

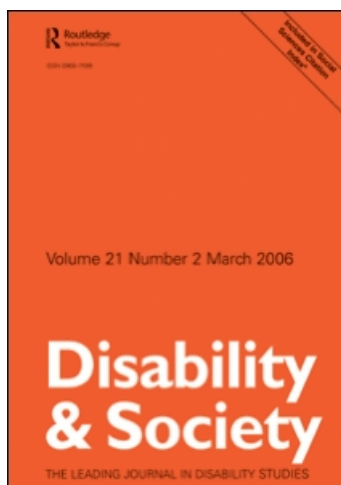
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### Citizenship and culture: the role of disabled people in Navajo society

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# Citizenship and Culture: the role of disabled people in Navajo society

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**ABSTRACT** *Cultural constructs of disabilities can vary from one culture to another and significantly affect how the individual with disabilities is perceived, accepted, and accorded citizenship rights and responsibilities. This anthropological study of Navajo individuals with disabilities investigates these cultural constructs in a non-Western society from the perspective of the Navajo community members. Factors analyzed include child-rearing practices, the Navajo concept of childhood, and Navajo notions of health and unwellness. Historical attitudes toward disabled people are also explored, as well as changing attitudes due to the influence of Western biomedical explanations and interventions.*

## **Introduction**

A citizen can be defined as "a member of a state; one who is claimed as a member of a state; one that is entitled to the civic rights and privileges of a freeman; a resident member of a community" (*Webster's Third New International Dictionary*, 1986). The relationship of individuals with significant disabilities to their state and to their communities has shifted with political fashions throughout recorded history. In Western European communities, these have ranged from being objects of loathing who must be destroyed to 'cretins', a corruption of the French 'Christian' indicating that the person is at least human and, therefore, part of the Christian community. In North America, this wide range of historical roles and experiences of these individuals is mirrored in the present-day attitudes and trends. In the past 10 years, for example, law courts have held that parents and physicians have the right to deny minor surgery required to continue the life of babies with Down's Syndrome (with the result that the babies starve to death) though no such right could be claimed by parents whose children do not have an obvious disability. The court's ruling was based on the notion that a person with Down's Syndrome would be doomed to a poor quality of life (Allen, 1989). Yet, in the same time frame other courts have held that individuals labeled as 'severely mentally retarded' have the

right to vote; have the right to marry; can refuse sterilization required by a state or provincial agency even against the wishes of their parents or guardians.

Broad community attitudes are just as varied. Today, individuals with obvious disabilities are starring on television shows and appearing in magazine and newspaper articles. Yet, in 1992 a respected national magazine published an *'op ed'* piece recommending that individuals with significant learning handicaps who misbehave in the face of what are obviously deplorable life situations ought to be destroyed as a kindness in the manner one puts a pet to sleep (Lyle, 1992).

North Americans obviously are heterogeneous in their notions of what constitutes citizenship. These notions can vary, not only regionally but also by socio-economic level, nationality, religious beliefs and race. Nevertheless, anthropologists recognize that all cultures share implicit meanings of their own unique systems. These 'cultural guidelines' provide only a standard against which actual behavior can be measured and judged; that is, cultural members acknowledge the existence of these shared meanings but are more often engaged in 'getting around the rules' than in living up to these ideals.

So while an argument can convincingly be made that the role of disabled people in the USA can vary according to whether one is poor, black, Mexican, white, upper class, Jewish, or Protestant, and so on, there is an understood, but not necessarily accepted, notion of how 'Western' society views disabled people that most people in North America share, depending upon which trends and attitudes are currently in vogue at the time. For purposes of clarification, it should be noted that the authors use the term 'Western' in the anthropological sense, in that it refers to a common European ancestry, a Judeo-Christian ideology, a Protestant work ethic, and a dominant white male-oriented power structure that largely determines Western norms, standards, values, and ethics—very often to the exclusion of many of its members.

Within the USA and Canada, however, there are many nations, specifically communities of native peoples, who constitute a much more homogeneous subculture and whose traditional values and shared meanings persist with remarkable tenacity over time. Innumerable studies of these cultures document that they are often very different in their non-Western sense of community and personhood from the surrounding white-dominated society; that is, they do not share the cultural overlay that the Western society has historically imposed upon its members. Until now, however, there have been few studies of the role and experience of individuals with significant disabilities in native communities from an anthropological perspective. Nor have social scientists attempted to document the changes in these roles and experiences as native peoples interface with modern Western culture and ideas.

The present study was conducted to gain insight into the traditional and perhaps changing roles and experiences of individuals labeled severely impaired, retarded, and autistic in the Navajo Nation, the largest community of native peoples in North America. The purpose is to present the societal construct of the Navajo, in which the concepts of both social competence and disability are defined, and the degree of citizenship and respect to which Navajo people with handicaps are accorded in Navajo society. Data for this paper were gathered by Jeanne Connors

during 16 months of anthropological field-work, from January 1990 to May 1991, in which Navajo perceptions of autism, mental retardation, and physical disabilities were measured against Navajo standards of social competence (Connors, 1992)[1]. This was the first study specifically designed to gain an 'emic' or 'insider' view of disabilities from the perspective of the societal members, and differs from previous studies conducted by educators, social scientists, and other Western professionals who tend to apply the 'etic' or 'outsider' perspective to the issue of disabilities in non-Western cultures. Indeed, even anthropologists have rarely applied their unique talents to this issue, with a few notable exceptions (Edgerton, 1970; Joe, 1980). An intensive search of the Human Relations Area Files (HRAF) by Nowak & Dentan (1983) concluded that "relevant data are few and far between on how non-Western people define and respond to mental retardation" (p. 46) as collected by anthropologists. Although Nowak & Dentan were able to document responses ranging from the consideration of individuals with mental retardation as blessed by gods to the practice of driving them from homes and villages, these data were so minimal that it was impossible to place these responses into a cultural context. More recent searches of the literature by the authors led us to conclude that the picture has not changed significantly in the last decade. Despite the fact that blacks, Mexicans, Hispanics, Hmong, and other immigrant groups undoubtedly have their own cultural constructs and perspectives of handicaps, and while these differences may very well be acknowledged by professionals and educators, systematic emic studies that document these differences in detail are sadly lacking. Thus, the present study offers some new insights into Navajo notions of both handicaps and social competence that will hopefully lead to similar studies among other groups residing in North America.

### **Research Setting**

Approximately 160,000 Navajos live on a reservation located in northern Arizona, New Mexico and Colorado. In spite of almost 200 years of contact with whites, the Navajo culture has been maintained to a remarkable degree, including use of the native language, reliance on sheep, goats, and horses for livelihood and symbols of wealth, and belief in cultural traditions. This adherence to the Navajo culture is due in part to the size of the reservation—25,000 square miles, which provides a measure of isolation and homogeneity not found on smaller reservations. In addition, the Navajo have gained the status of a 'Nation' that allows them decision-making powers and a large degree of autonomy.

As is the case with all Native American reservations, however, poverty and unemployment are endemic on the Navajo Nation. The land is exceedingly poor and mining, logging, and tourism are the major industries, although most families still possess sheep and rely on small gardens for subsistence. There are no towns or cities on the reservation; about half of the population resides in or near population centers of 2000–3000 people, while the rest are scattered throughout the remoter areas of desert and mountains. Fully half of the homes do not have running water, electricity, or telephones. The traditional hogan, a one-room circular building of logs or stone

thatched with a clay and brush roof, is still the predominant form of housing, although trailers, one-room frame cabins, and low-income housing projects are increasing. Only 1500 of the 4500 miles of roads on the reservation are paved; the remainder are dirt or gravel roads that become impassable during rains and throughout much of the winter. Of all Native American groups, the Navajo is the only one with a population growth, with half of the population under the age of 16. Due to poor land and a lack of employment opportunities, this population growth is straining the limited resources of the reservation and posing tremendous challenges for the future of the Navajo Nation.

The Navajo are medically pluralistic, with home remedies, traditional medicine men and women such as herbalists, diagnosticians, and healers, and federally-run clinics and hospitals all available for various illnesses (Adair & Deuschle, 1970; Deuschle, 1986; Joe, 1980; Kunitz, 1981). Kunitz (1983) has noted that the traditional healing system persists with considerable internal consistency across the Navajo Nation, and both he and Joe (1980) have pointed out that Navajos tend to classify diseases by cause rather than by symptoms. That is, Navajo diseases are not known by the symptoms they produce or by the parts of the body they are thought to affect; rather, a single cause may produce any of several symptoms and, conversely, a single symptom may be caused by any of several agents (e.g. animals, natural phenomena, healing ceremonies, and evil spirits). Further, Navajo religious ritual is predominantly health-oriented, and although native healers are declining, religious figures associated with the Navajo Native American Church, Mormons, Protestant ministers, and faith healers are used by many Navajos to treat the causes of disease (Kunitz, 1983). Data gathered during the field-work also indicated that traditionalists, Native American Church members, and Navajo Christians, with the exception of the acculturated and highly educated, share a belief in witchcraft as a cause of disease. Depending on how an illness or disease is classified and its course, therefore, Navajo health behavior is flexible enough to encompass a number of treatment options, including the concurrent use of Western clinical medicine and traditional ceremonies.

This study revolved around 34 Navajo individuals ranging in age from 9 to 29 who were residing in a Navajo reservation residential facility in Arizona. Prior to the establishment of this facility in 1974, severely disabled Navajo individuals were sent to off-reservation institutions where family contacts were broken. These institutionalization proceedings were rarely at the instigation of the families; rather, they were the result of recommendations by white doctors and white Bureau of Indian Affairs (BIA) officials whose authoritative pressures were often too great for Navajos to withstand. Many of the families to whom the first author spoke whose children had been in off-reservation institutions in Arizona or New Mexico before returning to the reservation expressed bewilderment at the bureaucracy and paperwork that had removed their children from their care, often without their full understanding of the process. Other families spoke of 'hiding' their children for 12 or 15 years from white authorities, for fear that these disabled offspring would be 'taken' from them—a very realistic fear in the past when well-meaning authorities failed to properly communicate intentions and distances. The alacrity with which Navajo families brought back

their children when the reservation facility was established is mute testimony to the unhappiness of both children and parents at the often enforced separations of the past.

The diagnoses of the individuals in this study included severely multiply handicapped, severely mentally retarded, autistic, Down's Syndrome, and educationally mentally retarded. All were non-verbal and unable to express their own experiences; thus, data were gathered from families, neighbors, caretakers, and others directly involved with these individuals as to how they were regarded in the Navajo world view, to what extent the individual was considered a competent member of the culture, how the behavior associated with the disabilities as dealt with, and how problematic this behavior might be.

### **Methodology**

Data were collected from interviews, surveys, and daily observations. Responses to open-ended questionnaires based on Kleinman's (1980) model, which seeks an emic construct of unwellness, were gathered for 34 Navajo families of children with autism, physical or mental disabilities. Approximately 50 interviews were also collected from staff members most closely involved with the day-to-day care of the clients. An historical perspective was gathered on Navajo disabled individuals by interviewing 16 elderly men and women at the Chinle Valley Nursing Home. Throughout the 16 months of research, normal child-family relationships were also observed to note if any discrepancies existed between the treatment of children with disabilities by family members and the relationships of families with non-handicapped children. These observations provided a solid foundation for observations of family members with their disabled offspring.

The data were analyzed according to socio-cultural groupings (i.e. traditional, semi-traditional, and modern) to trace effects of Western-generated beliefs about disabilities on a non-Western culture. It is important to note that these acculturation categories are self-identified; that is, the Navajos themselves use these categories on employment forms, hospital records, census data, etc., for purposes of, for example, obtaining the services of a Navajo healer during hospitalization. 'Traditional' refers to those people who describe themselves as Navajo-speaking only or whose first language is Navajo, derive most of their subsistence from livestock, adhere to traditional practices such as morning and evening prayers, have little or no formal education, and are non-Christian. 'Semi-traditional' are those who are fluent in both Navajo and English, derive some income from wage work, attach less importance to traditional practices, have at least an eighth grade education, and are nominally Christian although still utilizing native ceremonies. 'Modern' Navajos are generally English-speaking only, profess Christianity or no religion at all, either renounce or declare ignorance of 'Navajo ways', derive all income from wage work, and have high school and/or some college or technical training. This population tends to live in apartments or trailer homes apart from their immediate relatives, but still maintains close obligatory ties with parents, sisters, and brothers.

The data gathered include distinctly Navajo cultural characteristics such as

information about cradleboard use (i.e. a wooden carrier to keep a child with mother) for both disabled and normal infants and the 'first laugh' ceremony for an infant which probes Navajo perceptions of developmental milestones.

## Results

The initial finding of this research was that the Navajo do not specifically discriminate disabling conditions as incompetence. This finding led to an examination of the broader social issues that might help to explain this lack of discrimination. Some important cultural factors were identified. One is the overwhelming tendency to view individuals with disabilities as children, set against the Navajo concept of childhood as it differs from the Western concept. This involves an approach where appropriate behavior is expected but not forced or coerced. This regard for individuality and autonomy extends the continuum of what is considered normal and appropriate behavior considerably beyond the narrower Western parameters. Another cultural factor is the Navajo tendency to define individuals according to their unique traits. For example, in the case of developmentally disabled individuals, seizures, running away, or temper tantrums are seen as being a part of that person and are not stated as either negative or positive qualities but simply as what makes that person unique—a 'presentation of the person/self' very different from that of Western culture. This ties in closely with the Navajo concept of wellness and/or sickness which extends beyond the mere restoration of health to a restoration of harmony of mind, body, and spirit that allows even a blind or mentally retarded individual to be 'cured', regardless of what physical manifestations might still be present.

The view of disabled individuals in Navajo society presents a very different picture from that of Western society. As noted, this difference is based on unique Navajo factors: child-rearing practices and regard for individual autonomy, and the presentation of self in Navajo society as seen within the concept of wellness and sickness. These factors will be discussed in detail below as discrete factors, but it should be remembered that they are interwoven in Navajo minds, along with many other unique Navajo beliefs, into a whole pattern of Navajo thought and ideology.

### *Child-rearing Practices*

There is no noun for childhood in Navajo. The concept used, rather, is one that represents movement—approaching, being and becoming. Before the age of 6 or 7, a Navajo child can virtually do no wrong and is allowed great freedom in exploring his/her world in an experiential way. Unlike many Western children who learn to manipulate objects and test themselves with brightly-colored toys and learning materials, Navajo children are allowed to handle and make decisions about objects of the adults' world: knives, horse bridles and saddles, weaving tools, cooking pots, typewriters, cameras and so forth. They are allowed to come close to a fire, toddle near the rim of a gully, or venture under a horse's belly. They are allowed to interrupt adult conversations, accept or reject food, come in from play when they choose, and sleep when and where they decide. As they learn to experience the

world around them, there is very little a Navajo child can do that is considered wrong or inappropriate behavior. This is in great contrast to Western society where 'no' is the word most often spoken to toddlers, where long lists of objects not to be touched or things not to be done are spelled out in detail, and where social training begins as soon as, or often before, an infant learns to walk, although the end result—a socially competent adult—is the goal for both cultures.

This childhood permissiveness reaches an abrupt end at about the age of 6 when parents begin to insist on appropriate behavior and to mold the child into the expected model of the Navajo adult. At this time children are expected to learn the duties and responsibilities of adults, to contribute to the family's welfare, and to recognize and apply proper kinship terms to family and clan members. This is accomplished by almost constant criticism, an emphasis on what the child is doing incorrectly, and an expectation that s/he should automatically know what is right and proper and does not require praise or encouragement to do so. For many of the Navajos interviewed, this time was remembered as one of confusion, stress, and unhappiness, when they abruptly went from having their own way to being unable to do anything right and being constantly criticized and scolded. Only when they had become more adept at pleasing their families, largely by trial and error, did they feel themselves considered as adults and equals within the family setting—a painful process that many recalled lasted for several years.

Individuals with significant disabilities, whatever their chronological ages, appear to be 'frozen in time' between the wide latitude of freedom accorded to youngsters and the assumption of adult duties and responsibilities expected as they end their childhood years and begin the journey to adulthood. It must be emphasized here that individuals with disabilities are not considered 'perpetual children' or that no expectations are held for them. Rather, they seem to have reached the critical turning point where they are poised on the brink of assuming adult privileges and duties. Young children, for instance, are not given livestock or expected to help with chores on a regular basis, but in so far as their abilities allowed, the individuals labeled severely retarded/autistic in this study were accorded such privileges and, it was hoped, would be able to assume some responsibilities. Nonetheless, there was also a very clear recognition of their limitations. For example, one young man was able to care for baby animals with some supervision and had personal ownership of livestock, while another, far more able, was not yet accorded this privilege as he was perceived still to be progressing toward adulthood, although eventually capable of assuming more responsibilities than he was currently carrying. Yet another young man was well into maturity before he was judged adequately responsible enough to be given his own animals. Thus, the more able the individual, the more that is expected of him/her; the less able a person is, the more latitude s/he is granted.

It is noteworthy, however, that actual skills mastered need to be no more than approximations to be considered social competence. Because a child is not expected to be able to care for him/herself, to have learned proper kinship terms, or to conform to appropriate social approaches, the behavior of the disabled individual is accepted with a great deal of tolerance, however disruptive it might be. Only one mother considered her son's approach to people as 'frightening'; for the others, their



social skills were considered sufficiently appropriate, given the perception of them as youngsters poised, as it were, 'on the brink'. Although many of those studied were unable to care for livestock, carry groceries, or meet their own basic needs, one who mastered a toileting skill or was able to partially dress him/herself was seen as contributing to the family's welfare in that the task did not have to be done by someone else. In another case, a young man with mental retardation and autism owned a number of livestock in the family herd although he was unable to undertake any of their care; when 'his' sheep or the wool from them was sold, it was 'his' money that contributed to the family's income. Similarly, federal government supplementary security income and tribal funds allotted to disabled individuals and used for their families' needs were also seen as financial contributions and family support donated by the disabled individuals. There was certainly the hope and desire that these individuals would eventually develop self-help skills more fully, but again, inability did not necessarily denote a lack of social competence but rather a prolongation of the becoming process.

These perceptions of and attitudes toward Navajo children are in sharp contrast to Western child-rearing practices where the dichotomy between permissiveness in childhood and assumption of adult responsibilities at the age of 6 or 7 is not so sharp or well-defined. Rather, instruction in conformity to the ideal begins in early childhood and continues throughout the developmental years, and children are constantly prompted and trained in appropriate social skills, restraint, and self-discipline. Much of this training revolves around future expectations for the Western child, even those with developmental disabilities, of holding a job, learning to tell time and to be prompt, understanding and handling money, being competitive and 'getting ahead', and acquiring a host of other skills revolving around interpersonal relationships in the work place. All of these skills are conspicuous by their absence in the responses of the Navajo families interviewed.

Several factors may contribute to these differences. First, employment for the able-bodied Navajos on the reservation is so limited that the usefulness of job-related skills for disabled people is not deemed of overriding importance. Second, the concept of 'work for work's sake' is not as firmly ingrained in the Navajos as it is in the Western 'work ethic' mentality. And third, the notion of such early childhood training is again not considered appropriate during the freedom years granted to the Navajo child. Given that the perception of individuals with significant disabilities borders more on that of children than of adults, it is not surprising that few parents stressed the mastery of academic or work-related skills as critical for their offspring.

In short, approximations of the Navajo ideal of social competence, coupled with the strong tolerance for childhood behavior and the reluctance to force conformity on individuals of any age, appear to be sufficient to denote severely disabled individuals as socially adequate, however limited their repertoires may be. For example, with their non-verbal children, many families had learned to interpret non-verbal behavior, and many felt that their children understood more than was readily apparent, something that is often seen in Western families as well. In the Navajo families interviewed, however, this non-verbal behavior seemed to be considered a close enough approximation to denote the children as competent within their

limits, and certainly within the broad limits of tolerance accorded by the Navajo to an individual, to the extent that more sophisticated verbal skills were not deemed necessary. Moreover, silence between people, including family members, is far more acceptable to Navajos than to Westerners. It is not unusual for Navajos to let long silences punctuate a conversation, or to let an appropriate interval of silence pass between turn-taking in dialogues, as answering a question or responding to a comment too quickly implies that the question or comment was too trivial to require thought. While Western individuals with developmental disabilities often have problems in keeping up with the comparatively fast-paced turn-taking of their culture, Navajo staff and families saw no problems with the individuals in this study in this respect, as their hesitations in dialogue turn-taking were considered perfectly polite.

The reluctance to force conformity on individuals also plays a major role in the acceptance of individuals with disabilities. For example, an intoxicated individual at a meeting will be allowed to disrupt that meeting for a far longer time than would be tolerated in Western society, and even when the behavior becomes overly obnoxious or disruptive, the individual will be quietly encouraged to leave rather than forcibly ejected. Similarly, the assistant director of a non-profit institution on the reservation was very often in jail for alcohol-related offenses, but his absences were tolerated for well over a year before he was dismissed from his position. Although such behavior may be disapproved of by community members, the alternative—forcing the individual to conform to community standards of appropriateness—is far more distasteful than tolerating the behavior. This reluctance to enforce conformity was also apparent in the perception of behavior often displayed by individuals with disabilities, e.g. spinning, hand-flapping, self-abusive behavior, or tantrums. Rather than attempting to curb such behavior, or mold it into more appropriate forms of self-expression, families and staff tended to tolerate it as the behavior unique to those individuals and saw little necessity to force the individuals to conform to another person's standard of appropriateness.

In addition, although not all individuals with disabilities were able to apply proper kinship terms, parents reported that they 'seemed to recognize' an uncle or grandmother and smiled when that person entered a room, ample evidence that their children were competent in this area. It was also noted that the avoidance of eye contact, considered as a Western-defined criterion of autism, is appropriate behavior for Navajo individuals, as looking someone in the eye while they are speaking is a form of rudeness and causes the Navajo speaker considerable discomfort. It is not unusual to see Navajos in conversation looking in different directions, at the ground, toward the sky, or over each other's shoulders; Navajo staff, therefore, had no difficulty instructing students with autism who displayed this same behavior, which they saw as appropriate. It should be emphasized here that lack of eye contact as problematic behavior is not confined to individuals with autism; children of Native Americans, blacks, and many other cultural groups also see direct eye contact as rude, which often leads to misunderstandings between the children and white teachers.

Finally, an important determination of the social competence of a citizen is the

ability to contract and maintain a marriage. Among the Navajo who were interviewed on this issue, responses varied. Many families saw this possibility as remote, not because of the individual's lack of competence but because of the physical care demanded by their disabilities that a prospective spouse might not be willing to assume. For the individuals with mild mental retardation, marriages were often arranged between families in the past, a practice which still continues today in remoter parts of the Nation. Other informants were aware of individuals with disabilities who were married, had children of their own and were 'doing just fine', because of extended family members who oversaw the day-to-day affairs of the couple. Some Navajos expressed concern that the condition of the individual with a disability was 'catching' and any children that might be born to the individual might be 'that way', too; for others, this contagion effect could be offset by the appropriate ceremonies that would assure the birth of normal offspring. In general, the possibility of marriage seemed to be an individual matter, depending on how well the person with a disability was able to function and on how much care a prospective mate was willing to assume.

In summary, it appears that the perception of individuals with disabilities as children, whatever their age, holds a different meaning for Navajos than for our larger Western culture. For the latter, it means constant instruction in conformity, while for the former it is a time of great tolerance and freedom to experience objects and events at their own speed and in ways automatically considered appropriate. There is less emphasis, therefore, on correcting the 'deficiencies' of individuals with disabilities, because these deficiencies are not necessarily considered significant.

### *Health, Sickness, and Presentation of Self*

As noted previously, Navajo concepts of wellness and sickness differ tremendously from Western notions, and are more concerned with identifying and treating external causes than with symptoms and disease. For example, a Western doctor performing surgery to treat a cleft palate will consider the condition cured if the operation is successful. For a Navajo, such surgery treats only the symptom and is considered incomplete until the external cause of the cleft palate is also treated—whether the condition stemmed from witchcraft, angering a spirit (or 'Yei'), or some form of disharmony or wrongdoing, committed either accidentally or deliberately. The cause is determined by a diagnostician, either a crystal gazer, star gazer, or hand trembler, who then prescribes the necessary healing ceremony, or 'Sing'. Some diagnosticians are also medicine men, or 'Singers', but in general their role is confined to diagnosing and prescribing. The Sings, based on Navajo myths and stories, are long, complex rituals that may last 3 days and nights or as long as 9 days and nights and involve repetitive chants and sandpaintings. If, for example, a patient suffering from arthritis is suspected of having inadvertently crossed a bear's trail (one cause of arthritis because the hero in the bear myth was forced to flee from a bear until his joints hurt), an elaborate 'Bearway' will be performed in which the spirit of the bear is summoned by repetitive chants that gain the Singer sufficient power over

the bear spirit to force it to stop tormenting the patient. Thus is harmony restored between the patient and the illness and the spirit of the bear.

In the Navajo world view, mind, body, and spirit cannot be separated, nor treated without regard to the whole person and his or her relationship to nature, spirits, and all other living beings. For this reason, Navajo have difficulty dealing with Western notions of biomedicine, in which mind and spirit are often relegated to second place or ignored. Being a pragmatic people, however, most Navajo have no difficulty in seeking biomedicine for a broken leg, diabetes, spinal meningitis, and other discrete disease, but as a complement to their own traditional healing ceremonies. In recent years, the Indian Health Service (IHS) has allowed traditional Singers into hospitals to treat patients, recognizing that the deeply-held belief in traditional healing often led to patients being taken out of hospitals for the purposes of having a Sing performed.

The concept of cure also differs markedly from that of Western culture. For example, a blind person who has had the proper ceremony performed is considered successfully cured although the blindness remains. To the Navajo, harmony has been restored that allows the person to live with the lack of sight. It is important to stress, however, that this does not translate to the Western idea of acceptance of or resignation to a disability; i.e. learning to live and cope with blindness. Rather, once the ceremony has been performed and harmony has been restored, the person is once again made whole—that is, a whole individual who happens to be blind. Terms such as blindness, paralysis, seizures, running away, temper tantrum, thinking slow or with difficulty, therefore, do not carry the negative connotations or value judgments associated with Western culture. Rather, they are descriptive terms, as neutral as terms describing height, weight, color of hair, and other physical characteristics which define the personal self.

Historically, the Navajo had no words for handicaps, disabilities, or mental or physical impairments beyond such descriptive terms. Only '*digiiis*', a derogatory term with connotations of incest, was used to label a 'crazy' person—one who was feared as having a condition that could be contagious. This is not to say that disabilities did not exist in the past, but interviews with elderly Navajo men and women suggest that they were not perceived as problems. After a lengthy discussion of handicaps, or what constitutes a handicap today, one elderly Navajo gentleman finally remembered that he had an uncle 'like that'; i.e. a man who couldn't walk. But because he was able to pull himself on to a horse and let himself down to the ground again, and crawl in and out of his hogan, he had never been considered handicapped: "He'd ride to a relative's place and they'd feed him. We liked to do that. We liked to share food with him". According to one elderly medicine man, any mental retardation that existed in the past was caused by 'Navajo things' (i.e. witchcraft, incest, or offending a *Yei*) and could be cured by the appropriate ceremony. The present-day mental retardation, however, caused by alcohol, accidents, or Anglo diseases such as spinal meningitis, could not, in his opinion, be cured by traditional ceremonies.

It is, of course, possible that infants with impairments did not survive in the past. One elderly informant suggested that a midwife, usually the grandmother of the newborn infant, might put aside a physically impaired infant and "tend to the

mother for a long, long time” until the infant expired, but the first author was unable to collect any other accounts of passive infanticide. Also, the harsh environment and stringent nomadic lifestyles in the past might well have contributed to child mortality among disabled people, whether by sheer inability to survive or by selective inattention on the part of the family (e.g. failing to watch a child near a canyon or cliff edge or one crawling under a horse).

Disabilities are increasing on the Navajo Nation, probably because of overcrowded and unsanitary living conditions, inadequate medical care, poverty, and alcohol abuse. Moreover, cultural barriers often discourage Navajo families from seeking available medical help. Diseases framed in biomedical terms are often incomprehensible to Navajos, and causes are poorly understood. Many of the Navajo families interviewed were able to give the biomedical explanation for their children’s conditions, but further probing revealed that they had no Western understanding of what ‘brain damage’ or ‘mental retardation’ meant. Urged to place a child in a residential facility after spinal meningitis had left the child mentally and physically impaired, some families expected that the child would be ‘cured’ there and did not understand why their condition remained the same years later. When they asked what might have caused their child’s illness, other families were told vaguely by a Western doctor that it “might have been something that the parents did”, leaving some fathers and mothers still wrestling with guilt 20 years later. One couple, having taken a seriously ill infant son to three hospitals on the reservation in one night and being told each time to “bring him back in the morning if he isn’t any better”, finally had him admitted at dawn to a fourth hospital off the reservation where they were told, “You waited too long; he’ll never walk or talk again”. In relating this incident to the first author, the mother said with a puzzled sigh, “He [the doctor] said that to us. He really said that”.

Still other families credited ceremonies with saving their children’s lives after doctors “had given up on them” or peyote healing rituals with bringing about improvements in their children’s conditions. Peyote ceremonies were seen as helpful in reducing seizures, in particular; although elderly medicine men scorned peyote meetings as worthless: “If peyote is so good, how come there’s so many people going to the Western doctors?” This attitude on the part of medicine men is not surprising, given that the peyote ceremonies associated with the Native American Church are abbreviated versions of the long and complex traditional Sings, in which both length and complexity are believed by Singers to be the agents of cure. The substitution of a brief peyote ceremony, therefore, is anathema to the Singers, although such treatment is often sought by Navajos unable to afford the services of a Singer.

### **Changing Perspectives on Navajo Disabled People**

Several factors are contributing to a greater awareness of disabilities among the Navajo. One is the increasing contact with Western culture including schools and hospitals, staffed predominantly by non-Navajos, that are becoming more accessible to the population and reducing their isolation. Rehabilitation programs and residential facilities offered as a result of US federal legislation are also instrumental in

identifying and defining 'handicapping conditions'. Some Navajo administrators and educators, accepting biomedical definitions, are attempting to translate such definitions into the Navajo language. However, even these bilingual Navajo experts admit that English-Navajo translations for genes, chromosomes, genetic or endocrine disorders become very complicated and vague when translated into Navajo and are difficult to conceptualize by Navajos even with the help of common analogies (Joe, 1980)—a not infrequent situation even for English-speaking white Americans who often find biochemical explanations difficult to comprehend.

For the educated staff at the field-work site, the tendency is to describe the conditions of the clients in descriptive terms: 'He can't walk' or 'She runs away' or 'He has tantrums' or 'She's in another world', rather than in terms of mental retardation, autism, or seizure disorder. Likewise, interventions are difficult to reconcile with the Navajo approach to personhood. It was observed that few of the staff who cared for the severely physically impaired clients fully understood the treatment plans laid out by the non-Navajo instructor, which consisted mainly of range of motion exercises to prevent further atrophy of muscles. The notion of exercising an arm or a leg rather than the whole person seemed ludicrous to them, while the instructor often complained that the staff were 'rolling' the client about and working on their entire bodies rather than the limb she had designated for physical therapy.

One potentially negative result of the increasing influence of Western perspectives of disabilities is that the Western notion of etiology is being interwoven with the Navajo sense of causality. As noted previously, causes of ill health or unwellness are generally attributed to some act of inadvertent wrongdoing on the part of the patient or the immediate family which results in lack of harmony. This leads to blaming, regardless of whether the wrongdoings were accidental or deliberate, and this tendency is still strong among the Navajo staff. Few are willing to admit that 'these things sometimes happen'; the majority assume it is something the parents have done, most often drinking during pregnancy. However, this plausible explanation for the clients' conditions may be due in large part to a Navajo Nation-wide campaign against alcoholism that describes fetal alcohol syndrome, and is often offered by staff as a new response reflecting Western perspectives, even when the records of their clients clearly indicated that this explanation did not apply in a particular case.

This tendency to blame misfortunes on either the patient or family, however, stops short of the 'blame the victim' syndrome more common in Western society. That is, while a person or family may be held responsible for somehow 'causing' a disability, their tolerance of the individual is not affected. Surrounded by a nearly infinite number of *Yeis*, evil spirits, and occasions for offense, no one can hope to go through life unscathed by fires, accidents, loss of sheep and other livestock, illness, divorce, death of loved ones, etc. A pragmatic people, the Navajo seem to shoulder the blame for these misfortunes, strive to restore harmony through proper ceremonies, and continue to accept the unfortunate victim with affection and tolerance.

This growing awareness of Western perspectives on disabilities is in part politically motivated. As a sovereignty, the Navajo Nation is in a unique situation *vis à vis* the federal government. Although Navajos vote in federal elections, they do not

vote in state elections held in Arizona or New Mexico, nor do they pay state taxes. This means that federal monies available for rehabilitation programs and residential facilities that are administered through the states are not controlled by the Navajos, while federal monies that are not channeled through state departments are controlled by the Bureau of Indian Affairs. To be eligible for funds requires Western-generated definitions of disabilities in order to satisfy the various bureaucracies with which the Navajo Nation is compelled to cope.

It should be noted, however, that in 1990 the Navajo Nation elected its first President and Vice-President, replacing the former offices of Chairman and Vice-Chairman. The successful candidate, Peterson Zah, based his platform in part on rights for disabled people in Navajo society; namely, that the Navajo Nation be allowed self-determination on how to manage and spend monies not only for disabled individuals but also for the Nation's programs to support these individuals. This support includes, among other things, transportation to assist disabled Navajos to reach polling places to vote in both Navajo Nation and federal elections, and informing Navajo individuals with mental retardation of their right to vote and the choices available to them. This latter program is currently aimed only at individuals with mild mental retardation. Although the only restrictions on voting are age (18 or older) and citizenship in the Navajo Nation (for the Nation's elections), the ability to make an informed choice at the polls is dependent upon the individual's ability to understand the choices. Guidelines for severely mentally disabled people are still under consideration, in which the Western concept of mental versus chronological age will play a deciding factor. It remains to be seen how and to what extent Western notions of disability and citizenship will be incorporated into the Navajo world-view and culture over time.

## **Conclusion**

Citizenship rights for disabled people depend to a large extent on cultural perceptions of disabled people and how members of a society view the behavior of these individuals. Inherent in this perception is the tolerance, or lack of tolerance, accorded to individual behavior, the respect, or disrespect, for individual autonomy, and the concept of exactly what constitutes a disability and how it can be 'corrected'—or, indeed, if it should be.

As we have pointed out in this paper, non-Western cultures may have radically different notions of disabilities and disabled people from Western cultures. For the Navajo of Arizona and New Mexico, families, staff, and community members went to great lengths to firmly situate a disabled individual within the family and societal setting as a legitimate, functioning member. Individuals at the residential school invariably were placed there because no other services were offered or available to the families, whose semi-nomadic lifestyles caused great difficulties in adequately caring for their members with disabilities (e.g. moving sheep up to the mountains during the summer and camping out in rude shelters, and returning to the desert areas during the winters). However limited an individual's repertoire might be, any approximation toward ideal and appropriate behavior is accepted as social adept-

ness. For the most severely disabled individuals, the view of them as children (becoming), with all the freedom and tolerance allowed a Navajo child, permits a deep tolerance of potentially disruptive behavior, while the respect for individuality and autonomy strengthens this acceptance.

Moreover, the practice of neutral descriptive terms to refer to disabilities avoids the necessity for value judgments. The disability itself is still apparent, but once a healing ceremony has been performed and the harmony of the individual has been restored, family and community members accept the individual as a whole person, one who happens to not be able to see or walk or talk. That is, it is the disability which defines the person as an individual and thus becomes an important component of that individual's 'personhood' or 'self'.

Traditional Navajo values about individuals with disabilities can be summed up by this comment of an elderly Singer: "Before the white man came, we were blind [to disabilities]. You brought us the gift of sight. I think we were happier when we couldn't see". Such attitudes are difficult for Westerners to understand and accept, and challenge our notion of identifying, labeling, and treating those who are different. It can, of course, be argued that smaller-scale societies have a responsibility to accommodate all their members, given their limited population and stronger kinship ties, but this begs the question of why larger societies, with many more resources on hand, cannot do the same. Cultures such as that of the Navajo Nation, indeed, offer important insights into what may happen when membership and citizenship are unquestioned rights.

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