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ABSTRACT

This project focused on the role of the family in providing support to a relative with a disability in two American Indian cultures, the Eastern Band of Cherokee Indians and the Mississippi Band of Choctaw Indians. A review of the literature notes the documented importance of involving family in the rehabilitation process. Ten families in each location were interviewed. In addition, five focus group interviews were held, one in each location for family members, one for persons with disabilities, and one for service providers. Content analysis was performed on transcripts, focusing on: structures of family support systems; description of, adjustment to, and impact of a disability; issues of access, assistance, and acceptance; family commitment and future concerns; and family needs, consumer needs, and vocational rehabilitation. Analysis showed that, though families often acknowledge extended family members as part of their support network, there frequently existed a lack of involvement of extended family and even immediate family in the daily lives of persons with disabilities. Analysis also addressed issues of social support, respite care, role validation, responsiveness of professionals, and transition. Recommendations are offered for future research, for rehabilitation professionals, and for participating Indian communities. (Contains 17 references.) (DB)

American Indian Family Support Systems and Implications for the Rehabilitation Process: The Eastern Band of Cherokee Indians and the Mississippi Band of Choctaw Indians

Executive Summary

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American Indian Family Support Systems and Implications for the Rehabilitation Process: The Eastern Band of Cherokee Indians and the Mississippi Band of Choctaw Indians

This *Executive Summary* consists of: (a) a brief review of the existing information on the utilization of families in the rehabilitation process; (b) a summary of research methods used in the study; (c) a summary of the results of the study; and (d) recommendations for future research, for participating Indian communities, and for rehabilitation professionals. The *Final Report* of this study is available from the American Indian Rehabilitation Research and Training Center and describes the study in detail, including extensive quotes from the qualitative data.

The purpose of this research was to better understand the informal support systems of Native peoples with disabilities, in particular, the role of the family. The literature indicated that families could be better utilized by rehabilitation professionals to facilitate the rehabilitation process and may contribute to successful rehabilitation outcomes. Typically, however, the rehabilitation literature does not take into account ethnicity, and the stronger role that the family can have in some minority cultures. Where ethnicity is mentioned, sweeping generalizations are often made, with little emphasis on variations within and between specific cultures. This project focused on the role of the family in providing support to a relative with a disability in two American Indian cultures, the Eastern Band of Cherokee Indians, with tribal headquarters in Cherokee, North Carolina and the Mississippi Band of Choctaw Indians, with tribal headquarters located in Pearl River, Mississippi.

Research Questions

Researchers from the American Indian Rehabilitation Research and Training Center (AIRRTC) addressed the following research questions:

1. What is the structure of the family support system for Native peoples with disabilities, in particular, the Cherokee and the Choctaw? How do they compare to one another?
2. What is the process by which these families provide support to the individual who has a disability?

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REVIEW OF THE LITERATURE

3. To what extent do vocational rehabilitation counselors utilize the family as a resource in the targeted communities? What specific implications does family support have for ensuring the success of the rehabilitation process with individuals from these cultures?

The importance of involving the family in the rehabilitation process has been well documented (see e.g., Dell Orto, 1984; Herbert, 1989; "Families," 1987; Marshall, 1989; Marshall, Martin, & Johnson, 1990; Power & Dell Orto, 1980; Sutton, 1985). Dell Orto (1984) specifically pointed to the need for vocational rehabilitation counselors to work with families and to understand the importance of family to the client. English (1990) has discussed how family support can contribute to success in the transition of a person with a disability from school to work. For example, he noted that family members may assume many potential roles in assisting their relative with a disability. He described various caretaking activities which included being the provider of essential support (food, shelter, love), as well as skill trainer, teacher, counselor, advocate, policy maker, and case manager. In addition, family members can play important roles in the teaching of coping, communication, and work skills (Dunst, Trivette, & Cross, 1986). Researchers (e.g., Blalock, 1988; Fewell & Vadasy, 1986) have discussed how family support can be multifaceted and sustained across the lifespan of the person with a disability, in contrast to most service providers who offer focused attention on a time-limited basis. As family members can represent permanent support systems for the person with a disability, utilization of these natural networks may facilitate the work of the rehabilitation counselor.

State rehabilitation service agencies are authorized to include families in the rehabilitation process, and to provide services to the family members of the client through the Rehabilitation Act of 1973 (Public Law 93-112). Under the section entitled, "Scope of Vocational Rehabilitation Services," Section 103(a)(3), in referring to "handicapped individuals," the legislation provides for "services to the families of such individuals as are necessary to the adjustment or rehabilitation of such individuals." Recent federal regulations confirm that "services to members of an individual with handicaps's [sic] family . . ." can be provided by the rehabilitation counselor [34 CFR Ch. III (7-1-90 Edition, p. 287)]. To effectively work with families, rehabilitation professionals must be sensitive to cultural differences in the definition of family and in the function of family members. In regard to helping professionals who work with American Indians, Newlon and Arciniega (1983) have stated that "a generic understanding of Indian cultures is essential. Of equal importance is learning about

the differences that exist between each member, family, and tribe" (p. 6). These researchers concluded that "counseling will have to assume a contextual frame of reference compatible with the view of the Indian individual and family" (p. 6). Herring (1989) identified qualities of the American Indian family structure including: participation of the families of both spouses in family life, flexibility of roles, value given to extended family relationships, respect for women, the importance of child rearing in values transmission, and an emphasis on symbolic leadership of grandparents and elders. Attneave (1982) has encouraged therapists to optimistically seek "encounters with the strengths of Indian families" and to enjoy discovering ways in which they can work together (p. 82).

METHODOLOGY

The primary participants in this research were the families of American Indians with disabilities from two tribal nations located in Federal Region IV (Alabama, Florida, Georgia, Kentucky, Mississippi, North Carolina, South Carolina, Tennessee), that is, the Eastern Band of Cherokee Indians and the Mississippi Band of Choctaw Indians. Including more than one population of Native people in the study enabled researchers to explore any unique characteristics of family support systems within the two groups and prevent overgeneralization.

Project Advisory Committee

A Project Advisory Committee (PAC), comprised of individuals from both communities, assisted the researchers in selecting culturally sensitive and culturally appropriate research procedures. PAC members were approved by their respective tribal councils and included people with disabilities, their family members, service providers, and tribal council members. The PAC agreed on the importance of conducting a qualitative study--collecting data which consisted of people's stories, their ideas, worries, and thoughts. PAC members expressed the belief that a qualitative study would involve a methodology comfortable for research participants and would produce results of interest to Indian people. The principal investigator (PI) met with PAC members in each community at least twice prior to data collection. PAC members assisted the PI in developing questions for the family interview and in selecting items from an existing survey instrument which were modified for use in this research (North American Indian Women's Association, 1978). The PAC reviewed and approved all materials and procedures used in the research.

Family Interviews

Individual family interviews included use of the eco-map (see, e.g. Goodluck, 1991). The person in the family who had a disability was included in the interview if he or she desired to participate. The study focused on understanding the needs of

Focus Group Interviews

families who had a relative with a disability age 15 or older. Ten families were interviewed in each location; however, consumers whose family members were not interviewed, as well as service providers from the local communities, also contributed to the results of this study. The family interviews were conducted using a semi-structured format, with standard questions; however, the PI also used a journalist style, asking follow-up questions as appropriate. The length of interviews varied, with an approximate range of 45 minutes to 2 hours. In most instances, two members of the research team, the PI and the on-site research coordinator, were present during family interviews. The data were collected throughout July and August 1992.

Five focus group interviews were held as a part of this study. Two focus groups in each community were held separately for: (a) family members and (b) consumers (persons with disabilities). Members of the PAC committee in Cherokee requested a third focus group be held with service providers in order to enhance networking efforts. Generally, the focus group meetings were conducted in English; however much of the Choctaw family focus group meeting was conducted in Choctaw, or with concurrent Choctaw translation.

Family focus group interviews were held after the individual family interviews. The primary purpose of the family focus group interviews was to give participants information about what had been learned through the individual family interviews, and to ask family members to build on that knowledge. Family members were also asked to make recommendations as to any action which needed to be taken to meet their needs.

Initially, it was expected that only the "key informant," that is, the "primary caregiver," would participate in the family focus group interview. However, it quickly became clear once the interviewing process began that members of these families did not "divide" themselves into the categories of "primary caregiver" versus "consumer," or "primary caregiver" versus "other caregiver." Thus the practice evolved during the interviewing process of inviting all family members to attend—families appeared to be more comfortable with an inclusive approach versus an exclusive approach—with little regard given to research literature citing appropriate group size and concerns about group dynamics. Seven (7) of the 10 Cherokee families (12 total participants) and 6 of the 10 Choctaw families (8 total participants) attended the family focus group interviews.

On-site Research Coordinators

Native people were hired as on-site research coordinators in both communities. Duties of the on-site research coordinators

Data Management and Preparation for Analysis

included: (a) meeting with local PAC members to identify families and to finalize the questions to be asked of family members; (b) scheduling family interviews and focus group interviews; (c) informing families of the research process; (d) conducting interviews and serving as a translator when necessary; (e) securing meeting space as well as additional local support staff, and (f) coordinating their project-related activities with the PI. In addition to carrying out the above duties, the on-site research coordinators contributed to the success of the project through their familiarity with the customs, cultures, and environments of the local communities.

All interviews were tape-recorded and transcribed, with the qualitative data stored on computer disks in a format required by *The Ethnograph* (Seidel, Kjolseth, & Seymour, 1988). *The Ethnograph* was used to assist the researchers in the mechanical tasks of content analysis. Data from the interviews were subjected to content analysis in the areas of: structure of family support systems; description of, adjustment to, and impact of disability; issues of access, assistance and acceptance; family commitment and future concerns; family needs, consumer needs, and vocational rehabilitation.

RESULTS

The 20 family interviews and 5 focus groups resulted in 899 double-spaced pages of qualitative data. [Space limitations in this *Executive Summary* prohibit extensive reporting of the families' stories. However, their concerns are detailed in their own words in the *Final Report* of this research.] Comparisons between the needs of the Choctaw families and the Cherokee families must take into consideration both the age differences between the consumers and the different disabilities represented. The mean age of Choctaw consumers (29) was considerably lower than that of the Cherokee consumers (44), and would suggest that any differences in the support systems or needs of these families could be attributed to the age difference alone. For example, Choctaw families more often than Cherokee families identified the services of special education as a part of their support system; indeed, the majority of Choctaw family members with disabilities were under the age of 21, and still eligible for special education. This was not the case for any of the Cherokee family members with disabilities.

Structures of Family Support

Of the 10 Choctaw families interviewed, 5 represented nuclear family arrangements with two parents, or guardians, and children. Of these 5 families, all were made up of parents ranging in ages from 27 to 42 with children under the age of 21. In addition, 4 of the 10 families consisted of at least three generations—typically a combination of grandparents, parents and grandchildren. In 3 of the families interviewed, the person with a

disability had children and/or grandchildren. In 6 families, the person with a disability was under the age of 21. Further, 5 of the families in the Choctaw sample consisted of women who were primary figures in their household. Over half of the interviewed families reported that their relative with a disability experienced more than one disabling condition. Based on an analysis of the compositions of the interviewed families, a typical Choctaw family is portrayed in Figure 1 within the context of its support network.

The interviewed Cherokee families also typically described their families using a nuclear family model; 7 of the 10 families indicated such an arrangement. Only one of these seven nuclear families consisted of younger parents in their 30s and children under the age of 21. Six of the nuclear families were made up of adults ranging in age from 22 to 53, who lived with parents in their 50s, 60s, and 70s. Three of the Cherokee families had at least three generations represented, with grandparents and grandchildren included in the family. In three of the interviewed families, the person with a disability had children and/or grandchildren of their own. Finally, 3 families in the Cherokee sample had a woman as head of household, with her spouse being deceased. One family consisted of a male head of household with his spouse being deceased. A typical interviewed Cherokee family is portrayed in Figure 2.

Family Narratives

A number of issues emerged from the interviews with family members, consumers, and service providers in the two study areas. These issues have been extensively described in the *Final Report*; several are presented here. For families who discussed adjustment to disability, adjustment ultimately meant acknowledging the disability and accepting its influence on their lives. Accepting the person with the disability never seemed to be an issue—it was a given. One parent noted:

Choctaw Family #6 (mother): And part of it is finally accepting. Accepting what he is like. And there's nothing else that you can do to change. I mean, you can try to provide physical therapy, and do as much as he can to make sure that he has access to everything. But it's coping and accepting the situation. And when you finally do that, things will fall into place. But that's the hurdle. Accepting it.

The need for both social support and formal support was echoed frequently by participants in the research:

Figure 1
Eco-map: Typical Supports of a Choctaw Family

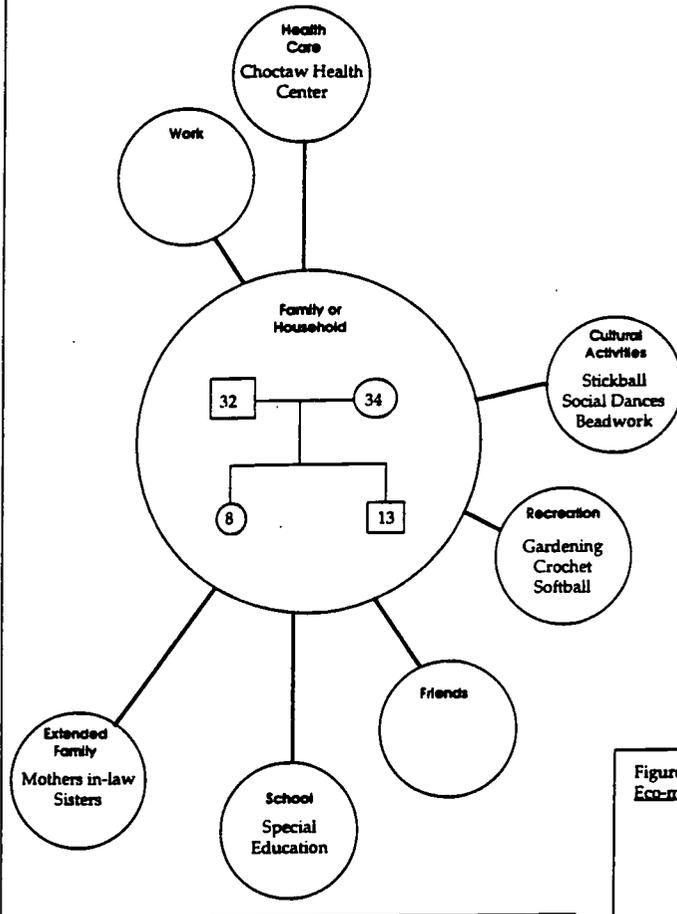
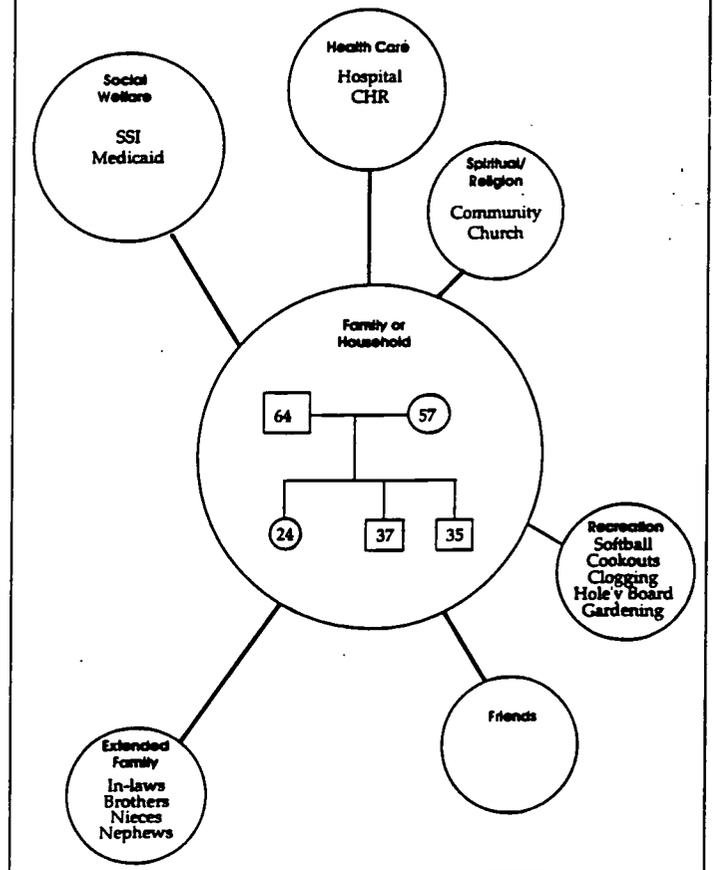


Figure 2
Eco-map: Typical Supports of Cherokee Family



Cherokee Family #1: I tell you. When I didn't have nobody to talk to... I've, I've got, I don't know, I felt awful. And when my parents moved up here I talked to my parents, my mother. She's a lot of help.

Among those concerns affecting families was access -- access within the home; access to and from the home; access to and from school or work; access to shopping, entertainment and social events; access to tribal offices. As one Choctaw participant noted:

Choctaw Family #3: She's got a small bedroom and there's no wheelchair can go in the bathroom, not at all.... And she needs her own private roll-in shower, or something like that.... If there was a fire, or something like that, there's no way we can get her out of here quick.

Family members described the varieties of care or assistance they provided for their relative with a disability. Often the discussion regarding assistance included statements acknowledging the abilities of the family member with a disability:

Choctaw Family #1: Well, the main thing is, cook [laughter]. [I] cook breakfast and supper and wash his clothes and have them ready, and that's it. Well, he dresses himself and everything, so, I guess just being here--just being his wife is mainly it now. 'Cause he handles himself pretty good; he does everything himself.

Many talked about the impact of the disability upon the family. For some, adjusting to the disability meant changing their lives:

Cherokee Family #8: It's changed our lives; I mean we, we're here 24 hours a day and he, he needs that care.... We can't go nowhere, we can't, you know, go to town or anything like that unless we know that somebody's here with him that will take care of him.

In spite of the difficulties, families talked about their level of commitment to relatives with disabilities:

Cherokee Family #1: You gonna' have to wanna' help them. And I believe any, anybody in the world, if they love the one they're taking care of, they're gonna' help them the best they can.

Families expressed their concerns and needs; however at times it was difficult for people to identify concerns beyond the needs of their family member or to think of themselves apart from their

relative. Many expressed concern about their ability to provide ongoing care for their relative as both they and their family members grew older:

Choctaw Family #7: The most difficult was dealing with her during the death of her father; I was wondering how in the world will I take care of her by myself....

Family members described satisfaction and occasional dissatisfaction with a wide variety of services available to them. In particular, they were asked to explain their understanding of services available through vocational rehabilitation. None of the 20 participating families was aware of the full range of services available to family members. In the words of one family:

Choctaw Family #1: To me, I don't know. I don't think they have a service for me--that it is just for only applied to the handicaps, you know. But I'm glad they can send him to school.

In terms of family needs, people reported needing more education, information, emotional support, assistance with in-home care, and respite care. For example:

Choctaw Family #10: Like maybe they would be able to find, if I need to go away, you know ... would somebody be there for that week, nights?

Cherokee Family #9: Somebody to stay with him and let us get away [crying]. He stays by himself [during the day]; he just can't stay at night.... Even if we just had somebody you could trust....

DISCUSSION

One result most striking to the PI was the amount of emotion expressed during interviews. A long list of complaints and concerns regarding service delivery did not emerge from the interviews, but emotion did. Approximately half of the families, both Cherokee and Choctaw, were affected emotionally by the questions asked during the interview. Some family members, for example, responded in tears when asked about the impact of the disability on their lives, others when asked about their future fears or concerns. These were not situations where a baby had just been born with a disability, for example, and people were immediately having to face a crisis situation. In most cases, these were situations where the disabling condition had existed for 15 to 20 years.

Family members as well as consumers expressed a need for **social support**—consumers on the Choctaw reservation wanted to meet and network with other people with disabilities; family members in Cherokee also wanted to network and share their experiences. Some families needed help, but did not seem to believe that help could be available. Access concerns related to health and safety also prevented socialization. Persons who attended the service provider focus group interview in Cherokee commented on the feelings of isolation expressed by family members and their need for support:

Rehabilitation Counselor: Well, it affects me. I guess it's just my natural inclination to think, where are their neighbors, why isn't the rest of the family coming and saying, "How are you? Can I help you?"

In both the Cherokee and Choctaw communities, it was evident that families worked hard to take care of their family member with a disability. In most cases, this work was done without complaint and without concern for personal relief from stress. The idea of **respite care** was foreign to some families, but clearly the need for some reprieve was consistently being expressed. Families agreed that various forms of respite care would be of benefit to them; however, such services would need to be very specialized and under the control of family members in order for them to be utilized.

In general, researchers were left with the impression that while families often acknowledged extended family members as being a part of their support network, there frequently existed a lack of involvement of extended family, and even, at times, immediate family, when it came to the daily lives of persons with disabilities. Such a situation, of course, requires individual family assessment, with human service and health care professionals being available to provide assistance as necessary. A blanket statement such as "Indian people can always count on family to help," would appear to be just as erroneous as any other over-generalization.

The stories of some families indicated that recognition, acceptance, appreciation, and utilization of the contributions of the family are needed by professionals involved in rehabilitation process. In one family where the husband with a disability readily acknowledged the **contributions of the spouse** in ensuring his adherence to medical treatment (She reminded him of medical appointments, reminded him when to take his medication, and drove him to his appointments), medical personal off-reservation did not acknowledge her role. Family members may need to have their **role validated and supported** by service providers who value

their contributions. While this woman knew what she wanted, and knew her role in supporting her husband, she was not confident she would carry out her plan to accompany her husband if met with opposition.

More responsiveness by professionals is also needed--responsiveness in the sense of assessing with family members, "Is this what you really need; is this what you really want?" In some cases, the lack of responsiveness of professionals might be countered with more education and training for American Indians with disabilities and their families--training which informs them that as consumers, they have the right to ask questions of physicians, rehabilitation counselors, and other health care and human service professionals.

On the Qualla Boundary, the interviewed families were involved in the support of their relatives with disabilities even if the person no longer lived in the family home. Families often mentioned the strengths or abilities of their relative with a disability. This was particularly noticeable to the PI, who as a rehabilitation professional, has always been committed to the rehabilitation philosophy of focusing on assets and strengths, yet failed to ask a question regarding abilities!

While very few complaints were heard, the comment, "It hasn't been easy," was made frequently. Parents, pleased with the services of the school system, were without supports once special education services were no longer available to their children as adults. The majority of families were not aware of the extensive range of vocational rehabilitation services, either for the person with a disability or for themselves as family members.

The issue of transition was more of a concern to the families interviewed on the Choctaw reservation--families with teenagers and young adults. While one family on the Choctaw reservation was considering out-of-home placement as an appropriate "independent living" alternative, the majority of families interviewed were content to have their young adult family member live at home. From the families interviewed in this research, for a young adult to live at home with his or her family is not a major burden for American Indian families, nor would the young adult's development be compromised. Clearly, if parents choose not to use an independent living facility, the situation may not call for family therapy, but recognition of cultural values by the rehabilitation professional.

CONCLUSIONS AND RECOMMENDATIONS

Recommendations for Future Research

While each of the participating Indian communities has different needs and different resources, they share a desire to have something "come out of" research. As one participant stated at the service provider focus group interview held in Cherokee, "People come in and do research projects and they tell us what they see; they do not tell us how to fix it. And so, we're looking for ways to fix it. We're looking for recommendations on ways to fix it" Researchers should be aware that while some communities can go forward with their planning based on the data provided in a research report, others may need technical assistance in order to benefit by having the data returned to them as a documentation of needs.

1. Investigate the interviewing styles of Native people versus "outside researchers." What styles are most effective and/or culturally appropriate with what interviewers (Indian versus non-Indian; male versus female) as regards obtaining the desired information?
2. Conduct interviewer training with Native interviewers/ translators. While initially it was thought that for interviews conducted in a Native language, the primary role of the on-site research coordinators would be to serve as translators, the decision was made that they should serve as interviewers in order to keep the interview to a reasonable amount of time. Interviewer training would enhance the uniformity of the interviewing process across interviewers—both Native and non-Native—should this be found to be desirable and/or culturally appropriate.
3. Budget sufficient fiscal resources to pay for not only translation but also for back-translation of interviews conducted in a Native language (if not spoken by the researcher). Having a second person verify the accuracy of the translation may be sufficient. Without such translation procedures, data verification is not possible.
4. Hire trained transcriptionists who are skilled in ethnographic transcription. If using a software program such as *The Ethnograph*, require that transcriptionists conform to the formatting requirements of the program.
5. Engage American Indians more fully in the research process. The Indian communities involved with this study actively participated in the research design through the PAC; however, community members can participate even further in research by identifying research questions of particular interest to individuals or to the community. Researchers should build into their budgets and work schedules the opportunity to return to participating

**Recommendations
for Rehabilitation
Professionals**

communities after the data have been analyzed. In this way, the researcher can become known for not only "collecting data" but also for "returning data." Ideas for further research can be exchanged between the researchers and the community and action plans developed.

6. Be prepared, upon request, to provide technical assistance to the participating community--to meet with community leaders and family members, look at the data, and make specific recommendations on how to best resolve community concerns identified through the research effort.

7. Advocate that ethical outcomes be considered just as important as statistically significant findings.

1. Provide orientation with information about rehabilitation services for families of new clients; provide orientation in Native language upon request and when necessary to ensure communication.

2. Include an assessment of family needs, as well as family strengths, with each client assessment. Family needs, for example, might include financial assistance, transportation, or advocacy with a social service agency.

3. Identify the family's expectations for their relative's rehabilitation, as well as their understanding of the counselor's role and their roles. Ensure that specific information about the particular disability, secondary health effects, and potential progression of the disabling condition, has been given to the family members as well as the person with a disability.

4. Include appropriate family members in goal-setting and progress reviews.

5. When necessary for a client to achieve his or her rehabilitation goals, meet the family's needs. For example, provide family counseling and guidance, either directly or as a purchased service. Remember that the person with a disability may function as part of a larger social unit, not in isolation.

6. Consider sponsoring a family support group where families can coach each other in positive reappraisal, or focusing on their relatives' abilities, as well as share similar experiences in coping with disabling conditions.

Recommendations
for Participating
Indian
Communities

7. Consider sponsoring a family action group, where families can work together to: (a) develop vocational and independent living opportunities on the reservation, (b) make recommendations to tribal councils regarding policies that would meet the needs of tribal members with disabilities, and (c) keep communication lines open regarding available services and funding opportunities.

8. Advocate for a system to be developed, such as a new status code, for documentation of the services provided to families. In this way, the role family members play in the rehabilitation process can be better understood, as well as their contributions to successful rehabilitation outcomes.

1. Identify a spokesperson/advocate/ombudsperson for disability issues on the reservation. One function of this person would be to inform family and other consumer groups of relevant tribal funds which might be available for a short time only.

2. Form a support group of families and consumers. This group, for example, could share information regarding their experiences with service delivery, such as information regarding the quality of services of in-home respite care providers.

3. Form an action group of families and consumers. This group, for example, might work with tribal government to develop access and other rehabilitation-related policies for the reservation.

4. Have appropriate tribal bodies and consumer groups review and decide whether or not to endorse the "*Recommendations for Rehabilitation Professionals*" included in this report. If endorsed, these recommendations would then apply to those rehabilitation programs, whether tribal or public, that serve a particular reservation.

5. Review the policies and programs of existing tribal health services, social services, and rehabilitation services to ensure that they are *family-oriented and meet the needs of people with disabilities*. For example:

(a) Are adequate respite care services available on the reservation?

(b) Are adequate in-home physical care services available on the reservation?

(c) Are reservation housing authorities responsive to families whose homes need modification to improve access, especially where lives are in danger without such modifications?

(d) Do special education programs and rehabilitation services work together with families and young adults to develop transition goals and plans? Are the support services available to parents when their children are in school, still available after their son or daughter is 22 and no longer eligible for services through special education?

(e) Do vocational rehabilitation services, independent living services, and tribal social services work together to meet the needs of people with disabilities on the reservation? In particular, are programs flexible enough and extensive enough to meet the needs of individuals for whom standardized programming is inadequate?

(f) Do tribal transportation programs and policies adequately address the needs of people with disabilities and their families?

(g) Are tribal offices and administration buildings accessible to people with mobility impairments?

(h) Are in-home outreach or "home visiting" services available to provide support and intervention to families as needed?

6. Identify and prioritize research needs related to improving health and human service delivery to people with disabilities and their families. As one Choctaw woman commented, "I think it's important because, see, if you didn't do the research, nobody would know what we were thinking and what we were feeling and such"

7. Conduct a local media campaign regarding the diversity of disabling conditions and the need for American Indians with disabilities to have the opportunity to participate more fully in all aspects of community life.

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