

## Navajo and autism: The beauty of harmony

### Navajo and Autism: The Beauty of Harmony

Steven K. Kapp

Division of Psychological Studies in Education

Graduate School of Education & Information Studies

University of California, Los Angeles

Los Angeles, CA 90095 USA

E-mail: [kapp@ucla.edu](mailto:kapp@ucla.edu)

Phone: 310-384-3263

Fax: 310-641-3327

Steven Kapp studies Autistic people at UCLA, which diagnosed him with Asperger's at age 13 in 1999. Steven has wide research and self-advocacy interests in the autism spectrum, as partially related to his service as Co-Director of the Autistic Self Advocacy Network – UCLA/LA Area

Chapter.

Abstract

With so much unknown about autism, the disability tends to reflect the socio-cultural preconceptions people project onto it. The predominant narrative in Western society of autism as a “disease” within the medical model contrasts with the more positive, empowering view of autism as a “difference” in the social model and neurodiversity movement. Society has also discriminated against and disabled the Navajo Native Americans since the arrival of Euro-Americans. Navajos resiliently balance between exercising self-determination within their own Nation and adapting to outside society, with a culture that remains remarkably intact. The Navajo thus presented exceptional opportunity for cross-cultural analysis. It suggested that the traditional Navajo social constructs of harmony and beauty, as encompassed by a wellness philosophy called Hozho, better serve the needs of Autistic people than the Western notion of “progress” through science and technology.

Key words: autism; Navajo; culture; self-determination; inclusion; acceptance

Points of Interest

- Much remains unknown about autism, a complex disability diagnosed and often constructed as primarily affecting social functioning.
- A cross-cultural analysis between the Navajos and the West toward autism thus enables examination of the social model of disability, which argues that social injustice, rather than internal impairment, causes disability.
- Western cultures like the United States have historically denied indigenous peoples and people with disabilities their human rights to self-determination, disabling both groups.
- Navajos now enjoy more control over their lives, and their culture has demonstrated “survivance” – respecting tradition while adapting to modern society as needed.
- The West could learn from the Navajos’ wellness philosophy; its balance of individuality within community appears to offer more acceptance, inclusion, and support for Autistic people than the medical model.

## Introduction

Disabilities do not exist outside of culture; the classification of, and attitudes, practices, and laws regarding, behaviors reflect socio-cultural worldviews (Grinker 2007). Similarly, the social model of disability distinguishes between *impairments* internal to the mind or body and *disability* created through social oppression, a distinction disability scholars have criticized as overly simplistic rather than practically empowering for people with disabilities (Tregaskis 2002). An analysis of and between a people defined by Western societies as socially disabled (those on the autism spectrum) and a people who historically lacked even a word for disability (the Navajo) within an American context offers an exceptional opportunity to further test the social model.

An analysis involving autism and the Navajo also allows exploration of self-determination. The construct of disability concerns concepts as critical as the notions of personhood, self-determination, and individual and group norms. Self-determination for individuals with intellectual and developmental disabilities involves self-knowledge of strengths and weaknesses; setting goals, problem solving, and making decisions regarding preferences; believing one has the skills and opportunities to achieve these goals; and having free choice in making preferences (Wehmeyer, Kelchner, and Richards 2006). For the general population, Deci and Ryan (2000) define self-determination as involving the feeling competent, autonomous (in control over one's actions), and related to others. They also provide evidence that it strengthens self-motivation, social development, and psychological well-being. Autonomy and internal motivation relate to well-being regardless of cultural individualistic-collectivistic orientation; furthermore, societies with more equal social structures appear to produce the highest well-being (Chirkov et al. 2003). Similarly, self-determination positively relates to quality of life across culture for people with intellectual disabilities (Lachapelle et al. 2005). While parents of disabled children from Euro-

American, as opposed to minority or non-Western, cultures report less knowledge and activity with their child about self-determination (Zhang et al. 2010), Schwartz (2000) argues that excessive self-determination and autonomy in the United States has led to personal dissatisfaction and depression. This contrast appears to reflect that most effectively satisfying the compatible human needs of autonomy and relatedness requires an emphasis on interdependence in familial and social contexts (Kagitcibasi 2005). Indeed, individualistic and communal qualities promote well-being and protect against distress, especially when combined (Saragovi et al. 1997). Frankland et al. (2004) found self-determination characteristics highly relevant to the Navajo for people with disabilities; my analysis with the Navajo will argue that this results from their particular balance on supporting wide individuality within an orientation to the family clan and community.

Community members and groups thus derive meaning from their social context. A study of outlook on disability by a group also disabled by society and experiencing challenges in self-determination offers a lens through which to examine its core values, the significance of cultural differences, and lessons to draw from these differences in relation to the predominant culture. Since contact with Euro-Americans, Native Americans like the Navajo have experienced a range from control by and compromise, consultation, and cooperation with them. Like other Native Americans and indigenous peoples, the Navajos' way of life has adapted to meet socio-economic realities, both on and off their Nation (semi-autonomous reservation). This article's focus on the Navajo does not intend to encourage segregation but rather to investigate a well-researched people who often successfully weave together modern and traditional cultures (Lamphere 2007) in comparison with the predominant American or Western culture regarding autism. Because much remains unknown about autism from Western and non-Western perspectives and autism

has no effect on physical appearance, its uncertainty and physical invisibility offer distinctive insight into cultural values and prejudices (Grinker 2007). A cross-cultural analysis of Western and Navajo cultures presents a framework in which to examine how the Navajo conceptions of harmony and beauty may better serve the needs of Autistic people than the Western notion of “progress” through science and technology.

As personal experiences and perspectives shape our knowledge, I feel responsible to share my background and values. An autism researcher in educational psychology and Autistic self-advocate, I view autism as a complex, inseparable part of personality, and as such employ self-empowerment, rather than people-first, language with autism and sometimes other disabilities (Bagatell 2010). I also took and taught a course on Native Americans, and participated in service and cross-cultural learning activities on the Navajo Nation, where I shared an earlier draft of this paper with any interested Navajo.

#### Construction of Autistic and Navajo People as Disabled

The medical model of health and disability seeks to remove responsibility from people with disabilities like autism so that they may receive help in the form of sympathy, charity, or (often professional) care (Brickman et al. 1982). While often well-meaning, this orientation’s focus on behavior, impairments, and childhood for disabilities like autism has notable limitations (Watson and Clark 2006). The limited attention on observable behaviors rather than neurology overlooks autism’s standing as a disability of information processing, including sensory, motor, cognitive, physical, psychological, and perceptual areas (Bumiller 2008). Such wide-ranging effects of autism suggest its inseparability as part of personality to many Autistic self-advocates (Bagatell 2010). Additionally, the selective attention to negative aspects of disability ignores or minimizes possible strengths related to autism like independent thinking, and segregate people despite

shared humanity (Brownlow 2010). Accordingly, in the absence of rigorous evidence to the contrary, professionals have often invented knowledge about autism that suggest low abilities (Donnellan 1999), rather than making the least dangerous assumption of presuming competence (Donnellan 1984). Research, media, and advocacy organizations sometimes further perpetuate disabling myths about autism (Broderick and Ne'eman 2008). Moreover, the predominant focus on childhood for those living with autism, especially historically, has meant less attention to the needs of adults, who often face significant adaptive challenges (Matson and Neal 2009).

The Navajo, along with other Native American tribes, similarly have suffered for their classification and perception as inferior by outside authorities. Euro-Americans' condescending stereotypes of indigenous people contributed to a sense of entitlement in dispossessing those peoples of their land and ways of life through the forces of bloodshed, churches, and government (Wilson 1998). Such invasion, and denial of treaty and civil rights (often despite formal contracts or promises by the Anglo people), has robbed the Navajo and other Native Americans of their full human rights to sovereignty and self-determination. Even those with federal recognition remain legal "wards" of the U.S. government, and those who also have their own reservation (as in the case of the Navajo) have limited status as "domestic dependent nations" (Wilson 1998). Thus, while some Native peoples enjoy some rights to determine membership and even govern themselves, the U.S. determines what and how peoples may benefit from those limited rights. Similarly to the situation of people with disabilities, who often lack technical disability status without a formal clinical diagnosis or educational label, Native Americans have endured "scientific" measurements such as photographs and IQ tests to determine race and "progress" for legal or policy considerations. In fact, the U.S. Bureau of Indian Affairs issues a "Certificate of Degree of Indian Blood" to people with adequate "blood quota". In turn, lay stereotypes have

included the conception of Native Americans as no longer “real Indians” and the related ideas of Native peoples as all alike or a “vanishing race” (Wilson 1998).

These portrayals of people with disabilities and Native Americans have disabled both groups, and those who identify within either broad community have tried to resist images against them. The pathology of difference relates to a cultural narrative of “overcoming” a disability through “heroic” individual effort or public pity for those seen as incapable of taking care of themselves (Shapiro 1993). Portraying autism as a burden or threat to society’s tax dollars, comfort, or safety, when combined with the hope for a “cure,” thus offers a convenient way to promote fundraising and service provision (Broderick and Ne’eman 2008). A diagnosis attempts to remove perceived personal responsibility such that people understand unusual behavior as medical rather than as somehow immoral. For example, disclosure of a child’s autism to strangers results in less harsh judgments of the child’s behavior, but lowers their expectations of the child, assessed as less cognitively competent and more emotionally disturbed (Chambres et al. 2008). Yet this well-meaning but misguided model results in unfortunate consequences, such as a negative self-concept and disempowerment of Autistic people. Many youth on the autism spectrum view their autism as a barrier to their goal of fitting in with typical peers (Humphrey and Lewis 2008), as the self-perception of dissimilarity from others relates to depression in the population (Hedley and Young 2006). Moreover, despite the fascination with losing a diagnosis, its behavioral definition means that individuals who manage to do so may have put extreme pressure on themselves to reach a self-perceived abstract standard set by others. An internalized need to inhibit and remain vigilant against natural behaviors may relate to why many people who lose a diagnosis on the autism spectrum replace it with or maintain a psychiatric diagnosis like anxiety or depression (Helt 2008).



Likewise, Native Americans have faced extreme pressure, first against their mortality and then against their worldview and identity. As Euro-American settlers' movements encroached into tribal lands, they saw to the First People's extermination or relocation to segregated reservations with institutionalized boundaries. The Navajo infamously suffered a forced march known as the Long Walk around the time of the Civil War, but unlike most Indian nations, managed to return to their homeland because the U.S. assessed the land as possessing little value and the Navajo threatened to add to their already heavy losses with mass suicide. For other peoples, U.S. government policies have had white Americans settle around Native residences to "civilize" them or forced Native Americans into urban areas. Yet the U.S. included the Navajo among the peoples it forcibly sent to boarding schools for most of the twentieth century, often hundreds of miles from their family, as part of the American melting pot experiment (Wilson 1998).

Indeed, such relocations took place within a wider effort to conform people to an American ideal using the efficiency model of scientific management (Connors and Donnellan 1998). These principles also inspired the development of special education, so that one form of instruction could accommodate the needs of every student with "educable" disabilities in a segregated classroom, while those with disabilities considered more significant received no education or lived in institutions. As they have done since contact, Native Americans responded to these changing conditions by adopting some of the tools used to control them to sustain their cultures and societies. When deinstitutionalization arrived in the 1970s, Native societies like that of the Navajo often rushed to rescue their children (Connors and Donnellan 1998).

#### Self-Determination among Autistic and Navajo People

In response to these various dangers to their ways of life, Native Americans and people with disabilities have organized civil rights movements to claim their commitment to their cultures and fight for their rights. Resistance began in Native homes and broke out publicly in the 1960s and 1970s as Native Americans' cultural, spiritual, and political consciousness adapted from individual native tribes or nations to a minority group of Native Americans. Protests and the embracing of Native pride and "Red Power" often became concentrated in the organization American Indian Movement (Wilson 1998). With the passage of the Indian Self-Determination Act of 1975, nations such as the Navajo became responsible for administering federal Indian programs. The Navajo Nation now has its own three-branch government and legal system, and is mutually thought of as a sovereign state despite its dependent relationship on the U.S (Frankland et al. 2004).

Likewise, the disability rights movement (DRM) grew in the U.S. out of the civil rights movement, largely to protect against discrimination and to ensure appropriate access to educational, employment, and independent living opportunities. Also like its American Indian counterpart, the DRM marked a shift from an individual (if not absent) identity to that of a mosaic of different disabilities. It opposes the appropriation of disabled people's voices and any underrepresentation in such matters as advocacy organizations, research, and legislation concerning them (Shapiro 1993). The autism rights, or neurodiversity, movement launched more recently in this spirit with the founding of Autism Network International by Autistic adults in 1992 (Ward and Meyer 1999). Viewing autism as a difference on the spectrum of human diversity rather than a "disease" and opposed to normalization for its own sake, adherents engage in self-advocacy and self-determination (Bagatell 2010). Self-determination becomes especially relevant in adulthood and the autism community would benefit from greater orientation toward

addressing the practical needs of adults to build skills and achieve a high quality of life (Robertson 2010). This can include self-presentation skills in role-playing as more typical for self-protection, as a discourse analysis of forty-five autobiographies and personal narratives of Autistic people suggests that many try to “pass” or apply additional effort to manage their social challenges in public to avoid discrimination, as opposed to among family and loved ones (Davidson and Henderson 2010).

Similarly, Native Americans like the Navajo strive to find balance between maintaining cultural integrity while making necessary adaptations to reflect modern realities they face in the social environment. Many Native self-advocates term this need to respect the past while preparing for the future *survivance* (Powell 2002). Structural economic changes have reduced the Navajos’ traditional subsistence on livestock, contributing to poverty and unemployment on the reservation. As the Navajo become more integrated into the economy off the reservation and more educated, they have begun to assume more Western lifestyles like two-parent households rather than the traditional kinship system (Schoepfle, Burton, and Begishe 1984). The Navajo have resiliently incorporated elements of the broader American culture into their own to help preserve a distinct identity relevant to their context (Lamphere 2007), a phenomenon especially apparent among younger Navajo who grow up with more exposure to Western influence. For example, adolescent Navajos have expressed messages against racism their community experiences through break dancing and heavy metal (Deyhle 1998). Exploration of their heritage and commitment to their culture promotes positive psychosocial functioning among these adolescents (Jones and Galliher 2007), while their limited fluency in the Navajo language does not relate to Native identity, highlighting the importance of conscious identity rather than proficiency with the traditional culture (Lee 2009). As they navigate between these cultures,

traditional Navajo ritual healing plays the strongest role in fostering a sense of connectedness (Dole and Csordas 2003), as it draws from a worldview that relies more on spirituality than science in its construction of knowledge and meaning (Csordas, Storck, and Strass 2008).

#### Hozho: A Positive, Relational Wellness Philosophy Beneficial to Autistic People

The essence of Navajo philosophy that guides their views on health and illness and way of life stems from Hozho (Kahn-John 2010). It includes animistic spirituality, meaning the belief that everything has a spirit, is interconnected, and thus merits equal respect. In addition, it appreciates the mystery of life rather than absolute knowledge, thereby enabling flexibility to multiple truths. Accordingly, Navajos generally do not see a conflict between native healers and conventional medicine (Kim and Kwak 1998) and healing in Navajos who subscribe to the traditional religion, the Native American Church, and Pentecostal Christianity have similar emotional and relational foundations in this harmonious philosophy (Lewton and Bydone 2000). The spirituality also means that Navajos seek to live in harmony with the Earth. Similarly, autobiographical accounts by Autistic people suggest many form intensely meaningful relationships with nature and objects (Davidson and Smith 2009). A related Hozho principle, positive thinking, encourages the Navajo to avoid saying anything offensive, which would naturally mean offending everyone and everything (Kahn-John, 2010). Therefore, using negative medical language lacks cultural sensitivity and effective practice (Carrese and Rhodes 2000), which seems relevant to stigmatized individuals like Autistic people who advocate for more respectful language, if not everyone (Broderick and Ne'eman 2008). A third Hozho principle, relationship, states that individuals' identity comes from belonging to their family and community, an emphasis that may protect Autistic people from the loneliness many feel (Causton-Theoharis, Ashby, and Cosier 2009) and at least act against isolation, which itself

likely means a longer, healthier life (House, Landis, and Umberson 1988). Reciprocity, another principle of Hozho, relates to natural helping among Navajos, which involves closer relationships that feature more commonalities and requests for help compared to many other populations (Waller and Patterson 2002). These relationships may help to address the significant social needs of people on the autism spectrum, and their strength may overcome the lack of help-seeking behavior that may occur without greater support. Finally, the principle of discipline refers to specific patterns of behavior personalized to the character and abilities that members of Navajo society exercise (in so doing “walking in beauty” – traveling a path through time in harmony with the universe), which bodes well for Autistic people inclined toward predictability and routines.

The concepts of harmony and beauty differ sharply from the Western tendencies toward materialism, competition, self-indulgence, and environmental degradation. Conversely, in a shamanistic society like that of the Navajo, selfishness and jealousy constitute the greatest violation of the spiritual order (Begay and Maker 2007). The Western fixation on goods and services and view of economic productivity as a component of health clashes with the needs of Autistic people limited in work-related skills by marginalizing them as a drain on society. In contrast, the Navajo, who pragmatically do not value work for its own sake or always “getting ahead” in life, do not fault disabled people for challenges with such skills (Connors and Donnellan 1993). Furthermore, the collective structure of societies like that of the Navajo help socialize and foster the development of these social and other life skills.

The Navajo embrace understanding, acceptance, and support of people with disabilities like autism throughout the lifespan. The Hozho worldview transcends neurodiversity to resemble what Patson (2007) calls functional diversity, extending the concept of typicality to include

everyone, since all serve unique functions in society. The Navajo lacked a word for “disability” until acculturation through American influence and, although traditionally people identified as ill receive ceremonies to integrate the person with the universe (in effect a cure), after the performance of the ceremony the person receives full acceptance. Appreciation of and affection for the person therefore is unaffected by his or her condition, which is seen as a neutral characteristic of personality. Consequently, no value judgments are made on behaviors associated with autism, like spinning and flapping (Connors and Donnellan 1993). In contrast, Western attempts at prevention or cure may lead to prenatal testing, which many parents already seek, raising ethical concerns (McMahon, Baty, and Botkin 2006). Navajos and many other Native American peoples, meanwhile, often feel oppositely about eugenics and avoid participating in genetic research (Jacobs et al. 2010).

Traditionally believing that the Creator pre-determined people’s identities, the Navajo encourage children to explore their place in the universe (personal strengths and role in the family and clan) and instill a sense of self-worth useful for assuming responsibilities later. Instead of disciplining the children or telling them how not to act, adults lead by example and provide detailed reasons for desirable behavior, which serves well Autistic people’s cognitive learning style favoring direct instruction in social information (Müller, Schuler, and Yates, 2008). Adults tell traditional stories to teach the difference between bad and good – for which they are praised – behavior. This effort to build self-respect and teach early self-determination skills helps an Autistic population that often presents with mental health and executive functioning challenges (Causton-Theoharis et al. 2009; Müller et al. 2008). Of course, the Navajo conception of autonomy differs from that of Americans, concerning the ability to become self-sufficient and require less support from the nuclear, immediate, and extended families so as to be able to give

more support for others. A patient people, the Navajo people have no particular expectations about when such change may come about. For the Autistic person's developmental milestones, when they are achieved is not important, but that they happened and that they are celebrated as a family (Frankland et al. 2004).

Furthermore, because the Navajo traditionally also believe that all people will develop into adults to fulfill their predetermined identities, the people unable to perform typical adult responsibilities are perceived as in a state of becoming on the brink of adulthood. Navajo are generally reluctant to enforce conformity on others, believing doing so would result in disharmony (Frankland et al. 2004). Disabled people's special age status means that they are expected to help out with tasks appropriate to their level of functioning (such as carrying groceries or gathering firewood), focusing on ways in which the family can best support the individual to be self-governing and ways in which the child can contribute to the family's well-being. For example, if an Autistic woman can dress herself, her ability is seen contributing to the family's health in that it relieves others of the responsibility (Connors and Donnellan 1993). Furthermore, Navajo culture goes out of its way to include Autistic people in society as much as possible, as skills only need to approximate typical behavior to be socially competent. Therefore, an Autistic man able to help care for livestock with supervision may be recognized as having personal ownership of the animals, a privilege restricted to adults (Connors and Donnellan, 1993).

Guided by the idea of the holy Changing Woman as First Mother, the Navajo traditionally have a matrilineal society, meaning women determine family lineage and identity (Begay and Maker 2007). Possessing special spiritual powers, women own the land and have traditionally led political decision making. Nuclear families live together surrounded immediately by extended family, within which members have specific roles to fulfill such as tending to local

farms or caring for the sick or elderly. Farther out live clans of distant or no blood relation, which guide and teach the young and provide a foundation for ethics that further defines responsibilities within the clan and community (Frankland et al. 2004). Women's elevated status, coupled with the emphasis on family cohesion, ensure that children receive the care they need from a variety of loved ones, with such nuclear and extended family relations as older sister, aunt, grandmother, and great aunt acting as additional "mothers" in their upbringing (Joe 1982). With such dense, involved family networks, the plurality of caretakers at any one time means that Navajo can absorb people with disabilities smoothly into the existing family structure, and that other family members can compensate if one or two make poor nurturers.

Clearly, although in both Navajo and Western societies women are the primary caregivers and the nuclear family is the basic social unit, Navajo kinship networks ensure greater stability and support. The much thinner family model in modern Western society forces radical changes in lifestyle to accommodate the needs of Autistic members. In these families generally at most two members (parents) care for Autistic children and their participation in intense behavioral management programs, as well as the maze of treatment options with little knowledge of which work best, often overwhelms parents; they may feel unsupported and stressed financially or psychologically (Woodgate, Ateah, and Secco 2008). Furthermore, because the bond of mother and child is the Navajo's most sacred and powerful relationship, all Navajo reserve the right to live with their mother throughout life and doing so draws no unusual attention. American families, meanwhile, struggle with options of care for their offspring as adults because of the Western construct of independence as living either by oneself or with one's own spouse and children, coupled with the poor supports in the community and the reality that parents will likely become unable to care for their child or pass on before their child (Krauss, Seltzner, and



Jacobson 2005). Even those who may have the resources to continue to care for their grown child often leave the responsibility to a group home or institution, which many Autistic people find dehumanizing (Hurlbutt and Chalmers 2002).

Acceptance of autism in Navajo society also has positive implications for the well-being of parents. Accepting the child's autism and has positive effects on parents' mental, social, and familial, including marital, health (Milshtein et al. 2010). Parents who cope well make cognitive and lifestyle changes, such as placing less importance on their careers and material concerns and more importance on their role as parents and the enjoyment of daily routines, leisure time, and social interactions with family, friends, and neighbors (Luther, Canham, and Young Cureton 2005). In both Navajo and American cultures, acceptance of autism does not preclude intervention services so long as they focus positively on building skills. Applequist and Bailey (2000) reported that Navajo parents generally felt satisfied with early intervention services for children with developmental disabilities, related to level of family involvement but not level of acculturation.

### Conclusion and Implications for Schooling

This cross-cultural analysis suggests Navajo culture behaves with more humanity, flexibility, and personalization toward Autistic people than does the more disabling Western culture. In striving for harmony, peace, balance, regularity, elegance, and beauty as part of Hozho philosophy, the Navajos appear to achieve success with full inclusion. They help individuals achieve self-determination in an interdependent context that empowers extensive individual differences, striking a balance in life between abilities and disabilities and support given and received. In achieving this balance, Autistic people walk in beauty and are fully accepted and participating members of society, while Western Autistic people often face rejection. The United

States and other nations may be repeating terrible history; current Western attempts to “cure” autistic people by wiping out differences appear to draw similarities to past American efforts to “improve” and “civilize” Native Americans by extinguishing native identity and ways. The cross-cultural analysis exposes knowledge itself as a cultural construct and the subjectivity of quality of life, with broader implications for Western society. It suggests the need to invest in raising Autistic people’s adaptive skills and quality of life, but also to change the social environment for intercultural survivance in this age of global interdependence and instability.

It appears that these social changes could begin in the schools, such as through training teachers and staff about intercultural commonalities and differences that transcend possible exclusion brought by multiculturalism and special education, and passing on this education to students in the curriculum and school culture. For example, after completing a preservice teacher education course in Australia, students reported in interviews gaining not only more knowledge of knowledge of Down syndrome and more positive attitudes toward inclusive education toward children with Down syndrome, but more positive attitudes toward disability in general and more comfort and skill when interacting with disabled people (Campbell, Gilmore, and Cuskelley 2003). This might be accomplished through differentiated instruction within a universal design, as Navajo youth clearly seek to remain close to their indigenous culture while striving to succeed in the wider environment, which Shields (1999) interpreted as suggesting the need for schools built on diversity. Further studies are needed to determine how this might be achieved and what kinds of classrooms and schools Autistic people and others with disabilities prefer and better fit their needs, but it is clear that attitudes must change to prevent and address the discrimination Navajos, people with disabilities, and others face (Deyhle 1995).

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