Abstract

Disability research and program evaluation have generally been viewed with suspicion in Indian country because research designs, procedures, instruments, and interpretation and dissemination of outcomes have often ignored potential cultural conflicts. This paper explores a national evaluation in eight tribal communities that established systems of care for children with serious emotional disturbances and their families. Examples of psychological and evaluation research in Indian country are briefly reviewed. A first step toward identifying challenges that Native children and their families face, and toward identifying strengths and weaknesses of service systems available to them, is to understand the extended family system of care. Systems of care and the "wraparound process" are culturally relevant concepts for service delivery. The federally funded Comprehensive Community Mental Health Services for Children and Their Families program has supported development of systems of care in 43 states, including 8 tribal communities. These eight tribal programs and their common structures and approaches are described, focusing on culturally appropriate assessment instruments and interventions. Evaluation of these programs is described, including system-level assessment of infrastructure and service delivery, longitudinal outcome study, language and translation issues, and how cultural incongruities between the national and tribal evaluations were handled. Community empowerment was enhanced through extensive, collaborative relationships between the evaluation teams and community-based advisory committees. (Contains 48 references.) (SV)
Cultural Competence Approaches to Evaluation in Tribal Communities

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Abstract

Disability research and evaluation in Indian Country are rare and have generally been viewed with suspicion by both rural reservation-based and urban tribal communities because designs, procedures, instruments, and interpretation and dissemination of outcomes have often been developed or selected without regard for potential cultural conflicts. This paper explores the implementation of a national evaluation in eight tribal communities that obtained grants to establish systems of care for children with serious emotional disturbances and their families. The congressional mandate to participate in the national evaluation has resulted in tribal communities taking a step into the world of research and evaluation. Some of the challenges and successes these tribal communities have experienced through their participation in the national evaluation are explored.

In the year 2000, American Indians and Alaska Natives (AI/AN) represented nine-tenths of 1% of the general U.S. population (U.S. Census Bureau, 2002); however, children and adolescents (under 15 years) in this population represent a greater proportion of the total population (33%) as compared to 22% for the general U.S. population (Hodge & Fredericks, 1999). It is important to note that AI/AN children and adolescents have been identified as being at a higher risk for mental disorders, depression, substance abuse, dropping out of school, delinquency, suicide, and homicide (in particular through vehicular accidents) than other ethnic minority groups and the general U.S. population (Nelson & Manson, 2000). It has also been suggested in the literature that these AI/AN incidence rates will increase with age at an accelerated rate as compared to all other racial or ethnic groups in the United States (Barlow & Walkup, 1998; Dion, Gotowiec, & Beiser, 1998; Goodluck & Willeto, 2000; Middlebrook, LeMaster, Beals, Novins, & Manson, 2001). It is clear that AI/AN children and families are in need of social and mental health services; however, determining the actual nature of a behavioral, emotional, or developmental disability is

1 The term American Indians/Alaska Natives (AI/AN) is not meant to homogenize individuals from distinctly different cultures into a single ethnic group; rather, it is the current term used to represent more than 500 federally recognized tribes, including approximately 2.4 million American Indians and Alaska Natives. Each of these sovereign nations has distinct languages, religious beliefs, values, and cultural, social, and political histories. With apologies, the terms AI/AN and AI will be utilized throughout this manuscript as an attempt at brevity.
fraught with challenges rooted in the sociological, cultural, and political histories of AI/AN people themselves and their experiences with psychological and evaluation research.

To further exacerbate the challenges evaluation researchers face, services and research in Indian Country (urban and reservation tribal communities) have been noted throughout the literature as being based in western psychological theory, which is contrary to the value structures and worldviews of these tribal communities. Issues such as tribal sovereignty, tribal government permission to conduct research, data ownership, isolation, cultural barriers, and methodological and dissemination issues (Ericksen, 1996; Manson, 1997; Mihesuah, 1993; Stubben, 2001; Trimble, 1977) continue to plague service delivery and research and evaluation efforts with this population. Today we continue to ask questions such as: “What services?” “Where should services be provided?” “How should service be provided?” “Who should provide services?” “Are services culturally appropriate?” “Are services effective?” “Who are the children and families being served?” “What are children and families experiencing?” and “How do children and families change across time?”

This paper will provide a brief overview of psychological and evaluation research in Indian Country, describe service programs, and offer examples of how current tribal community recipients of a services and evaluation grant program, the Comprehensive Community Mental Health for Children and Their Families Program, are dealing with the challenges of conducting evaluation research in their communities. Using descriptive data collected through the national evaluation of this grant program, it will discuss how these and other findings may be influenced by historical, cultural, and other factors.

Only a few tribal or regionally specific community studies (Beals et al., 1997; Cross, 1986; Novins, Duclos, Martin, Jewett, & Manson, 1999) and a handful of larger scale studies have been completed with the AI/AN child and adolescent populations (Beiser & Atteave, 1982; Cummings, Ireland, Resnick, & Blum, 1999; Dion, Gotowiec, & Beiser, 1998; Mitchell & O’Nell, 1998; Roy, Chaudhuri, & Irvine, 1970; Sampath, 1974; Shore, Kinzie, Thompson, & Pattison, 1973), raising at least as many questions as they attempted to answer. The largest and most recent study, which included 13,454 AI/AN children, concluded that “the connection to family remains a consistently powerful factor in the lives of these youth” (Cummings et al., 1999, p. 38). We will see this theme recurring throughout our discussion, revealing some of the many and significant meanings of family relationships in Indian Country and their implications for services, research, and evaluation.

The few smaller regional or tribal-specific studies often cited in the literature did result in raising an awareness of the “handicapping” and assessment issues with the AI/AN child and adolescent population. For example, early on, researchers found that as many as 75% of AI/AN children living in boarding schools have experienced school-related social or emotional problems (Dlugokinski & Kramers, 1974; Kleinfeld & Bloom, 1977), and Ramirez and Smith (1978) noted that as many as 38% of American Indian children in Bureau of Indian Affairs (BIA) (non-residential) schools were handicapped. Dion, Gotowiec, and Beiser (1998) found that both non-Native children and their parents rated themselves higher on depression than did AI children and their parents. However, the teachers of AI children had a tendency to assign these children higher depression and conduct disorder ratings than non-Native children. Fisher, Bacon, and Storck (1998) attempted to address the methodological issues in urban-rural comparisons by examining teacher ratings in these settings, finding that although American Indian youth have higher levels of internalizing and externalizing behaviors (e.g., depression and conduct disorder) than Caucasian youth in the same rural community group, differences are much less general and pronounced than previous research suggested. Additionally, the disproportionate
diagnosis of psychosis, mental retardation, and learning disabilities among Al/AN children, both in the hospital and public school systems, has long been noted in the literature (Fritz, 1976; LaFromboise & Plake, 1983; O’Neill, 1989; Roy et al., 1970).

Though the research cited above certainly provides information that may be useful to many psychologists and service providers, the concept of “disability” has little meaning in Al/AN communities where there is typically no distinction among cognitive, emotional, physical (developmental delays) and spiritual concerns or illness (Adair, Deuschle, & Barnett, 1988; Barlow & Walkup, 1998). Furthermore, the concept of illness (cognitive, emotional, physical, and spiritual) is often grounded in a relational worldview that is cyclical in nature and identifies the individual with an illness or disability as being “special” (Cross, 1986, p. 11) or as having been gifted with special abilities or personality characteristics. Therefore, words such as “disabled” and “handicapped” impose a worldview that conflicts with that of many Al/ANs. Those children and adolescents who experience serious emotional or behavioral problems, or both, are often considered to be passing through a developmental stage, and rather than intervene, parents and families tend to assume a “wait and see” approach. In order for program evaluation research to be effective and accurate, it must address underlying issues of the definition of, and expectations for, behavior and change among program participants.

Systems of Care in Tribal Communities

A first step toward identifying challenges that Al/AN children and families face, and toward identifying strengths and weaknesses of service systems available to them, is to understand clearly and comprehensively the roots of the key system from which these children emerge: the family system. Red Horse, Lewis, Feit, and Decker (1978) provide remarkable insight into the extended family system, identifying three primary differences between Al/AN families and White European or Caucasian families. The first difference they note is in the definition of extended family. The White European or Caucasian definition identifies the extended family as three generations living in the same household, whereas in Al/AN cultures it is defined as a village-type network construct which has a significant impact on behavior and socialization processes. Secondly, in Al/AN tribal communities this extended family structure transmits culture and conserves family patterns, which in turn contributes to identity development. Finally, according to Red Horse et al. (1978), the family promotes accountability in that it sets standards and expectations which then maintain the wholeness of the group through the enforcement of values. It is interesting to realize that we have come around full circle: from the establishment of reservations and the imposition of a nuclear family model which was used as an instrument to “civilize” tribal people and assimilate tribal culture, to modeling community mental health services after Al/AN systems of care (Medicine, 1981, p.14). Unfortunately, until recently, reawakening and operationalizing tribal systems of care in Indian Country has lacked organizational, political, and financial support. Instead, as in years past, these systems operate quietly underground and often go unrecognized or untapped as resources.

Scattered throughout the literature are “gems of wisdom” (Cross, 1986; LaFromboise, 1988; Medicine, 1981; Red Horse, 1980; Swinomish Tribal Mental Health Project, 1991; Trimble, Manson, Dinges, & Medicine, 1984), each of which has offered “road markers” for service development and delivery to Al/AN populations. Respected American Indian leaders in the field direct us to turn to the extended family unit to answer questions about service development. Bea Medicine (1981) summarizes the discussion of future directions in the field with, “We should be discussing the underlying orientations, beliefs, and kinship systems of a variety of Indian families” (p. 13). This suggests that we need to pave our services
highway with those family-based cultural values, beliefs, and kinship systems that are specific to the tribal community and to those families who may depart from the "norm" in their community. The concepts of systems of care and the "wraparound process" (interagency services addressing emotional, physical, mental, and spiritual needs of the child and family, from therapy to respite care), were initially introduced by Stroul and Friedman (1986); however, as Debbie Painte (in Kendziora, Bruns, Osher, Pacchiano, & Mejia, 2001) noted, the wraparound concept was not a new concept in Indian Country but "is a revisiting of our former village and clan and tribal structures" (p. 31). She further explained how the wraparound process represents a return to traditional ways. "This whole cultural erosion that we've had really has led to some of the challenges that we face. We needed to find a way to rebuild those structures that we had for our families before. When we heard about Wraparound, it clicked. This is how we bring those interventions back. Those cultural ways that we had. This is the validation of our culture" (p. 31). Most, if not all, Al/AN individuals, families, and communities would concur.

Federal funding began in 1993 for grant communities to develop "systems of care" for service delivery to children and adolescents with serious emotional disturbance and their families through the Comprehensive Community Mental Health Services for Children and Their Families Program. This program, supported by the Center for Mental Health Services (CMHS) in the Substance Abuse and Mental Health Services Administration (SAMHSA), has a strong commitment to program evaluation and to building evaluation capacity in grant communities. This federal initiative has supported the development of systems of care in 43 states, including eight Al/AN communities. The initiative includes a mandated national evaluation component that follows congressional efforts toward program accountability.

The congressional mandate that federally funded programs must be evaluated, as well as the program's investment in building community capacity for evaluation, have resulted in grant-funded tribal communities taking a step forward into the world of research and evaluation. The following section provides a brief description of the tribal communities funded by CMHS to develop systems of care. It will be followed by a description of the national evaluation developed for CMHS-funded grant communities and will include a description of evaluation activities in these communities that include efforts to implement the national evaluation in tribal settings, as well as efforts to develop community-specific evaluations that address unique characteristics of tribal programs not captured by the national evaluation.

Among the eight tribal communities receiving CMHS funding to develop and implement systems of care since 1993, two communities had previously participated in CMHS Circles of Care planning grants (Sault Ste. Marie and Oglala Lakota). Together, these two federal initiatives offered financial support that, for the first time, provided opportunities to "reawaken" historically and culturally based systems of care within these tribal communities. The first American Indian tribe to receive funding by CMHS was the Navajo Nation, in 1994, through its K'é project. In subsequent funding cycles seven additional tribal programs were funded: in 1997 Kmihtqitasultapon (Passamaquoddy Tribe, Maine), and Sacred Child (Inter-tribal in North Dakota, South Dakota, and Montana), in 1998 Mno Bmaazid Endaad (Sault Ste. Marie Tribe of Chippewa Indians and Bay Mill Anishnabe tribal communities, Michigan), and With Eagles' Wings (Northern Arapaho and Eastern Shoshone, Wyoming), and most recently, in 1999, Yuut Caliriit Ikaiyuquulluteng (Yukon-Kuskokwim Health Corporation, 58 villages, Alaska), AK-O-NES (United Indian Health Services, Humboldt and Del Norte Counties, California), and Nagi Kicopi (Oglala Sioux, South Dakota).
In 2000, Terry Cross and his colleagues conducted a series of focus groups and presented a number of common themes inherent in the structures of five of these tribal programs. They included the use of 1) extended family; 2) traditional teachings; 3) culturally specific approaches; 4) cultural restoration (mentors, crafts, language); 5) methods that promote healing of Indian identity and self efficacy; 6) methods that build connections to community, culture, group, clan, extended family; 7) methods that are based in spiritual beliefs and support systems; 8) approaches incorporating elders or intergenerational approaches; 9) individual and family skill building for living in two cultures; 10) traditional helping values (e.g., 24-hour staff availability); 11) conventional and cultural methods to recognize and treat historic cultural, intergenerational, and personal trauma; 12) approaches that strengthen or heal the community; 13) incorporation of a respect for diversity within the tribe and within the service array; and finally, 13) conventional services (individual and family therapy, and health care services) (Cross, Earle, Echo-Hawk Solie & Manness, 2000, p. 48).

The eight tribal grant communities have other similarities, such as their organizational structures. The systems of care in some of these communities are grounded within programs offered historically by their respective tribal, social, and health programs and sponsored by their tribal governments (Navajo, Passamaquoddy, and Oglala Lakota). The other five programs (Sacred Child, Wind River, Sault Ste. Marie/Bay Mills, Humboldt, and YKHC) have an intertribal structure based on shared resources and geographic location, and have had an intertribal approach to the development of services and sponsorship for funding. They may be co-utilizing health clinic services under a single health care provider, such as United Indian Health Service (for Humboldt and Del Norte counties in northern California) and the Yukon-Kuskokwim Health Corporation, or have joined together to access funding because they are geographically close to one another, as are the Sault Ste. Marie Tribe of Chippewa Indians and the Bay Mills Tribe of Anishnabe (Ojibway), both located in the northeastern end of the Upper Michigan Peninsula, and the Northern Arapaho and Eastern Shoshone Tribes that share the Wind River Reservation in Wyoming.

For the most part, many of these tribal communities share similar challenges based on their geographic isolation, unavailable or unreliable transportation, severe weather, large geographic distances in their service delivery areas, and having access to few if any community-based mental health services within a radius of forty to a hundred miles of their communities. This is in contrast to some of the other tribal grant communities that are seemingly surrounded by the general population and therefore have limited (though possibly not culturally appropriate) services for their children and adolescents.

These eight tribal and intertribal programs are fairly representative of the diversity in reservation and urban service delivery settings across the country in terms of their levels of self-identified acculturation/assimilation. The differences between and within these tribal grant communities are clearly evident in both the service delivery structures and the arrays of services they have established and are demonstrating. Of great interest is the development of culturally appropriate assessment instruments and the use of unique treatment methods that are major contributions to the field. For example, the Navajo tribal grant community's service delivery structure is based on “K'é [which] means to have reverence for all things in the universe and to maintain balance and harmony by acknowledging and respecting clan and kinship” (Cross et al., p. 32). Accordingly, they developed the position of a “traditional behavioral management specialist” that is grounded in their traditional clan system while utilizing a Navajo approach to counseling and to coordinating other traditional treatments or ceremonies as needed and as identified by the healers and desired by the families themselves.
In contrast, both the service delivery structure and the types of services provided in the Passamaquoddy tribal community are focused on providing multiple levels of interventions. Younger children, families, and the community itself are provided with opportunities (services) to reintegrate Passamaquoddy culture into their lives. This in effect works toward reestablishing tribal values and traditions, ultimately assuring the continued survival of tribal culture while reframing it as a viable resource or system of care for children and their families. Many of the mothers in the study were formerly enrolled in services themselves, providing a longitudinal, multi-generational aspect to the project.

The Sault and the Bay Mills tribal communities seek to enact a “cultural renaissance” and are committed to the incorporation of Anishnabe (Ojibway) cultural values as a critical component of system development, system reform, and system evaluation. A unique focus of this project is its partnership with the Hiawatha Behavioral Health (community mental health center) in order to address service delivery issues. This is a highly unusual undertaking in Indian Country, as the partners must collaborate on administrative and programmatic responsibilities. The project strives to support and reclaim the tribe’s language and other cultural practices as part of a movement towards overall improved mental health of tribal children and their families.

In response to distinctly different service delivery issues and needs, the primary goal of the Sacred Child program is to reduce the high number of American Indian children who are sent to residential facilities, and to assist in the reentry of those who are returning from out-of-community placements. Like the program of the Passamaquoddy tribal community, the Sacred Child program is strongly grounded in family-centered philosophy and the staff firmly believes that services need to address the family as a whole unit. They have developed a tool for the extensive assessment of child and family needs that is focused on a treatment planning model which utilizes twelve distinct “life domains”: family, social, behavioral, educational, safety, legal, health, crisis, spiritual, cultural, financial, and housing. Families choose their priority domain(s), with community-based care coordinators assisting in establishing the wraparound process to develop their own family-based goals. The program’s process also incorporates important American Indian traditions of group healing and community-based resources.

The Nagi Kicopi “Calling the Spirit Back” program has made extensive efforts to reflect the Lakota healing and cultural practices as the foundation of the service delivery model, rather than attempting just to integrate these practices into a service delivery model grounded in western therapeutic practices. These efforts were initially supported by a Circles of Care grant that provided an opportunity for the grant community to identify existing systems of care and explore the gaps in services (through a series of community focus groups and parent, youth, teacher, and provider focused surveys) and the cultural shortcomings of these services. This community also developed the Tiwahe (family) advocacy group, which in turn assisted in the development of a culturally grounded services curriculum and intake assessment instruments based on functional knowledge of Lakota culture. The intake instrument is used as a tool for the extensive assessment of the youth’s and family’s level of Lakota cultural knowledge which, in turn, is used to develop a culturally appropriate treatment plan. Following referral, this community has an extremely detailed four-phase enrollment process that includes preenrollment, enrollment, and initial assessment and provides for a fully informed consent process. A purification ceremony is held that brings the family and extended family together to determine a course of action. The Lakota system of care at Nagi Kicopi has become a family- and community-based intervention that is guided by the care coordinators who assist families in reclaiming their Lakota language, values, and beliefs through participation in traditional healing ceremonies.
Evaluating Systems of Care in Tribal Communities

The national evaluation was initiated in 1994 and developed for use in a broad range of communities across the United States that provide services to children and families from all walks of life. Across all cycles of program funding, the national evaluation has included four components implemented in each funded community: 1) the assessment of infrastructure and service system development (system level assessment), 2) description of the children served by the program, 3) assessment of the service experience and longitudinal outcomes for children for up to three years, and 4) assessment of services provided and related costs as recorded in management information or billing systems to the extent available in each community. Assessment of system development and assessment of costs and services are conducted by the national evaluation team with assistance from the grant community. Communities are financially supported through their grants to collect descriptive information and to conduct the longitudinal outcome study by implementing national evaluation protocols locally with guidance from the national evaluation team.

The national evaluation protocol includes collection of descriptive, demographic, and diagnostic information about each child at intake, and longitudinal data for a subset of children and adolescents. Data for the longitudinal outcome study are collected every six months for up to three years through interviews with caregivers and youth aged 11 years and older. Among currently funded grant communities, data are collected using four clinical measures: Child Behavior Checklist (CBCL; Achenbach, 1991a), Youth Self-Report (YSR; Achenbach, 1991b), Child Adolescent Functional Assessment Scale (CAFAS; Hodge, 1990), and the Behavioral & Emotional Rating Scale (BERS; Epstein & Sharma, 1998); four functional measures that assess children’s living situations, education, delinquent behaviors, and substance use (these last three measures are administered only to youth); three family measures that assess adequacy of family resources (Family Resource Scale, FRS; Dunst & Leet, 1987), family functioning from the caregiver’s and youth’s perspectives (Family Assessment Device, FAD; Epstein, Baldwin, & Bishop, 1983), and caregiver strain experienced as a caregiver to a child with serious emotional disturbance (Caregiver Strain Questionnaire, CGSQ; Brannan, Heflinger, & Bickman, 1998); and two service experience measures to assess which services were received and in what settings, and satisfaction with the cultural competence of services from the caregiver’s and child’s perspectives.

Implementing a national evaluation protocol in diverse communities raises issues of cultural competence because these protocols were not developed with a particular community’s needs and circumstances in mind. Indeed, many communities have argued that the national evaluation itself is incongruent with the system-of-care principle of cultural competence. For example, assessment at the service system level using a global protocol may obscure some of the unique factors that influence characteristics of service delivery in specific communities. In addition, conducting a longitudinal study is generally an intensive and difficult process and must be tailored to the unique circumstances of the community within which it is conducted without compromising the goals of the research. Because this study has a lengthy protocol that may include questions that have different meanings in different cultural contexts, are inappropriate to ask of certain people, or require extensive introduction or debriefing, considering how to introduce the evaluation to the community, how best to recruit participants, conduct interviews, and maintain contact with families over time are issues that must be addressed with each community.

System Level Assessment

Assessing system development at the infrastructure and service delivery levels in
relation to the principles that guide systems of care (family-focused, individualized, culturally competent, collaborative/coordinated, accessible, community-based, least restrictive) involves conducting semistructured qualitative interviews (every 12 to 18 months) with a cross-section of administrators, service providers, and families involved in the service system in each community. A draft report is developed, reviewed by the community for accuracy, revised, and then disseminated.

These system-of-care assessments for the national evaluation have been conducted in all tribal communities except those most recently funded, where the assessment process is in the initial planning stages. Interviewer training was conducted by tribally identified and nationally recognized trainers in preparation for the system-of-care site assessment visits. This training was held to give interviewers a historical perspective on the strengths of American Indian families, the breakdown of American Indian communities resulting from dominant culture oppression, and the renewal and healing strengths of today's families and communities. Information was also presented regarding life differences in worldview, communication styles, customary behaviors, and cultural assumptions and values. Medicine Wheel Teachings were also presented as well as interactive experiences in the use of oral traditions and story telling.

Communities also conduct culture-specific orientations for interviewers as they enter the community and before any interviews are conducted. For example, site visits have been extended by one or more days so that interviewers have adequate time to become acquainted with historical issues and their impact on tribal members, participate in traditional activities and ceremonies (at the invitation of community members), take tours of local historical and contemporary points of interest, and be included in informal conversation with community members and program participants where culture-specific information has been shared. This culture- and community-specific evaluation training has occurred before any evaluation training or data collection interviews have been conducted.

In order to obtain meaningful information about a service system, it is important that appropriately knowledgeable persons are interviewed. Although it is the community's role to identify individuals who should be interviewed, factors such as language, political alliance, the appropriateness of individuals from outside the community conducting interviews, and the appropriateness of posing certain types of questions to certain community members or to healers may have an impact on the selection of members of the community who are interviewed. In addition, lack of familiarity with culture- or community-specific protocol ultimately may have an impact on the success of the interview process. Such protocol might include, for example, unique elements of verbal and nonverbal communication, and impacts might be related to the dissonance of perspectives of persons unfamiliar with a specific AI/AN culture and members of that culture, limited personal understanding of historical and inter-generational trauma and fears associated with participating in research, fears associated with differential types of responses and consequent continuation of or access to services and supports for services by tribal communities.

The system-level assessment of the national evaluation offers some potential benefits for grant communities to build into their systems a community-based self-evaluation which gives voice to those receiving services. The issue critical to the success of this process is in building capacity and in understanding the process itself with both the service providers and those receiving the services. One way this may be achieved is by providing opportunities for the process to become more participatory. Although communities currently determine who should be interviewed, contribute to the completion of the report, and are encouraged to utilize and disseminate the report, engaging the community (or parents and families) in determining some of the interview questions, utilizing individuals from the community as
interviewers, promoting greater involvement by the community in the development and dissemination of the report and, most importantly, in strategizing how to utilize the information to enhance and improve services would contribute to building evaluation capacity. System-level assessments for the national evaluation have been conducted in all tribal communities except those most recently funded, where the assessment process is in the initial planning stages. To facilitate this process, some communities provide a type of cultural immersion training to individuals who come into their communities or provide a community “presence” via the participatory role of elders.

**Longitudinal Outcome Study**

Although the national evaluation protocol for the longitudinal outcome study is the same for every community and a set of guidelines is provided for the implementation of the evaluation, community-level differences do exist in the overall structure of the evaluation teams and some differences exist in how communities deal with geographic, cultural, and other factors. For example, the Wind River, Sault Ste. Marie/Bay Mills, Humboldt, and YKHC projects all conduct their evaluation as if they are serving one large tribal community with multiple service delivery offices. This provides some advantages, such as maintaining a central data collection and management system and assuring consistent training of evaluation team members, and some disadvantages, such as use of a generic implementation protocol for people who may have distinctly different cultures and provision of data findings based on the aggregate versus community-level experience. The Sacred Child project, in contrast, subcontracts data collection to each of the four participating tribes, although a central evaluation coordinator provides data collection training and collects and consolidates the data into one data bank that represents all four tribal communities. The Sacred Child project’s challenge is in administering this intertribal project in such a way that it provides some autonomy to allow for a more culturally appropriate evaluation implementation while collecting the data in a centralized manner.

The K’é project of the Navajo Nation developed a comprehensive cultural self-assessment tool which was completed with each participating family. This cultural assessment tool gathered basic information about a family’s level of understanding and involvement in traditional beliefs and practices, providing a cultural framework for treatment plan development. The K’é project was faced with a need to address the language and translation issues associated with implementing the national evaluation protocol in communities where English was the second language for some adult caregivers as well as for some of the children and adolescents. Further, because many family members speak only the Native language, accurate and understandable translation was difficult if not impossible, as many of the items on the instruments in the national evaluation protocol did not have similar concepts in Navajo. The YKHC project in the Alaskan Native villages and the Nagi Kicopi project also face some of these challenges as they implement the national evaluation in their communities.

The Passamaquoddy evaluation team was faced with dealing with the contrasting values of traditional child development research methodology, which emphasizes the individual child and caregiver, and Passamaquoddy culture, which is family-oriented. The evaluation team has attempted to deal with this cultural incongruence by modifying the national protocol in a number of ways. First, the family is enrolled in the evaluation, so that one child is not targeted as a “problem child.” Therefore, caregivers may complete child-specific questionnaires such as the Restrictiveness of Living Environments Scale (ROLES; Hawkins, Almeida, Fabry, & Reitz, 1992) or the CBCL for more than one child in the family. In addition, for caregiver-specific measures (e.g., the CGSQ or the FAD), the caregiver is asked to rate the impact of all of the children’s needs on both the caregiver and the entire family unit. This provides an
The Sault community also initiated a series of focus groups with the evaluation team and service providers to develop a clearer understanding of how well-being might be conceptualized among those served in the system of care and how this well-being might be assessed using an evaluation framework. These focus groups stemmed from conversations held among evaluators of tribal grant communities who were struggling with the concept of "functional impairment" and its application to AI/AN children. This focus group work had not been completed at the time of this report. Unlike the Passamaquoddy community, the Sault grant community has been successful in using data drawn from the national evaluation at the community level. Presentations are made by the evaluator or the project director to local advisory boards, family groups, and service providers. This information is used to enhance the service delivery system and to obtain feedback on the evaluation process and program in general.

The Sacred Child program, with its four distinct evaluation teams, conducted a thorough review of all of the national evaluation measures, made some modifications to assure a more culturally appropriate evaluation, and provided critical feedback to the national evaluation team as well as to CMHS. Upon initiating the national evaluation protocol, they found the estimated time needed to complete the caregiver packet exceeded two hours and often took four or more hours. The parents (or caregivers) experienced the evaluation as a large time burden and were often overwhelmed by the sheer volume of questions. The evaluation team decided to use clinician reports to complete the CAFAS in place of the longer caregiver interview. Though this clearly had an impact on the time needed to complete the caregiver packet, the grant community faced additional challenges regarding time and the overall comfort level caregivers experienced when completing the interview. The grant community made minor modifications to items that were potentially confusing (e.g., contained double negatives),

additional reporting burden for the parent or caregiver respondents and causes some unique interpretive challenges in analysis of the evaluation data; however, this approach responds to some of the culture-specific needs of the community. This community has also developed a comprehensive local-level evaluation initiative which includes a parental satisfaction questionnaire, a documentation process for social and cultural activities, and a series of qualitative community-wide interviews (documenting community and family perceptions of change). Qualitative reviews of 30 case records and the development of a number of family case studies (which will not be representative of a particular family unit but rather a compilation of characteristics in order to preserve confidentiality in this small community) complete the local assessment package. Development and implementation of the national evaluation are often considered the main challenges tribal grant communities face and may overshadow challenges related to dissemination. The Passamaquoddy evaluation team made early efforts to provide feedback to community members from the data they had collected. They used a traditional research conference presentation style and provided findings in the aggregate. Family members found the presentation difficult to follow and relatively useless. The evaluation team had to reconsider the utility of the data at the community level and develop new methods for dissemination.

The Sault Ste. Marie community is utilizing what is perhaps the first computerized cultural assessment tool to assess a participant's degree of identification with the culture and values of the Anishnabe (Ojibway) people. This tool is used by the Mno Bmaadzid Endaad project to begin to evaluate the interaction between children's and the caregivers' identification with the culture and the services provided by project staff. In addition to this tool, the project is using a computerized version of the Diagnostic Interview Scale for Children (DISC-IV; Shaffer, Fisher, Lucas, & The NIMH DISC Editorial Board, 1998).
generated alternatives for items with multiple meanings (e.g., "seeing things" might be interpreted as "having visions"), and offered alternative language for words not commonly used in their community. Many of the changes this grant community made have been shared with other grant communities through national evaluation team members. In addition, the Sacred Child Project was identified as a CMHS “host” community, functioning as an informal mentor to more recently funded tribal grant communities that are dealing with cultural concerns as they apply the national evaluation protocol.

The Nagi Kicopi project has effectively utilized its experience as a Circles of Care grant community to inform and influence the evaluation of its more recently funded system of care. This grant community developed a complex process to explore the meaning of health among Lakota children and families. They used this process to develop an assessment tool that is specifically for assessing functioning from a Lakota cultural framework. The project is also considering expanding the Multi-Sector Service Contact (MSSC; ORC Macro, n.d.) instrument used to collect information about services received, to incorporate their culturally specific service delivery structure and to assess whether these services are meeting the needs of the child and family. As with the K'e project and the Sacred Child Project, wording for some individual items is modified as needed. In addition, portions, if not all, of the interview (and introduction protocol) can be offered in the Lakota language through on-the-spot translation.

These are a few examples of how tribal communities participating in the Comprehensive Community Mental Health Services for Children and Their Families Program have attempted to make the longitudinal outcome study of the national evaluation more consistent with the cultural values of their communities and the overall goals of their systems of care. It is important to note that while the tribal grant communities have made significant strides towards implementing the national evaluation, the national evaluation team itself is pilot testing modifications made in response to some of the broader concerns of these grant communities. The process that led to the development of modifications involved addressing tensions and evolving awareness regarding the conflicting needs of the communities, the federal funder, and the contracted evaluator. The need to address this conflict with the national evaluation was further heightened with the funding of additional tribal communities in subsequent funding cycles. Of particular concern among all tribal communities (and addressed, in part, by the Sacred Child program) is the length of time required to complete an interview with caregivers in their community. Evaluators report that cultural protocols, such as sharing “small talk” and listening to stories told by caregivers, lengthen the interview time, thereby creating an undue burden on caregivers.

As discussions regarding implementation of the national evaluation developed, the tribal grant communities recognized the importance of the granting agency in determining modifications to the national evaluation, and collectively directed their concerns directly to CMHS. The feedback obtained through this process provided valuable information to assist CMHS and the national evaluation team in developing some alternatives for evaluation implementation with the concerns of the tribal communities in mind. These alternatives have become identified as the “flexibility plan,” available to tribal grant communities as a pilot test for future evaluations.

Of interest in this process is the change in perceptions of the national evaluation team among tribal communities, which resulted in a more collaborative approach to implementing the national evaluation. This process serves to remind evaluators and researchers that tensions signal that there are important issues to address that will not disappear if they are ignored. This tension can be utilized as an opportunity to return to the drawing board and
collaboratively address the situation. Further, it is important to note that often fears associated with the evaluation process are in direct proportion to the personal responsibilities of each participant. For example, tribal grant communities have a responsibility to their children, families, and communities as a whole, while an evaluation contractor has responsibilities to a client (in this case the federal government), and the funding agency has responsibilities to Congress.

The flexibility plan provides tribal communities with the option of excluding the Child Adolescent Functional Assessment Scale (CAFAS; Hodges, 1990) and the Caregiver Strain Questionnaire (CGSQ; Brannan, Hefflinger, & Bickman, 1998) or the Youth Self-Report (YSR; Achenbach, 1991b) and Family Resource Scale (FRS; Dunst & Leet, 1987) from the interviews. In return, tribal communities agreed to work on the development of a culturally competent instrument that could be used across tribal communities to assess functioning. Thus far, two tribal grant communities have opted to drop the CAFAS and all communities are utilizing the CGSQ, YSR, and FRS. If participant burden has an impact on enrollment or attrition rates, some tribal communities may decide to drop the CAFAS from the protocol. Although few communities have chosen to adapt the evaluation protocol, evaluators and administrators from the tribal communities initiated conversations about how to best develop a new evaluation tool. They considered development of a universal tool and community-specific tools. Some communities, like Nagi Kicopi, had already developed a process and a draft tool. Others, like Sault Ste. Marie, initiated a series of focus groups (described above). All are continuing to work together to develop a survey instrument which will examine the processes of system development, implementation of the national protocol, and the processes of developing culturally specific instruments.

**Community Empowerment in Evaluation**

It is important to identify methods that not only empower parents, families, and communities but that enhance their capacity to conduct culturally relevant research and evaluation in their own tribal communities. The two primary methods that need to be highlighted are the use of community-based advisory committees and the establishment of a collaborative skill-building relationship with their evaluation team. The metaphor of putting Indian Country “behind the wheel” of the research-evaluation bus is an apt description of the potential this kind of collaborative work can have.

The Sault Ste. Marie project was the first tribal community to provide a model for other tribal grant communities, as they early on established an advisory committee that is representative of the communities that the grant serves. Many of the advisory committees assume responsibilities to provide staff with both programmatic and evaluation input and guidance. For example, some committees provide valuable staff feedback and direction on staffing (e.g., interviewers) for the national evaluation, cultural protocols needing to be addressed or developed, suggestions for motivating parents to participate (e.g., participant payments and participation in special activities), piloting or trying out the instruments (with volunteers from the community), topical focus group participation, presentation (topic, style, and content) feedback on data dissemination, use of evaluation data by clinicians, and presentations to families, tribal communities, tribal stakeholders, tribal business councils, and non-Indian stakeholders. The Oglala Lakota project grounded their development within the Tiwahe (family) advocacy group, which was instrumental in the many facets of the project’s development from the beginning and continues to be utilized for multiple purposes as the needs and issues arise in terms of assessment, services, service delivery, local-level evaluation initiatives, and the national evaluation.
contrast to the other grant communities that provide service to a larger population of males (69.76%) than females (30.24%), with an average age of 12.4 years. This would suggest that proportionately the numbers of AI male children and adolescents served are similar to the general population, although in AI communities they are served at a much younger age (10.4 years versus 12.4 years). This brings to the forefront issues associated with aggregating data with such diverse tribal communities. The targeted service population ages of at least two of the AI grant communities are much younger than their peer programs (as young as 6 in one community). This age difference clearly informs the types of services offered to children and families, and is likely to affect the overall rate of change children and families experience. This may impact the interpretation of “effectiveness” statistics that emerge locally or when compared to a tribal or national aggregate.

Custody status and living arrangements, factors typically examined across time as indicators of functioning (multiple changes considered a negative indicator, no change considered an indicator of stability), are examined at length in the national evaluation. Custody status is a highly sensitive variable in tribal communities where illness, alcoholism, death, and other factors may force a custody situation on a family. Actual living arrangements may be described and valued differently among tribal communities, particularly those where the “extended” family is considered the immediate family. Living in three or four different “households” in a given period of time may be considered a strength if a child is spending time with relatives and important family friends. Though standard analysis of living arrangement data might consider these moves a sign of instability, they may instead be a sign that a child has positive social relations, is able to adjust to multiple environments, or is playing a key role as family member or even caretaker. Furthermore, the rural or urbanized nature of a reservation or levels of acculturation may have further impacts on the distribution of children in different custody or living situations and on the overall interpretation of these data. Among children for whom living arrangement data are available, approximately 44% of children in tribal communities lived in two-parent households compared to about 30% of children from non-tribal communities. About equal percentages of tribal community and non-tribal community children lived in mother-only households (28%). A greater percentage of tribal community children resided with relatives (11.3%) than non-tribal community children (8.9%).

Referral source may provide an indication of the interagency nature of a system of care or may be indicative of previous service utilization by children and families referred to systems of care. Referral source information drawn from tribal (n = 412) and non-tribal communities (n = 3429) were obtained through the examination of client records. Fifty percent of all referrals in the tribal communities were made by the caregiver himself or herself. This is in contrast to the less than 7% of caregiver referrals to non-tribal systems of care. The self (child) referral for the tribal communities (3.64%) was also greater than the other grant communities’ rate (1.1%). The largest referral source for all other grant communities was mental health agencies and clinics (28.8%), which is more than double the mental health referral rate for AI communities (11.2%). While it seems logical that the schools would be a large referral source (17.6% in all other grant communities), in the AI communities this rate was significantly lower (8.3%). In this same vein, the referral source from corrections agencies or facilities for the AI child or adolescent is ten times less (1.2%) than the referrals identified for all other grant communities (16.5%). Interpretation of these findings requires communication with the grant communities themselves.

Previous service utilization data indicate that children served in tribal systems of care are less likely than other children to have received services prior to entry to systems of care. Thus, these children may not have been in contact with mental health services and thus would not be referred by them. Schools in tribal
Additionally, as a result of the established relationships with certain faculty at the University of Wyoming, the on-site evaluator for the Wind River project incorporated a procedure to allow clinically useful information collected during evaluation interviews to be exchanged with clinicians identified by the family. This process allows parents or caregivers, as well as the children or adolescents, the opportunity to have their participation in the national evaluation be of use to them clinically, which makes participation in the evaluation potentially useful beyond the needs of the evaluation. In contrast to conventional evaluation and research relationships, this approach to establishing relationships among an evaluation team (both on-site and off-site evaluators), administration, parents and families, and the community—all within the framework of evaluation—promotes collaboration, cultural competency, and community empowerment while building evaluation capacity in tribal communities.

**Continuing Challenges**

Many tribal communities have tailored to the specific cultural needs and the varying levels of acculturation of their communities. Anything from the service delivery framework to the types of services available. Tribal grant communities funded by the Comprehensive Community Mental Health Services for Children and Their Families Program provide a powerful example of how systems can be developed or modified by community members to meet community needs. In addition, though the evaluation activities of these communities are far from perfect, the communities have made a good faith effort to involve themselves fully in national and local evaluation efforts. Though the systems are serving children and families and the national and local evaluation teams are collecting information regarding system development, child and family characteristics, and child and family outcomes, challenges still remain.

These communities are interested in demonstrating the efficacy and utility of the service delivery structure and culturally grounded treatment approaches to "outside" entities, which could provide financial sustainability following the end of the funding period. However, these cultural approaches, many of which are described above, are typically seen as suspect by funding agencies, since they fall outside the norm of other western-based service providers and systems in their states. The challenge these communities face and for which they need support is to gain recognition of the therapeutic value of these culturally specific services and service delivery structures, which in turn will generate opportunities for future financial sustainability. The research reviewed above indicates that it is not just the prevailing methods used to evaluate children and families that are inappropriate or inaccurate to fulfill this need, but also the underlying assumption of what it means to be "healthy." Though small changes made in the national evaluation protocol begin to address the needs of these tribal communities, the accuracy of this information in reflecting the true nature of the challenges faced by the children and the true nature of the changes they experience (which will ultimately be used to reflect the success or failure of a system) must constantly be questioned.

One challenge, which cannot be overcome in this project, is the need for these small communities to protect the confidentiality of the participants and the communities in general. Thus, data presented to the general public must be presented in aggregate form. This alone overshadows unique cultural characteristics of the children and families and the programs designed to serve them.

Of interest in the aggregate data are the significant gender, age, and income differences between the AI grant communities and all other CMHS grant communities. The AI grant communities tend to provide services to significantly more males (61.1%) than females (38.9%), with an average age of 10.4 years, in
communities may not have personnel available to assess the service needs of children and therefore be unprepared to refer them to a system of care. Tribal systems of care may not have developed collaborative relationships with mainstream agencies and therefore may not receive referrals from them. It may be the case that historical, cultural, or economic factors influence the nature of relations that caregivers have with mainstream service systems, which results in a reduced use and trust of these systems. Other factors may also influence these differences. Factors such as previous service utilization or history with service systems may have an impact on the way children and families experience or respond to the systems of care set up in tribal communities.

The information presented above is drawn from descriptive data provided by caregivers or obtained from administrative records. At first glance it may be considered simply descriptive, with no inherent meaning or implication for interpretation of other data drawn for national evaluation purposes. It is clear, however, that even these few variables are likely influenced by cultural, historical, social, and other factors that are typically unique at a community level, and that will likely have far-reaching implications for the structure and effectiveness of the tribal community systems of care. It is important to note that many of the evaluation outcomes based on clinical, behavioral, and functional measures could be easily misconstrued or interpreted within a western theoretical model. From a tribal community perspective an entirely different, culturally grounded perspective could be drawn, which would be based on the knowledge of both the historical impact as well as contemporary issues obvious only to community members. Additionally, there are community level differences in interpretation, so results must be examined and interpreted by communities from their own knowledge of their community, their worldview, and other community-specific historical issues that may be relevant.

Summary

Comprehensive and culturally competent evaluation in AI/AN communities may become a reality as tribal communities are offered opportunities to assume leadership roles in this process. Funding provided through the Comprehensive Community Mental Health Services for Children and Their Families Program supports these eight tribal communities to step to the front of the room and reply to questions such as: "What services?" "Where should services be provided?" "How should services be provided?" "Who should provide services?" "Are services culturally appropriate?" "Are services effective?" "Who are the children and families being served?" "What are children and families experiencing?" and "How do children and families change across time?" Though these questions and the methods used to address them were not developed by tribal communities, they have given communities something to work with, react to, and modify, and in many instances have motivated communities to develop their own tools and methods based upon their own worldview.

Indeed, these tribal communities have provided us with a number of lessons learned. For example, the utilization of a broadly representative advisory committee composed of youth, parents, elders, community members, and community stakeholders provides significant culturally appropriate feedback and contributions not only to evaluation design, instrumentation, and implementation protocols, but also in the dissemination of the data to the community and other entities. Taking the use of an advisory committee a large step further, Nagi Kicopi’s Tiwahe (family) advocacy group developed the programmatic framework, intake and assessment instruments, and service delivery curriculum. The Tiwahe continues to provide ongoing feedback to project staff, who rely on this group which serves as the community’s “voice.” Local-level evaluation protocols, cultural assessment instruments (such as Sault Ste. Marie’s and Oglala Lakota’s), community focus groups
(defining cultural wellness and other constructs), cultural protocols for interviewing families, and other qualitative and quantitative tribally developed measures are all excellent examples of the outcomes that are possible when tribal communities are empowered. It has taken decades for the scientific community to come to the realization that tribal communities can become empowered to identify their needs, determine a course of action, and take the necessary steps toward achieving the goals they have set for themselves.

What is truly exciting is that the current national evaluation design for the Comprehensive Community Mental Health Services for Children and Their Families Program provides opportunities for tribal communities to examine more closely culturally based traditional assessment, treatment, and healing methods as well as to build a skills-based capacity for research and evaluation. Stubben (2001) succinctly describes a culturally competent framework for working with and conducting research in AI/AN communities, in particular noting the need to adapt the design and instruments to fit the culture. CMHS funding has provided tribal communities with a small measure of flexibility in implementing the national evaluation, which has resulted in bringing these communities into the next developmental stage of research capacity as they tailor their evaluation protocols to be more culturally sensitive and begin the process of designing local-level evaluation plans that answer questions posed by their own tribal communities. Services, evaluation, and research with handicapped children and adolescents continue to be desperately needed in Indian Country. The road to evaluation and research in AI/AN communities is clear, the road markers are in place, and the time is now.

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