN.pdf
- National Indian Child Welfare Association [NICWA] (2005, April). American Indian/Alaska Native Fact Sheet for the State of Arizona.
- Szlemko, W.J., Wood, J.W., & Thurman, P.J. (2006). Native Americans and Alcohol: Past, Present, and Future. *Journal of General Psychology*, 133(4), 435-451.

Urban Indian Health Institute (2009). Seattle Indian Health Board. Visibility Through Data: Health Information for Urban American Indian and Alaska Native Communities. Seattle: Urban Indian Health Institute

US Census Bureau (2009). Corporate Achiever Awards for Individuals with Disabilities (CAAID). Disability rates varied among the major racial and ethnic groups. Disability Status: 2000. Retrieved from <http://www.caaaid.us/DisabilityVaries.html>.

US Department of Education (2000). Twenty-second annual report to Congress on the implementation of the Individuals with Disabilities Education Act (IDEA). Washington, DC: U.S. Government Printing Office.

Zhang, D. & Katsiyannis, A. (2002). Minority Representation in Special Education: A Persistent Challenge. Remedial and Special Education, 23(3), 180-187. Retrieved from <http://rse.sagepub.com/content/23/3/180.full.pdf+html>

Appendix A: Native American and Developmental Disabilities Articles and/or Websites

Disability/ Services	Title	Description	Source
Fetal Alcohol Syndrome	Support for Native Americans with Developmental Disabilities	This report addresses the high incidence of FAS and fetal alcohol affects among Native Americans & suggests that there is a lack of comprehensive effort to provide outreach services to the Native American population.	http://www.eric.ed.gov/PDFS/ED408118.pdf
Trauma & Mental Health	Trauma Exposure in American Indian /Alaska Native Children	Describes how trauma is experienced in Indian Country and covers information on lack of mental health services, education, poverty, death rates, victimization, and chronic health problems. Also includes info on major mental health problems such as depression, suicide, PTSD, child abuse and neglect, domestic violence, and substance abuse.	http://www.icctc.org/Resources/Trauma_AIs_Children_Factsheet2.pdf
Traumatic Brain Injury (TBI) & Fetal Alcohol Syndrome	Traumatic Brain Injury Among American Indians/Alaska Natives United States 1992-1996	CDC analyzed the Indian Health Service (IHS) hospital discharge data: injuries are the second leading cause of death among AI/AN. The report also covers information on fetal alcohol syndrome in Alaska, Arizona, Colorado & New York.	http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5114a3.htm
Various - Special Education	Epidemiology Across Cultures: American Indian and Alaska Native Populations	Percentage of students ages 6-21 receiving special education services for learning disabilities, speech/language impairment, mental retardation, emotional disturbance, multiple disabilities, hearing impairment, visual impairment, Autism, deaf-blindness, and TBI.	http://www.asha.org/Practice/multicultural/american-indian/
IDEA	28th Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act, 2006 Vol. 1	There is some information relating to American Indians and Alaska Natives in this 2006 Report to Congress on IDEA implementation.	http://www2.ed.gov/about/reports/annual/osep/2006/parts-b-c/28th-vol-1.pdf
FAS, Trauma, Behavioral & Emotional Disorders	Disabled American Indians: A Special Population Requiring Special Considerations	Needs assessment initiated and conducted by the Native American Research & Training Center at the UA and 3 tribal-operated and managed vocational rehabilitation programs (Navajo, AZ; Chippewa-Cree, MT, & Shoshone-Bannock, ID).	http://aisc.metapress.com/content/j8kl71657h1400w2/fulltext.pdf (purchase only)

Disability/ Services	Title	Description	Source
Various	Disabilities Prevention and the Distribution of Risk Among American Indians	Information on how many American Indians live with disabilities and the most prevalent disabilities that affect Native people.	http://www.ucdenver.edu/academics/colleges/PublicHealth/research/centers/CAIANH/journal/Documents/Volume%205/5%283%29_Mendola_Developmental_Disabilities_30-44.pdf
Various	American Indian and Alaska Student with Disabilities by Eve Muller and Joy Markowitz	Information from the National Association of State Directors of Special Education (NASDSE) in cooperation with the US Department of Education's Office of Special Education Program (OSEP). Covers prevalence of disabilities, and rates provided.	http://www.projectforum.org/docs/AI_AN.pdf
Various - Chronic Physical, Developmental, Behavioral, or Emotional Conditions	Prevalence of Children with Special Health Care Needs	An article reviewing survey findings about the prevalence of special health care needs among children by age & race/ethnicity.	http://mchb.hrsa.gov/chscn/pages/prevalence.htm
Disabilities (General info)	Racial/ Ethnic Disparities in Self-Rated Health Status Among Adults With and Without Disabilities-- United States, 2004-2006	Within each racial/ethnic population, adults with a disability were more likely to report fair or poor health than adults without a disability, with differences ranging from 16.8 percentage points among Asians to 37.9 percentage points among AI/ANs. The prevalence of disability was highest among AI/ANs (29.9%) and lowest among Asians (11.6%)	http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5739a1.htm
Health Disparities (General info)	Fact Sheet- CDC Health Disparities and Inequalities Report- U.S., 2011	Covers general health disparities for several races, including Native Americans having some of the highest rates for motor vehicle-related deaths in 2007, suicides, diabetes, and an increased prevalence of HIV infection, cigarette smoking, and adolescent pregnancy and childbirth.	http://www.cdc.gov/minorityhealth/reports/CHDIR11/FactSheet.pdf

Disability/ Services	Title	Description	Source
Mental health	American Indian and Alaska Native Communities Mental Health Fact Sheet	Covers facts about AI/AN and mental health. Contains information about substance abuse, suicide, traumatic events, poverty, and psychiatric disorders.	http://www.nami.org/ContentManagement/ContentDisplay.cfm?ContentFileID=79888
Mental Health- Depression, PTSD, Suicide, Anxiety, and Substance Abuse	Mental Health Disparities: American Indians and Alaska Natives	Facts about population, health disparities on poverty, life expectancy, violence victimization, unintentional injuries, and alcohol related issues. It also covers AI/AN Mental Health Status and use of services and disparities.	http://www.psych.org/Share/OMNA/Mental-Health-Disparities-Fact-Sheet--American-Indians.aspx
Developmental Disabilities	Developmental Disabilities Services Recipients by Race/ Ethnicity and County	Contains valuable information on American Indian usage of DD services by county.	http://www.okdhs.org/NR/rdonlyres/C32DF99C-55A6-4118-BC99-634C082E69FC/0/MSBT14_oprs_012011.xls
Special Health Care Needs	The National Survey of Children with Special Health Care Needs Chart book 2005-2006	Information on children with special health care needs by race/ethnicity, and state.	http://mchb.hrsa.gov/cshcn05/MI/NSCSHCN.pdf
Spinal bifida	Prevalence of Spinal Bifida at Birth-- United States, 1983-1990: a comparison of two surveillance systems	Explains that the spinal bifida rates for American Indians did not differ significantly from rates of other ethnic groups.	http://www.cdc.gov/mmwr/preview/mmwrhtml/00040954.htm
Mental health	Chapter 4 Mental Health Care for American Indians & Alaska Natives	Well developed summary of major issues affecting AI/AN. Covering historical context, current health status, the need for mental health care, availability, accessibility, and utilization of mental health services.	http://www.ncbi.nlm.nih.gov/books/NBK44242/
Various - General	Understanding Disabilities in American Indian and Alaska Native Communities: Toolkit Guide.	Covers disabilities, whether visible or hidden, that may be experienced by individuals in the American Indian and Alaska Native Community. Mentions prevalence and types of disabilities affecting AI/AN individuals.	http://www.ncd.gov/publications/2003/Aug12003

Disability/ Services	Title	Description	Source
Spinal Cord Injury, Diabetes, Blindness	Navigating Through Life on a Tightrope: A look at American Indian Women With Disabilities by Cinda Hughes, Legislative Associate	Covers lack of funding and services for NA populations. Gives percentage of disability by gender and ethnicity: Native American Females= 21.9% and Native American Males=21.8%	http://www.hhs.gov/od/NLS0601Hughes.html
Special Education	Status and Trends in Education of American Indians and Alaska Natives: 2008	Notes that a higher percentage of American Indian/Alaska Native children were served by the Individuals with Disabilities Education Act (IDEA) than children in any other racial/ethnic group in 2006.	http://nces.ed.gov/pubs2008/nativetrends/ind_2_3.asp
Various	Young American Indian/Alaska Native Children with Disabilities: Implementation for Policy, Research, and Practice	Covers incidence of disabilities among infants and pre-school -age AI/AN children relating to rural or urban setting. Also covers percentages that received early intervention under IDEA.	http://www.createwisconsin.net/ecwebcastdocuments/EC_Forum_Report.pdf (p. 114-131)
Services	Native American with Disabilities Don't Get Services People with Disabilities on Tribal Lands: Education, Health Care, Vocational Rehabilitation, and Independent Living	This National Council on Disability (NCD) report documents that AI/AN with disabilities living in tribal lands are not receiving the services to which they are entitled.	http://www.nea.org/home/18912.htm http://www.ncd.gov/publications/2003/Aug2003
Education	Intervention in School and Clinic- Working With American Indian Students and Families: Disabilities, Issues, and intervention	Covers educational outcomes of American Indian Students in the public school system, specifically relating to special education, disability issues, and the relationship between school and family. This article provides culturally responsive research-based practices to help foster school and family relationships and improve the educational outcomes of American Indian students.	http://lshss.asha.org/cgi/content/full/39/4/521
Special Education/ IDEA	Minority Representation in Special Education: A Persistent Challenge	Discusses the overrepresentation of minority students in special education. American Indians have the highest percentage of disabilities: learning disabilities and emotional -behavioral disturbance; and have the second highest percentage of intellectual disabilities after African Americans.	http://rse.sagepub.com/content/23/3/180.full.pdf+html (for purchase)

Disability/ Services	Title	Description	Source
General Disability Information	2000 Census American Indian and Alaska Native Summary File	According to the 2000 Census, the total population of AI from 5 to 20 years of age was 729,256 and those with disabilities were 75,294, or approximately 10.3%. The total population 21 to 64 years of age is 1,325,911, and those with disabilities make up 28.6% (379,461). Out of the 28.6% of AI with disabilities, 48.3% of them are employed.	http://factfinder2.census.gov/faces/nav/jsf/pages/index.xhtml
General Disability Information	Chronic and Disabling Conditions among American Indian & Alaskan Native Children and Youth, by George Brenneman, MD	Prevalence of disabilities and information on the types of disabilities affecting AI/AN youth.	http://www.deepdyve.com/lp/psycarticles-reg/chronic-and-disabling-conditions-among-american-indian-and-alaskan-gHcXPERPdb
General Disability Rates	Disability rates varied among the major racial and ethnic groups	2000 Census information on disability among several ethnic groups, including American Indians.	http://www.caaid.us/DisabilityVaries.html
General Disability Rates	Disability Status: 2000, Census 2000 Brief	Disability Rates by age, sex, race, and ethnicity	http://www.census.gov/prod/2003pubs/c2kbr-17.pdf

References to Studies Including Navajos

- Begay, R. C., Brown, B. G., & Bounds, R. G. (2009). Disability as a human perception: Personal and professional reactions to American Indian families' narratives about their Children's disabilities. *Disabilities: Insights from Across Fields and Around the World* (Vol. 1, pp. 87–107). Santa Barbara, CA: Praeger/ABC-CLIO.
- Cheema, T. A., & Swanson, S. (2011). Hand involvement in Navajo neurohepatopathy: A case report. *Hand*, 6(2), 217-219.
- Goldstein, S., & Cunningham, S. (2009). Current issues in the assessment of intelligence, Specific learning disability, and attention Deficit hyperactivity disorder. In J.A. Naglieri & S. Goldstein (Eds.), *Practitioner's Guide to Assessing Intelligence and Achievement* (pp. 11-23). Hoboken, NJ: John Wiley and Sons, Inc.
- Guy, E. (2009). Factors associated with both successful and unsuccessful vocational rehabilitation case closures of Navajo people with disabilities: A qualitative study. Ph.D. dissertation, The University of Arizona, United States -- Arizona. Retrieved from Dissertations & Theses @ University of Arizona. (Publication No. AAT 3359194).
- Kapp, S. K. (2011). Navajo and autism: The beauty of harmony. *Disability & Society*, 26(5), 583-595.
- Page, T. O. H. (2008). A formative program evaluation of a disability services office. Thesis (M.A.)--Wichita State University, College of Liberal Arts and Sciences, the Program of Liberal Studies. Retrieved from <http://hdl.handle.net/10057/2012>.
- Pedersen, M. J., & Vining, C. B. (2009). Early intervention services with American Indian tribes in New Mexico. *Perspectives on Communication Disorders and Sciences in Culturally and Linguistically Diverse Populations*, 16(3), 86.
- Sauer, J., & Sauer, C. (2010). Challenging pre-service teachers' understanding of the intersection of disability and cultural diversity. *Journal of Praxis in Multicultural Education*, 5(1), 6.
- Schwartz, C. (2005). Parental involvement in residential care and perceptions of their offspring's life satisfaction in residential facilities for adults with intellectual disability. *Journal of Intellectual and Developmental Disability*, 30(3), 146-155.
- Sosenko, J. M. (2009). The Prevalence of Diabetic Neuropathy according to Ethnicity. *Current Diabetes Reports*, 9(6), 435-439.
- Yazzie-King, E. (2009). How Rich and Fulfilled my life has been: A personal perspective of mobility "Impairment". In Marshall C. A., Kendall E., Banks M. E., Gover R. M. S. (Eds.), *Disabilities: Insights from across fields and around the world* (Vol. 1, pp. 1–4). Santa Barbara, CA: Praeger/ABC-CLIO.
- Young, F. W. (2005). Social activism and disability rates in American Indian tribes. *Cross-Cultural Research*, 39(4), 418.

Appendix B: American Indians/Alaskan Natives and Disability Organizations

Source: Family Village, University of Wisconsin. http://www.familyvillage.wisc.edu/living/native_american.html ; retrieved September 19, 2011

Native American Resources on Disability

American Indian Disability Technical Assistance Center

<http://aidtac.ruralinstitute.umt.edu/>

The American Indian Disability Technical Assistance Center or AIDTAC was information and technical assistance center that works with American Indian tribes and Alaskan Native villages to help their members with disabilities live healthy lives as part of the community. Although the Center is no longer funded, the Rural Institute website has many resources.

Association of American Indian Physicians

<http://www.aaip.org/>

Has a mission to pursue excellence in Native American healthcare by promoting education in the medical disciplines, honoring traditional healing principles and restoring the balance of mind, body, and spirit.

Capacity Building For American Indians Project

<http://www4.nau.edu/ihd/CBAIP.asp>

Assisting American Indians, Alaska Natives and minority entities to develop and maintain culturally appropriate vocational rehabilitation programs.

Consortia of Administrators for Native American Rehabilitation (CANAR)

<http://www.canar.org/>

The mission of CANAR is to serve as an avenue for collaboration and cooperation between Administrators of rehabilitation projects serving Native American persons with disabilities, to increase and enhance the quality of services, resulting in positive outcomes for Native American persons with disabilities

Indian Children's Program (ICP)

<http://www.icpservices.org/>

ICP strives to provide responsive, family-centered and community based services for Native American children with known or suspected disabilities. ICP programs embrace the spirit of cultural diversity, collaboration and innovation. ICP works to improve the quality of services for Native American children with special needs by facilitating integrated development of family and community capabilities and resources.

Indian Country Child Trauma Center (ICCTC)

<http://www.icctc.org/>

Established to develop trauma-related treatment protocols, outreach materials, and service delivery guidelines specifically designed for American Indian and Alaska Native (AI/AN) children and their families. The Indian Country Child Trauma Center is part of the National Child Traumatic Stress Network funded by the Substance Abuse Mental Health Services Administration (SAMHSA) under the National Child Traumatic Stress Initiative. It is housed at the University of Oklahoma Health Sciences Center in the Center on Child Abuse and Neglect. A current program includes Project Making Medicine (PMM).

Indian Health Service

<http://www.ihs.gov/>

Has a mission to raise the physical, mental, social, and spiritual health of American Indians and Alaska Natives to the highest level and to assure that comprehensive, culturally acceptable personal and public health services are available and accessible to American Indian and Alaska Native people.

Indian Law Resource Center

<http://www.indianlaw.org/>

Legal advocacy for the protection of indigenous peoples' human rights, cultures, and traditional lands so that Indian tribes and nations may flourish for generations to come

Intertribal Deaf Council

<http://www.deafnative.com/>

Preserves and carries out traditions, languages and cultures of First Nations deaf, deaf-blind and hard of hearing people. Provides information exchange, traditional and education activities, and awareness activities for non-Native and/or non-deaf people.

National Indian Child Welfare Association

<http://www.nicwa.org/>

A comprehensive source of information on American Indian child welfare and works on behalf of Indian children and families. NICWA provides public policy, research, and advocacy; information and training relating to Indian child welfare; and community development services to a broad national audience including tribal governments and programs, state child welfare agencies, and other organizations, agencies, and professionals interested in the field of Indian child welfare.

National Indian Health Board

<http://www.nihb.org/>

The National Indian Health Board will advocate on behalf of all Tribal Governments and American Indians/Alaska Natives in their efforts to provide quality health care.

National Indian Parent Information Center

<http://www.nipic.org/>

Nation-wide resources for Native American families, tribes, communities, and parent centers

National Native American AIDS Prevention Center

<http://www.nnaapc.org/>

The National Native American AIDS Prevention Center's (NNAAPC) mission is to stop the spread of HIV and related diseases among American Indians, Alaskan Natives, Native Hawaiians, and to improve the quality of life for those infected and affected by HIV/AIDS.

Native American Advocacy Center

<http://www.nativeamericanadvocacy.org/>

The mission of the Native American Advocacy Program, which strives to maintain a healthy organization, is to assist Native Americans with disabilities and Native American Youth by: promoting a healthy lifestyle, providing prevention, education, training, advocacy, support, independent living skills and referrals.

Native American Disability Law Center

<http://www.nativedisabilitylaw.org/>

The Native American Disability Law Center is a private nonprofit organization that advocates for the legal rights of Native Americans with disabilities. Through advocacy and education, we empower Native people with disabilities to lead independent lives in their own communities. The Law Center's service area covers over 25,000 square miles of high desert in the Four Corners region of Arizona, New Mexico, Utah, and Colorado, an area approximately the size of Michigan.

Native American Health Links

<http://www.nlm.nih.gov/medlineplus/nativeamericanhealth.html>

Department of Health and Human Services

NativeWeb News Digest

<http://www.nativeweb.org/news/>

Up-to-date Indian news on the web.

Native American Women's Health

<http://www.nativeshop.org/>

The Native American Woman's Health Education Resource Center has a Fetal Alcohol Syndrome (FAS) awareness program and a Child Development Program is designed for children in the community with special needs.

Office of Minority Health

<http://www.omhrc.gov/>

Advises on public health issues affecting American Indians and Alaska Natives, Asian Americans, Native Hawaiians and Other Pacific Islanders, Blacks/African Americans, and Hispanics/Latinos.

One Sky Center

<http://www.oneskycenter.org/>

To improve prevention and treatment of mental health and substance abuse problems and services among Native people.

Pathways to Improving Outreach to American Indians and Alaska Natives who are Deaf, Deaf-Blind, and Hard of Hearing

<http://www.uark.edu/depts/rehabres/AmericanIndian/Study.htm>

Project to address key rehabilitation outreach needs of American Indians and Alaska Natives who are Deaf, Hard of Hearing, and Deaf-Blind, and who are living in urban settings or are in transition from tribal lands.

Three Feathers Associates

<http://www.threefeathersassoc.com/>

Has a mission to promote the health, education and welfare of American Indian and Alaska Native people.

Visions

<http://fndfl.org/default.aspx>

Parent Training and Information (PTI) services to Native American, Native Hawaiian, and Alaskan Native families across the country.

Appendix C: Native American Developmental Disabilities Needs Assessment: Survey Instrument & Interview Format

Interview Information

Name:

Contact info: (phone, email, address)

Position/role:

Tribe (employment and membership):

Date:

Interviewer:

Introduction

The Sonoran University Center for Excellence in Developmental Disabilities (UCEDD) at the University of Arizona in conjunction with the Native American Research and Training Center (NARTC) is conducting a needs assessment of American Indians and Alaska Natives (AIAN) to explore their familiarity with and utilization of DD Network Program agencies, the availability of services and support for individuals with DD and their families in AIAN communities, and the needs of DD tribal members and their families. This project is funded by the Administration on Intellectual and Developmental Disabilities (AIDD) (ACF, HHS) and the information we are gathering will be used only for internal purposes for AIDD to set priorities for its work and projects.

Definitions

Developmental Disability (Commonly referred to as DD). For purposes of this interview we are using the following definition: DD is a severe, chronic disability of an individual that is attributable to a mental or physical impairment or combination of mental and physical impairments; occurs before the individual attains age 22; is likely to continue indefinitely; and results in substantial limitations in 3 or more areas of major life activity (self-care, language, learning, mobility, self-direction, capacity for independent living, economic self-sufficiency). The individual with DD is likely to need specialized support or assistance on a life-time basis (examples include: cerebral palsy, autism, traumatic brain injury (occurring prior to 22); fetal alcohol syndrome, intellectual disability).

Each state defines a developmental disability according to state law. That state law may govern what services and supports are available in your state, including on American Indian nations or an AI/AN nation may have its own definition for DD services.

We are asking about both children and adults with developmental disabilities.

The Administration on Intellectual and Developmental Disabilities (AIDD) is the federal agency charged with supporting people with developmental disabilities and their families pursuant to the DD Bill of Rights Act. AIDD funds three main programs in each state which I will be asking you about. The AIDD Commissioner wants to know whether the programs it funds are serving AI/AN individuals and families with DD.

Professional, Provider, or Administrator Interview

- Explain role and job duties and agency mission
- Does your agency provide services or supports to people with DD?
 - If Yes:
 - What is eligibility for “DD” services and supports you provide (i.e. who is eligible, what is criteria for services, catchment area, etc)
 - What are the characteristics of the DD population you serve -- #s, age range, where located, types of disabilities, living situations, etc.
 - Explain in detail what kinds of services and supports your agency provides to people with DD.
 - How do you think you are doing in meeting the needs of people with DD and their families?
 - What do you think people with DD and their families in your community need that you aren’t able to provide?
 - What are the greatest challenges you face in providing these services?
 - What are the greatest strengths of your agency in providing these services?
 - Can you tell us a story of what has gone well for a person with DD and their family in your community?
 - Can you tell us a story of a challenge faced by a person with DD and their family in your community?
 - If no:
 - Are you familiar with where people with DD and their families go to get help in your community?
 - If yes:
 - Explain how you have come to be familiar with DD individuals and their families and where they go to get help? (Wanting to find out their base of knowledge of people with DD and their families in their community).
 - How often do you come in contact with people with DD and their families?
 - How many people with DD and their families have you referred for services in the last year?
 - Do you know what services are provided in your community?
 - If no: end

Family/Individual with DD Interview

- Can you tell us a little about your family/family member (son, daughter, grandson, etc) with DD? (Information on family member with DD, age, relationship, where living, is the individual in school, working, what do they do during the day, etc – depending on the age and situation)
 - Can you tell us a story of what has gone well for family member with DD in your community?
 - Can you tell us a story of a challenge faced by your family and family member with DD in your community?
 - Who has been the most help in your community for your family?
 - Are you familiar with other people with DD and their families in your community?

All Respondents

- Where do people with DD and their families go to get help in your community? Please specify names of agencies, people, etc.
- Specifically, where do people with DD and their families get the following services and supports:
 - Health Care (Place or Name) -- Don’t know
 - Early Intervention services (Place or Name) -- Don’t know
 - Early Childhood services (Place or Name) -- Don’t know
 - School based services (including Special education and related services) -- Don’t know
 - Therapies (like speech, physical therapy, habilitation) -- Don’t know
 - Vocational Help (help to get a job) -- Don’t know
 - Advocacy or legal help -- Don’t know
 - Information on Developmental Disabilities and Services -- Don’t know
 - Home Modification (accessibility) -- Don’t know
 - Other
- In every state, the Administration on Intellectual and Developmental Disabilities (AIDD) funds three agencies to engage in activities and projects to assist people with developmental disabilities. AIDD is interested in knowing if you are familiar with these agencies and if these agencies provide assistance, including information and referral or services and supports in your community.
 - The **Protection and Advocacy System** in your state for people with DD is called: [P&A NAME]. The Protection and Advocacy System assists people with DD on legal and human rights issues related to their disability, including: information and referral; investigation of complaints of violation of rights of individuals with developmental disabilities; and working to resolve complaints through mediation, alternative dispute resolution and litigation.
 - Where do people with DD and their families go for legal or advocacy on disability related issues in your community?
 - Have you heard of [P&A NAME]?
 - What do you know about [P&A NAME]?
 - Have you had contact with [P&A NAME]?
 - Do you know families who have been in contact with [P&A NAME]?
 - Is information about the [P&A NAME] available in your community? Ever seen flyers? Educational Material? Brochures? Where?

- Do staff of the [P&A NAME] come to your community? Give presentations? Trainings? Have office hours?
- Can you tell us about any stories you know of [P&A NAME] helping individuals with DD and their families with disability related issues.
- The **Developmental Disabilities Planning Council** in your state is called [DDPC NAME]. DD Planning Council is made up of individuals with DD, family members and agency personnel across the state. The [DDPC NAME] engages in advocacy, capacity building and systems change activities which may include: training and education, information and referral, funding model projects and programs, coalition building, and informing policymakers.
 - Where do people in your community go to learn about developmental disability issues, policies and plans in your state?
 - Have you heard of the [DDPC NAME]?
 - What do you know about [DDPC NAME]?
 - Have you had contact with [DDPC NAME]?
 - Do you know people who have been in contact with [DDPC NAME]?
 - Is information about the [DDPC NAME] available in your community? Ever seen flyers? Educational Materials? Brochures? Where?
 - Do staff of the [DDPC NAME] come to your community? Give presentations? Trainings? Have office hours? Are any members of your community or tribal representatives' on the [DDPC NAME]?
 - Can you tell us about any stories you know of [DDPC NAME] helping individuals with DD through any of its activities?
- The **University Center(s) for Excellence in Disabilities** in your state is/are [UCEDD NAME(S)]. UCEDD core functions include: interdisciplinary training; community service (e.g., training, technical assistance, exemplary services); research; and information dissemination.
 - Where do people with go in your community to find out information on developmental disabilities research, best practices for services or model programs?
 - Have you heard of the [UCEDD NAME]?
 - What do you know about [UCEDD NAME]?
 - Have you had contact with [UCEDD NAME]?
 - Do you know people who have been in contact with [UCEDD NAME]?
 - Is information about the UCEDD NAME available in your community? Ever seen flyers? Educational Material? Brochures? Where?
 - Do staff of the [UCEDD NAME] come to your community? Give presentations? Trainings? Provide services or therapies? Do families in your community travel to the [UCEDD NAME] to obtain services or therapies?
 - Can you tell us about any stories you know of [UCEDD NAME] helping individuals with DD and their families?
- Who else in your tribe or community knows about the needs and challenges of people with DD and might be willing to talk with us?
- Are there other things you think the AIDD Commissioner should know about the lives of people with DD in your community that you would like to share with me?

American Indian and Developmental Disabilities Survey (template)

1. Introduction to American Inidan and Developmental Disabilities Survey

Thank you for taking a few minutes to take this survey from the Native American Research and Training Center (NARTC) and the Sonoran University Center for Excellence in Developmental Disabilities (UCEDD) at the University of Arizona. We are trying to find out what you know about programs and agencies in your area. We would also like to know if you are familiar with services and support for individuals with developmental disabilities (DD) and their families and what you consider are the strengths and challenges for them. The purpose of this project is to provide information to the U.S. Department of Health and Human Services, Administration on Developmental Disabilities (A.D.D.) for their use in setting strategic plans for activities and funding for the next five years.

For purposes of this survey developmental disabilities (DD) include any long lasting mental or physical disability affecting 3 or more major life activities (such as learning, walking, talking, self-care) that begins prior to the age of 22 and is likely to require lifetime specialized services and supports.

The Administration on Developmental Disabilities is the federal agency charged with supporting people with developmental disabilities and their families

1. How are you acquainted with people with DD and their families in your community? (check all that apply)

- Teacher
- Provider of services to people with DD
- Health care provider
- Family member of individual with DD
- Individual with DD
- Other professional
- Person with disability (not developmental)
- Family member of person with other disability (not developmental)

Other (please specify)

2. In every state, The Administration on Developmental Disabilities (A.D.D) funds three agencies to provide support of people with DD. A.D.D. is interested in knowing if you are familiar with these agencies.

Protection and Advocacy System (NAME)

- Never heard of it
- Have heard of it, but that's about all
- I know about the agency and what it does
- I have referred people in my community to this agency
- I have been assisted by or participated in its activities or programs

Other (please specify)

American Indian and Developmental Disabilities Survey (template)

3. DD Planning Council (NAME)

- Never heard of it
- Have heard of it, but that's about all
- I know about the agency and what it does
- I have referred people in my community to this agency
- I have been assisted by or participated in its activities or programs

Other (please specify)

4. UCEDD (NAME)

- Never heard of it
- Have heard of it, but that's about all
- I know about the agency and what it does
- I have referred people in my community to this agency
- I have been assisted by or participated in its activities or programs

Other (please specify)

5. In your community, please tell us about where people with DD and their families would go to get the help they need. Please provide the name of the place or program or tell us if you don't know by writing "Don't Know" in the box provided.

Health Care (Clinic or Hospital or name)	<input type="text"/>
Early Childhood services – ages 0 -3 (Place or Name)	<input type="text"/>
School (special education and related services)	<input type="text"/>
Therapies (like speech, physical therapy, self-care)	<input type="text"/>
Vocational Help (help to get a job)	<input type="text"/>
Advocacy Assistance or Legal Help	<input type="text"/>
Information on Developmental Disabilities and Services	<input type="text"/>
Tribe (programs, departments or offices)	<input type="text"/>
Other	<input type="text"/>

American Indian and Developmental Disabilities Survey (template)

6. What are the strengths of your community for people with DD and their families? (please check all that apply)

- Family
- community
- schools
- job training
- therapies available
- tribal support
- early childhood services (ages 0-3)
- clinic or health care provider
- specialized programs

Other (please specify)

7. What are the greatest challenges and/or needs for people with DD and their families in your community? (please check all that apply)

- DD services
- Education
- Transportation to services
- Therapies
- Health care
- Job training and jobs
- Accessible housing
- Attitudes toward people with DD
- Training for providers of services
- Information about DD
- Support for family and caregivers

Other (please specify)

8. What would be the one thing that would make life better for people with DD and their families in your community?

American Indian and Developmental Disabilities Survey (template)

9. Tribal Membership:

Other (please specify)

Appendix D: Survey Comments to AIDD Commissioner

QUESTION: Are there other things you think the AIDD Commissioner should know about the lives of people with DD in your community that you would like to share with me?

Cultural Values

“There are many within the community/tribe who have a sense of pride about their community, their culture and the possibilities for the future. Thank you for making things possible and providing the opportunity for them to be more self-aware, self-disciplined, self-directed and promote their culture and heritage.”

“Cultural lives and traditional values are needed in advocacy to be able to advocate for tribal communities. Also medical providers and other providers need this awareness. We need to get tribal trust and support for DD issues and support for DD health issues that are not available presently”

“Diversity training for upper-level staff to learn more about the Native peoples and cultures in the regions they serve”

“It’s not all in the book and knowing the individual and listening to Native consumers and families are a way of learning not taught in school or through reading”

“Consider Native American diversity training for their staff at the state, regional, county levels”

“Listen to the stories of Native peoples as a way of learning and training”

“There needs to be better training for teachers in the schools to identify and teach about DD and Native children. Often times the testing is not appropriate for Native children and that assessments are either not culturally normed to test properly and thus they are classified as DD when in fact they are not. Native children are often developmentally and culturally different in ways that the mainstream screening tools are not sensitive to, including environmental contexts.”

Need for services in AIAN Communities /Native controlled services and supports

“I think lack of services results in a lifetime of dependency on others and poverty due to the lack of employment and education. They become potential victims in society; have hazardous living conditions and a life of nothingness if these services are not provided. BABYSITTERS!! The kids that have nothing”

“Make it easier for tribal communities to become their own direct service providers.”

“Please allocate some money for Native American Independent Living Centers.”

“Need to concentrate on whole person and their environment – housing, utilities, school, advocacy, etc”

“We need advocacy for kids and their families.”

“There is a general lack of programs for people with disabilities in Indian country, e.g., recreation opportunities.”

“Paying attention to “funding gaps” where does it go and help, specifically, with Native American peoples. It does not seem that the proper funding makes its way into Indian Country”.

“The Nation depends too much on outside agencies and we need to continue developing our own infrastructure to help in this area.”

“There is an overall lack of support groups for: mental health and rural based programming.”

“There is a greater need for housing for Natives with disabilities. Especially those with dual diagnosis and for those that are homeless.”

“No information available even for those working in the clinic, no presentations, no trainings, no information given out. They should be visible at health fairs. And we know people that need the services. They need to have more outreach to the community.”

“That there are DD needs for all ages, kids and adults.The agencies need to know about each other so that people like me don't get the run around like I have for months and months.”

“Need more mental health [services] too. Sister with depression symptoms, no easy place for evaluation and treatment.”

“More and better transportation. Inadequate tribal transportation services.”

“Better housing options on the reservation.”

“Need more money to get services for clients; cuts are always to resources for the elderly and disabled.”

“We need: assistive technology, help getting resources in timely manner, more case management capacity, taking families ‘by the hand’, and more respite care for families.”

Information and training: Relationship to State Services and DD Network Programs

“Get information about these agencies (DD Network) out to people living on AI tribal lands. If social workers and case managers don't know about them, families don't. Need information and resources!”

“If I haven't heard of these agencies, how can our clients? It would be nice if they would at least mail us information.”

“There's a lot of red tape to get Natives into the right programs for assistance.”

“State programs call three times and then close the case if they don't hear back, it don't work. “

“More information available to school systems that have a large population of Native children.”

“Increase communication between the state DD departments and (native communities) be consistent in their efforts. Marketing information through posters, email, listerservs.”

Other

“We need a plan to help parents understand the importance of early childhood intervention; that it is okay to get help. How do we get equal services on the rez?”

“How do we eradicate the mixed drug/alcohol use in pregnancy leading to all the developmental delay and disabilities we see?”

“Education of elected officials on our needs.”

