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Attitudes about Disabilities in a Southeastern American Indian Tribe

**BETTE R. KELTNER, NANCY A. CROWELL, AND
WILFORD TAYLOR**

American Indian families experience many of the societal forces common to American family life, as well as those that are unique to their historical, regional, and cultural context. They have survived aggressive efforts to abolish their culture and continue to endure the effects of systems that disregard their values and discredit their identity. It is apparent that American Indians have impressive reservoirs of strength and coping in spite of adversity, but that adversity is not without cost, for they do experience high rates of disorders associated with social stress.¹ What is lacking in the empirical literature are studies of effective adaptation strategies (in contrast to pathological ones) used by American Indian families in response to numerous challenging life circumstances.²

One such challenge is the presence of a family member with a disability. American Indians have a disability rate that is higher than other groups in the United States—21.9 percent compared to 9.9 percent for Asian and Pacific Islanders, 15.3 percent for Hispanics, 19.7 percent for white people, and 20 percent for black people.³ Furthermore, American Indian children are frequently labeled as having a disability. A national survey found that only half (53 percent) of American Indian students were classified as “not handicapped in any way and 11 percent were classified as mentally retarded.”⁴ The higher disability rate may be associated with economic conditions. Disabilities in general are more prevalent among children in poor families than in families

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who are not poor.⁵ Without doubt, American Indians are among the most impoverished people in the United States. The 1999 per capita income of American Indians and Alaska Natives was \$12,893, much lower than the national average per capita income of \$21,597 and lower than the \$14,437 per capita income of African Americans.⁶ These data define the scope of a significant cultural and societal challenge that has not been systematically addressed.

Research has begun to examine the resilience and coping strategies of families with members who have disabilities, but little empirical work looks at American Indian families' experience with and adaptation to family members with disabilities.⁷ An examination of large national datasets by Robert Schacht and colleagues noted that American Indians and Alaska Natives are "virtually invisible."⁸ The researchers also underscored the importance of personal face-to-face interviews with this population.

How people define disability may play a role in the types of services they seek and use effectively. Disability researchers have found that functional limitation is one of the most commonly accepted meanings of disability in popular understanding. In contrast to these functional definitions, health professionals tend to focus on the specific diagnoses that result in limitations, prognoses, and the use of health services. Hahn suggests that the medical view leads to an emphasis on etiology rather than consequences and prevention rather than adaptation.⁹ For individuals and families dealing with a disability, it is precisely the consequences and how to adapt to them that becomes most important. It is the daily, lived experience that is meaningful for families who deal with limitations, prospects, and community relationships.

Key cultural themes—such as harmony, spirituality, connectedness to nature, and strong family ties—theoretically may facilitate positive family adjustment to a child or other member with a disability among American Indian and Alaska Native populations. Family practices intended to heal, restore, or prevent diseases and disorders can reflect how humans relate to a higher power and connect the meaning of one's life to its place in a larger universe. The general public perception of American Indian spirituality is one of adherence to traditional ceremonies and rituals. Many tribes preserved spiritual beliefs during generations of systematic European efforts to eliminate those beliefs and practices. More recently, increased acknowledgment of traditional tribal spiritual beliefs has fostered a "revival" of sorts of Native spirituality among American Indians. Non-Indians also have become interested in learning about and participating in Native traditions. Most American Indian tribes, however, also have been exposed to Christianity, in some cases for several hundred years, and consequently, some Indian people are strongly allied with organized religion. In the Southeast, conservative Christianity has had a strong influence.

Many American Indian family and cultural traditions and values appear likely to promote inclusion of all people, regardless of their level of intelligence or physical capabilities. The importance of family and community in successful vocational rehabilitation projects for American Indians has been noted in several studies.¹⁰ Other aspects of contemporary American Indian

life, however, may limit families' abilities to provide a full range of social, educational, health, and recreational opportunities for their members affected by disability.

This article reports the results of a structured interview with members of a southeastern American Indian tribe on attitudes about disabilities and experiences with people with disabilities. The interview was part of a five-year study of how American Indian communities view disability and how American Indian families adapt to having a member with a disability. For nearly a century and a half after the forcible removal of most American Indians from the Southeast, members of this tribe lived an isolated existence, sometimes hiding their Indian heritage for fear of removal or worse.¹¹ One result of the prolonged isolation is a relatively high number of cases of a rare recessive genetic disorder, Marinesco-Sjögren syndrome (MSS), among members of this tribe. Isolation and fear of outsiders fostered intermarriage, allowing the recessive genetic disorder to manifest. More than one hundred cases of MSS have been diagnosed worldwide; nearly a fifth of those cases are members of this southeastern tribe, although prevalence rates are not available.¹² This syndrome is characterized by cataracts, short stature, progressive muscular weakness, and mental retardation.¹³ The presence of this disorder makes the tribe a particularly rich one for examining attitudes toward and experiences with disability. The distinctive history of this tribe, however, does limit the extent to which the findings apply to other American Indian tribes.

The goal of this study was to gather information from a wide group of tribal members on the cultural meaning of and experience with disability, as well as to document family needs and perceived quality of service. An interview instrument to collect such information was developed in conjunction with tribal representatives and administered to members of this southeastern tribe. The study focused on answering several questions: (1) what is the extent and type of disability among tribal members in this southeastern tribe? (2) how do tribal members define disability? (3) how have families had to change in order to deal with a member with disabilities? and (4) what resources are needed for members with disabilities? This report presents descriptive findings from the interview.

METHOD

The Sample

A cross-sectional design was used in this study. A voluntary convenience sample of 151 households, containing 494 people, completed the interview in 1995. The household members represent approximately 20 percent of the tribal members living on and around the reservation and about 8 percent of total tribal membership.¹⁴ Interviewers were members of the tribe who had received training in adherence to the interview protocol and confidentiality requirements. Information about the interview was mailed to all families who lived in or around the reservation, where approximately 2,500 tribal members reside. Interviewers then went door-to-door throughout this relatively small

community to solicit participation. Care was taken to have interviewers cover all parts of the community. Interviewers did not maintain logs of refusals and therefore the refusal rate is unknown. Interviews took place in the homes of the respondents. One adult in each household provided the answers to the interview after giving written informed consent.

Households ranged in size from one person to seven people. On average, 3.3 people lived in a household. The tribal household size was slightly higher than the average household size for the state in 1990 (2.6).¹⁵ Household members ranged in age from newborns to ninety-one years old. Seventy-two percent of all households had children under the age of eighteen living in them, far higher than the state average of 35 percent but consistent with national demographics for American Indians, which is an ethnic subgroup characterized by its relative youth compared to the general population.¹⁶

Many of the participant families live in poverty. As can be seen in Table 1, the median monthly income was \$1,000 to \$1,499 per month (\$12,000 to \$17,988 per year). Over a quarter of the interviewees reported a monthly income of less than \$500. It appears from these data that between 43 percent and 68 percent of the households were below the US Census Bureau poverty thresholds and their median income was below the median for the state.¹⁷

Although national surveys have found American Indians to have a higher rate of disability than other racial or ethnic groups (American Indian 19.4 percent versus other 15 percent), the disability rate for this sample was 14.7 percent (73/494), lower than that reported for American Indians as a whole in 1991–92. The rate is similar to the 15 percent national average found in the National Health Interview Survey for 1994.¹⁸ The lower percentage of disabled persons may reflect a greater reluctance among the disabled to respond to the interview, potentially biasing the results. The low rate may also reflect differential definitions of disability wherein a medical diagnosis is not a key driver of identifying persons as having a disability.

Instrument

A twenty-five-question interview instrument was developed specifically for this study. Topics to be included and the wording of questions were determined in conjunction with a local advisory board from the tribe. Collaboration with the local tribe both assured that questions were asked in a way that was meaningful to tribal members and provided the tribe with information in which they were interested. The interview was approved by both tribal and university institutional review boards. Thirteen of the questions were asked of all participants; the remaining twelve questions were asked only of participants with a family member diagnosed with a disability. A copy of the interview questions can be found in the appendix to this article. The interview was administered by one of four tribal members who had received extensive training by university research staff for this project. Interviews were conducted in participants' homes. Interviewers took as much time as needed to complete the interview but did not record the length of time of the interview. The interviews consisted primarily of open-ended questions that do not lend themselves to measures of

Table 1
Sample Demographics

	Household with Member with Disability (N=59)	Household without Member with Disability (N=92)	All Households (N=151)
Mean number of people in household	3.5 (1.5)	3.1 (1.4)	3.3 (1.4)
Percent with children under 18	73 (.5)	72 (.5)	72 (.5)
Head of household occupation (%)			
Industry, unskilled labor	10.7	33.7	24.6
Skilled labor	17.9	23.3	21.1
Service industry, education, clerical	3.6	12.8	9.2
Administration	3.6	3.5	3.5
Self-employed	1.8	4.7	3.5
Health care	1.8	2.3	2.1
Unemployed	14.3	15.1	14.8
On public assistance	32.0	3.4	14.8
Retired	14.3	1.2	6.3
Monthly income (%)			
Less than \$500	32.2	22.7	26.5
\$500-\$999	30.5	8.0	17.0
\$1000-\$1499	18.6	33.0	27.2
\$1500-\$1999	5.1	18.2	12.9
\$2000 or more	13.6	18.2	16.3
Median monthly income	\$500-\$999	\$1000-\$1499	\$1000-\$1499

Note: Standard deviations in parentheses

validity and reliability. The involvement of local tribal members in the interview development and pretesting of the interview with members of the tribe helped to assure that the questions were clear and would elicit answers.

Analyses

Responses to open-ended questions were coded by research staff under the supervision of the principal investigator. A random sample of responses from

each open-ended question was read by research staff to develop initial categories of responses, using an inductive approach. These categories were discussed with and revised by the principal investigator. As the codes were applied to the full set of responses for that question, additions were made to account for ideas not encountered in the subsample. Coders were required to achieve 85 percent reliability with the primary coder before coding on their own. Throughout the coding process, the primary coder recoded a random set of interviews coded by other coders to ensure that reliability remained high.

Quantitative data from the interviews were analyzed using SPSS (Statistical Package for Social Scientists), version 12. This paper presents descriptive data about the tribe's attitudes toward and experience with members with disability. Comparisons between subgroups are based on chi square and students' *t* tests, using an alpha level of .05. Note that more than one answer was accepted for many of the open-ended questions; therefore, the percentage of respondents totals more than one hundred for many questions.

RESULTS

Experience with Disability

All interviewees were asked to give their definition of disability. Nearly two-thirds (63.3 percent) of the interviewees said that disability meant that a person could not do things that other people could do. Not being able to work was part of the definition of disability for 45.3 percent of the interviewees. Nearly as many people (43.3 percent) cited mobility impairment, other physical problem, or chronic illness as part of their definition of disability. Less than a fifth (18.7 percent) mentioned mental health problems or mental retardation as part of their definition of disability. There were no significant differences in the definitions of disability between families that had a member with a disability and those that did not. (See Table 2 for actual percentages and statistical test results.)

Table 2
Definitions of Disability by Family Disability Status

Definition	Member with disability N (%)	No members with disability N (%)	χ^2	<i>p</i>
Physical problems	20 (33.9%)	45 (49.5%)	3.526	.060
Mental problems	7 (11.9%)	21 (23.1%)	2.964	.085
Inability to work	24 (40.7%)	40 (47.3%)	0.626	.429
Needs help with everyday things	39 (66.1%)	55 (60.4%)	0.490	.484

Disability researchers have found that a focus on functional limitations is one of the most commonly accepted meanings of disability in popular understanding. Although 19 percent of the interviewees mentioned mental problems in their definition of disability, the main focus was on physical problems and inability to work. Examples of the definitions of disability offered by participants in this study include:

- People who cannot work or do things for themselves without having to depend on other people or things like wheelchairs.
- A disability is a sickness or handicap that stops you from doing things you could do long ago.
- Something is wrong with you when you can't take care of yourself. It could be mental or physical and when you can't function on normal things.
- People who cannot work and have to depend on others.

Fifty-nine (39.1 percent) households reported that a member of their family had been identified as having a disability. The meaning of the term *disability* was left to the respondent. Although most (80 percent) families with a member with a disability had only one such member, 17 percent had two members with a disability and 3 percent had three members with a disability. There was a wide range of disabilities reported, with the most common being developmental delay (17.8 percent), orthopedic (16.4 percent), respiratory (15.1 percent), neurological (12.3 percent), cardiovascular (9.6 percent), Marinesco-Sjögren Syndrome (6.8 percent), Mental illness (6.8 percent), Sensory (5.5 percent), Cancer (2.7 percent), Metabolic disorder (2.7 percent), and Other (4.1 percent). (See fig. 1.)

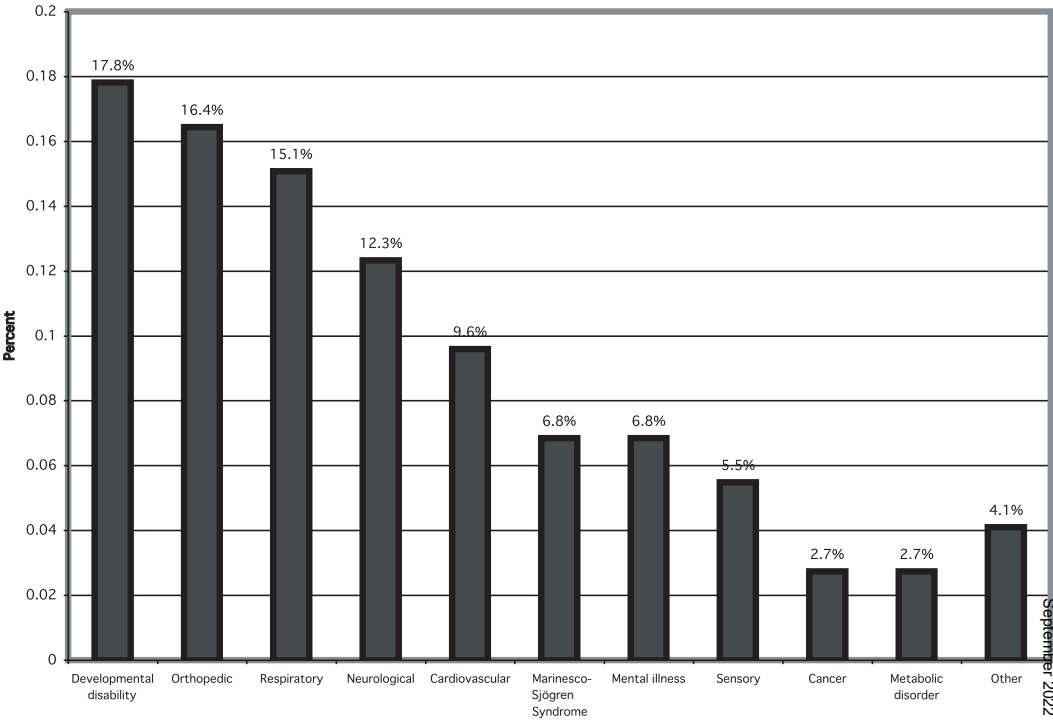


FIGURE 1. Distribution of disability types in families.

In this sample the onset of most of the disabilities was relatively early in life. Nearly a quarter (24.7 percent) of those identified as having a disability were born with it or had the onset in the first year of life. Nearly half of all those with disabilities had the onset by age five, three-quarters had onset of a disability by age twenty-one, and 90 percent of those with disabilities had the onset by age forty-five. Comparable national data are not available.

In light of the age of onset, it is not surprising that interviewees reported that in 24 percent of those identified as having a disability, the cause was a birth defect or problems during pregnancy or birth. Another 16 percent of disabilities among family members were attributed to genetics. Nearly 19 percent of the disabilities were attributed to an injury or accident. (See fig. 2 for all causes reported.)

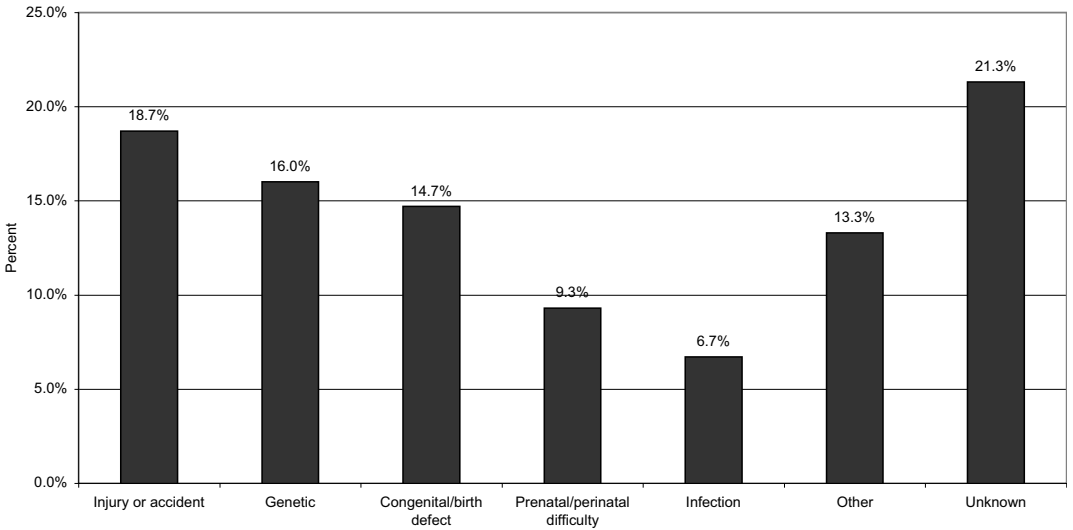


FIGURE 2. Reported cause of family member's disability.

Interviewees were also asked if they believed there were causes of the disability that were different than what the doctor said, for example, that children with disabilities are sent to teach lessons to their families or that arguing during pregnancy caused the disability. Nearly two-thirds (65 percent) of the interviewees said they did not believe in such nonmedical causes of disability. Another 16 percent said that they thought the cause was genetic. The remaining responses included accidents or injury (7 percent), religious reasons (5 percent), stress (5 percent), and disability considered as a natural part of life (2 percent).

Impact of Disability

Families with members with disabilities were asked a series of questions about the impact of the disability on the family, beginning with, "What kinds of

things do you or your family members wish you could do but cannot because of the disability?" The two responses most frequently cited were being able to work (mentioned by 28.6 percent of interviewees) and participate in sports or other physical activities (mentioned by 26.8 percent of interviewees). Not being able to go out or spend time with family and friends (social activities) was missed by 14.3 percent of families. Nearly 11 percent of the families indicated there was nothing that they could not do because of the disability.

When asked, "How has your family had to change the way you do things because of the disability?" more than a quarter of the interviewees said the person with disabilities could not do things such as work or engage in physical activities. Twenty percent mentioned making adaptations, including not being able to smoke in the house, making the house accessible for a wheelchair, and learning to use a cane. Nearly 15 percent said they had to make no changes in the way they did things.

The final question in this series asked, "How has disability changed your life or your family's life in how you feel about things or how you cope with difficulties?" The most frequent response, given by over a third of the interviewees (35.3 percent), was learning about the disability and how to adapt to it. The next most common response (13.7 percent) was that the disability had not resulted in any changes in how they felt or coped with difficulties.

Need for Equipment and Services

We anticipated that poverty and isolation would present difficulties in meeting the needs of members with disabilities. In fact, the effects of cultural heritage, poverty, and isolation intertwine in this sample. For example, the isolated living conditions and poverty of this tribe for much of the nineteenth and twentieth centuries resulted in a reliance on herbal and folk remedies for medical care.¹⁹ Some of the respondents still use these traditional remedies. One respondent reported: "I use a lot of yellow root; you boil it and put it in your bath water. My aunt taught me that for muscles." The maintenance of cultural practices related to health and disease can be especially comforting and appears to have some practical benefit for certain people. In addition to providing a connection to other generations and family members, the use of traditional medicine addresses more directly the functional aspect of disability rather than the specific diagnosis. The most commonly mentioned effects of disability, however, were not being able to work or participate in physical activities.

Adaptive equipment and devices mediate the impact of disability for many Americans. About a third (30 percent) of the fifty-nine households with members with disabilities indicated that the person with the disability used some kind of adaptive equipment. Another third reported a need for some type of equipment. The most common type of device used was something to do with physical mobility. Fifty percent of those who used equipment used a cane, crutches, brace, wheelchair, or other device to aid in mobility. Table 3 displays the types of equipment used by family members with disabilities and the unmet equipment needs. Both equipment use and needs reflect the types of disabilities reported.

Table 3
Households Reporting Equipment Use or Need for Person with Disabilities

	Equipment used (N=18)		Equipment needed (N=17)	
	N	%	N	%
Orthopedic device	9	50.0	5	28.0
Respiratory aid	5	27.8	4	24.0
Hearing aid	2	11.1	4	24.0
Structural changes to home	0	0	3	18.0
Basic supplies	2	11.1	1	6.0

A large proportion of families with members who have disabilities (61 percent) reported that the person in their household with disabilities used traditional medicines or healing methods. When asked to describe what methods were used, 44.4 percent responded that they prayed, and 20.4 percent said that they used herbs, plants, teas, or other home remedies. There were no differences by type of disability in use of traditional remedies, but it should be remembered that the number for each disability group is quite small and may have precluded finding any differences.

All interviewees, whether or not their family had a member with a disability, were asked what the tribe could do to be more helpful to families with a member with disabilities (see fig. 3). The leading response, given by one-third of respondents, was help with transportation to get treatment and services. A quarter said that the tribe should provide home health care and home visits to those with disabilities. Both these answers reflect the difficulty of accessing services in a rural community. The relative poverty of the population is reflected both in the high percentage who mentioned transportation needs and in the fact that nearly one-fifth (18.9 percent) said there was a need for financial help with medical care.

Overwhelmingly, the mother of the person with the disability was said to be the one most helpful to that person. The mother was cited by 27.3 percent—more than twice as often as any other person. Not surprisingly, the person with the disability was a child in 80 percent of the households who said that the mother was the most helpful person. The entire family was said to be the most helpful by 12.7 percent of interviewees. Mother, wife, and daughter were ranked in the top four most helpful family members, followed by husband and son.

Marinesco-Sjögren Syndrome

A rare genetic disorder, Marinesco-Sjögren syndrome (MSS) has been documented among members of this southeastern tribe. In this sample, five members of the interviewed families had this disorder. All interviewees in this study were asked if they knew anyone with MSS. Nearly one-fifth (19 percent) knew someone affected with MSS. This is undoubtedly a much higher

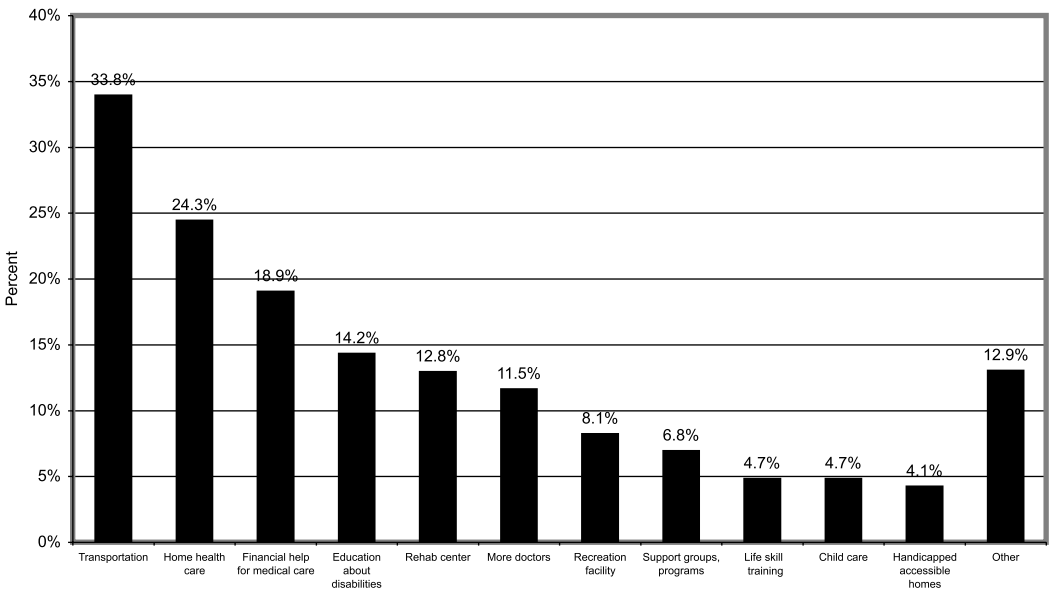


FIGURE 3. *Reported ways in which tribe could help those with disabilities.*

percentage than would know someone with the syndrome among the general public. Only about one hundred cases have been diagnosed worldwide.²⁰ This familiarity with MSS underscores the relatively high prevalence among this tribe. In fact, tribal members refer to the syndrome with a common surname in the tribe, indicating recognition that this condition is hereditary.

Those who had heard of MSS were asked if they knew of any “success” stories of a person with MSS (that is, any achievement or obstacle overcome, or any positive experience of a family with a child with the syndrome). Of the twenty-nine people who were familiar with the syndrome, nine (31 percent) gave a success story. Seven of the nine mentioned going to school or graduating from high school as a success for these individuals. Four of the nine mentioned that the person could do something that the doctor said he or she would not be able to do. One parent, whose answer had both themes, said: “One of my children’s success stories is that she went through school and graduated. And the biggest of all is that the doctor said she would not live at all. My son was not supposed to live over twenty-four hours and now he is fifty years old.” Six interviewees reported success stories for children with disabilities other than MSS. These six stories had the same two themes—doing things the doctors said they would never do and going to school and graduating in spite of the disability. For example, a parent reported that, although it was not MSS, when her son was born, she was told he would never walk, talk, see, or hear. Nevertheless, he does these things and is in school.

Tradition and Culture

Culture and tradition play a role in how people define disability, as well as how they deal with members with disabilities. Most American Indian languages do not even have a word for “disability.”²¹ Indian culture traditionally allows each person to find a meaningful role in the tribe according to his or her own abilities. For example, in the course of this research project, one family related how medical professionals were intent on discussing the intellectual limitations their child would face when the family’s main concern was whether the child would be able to help feed the chickens. Being able to help with tasks related to raising the family’s chickens was seen as a very valuable role and one that would allow the child to be a contributing member of the community.

In order to understand the cultural heritage in which attitudes about disability play out in this tribe, participants were asked if their family had passed down traditional stories or practices that they would be willing to share with the project. Most relevant to attitudes about disability were family traditions concerning the use of herbs and home remedies for medicinal purposes, which were reported by 59.5 percent of the families. Commonly used were sassafras and pine-straw teas for various illnesses, including colds; clay and vinegar applied to sprains; tobacco for insect stings; and turpentine for worms and to put on wounds or sprains. These were not treatments for disability or disease but rather treatments for symptoms. The lack of access to medical providers contributes to the continuing use of many of these remedies today.

Cultural elements that are metaphysical in nature were also mentioned in response to questions about dealing with a family member with disabilities. In this sample the Baptist religion is the predominant spiritual affiliation mentioned. More than two-fifths of the respondents in this study rely on prayer as a way to deal with disability. Many report having prayers said at their church for the person with disabilities. This practice is in concert with the tribal values that emphasize community. Other families specifically mentioned that they were Christian and relied on prayer to help them in all manner of life situations, including disability. Prayer is not limited to Christian practice, however, and is also used by those who attempt to merge non-Native religious beliefs and traditional spiritual practices.

Medical care and advice are also sought and valued. Forty percent of those with a family member with a disability said they used only medicines prescribed by the doctor, avoiding even over-the-counter medicines. In fact, the greatest perceived need of families with members with disabilities is access to medical care. Transportation topped the list of services that respondents would like to see the tribe provide, followed by requests for home health care, financial assistance for medical services, and information about various disabilities. Yet there was a strong undercurrent of skepticism about the accuracy of medical prognoses. Story after story told of doctors saying a child would never be able to do something, such as walk or talk or attend school. Nevertheless, that child did learn to walk or talk or go to school. In this respect, the experiences of these families with medical professionals are similar to those found among families of children with disabilities around the

world.²² The words of several of the respondents in this study clearly demonstrate that they retained hope in spite of their medical prognoses:

The doctor said my son would be in a wheelchair, but he's not.

I have a friend's child that was born with a disability. The doctors told her that her baby would never walk or anything. Now he is going to school and getting around extremely well—a little slow in speech, other than that is moving very good.

The doctor said he would never read or write, but he can now. Not as good as he should be, but he can. It is something he kept trying to do and the school really helped him a lot.

DISCUSSION

The goal of this study was to gather information on the cultural meaning of and experience with disability among members of a southeastern American Indian tribe. A structured interview instrument was developed for this project in conjunction with an advisory board of tribal members. Because of the paucity of research documenting the experience of American Indian populations and the diversity of those populations, the current study was designed to be descriptive. The study focused on the extent and type of disability among tribal members, tribal members' definitions of disability, families' accommodations to a member with disabilities, and resources needed for members with disabilities.

Because many tribal languages lack a word for disability and studies of other tribes have suggested that an attitude of acceptance and inclusion predominates, we hypothesized that tribal members would describe disability differently than it is defined by the non-Native US population. This did not turn out to be the case. Most of the respondents defined disability from a functional perspective—not being able to work or do other things that most people can do. The focus on physical problems may be a reflection of the fact that physical difficulties are often more visible than mental ones. Physical problems accounted for a relatively large percentage of disabilities in these families. In light of this focus on physical impairment, it is interesting that—when relating success stories of people with disabilities—going to or completing school was often cited as an accomplishment, in addition to overcoming physical mobility problems. The emphasis on physical impairments may also be a result of the stigma that is attached to mental disorders, particularly mental health problems for which services are few to nonexistent in poor, rural communities.

Family members—particularly mothers—were overwhelmingly the ones mentioned as most helpful. It should be noted that many American Indians define *family* broadly to include extended family members and close friends. The lack of transportation and access to services could also explain why family

members are seen as the most helpful individuals to those with disabilities. That is not to say that traditional medical services are not sought. They are, but the diagnoses are seen as potentially inaccurate, as evidenced by reports of children who did much better than doctors predicted. These stories, while demonstrating some skepticism toward medical prognoses, may also be explained by the difficulty of predicting outcomes at an early age and by the perseverance and resilience of the individuals and their families.

There is evidence of confidence in the mainstream health system or at least an expectation that it will be used. It is likely that for the most part diagnosis, treatment, and follow-up are perceived to be beneficial. It is also the case, especially with children, that if the health system is not used, parents can be found to be negligent by the state. Both dynamics appear present in this community.

Although providing much information about this southeastern tribe, the study has limitations. Most importantly, the findings pertain only to the members of this one, somewhat unique tribe and cannot be generalized to members of other American Indian tribes. The study was based on a convenience sample, limiting the ability to generalize even to all members of the tribe. We had hypothesized that the disability rate among the tribe would be higher than the national rate. Our assumption about disability rate was not borne out in this tribe, but it is possible that this reflects a greater reluctance among families of those with disabilities to participate, potentially biasing the results.

Furthermore, at the request of the tribe, only limited demographic information was collected on participants. Information that might have been useful in interpreting some of the results, such as the type and extent of medical insurance coverage, is therefore not available. The focus of this study was on attitudes and perceptions—information best gathered by self-report. Self-report is subject to a variety of error sources, primarily centered on respondent interpretation of the definition of disability.

Much remains to be learned, but the strength of this community despite much poverty and isolation is evident. The resilience and sense of community of the tribe as a people was summed up by the following words of one respondent: “My family always practiced Indian tradition. There have been many of these cultural traditions passed down from generation to generation. In doing so, it assures me that my child will be raised to believe as I was always taught, and pass these traditions on down to her children. The Indian community has always been an area of a small group of people, which by choice, the majority remains today. In some sense this type of living closely together, sharing and caring for each other, creates a tribe. Our Indian community—our people are religious and we trust in God, the Great Spirit.”

Similar research with other tribes will help clarify differences and similarities among tribal views on disability. Information on attitudes toward people with disabilities and toward their medical care is important for structuring services that are culturally appropriate.

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APPENDIX: DISABILITY INTERVIEW

We are concerned about needs that families have when they have a family member who is disabled. There are high rates of disability in most Indian communities and our tribe also seems to have many people with disabilities. I am one of 3 people from the tribal headquarters asking questions about the kinds of disability people have and the ways we can help people with disabilities and their families. As you know, everything you say to us is confidential. There are no right or wrong answers. Your help in answering these questions can provide important information to improve services.

First we need some general information about your household:

1. What is the occupation(s) for the head of household in your family?
2. How many hours a week does he or she work, on the average?
3. What is your monthly income (select one)?

<input type="checkbox"/> \$0-499	<input type="checkbox"/> \$1000-1499		
<input type="checkbox"/> \$500-999	<input type="checkbox"/> \$1500-1999	<input type="checkbox"/> >\$2,000	
4. How many people live in your household?
5. How old is each person in your household?
6. We have one question about things that people do to stay as healthy as possible. How many people in your family can be described by the following health behaviors:

<input type="checkbox"/> smoker
<input type="checkbox"/> exercises vigorously at least 3 x week
<input type="checkbox"/> overweight
<input type="checkbox"/> eats fresh fruit or vegetables daily
7. People think about disability in different ways. What do you think a disability is? (you may give examples if you want)
8. Has anyone (for example at the health clinic or school) ever said that someone in your household had a disability?
IF THE ANSWER IF NO, SKIP TO QUESTION # 20
9. What is the age and type of disability for each person in your household?

Age of family member	Type of disability
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10. How old was each person when the disability was first discovered?
11. What was the cause of disability for each person in your household?
12. Many people believe that there are causes for disability other than what the doctors and nurses say about disability. For example, some people believe that children with disabilities are sent to teach important lessons to their families and communities or that a woman doing certain things (like arguing or eating strawberries) when she is pregnant causes certain kinds of disabilities.

What, if any, are the non-medical causes for disability your family member(s) has?

13. What kinds of things do you or your family members wish you could do but cannot because of the disability?

14. How has your family had to change the way you do things because of disability?

15. How has disability changed your life or your family's life (in how you feel about things or how you cope with difficulties)?

16. Does the person in your family with a disability use or need any kind of adaptive equipment like a wheelchair or a hearing aid? If yes, what kind of equipment is used?

17. What kind of equipment, etc., is needed that you don't have?

18. Who is the most helpful to the person in your family with a disability and what does that person do?

19. Does the person in your family who has a disability use any traditional healing methods and, if yes, would you describe what they are? (things like over the counter medicine, medicine or ceremonies from a medicine man, prayers, etc.) Please give some detail so we can understand what kinds of things you do to help your family.

20. Alcohol and drugs are a problem for many families on the reservation. How has alcohol or drug abuse affected your family?

21. How do you think alcohol affects people with disabilities?

22. Marinesco syndrome affects several families in our tribe. Have you known anyone with this disability and what kinds of problems did that person(s) experience?

23. Can you tell us about any "success" stories of a person with Marinesco syndrome? That is, some achievement or obstacle an individual has overcome or a family that has in some way had positive experience as a result of having a child with Marinesco syndrome.

24. What do you think the tribe could do to be more helpful to families who have a member with a disability?

25. Sometimes families have stories about their past. These stories can be about where the family came from, experiences that great-great-grandparents had, or about family traditions. Many of these stories tell about ancient Indian ways. Is there any story like this in your family that you would share with us?