

## National Council on Disability Summary of the Native American Forum: “Disability Matters in Tribal Communities”

When the National Council on Disability (NCD) invited public participation in the Native American Forum (Native Forum) held April 15, 2004 at the Santa Ana Pueblo Hyatt Regency Tamaya Hotel and Resort near Bernalillo, New Mexico, the purpose was to provide a dialogue opportunity for learning about issues and concerns linked to federal policy. In his delivery of the charge to forum discussion groups, NCD’s Cultural Diversity Advisory Committee Liaison, Milton Aponte indicated that the Native Forum was less about one size fits all solutions and “more about trying to obtain authentic perspectives from [the participants].” NCD wanted to learn directly from people with disabilities, their families, other advocates, tribal and state leaders, service providers and other disability professionals.

**Background:** From an historical point of view, the Native Forum was aligned with NCD’s record of broad and inclusive outreach to unserved and underserved people at the grassroots level. Building upon its work during the past 14 years with people across the full spectrum of disabilities, NCD recognized an abundance of matters impacting daily living that need to be addressed in Indian Country. The forum focused on a select few—education, health care, vocational rehabilitation, and independent living—as initial areas for discussion based in part on findings in NCD’s report, *People with Disabilities on Tribal Lands*.<sup>i</sup>

**Participants:** The participant list included people who paint the multi-ethnic landscapes of New Mexico and nearby Arizona, as well as California. People self-identified as self-advocates, family members, service providers, representatives of public and private entities such as local, state, tribal, and federal governments, businesses, and organizations serving people with disabilities. More than 120 native and non-native participants were counted—three quarters were pre-registered. This was the first time that NCD conducted a forum in a tribal community. Months of planning with a cohort of cross-cultural volunteers resulted in pre/post forum and onsite input by people from various indigenous cultures. Included at various points were members of Laguna Pueblo, Acoma Tribe, Eastern Band Cherokee, Prairie Band Potawatomi Nation, Nakota, Santee Sioux, Turtle Mountain, Chippewa-Cree, Sandia Pueblo, Santa Ana Pueblo, Zia Pueblo, Dine’/Navajo Nation, San Felipe Pueblo, Santa Domingo Pueblo, Jemez Pueblo, Zuni Pueblo, Hopi Nation, Apache Nation, Nez Perce Nation, and Isleta Pueblo.

**Proceedings:** At the start of the half-day gathering, NCD Council member Kathy Martinez told participants that her family was from Tierra Armarilla, as she conducted the general opening session. Between a cultural welcome by Santa Ana Pueblo member, Mr. Gino Lujan, and comments by Treva Roanhorse,<sup>ii</sup> on behalf of American Indians and Alaska Natives across the country, Chairperson Lex Frieden provided an official welcome. He stated, “We are ever mindful of the fact that we live in a nation with many diverse cultures; and despite this reality, sometimes people in the United States forget about the Indian Nations.” He also emphasized NCD’s interest in learning from the participants what the agency can do in its “role of advising the President and Congress to make life better, to make opportunities, and to ensure independent living for all people, including Native American people.”

The framework for group discussion<sup>iii</sup> focused on three guiding questions: (1) What seems to be working well for whom and why? (2) What changes would you suggest to address challenges or barriers to other things not working as well? and (3) What are some of the key issues that NCD and/or DC-based representatives from tribal communities (spokespersons) need to bring to the attention of federal policy makers on behalf of people in Indian Country and how would you prioritize the issues?

Participants convened in two assigned groups that included NCD Council members. Discussion leaders encouraged participants to share not only their perceptions of promising practices, but also their personal or family member experiences with government-funded services, programs, policies and practices. The reality of time constraints and a need for flexibility were apparent early and would characterize the morning. Accomplishments of the forum included: (1) NCD's raised awareness about longer timeframes for future dialogue and (2) NCD's provision of an environment supportive of people engaging in dialogue and exchanging candid perspectives on disability matters that influence public policy decisions.

**Key Messages:** The group discussions generated descriptions of issues, personal stories, and perceptions of actions needed. Many of the unmet needs that are identified in NCD's *People with Disabilities on Tribal Lands* report were reaffirmed when forum participants shared their perceptions of promising practices, as well as unmet challenges and needs.

**Promising Practices:** Improve methods and efforts of evaluating and capitalizing upon what seems to be working in order to compile evidence-based data, and in this regard take note of changes that begin in small steps. The forum participants identified examples that were focused on opportunities for policy and decision-making. This was consistent with NCD's findings in its earlier report. For example:

- Several participants identified efforts that New Mexico state level bodies have undertaken to build on the notion of greater inclusion of Native Americans on state health department committees, and as one person described: . . . "they are getting what I would consider true representations of the state on those committees". . .
- In the words of one participant: I think in the state of New Mexico right now, one good thing that's happened with our governor is that he put a lot of Native Americans on a lot of the [state] councils, and task forces, and boards here in the state, so that he can actually get the grass roots input."
- "In New Mexico we have a Department of Indian Affairs and that's a cabinet level. Some of the Health and Human Services Departments have tribal liaisons that work at the secretary level or division levels, like I do."
- "Laguna Pueblo has a really neat skilled nursing facility . . . but it is one of the few [where people can stay in their communities for long-term care]. . ."
- Across Indian Country we have "a lot of neighbors helping neighbors . . . that goes unrecognized . . . It would be helpful to have support for these folks, perhaps a type of ombudsman serving as liaison for homebound or medically fragile people. . ."
- Forum participants also indicated that New Mexico state level special education bodies had a pretty long track record of including among stakeholders on coalitions and advisory groups people that show the multi-ethnic make-up of the state, including the prominence of

people from various pueblos, tribes, and nations. Nonetheless, smooth and effective transition from school to post school life was identified among the remaining challenges and needs for people in Indian Country.

Challenges And Needs: The perceived conditions and actions needed at the federal, state, tribal, and/or local level included, yet were not limited to three “needs” categories—Awareness, Outreach, and Funding. The discussion highlights are summarized as follows:

*1. Awareness Needs:* Raise non-native public, program staff and service provider awareness about cultural responsiveness and tribal government awareness about disability matters in ways that encourage inclusion in tribal plans and agendas.

- Dispel and move beyond some of the myths that have shaped attitudes of apathy. For example, it is a fact that like other workers in this country, American Indians and Alaska Natives have the same income taxes withheld from their paychecks and pay taxes on purchases made. As one participant put aside the myth about government issued checks and pick-up trucks, she indicated that like other people in Indian Country . . . “I never got mine [referring to the monthly check myth] . . . and the brand new pickup. Who’s got a brand new pickup? There are many things like that...that are misunderstandings . . . that really, really bother us . . . they keep us from getting to the [factual] issues like bad roads, and the health issues, and employment, and long-term care, and Social Security reform. . . impacts on our people. . . Just the whole independent living, or interdependent living, as some called it today.”
- Several consumers with disabilities, and providers said that “you must understand culture to work [effectively] with Native Americans on reservations and in Alaska villages . . . be creative to get services on reservations . . . combine new and traditional [strategies] to raise spirits.”
- A forum participant with a state run Client Assistance Program told NCD about the need for consumer education and training programs in Native American languages and cultures to encourage self-concept of people with disabilities. “Sometimes when they are not taken away to rehab programs in long term facilities [outcomes are better] when involved in traditional activities and extended families [in their own communities].”
- A native parent of children with disabilities said, “Tribal governments need to understand disability issues.”
- A Family Voices participant who works with Native American tribes across the country shared a finding that often to native elders “disability is understood as alcoholism and drug addiction.”
- As one of several state level officials and government level representatives in attendance, a New Mexico state Department of Health official stated near the start of the discussions, “Understanding that there continue to be barriers, and obstacles that need to be overcome, it is pleasing to see that we are all here together to try to work out some of those difficulties and I’m here to listen and take your information back.”

*2. Outreach Needs:* Establish standards for meaningful outreach efforts aimed at increasing consumer awareness of services and programs and make them available where consumers are located to address consumer and service provider concerns. In addition, Native Americans are needed on national level committees, councils, review teams, boards, and other decision-making

bodies, as are other people from diverse communities. In response to the lack of Native American representation on NCD, information was shared on Council members being appointed by the President and confirmed by the Senate; thus, the Council itself would not be the appropriate body to make any changes in who is appointed. Forum participants indicated a place for any inquiry to begin might be the White House Domestic Policy Council. Comments on other outreach included . . .

- “People want services where they live . . .
- “We need a compiled list of available resources . . .”
- Many people with disabilities who were sent to live in urban locations in order to get services want to reconnect with their families and communities . . . however, there are more services in urban settings and often no services on tribal land . . . ”
- At the national level, “a good thing is that the Centers for Medicaid and Medicare have Native American contacts . . . and they do also have one who is headquartered in Baltimore and that’s a start [with Native representation]”
- “Many people with disabilities, and elders don’t ask for help anymore, because there is no service and no assistance in rural areas . . . many have inaccessible housing and have difficulty getting into their own homes...so they don’t go out . . .”

3. *Funding Needs:* Provide adequate resources and flexibility to remedy deficient funding streams for state and federal disability services and programs, as well as Indian Health Service (IHS). Consumers and providers told NCD . . .

- “IHS is not adequately funded . . . and needs reform . . . a good thing is that we have IHS on reservations or nearby, yet the bad thing is that their funds have been cut so they cannot provide the services we need either for people with special needs or for the general population of people in Indian Country.”
- “IHS has a lot of unfunded mandates, and what happened is, they have to work within a certain budget [with no increases] and finding out, what can we take away?”
- State cuts in Medicaid have negative impact on people with disabilities and older people in native communities . . . older [people with disabilities] need legal assistance
- “Tribal communities don’t have special education and related service providers the children need . . . no incentives that attract providers to work—in under funded locations”
- A parent advocate told how lack of funding had an unfavorable impact on people leaving developmental disability institutions: . . . “none of my Native American clients actually went home. They went to border towns because there were residential placements on or near their reservation . . . their ability to be taught their native skills in their native language was lost.” Similarly an art teacher stated about his client/students . . . “they hunger for connection to their tribes, to their own homes. They are in an urban setting. They have been taken away from the tribe because we don’t have the facilities to help them stay there on the reservations . . . Native Americans are very tight with their roots and their family.”
- “We need people to bring attention to Senate Bill 556 that looks at creative services under the Indian Health Care Improvement Act.”

**Conclusion:** NCD was able to communicate with people who came together from an array of backgrounds for a time on Native American land to begin a dialogue. The Native Forum succeeded in providing Council members with perspectives directly from authentic stakeholders in Indian Country. Overall, the information supports NCD's ongoing efforts that refocus attention on outreach and more inclusive practices and that incorporate authentic representation of underserved groups in the broader disability and public policy arena. Comments from a family member and an NCD Council member near the closing of the group discussion time are also fitting points for closing this summary paper.

Family member: "I have a disabled brother who is sitting next to me and a mother who is a double amputee. She is now in a nursing home because we are not able to care for her or provide the services to her. I'm just wanting to express that we have a lot of government agencies and different resources available out there for us nationally, but what about the little bitty communities and our villages . . . we also need a lot of people who are very educated to help us understand some of these available resources to us in plain language that we can understand."

Council member (Joel Kahn): "I'm hearing a lot of commonality and a lot of differences . . . commonality that service providers have across the United States with rural areas, roads, and so forth . . . unique needs [related to] Social Security reimbursement issues, needs around the cultural language issue and then services delivered in languages that are understood by the population . . . This has been very informative to me, because it has provided emphasis on some of the common problems that we are working on, one of which is rural service delivery. But it also put emphasis on some problems that I was not aware of, like the language issue and the Social Security reimbursement issue, and I know someone is going to wrap up other than me, but I'd like to personally thank you for informing me this morning. Thank you."

Readers of this summary paper may also find that some of the revelations and needs participants identified during the Native Forum can stimulate further dialogue and actions among appropriate parties at the state, tribal, and federal levels.

---

<sup>i</sup> The August 2003 NCD report addresses the status of service and support systems and documents significant unmet needs facing American Indians and Alaska Natives with disabilities. The report is supplemented with a toolkit guide, [\*Understanding Disabilities in American Indian and Alaska Native Communities: Toolkit Guide\*](#) that provides resource information for consumers, tribal communities, and local, state and federal personnel.

<sup>ii</sup> The president of Consortia of Administrators for Native American Rehabilitation (CANAR) shared highlights from the national policy positions of the organization that also includes state agencies, consumers, parents, and others across the country representing more than 80 member who manage 69 tribal rehabilitation projects (also known as the 121 projects) serving Native American people with an employment outcome.

<sup>iii</sup> **Acknowledgements:** NCD expresses appreciation for the assistance of two groups of volunteers. Native discussion leaders, Dr. Carol Locust (Eastern Band Cherokee-AZ), Ms. Martha J. Gorospe-Charlie (Laguna Pueblo-NM), and Dr. Marilyn Johnson (Acoma Tribe-NM) worked with NCD staff to plan and implement the forum discussion groups. From the Independent Living Resource Center of Albuquerque, NM volunteers, Ms. Carla Baron and Ms. Judith Rogers provided preliminary planning support, as well as onsite written highlights from the workgroups