

INDIAN FAMILY ADJUSTMENT TO CHILDREN WITH DISABILITIES

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The purpose of this study was to explore the community response of how American Indian families adapt to having school age children with disabilities in two diverse American Indian communities. An ethnographic design was utilized to construct a taxonomy about family adjustment of American Indian families with disabilities. Community Assessment interviews were conducted with 143 community members in the Great Plains and Southeastern parts of the United States. A taxonomy of American Indian family adjustment to a child with disabilities was developed. American Indian families were described as adjusting to their child with disabilities in two ways: by constructive adjustment or limited adjustment. In the constructive adjustment, American Indian families believe that the child with disabilities is given to them for a reason. There is a purpose for the child being a member of the family. Because of this purpose, American Indian children with disabilities are included in everyday family activities such as going to the store, eating dinner together, attending ceremonies, going to pow wows, and going to social gatherings. These families are healthy and "in harmony." In the limited adjustment, American Indian families become restricted in how they adjust to having a child with disabilities. Families may not know how to make changes within the family so that the child is cared for properly. These families may be "out of harmony" and need support to adjust.

American Indians (AIs) have the highest rate of disabilities of any ethnic group in the United States (Ma, Wares, & Cornell, 1999). The leading causes of disabilities for AI children are accidents, infections, and congenital abnormalities (Joe, 1997). Maternal use of alcohol during

pregnancy and premature births have been attributed to congenital abnormalities like Fetal Alcohol Syndrome (FAS) and mental retardation (Joe, 1997).

AI families must make adjustments in their families to care for a child with disabilities. Children with disabilities require an enormous amount of care from family members thus making both the family and child vulnerable. Children with disabilities may need specialized medical, physical, social, and psychological care and without this care they may not reach their potential abilities and may not grow and develop into adulthood. Family members are usually the ones to provide the care and may not always be able to provide the child care that is needed. However, AI communities also contribute to the care of children with disabilities. AI customs and ceremonies involve practices intended to restore harmony and health. These practices vary among tribes but are similar in their supportive and affirming qualities and their inclusion of the family. Many cultural practices that focus on harmony are likely to foster inclusion of people with disabilities. Therefore, most children with disabilities in AI communities can be supported to be productive members of their families and communities.

AIs have a different worldview from mainstream culture. There is a shared belief that man and nature need to live in harmony and a lack of harmony can result in varied signs and symptoms (some overlap with conventional medical diagnosis while others do not). Culture influences the way AI families and communities care for their children and accommodate their needs. Also, community responses to disabilities are powerfully influenced by culture; therefore an AI community can influence the support and care of families with children with disabilities and the adjustment families make to their children with disabilities. Living in harmony is a cultural perspective that offers health care professionals an alternate approach as to how to view family adjustment to children with disabilities (Wing & Thompson, 1995; Seideman, Jacobson, Primeaux, Burns, & Weatherby, 1996). There is, however, a lack of knowledge among health care professionals about ways in which AI communities and AI families adjust to having a child with a disability.

There are several reasons for this lack of research that explores how AI families adjust to a child with disabilities. The AI plays an important part in United States history, yet there has been a tremendous misunderstanding of the AI's worldview of living in harmony. The AI has a worldview of harmony and unity which is different from the mainstream non-AI culture of individualism found in the United States. AIs, comprised of nearly 500 tribes, have been characterized in terms of common values (self-sufficiency, group identity, and strong spirituality) and traditions (traditional healers, practices that promote harmony, and celebrations). As part of this heritage, AI communities share these beliefs and these beliefs are passed onto the community members. These beliefs become

reflected in how AI families adjust to having a child with disabilities and how AI communities support these families.

Knowledge about AI family adjustment to life challenges is passed from one generation of AIs to the next. These adjustment behaviors are subtle in nature and are ingrained in the cultural beliefs of the AIs (Seideman et al., 1996). AIs believe all children, including children with disabilities, are important, have a purpose, and can contribute to the family and community. Constructive family adjustment means children are cared for with support, sustenance, and nurturing and this ensures the continuity of cultural ways. Caring for all children in the community insures the preservation of tribal beliefs and traditions.

Purpose

The purpose of this study was to explore the community response of how AI families adjust to having school age children with disabilities in two diverse AI communities. AI family adjustment is defined as the process of settling or bringing the family to a satisfactory state. The research question asked was, "How do you (the informant) think families are changed by having a child with a disability?"

Review of Literature

There is a lack of literature in regards to how AIs adjust to having a school age child with disabilities in the family; however, culture does strongly influence the way AI families and communities respond to disability. AI families deal with the issues related to disability within the cultural framework of their tribal community as well as within the framework of the mainstream culture (Joe, 1997). Sometimes, families struggle to understand disability from an AI cultural framework. In their struggle, they may delay a modern treatment as they seek help from tribal healers and tribal community supports (Joe, 1997). This kind of family adjustment may seem as not caring by health care professionals and can lead to misunderstandings in supporting the AI family's adjustment to the disability.

Disability is defined differently in AI communities than it is in mainstream culture (Joe, 1997; Pichette, Garrett, Kosciulek & Rosenthal, 1999; Siantz & Keltner, 2004). Most tribal languages do not contain a word for disability (Connors & Donnellan, 1993; Joe, 1997; Siantz & Keltner, 2004). There is also no negative terminology or slang used to refer to disability (Connors & Donnellan, 1993; Joe, 1997). In Navajo, there is no word for mental retardation, the child is described as "lags or falls behind others." A Navajo child who is diagnosed with mental retardation may not be viewed as disabled if he or she is able to function well at home and exhibits no signs of physical disability (Joe, 1997; Siantz & Keltner, 2004).

The family has been able to adjust to the child with mental retardation and find a place for the child in the family and community. For some tribal communities, some disabilities have compelling meanings. For example, among Southwest tribes, epilepsy is by tradition considered a sign of sibling incest, thought to be harmful to the community as well as the individual (Siantz & Keltner, 2004). In other AI communities, "true" disability is defined as a person who has few or weak relationships with others in the tribal community (Pichette et al., 1999). Because of this definition, some AI families are reluctant to label a family member as being disabled or may delay seeking additional or outside care for the person with a disability. The relationship or network of relationships within the tribe may be viewed as the most important factor for the person with the disability.

Different AI tribes hold different views about why a child has acquired a disability (Patterson, 1997). Some tribes do not see disability as stigmatizing but rather is treated with acceptance and respect (Patterson, 1997). The child with disabilities may be seen as special or seen as a messenger from the spiritual world (Patterson, 1997). Children with disabilities are defined according to their unique traits (Conners & Donnellan, 1993). Temper tantrums or flapping of arms are not seen as negative or positive behaviors but simply as being a part of the child (Conners & Donnellan, 1993).

AI family structures are different from mainstream family structure of a three generation household (Seideman et al., 1996). These large family units, called clans, exert powerful influences on family relationships and functioning (Buehler, 1992; Seideman et al., 1996). AI communities are extended clan systems and family members are related by blood, marriage, or adoption (Red Horse, 1997). The extended family includes vertical and horizontal dimensions (Red Horse, 1997). Connections between extended family exist and extend into generations of past and future (Weaver & White, 1997).

AI family includes a wide variety of individuals, including those not connected through biological ties (Weaver & White, 1997). All these—cousins, aunts, uncles, grandparents, and other relatives—are significant people in a child's life (Weaver & White, 1997). Often, children view other family members such as aunts or grandparents as additional parents (Dykeman, Nelson, & Appleton, 1995). Grandparents often have a say in child rearing and in other decisions affecting family members (Dubray & Sanders, 1999). Sometimes children are raised to address all elders as grandparents and to relate to them as close family members (Weaver & White, 1997). Children are encouraged to take care of each other; sibling care is common in tribal communities (Greenfeld, 1996). When family members live in urban settings away from grandparents and significant others, some families will travel great distances to maintain contact with family members and perpetuate family traditions (Red Horse, 1980;

Seideman et al., 1996). Because of the extensive family network, there are many caretakers to care for the children in the families, including children with disabilities (Dykeman, Nelson, & Appleton, 1995; Nichols, 2004). In Crowe society, clan members are sought for spiritual counsel when important decisions are made and for any life event important to the clan (Buehler, 1992). Childrearing is seen as the entire tribal community's responsibility (Dykeman, Nelson, & Appleton, 1995).

In Navajo culture, understanding family kinship and clan relationship is important for children to know. Conners and Donnellan (1993) described how Navajo parents reported that their children with disabilities were not always able to apply kinship terms to family members but said that the children "seemed to recognize" an uncle or grandmother and smiled when that person entered the room. This provided the parents with evidence that their children with disabilities understood the importance of family ties.

AI families parent their children differently from mainstream culture (Red Horse, 1997) AI children are highly valued in traditional tribal communities (Red Horse, 1997). Children are not disciplined by means of physical punishment (Nichols, 2004; Red Horse, 1997). In fact, many AI children experienced physical punishment for the first time when they attended the Bureau of Indian Affairs mandatory boarding schools (Seideman et al., 1996). Children are taught how to behave appropriately through the use of permissive methods such as using adults and older children as role models (Red Horse, 1997), mentoring (Garrett, 1994), through the use of "watch and listen" visual mode of learning (Seideman et al., 1996), the use of milder rebukes (Dykeman, Nelson, & Appleton, 1995), through non-verbal signals from parents or elders, and are praised for good behavior rather than punished for wrong behavior (Dubray & Sanders, 1999). Young children are included in every aspect of AI life and actively participate in events such as pow wows even as toddlers (Dykeman, Nelson, & Appleton, 1995). Young children are allowed to make personal decisions (Weaver & White, 1997). Expectations related to self-care and self-sufficiency occurred significantly earlier for AI children compared to non-AI children. AI children are taught to prepare meals, to complete household chores, and to care for the sick and elderly (Dubray & Sanders, 1999). Children are taught the value of being modest and not displaying or showing assertiveness (Garrett, 1993/1994). Children are accorded the same degree of respect as adults (Dykeman, Nelson, & Appleton, 1995; Good Tracks, 1973). Children are taught to respect others by experiencing love, affection, and respect for themselves (Red Horse, 1997).

Tribal AI societies are tolerant of tribal members who might be shunned in mainstream society (Red Horse, 1997). Red Horse (1997) called this "inclusion." The uniqueness of each child is valued in tribal communities (Weaver & White, 1997). Children with developmental

disabilities who are defined as having human deficiencies in mainstream culture were described as having special strengths in traditional AI communities (Red Horse, 1997). These children are given viable social roles and respect among tribal members. Children who have conditions such as FAS or mental retardation are accepted and the children are valued to the same degree as other children (Dubray & Sanders, 1999).

Healing is viewed differently by AI communities and differs markedly from that of mainstream society (Conners & Donnellan, 1993). In AI worldview, mind, body, and spirit cannot be separated, nor treated without regard to the whole person (Conners & Donnellan, 1993; Dubray & Sanders, 1999; Kimbrough & Drick, 1991; Williams & Ellison, 1996). The concept of cure also differs in AI communities (Conners & Donnellan, 1993). AIs may only see the treatment of a wound as only treatment of the symptoms of a person who is out of harmony (Williams & Ellison, 1996). The underlying cause of the wound may be a spiritual matter. Treating the spirit means changing whatever in the mind, body, and spirit that is out of harmony and caused the wound. Biomedical physicians may treat the symptoms of the wound but to complement the treatment of biomedical medicine, AIs may use traditional healing ceremonies to heal the whole spirit of the person (Conners & Donnellan, 1993; Williams & Ellison, 1996).

Use of traditional medicine varies among tribal families. Generally, the more traditional the family, the more the family will adhere to the use of traditional medicine to heal themselves. Buehler (1992) describes five patterns of use of traditional medicine and/or biomedical medicine among Crow people: (a) traditional medicine followed by biomedical medicine, (b) biomedical medicine followed by traditional medicine, (c) simultaneous bicultural use of biomedical and traditional medicine, (d) only traditional medicine, and (e) only biomedical medicine. Traditional ceremonies or healing medicines have been credited with saving children's lives or helpful in reducing symptoms of illnesses and disabilities (Buehler, 1992; Conners & Donnellan, 1993).

Healing of a child with disabilities may be viewed differently in AI communities. Conners and Donnellan (1993) described an example of about Navajo belief where a blind person is considered cured after he has had the proper healing ceremony performed. The person is still blind but harmony has been restored that allows the person to live with the lack of eye sight. The person has been made whole. Ceremonies are performed to make a child with disabilities whole again and to restore harmony.

In summary, AI communities have many traditional ways to assist caring for children with disabilities. However, it is important to point out that many of these traditional ways may not immediately be apparent to non-AIs, particularly non-Indian health professionals (Seideman et al., 1996).

Methodology

This study was designed to investigate the community response of how AI families adjust to their school age children with disabilities. School age children were children ages five through twelve years. The diagnosis of a disability was made by medically trained staff or appropriate school officials and community members self-identified the families with children with disabilities. Disabilities for the children identified in this study included children with learning disabilities, muscular-skeletal disorders, visual and hearing impairments, mental and cognitive disorders, and mental health disorders.

Given the dearth of knowledge about this process and its significance to the health and well being of AI families, a qualitative ethnographic methodology was the approach to building scientific knowledge in this area. Procedures and decisions were developed or affirmed by local Advisory Boards composed of tribal leaders.

Conceptual Framework

A conceptual model from another study of AI infant care was utilized for this study (Nichols, 2004). This model has been refined and enhanced from the original version. This model uses AI ideals to explain how AI values are used by families to adjust to having a child with a disability. The Pattern of AIs: Harmony Ethos, is represented in Figure 1. The following sections describe the Harmony Ethos model.

Identification with Tribe

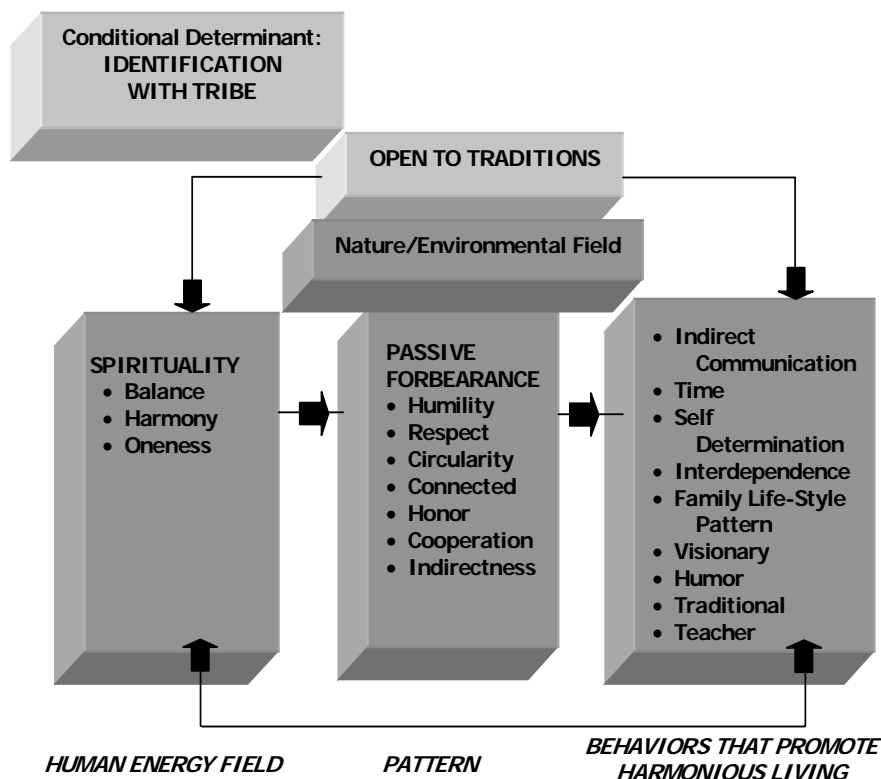
Cultural identity is the conditional determinant. Cultural identity differs among the various AI groups found in the United States. There are over 500 tribes in the United States and cultural identity will vary among the members of the tribes at various times at various points of an AI's life (Weaver, 1998). The more the family member identifies with the tribe, the more "Indian" the person may feel and the more likely the person will follow the traditional parenting ways of the tribe. An AI person's identity includes the family, tribe, and community (Sampson, 1988).

Spirituality

Spirituality and health are believed to be the same in many AI religions and beliefs (Heinerman, 1989). In order to stay healthy or spiritual, the AI family needs to stay in harmony with the environment. French (1987) described living in harmony as the AI harmony ethos. AI families have to constantly adjust to their environments to maintain their health and spirituality. Balance, harmony, and oneness are the attributes of spirituality (Nichols, 2004; Wing & Thompson, 1995; Wuest,

Figure 1
The Pattern of American Indians: Harmony Ethos

(Based on the model from Nichols, 2004. Reprinted with permission from Sage Publications.)



1991). AI families need to maintain balance, live harmoniously, and maintain a oneness with their environments to be healthy. Families that lack spirituality may lack harmony and be out of balance and need to be returned to a state of health. Spirituality determines how the AI family adjusts to the environment in the family home (Nichols, 2004).

Pattern of Passive Forbearance

The term used to describe the pattern of the AI in the family environment is passive forbearance (Greenfield, 1996; Good Tracks, 1973; Nichols, 2004; Red Horse, 1997; Rogers, 1990; Strong, 1984; Wax & Thomas, 1961; Weaver & White, 1997). Humility, respect, circularity, connected, cooperation, indirectness, and honor are the attributes of passive forbearance. Nichols (2004) defines passive forbearance as:

The innate potential of each family member as the personality unfolds and the right of that person to choose whatever type of behavior he or she might wish to exhibit. Another family member is not allowed to intervene (or expected to intervene), even if self-destructive behavior is exhibited. In addition, neither can the person oppose the goals of the group. (p. 230)

In order to maintain the spirituality of the family or live in harmony, family members interact within the family environment (individuals, family, tribe and community) in a non-interfering and cooperative manner (Nichols, 2004; Red Horse, 1997; Seideman et al., 1996). Cooperation, not dominance, is the pattern of living of most AI communities (Good Tracks, 1973).

Behaviors that Promote Harmonious Living

Living in harmony or in a non-interfering and cooperative manner is reflected in the behaviors of the AI family. To maintain the balance and spirituality of the family, AI members behave in such a way that contributes to the health, spiritualness, and balance of the family and to the community as a whole. Living harmoniously has provided AI families with the capability of being able to face many challenging life situations—forced assimilation, forced relocation, mandatory boarding school for AI children, and termination of tribes (Kimbrough & Drick, 1991; Solbralske, 1985; Upvall, 1997). By using behaviors to promote living in harmony, AI families are maintaining the spirituality of the family. Nine concepts—indirect communication, time, self-determination, interdependence, family life-style pattern, visionary, humor, traditional, and teacher—are some of the behaviors that are respected by AIs in promoting harmony within the family, tribe, and community (Nichols, 2004; Red Horse, 1997; Wuest, 1991).

Open to Traditions

AI families are more receptive to traditional AI values, beliefs and behaviors than U.S. cultural ways (Nichols, 2004; Weaver, 1998). AI families, even families acculturated in the mainstream culture, will turn to traditional beliefs and practices in times of stress or unknown to maintain the balance and spiritualness of the family and community (Keltner, 1993). Traditions and traditional values provide ways for AI people to promote the health of the AI family and tribe.

Sample and Setting

AIs are both familiar and foreign to the general American public. The public image of an AI may be of an AI on a horse wearing buckskin

clothes and feathered bonnets, another image is as a drunken Indian, or the image of a granite-faced grunting redskin with no feelings or sense of humor (Backup, 1980). Sometimes, stereotypes obliterate true appreciation for the diversity and complexity of contemporary AI culture. There are 4.1 million AIs in the U.S. (Census, 2000) comprised of more than 500 tribes. Most tribes have less than 1,000 members and are widely dispersed in urban "pockets" and rural communities. Some tribes have no land base at all, some AI families move on and off reservation land and others have been in the same location for generations. There are 278 reservations, the largest being the Navajo. An estimated 200 indigenous languages still survive, the majority of which can be spoken by only a few elders (Utter, 1993). The focus of this study was to document from an ethnographic perspective the traditional values, beliefs, and cultural responses of family adjustment to disabilities in two AI communities. Participants were selected from two broad tribal groups, one a large reservation in the Great Plains (reservation AI community), the other a coalition of several small tribes in the southeastern U.S. (urban/rural AI communities).

Participants for a community assessment were selected using theoretical sampling. Theoretical sampling refers to the selection of informants who will most facilitate the development of emerging taxonomies. Informants were selected because they could provide rich and meaningful data. Community members who were individuals most familiar with family adjustment to children with disabilities were selected to be informants for this study. Initial selection of informants was based upon several factors such as having a child with a disability, having a child without a disability, being a tribal leader, being an elder in the community, and being a service provider who worked with AI children with disabilities in the community. The Advisory Board members nominated potential participants for the study. This nomination process ensured selection of informants who were diverse and representative of the communities. These participants served as the key informants for this study. Informants included 26 AI families with disabilities, 36 AI families without disabilities, 20 service providers, 15 tribal leaders, and 23 AI elders. (Family Associates did not identify 23 of the informants in the study.)

Procedure

Interviews with 143 informants were conducted. Nine community members from the two sites collected the data (interviews). The local Advisory Board nominated the interviewers (Family Associates). Extensive yearly training for the Family Associates was conducted so each interviewer asked the interview questions in the same way and collected the data in the same manner. In addition, the researchers made regular site visits to

the participating communities to ensure that data collection was consistent among the Family Associates. Due to the use of local individuals for Family Associates, the interviewers were extensively trained in the ways to insure confidentiality of the subjects was maintained.

Data Collection: The Interview

The Community Assessment Interview was developed to gather information on the community's perspective of families caring for a child with disabilities and the community's responses to families with children with disabilities. The interview had eleven open-ended questions (Appendix A). The interview was developed in collaboration with the local Advisory Boards to reflect the participants' culture in content and form. The Community Assessment Interview was used for each interview. Interviews were handwritten and audio-tape recorded.

Data Analysis

The 143 interviews were transcribed and entered into the computer for analysis. The interview data was content-analyzed using ethnographic methodology. Ethnographic computer software, The Ethnograph (Version 5.0; Seidel, 1998), was used in the analysis to cross-reference and categorize the data. Each piece of interview data was analyzed for the linguistic expression of cultural meaning and then compared to other pieces of interview data. Data were coded to reflect common themes and divided into domains of cultural meaning or taxonomies. The ones with common themes were merged into a central theme (cultural theme), for example "getting services needed for the child." Cultural themes (taxonomies) about AI family adjustment were identified. Taxonomies such as: getting Social Security Income for the child with disabilities, getting counseling, learning sign language, taking long trips to medical specialists, and transporting the child with disabilities, were merged into a central theme or taxonomy of "getting services needed for the child." The taxonomies were then compared to the conceptual framework for fit. For example, the spirituality of family adjustment was "being aware of the balances in the family." The pattern of passive forbearance was the "indirect responses of accepting the child with disabilities" and some behaviors of promoting harmonious living included "getting services needed," and "altering the home environment." The researchers formulated a definition based on the properties inherent in the taxonomies using the conceptual model. Then, two patterns were formulated to describe how AI families adjust to having a child with a disability.

Trustworthiness and Credibility

Lincoln and Guba (1985) used the terms trustworthiness and credibility, which refer to the level of confidence of the truth of the findings, the degree to which the findings are applicable in other contexts, and the consistency of the findings. The following techniques were utilized to establish trustworthiness and credibility of the data.

Prolonged Engagement

Prolonged engagement is the investment of sufficient time to achieve certain purposes: learning the "culture", testing for misinformation introduced by distortion either of the self or of the informants, and building trust. The researchers had an extensive history with the participants' sites.

Persistent Observation

The technique of *persistent observation* was used to identify those characteristics and elements in the situation that are most relevant to the problem being pursued and focusing on them in detail. The researchers attended tribal meetings, pow wows, naming ceremonies, honoring ceremonies, traditional ceremonies, and family gatherings. Extensive field notes were written about these events and used as part of the data analysis to support or refute the verbal data gathered.

Member Checks

Member checks were made by sharing the data, including emerging definitions, categories, and theory with the informants. The *member checks* were done informally and formally. The findings were shared with the informants, Family Associates and Advisory Board members at various levels of analysis. Data were confirmed or refuted at these meetings.

Peer Debriefing

Peer debriefing is a process of the investigator sharing the data with others in a manner paralleling an analytic session and for the purpose of exploring aspects of the study that might otherwise remain only implicit within the investigator's mind. The researchers met frequently and discussed the data extensively in terms of how the domains of analysis should be developed.

Negative Case Analysis

Negative case analysis is the process of continuously refining a hypothesis until it accounts for all known cases without exception. Constructive and limited family adjustment behaviors were compared and formulated into two patterns of care. The researchers were able to account for the variations in behaviors of family adjustment through comparison of the different behaviors.

Audit Trail

The *audit trail* is a residue of records stemming from the study. The audit trail helps to systematize, relate, cross-reference, and attach priorities to data that might otherwise have remained undifferentiated until the final preparation of the study. Ethnographic computer software was utilized to analyze, store, and cross-reference the data. Taxonomies were developed and type written and diagrams constructed to identify cultural meanings and relationships among the taxonomies.

Authenticity

Pareek and Roa (1980) address the issue of the *authenticity* of the interview. *Authenticity* refers to the authentic or genuine response provided by the informant during the interview. The Family Associates (data collectors) were from the tribes that participated in the study. Being a “familiar face” and familiar within their own AI communities, the Family Associates were able to collect rich data for the study. Informants were more willing to share their varied perspectives of family experiences regarding disability with a familiar face from the community.

Findings

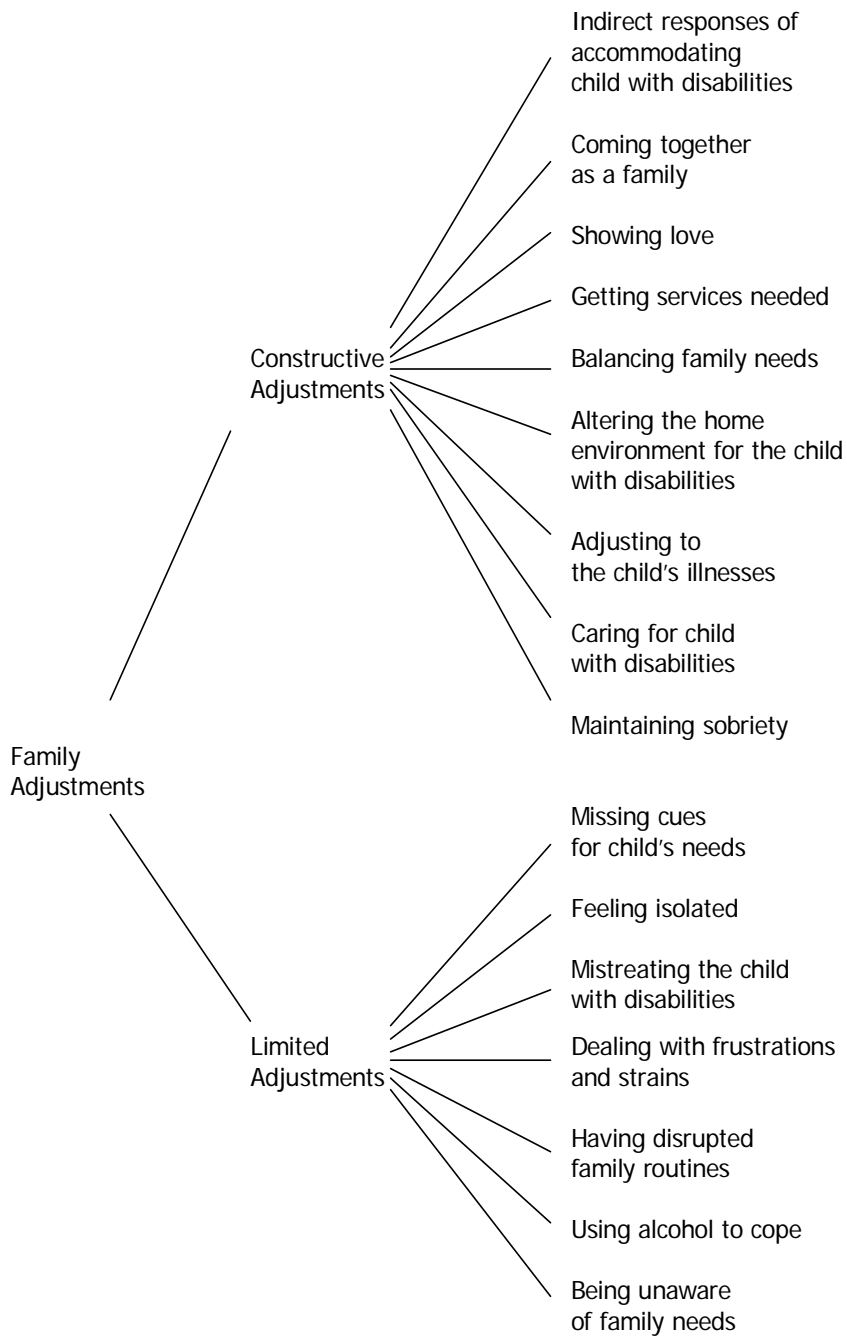
The following sections will describe the taxonomy development of AI family adjustment to a child with disabilities. Figure 2 represents the American Indian Family Adjustment Cascade Model. The model identifies the linguistic and cultural meanings among the taxonomies. Community members described AI families as adjusting to their child with disabilities in two ways: by constructive adjustment or limited adjustment. The following sections describe the ways in which these families made constructive or limited adjustments.

Constructive Adjustments

Indirect (Passive Forbearance) Responses of Accommodating a Child With Disabilities

AI families were depicted as accommodating their child with disabilities in indirect ways. Indirect accommodation was subtle and not always observable by outsiders in the family—“they just learn to make adjustments.” Some family members adjusted by accepting the illness, “you just accept it and you both grow.” Some family members stated they learned from the child with disabilities, “learned more about ourselves, our inner strengths.” Other informants described families as accommodating by being understanding, trying harder, being more patient, overcoming obstacles, being there, and not being ashamed of the child with disabilities. Families were portrayed as using humor to make family adjustments to the child with disabilities. Acceptance and inclusion of

Figure 2
American Indian Family Adjustment Cascade Model



the child with disabilities was how most families were portrayed as subtly accommodating the child with disabilities (Red Horse, 1997). "Some just accepted it and included their (disabled) child in their activities. In our Indian society, our feelings come from our heart and we learn to accept the unique things that happen to us."

Coming Together as a Family

Informants stated having a child with a disability brought AI families together. Informants explained AI families made adjustments by staying together as a couple, utilizing family members to assist in caring for the child with disabilities, and bonded more when caring for the child with disabilities. One mother of a child with a disability stated, "We both went to an Indian ceremony and talked to a medicine man and we got back together and that we were both going to help raise our child. She is the one that needs us most."

Showing Love

Informants said families showing love to the child with disabilities was one way of adjusting to the child. Informants described the child as special, "some families accept their child the way he or she is. To the family the child is special." Some AI families were depicted as being joyful at having the child, and felt that there was meaning in having a child with disabilities. One father said, "The joy and strength from this (child going deaf) is we are all adjusted and very proud of her. She likes her school. She also loves to watch birds." Some community members explained how families appreciate the child for what he or she is. One family member stated, "If the child is born with any kind of disability it is not the child's fault. God already planned it and it's the parents that need to help their child and to love and care for the child with a disability. My grandchild that has the disability, his uncle really cares a lot about him. They all give him special attention."

Getting Services Needed

Families were described as being adjusted by being able to get some of the services they needed for their children with disabilities. Some families stated they got Social Security Income for their children and Medicaid. This enabled the families to take the child to physicians who were not affiliated with Indian Health Services. Some families said they adjusted by driving long distances to take the child to medical specialists. Other families were portrayed as accommodating the child with special needs by learning sign language. An aunt said, "My whole family had went to sign language school because my niece, my brother's daughter is mute. We learned how to communicate with her."

Balancing Family Needs

Informants observed changes in the stability of families with disabilities. Informants described how by being aware of the different changes and balances families were able to function more smoothly as a family with a child with a disability. Some families were depicted as adjusting by putting their family on a schedule and others families adjusted by making subtle changes in the family routines. Some families were observed as slowing the pace of the family to accommodate the child with disabilities, for instance eating dinner at a slower pace. One niece related this story.

My aunt has a child who has Down Syndrome. My other aunts passed away young, but my aunt who had this child lived a long time. So there's something there where all the rest have died, she lived a long time. She is now dead, but her child is still living. She's a grown woman now. They had a special bond and because of that they both lived a long time. Because kids who have Down Syndrome are said to die young, but this one lived a long time. My aunt was really quiet but her child really helped her, they didn't have much. It seems that when they have a child like these families think about more things than a normal person. A normal person is almost greedy like they have blinders. With a disabled child, it forces families to be more aware of different balances that you have to have in your life to live your life. It does strengthen your family. That's just one example that I know of that a disabled child was able to do that. The blinders were taken off their parents.

Altering the Home Environment for the Child with Disabilities

Home environments were altered to adjust to the child with disabilities. Families were described as altering the home by making the home smoke free, rearranging the furniture, changing the structure of the home (adding a wheel chair ramp), changing laundry soap, eating different foods, and getting the equipment needed (potty chair, bars). One mother of a child in a wheelchair said, "We had to change the structure of our home so he could get around."

Adjusting to Child's Illnesses

Some children with disabilities were described as having many illnesses and community members described how families had to adjust to these illnesses. Some of the families had to adjust to their child having surgery. A family member had to stay with the child at the hospital and stated, "She had to go through surgery and the parents were both there

for her.” Many of the children were sick frequently and families were described as adjusting to the repeated illnesses of the child with disabilities by staying at home with the child or taking the child to the physician or medicine man repeatedly.

Caring for the Child with Disabilities

Families were illustrated as caring for their children with disabilities in different ways. Families were described as doing things for the child with disabilities, helping the child, staying up all night, adjusting their job situation, getting a sitter with special training, letting the child do things for him/herself, learning to care for the child, and carrying the child when the child was big. “My neighbor has several children with disabilities. She is very supportive of her older son who uses braces to walk. She lets him do things for himself.”

Maintaining Sobriety

Informants said some families adjusted to having a child with a disability by getting sober and maintaining sobriety. One family member acknowledged, “My aunt had a little girl who was born with a cleft palate. She had difficulties in the beginning, she had to go through surgery and she also had problems feeding her. She also had to make adjustments in her family life because she had to give her (child) a lot of attention. But as time went on she was strengthened, she quit using alcohol and changed her life. And I think her new joys are that her daughter is now at a school and she is doing very well. She gets to come home for holidays.”

Limited Adjustments

Missing Cues for Child’s Needs

Some families were portrayed as not being able to identify their child’s needs and, hence, were not able to meet their child’s needs. One family member stated, “I know in so many of the families they experienced denial for a great period of time. They believe if the child is having a hard time learning, the child will catch up.”

Feeling Isolated

Informants described how family members felt isolated in several ways: by the loss of friends, not being able to go places, having no one available to help, being reluctant to ask for help, not being able to do the things the family wants to do, and feeling helpless when the children without disability feel left out. One mother of a child with disabilities stated, “The difficulties are when you need help and there seems to be no one available to help.”

Mistreating the Child with Disabilities

Community members described how some families and tribal members were not able to adjust to having a child with a disability and mistreated the child. Some members in the community were observed ridiculing the child with disabilities. Some families were depicted as ignoring the needs of the child with disabilities. "Everybody has to change (when a child has a disability) and some children get ignored." Some families were described as abusing the child with disabilities by misusing their Social Security Income. "Some families just want monies (social security benefits). They are not really helpful for their children." "Some families put their children in homes because they are not ready to make adjustments. There are some who just keep the child for money; the child usually suffers from neglect."

Dealing with Frustrations and Strains

Some families were depicted as to not being able to adjust to all the frustrations and strains of having a child with a disability. These families were described as feeling burned out, being in denial, feeling devastated, being disappointed, blaming someone, being mistrustful, and being angry. Some families said they could not deal with the stress of having a child with a disability and felt strained as a family. One mother of a child with disability said, "We dealt with the stress, not knowing where the disability was coming from."

Having Disrupted Family Routines

Some families were depicted as not being able to adjust family routines to the child with disabilities. For these families disrupted routines affected the functioning of the family unit. Families were described as not being always able to plan meals or family outings because the child with the disability might need care. Informants describe how family members with children with disabilities were not able to attend pow wows, family gatherings, naming ceremonies, or traditional ceremonies for fear the child would be exposed to family members' "germs." One family member said, "Family members have to arrange plans and activities around the disabled child."

Using Alcohol to Cope

Informants describe how some families adjusted to having a child with disabilities by drinking alcohol or using illegal drugs or both. "Some people who have a disabled child usually need something or someone to blame it on, even if the child is FAS (Fetal Alcohol Syndrome)." Informants said some families were not always able to deal with the disappointment of having a child with a disability or were not able to physically care for the child. One community member said, "Some people can't handle it, they try to find someone to blame or they're in denial, telling people it'll

get better than feeling helpless especially if their child is seriously disabled. Some people stay in that helpless state and don't want to accept the disability. A lot of the times they start drinking (alcohol)."

Being Unaware of Family Needs

AI families were portrayed as being not able to identify the needs of their families. When the family dynamics changed because of the birth of a child with a disability, the family was described as not able to function smoothly and that the balance of the family altered. Sometimes informants said the family would break up because the family could not adjust family care to meet the specialized needs of the child or even the needs of the family as a whole. Sometimes, children were sent away to school or a health care facility when the family could not meet the demands of the family. A community member said, "It (the disability) sometimes breaks families up or else the child gets sent off to school, then when they get back for summer, it's bad because the families haven't gotten help the child needs, it don't help the child at all."

Patterns of Family Adjustment

The conceptual model, Figure 1, was used to identify the relationships between the different taxonomies. A fit between the Cascade Model and the Harmony Ethos Model was developed. Two patterns of family adjustment were developed using the Harmony Ethos Model, the pattern of constructive family adjustment of AI families with disabilities and the pattern of limited family adjustment of AI families with disabilities. For example, the pattern of constructive family adjustment of AI families with disabilities, the domain of "balancing family needs" was identified as the essence of the spirituality. Living in harmony meant balancing family needs to maintain family health. The domain of "indirect responses of accepting the child with disabilities" was identified as the pattern of passive forbearance. A non-interfering and cooperative manner was indirectly accepting the child with disabilities as a family member. The behaviors to promote harmonious living included: coming together as a family, showing love, getting the services needed, altering the environment, adjusting to illnesses, and caring for the child with disabilities in indirect ways. These behaviors promoted the family living in harmony and maintained the balance of family health.

Some families were limited in how they adjusted to their child with disabilities and family health or family harmony was not always in balance. For the pattern of limited family adjustment of AI families with disabilities, "being unaware of family needs" was the dispiritedness of the family. Spirituality or living in harmony was not maintained. The pattern of discordant living was identified as the domain of "missing cues for the child's needs." This may have been a subtle and limited manner of

not always providing care for the child with disabilities. Behaviors that did not promote living in harmony as a family with a child with disability included the domains of: feeling isolated from others, mistreating the child with disabilities, having frustrations and strains of having a child with a disability, having disrupted routines, and using alcohol and drugs to cope. These behaviors did not promote the family living in harmony and did not contribute to the balance of family health.

Pattern of Constructive Family Adjustment of American Indian Families with Disabilities

Spirituality

A part of AI spirituality is the belief that everything has a place and a purpose. Because of that purpose, everything is in balance. A child becomes a part of the AI family for a reason. The child becomes a member of the clan and the clan welcomes the child with (or without) disabilities. The balances within the family are adjusted to provide care for the child.

Passive Forbearance

The way the AI family creates balance within the family is through non-obtrusive behaviors. The AI family becomes aware of the different changes that occur in the family when a child with disabilities becomes a member of the clan. This changes the balance of the family and the clan provides subtle and non-obtrusive care for the child with disabilities so that balance is maintained.

Harmonious Living

Harmonious living is accomplished by being more aware of different balances in family life in order to adjust family life to the child with disabilities. By adjusting to the child with disability, the family is able to integrate that child into the clan and provide a purpose for the child's being.

Behaviors to Promote Harmonious Living

There are several ways that AI families adjust to having a child with a disability. These include: coming together as a family to care for the child, showing love to the child, getting the services the child needs to be healthy, altering the home environment to accommodate the child with disabilities, adjusting family life to the illnesses of the child, caring for the child in non-obtrusive ways, and maintaining sobriety to care for the child.

Pattern of Limited Adjustment of American Indian Families with Disabilities

Dis-Spiritedness

Everything in the universe feels out of balance. The family is out of balance. The purpose of having a child with disabilities is not clear or understood. The balance in the family is altered and the clan is not always able to adjust and provide care for the child with (or without) disabilities.

Lack of Passive Forbearance

The AI family is not aware of the different changes that occur within the family when a child with disabilities becomes a member of the clan. This alters the balance of the family to the point that the family cannot function smoothly or maintain a healthy balance. Clan members may not provide subtle and non-obtrusive care to the child with disabilities and may have difficulty accepting the child into the family or clan.

Discordant Living (Out of Harmony)

Discordant living or being out of harmony is being unaware of the different balances within family life and not being able to adjust family life to the child with disabilities. The family may not integrate that child into the clan and the purpose for the child's being is unclear and not understood.

Behaviors of Discordant Living

There are behaviors that can limit AI families adjusting to having a child with disabilities. These behaviors include: missing the cues of the child's needs, feeling isolated from others, mistreating the child with disabilities, not being able to deal with the frustrations and strains of having a child with a disability, having disrupted routines, and using alcohol and drugs to cope.

Conclusion

AI family adjustment impacts how AI children with disabilities are cared for by their families and tribal community. Two patterns of AI family adjustment have been described by informants from two AI communities. AI families were described as adjusting to having a child with disabilities in constructive and limited ways. In the constructive adjustment, AI families believe that the child with disabilities is given to them for a reason. There is a purpose for the child being a member of the family. Because of this purpose, AI children with disabilities are included in everyday family activities such as going to the store, eating dinner together, attending ceremonies, going to pow wows, and going to social gatherings. The family is able to balance the care that is needed to care for the child with disabilities. These families are able to meet the needs

of the child and accommodate family adjustment to meet those needs. The family and community are assisting the child with disabilities to meet their full potential. These behaviors make the AI family function more smoothly. The AI family is able to take action utilizing community supports to assist them in adjusting to the child with disabilities. AI families adjust to their children with disabilities using non-obtrusive behaviors. These behaviors include: coming together as a family to care for the child, showing love to the child, getting the services the child needs to be healthy, altering the home environment to accommodate the child with disabilities, adjusting family life to the illnesses of the child, caring for the child in non-obtrusive ways, and maintaining sobriety to care for the child.

In the limited adjustment, AI families may be restricted in how they adjust to having a child with disabilities. The family may feel out of balance, strained, and the purpose of having the child may not seem clear. The family is not able to identify the needs of the child with disabilities. Families are not aware of how to make changes in the family so the child can be cared for. These families can be described as being "out of harmony". These AI families are vulnerable to the needs of the child and the child becomes vulnerable to the care of the clan members. The AI family may not be able to provide for all the needs of the child with disabilities and if the family is not able to provide the care, the child may not reach his or her full potential and may even become at risk for child neglect or possibly child abuse. These AI families become limited in how to adjust to having a child with disabilities and may need assistance and support to return them to a healthy balance. Family behaviors include: missing the cues of the child's needs, feeling isolated from others, mistreating the child with disabilities, not being able to deal with the frustrations and strains of having a child with a disability, having disrupted family routines, and using alcohol and drugs to cope.

Health care professionals need to be aware of how families adjust to having a child with disabilities and the role that community and culture plays in that adjustment. Health professionals need to be aware that these family adjustment behaviors may be subtle and not readily observable by the professional. When health professionals are knowledgeable about AI family adjustment, they can assist the AI family and tribal community in balancing the care of the child so the family is healthy and functioning smoothly.

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Appendix A

1. To begin, we are interested in learning about family life in our community. We'd like to know about the kinds of things families with elementary school children do.
 - 1a. When you think about families in our community, what are some of the good ways they spend time together?
 - 1b. What are some of the problems or worries that you think are most common for families with elementary school children in our community?
2. Almost all families have special hopes and goals for their children. When you think about families in our community, what do you think are common goals and hopes that families want for their children?
3. This question is for families that have one child in elementary school now. When you think about your family, what are some of the things that are the most important for you. Would you like to share some of the things that your family does that seem to make you feel close to each other?
4. In our community, when and where do you come into contact with people with disabilities? (This includes both children and adults with disabilities. Also, this can include contact in your job or work as well as in your everyday activities.)
5. One of the best ways to learn about community life is through stories that people share with each other. Do you have a story to tell that features someone with a disability? Family stories sometimes include ways siblings or cousins help each other. Tribal stories sometimes

tell about people who had a disability but helped the tribe or community in some way. Could you tell us any stories about a person with a disability in your family or tribe?

6. Some disabilities are easy to see (like a person who uses a wheelchair or wears a hearing aid), while others are not so easy to see (like learning disabilities or mental retardation). Sometimes people will help someone who has a disability you can see. Other times they may not know if a person needs or even wants help. In our community, what are some of the ways you have seen people respond to a person with a disability? *Note: Item 6 asks for both positive and negative responses, and item 6a and item 6b were broken out separately to accommodate getting both positive and negative responses from the subjects. This was done to make it easier for the data collectors to collect the data (responses) and clearly identify what the subjects identified as a positive answer to the question and what the subjects clearly identified as a negative answer to the question.*
7. One of the “invisible” disabilities is sometimes called mental retardation. What does the term mental retardation mean to you? Are there other words or terms people around here use to describe mental retardation?
8. All of us have heard different people talk about the good things that happen to them and talk about the bad things that happen to them. Most people live their lives in a way that is comfortable for them (doing certain things at certain times like dancing or special ceremonies, giving a ride to a cousin who needs to go into town, or listening to elders), Sometimes Indians call this living in harmony and teach their children how to live in harmony. Can you tell me some things you know that families can do to help their children with disabilities live in harmony?
9. There are many different causes of disability. We don’t know all the answers as to why some children have disabilities. For some situations, there are both medical reasons for disability and also traditional explanations. At other times, there are no known causes of a disability. Do you know of any tribal stories or beliefs in our community about what causes disabilities? What are some of these?
10. How do you think families are changed by having a child who has a disability? This can include how the family has been strengthened or had new joys. This can also include adjustments or difficulties the family may have experienced.

11. Sometimes families need help with meeting the special needs of their child with disabilities. Depending upon what the special need may be, families may try to use a variety of resources or services. Some of these resources may be within the family (grandmother's advice, uncle familiar with Indian medicines, sister who also has a child with a disability) or some of these resources are from organizations like churches or support groups, or some resources may be from the mainstream society (schools, clinics, physicians). In our community, what kind of resources do you think families use? Would you recommend them to a family you know and cared about? If you would not recommend a resource, could you tell us why not?