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Culturally Competent Research with American Indians and Alaska
Natives: Findings and Recommendations of the First Symposium of the
Work Group on American Indian Research and Program Evaluation
Methodology

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Robert Schacht, Ph.D., and Joseph B. Stone, Ph.D.* 1

Indian Family Adjustment to Children with Disabilities

*Lee Anne Nichols, Ph.D., R.N.
and Bette Keltner, Ph.D., F.A.A.N.* 22

An Exploratory Study of Binge Drinking in the Aboriginal Population

*Dennis Wardman, M.D., F.R.C.P., M.C.M
and Darryl Quantz, M.Sc.* 49

Social Networks, Support, and Psychosocial Functioning among
American Indian Women in Treatment

*Jenny Chong, Ph.D.
and Darlene Lopez, M.S.* 62

**CULTURALLY COMPETENT RESEARCH WITH
AMERICAN INDIANS AND ALASKA NATIVES:
FINDINGS AND RECOMMENDATIONS OF THE
FIRST SYMPOSIUM OF THE WORK GROUP
ON AMERICAN INDIAN RESEARCH AND
PROGRAM EVALUATION METHODOLOGY¹**

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This article describes the collective experience of a multidisciplinary network of researchers, practitioners, and program evaluators who support appropriate research and evaluation methods in working with Native peoples. Our experience underlines the critical importance of culture in understanding and conducting research with the diverse populations of American Indians and Alaska Natives, and documents the need for community-based, collaborative, participatory action research. We discuss the major findings of the first American Indian Research and Program Evaluation Methodology national symposium, and articulate a set of 20 guiding principles for conducting research and program evaluation.

Keywords: American Indians and Alaska Natives, Community-based Participatory Research, Participatory Action Research, Culture

This article presents a call for systematic change in how research and program evaluation are conducted in Indian Country.³ The authors do not intend to offer innovative research and evaluation methods; rather, we draw upon our collective experience, much of it based on working with individuals who have chronic illnesses and disabilities, to offer consolidated documentation for requiring that research and program evaluation in Indian Country be participatory. Further, we offer 20 guiding

principles, derived through the First Symposium of the Work Group on American Indian Research and Program Evaluation Methodology (AIRPEM), that we believe are basic to culturally respectful research and program evaluation. While the purposes of research and program evaluation activities often differ, the methods employed may be quite similar; for this reason, reference to research throughout this article can generally be assumed to apply to program evaluation as well.

The special circumstances of American Indians and Alaska Natives (AI/ANs) affect research, program evaluation, and service delivery in Indian Country. In this regard, two fundamental considerations merit particular mention: tribal sovereignty and diversity. Tribal sovereignty means that AI/AN communities are sovereign political entities, each with its own form of governance, culture, and history. Second, AI/ANs are often mistakenly viewed as a single ethnic minority population (also referred to as the homogeneity assumption). In fact, over 560 Native nations and tribal entities exist in this country, constituting distinct cultural as well as political groups. In Alaska, for instance, there are at least four different cultural groups often referred to as Alaska Natives: Eskimos, Aleuts and Alutiiq, Athabascan Indians, and Northwest Coastal Indians.⁴

Members of Native communities and research ethics require that research and program evaluation in Native communities benefit those communities and that research be carried out (from inception to conclusion) in collaboration with participating communities, and that the research be conducted in culturally competent ways. The authors affirm the critical importance of culture for policy, planning, funding, and service delivery as well as for research and program evaluation. Research that focuses on AI/ANs should be conducted in a culturally competent manner, and programs serving these populations should be designed to meet their needs in culturally appropriate ways.

The AIRPEM symposium discussions of research, evaluation, and service delivery recognized that human beings are all, to varying degrees, culture bound. People view the world through the lens of their own culture; for researchers, this reality affects our science (Du Bois, 1983; Gergen, Gulerce, Lock, & Misra, 1996; Hughes, Seidman, & Williams, 1993). Our cultural lens operates as both window and blinders, giving us different perspectives, while simultaneously obscuring our ability to perceive in terms other than our own. In a pluralistic society, members of the dominant group may be particularly limited in their understanding of other groups. Political, economic, and other pressures may force members of minority cultures to learn about the dominant culture. Conversely, members of the majority group tend to be free from pressures to understand minority cultures. Consequently, relatively few have in-depth understanding of and experience with Native communities and their cultures. This paper was written to address problems associated with

research conducted in Indian Country by investigators who lack understanding of the history, cultures, needs, and circumstances of AI/AN communities and their residents.

Culture as Essential Context in Research and Service Provision

Psychologists Segall, Lonner, and Berry (1998) asked, "Can it still be necessary, as we approach the millennium, to advocate that all social scientists...take culture seriously into account when attempting to understand human behavior?" (p. 1101). Discussions at the AIRPEM symposium underlined the importance of recognizing that culture informs the design and process of research, instrumentation, interpretation of results, and dissemination. Failure to understand the cultural context can result in misunderstanding the causes and consequences of human behavior. Critical to understanding, and thus to valid results and information, is appreciation of the inter- and intra-tribal diversity among AI/ANs—diversity that affects research design and service delivery in Indian Country.

In order for researchers and program evaluators in Native communities to be effective, they must be culturally competent and sensitive to traditional values, taking into account definitions and expectations of behavior within the community and myriad factors that affect the research. For example, AI/AN families and families in the Euro-American culture may differ in many ways, such as in the definition and meaning of extended family and in child rearing practices (Cummings, Ireland, Resnick, & Blum, 1999). The dominant culture defines the extended family as three generations living in the same household, while in some AI/AN communities, extended family is defined as a network of relations, distinct from one's clan or tribe. For members of such cultures, extended family affects one's identity and role in the community, transmits culture, and conserves family patterns (Red Horse, Lewis, Feit, & Decker, 1978). The definition of self as a member of the extended family in such Native cultures affects key variables such as family values, independence, individual responsibility, and child rearing practices. Different interpretations of extended family can influence issues like child custody and living arrangements in Indian Country, where high rates of morbidity and mortality may result in the death or loss of a custodial parent or guardian. Growing up in several different extended family households may be considered a strength. From the dominant culture perspective, changing households might be seen as a sign of instability and as injurious to the child. In a Native community, growing up in the homes of different extended family members might be viewed as a sign of positive social relations for the child and an opportunity to develop in multiple supportive environments.

Attention to cultural factors is required for ethical research and for effective service provision in Indian Country. It is important to consider the potentially negative impacts of the research process on indigenous communities as well as the expected benefits of research (Tapp, Kelman, Triandis, Wrightsman, & Coelho, 1974). Lang (1998) noted the problem of “proselytizing western-based individualism” in service delivery. Unless they are working in partnership with the communities being studied, researchers can be certain that their own cultural expectations, values, and biases influence the framing of their research questions, choice of methods, interpretation of data, conclusions, and recommendations (Segall et al., 1998). This culture-centric error tends to occur regardless of the quantitative or qualitative nature of the research.

The Historical Context

Understanding and appreciating the circumstances of contemporary AI/AN communities requires some knowledge of their history since first contact with Europeans—a history of invasion; violent dispossession of property, homeland, culture, language, and religion; and attempts at genocide through the use of biological agents (Stone, 2002). The first reservation, established in Connecticut in 1638, officially signaled the beginning of the relocation efforts that would tear at the fabric of all American Indian communities (Equity Center Infoline, 1999). A second phase of extensive relocation and forced removals followed during the early- to mid-1800s with the result that some Native communities and entire tribes were destroyed. The next phase, beginning in the late 1870s, was characterized by federally mandated assimilation through compulsory boarding schools for Native youth. Many reservations saw children forcibly removed from their homes and sent to these schools. By the early 1900s, such schools were located in over 15 states and territories (The Brown Quarterly, 2001; Equity Center Infoline, 1999). Forced assimilation was destructive to Native individuals and communities. The pernicious effects of the federal Indian boarding school era reverberate in Indian communities today, influencing community, health, family and other relationships, and politics. At boarding schools, children were punished for speaking their language, practicing their religion, or engaging in traditional activities and ceremonies. Many children were subjected to emotional, physical, or sexual abuse by school officials. Older children were taught to enforce the prohibitions on Native language and culture (Stone, 2002).

The Termination Act of 1954, a U.S. government experiment from 1953-1962, attempted to manage the “Indian problem” by declaring that specific reservations and tribes were null and void, no longer recognized by the federal government (American Indian Lawyer Training Program, 1988). Research has found that following termination, the test scores of tribal members revealed a rate of posttraumatic stress disorder 10 times

greater than that of the U.S. population at large (Ball, 1998). Thus, the post-colonial history of Indian Country reveals a legacy of trauma and grief that continues to influence AI/AN communities across and within generations, immersing tribal families in a crucible of stress. Post-colonial trauma is associated with a high level of posttraumatic stress among Native individuals, families, and communities, with secondary consequences similar to those exhibited by Jewish Holocaust and Khmer Rouge survivors (Last & Klein, 1984; Nadler, Kav-Venaki, & Gleitman, 1985; Rowland-Klein & Dunlop, 1998; Sack, Clarke, & Seeley, 1995; Yehuda et al., 1998). High rates of psychiatric disorders, substance abuse, and social problems, including violence, also have been observed in Native communities (Ball, 1998; Beals et al., 2002; Gagne, 1998; Weaver & Yellow Horse Brave Heart, 1999). The effects of prolonged and complex trauma on psychological functioning (Herman, 1992), similar to those seen in long-term sexual abuse survivors and combat veterans, are critical to understanding the symptoms and issues faced by AI/AN individuals and communities (Ford, 1999; Ford & Kidd, 1998; Zlotnick, Zakriski, Shea, & Costello, 1996).

Implications for Research

These historical events and their painful and oppressive dynamics continue to affect Native people and their communities. Critical issues facing the current generation of AI/ANs include poverty; substance abuse; psychiatric disorders; culturally, economically, and politically oppressive political and racial systems and agendas; culturally inappropriate child protection efforts and treatment methods; and the cumulative effects of several generations of post-colonial stress. On the other hand, many American Indian tribes and Alaska Native communities have survived, are growing, and are working to achieve their goals and aspirations. The AIRPEM Symposium discussions emphasized that researchers be aware of the resilience AI/AN communities have demonstrated across generations—strength for physical survival, for community resurgence, and for spiritual integrity (McCubbin, Thompson, Thompson, & Fromer, 1998).

Historical views (including ignorance of history) and societal norms influence ways researchers interact with people and their communities. A parallel relationship exists between the historical treatment of AI/ANs and the research methods used to study them. Formal research has been conducted on AI/ANs since the early 19th century. Research reported during the period of early contact reflects Eurocentric beliefs about AI/ANs, referring to them as savages to be conquered and socialized (e.g., Dowler, 1857). This paternalistic approach continues to exist in some research. Although all American Indians were granted U.S. citizenship in 1924, AI/ANs continued to be exploited by researchers (American Indian

Lawyer Training Program, 1988). Many researchers in Indian Country have collected and/or disseminated data without the full knowledge and consent of participants and without respect for local culture and tradition (Hodge, Weinmann, & Roubideaux, 2000; Macaulay, 1994; Shafer, 2004).

Although the paternalistic approach has continued in some research, significant improvement has occurred. The Indian Self-Determination and Education Assistance Act of 1975 [Public Law 93-638] supported the autonomy of AI/AN communities (Kunitz, 1996) and, since the early 1960s, the Indian Health Service has set forth guidelines and oversight for research (Indian Health Manual, 2001). During this period, increased numbers of AI/ANs were obtaining advanced degrees and beginning to influence the research process (Medicine, 2001; Trimble, 1977). Carolyn Attneave, a Delaware and Cherokee psychologist, is one such example. Her work on the importance of culture for families and communities helped change the way research is thought about and conducted in Indian Country (Attneave, 1982). Since the 1970s, researchers have increasingly involved community members in planning and conducting research (Brelsford, 1977; Patrick & Tyroler, 1972; Taylor, 1975).

Nevertheless, the history of maltreatment and exploitation is reflected today by mistrust and suspicion of research. Actual violations of trust by researchers in AI/AN communities, such as the Barrow alcohol studies (Foulks, 1989; Norton & Manson, 1996) and the Havasupi medical genetics case (Shafer, 2004), have compounded these attitudes, negatively affecting willingness to participate in the research process. While strides have been made in involving AI/ANs as *partners* in the study of physical, emotional, social, educational, and environmental problems (Manson, Garrouette, Goins, & Nez Henderson, 2004), researchers and others working in Indian Country must simultaneously ensure *both* that their work does no harm to Native communities *and* that it builds upon the strengths of these communities.

Increasing Tribal Control of Research

During the last 10-15 years, tribes, Native villages, and consortia have taken an increasingly active role in challenging as well as generating research, program evaluation, and service delivery. These entities are seeking opportunities to influence research agendas and funding priorities. At a minimum, tribes are exercising power to reject unwanted research on their lands and with their people. These trends reflect increasing tribal autonomy in education, health care services, employment, training, welfare, and other programs formerly operated by federal and state agencies. The emergence of requirements of research by institutional review boards (IRBs) has also facilitated the influence of tribes on research conducted in their communities. Federal sponsors of research have begun

to consult with tribes and tribal organizations (e.g., National Indian Health Board, National Congress of American Indians, National Indian Education Association) regarding research agendas in Indian Country. Congress and federal agencies are soliciting input from tribes and tribal organizations with respect to research goals and budgets. Some tribes have constituted their own IRBs to review all research that involves tribal members as research subjects.

Some cultural factors affecting perceptions of and participation in research may seem obvious, such as the need to present information in a participant's primary language, but others are more subtle, such as norms about the expression of disagreement or conflict, interaction among related individuals, and models of health and disease. In addition, service delivery and research in Indian Country have been based on Western theory, which may markedly differ from tribal value structures and worldviews. Tribal sovereignty, data ownership, cultural barriers, and appropriate methods and dissemination (Ericksen, 1996; Manson, 1997; Mihesuah, 1993; Stubben, 2001; Trimble, 1977) continue to challenge service delivery, research, and evaluation efforts.

Conducting research in Indian Country presents even the most seasoned and careful researcher with numerous methodological issues. Two of the most salient issues represent complex and interwoven challenges: appropriate understanding and acknowledgement of post-colonial stress in tribal communities, and the use of collaborative, participatory research models and methods in a culturally competent manner (Brydon-Miller, 1997; Duran & Duran, 1995; Locust, 1995; Lewis, Duran, & Woodis, 1999; Marshall, Johnson, Martin, Saravanabhavan, & Bradford, 1992; Park, 1999; Walters & Simoni, 1999; Weissberg & Greenberg, 1998; Yellow Horse Brave Heart, 1998).

Culturally Competent Research

Despite the problems of the past, AI/AN communities often recognize the need for research and evaluation in multiple arenas. Research that primarily considers the interests of the community, rather than larger society and academia, can bring significant benefits to the community. Community-based, collaborative, and participatory research makes tribal people full partners, benefits the communities studied, and empowers people to define and address the issues that affect their lives; in this process, community members set the agenda of research that affects them. Scientists and community members must share equally in the research planning, implementation, evaluation, and results dissemination phases, as well as in any resulting benefits (Davis & Reid, 1999). Such a process would also lead to what has been termed culturally anchored methodology (Hughes et al., 1993). The ultimate goal of

participatory research is to empower communities to assume ownership of the research process and to utilize the results to improve their quality of life (Macaulay et al., 1998).

Participatory action research is an ongoing process of interaction between the researcher and research participants that allows the examination of Native strengths and emphasizes the use of Native knowledge to address issues (Fisher & Ball, 2002a; 2002b). Participatory research and program evaluation processes provide opportunities for AI/AN communities to incorporate "re-traditionalization" into methods. The concept of wraparound services (e.g., interagency services addressing emotional, physical, mental, and spiritual needs of the child and family), introduced into the clinical literature in the mid 1980s (Stroul & Friedman, 1986), is not a new concept in Indian Country (Kendziora, Bruns, Osher, Pacchiano, & Mejia, 2001). Cross and colleagues identified a number of re-traditionalization themes inherent in the structures of five out of eight tribal Comprehensive Community Mental Health for Children and their Families programs (Cross, Earle, Echo-Hawk Solie, & Manness, 2000). Themes included the use of extended family, traditional teachings, culturally specific approaches, and cultural restoration (mentors, crafts, language). In addition, these programs incorporated methods that promote healing of Indian identity and self-efficacy; build community connections, culture, group, clan, and extended family; and are based on spiritual beliefs and support systems. Additionally, methods were identified that incorporated elders or intergenerational approaches; individual and family skill building for living in two cultures; traditional helping values; and conventional and cultural methods to recognize and treat historic cultural, intergenerational, and personal trauma.

The systems of care in some of these communities were grounded within programs offered by their respective tribal, social, and health programs and sponsored by their tribal governments. Of great interest is the development and validation of culturally appropriate assessment instruments that could be used to document the effectiveness of traditional healing methods. For instance, a Navajo tribal grant community's service delivery structure is based on "K'é," which means to have respect for all things and maintain balance by acknowledging clan and kinship (Cross et al., 2000). Accordingly, tribal staff developed a behavioral management specialist position designed to use culturally relevant approaches to counseling, and coordinating traditional treatments as appropriate. In the Passamaquoddy tribal community, younger children, families, and the community itself are provided with service opportunities to reintegrate Passamaquoddy culture into their lives. This method works to reestablish tribal values and traditions, ultimately assuring the continued survival of tribal culture.

It has taken decades for the scientific community to recognize that Native communities can identify their needs, determine courses of

action, and achieve the goals they have set for themselves. These few examples illustrate how tribal communities are creatively using contemporary research, evaluation, and service structures to address simultaneously their pressing needs and their inherent strengths. Participatory and collaborative research balances the needs and wants of the community with those of the researchers. Without this balance, trust may be broken, and significant problems may arise. Research is a give-and-take relationship and authentic partnership calls for both researchers and tribal communities to initiate and identify issues to be researched. Engaging in reciprocity allows community members and researchers to remain equal partners. If researchers make use of participants' ideas and time, they must give back by providing resources, skills, employment, and/or training (Davis & Reid, 1999). It is our hope that respectful, culturally competent and empowering research approaches will bring support from policy makers and funding sponsors to ensure that research, program evaluation, and service delivery in AI/AN communities meet the concerns and needs of those communities and build on their strengths, both manifest and subtle.

Practical Issues Associated with Increasing Participation in Research

Hiring tribal members to assist in research activities can have several benefits, such as increasing employment, contributing to the tribal economy, and promoting skill acquisition. Having tribal members participate on the research team has other benefits: The research team is less likely to exploit research participants, expose them to unnecessary risk, or demean them; and researchers are less likely to employ or express invalid stereotypes, or to express, explicitly or implicitly, prejudicial perceptions, opinions, or expectations about the tribe or Native village. Furthermore, enhanced communication and rapport between researchers and study participants may improve data quality.

On the other hand, employing tribal members on the study team may also be associated with a variety of costs. Hiring, training, and using tribal members on a research team can increase both the time required to complete the project and project costs. Using tribal members to collect data can also create special problems for study participant confidentiality. Study participants may conceal taboo or socially undesirable expectations, beliefs, or behaviors from other tribal members; paradoxically, such expectations, beliefs, or behaviors might be less concealed from outside investigators whom the research participants are unlikely to encounter in the future.

It is customary for researchers to describe the anticipated benefits, risks, and costs of the research when preparing grant proposals and in submissions to IRBs. Prior to tribal control of research, discussions of

anticipated research benefits in Indian Country tended to be abstract. Requiring researchers to explicitly outline concrete costs and benefits to the participating tribe(s) tends to clarify thinking and make assumptions and expectations explicit. In our experience, this process is beneficial to all parties involved.

Research in Indian Country, like research everywhere, is conducted within a social and political context. Perceptions of benefits and costs associated with a particular study may vary. For example, managers of tribal programs can perceive costs and benefits of a study differently than members of the tribal judiciary or legislature. Advocates for change and proponents of traditional values and approaches may have differing opinions. While involvement of tribal stakeholders with conflicting agendas or perspectives can improve study acceptance, such involvement can also mire the research in conflict, leading to disorganization or even project abandonment. Finally, depending on their interests, stakeholders may embrace or repudiate research findings.

Tribes often do not object to the identification of the tribe or communities in research reports. However, when research is conducted on sensitive topics, a tribe may insist that the research report not identify the tribe or communities participating in the research. Protecting the privacy of research participants and keeping their identity anonymous can pose a special challenge for small tribes and communities. As one example, if the program being evaluated is small, it can be almost impossible to maintain the anonymity of key informants.

In general, research in Indian Country may have neither more nor fewer ethical problems and dilemmas than research conducted elsewhere. Still, issues such as cultural competence, relatively high rates of poverty, illness, and prevalent rural infrastructure deficits can exacerbate ethical problems. Making judgments about ethics and values can be challenging to researchers because of potentially conflicting roles and circumstances. For instance, the sponsor of the research may have agendas, rules, and expectations that are different from or in conflict with those of the tribe(s) participating in the study. In such circumstances, it is prudent for the researcher to seek guidance from a project advisory committee, the research sponsor, and/or legal authorities without disclosing information that would violate the identity of the research participant(s) or violate the confidentiality of participant data.

Guiding Principles for Research

The AIRPEM symposium generated practice-based recommendations, presented here as 20 guiding principles of collaborative, participatory, and culturally competent research with AI/ANs. These principles build on valuable precursors (e.g., Fisher & Ball, 2002a; 2002b; Stubben, 2001), including Dr. Justin D. McDonald's "A Model for Conducting

Research with American Indian Participants” (2000). Not all of the following principles will be applicable to every situation, but together they constitute a basis for planning research and program evaluation with AI/ANs. It is important to note that there is no universal model of research. We do believe, however, that these principles are basic to culturally respectful and appropriate research activities.

1. Research with AI/ANs should be conceptualized, framed, carried out, and reported in accordance with the principles, methods, processes, and procedures of *community-based, collaborative and participatory research*, and should be *informed by understanding of the issues and dynamics of postcolonial trauma and stress* faced by individuals, families, and communities. This approach can help transform research from being a cause of trauma to being a source of healing.

2. Research with AI/AN communities must be *relational research*; research conducted in relationship and partnership with the communities. Recognizing the privilege of being in relationship with families and communities fosters the respect, open-mindedness, and humility that encourage both good relationship and good science.

3. Research projects should be *authentic partnerships*. Differences between researchers and tribes or communities should be understood as differences in responsibilities, not differences in status.

4. AI/AN *community partners should be involved in the oversight of research* from inception to completion of the project, including data interpretation and dissemination, authorizing publication, and ownership of data. Specific guidelines for balancing tribal or community oversight with researcher responsibility should be established collaboratively between community and researcher, and in line with IRB regulations; see also Principle #15.

5. Researchers should be informed and directed by existing *ethical guidelines and research codes of ethics*, specifically those developed by AI/AN communities.⁵ In general, researcher obligations include continuous consultation and collaboration on all aspects of the research, involving the community through active participation rather than passive acceptance, transferring new skills to the community during the research process, and being available to help address any health or human services issues raised because of the research.

6. The factors of *tribal, cultural, and linguistic diversity* need to be taken into account in the development of research designs. Researchers are not expected to be experts on the cultural diversity among all AI/AN communities, but should understand the history, culture, and circumstances of the Native community or tribe with which they are going to partner in research.

7. Research design, instrumentation, data collection and interpretation, dissemination and other post-research activities should give prominent attention to the *strengths and cultural protective factors*

of Native communities rather than basing research agendas and designs primarily on deficit models.

8. Research should involve *culture-specific interventions and locally meaningful constructs*. In experimental research, consideration should be given to deriving experimental variables from tribal beliefs and values. This approach can facilitate bringing research and service delivery into the cultural rebuilding process known as re-traditionalization.

9. Researchers must explicitly identify *how the research findings will benefit the tribe* and its members. Requiring researchers to relate costs and benefits to the participating tribe or community tends to clarify thinking and make assumptions and expectations explicit—results often beneficial to the proposed research, the researcher, the participating tribe, and other stakeholders.

10. *Training and employment of tribal members* as research or evaluation project staff should be a priority; such employment might include local or on-site research coordinators and evaluation specialists. The potential implications for participant anonymity and confidentiality must be carefully addressed.

11. Researchers must *be concerned that the research protocol does not harm* the tribe, its members, and the environment. Any potential negative effects of participation must be made clear at the outset, and informed consent obtained from participants (or tribal authorities, when they claim this responsibility for tribal members). Preventing harmful effects includes the need to embed presentations of research findings in the historical and cultural context necessary for accurate interpretation.

12. Research participants must be *guaranteed confidentiality and anonymity*. These guarantees must be extended also to tribal communities and to tribes, when called for by community or tribal authorities. Tribal communities may not object to the identification of the tribe or of communities in research reports, but sometimes, especially when the research is on sensitive topics, a tribe may insist that a research report not identify the tribe or communities participating in the research.

13. *Tribal or community review of all research findings* is essential. This review must include the freedom to be critical and, if needed, to include dissenting opinions in any publication of research findings. Results should be presented in a form that is understandable and meaningful to the tribal council and community members as well as to service providers, academics, funding agencies, and policy makers and planners (Macaulay et al., 1998; Norton & Manson, 1996). Necessary language and conceptual translation should be provided, and direct, face-to-face communication of findings in the Native language should be made available.

14. *Active tribal or community involvement in data interpretation* is essential. It is important to note that many research and evaluation outcomes based on clinical, behavioral, and functional measures can be easily misconstrued or interpreted according to a Western theoretical

model. From a tribal community perspective, an entirely different, culturally grounded interpretation could be drawn based on knowledge of historical impacts as well as contemporary issues obvious only to community members.

15. *Community control of the data* throughout the research process can help ensure its appropriate uses (Macaulay et al., 1998) from the viewpoint of community or tribal representatives, who may wish to have the ultimate decision over how results are to be used, including whether to publish in scientific journals. However, sponsoring federal and state agencies may consider that they, too, have ownership of the data. This issue needs to be addressed explicitly at the outset and agreement reached before data collection begins.

16. Researchers need to work with Native communities and tribes to *define culturally appropriate standards for excellence* in research design, reporting, and methods of demonstrating research success. Funding agency criteria for research are not always appropriate to the needs, cultures, and capacities of tribes and other Native entities, due to sampling concerns, small and isolated communities, communications challenges, and so on.

17. *Capacity building* for research and program evaluation should be a part of every research project in Indian Country. This guideline should include building capacity to meet both the currently prevailing evidence-based standards and for developing other kinds of methods and evidence more appropriate to the small samples and cultural contexts of indigenous populations.

18. Research scientists working in Indian Country may increasingly need to accept responsibility to support tribes and communities by *advocating for solutions* to problems identified in their studies. The role of scientist as advocate is not presently in the professional repertoire of most investigators; educators might consider addressing this need in graduate and professional curricula. Researchers may need to consider the policy implications of their work and be willing to communicate with policy makers of their research findings and recommendations.

19. *Linkages, networking, and multidisciplinary approach*: Creating and maintaining networks of communication and collaboration among professional disciplines and a diversity of agencies working in Indian Country is important, for exchange of knowledge and information and for joint activities to benefit Native communities. In particular, it is important to bring culturally sensitive research philosophy and practices into graduate and professional curricula. Within networks, each group and discipline needs to preserve its particular focus, in order to fulfill its mandate and to enrich the common effort.

20. *Research that focuses on individual tribes, Native villages, or communities* can be essential for local participation in research, for community relevance, and for community action planning. Individual

community focus allows researchers to avoid the problem of overgeneralization and the homogeneity assumption of results referred to earlier. Showing genuine concern as well as a willingness to learn and be a part of the community can foster both trust and efficacy.

Conclusion

The succinct historical and cultural perspective on research with AI/ANs presented here is based on the broad, multidisciplinary experience of researchers in the AIRPEM network. It underlines the critical importance of culture in understanding and conducting research with this diverse population, and strongly affirms the need for community-based, collaborative, participatory action research in Indian Country. This work rests on the foundation laid by previous scholars and practitioners (e.g., Deloria, 1995; Medicine, 1981; Pinto, 1973) whose work opened up for consideration the significant challenges and opportunities of research with indigenous communities. We recognize that at this time there are enough people in enough different disciplines—an emerging critical mass—to carry forward the development of positive models of community-based, participatory, culturally competent research that can bring genuine benefit to both indigenous communities and the broader society.

We hope that through appropriate and accurate needs assessments, substantive research, and program evaluations, AI/AN communities can see an increase in dollars for community development and problem-solving service delivery. We hope that the experience, findings, and recommendations of the AIRPEM network will be used by researchers, evaluators, and service providers. Specifically, we encourage incorporating these principles into university and graduate school training and curricula for research theory and practice. We ask for serious consideration of the principles by research sponsors in making their funding decisions, and hope they are of both educational and practical use to planners and policy makers at the federal, national, state, and tribal levels.

AIRPEM researchers and program evaluators are called to communicate and to act with conviction in disseminating our research. We affirm that our research processes must be and are influenced by the cultures of AI/ANs. We are certain that this awareness and the research it allows us to create in partnership with community members allow for the enhanced validity of our research. We trust that our research can thus demonstrate its value and usefulness to the people whom we aspire to serve as researchers and practitioners. Although the focus of this paper is the indigenous peoples of what is now the United States, the need to develop true collaborations with indigenous people has no boundaries. International collaborations that focus on research methods and indigenous issues, to include where these topics intersect with issues of chronic illness and disability, are needed; researchers in the United

States can learn from the experiences of the world's indigenous peoples and researchers in other countries as they work to define research practices that take culture as essential context in research.

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Footnotes

- ¹ The first AIRPEM symposium, "Research and Evaluation Methodology: Lifespan Issues Related to American Indians/Alaska Natives with Disabilities," was held April 26-27, 2002, in Washington, DC. The symposium was administratively supported by the American Indian Rehabilitation Research and Training Center (AIRRTC), Institute for Human Development, Northern Arizona University. The Indian Health Service and the National Institute on Disability and Rehabilitation Research, through a supplemental grant to the AIRRTC, funded the symposium. Significant staff support was provided by the Center for Mental Health Services of the Substance Abuse and Mental Health Services Administration. The resulting monograph, *Symposium on Research and Evaluation Methodology: Lifespan Issues Related to American Indians/Alaska Natives with Disabilities* (Davis et al., 2002), represents the current experience, thinking, and recommendations of this collegial effort and provided the substantive base for this article. The authors of the monograph included: Jamie D. Davis, Ph.D., and Kelly Keemer, "A Brief History of and Future Considerations for Research in American Indian and Alaska Native Communities"; Walter Hillabrant, Ph.D., "Research in Indian Country: Challenges and Changes"; Paulette Running Wolf, Ph.D., Robin Soler, Ph.D., Brigitte Manteuffel, Ph.D., Diane Sondheimer, Ph.D., Rolando L. Santiago, Ph.D., and Jill Shepard Erickson, M.S.W., A.C.S.W., "Cultural Competency Approaches to Evaluation in Tribal Communities"; Catherine A. Marshall, Ph.D., Sharon R. Johnson, M.A., CRC, Elizabeth Kendall, Ph.D., Howard Busby, Ph.D., Robert Schacht, Ph.D., and Calvin Hill, B.S., "Community-Based Research and American Indians with Disabilities: Learning Together Methods That Work"; and Jennifer Olson, Ph.D., Philip Olson, Ph.D., Teresa Pingayak, Katherine W. Sterling, M.A., and Lenea Pierzchanowski, M.H.R., "Learning From and Working With Yup'ik

Professionals.” Critiquing the papers and offering insight into the challenges of conducting research with indigenous communities that is both scientifically sound and culturally appropriate were three distinguished American Indian social scientists and social policy experts: Dr. Velma Mason, Director for the Office of Alcohol and Substance Abuse Prevention in the Office of the Assistant Secretary of Indian Affairs, U.S. Department of the Interior, speaking on “Implications for Policy and Practice”; Dr. Spero Manson, Professor and Head, American Indian and Alaska Native Programs, Department of Psychiatry, at the University of Colorado Health Sciences Center, on “Research Methods”; and Dr. Joseph Stone, Program Manager and Clinical Supervisor, Confederated Tribes of the Grande Ronde Behavioral Health Program in Oregon, on “Cultural Issues in Research: Developing and Implementing Native American Postcolonial Participatory Action Research.” Holly Echo-Hawk, M.S., organizational behavior and management consultant, facilitated the one and a half days of discussion.

- ² The authors of this article are listed in alphabetical order; their time and involvement in both writing and reviewing this article have varied as it has evolved.
- ³ Throughout this paper reference is made to American Indians and Alaska Natives, Native people, or indigenous people, reflecting issues of specificity versus generalizability as well as the challenges of rhetoric. Communities are also referred to as Native or indigenous communities. “Indian Country” refers to any lands owned by Indian tribes, Alaska Native villages, and areas where large numbers of American Indians and Alaska Natives reside such as the states of Alaska and Oklahoma.
- ⁴ Many fail to appreciate the unique circumstances of Alaska. For example, it is farther from Anchorage to half-way through the Aleutian Islands than from Washington, DC to San Francisco, CA. Most Alaska Native villages have a single, unpaved road with an airstrip at one end. While there may be 20 trucks and cars in the village, they can leave the road only in winter when the tundra, lakes, and rivers freeze hard.
- ⁵ E.g., the Code of Research Ethics developed with the Native Mohawk community of Kahnawake in Canada (Macaulay et al., 1998); the Model Tribal Research Code developed by the American Indian Law Center, Inc., (1999); and Principles for the Conduct of Research in the Arctic (Retrieved August 1, 2005 from <http://arcticcircle.uconn.edu/SEEJ/ethics.html>). Also, see the comprehensive guidelines of the Australian Institute of Aboriginal and Torres Strait Islander Studies (2000) as well as extensive research information available through the Alaska Native Science Commission (<http://www.nativescience.org>).
- ⁶ Dr. Running Wolf is the corresponding author for this article.

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

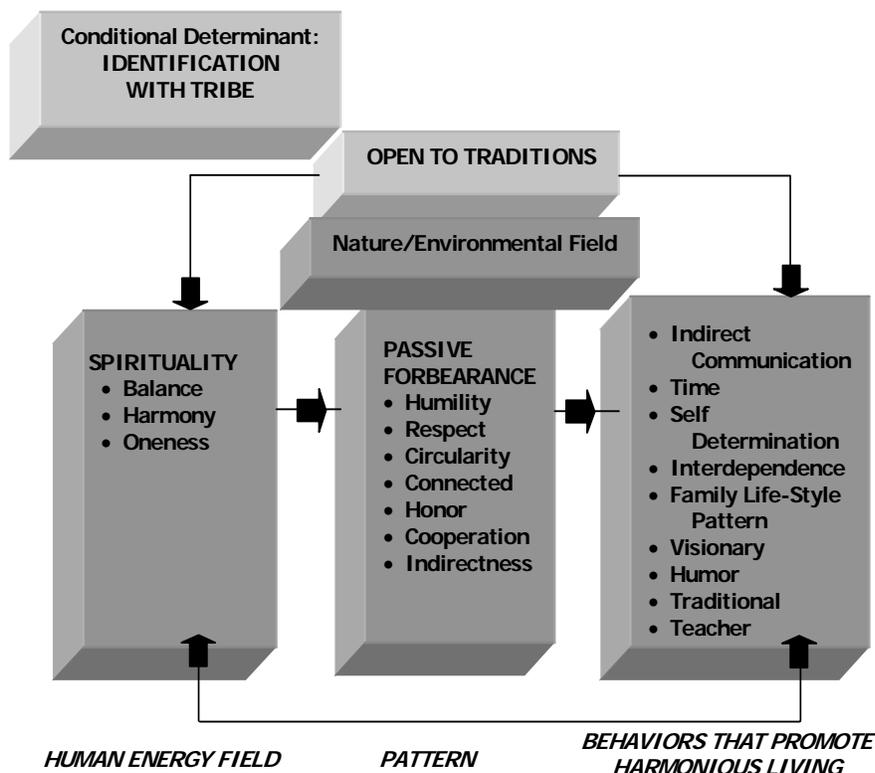
Cultural identity is the conditional determinant. Cultural identity differs among the various AI groups found in the United States. There are over 500 tribes in the United States and cultural identity will vary among the members of the tribes at various times at various points of an AI's life (Weaver, 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

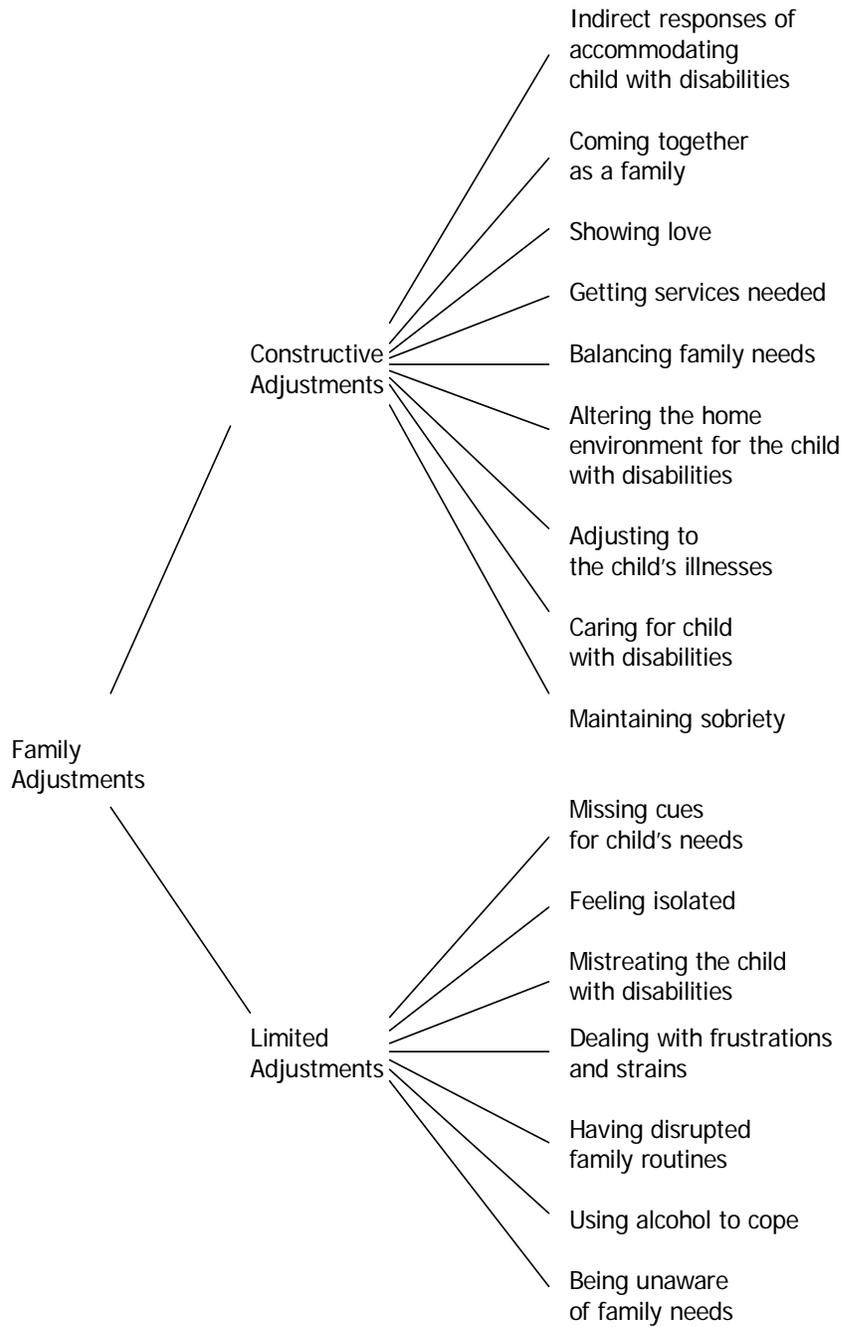
The following sections will describe the taxonomy development of AI family adjustment to a child with disabilities. Figure 2 represents the American Indian Family Adjustment Cascade Model. The model identifies the linguistic and cultural meanings among the taxonomies. Community members described AI families 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?

AN EXPLORATORY STUDY OF BINGE DRINKING IN THE ABORIGINAL POPULATION

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There is little research available on binge drinking among the Aboriginal population. Between March and June 2004, 15 Aboriginal persons participated in a semi-structured interview related to their binge drinking behaviors. The majority of participants were women and described a family history of alcoholism and childhood abuse. Factors that contributed to a reduction in binge drinking were often related to an acute event combined with gradual life changes. Supporting influences to remain sober included positive social support networks, role models, personal development, and cultural/spiritual practices.

Introduction

The terms Aboriginal population and First Nations used in this paper refer to those people who are North American Indian, Métis, and/or Inuit. Within Canada, over 1.3 million people identified themselves as having at least some Aboriginal ancestry (Statistics Canada, 1993). This number represents approximately 4.4 % of the total population. The highest concentrations of Canada's Aboriginal population are found in the North and in the Prairie provinces. There is also continuing growth in the proportion of Aboriginal persons living in urban areas. Approximately one half of Canada's Aboriginal persons now reside in urban areas, creating implications for education, social services and health care.

Alcohol abuse has been reported as a major concern for Aboriginal communities across Canada and was identified as a key issue during a national inquiry into the needs of the country's Aboriginal peoples (Royal Commission on Aboriginal Peoples, 1996). Seventy-three percent of communities surveyed in the 1991 Aboriginal Peoples Survey felt that alcohol abuse was a major concern (Statistics Canada, 1993). A number

of community surveys also found a perceived lack of progress in reducing alcohol abuse in Aboriginal communities (Svenson & Lafontaine, 1999; BC Provincial Health Officer, 2002). Of growing concern are the high rates of injury and mortality associated with alcohol use in Aboriginal communities. In British Columbia, 170 deaths each year are alcohol related, and alcohol is a contributing factor in 4 out of every 10 accidental and violent deaths (British Columbia Provincial Health Officer, 2002). In an analysis of Saskatchewan data, alcohol was implicated in 92% of motor vehicle accidents, 46% of suicides in the 15-to-34 age group, 50% of fire and drowning deaths, 80% of exposure deaths and 48% of deaths in the 'other' category (Health Canada, 2002). There are also indications that alcohol related deaths are on the rise (British Columbia Provincial Health Officer, 2002).

Adult Aboriginal persons dwelling on reserve have higher weekly binge drinking rates than the rest of Canadians (Wardman & Quantz, 2005). For comparison, 79.3% of Canadians consumed alcohol and 6.2% binge drank on a weekly basis during the previous year (Wardman & Quantz, 2005). In a small survey in Saskatchewan, binge/chronic/problem drinking was reported by 37.7% of the adult population; a Northwest Territories survey reported that a third of Aboriginal persons surveyed were heavy drinkers, compared to 16.7% of the non-Aboriginal population (Health Canada, 2002). Males have also been found to have higher rates of heavy drinking in a number of studies (May & Gossage, 2001). Epidemiology from studies of American Indians have found greater amounts of alcohol consumed during drinking episodes, indicating that binge drinking disproportionately impacts this population (May & Gossage, 2001; O'Connell, Novins, Beals, Spicer, & AI-SUPERPPF Team, 2005). Heavy drinking is also associated with an increased likelihood of both health problems and injury (Robin, Long, Rasmuseen, Albaugh, & Goldman, 1998; Curry et al., 2000). In summary, binge drinking is of significant public health concern to Aboriginal communities.

For the purposes of this study, we use the definition of binge drinking from the National Institute on Alcohol Abuse and Alcoholism (NIAAA) National Advisory Council.¹ Binge drinking behavior may or may not be reflective of chronic/heavy drinking. The current study provides an opportunity to develop an understanding of the etiology and impact of binge drinking among Aboriginal persons. Reported in this paper are the results of an exploratory qualitative investigation into the behaviors and perceptions of binge drinking in a sample of Aboriginal adults. Although the current study is exploratory in nature, the results are valuable as this issue has not received attention in the literature. The results of this work also have implications for a larger study and may help in the planning of community programs to address the needs of those at risk. Two objectives

were outlined for this work: 1) identify and describe risk factors that exacerbate/trigger binge drinking episodes, and 2) identify protective factors against binge drinking.

Methods

Participant Recruitment

The sampling methods for this study included Aboriginal persons who have experienced or are currently experiencing episodes of binge drinking. A convenience sample was used for this study and participants were obtained via third-party recruitment. The first author is an Aboriginal person and is an addictions specialist who works with and is in contact with a number of addictions and community agencies in Western Canada's Aboriginal communities. Two of these agencies agreed to participate and were sent a letter requesting them to pass on to staff and clients an open letter of invitation to agency clients. These agencies offered an opportunity to capture a wider range of participants as they served clients from both rural and urban areas in two Canadian provinces (British Columbia and Alberta). The letter of invitation requested that clients contact the researcher directly if they were interested in being part of the study. Ethical approval for the study was obtained from the Office of Research Services at the University of British Columbia.

From this strategy, 15 Aboriginal persons were recruited to participate in a semi-structured interview between March and June 2004. The participants ranged in age from their 20's to their 60's; 13 were female and 2 were male. All participants were either part of an Aboriginal support group or were staff at an Aboriginal social service agency or Aboriginal Addiction Treatment Centre. Of the 15 participants, 10 were currently in the support group and 5 were staff members. All had received treatment for binge drinking at some point. As none of the participants were part of an addictions treatment program at the time of the interview, we did not anticipate their responses would be influenced by any particular addictions treatment approach. Unfortunately, it is not possible to determine how many individuals refused to participate, as only those who contacted the investigator to participate were known.

Data Collection and Analysis

The study adopted a qualitative approach and consisted of a series of in-depth interviews. To facilitate this process, an interview guide was developed and included questions on the characteristics of binge drinking episodes, personal perceptions of binge drinking and the risks and protective factors for binge addictions. Interviews were conducted either

face to face or by telephone over a two-month period and lasted between 30 and 60 minutes each. The first author conducted all of the interviews. Written consent was obtained from all participants and interviews were audio taped and transcribed verbatim into Microsoft WORD.

Initial analysis of the data was undertaken simultaneously with data collection. Through this review, emerging themes were sought and additional prompts and questions were identified for future interviews. The formal analysis process began with an independent review by both authors of all transcripts, during which units of data were coded by themes and issues. Codes are "tags or labels for assigning units of meaning to the descriptive or inferential information compiled during a study and are used to retrieve and organize data" (Miles & Huberman, 1994). The next stage of data analysis involved the task of categorical aggregation (Creswell, 1998). In this process, the coded data are reviewed to collect similar instances in an effort to elicit common themes and create a framework to answer the research questions. This process was facilitated through the use of various tools such as charts, matrices and memos (Miles & Huberman, 1994). Emerging themes were explored between the interviews in an effort to search for relationships, consistencies and/or inconsistencies. Both authors met regularly to compare and contrast analysis results in order to ensure that all themes and events were captured. Credibility was assessed through member checks, a technique in which the findings and interpretations of the researcher are taken to informants for verification (Creswell, 1998). In this case, a transcript of the interview and a summary of the final themes were taken back to participants for feedback and verification.

Results

This study provided an opportunity for a diverse group of individuals to share their experiences around binge drinking in a confidential and personal setting with a trained Aboriginal addiction specialist. The participants in this study identified themselves as being at various phases in their recovery and, with the exception of two participants, all had been alcohol- and drug-free for 6 months or more. We report the results of the research by the following categories: a) description of binge episodes, b) triggers/risk factors for binge episodes, and c) factors that reduce binge episodes.

Description of Binge Drinking Episodes

Participants were first asked to describe their binge drinking behaviors, including the frequency/duration of their binge episodes. For the majority of participants, individual episodes lasted 1 to 2 days with a

few participants noting that their episodes could last up to a week or longer. The frequency of binge episodes was weekly; binges primarily took place during the weekend. Participants reported that the frequency and duration of episodes steadily decreased both with age and their personal efforts to quit drinking.

Triggers/Risk Factors for Binge Drinking Episodes

Participants were asked to describe the influences and factors in their environment that they felt triggered individual bingeing episodes. As previously noted, weekends were the likeliest time for binges to occur; this finding was attributed to personal responsibilities (i.e., work, school, children, and money). As such, weekends were viewed as the only practical time to partake in binge drinking. Coupled with these constraints, other potential triggers for episodes included boredom, entertainment, and loneliness.

In addition, the prevailing attitude from participants towards binge drinking was one of normality. Many participants described binge drinking as something that everyone was doing and noted that the consumption of alcohol was the norm in their communities and/or social groups. This sense of normality was also conveyed by participants in the discussion of their own personal experiences with alcohol. Many described the cycle of alcoholism and substance abuse that took place in their own families and which subsequently became a part of their own lives.

It was a learned thing; I saw it as a child and would hopefully drink myself to death. I didn't want to see anything, it was an escape route.

Almost all participants described their binge drinking as part of a larger picture of substance abuse in their lives. Many described themselves as alcoholics and several noted concurrent substance abuse issues around IV drugs, prescription medications, and marijuana.

Participants also identified other immediate triggers for their binge drinking episodes. For example, two participants described anger as a reason behind their binge drinking and saw binge drinking as a way to release their frustration. Stress from work and relationships often pushed individuals into a binge. Several noted problems in parenting often motivated their drinking and that a binge was an escape from or numbing of this stress.

I didn't know how to be a parent and when it came to pressure and stress, that's when I would do my drinking.

In addition to these immediate triggers, participants also described broader elements in their lives that they felt contributed to their binge drinking. Foremost of these was a background of abuse including mental, physical and sexual. For some, the source of abuse was family members during childhood and adolescence. For others, the abuse continued and/or started during adulthood relationships, usually a spouse. Participants described their binge drinking as a way of escaping from, or numbing the emotional pain caused by the abuse.

I was dealing with so many issues, dealing with sexual abuse and physical and mental abuse from my family and what not. And I just had no support systems at home. I couldn't connect with my mom and dad. And the only real friends that I had were drug addicts or alcoholics so I sunk to that road.

Furthermore, many participants also described low self-esteem and a lack of identity as contributing to their binge drinking. Participants expressed shame and feelings of insecurity about themselves and a desire to be accepted by spouses and/or peer groups. Individuals provided similar descriptions of the negative self-images that they felt contributed to their drinking.

I think I was drinking because I wanted to be accepted by others, by my peers. And I drank because I was insecure.

Like I knew somewhere I didn't understand at the time who I really was. I guess I worked out what my potentials were. Like I didn't know at the time that I really wanted to find out who I was and I hated that feeling of being looked down on.

Closely related to the feelings of low self-worth expressed by participants were feelings of a loss of cultural and community identity, as well as racism. Most participants related their binge drinking to a broader perception of shame and cultural loss within their community.

The way I look at it, it was a total negation of being Indian. When I was born, nobody wanted to be Indian; there was so much drunkenness in those days. When we were children, that's when all this racial discrimination eroded our identity. We felt inferior because that whole brand of being Indian was so negative. We had to get our culture back, claim it back. And that's what I gained.

For some, the loss of culture and identity began in residential schools, where they were forbidden to practice Aboriginal culture and traditions.

I think the culture part is, when I went to residential school, I was being forced to put it aside. I was forced not to practice anything that I was taught when I was a little child.

Cessation of Binge Drinking Episodes

Individual binge episodes were usually brought to an end by practical constraints such as the end of the weekend, running out of money, or the need to take care of children. For some participants, a binge episode would only come to a close when they were no longer physically able to continue.

Factors that Prevent Binge Drinking Episodes

As described earlier, a number of causes were described that brought an end to a binge episode. These factors are different from those that can actually prevent the initiation of a binge episode. Binge prevention factors often played a role in allowing participants to remain abstinent.

Most individuals described an acute event or a personal realization of hitting rock bottom that forced them to quit drinking, such as the loss of a relationship or employment. For several participants, this came in the form of an accident or near-death experience during a binge-drinking episode. They noted that this event seemed to jolt them into seeking help and/or quitting.

I got ganged up on a couple of times, a couple of car accidents and a few work related accidents too. I wasn't in the right frame of mind...it just stuck with me that I could have died. I just wanted to turn my life around finally, not only that too but that point where you know people say you get sick and tired of being sick and tired.

I started drinking and got up the next morning and had to go the hospital with alcohol poisoning. So, that's what made me decide that it's got to come to a complete stop.

Changing responsibilities and/or perceptions about family were other reasons for quitting. One individual said it took the birth of her children to end her drinking, while for others who already had children, it was a

growing desire to be a positive role model and not expose their children to a drinking environment. Several individuals expressed deep concern that their children would continue the cycle of alcohol abuse that was passed on to them from their own parents.

Participants also identified factors that supported the continued cessation of their binge drinking after they had decided to quit. Foremost of these was the establishment of positive social support networks that assisted them in their efforts to keep away from alcohol and directed them to other supports. Friends, members of support groups, or individuals met through cultural events were all described as potential role models.

There stood a man who told his story who said he had a similar problem. He was the living proof that if he can do it, I can do it. And then it was the cultural way.

Many participants told of the personal implications of choosing Aboriginal persons as part of their support networks. Such choices provided participants an opportunity to share similar experiences and backgrounds, which were part of what several individuals described as the "Aboriginal experience."

Finally, personal development played a key role in allowing participants to continue their binge drinking cessation. Most participants described a perceived lack of personal and coping skills throughout their lives and noted that the lack of such skills was connected to their binge drinking. The recognition of the need to build these personal skills was key to stopping their binges.

It was a whole learning mode, personal development, interpersonal relationship, and problem solving skills, communication skills. There were other ways to do things that weren't a destructive way.

Cultural participation also assisted participants in their initial efforts to quit drinking and played a key role in allowing them to remain sober. Participating in cultural events such as sweats, round dances, and smudging on a regular basis was described as part of the abstinence process.

Yes, if I hang on to that then I'm gonna stay sane and sober. It's when I don't think about my culture and the belief that I have.

In conjunction with recapturing cultural traditions, participants also described a renewal of spiritual elements in their lives that they felt gave them power to remain sober. This came through in participants'

descriptions of turning to a Creator through prayer and the practice of traditions. Two participants described vivid spiritual experiences that they identified as playing an ongoing role in keeping them from binge drinking.

My culture, that's the other thing that's really helped me along the whole way, is my culture has always been there for me, and a higher power. When I straightened out, who I turned to was my creator, the ceremony, my traditions...pulled me out of where I was.

Discussion

This research is the first of its kind and represents an exploratory qualitative inquiry into the binge drinking behaviors of a sample of 15 Aboriginal persons who either were participants in an Aboriginal women's support group or were staff at an Aboriginal social service agency or an Aboriginal Addiction Treatment Centre. Typical binge episodes of participants lasted 1 to 2 days and usually took place on a weekly basis. Responsibilities and constraints due to work or family created boundaries and limitations for the frequency and duration of these episodes. Triggers and risk factors for binge episodes included social influences, boredom, a sense of normality around binge drinking, a personal history of addiction, anger management issues, life stressors, a history of abuse, low self-esteem, and a sense of cultural loss. Factors that contributed to a reduction in binge drinking were often related to an acute event combined with gradual life changes. Supporting influences to remain sober included positive social support networks, role models, personal development, and cultural/spiritual practices.

The results of this study in part reflect those found in previous research undertaken on risk factors for binge drinking. It has been suggested that binge drinking is influenced by a range of factors that encourage this kind of drinking (i.e., celebrations, social interactions) and the belief that the decision to engage in binge drinking is under the person's control (Norman, Bennett, & Lewis, 1998). Having a social network of individuals who drink relatively heavily has also been shown to be a risk factor for binge episodes (Reifman & Watson, 2003) and is reflected in the findings from our study. Most participants in our study described a family history of alcoholism, as well as childhood abuse. Past research has revealed a significant relationship between these factors and chronic/heavy drinking in later life (Hasin, Paykin, & Endicott, 2001; Jasinski, Williams, & Siegel, 2000). Similarly, participants in our study identified and discussed the negative impact of this background on their own drinking behaviors. Participants also described a broader pattern of addiction to alcohol beyond bingeing episodes, as well as other substance abuse issues.

This finding is also reflective of previous work that found higher rates of alcohol dependence and substance abuse issues among heavy/binge drinkers (Robin et al., 1998; Curry et al., 2000). The issue of self-esteem and identity as a risk factor for binge drinking was also evident in this study and again mirrors the results of previous work that describe this relationship (Blume, Schmaling, & Marlatt, 2003).

Our study identified characteristics related specifically to Aboriginal binge drinking. Key unique findings from this study relate to the etiology of personal issues stemming from residential school experiences, family disconnect, loss of culture, and an expressed sense of shame. Participants described these factors as part of the "Aboriginal experience." Not surprisingly, the development of personal skills and the embracing of Aboriginal culture were key elements for participants in their successful reduction of binges. This fact highlights the need for community-based skills development and cultural programs during addictions treatment. Studies describe the importance of Aboriginal cultural/spiritual components in reducing alcohol consumption (Stewart-Sabin & Chaffin, 2003; Kunitz & Levy, 2004). Programs incorporating these components have sought to foster cultural pride, identity, and values through cultural teachings and activities (Stewart-Sabin & Chaffin, 2003).

The application of these traditional beliefs and practices may also have implications for the larger community, as well as for prevention services. Such beliefs are currently being embraced as a key component of many addictions and health promotion programs. Our study results also contribute to the understanding of the role and mechanisms of these cultural programs by providing personal descriptions of their impact on substance abuse recovery. In addition, given the apparent effectiveness of interactive websites among binge drinkers, such needs to be considered for Aboriginal people who often dwell in rural communities in which there are well-know barriers to accessing addiction services (Chiauszi, Green, Lord, Thum, & Goldstein, 2005).

The limitations of this study are reflective of the sample that was selected. First, all of the participants in this study were clients/staff from Aboriginal service agencies. Many Aboriginal people do not access Aboriginal-based services, either because of personal preference or a lack of access to these services. Further, those individuals who do choose Aboriginal services may purposely be seeking cultural approaches to their treatment. As such, their responses regarding the importance of these factors in their recovery/treatment may reflect this preference. However, it should be kept in mind that almost three quarters of Aboriginal people preferred Aboriginal oriented services (Wardman, Clement, & Quantz, 2005). Second, individuals who have not yet sought treatment for binge drinking are not included in the selected sample. Their perceptions, risk factors and behaviors related to binge drinking may differ from the selected sample. Third, although binge drinking is more often associated with

males, the majority of participants in the study were female. Gender differences are likely in binge drinking behaviors (i.e., impact of family), treatment and recovery patterns. The higher rate of participation from females may also reflect a greater willingness and comfort for women to share their stories and experiences. Finally, as a third of participants were staff members, it is possible that they may be denying drinking behaviors in spite of confidentiality assurances. Although the results are not necessarily generalizable to larger populations, the purpose of this work was to explore the impact and perceptions of binge drinking among Aboriginal persons, which have not previously been examined in the literature.

The results also highlight a number of gaps and opportunities for further research on this topic. First, the role of controlled drinking needs to be better understood in Aboriginal populations. Abstinence rates are traditionally higher among Aboriginal persons (Wardman & Quantz, 2005) and considering the role of social networks and community perceptions found in this study, further research is needed on the impact of this relationship to community levels of binge and heavy drinking. Second, the role of cultural interventions on binge drinking also warrants further work. All participants emphasized the role that culture played in reducing their binge drinking and further research should focus on describing and evaluating the pathways and impact of culturally based treatment programs. A third area of need is more rigorous study of the prevalence and impact of binge drinking. Many of the participants described their binge drinking as private and expressed the desire to hide these behaviors. This finding may impact prevalence studies by underestimating the actual numbers of binge drinkers. Further work must also attempt to identify the health and social outcomes of binge drinking behavior. Participants in this study identified a number of personal impacts including poor health, mental health issues and injuries. Future research should focus on providing community-level data on these outcomes and elicit a clearer conception of these issues. Finally, the role of health professionals as a point of intervention for identifying problem drinking should be assessed. Curry et al. (2000) note the opportunity to identify at-risk drinking behaviors during routine primary care visits. The ability of health providers serving Aboriginal clients to identify binge drinking warrants further investigation.

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Footnote

- ¹ A "binge" is a pattern of drinking alcohol that brings blood alcohol concentration (BAC) to 0.08 gram percent or above. For the typical adult, this pattern corresponds to consuming 5 or more drinks (male), or 4 or more drinks (female), in about 2 hours.

SOCIAL NETWORKS, SUPPORT, AND PSYCHOSOCIAL FUNCTIONING AMONG AMERICAN INDIAN WOMEN IN TREATMENT

Jenny Chong, Ph.D. and Darlene Lopez, M.S.

The relationship of social networks and social support to the psychosocial functioning (self-efficacy, self-esteem, anxiety, depression, and hostility) of 159 American Indian women undergoing residential substance abuse treatment at Native American Connections was assessed. Social support and active participation by clients' families during treatment were found to be significantly related to improved psychosocial functioning. No relationship was found between positive social networks and psychosocial improvement. Interventions for substance abuse should aim to include family and friends in clients' treatment.

Keywords: Social support, social network, substance abuse, treatment, American Indian, women

American Indians with substance use problems report a large number of stressful life circumstances, including domestic violence, child abuse trauma, negative family relationships, and social isolation (Brindis et al., 1995; Gutierrez, Russo, & Urbanski, 1994). Major obstacles to recovery for American Indian women were reported to include unsupportive partners and returning after treatment to a community where substance abuse is widespread (Brindis et al., 1995). High rates of continued drinking and relapse are common (Herman-Stahl & Chong, 2002; Kivlahan, Walker, Donovan, & Mischke, 1985; Westermeyer & Neider, 1984). Nevertheless, American Indians with high self-esteem and low levels of anger have been shown to have a low relapse rate (18%) 18 months post a substance abuse aftercare intervention (Hassin, 1998).

The risk of relapse among the general treatment population is also associated with psychosocial functioning issues such as self-esteem, depression, self-efficacy, and distress (e.g., Booth, Russell, Soucek, & Laughlin, 1992; Dodge, Sindelar, & Sinha, 2005; Flynn, Walton, Curran, Blow, & Knutzen, 2004; Rychtarik, Prue, Rapp, & King, 1992), as well as the types of social networks the clients have. An evaluation of over 1500 women clients of different ethnic groups (with children or postpartum) funded by the Center for Substance Abuse Treatment showed that the

risk of relapse was significantly reduced if the clients reported fewer associations with negative peer networks, or if they reported having positive family relationships six months post discharge (Ellis, Bernichon, Yu, Roberts, & Herrell, 2004). These findings suggest that for substance abuse treatment to have a long-term positive impact, programs should facilitate the development of social support, positive coping skills, and self-efficacy to combat the negative environmental factors that face the newly rehabilitated individual (Annis, Sklar, & Moser, 1998; McCrady, 2004).

The purpose of this paper is to describe the social networks and their relationship with social support and psychosocial functioning among American Indian women in an urban substance abuse residential treatment program. Social support is assessed by perceived social support, a self report measure from a social support scale (described below), and observed social support, measured as the presence of actions taken by others for the client. Two hypotheses are tested to determine the influence of social support: 1) Social support (perceived or observed) will significantly improve the psychosocial functioning of clients; and 2) Women who have more supportive family and/or friends will be more likely to improve their psychosocial functioning than those who do not. Improved psychosocial functioning will be indicated by an increase in self-esteem or self-efficacy, or a decrease in anxiety, hostility, or depression from intake into the program to discharge from the program.

Israel and Rounds (1987) described social networks as referring to ... "linkages among persons," and social support as referring to "functions that may or may not be provided by these linkages" (p.316). Social support received from others may be perceived or actual (Beattie & Longabaugh, 1997, 1999) and differ with different social networks. Research on general treatment populations showed that social support improved treatment engagement (Lash, Burden, Monteleone, & Lehmann, 2004), increased clients' commitment to treatment (Broome, Simpson, & Joe, 1999), decreased anxiety (Mallinckrodt, 1989), and reduced psychosocial distress (Thoits, 1985). A decrease in relapse was associated with social support that enhanced self-esteem (Booth, Russell, Soucek, & Laughlin, 1992) and encouraged abstinence (Beattie & Longabaugh, 1999; Gordon & Zrull, 1991; Weisner, Delucchi, Matzger, & Schmidt, 2003).

Involvement of individuals from outside of the therapeutic milieu in clients' treatment was significantly related to clients' improved psychosocial well-being (Broome et al., 1999; Galanter, Keller, & Dermatis, 1997; Mallinckrodt, 1989). This is an important consideration for American Indians since they tend to rely on family and extended family networks for social support (MacPhee, Fritz, & Miller-Heyl, 1996). Among socially well-adjusted American Indians, supportive parents and other network support were credited for their success (Neumann, Mason, Chase, & Albaugh, 1991).

Family and peer social relationships have been shown to influence treatment outcome among women (with children or postpartum) six months post discharge (Ellis et al., 2004). They were also found to have an influence during treatment among multi-ethnic clients who were daily users of heroin admitted to three community-based methadone maintenance clinics (Knight & Simpson, 1996). An exploratory factor analysis conducted on items describing family and friends among this population yielded two factors describing peer deviance and family conflict or dysfunction (Knight & Simpson, 1996). Both factors were found to predict poor psychosocial functioning during treatment (Griffith, Knight, Joe, & Simpson, 1998). A reduction in family conflict was associated with less drug use and less criminal activity (Knight & Simpson, 1996). However, if family conflict or peer deviance remained the same or worsened during treatment, the likelihood of clients engaging in drug use or criminal activity increased.

The influence of familial and peer relations on treatment engagement and psychological functioning has not been sufficiently described for American Indian women. Those with a substance use problem report unsupportive partners and family members who drink as experiences in their adult life (Brindis et al., 1995; Chong & Herman-Stahl, 2003). For clients who live in rural areas such as the reservation, participation in the treatment program that helps clients to improve relations with family members who are abstinent or choose new friends is limited. Once clients leave the treatment agency, their chances of resuming relationships with individuals who may have contributed to their earlier use of substances (e.g., partner, family) are high. Being placed in such a situation will require relapse prevention skills (Falkin & Strauss, 2003). In a study aimed at providing telephone aftercare support to American Indian clients who were returning to their reservations after substance abuse treatment, four out of five clients were found to have left their partners at the three-month follow up (after discharge). By the six-month follow up, most were living with their family, and none reported being satisfied with their living conditions (Chong & Herman-Stahl, 2003). This dissatisfaction may predict a relapse if it indicates a less than supportive family network.

Recognizing that including family members and friends in clients' treatment may be beneficial, the urban treatment center involved in this study (Native American Connections) adopted a policy to encourage their active participation and improve clients' social support in agency-sponsored events such as family weekend retreats. The center also encouraged families and friends to come to graduation, as well as to other less regular events. To measure support that was observable while the client was in treatment, we selected two activities for which we had information: participation of family and friends in family weekend retreats and client graduation. The family weekend was a three-day intensive retreat for

clients and family. The definition of family by the program was broad and included anyone that the client felt was important to her. Such events were organized for no more than four families at a time. Outside support systems were encouraged to attend graduation ceremonies to mark an important milestone, and to help clients feel proud of their achievements. Family and friends who attended these events included probation officers and tribal counselors from within and outside of the State.

The salient characteristic shared by these two activities is their resource-intensive nature. Participation may be difficult for clients' families and friends due to the distance that most have to travel from rural reservations. The knowledge that her family and associates are willing to show their commitment and support by making the journey to the treatment center may have an immediate and lasting influence on how a client interacts with friends and family when she returns home. We believe that this measure, which we term observed social support, is an indicator to the client of others' commitment toward her. Psychosocial changes between those who had such observed support and those who did not have involvement of family and friends when they were in treatment were compared.

Methods

Adult American Indian women entering a residential substance abuse treatment program at Native American Connections were recruited within 3 days of entry to participate in a treatment outcomes study as part of a Treatment Capacity Expansion grant funded by the Center for Substance Abuse Treatment (CSAT). The period of recruitment was between February 2002 and May 2004. The clients came from urban and rural areas, with a large proportion from southwest American Indian reservations. Only two criteria were needed for participation in the research part of the project for these clients: that they are American Indians and that they were willing to be interviewed for research purposes (and indicated so by signing a consent form which described the research procedures). No compensation was given for the intake or discharge interviews.

Previously approved informed consent procedures used for recruitment included informing the clients that their responses were voluntary and that results to be reported would be in summary form and not identifiable. Honesty in responses was stressed. The recruitment and interviews were conducted by two trained American Indian research interviewers in a private office. A total of 346 American Indian women were interviewed at baseline. Thirty-five women who were approached refused to participate in the research (9%).

Several questionnaires developed by the Institute of Behavioral Research at the Texas Christian University (TCU) were used (questions about family, friends, and psychosocial functioning). They are the TCU's Intake Questionnaire for women in residential treatment and the Client Evaluation of Self and Treatment (CEST). To compare differences between clients who were included in the study and those that were not, severity composite scores from the Native American Addiction Severity Index (ASI-NAV; Carise, Wicks, McLellan, & Olson, 1998) were used. These questionnaires (TCU questionnaires and ASI-NAV) were used in addition to those required by CSAT, the funding agent.

Relationship with Family and Friends

Information about clients' social networks was collected using items taken from the TCU Intake Questionnaire (see Appendix 1). Clients were asked to rate specific sentences with regard to their family and their friends. This instrument had been in use by the Drug Abuse Treatment for AIDS-risks reduction (DATAR) Project since the late '80s (Simpson, 1991), and is available on the TCU-IBR Web site. Clients were asked to rate what it usually was like when they spent time together with their family, as well as to rate sentences that describe their friends in terms of their activities and their attitudes. For all questions, the rating was from never, rarely, sometimes, often, to almost always. Similar to that reported by Knight and Simpson (1996), two factor analyses were conducted, one for the client's family, and the other, the friends. The varimax rotated factor scores from each analysis were used as variables to describe clients' social networks.

Clients' psychosocial functioning was measured using the CEST. This instrument provides a comprehensive but brief means of measuring a number of psychosocial and treatment attributes of clients as well as program characteristics while in treatment (Joe, Broome, Rowan-Szal, & Simpson, 2002). Several of its subscales were used in this paper: self-esteem, depression, anxiety, self-efficacy, hostility, and perceived social support (see Appendix 1). Clients rate sentences regarding whether they strongly disagree (1) to strongly agree (7) with each sentence. Some ratings were recoded to ensure that high values denoted a higher value of the attribute. The scales have been found to be comparable to other established scales (Joe et al., 2002). The subscales have good psychometric properties with relatively high reliability and goodness of fit coefficients across split half samples (N = 787) (Knight, Holcom, & Simpson, 1994). More recent psychometric data with a larger group of respondents (N = 1702) from 85 treatment units showed that alpha for self-esteem, depression, anxiety, hostility, and social support were 0.75 or better. The alpha coefficient for self-efficacy was 0.63 (Joe et al., 2002). No information is available regarding how well the scales apply to American Indians.

General self-efficacy was measured using 7 items. Self-esteem was measured using 6 items, hostility was measured with 8 items; anxiety was measured with 7 items; depression with 6 items; and perceived social support with 12 items. For each scale, the maximum score would be 7 (highest possible score per item) multiplied by the total number of items in that scale, and the lowest score would be 1 (lowest possible score by item) multiplied by the total number of items in that scale. Dependent measures were difference scores of these constructs (Discharge – Intake). For self-esteem and self-efficacy, a positive difference score suggests higher self-esteem or self-efficacy at discharge. In contrast, for anxiety, hostility, and depression, a negative score indicates a good outcome; that is, lower anxiety, hostility, and depression at discharge. Since changes across the measures were not compared, the difference scores were not standardized.

The perceived social support measure was also taken from the CEST and contains 12 items describing the existence of unspecified individuals who provide support and have expectations of the clients as well as an item each on family, friends, and the work environment. Only the baseline measure of social support was used in this set of analyses because the clients' perceptions upon entry into the program may be an important predictor of changes in psychosocial functioning.

The observed social support did not depend on client self-report but instead was information collected from the counselors as well as administrative records. This measure indicated whether family, friends, or associates participated in organized events such as the client's graduation, or weekend-long family therapy events (coded yes/no).

Addiction Severity Index Native American Version

The Addiction Severity Index Native American Version (ASI-NAV) was used to compare the problem severity of clients who were included in the analysis for this article with those who were not. The ASI-NAV is an adaptation of the Addiction Severity Index (ASI) and was developed to accommodate Native American cultural practices (Carise et al., 1998), based on pilot tests with North Dakota tribes (Carise & McLellan, 1997). The composite scores are derived in the same manner as the ASI. The ASI has been used in a variety of settings and has been shown to have good reliability and validity among different populations (Grissom & Bragg, 1991; Kosten, Rounsaville, & Kleber, 1983; McLellan et al., 1985). The composite scores indicate the severity of specific problem areas (medical status, employment/support status, substance use, legal, family/social, and psychiatric status) in terms of the need for further or additional intervention. The ASI composite scores range between 0 (denoting no problem) and 1 (denoting most severe problem).

Data collected were entered into a Microsoft ACCESS database and subsequently converted into an SPSS database for statistical analyses. Factor analyses were used to obtain information about the clients' social networks; these networks were then assessed to determine their relationships with social support as well as with the clients' psychosocial functioning. Data analyses included exploratory factor analyses, correlations, multiple regressions and Analysis of Variance (ANOVA). Varimax rotations were used for the factor analyses, and only factors with eigenvalues of 1 or greater were accepted. Statistical significance was set at $p \leq 0.05$, with Bonferroni corrections used for post hoc tests. Power for the multiple regressions, given a small r square of 0.1 for a sample of 159 individuals, was calculated to be at 0.91 using the PASS power software (Hintze, 2000).

Only individuals who had completed all three sets of questions that were used for this paper were included in this analysis. These questions were in regard to clients' families and friends, and for the CEST questionnaire, completed twice, once at intake and once at discharge. Not everyone received all of the intake questionnaires or the discharge questionnaire for a variety of reasons. Some clients were "lost" because they left before completing all the baseline/intake questionnaires. Since the priority questionnaires, that is, those required by the funding agent (CSAT), have to be administered first, the set of questions to be used for this study may not have been administered if clients dropped out within the first seven days of the program, but after they had been given the CSAT questions. Clients were considered to be a part of the project if they completed the CSAT intake questions, regardless of whether they completed the other questions. Clients who did not receive the discharge questionnaire include those who left earlier than expected, either against staff advice (19%) or for logistical reasons. These reasons include being transferred, hospitalized, or jailed, or having unexpected transportation available for clients to go home prior to the interview appointment. Out of the 346 American Indian women interviewed at baseline, 159 clients were included in the analysis because they satisfied the prerequisite of completing all of the questions for this study.

Results

Table 1 shows the demographic characteristics of clients who received all three questionnaires (and, therefore, were included in the analyses for this paper) and those who did not. The group that was not included in the analysis stayed for significantly fewer mean number of days in the program, was significantly less likely to be classified as having completed treatment, was significantly more likely to have used drugs in the 30 days before entering treatment, and had fewer years of education than the group that was included in the analysis. Additionally, the group

Table 1
Differences Between Clients Who Had a Complete Set of Data Versus Those Who Did Not

	Std. Error Difference	Not included (N = 187)	Included (N = 159)	Mean Difference	95% Confidence Interval of the Difference		t	df	Sig. (2-tailed)
Length of Stay (days)	2.01	36.30	49.35	-13.05	-17.01	-9.09	-6.48	344	0.00
Age (years)	0.82	31.41	32.19	-0.78	-2.38	0.83	-0.95	344	0.34
Treatment Completion (1,0)	0.04	0.68	0.99	-0.31	-0.38	-0.24	-8.27	344	0.00
Education (years)	0.23	10.91	11.45	-0.53	-0.99	-0.07	-2.28	344	0.02
Past 30 day Substance Use (1, 0)									
Alcohol	0.03	0.89	0.94	-0.04	-0.10	0.02	-1.45	344	0.15
Drug	0.05	0.64	0.46	0.18	0.07	0.28	3.35	344	0.00
Alcohol problems	0.03	0.35	0.36	-0.00	-0.06	0.06	-0.02	342	0.98
Drug problems	0.01	0.14	0.09	0.05	0.02	0.07	3.45	343	0.00
Employment problems	0.03	0.85	0.80	0.05	-0.00	0.10	1.88	344	0.06
Legal problems	0.02	0.26	0.24	0.02	-0.02	0.07	1.05	344	0.29
Social problems	0.03	0.32	0.29	0.03	-0.03	0.09	1.07	340	0.29
Psychiatric problems	0.03	0.39	0.31	0.08	0.03	0.14	3.05	344	0.01
Perceived social support (12 – 84)	1.22	60.72	64.38	-3.67	-6.06	-1.29	-3.01	320	0.01
Observed social support (1, 0)	0.05	0.40	0.54	-0.14	-0.25	-0.04	-2.62	344	0.01
Self-efficacy (7 – 49)	0.82	35.03	35.52	-0.49	-2.10	1.13	-0.59	320	0.55
Self-esteem (6 – 42)	0.76	27.91	27.58	0.33	-1.16	1.82	0.44	320	0.66
Depression (6 – 42)	0.75	20.47	20.10	0.37	-1.11	1.85	0.49	320	0.62
Anxiety (7 – 49)	1.03	25.78	24.84	0.94	-1.09	2.98	0.91	320	0.36
Hostility (8 – 56)	1.08	24.15	22.86	1.29	-0.83	3.42	1.20	320	0.23

Nb: Range of scores are provided in parentheses.

that was not included also showed significantly more severe drug and psychiatric problems as indicated by the ASI composite scores. Finally, this group also reported significantly lower perceived and observed social support. No significant differences were found between the two groups in their intake psychosocial functioning, as measured by the CEST.

Social Networks

Two rotated factors emerged in the factor analysis of the family questions, accounting for 61.85% of the variance. To facilitate interpretation, only items with loadings (or correlation) of at least 0.45 (the lowest loading that provided the most unique items for each factor) were considered. These items are boldfaced in Table 2. The variance explained by each factor and the reliability analyses (coefficient alphas) are shown. The first factor describes a family that is considered close knit ("Close-Knit" family), and the second describes a family that uses substances together and appears to have negative social interactions ("Substance-Using" family). The coefficient alpha is high for the "Close-Knit" family items and lower for the "Substance-Using" family items. From the factor analysis of the questions about the clients' friends, five rotated factors emerged, accounting for 61.48% of the variance. The factors are termed "Substance-Using," "Family-Oriented," "Unsupportive," "Problematic," and "Respectful" friends respectively (Table 3). Items used to describe "Substance-Using" friends and "Unsupportive" friends showed high consistency.

The mean **Perceived** Social Support score was 64.38 (sd 10.29), ranging from 25 to 84. For **Observed** Social Support, approximately one half (46.5%) of the clients had outside family participate in their graduation, and 16.4% of the clients participated in the program's sponsored family weekend retreats. With the two groups combined, 54.1% of clients were coded as having observed support, that is, had family and/or friends participating in program events while they were part of the treatment program.

Table 2
Factor Analysis Results Describing Family Types

	"Close-knit"	"Substance-Using"
Have disagreements?	-0.38	0.52
Get drunk together?	-0.07	0.83
Use other drugs together?	-0.02	0.79
Have loud arguments or fights?	-0.55	0.50
Feel bored?	-0.58	0.35
Help each other with problems?	0.80	-0.07
Talk as friends?	0.84	-0.11
Get along together?	0.84	-0.19
Really enjoy being together?	0.85	-0.07
Variance accounted (%) Total: 61.85%	39.46	22.39
Coefficient Alpha	0.88*	0.69

Nb: Question: What was it usually like when you spend time together with your family?
How often did you (Response: Never, rarely, sometimes, often, almost always):
* Only those loading positively on the factor (Close-knit) were used

Table 3
Factor Analysis Results Describing Friend Types

	"Substance-Using"	"Family-Oriented"	"Unsupportive"	"Problematic"	"Respectful"
^b Ask for your advice about their problems?	-0.00	0.03	-0.11	0.35	0.69
^b Agree with your ideas?	0.17	0.01	0.01	-0.15	0.81
^b Look to you as a leader?	0.02	-0.09	0.09	0.01	0.81
^a Friends get into arguments	0.15	-0.22	0.01	0.75	-0.09
^b Take risks/chances?	0.29	-0.03	0.24	0.57	0.23
^b Cause trouble for you?	0.34	0.03	0.36	0.59	0.09
^b Encouraged you to enter this program?	-0.05	0.33	-0.71	-0.18	0.05
^b Really care about you?	-0.38	0.28	-0.69	0.13	-0.00
^b Will help you quit drugs?	-0.37	0.37	-0.64	-0.22	0.06
^b Laugh or make fun of you?	0.06	0.16	0.57	0.12	0.05
^a Like being with their family?	-0.14	0.84	-0.13	-0.16	-0.01
^a Seem positive or optimistic about life?	-0.43	0.47	-0.13	-0.26	0.06
^a Spend time with their families?	-0.09	0.78	-0.09	-0.05	-0.13
^a Work regularly on a job?	-0.44	0.46	-0.01	0.13	0.05
^a Get high from too much alcohol?	0.44	-0.36	0.32	0.39	-0.07
^b Do things that get them into trouble?	0.49	-0.11	0.51	0.44	0.11
^a Go to jail/prison?	0.52	-0.17	0.15	0.24	0.23
^a "Hang out" with other gangs?	0.60	0.01	0.13	0.17	0.08
^a Use other drugs?	0.68	-0.33	0.12	0.17	0.05
^a Do other things against the law?	0.84	-0.15	0.21	0.21	0.09
^a Trade, sell or deal drugs?	0.87	-0.11	0.12	0.09	0.01
Variance accounted (%)					
Total: 61.48%	18.68	11.81	11.55	10.07	9.37
Coefficient Alpha	0.86	0.69	0.76*	0.63	0.69

Nb: Two questions (Response: Never, rarely, sometimes, often, almost always):

^aWhat are your friends and associates like? In general, do they:

^bHow often would you say that your friends:

* Only those loading negatively on the factor (Unsupportive) were used.

Prior to the regression analyses, correlational analyses were conducted with the "Family" and "Friend" variables from the factor analyses, perceived and observed social support, and changes in the five psychosocial variables. Unless specified otherwise, all correlations mentioned are significant and positive. Perceived social support was significantly correlated with "Close-Knit" family ($r = 0.22, p < 0.01$) and "Respectful" friends ($r = 0.17, p < 0.05$), and negatively correlated with "Substance-Using" friends ($r = -0.22, p < 0.01$). Observed social support correlated only with "Respectful" friends ($r = 0.23, p < 0.01$). Perceived and observed social support did not correlate significantly with each other ($r = 0.01, p > 0.1$), even though both were significantly correlated with "Respectful" friends. The "Substance-Using" family variable was significantly correlated with the "Substance-Using" friends variable ($r = 0.18, p < 0.05$). None of the other factors for "Friends" correlated with the two factors for "Family." The factors could not correlate with each other within each factor analysis since, by definition, they are independent factors.

Relationship Between Social Support and Changes in Clients' Psychosocial Functioning

Mean scores for the levels of psychosocial functioning at discharge did not differ between those with high perceived and high observed social support. Perceived social support at intake was found to correlate significantly with changes in psychosocial functioning: negatively with self-efficacy and self-esteem, and positively with changes in anxiety, hostility and depression. Observed support negatively correlated with depression but positively correlated with self-esteem. Greater improvements in self-efficacy and self-esteem are seen among clients with low perceived social support and among clients with high observed support. Similarly, the significant positive correlations between perceived social support with anxiety, hostility and depression indicate that lower perceived social support at intake was associated with greater decreases in those measures. The "Substance-Using" friends variable showed a significant negative correlation with hostility and depression, and a significant positive correlation with self-esteem. Clients who scored higher on the "Substance-Using" friends factor improved more in terms of self-efficacy, and showed a greater decrease in hostility and depression than those who scored lower on that factor.

Linear regression analyses were conducted with the psychosocial change measures (Discharge – Intake) as dependent variables (see Table 4). To eliminate potential confounding, two sets of analyses were conducted: one with the social support variables, and the other with the "Family" and "Friend" factors as predictors.

Perceived social support at intake was significantly related to increases in self-esteem and self-efficacy, and with decreases in hostility, anxiety and depression. In contrast, observed social support was related significantly only to improvement in self-esteem, and a decrease in depression. While each of the models using the social support variables as predictors were significant, the best model only predicted about 11.4% of the variance (self-esteem). The models (for each psychosocial measure) using the "Friend" and "Family" factors were not significant with the exception of the depression model (Adjusted R squared = 0.05, $p < 0.05$; not shown). This suggests that other factors may be much better able to account for the variance than these social support variables. Consistent with the correlational analysis, "Substance-Using" friends significantly contributed to the model for depression ($t = -3.10$, $p < 0.01$).

Table 4
Linear Regressions of Social Support Variables
on Psychological Characteristics

Source	Measure	Unstandardized Coefficients		Standardized Coefficients		P
		B	Std. Error	Beta	t	
Self-esteem	Constant	17.36	3.45		5.04	0.00
Adj. R square =	Perceived social support	-0.20	0.05	-0.29	-3.82	0.00
0.114, p < 0.001	Observed social support	2.99	1.07	0.21	2.78	0.01
Self-efficacy	Constant	12.94	4.09		3.16	0.01
Adj. R square =	Perceived social support	-0.17	0.06	-0.21	-2.71	0.01
0.041, p < 0.02	Observed social support	1.48	1.28	0.09	1.16	0.25
Hostility	Constant	-18.98	4.34		-4.38	0.00
Adj. R square =	Perceived social support	0.25	0.07	0.29	3.85	0.00
0.084, p < 0.001	Observed social support	-1.80	1.35	-0.10	-1.33	0.19
Anxiety	Constant	-18.70	4.19		-4.47	0.00
Adj. R square =	Perceived social support	0.25	0.06	0.30	3.90	0.00
0.089, p < 0.001	Observed social support	-2.01	1.31	-0.12	-1.54	0.13
Depression	Constant	-14.91	2.88		-5.19	0.00
Adj. R square =	Perceived social support	0.17	0.04	0.29	3.80	0.00
0.107, p < 0.001	Observed social support	-2.32	0.90	-0.20	-2.59	0.01

The two social support variables (perceived and observed) show different relationships with self-esteem and depression from each other, as indicated by the beta coefficients. While the effect strengths are similar (comparing the standardized beta coefficients), they appear to work in opposite directions. To further assess the seemingly contrary finding between the two social support variables, another analysis was conducted. Since the two variables (perceived and observed social support) are uncorrelated with each other, they were combined into a general social support variable with four categories: High Perceived and High Observed, High Perceived and Low Observed, Low Perceived and High Observed and Low Perceived and Low Observed social support. High and low perceived social support was divided using a mean split. A one way ANOVA was conducted with the social support variable (4 levels) as the between subjects measure, and the changes in psychosocial functioning as the dependent variables (Table 5). Significant main effects of changes in self-esteem, anxiety, hostility, and depression were found. Comparisons (using

Table 5
One Way Analysis of Variance With Social Support (4 Levels)
and Changes in Psychosocial Functioning

		Sum of Squares	df	Mean Square	F	Sig.
Self-efficacy	Between Groups	329.70	3	109.90	1.66	0.18
	Within Groups	10253.07	155	66.15		
	Total	10582.77	158			
Self-esteem	Between Groups	652.68	3	217.56	4.52	0.01
	Within Groups	7468.27	155	48.18		
	Total	8120.96	158			
Anxiety	Between Groups	721.12	3	240.37	3.40	0.02
	Within Groups	10947.61	155	70.63		
	Total	11668.73	158			
Hostility	Between Groups	852.36	3	284.12	3.80	0.01
	Within Groups	11579.92	155	74.71		
	Total	12432.28	158			
Depression	Between Groups	659.34	3	219.78	6.88	0.00
	Within Groups	4952.22	155	31.95		
	Total	5611.56	158			

Multiple Comparisons using Bonferroni Corrections
with High Observed Low Perceived Groups

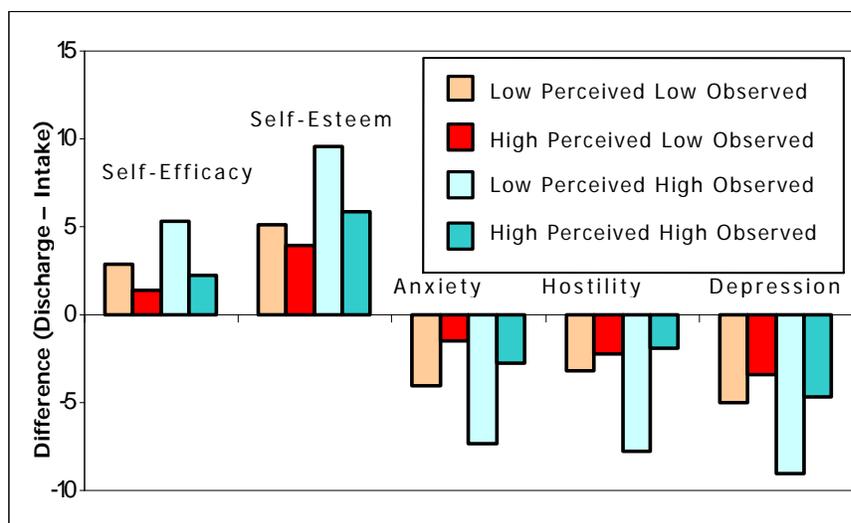
	Levels of social support	Mean Difference*	Std. Error	Sig.	95% Confidence Interval	
					Lower Bound	Upper Bound
Self-esteem	LPLO	4.42	1.59	0.04	0.17	8.68
	HPLO	5.61	1.63	0.00	1.27	9.96
	HPHO	3.63	1.51	0.10	-0.40	7.66
Anxiety	LPLO	-3.29	1.93	0.54	-8.44	1.86
	HPLO	-5.89	1.97	0.02	-11.15	-0.62
	HPHO	-4.57	1.83	0.08	-9.45	0.31
Hostility	LPLO	-4.58	1.98	0.13	-9.88	0.72
	HPLO	-5.48	2.03	0.05	-10.89	-0.07
	HPHO	-5.80	1.88	0.01	-10.82	-0.78
Depression	LPLO	-3.97	1.30	0.02	-7.44	-0.51
	HPLO	-5.57	1.32	0.00	-9.11	-2.03
	HPHO	-4.36	1.23	0.00	-7.64	-1.08

Nb: * Mean difference is difference between Low Perceived High Observed (LPHO) and the others. Positive difference means that LPHO has the higher score.

(LPLO Low Perceived Low Observed; HPLO High Perceived Low Observed;
 LPHO Low Perceived High Observed; HPHO High Perceived High Observed)

Bonferroni corrections) between the levels of social support indicated significant differences between individuals classified as having low perceived and high observed social support with those classified as having high perceived and low observed social support for all psychosocial changes except self-efficacy. The pattern of change was similar across all five psychosocial variables tested (Figure 1).

Figure 1
Changes in Psychosocial Functioning
as a Function of Perceived and Observed Social Support



Discussion

Our understanding of substance abuse treatment among American Indians is limited mainly to the environmental factors that led them to treatment and the factors that led them to relapse. In this paper, we have attempted to describe the relationship between the clients’ social networks, their perceived and observed social support, and changes in psychosocial functioning during treatment. The first hypothesis was supported: social support was significantly related to psychosocial functioning. The second hypothesis, however, was not. Women with more supportive families and/or friends did not appear to show greater improvement in the psychosocial measures. The “Substance-Using” friends factor was the only variable to show a significant relationship with clients’ psychosocial functioning. Nevertheless, families that are close knit and friends that show respect for the clients were significantly correlated with perceived social support, which in turn, was significantly related to improved psychosocial functioning.

Factor Profiles of Family and Friends

The two "Family" factors described opposite ends of the family spectrum, with one describing a close-knit family, and the other, a family that uses substances and appears dysfunctional. The absence of a strong relationship between clients' changes in psychosocial functioning and the two family networks is surprising. A study conducted on similar populations of American Indian women in substance abuse treatment reported a small but significant negative impact of families that use substances on clients' improvement in self-esteem (Gutierrez et al., 1994). That finding was not replicated in this study.

Friends, on the other hand, appear to have a stronger association with clients' psychosocial functioning. Out of the five "Friend" variables that were obtained from the factor analysis, the "Substance-Using" friends factor based on the intake data showed the strongest relationship with clients' psychosocial functioning. At the time of discharge from the treatment program, clients who scored higher on the "Substance-Using" friends factor became significantly less hostile and less depressed. There are at least two possible reasons for this finding. Further investigation showed that individuals who scored high on the "Substance-Using" friends factor were found to be twice as likely to have used drugs in the 30 days before entering treatment compared to those who scored lower. Alcohol use did not show such a difference. Second, being in a milieu that distanced the clients from negative networks may have weakened the influence of "Substance-Using" friends.

If clients are indeed influenced more by negative than positive social networks, then the approach adopted by the treatment program involving family and other individuals during treatment appears to be quite appropriate. Unlike the relatively impoverished social networks of outpatients on methadone maintenance reported by the TCU group (Griffith et al., 1998; Knight & Simpson, 1996), the clients in this study appear to have a varied group of social networks. Clients need to be guided toward those positive networks.

Social Support

Perceived social support at intake was shown to be a significant predictor of improved psychosocial functioning. Having perceived social support at intake indicates that clients believe they have people around them who would motivate and care for them, have confidence in, respect for, and expectations of them, and understand their problems. These clients showed higher self-efficacy and self-esteem, and lower depression, anxiety and hostility at the beginning of their treatment program than

those found to have lower perceived social support. The higher initial level of functioning may be a reason why they did not show as much improvement as those with lower perceived social support.

While the social support scale used here included statements that describe different types of social support (e.g., emotional, informational), there was no statement that asked about the provision of tangible social support (e.g., do tasks for client, show physical commitment, provide transportation, etc.). This may be the reason why perceived social support was not correlated with observed social support. The moderating effect of the observed social support on perceived social support is suggested from the combined perceived and observed social support variable. Clients with high perceived social support improved significantly less if they did not have family or friends providing observed social support than clients with low social support who did have family and friends involved in their treatment. This latter group improved to a level comparable to those with high perceived social support. These findings are consistent with existing literature showing that clients' mental health improved when they had others involved and demonstrating positive behaviors (Thoits, 1985).

Our findings with the observed social support agree with earlier findings which showed that involving family and outside individuals in therapy is associated with decreased depression and increased self-esteem (Broome et al., 1999; Mallinckrodt, 1989). Further analysis is needed to understand and define observed social support more clearly, as well as to assess the perceived quality of such support, a value found to be associated with psychological well-being (Israel, 1985). The activities that constitute observed social support may differ with different treatment populations. More research is needed to determine what actions are sufficient to be considered an act of observed social support, and whether different client types respond differently.

In addition, our findings are consistent with others and suggest that treatment interventions should aim to increase structural support (social network and integration) as well as to provide specific support to help maintain abstinence (Havassy, Hall, & Wasserman, 1991). The quality of relationships with extended family, friends, and partner/spouse has been found to predict long-term abstinence (Ellis et al., 2004; Humphreys, Moos, & Cohen, 1996). Thus, relapse may be mitigated if the treatment agency helps the client build up and strengthen her social support, maintain the relationships with those who provided observed social support during treatment, and discourage association with substance using (deviant) peers. If the size of the positive social network is increased, another positive outcome may result, since the number of individuals within a network is negatively associated with anxiety, depression, and hostility for females (Sarason & Sarason, 1985).

Study Limitations

A number of issues could not be resolved in this study. It is clear that other factors are involved in clients' psychosocial changes, as evidenced by the low amount of variance explained and significant residuals in the regressions. Additionally, it is not possible to attribute causal influences or impact of the social networks on psychosocial functioning.

Another limitation is that this study may not be generalizable, because there were significant differences between clients who were not included in the data analyses and those who were. Individuals dropped from the analyses had more severe psychiatric problems, more severe drug problems, or were current drug users. These individuals may not show the same results if provided the observed social support measured in this paper. Better methods are needed to minimize loss of data as a result of clients leaving earlier than expected. The TCU program suggests using the questionnaire quarterly to obtain data from clients; however, this is only appropriate for long-term programs. Since the length of the program in this project is 45 days, a mid-program assessment may be useful in future studies.

The questions regarding friends and family may not adequately describe the important social networks that clients have. This may be a reason why we were unable to show any relationship between observed social support and social networks (except for the "Respectful" friends variable, which nevertheless showed no relationship with changes in psychosocial functioning), and why the regression models explained little of the variance. However, the two main factors that were obtained (the "Substance-Using" family and friends) were similar to the family dysfunction and peer deviance factors reported by Knight and Simpson (1996) and had items similar to those reported by Ellis et al. (2004).

Unfortunately, we did not have information that would allow us to separately analyze the relationships between the client and her family and friends. A larger sample is needed to determine if different types of observed social support would show different results. Among clients who left early and were not included in this paper, the levels of perceived and observed social support were lower than for those who were included. One obvious reason for the lower observed social support score is that these individuals did not attend graduation. Nevertheless, it is also possible that if observed support was given early in these clients' treatment, dropout rates may decrease.

As mentioned earlier, the observed social support variable needs to be defined more precisely. While we were fortunate in selecting useful and predictive indicators of observed social support for this population, other exemplars need to be determined. How much effort (or commitment) that supportive individuals need to show for observed support is not known. One possible way to improve the observed social support measure would

be to record the number of times the clients had visitors, or the types of visitors they had. However, to count the number of visits may result in biased measures since such measurements assume that each client has visitors that have an equal opportunity to visit. As noted, it may be useful to determine whether the relationships between the client and the individuals (e.g., spouse, parents, siblings, professional associations, etc.) who provide the observed social support result in different psychosocial changes, as well as measuring the social support (perceived or observed) in terms of clients' social networks. Further research is needed to determine if clients who were shown observed support can reach out to those who provided the support when they leave the treatment environment.

Finally, this study did not address the longevity of the boost provided to clients by the observed social support, and whether the improvements would continue when clients are discharged from the treatment program. Further research is needed to study other types of social networks, and explore further how the different positive social networks can be garnered to counteract the negative social networks that represent the client's real world.

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Agency administrators and clinicians worked on informed consent procedures and protocols to ensure that the evaluation process is not stressful for the clients, and that clients do not feel coerced into participating in the evaluation process. Native American Connections works with clients with substance abuse problems, and is very clear on the need for confidentiality and HIPAA guidelines, on which all staff (including evaluation staff) has been trained.

Appendix A

Client's Evaluation of Self and Treatment (CEST)

<p>1 Strongly Disagree 2 3 4 Not Sure 5 6 7 Strongly Agree</p> <p>R) Reversed coding</p>	<p>Hostility (8 – 56) 'You feel mistreated by other people' 'You like others to feel afraid of you' 'You have urges to fight or hurt others' 'You have a hot temper' 'Your temper gets you into fights or other trouble' 'You get mad at other people easily' 'You have carried weapons, like knives or guns' 'You feel a lot of anger inside you'</p>
<p>Self-efficacy (7 – 49) 'You have little control over the things that happen to you' R) 'There is really no way you can solve some of the problems you have' R) 'You often feel helpless in dealing with the problems of life' R) 'There is little you can do to change many of the important things in your life' 'Sometimes you feel that you are being pushed around in life' 'What happens to you in future mostly depends on you' 'You can do just about anything you really set your mind to do'.</p>	<p>Anxious (7 – 49) 'You have trouble sitting still for long' 'You have trouble sleeping' 'You feel anxious or nervous' 'You have trouble concentrating or remembering things' 'You feel afraid of certain things, like elevators, crowds, or going out alone' 'You feel tense or keyed-up' 'You feel tightness or tension in your muscles'</p>
<p>Self-esteem (6 – 42) 'You have much to be proud of' 'In general you are satisfied with yourself' 'You feel like a failure' R) 'You feel you are basically no good' R) 'You wish you had more respect for yourself' R) 'You feel you are unimportant to others' R)</p>	<p>Depression (6 – 42) 'You feel sad or depressed' 'You have thoughts of committing suicide' 'You feel lonely' 'You feel interested in life' R) 'You feel extra tired or run down' 'You worry or brood a lot'</p>
<p>Social Support (12 – 84) 'Several people close to you have serious drug problems' R) 'You have people close you who respect you and your efforts in this program' 'You have people close to you who understand your situation and problems' 'You have people close to you who can always be trusted' 'You have people close to you who motivate and encourage your recovery' 'You have people close to you who expect you to make positive changes in your life' 'You have improved your relations with other people because of this treatment' 'Other clients in this recovery are helpful in your recovery' 'You have people close to you who help you develop confidence in yourself' 'You have close family members who help you stay away from drugs' 'You work in situations where drug use is common' R) 'You have good friends who do not use drugs'</p>	

Family and Friends Questions (TCU Intake)

FRIENDS

- What are your friends and associates like? In general, do they:
 0 Never 1 Rarely 2 Sometimes 3 Often 4 Almost Always
- 1 Work regularly on a job?
 - 2 Seem positive or optimistic about life?
 - 3 Get into arguments or fights?
 - 4 Spend time with their family?
 - 5 Like being with their family?
 - 6 Get high from too much alcohol?
 - 7 Use other drugs?
 - 8 Trade, sell or deal drugs?
 - 9 Do other things against the law?
 - 10 "Hang out" with other gangs?
 - 11 Go to jail or prison?
 - 12 Go to treatment for drugs and alcohol?

- How often would you say that your friends:
 0 Never 1 Rarely 2 Sometimes 3 Often 4 Almost Always
- 1 Look to you as a leader?
 - 2 Agree with your ideas?
 - 3 Laugh at or make fun of you?
 - 4 Ask for your advice about their problems?
 - 5 Cause trouble for you?
 - 6 Take risks or chances?
 - 7 Do things that can get them into trouble?
 - 8 Encouraged you to enter this program?
 - 9 Will help you quit drugs?
 - 10 Really care about you?

FAMILY

What was it usually like when you spent time together with your family? How often did you:

		Never	Rarely	Some- times	Often	Almost Always
1	Get along together?	0	1	2	3	4
2	Really enjoy being together?	0	1	2	3	4
3	Get drunk together?	0	1	2	3	4
4	Have disagreements?	0	1	2	3	4
5	Have loud arguments or fights?	0	1	2	3	4
6	Feel bored?	0	1	2	3	4
7	Help each other with problems?	0	1	2	3	4
8	Talk as friends?	0	1	2	3	4
9	Use other drugs together?	0	1	2	3	4