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Different Boundaries, Different Barriers:
Disability Studies and Lakota Culture
Lilah Morton Pengra, Ph.D.
Multicultural Consulting Services,
Buffalo Gap, SD
Joyzelle Gingway Godfrey, B.S.
Lower Brule Community College,
Lower Brule, SD

Abstract

The authors have chosen to show how anthropology can be engaged in disability studies by demonstrating its use in a study of Lakota (Sioux) constructs of impairment, disability, and handicap. The description is based on a questionnaire, open-ended interviews at several locations in South Dakota, and the personal knowledge of the authors, one of whom is Dakota and the other an anthropologist. Two models are employed to facilitate the contrast between Lakota and Euro-centric cultures: the concept of personhood and the bipolar typology of cultures as either collectivist or individualist. Values in Lakota culture that support collectivism are related to the kind of barriers faced by Lakotas.

Introduction

Anthropology provides a useful way to describe the human experience of disability in a variety of cultures. By comparing the beliefs and values of several cultures, regular patterns may be discerned that will help us understand the barriers presented as well as the opportunities afforded by our own cultures. There is, however, very little research about the social construction of disability in other cultures, with the notable exception of Ingstad and Whyte's ground-breaking anthology *Disability and Culture* (1995). Most texts using the tools of anthropology are written for the interventionist interested in learning about specific cultures in order to provide culturally sensitive services e.g., Lynch and Hanson's *Developing Cross-Cultural Competence: A Guide for Working with Young Children and Their*

Families (1992). This is a needed approach but one that still places professionals in the powerful position of implementing their ideas of assistance based on their conceptions of disability and society. For example, introductions to books about family structures in other cultures (e.g., Arms, Davidson & Moore, 1992; Ingoldsby & Smith, 1995; or McGoldrick, Giordano & Pearce, 1996) rarely suggest that social workers and psychologists should read them in order to change their personal family relationships.

The goal of this exploratory article is to challenge non-Indian readers to inspect their assumptions by learning about the Lakota concepts of impairment and disability. This endeavor might be misinterpreted as a shallow paean to the "noble savage" (Biolsi, 1997) but there are problems in Indian country, too. The boundaries of the cultural category "disability" are drawn in a way that disability rights activists might well envy but the beliefs and values that flow from that view present their own set of barriers.

Professionals should not and need not speak for people with disabilities, although they should stand with them in challenging misconceptions about disability. Anthropologists have a similar relationship with the people they study. They are seen as potentially exploitive, essentially well-meaning although sometimes misguided, and occasionally useful as informed allies (Biolsi & Zimmerman, 1997). It is hoped that including comments by Lakotas will counter-balance the power inherent in writing the questionnaire and choosing what responses to include in this article. This report is not intended as a comprehensive or scientifically representative sample of Lakota views. The identifications of the contributors are also not neatly typed and cross-matched. All respondents chose the labels they wanted and gave permission for or withheld the use of their names. Their directives have been honored in all cases.

This article is neither a complex interpretation of Lakota culture nor a comprehensive explication of the social model in disability studies. Both have been simplified in order to make the discussion of their intersection more intelligible. Critics might find the results simplistic and naive in their own discipline but thought-provoking and challenging in the other field of study. But, as Lakota speakers say when they have made their point, "Henala epikte," meaning: 'That's all I have to say about that.'

Point of View

Complete understanding of another culture is never possible because analysis is always "filtered through one's own cultural perspectives and experiences" (Selig, 1998, p. 8) although empathy and the tools of anthropology can facilitate increasingly sensitive interpretations. Complete understanding of one's own culture is nearly as impossible. Introspection can lead to personal insights but the insider "must almost become an 'amateur anthropologist'" (Medicine, 1998, p. 255) to comprehend his or

her culture from a more omniscient point of view. And, even when this is accomplished, understanding one culture does not necessarily generalize to understanding closely related cultures, e.g., Lakota culture is no more or less representative of all American Indian cultures than some other indigenous culture might be (Kramer, 1996).

This parallels the difficulties faced by people with and without labeled disabilities. It is impossible for people without disabilities to know about disability in the same way that people with disabilities do just as it is impossible for one person with a disability to speak for all people with disabilities. Further, people with the same disabilities may have very different experiences when they have different cultural backgrounds.

Anthropology has taught us that trying to comprehend our differences by communicating across cultural and disability boundaries, however faulty and inadequate, is better than assuming that there are no differences or that cultural and physical differences do not matter in the study of human behavior (Fish, 2000). This article came about because of the attempt by its authors to cross boundaries and compare the treatment of people with disabilities in their respective cultures, not to build theory but simply to describe the differences.

Godfrey is Dakota, lives on an Indian reservation in South Dakota, and teaches Lakota/Dakota culture at Lower Brule Community College. She has a deep understanding of Dakota mythology and religion gained through years of personal training with various Dakota Hierophant Spiritual Interpreters and by her research in Dakota thought and philosophy based on the materials gathered in the 1920s and 1930s by her Dakota great aunt, Ella Deloria. Her familiarity with the service system for people with disabilities in South Dakota comes from personal experience in periodically obtaining services for her son, Rodney Rilling, who has been labeled as having organic brain damage.

Pengra is not Indian but is an applied anthropologist and has worked with both Lakota and non-Indian people with disabilities, for the past 16 years (Pengra, 2000a), first in direct care, then as an administrator, and now as a consultant nationwide for agencies seeking to increase their cultural competencies. Pengra also has learned about Lakota culture from her good friend Freida Wounded, who rejects as irrelevant the label of disability applied to her by non-Indians. Wounded and Pengra have jointly advocated for changes in the local service system that provides supports for Wounded.

A Difference in Treatment

In South Dakota, there are nine Indian reservations or parts of reservations where 26,522 Lakotas and Dakotas live. An additional 23,847 Lakotas and Dakotas live in non-reservation areas of South Dakota (1990 U.S. Census). Outsiders have called them Sioux, but the preferred term of self-identification is Lakota, Dakota, or Nakota (Ross, 1989). For ease of reference, Lakota will be used as the cover term for Lakota, Dakota, and

Nakota. The most accurate generalization about contemporary Lakota people is that there is great individual variation based on whether their forebears worked for the army or resisted, settled near or far from reservation administrative centers, intermarried with French fur traders and other Whites (Pengra, 2000b), accepted or rejected Christianity, attended boarding or day schools, or moved to urban areas during the post-World War II relocation programs (Starita, 1995). But the "overwhelming heterogeneity" among individuals does not mean there is not a shared culture because they do have a "uniquely Lakota attitude, philosophy, and value system" (Grobsmith, 1981, p. 3).

The most immediately obvious difference between Lakota and local non-Indian culture is how people labeled as disabled by the non-Lakota world are treated. Marcia Surdez (age withheld by request), a Lakota woman living on the Lower Brule Reservation, has a rare bone disease that required the amputation of both of her legs a year ago. She now uses a wheelchair or prosthetic legs for mobility and attends college locally. Even before the removal of her legs, Surdez' condition was obvious to the casual observer.

She said that when she lived in Sioux Falls, SD, she was unable to find employment of any kind and was even turned down for a dishwashing job. She continued, "Here on the reservation I've been offered all kinds of jobs because of my personality. And I don't even want to work while I'm going to school." (personal communication to Godfrey, March 15, 2001)

Even non-Indians quickly become aware of the difference. Carol Maicki, mother of two adult sons with disabilities, described her experience of the difference as follows:

I believe we fight against our own culture in trying to be respectful of people with disabilities. . . . My white, mainstream culture is grounded in the survival of the fittest and the notion that people that are different are to be feared, pitied or hated. . . . I think we try to be compassionate but our conditioning makes even the trying to be a radical act. In comparison, over the past 17 years, I've been fortunate to have Lakota people as personal friends and professional colleagues. The difference in their culture and mine is like night and day. . . . To illustrate, the following describes how my sons are greeted when white and Native friends come to my home. . . . My white friends react to them in one of three ways. They forget they aren't deaf and speak in a loud voice. Women develop a "little girl" voice and speak to them as though they were children. They speak of them to me as though they were not in the room. My Native friends without exception always offer them a handshake, a smile and a sincere inquiry as to how they are doing. (Questionnaire response, February 1, 2001)

Lakota treat people based on the other person's behavior, irrespective of whether or not the person has a label of

disability from the dominant culture (Marshall & Largo, 1999). A person who is abusive is shunned. A person who is kind and considerate is respected. In general, great variation in behavior is accepted because personal autonomy is highly valued (Herring, 1999). However, Lakotas with physical and intellectual variations are routinely afforded slightly greater leeway in their behavior because it is recognized that they are coping with situations that are not in their control and that might require different kinds of actions or present different kinds of challenges. But this tolerance ends when their behavior becomes clearly unacceptable. They are held accountable for their negative behavior as well as respected for highly valued responses, such as generosity and wisdom, just as any person in the community would be.

When Lakotas attempt to access supports from non-Lakota service providers, they often receive additional labels such as non-compliant and behaviorally disordered because, when mistreated relative to their own values, they rebel or run away.

A Lakota man described his situation as follows:

My friend and I have what you White people call mental illnesses. We are in a place where they try to help us out. Most of the staff there are White. These people call us liars when we are telling the truth. Some staff are very cautious for us. We try to catch rides to school or work; we then get back and get called liars and cheats. I feel uncomfortable around these female staff. My friend is 41 and I am 31. Our Indian friends treat us with utmost respect. Some of these staff are around 20 years old. (Questionnaire response, name and city withheld by request, March 8, 2001)

Perceptions of mistreatment come from differences in values about how people, whether they have disabilities or not, ought to be treated. Physical and intellectual impairments, in the Lakota view, have nothing to do with the person's right to autonomy, independence, and respect.

Impairment, Disability, and Handicap

Definitions from the World Health Organization (quoted in Whyte & Ingstad, 1995) help clarify this cultural contrast. Impairment refers to parts of the body and mind that are perceived to be abnormal or malfunctioning; disability results from the restriction in activity or lack of function attributed to the impairment; and handicap relates to the social consequences of perceived deficiencies in body or activities. For Lakota, there is no impairment in intellectual functioning because the full range of intelligence is considered to be normal. Lakota recognize that some people are intellectually quicker or slower than others but this is simply part of the normal range of human possibilities. Differences in intellectual functioning are neither disabling nor handicapping although they may account for how the person contributes to the group. This is,

according to Lakota thought, not remarkable as many other situations also lead to variations in a person's contribution, such as having a good heart or being a jerk. A person may be more or less spiritual, kind, happy, helpful, or contribute to the group in other ways that are neither increased nor decreased by variations in intellectual functioning. This happens because how "you feel inside your heart will affect others . . . Your [feelings] will transfer to them." (Young Bear & Theisz, 1994, p. 175)

Physical differences, such as loss of an eye or limb or inability to walk or hear, are also all considered to be possible variations of the human condition. In older texts mention is rarely made of particular physical or intellectual variations. The single mention in *Black Elk Speaks* (Neihardt, 1972) is a straight-forward description and indicates no loss of function:

I remember two men who danced together. One had lost a leg in the Battle of the Hundred Slain and one had lost an eye in the Attacking of the Wagons, so they had only three eyes and three legs between them to dance with. (p. 34)

Some physical variations may lead to the need for assistance from others. But the need for assistance does not lead to a handicap, that is, to the person being marginalized or dis-empowered, because these physical variations are not within the control of the individual. They just "are" and must, therefore, be dealt with (Joe & Miller, 1987). Deloria (unpublished manuscript, p. 45) mentions a similar distinction between variations that are within one's control ("inhospitable, ugly-tempered, flirtatious, actually unfaithful, cruel to her step-children") and therefore can legitimately affect marital harmony or other variations that are not within one's control ("physical plainness or handicap, natural stupidity or lack of womanly skills") and therefore are not acceptable reasons for marital disharmony. Involuntary variations are how the world is and are neither cause for concern nor bad.

It is difficult to express this view of physical and intellectual difference because the Euro-centric notion of "impairment" as a "problem to be fixed" keeps intruding. A 25 year old Lakota man who lives in Rapid City, SD, expressed it this way:

Myself I respect handicap people for I know they can't help the way they are. . . I know native people would rather be home with their families, because everyone at home will help him or her, seems like they get to get better when they are around family. I think handicap native people don't feel handicap around their own people. I believe native people have respect and compassion for handicap people because we believe everything was created for a reason. (Open-ended interview, name withheld by request, February 22, 2001)

Roby Cottier, a Lakota resident of Rapid City, SD, explained that people are not disabled although they may need assistance.

I don't think anyone is disabled, because they are still the same as anyone else. But yes, at some point they need assistance. You got to consider the way they are because they have no choice to be the way they are. God made them that way. So you got to understand that . . . So what makes me happy is that I see handicapped parking and ramps at businesses. I'm so proud of those people for thinking of all the people. Then I'm disappointed in the business that doesn't take that into consideration. (Open-ended interview, March 1, 2001)

The kind of assistance needed and how it is given also differs from non-Indian conceptions of "helping the handicapped." For example, Brave Bird described a friend whose father was "sick and couldn't move his legs, so she danced for him. He later told in a meeting that while she was dancing for him, suffering, he could move his legs, and feel them, where he couldn't before." (Brave Bird & Erdoes, 1993, pp. 114-115) Suffering on behalf of the group in order to bring harmony and wellness to the whole group is one of the reasons people give for participating in the Sun Dance (Young Bear & Theisz, 1994).

People with physical or intellectual variations that might limit some of their activities receive assistance as part of the family's normal routine. Kinship responsibilities are an invisible and un-definable force that governs Lakota interpersonal relations. Family responsibilities to each other do not come under the category of "help" as they would for a non-Lakota family. Family living includes many activities that simply "are" and thus are not given much thought. Brave Bird, after visiting New York City and seeing homeless people, compared their treatment to her own experience while homeless on the Rosebud Indian Reservation in South Dakota:

It seems to me that the greatest difference between whites and Indians is the way that they treat those in need and their ideas of relationships. We might be poor, or even blind drunk, but somehow we take care of each other. If you have no roof over your head, you can knock on any door and somebody will take you in. They will give you their own bed or couch to sleep on. They feed you what they themselves are eating. And they won't make you feel that it's charity. It is just done automatically because there is a feeling that we are all in the same boat. There are no class distinctions. You might be only a sixth cousin but still be welcomed as a relative, part of the tiyospaye, the extended family. (Brave Bird & Erdoes, 1993, p. 137)

The assistance given by family members to each other is not burdensome and does not make the recipient feel powerless or

pitied. The person feels loved and is a fully functioning part of the family. Because Medicaid and social security programs provide subsistence payments to people who have been labeled as disabled, they may actually be providing more financial support to the family than other members are able to because the unemployment rates on reservations in South Dakota hover at 70 to 80%. The family member does not feel exploited when the disability check is shared within the family, although non-Indian social workers sometimes view this as abuse.

Steve White Hat, a Lakota father of young children and resident of Rapid City, SD, described this feeling of interconnectedness and respect:

When I see a person in a wheelchair I don't see a disabled person. I see someone who is different than me. I feel that it is human to want to try to help them when they need it. Just as we may need help. . . It is not respectful to pity a person. To be respectful would be to help them with their disability. (Questionnaire response, March 8, 2001)

Personhood

Another way to expose the contrast between Lakota and Eurocentric cultures is by considering the concept of personhood. Every society defines who and what will be considered a person (Harris, 1989). Personhood does not refer to a sense of self but is created by the evaluation of others. Therefore, "by looking closer at the symbolic forms through which personhood is both perceived and expressed . . . we may dig deeper into the conceptualizations that structure . . . [the] understanding of and reactions toward disability" (Nicolaisen, 1995, p. 48).

For American Indians in general (Locust, 1985) and Lakota in particular (Young Bear & Theisz, 1994), spirit is the essence of being a person. Spirit exists within the person and is nurtured through the actions of the person that create harmony. Harmony is not in events or environments but is the person's response to them (Crow Dog & Erdoes, 1996). Disharmony of spirit is disabling for an individual (Clay, 1992).

Harmony of spirit is actualized by living up to the Lakota values of generosity and respect and behaving correctly with relatives. It is assumed that all persons have relatives and sometimes that all persons in the community are relatives. Most Lakota still guide their everyday interactions with others by the definitions of appropriate kinship behavior, although the outward signs of kinship law are not as apparent as they were in times past. The first consideration between two Lakotas is whether they are related and how they are related. If they are not related, they still treat each other with generosity and respect because every Lakota will fiercely protect his or her own relative, and thus know not to attack anyone else's relative. Not having relatives or having only disabled relatives, in the Lakota sense, is disabling because there is then no way to nurture spirit (Thomas, 1981).

A Lakota woman living on the Pine Ridge Indian Reservation in Porcupine, SD, said that "a human is a person when they respect others and show love to everyone and share whatever they have with all the people." (Open-ended interview, January 17, 2001, name withheld by request). Marisa Abernathy, a 23 year old Cheyenne River Sioux responded that a "human has to be to some degree empathetic and/or sympathetic." (Questionnaire response, February 27, 2001) Dawn Middletent, a 40 year old, hearing impaired, Native American woman living in Lower Brule, SD, described a human as a "person who has feelings for their fellow man, and by that I mean they are compassionate for their sex, race, religion, age - not thinking of themselves first, but looking at the whole picture before doing or deciding something." (Questionnaire response, February 27, 2001) A 37 year old Oglala Lakota man who uses a wheelchair for mobility said that "a person who is caring, practices forgiveness, and helps his fellow man is a good human. Most of all he has a good heart." (Open-ended interview, January 17, 2001)

An individual who is less than a full person, that is, who is not acting as a human normally does, is said to be "acting foolish," i.e., without wisdom or generosity (Neihardt, 1972), "acting crazy" (Brave Bird & Erdoes, 1993), or "being goofy" (Godfrey, personal knowledge). These behaviors might be related to "meanness [that] makes you broken" (Wounded to Pengra, personal communication), or by showing too much of one kind of behavior and losing balance, e.g., becoming too creative (Young Bear & Theisz, 1994). Another way to characterize the boundaries of the category "disabled" in Lakota thought is to describe it as composed of people who exhibit behaviors that are connected to dementia believed to be a normal part of aging (John, Hennessy, Ray, & Salvey, 1996), affective states called mental illness in the non-Indian diagnostic system, behavioral states altered from the use of alcohol, and states similar to these three areas but not categorized and labeled in Euro-centric cultures (e.g., being too creative).

People who are foolish, crazy, goofy, broken, or unbalanced are not stigmatized because of their disability although relatives might try to decrease their interaction with them. When interaction is necessary, they are treated in terms of the behavior due them as a relative because treating another person disrespectfully decreases the actor's spirit, weakens him or her, regardless of the recipient's behavior. Deloria related the story of a man who went to a boarding school and came home determined to adopt the white man's ways which were classed as stingy by his relatives. She wrote:

His family relatives continued to be loyal, at a distance, and referred to him still in kinship terms. Because he had failed them was no excuse for them to fail him . . . But others dismissed him with the ugly epithet *hiyaze ca*, an idiom meaning 'hair stands on end, as it were,' which by implication classed him as austere, hostile, an unhuman

being: in short, a beast. (Deloria, unpublished manuscript, p. 10)

Cindi Roan Eagle, a Rosebud Lakota woman with fetal alcohol syndrome (FAS) who lives off the reservation, talked about her childhood and noted:

I stayed with my mom and dad, but they fought and everything. And then, my dad started abusing me. And my mom knew about it, but she didn't really care so that's why I have a lot of resentment toward my mom. But I'm strong now. If she treats me like she did when I was younger, then I say, "Maybe I should treat you like that." But I'm not going to because that's not what I am. (Pengra, 2000b, p. 199)

People labeled by the non-Indian service system as having a disability are treated like any other Lakota by Lakotas, unless they are "goofy" and have no relatives. Their marginalization is not because of their impairment, in the white man's sense, but because of disability, in the Lakota sense. However, from the Lakota point of view, the loss of spirit and lack of relationships may be what is happening to the individual, but the impairment is a condition of the group, a collectivist rather than individualist view of the world (Joe & Malach, 1992).

Collectivism and the Social Model of Disability

According to Shweder & Bourne (1984), "All societies are confronted by the same small set of existential questions," including "the problem of the relationship of the individual to the group" (pp. 189-190). Individualist cultures (Marsella, DeVos & Hsu, 1985) perceive individuals as collections of traits, with society built up of voluntary associations of individuals who share normal traits. Individuals with traits that are considered to be abnormal are thus impaired persons (Whyte & Ingstad, 1995) who are unable or not allowed to associate with others. Collectivist cultures (Triandis, 1989) construct society as primary with individuals created through their family relationships and appropriate interactions with others in the group. If the society is unable or not allowed to nurture all its members, then it is impaired.

For example, a non-Lakota writer described the "problem" of alcoholism on one reservation as "a disease that plagues young and old alike." (Grobsmith, 1981, p. 44) A Lakota writer addressed alcoholism as a "kind of slow death" for "our people" (Young Bear & Theisz, 1994, p. 136). The problem from the Lakota point of view is not the alcoholism of one particular individual, although that is unacceptable, but is the poverty and powerlessness that affect all the people and create the environment in which drinking dampens rage and grief. Social workers and health care providers who embrace a concept of individual responsibility view the patient out of context and ignore the complex social and political factors that maintain

oppression and adversely impact the physical and mental health of the people (Nuttall, 1998).

In the same vein, disability is not the problem of an individual, to be addressed (inappropriately) with charity or pity or even with services and supports designed just for that person. Disability is the inability of society to provide the resources and assistance needed by all the people and their full range of physical and intellectual variations. Social action and advocacy is, therefore, differently conceived by Lakota. An American Indian woman with traumatic brain injury described her view of the situation as follows:

[The] real disability is racism. Our people are crippled by racism. [If] my family had a good place to live, had enough food, so would I . . . We want our treaty rights. (Open-ended interview, name and location withheld by request, December 12, 2000)

The factors that in Euro-centric culture are identified as leading to the formation of a collective identity of people with disabilities, and thus to a "culture of disability" with norms and values distinct from the mainstream (Lipson & Rogers, 2000) or to self-advocacy movements by people with disabilities seeking their civil rights (Swain, Finkelstein, French, & Oliver, 1993), include marginalization and stereotyping by the dominant culture, poverty as a result of oppression and exclusion, and resistance to being the objects of pity or charity. This is an individualist approach to social change, that is, individuals with shared traits voluntarily band together for a collective purpose.

The same factors are identified by many Lakotas as causing dependence and disability. Lakota people are marginalized and stereotyped by the dominant culture and live in poverty because of that oppression. They, like other Native Americans, resist being the objects of pity or charity because their rights to sovereignty and land as well as health, food, and other services are entitlements from a long list of treaties (Deloria, 1974).

The parallel is striking in other respects as well. People in the individualist disability movement reject the medical model with its goal of curing them and the normalization model with its implication that their differences are devaluing, or, in other words, that the typical is what ought to be (Jenkins, 1998). Lakota reject that they need to be "civilized" (read "cured") or "assimilated" (read "normalized") (Deloria, 1969).

The "rise of capitalism with its emphasis upon individualism, achievement and independence" (Westbrook, Legge, & Pennay, 1993, p. 615) is the source of social exclusion of people with disabilities in Euro-centric cultures. Attitudes fostered by capitalism, such as seeing certain traits as necessary for competitive success, devalues people who are thought not to have those traits (Calvez, 1993). Disability rights activists argue that the barriers to their full inclusion in society are not their personal characteristics, but are the social structures and

attitudes that define certain characteristics as desirable or undesirable. They demand equal rights and access for all individuals, an individualist solution to an individualist-conceived problem.

It is unnecessary to ask how Lakotas with physical and intellectual variations can gain inclusion in Lakota society because they are not excluded. It is also unnecessary to ask how individual Lakotas with physical and intellectual variations can gain inclusion in non-Indian society because that is not the goal of most Lakotas and, even if it were, the answer is no different for them than for other people with disabilities. The collectivist-conceived problem is how do Lakota as a group gain the rights and privileges afforded other groups in the United States?

Community development to eliminate poverty, anti-racism initiatives, revitalization through spiritual renewal (Wax, 1997), and joint political action at the federal level on behalf of the tribe (Joe & Mallach, 1992) are collectivist solutions that will improve the lives of all the people, including people labeled as disabled by non-Indians. White middle-class professionals, and even some disability rights activists, have a difficult time accepting that this is a useful approach to empowering people with disabilities. Locust and Lang (1996) recount the bewilderment of some vocational rehabilitation counselors in Florida who met with the local Indian community to discuss barriers to services and found that "often the issues under discussion had no (apparent) relationship to vocational rehabilitation." (p. 7) Although there is some recognition that programs, to be successful, must be designed and controlled by the Indian community (Duimstra, et al., 1993), there is still no acceptance that successful "disability programs" need not address particular "disability issues." To fund, for example, an anti-racism initiative with vocational rehabilitation money is not only illegal but also ludicrous to most non-Indian professionals.

Misidentifying the Barrier to Inclusion

In a study that included health care providers working with Native American diabetics, researchers found that some providers "view patients' culture as a barrier to care . . . [and] often develop a fatalistic attitude toward clients, thinking that nothing they do will change patients' behaviors" (Tripp-Reimer, Choie, Kelley, & Enslein, 2001, p. 13, 17). And, indeed, when their services subtly require patients to change their beliefs and values about what is normal and what is disabled, they probably will continue to be unsuccessful. Many Lakotas resist being drawn into these kinds of cultural conflicts by choosing not to comply with selected requirements, refusing services, even to the extent of hiding their children from visiting public health nurses (O'Connor, 1993), or not allowing diagnosis and labeling at all (Joe & Miller, 1987; Kramer, 1996).

Because Indian communities are in difficult economic straits, they accept some services even when the design of the

program does not incorporate Lakota values. Through these programs parts of the individualist worldview are gradually insinuating their way into the outlook of some Lakotas. According to M. J. (Fee) Moran, self-described as a culturally disabled Native American female elder, this is occurring because "Due to the way services are provided now, we are learning the disability language." (Questionnaire response, February 27, 2001). For example, Head Start programs are found on all reservations and in off-reservation Indian communities in South Dakota. The philosophy of the Head Start program is clearly individualist: "Services for children `at risk' for developmental disabilities were established as a means of breaking the poverty cycle . . . [and were] to ameliorate poverty through educational intervention . . . to ensure equity or equality of opportunity for people who are disadvantaged" (Westlake & Kaiser, 1991, p. 430) but not to address the oppression that caused the poverty for those children's communities.

The irony is that just when disability rights activists are challenging the definitions of impairment and disability in Euro-centric cultures, people with a culture that already includes the full range of human physical and intellectual variations as normal, and therefore does not label, exclude, and devalue any particular set of individuals based on traits perceived to be impaired, are being advised to change their view. One of the recommendations of a vocational rehabilitation research group working with Native Americans, many of whom were Lakota, in Denver, CO, (Marshall, et al., 1992) was that they needed to improve "their sense of each other as a community of American Indians who have disabilities" in order to increase their access to services through self-advocacy (p. 19).

Lakota Barriers

Nonetheless, the Lakota world view does not create utopia for all the people and might not even do so with adequate food and housing and without racism or oppression by the dominant culture. The other side of being included in the group as an equal is that the person is responsible for contributing to the group and accountable for his or her actions. Rodney Rilling, in response to Godfrey's inquiry about the difference between living off or on the reservation, said, "At least in Whiteland they treat you disabled. Here you're on your own." (Personal communication, March 25, 2001). Put another way, barriers that limit inclusion and access for people with disabilities, in the Lakota sense, are related to Lakota values that support collectivism: generosity, fortitude, and respect.

Generosity emphasizes the welfare of the whole group and stresses meeting one's duties to others rather than asserting one's rights as an individual (Shweder & Miller, 1985). Although this value ensures that whatever the group has is equally shared and that people provide assistance, not charity, to others, it also means that the welfare of the group is more important than the needs of any particular individual. Life is valued but not a

life. A young man who is paralyzed pointed out that his inability to keep up with the group would, in times past, have made him "coyote bait." Another man expressed it this way:

From oral tradition, we know that if people couldn't take care of themselves, they were left behind. . . Medicine is now so far advanced that babies who would have died naturally are kept alive . . . it's a drain on everybody else. (Open ended interview, name withheld by request, March 1, 2001)

Fortitude means that one has the stamina to survive the vicissitudes of life and still be generous and respectful of others. Choosing to live in harmony with the environment rather than changing it to fit personal needs and fitting in with others in the group rather than controlling their actions are related to this value (Pengra, 2000b). It results in accepting whatever has gone awry and seeking solace rather than trying to fix situations or people (Joe & Miller, 1987). It also appears to be why there is relatively little push toward advocating for additional services and adaptive equipment.

Respect is shown by cooperating rather than competing with others and by supporting the autonomy of others rather than controlling their actions (Lee, 1959). It engenders accepting others' foibles and not interfering with their right to choose, even when their choices might be dangerous (Good Tracks, 1976). This value appears to account for the difficulty of maintaining FAS prevention programs (Masis & May, 1991) particularly ones that are directive rather than simply informative. Posters in public places and public service announcements have increased awareness about FAS which is now perceived as a voluntary injury to children not a normal variation of the human condition. Although there is growing recognition of the enormity of the problem, active intervention programs with particular at-risk families are not pursued because they are disrespectful and intrusive.

These descriptions of barriers connected to collectivism, at least as it is conceived and supported in Lakota culture, are necessarily very tentative because "no study has investigated the range of issues important to bringing knowledge of caregiving among American Indians to the level of caregiving literature on other populations, particularly Whites" (John, Hennessy, Ray, & Salvey, 1996, p. 190). In addition, few studies design their research questions to investigate barriers to people with disabilities by using alternative constructions of impairment and disability as has been attempted here. Culture, if it is considered at all, is relegated to the status of context for the individual, but is not the object of the disability study (Marshall & Largo, 1999).

Conclusion

It is hoped that this cursory description of some limited

areas of Lakota culture has raised interesting questions which might be pursued in disability studies. At the least, it has provided a contrast to the many studies that have been conducted in individualist cultures and should challenge some assumptions about the universality of the stigma of disability. It was an invigorating dialog between the two authors, one an insider and the other an outsider to Lakota culture. By crossing the boundaries of our own definitions, we may bring more understanding and respect into our relationships with the people in our lives who have been labeled as having disabilities. Seeing how all things are interrelated is the wisdom implied in the phrase offered at the end of a prayer or when friends part and is offered here in the same spirit: Mitakuye oyasin, all my relatives.

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