<table>
<thead>
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<td>California State University, Northridge</td>
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<td>University of Colorado H.S.C.</td>
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<td>Native American Studies Program</td>
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# Editorial

## Two Eskimo Villages Assess Mental Health Strengths and Needs
*Barbara A. Minton, Ph.D.*  
*Susan Soule, M.A.*

## Tewa Children Who Have Epilepsy: A Health Care Dilemma
*Lemyra M. DeBruyn, Ph.D.*

## Panic Disorder Among American Indians: A Descriptive Study
*Gordon Neligh, M.D.*  
*Anna E. Barón, Ph.D.*  
*Patricia Braun, M.D.*  
*Michael Czarnecki, M.D.*

## An Ethnographic View: Positive Consequences of the War on Poverty
*Bruce G. Miller, Ph.D.*
The substantive foci of the articles in this issue of the journal are quite divergent, ranging from an assessment of mental health strengths and needs in two Alaska villages to the capacity-building legacy -- individually and collectively -- of the War on Poverty throughout Pacific Northwest tribes. Yet, despite these differences, a common theme can be discerned. Specifically, family and community play important roles in each set of experiences and serve as the context for understanding the processes at work.

"Two Eskimo Villages Assess Mental Health Strengths and Needs," by Minton and Soule, describes a study that, at virtually every turn, hinged on local participation in the research endeavor, from conceptualization and instrument development, through sampling, to data collection and analysis. The thrust of this effort was to elicit local perceptions and knowledge of emotional and psychological well-being and problems. Village members refined the areas of inquiry, developed the protocol, interviewed 216 fellow villagers, and translated, transcribed, as well as coded the data. Content analyses revealed sources of both happiness and sadness -- culturally syntonic expressions of mental health and illness -- in the lives of these people and the resources available to them to cope with the latter. Minton and Soule emphasize the relevance of such information for subsequent intervention. They also underscore the supportive and facilitative functions served by the study itself.

"Tewa Children Who Have Epilepsy: A Health Care Dilemma," by DeBruyn, reminds us that many chronic physical diseases, in this case, epilepsy, plague Indian communities, child and adult alike. The author points out how social and cultural factors affect the understanding of as well as response to such diseases. Moreover, epilepsy, in particular, is both frightening and potentially stigmatizing, as reflected in harsh teasing by classmates. It should be no surprise, then, that these children are at high risk for emotional problems, which, in DeBruyn's experience, often come to pass. Parents, notably mothers, tend to deny the realities of their children's illness, further reducing families' ability to cope effectively with the attendant stress. Then, too, the burden of caring for more seriously impaired children increases the parent's isolation from other family and friends, jeopardizing her own well-being. Many of these circumstances, however, are not unique to the Tewa, leading DeBruyn to suggest closer examination of models of chronic illness in terms of their potential applicability across cultures.

"Panic Disorder Among American Indians: A Descriptive Study," by Neligh, Baron, Braun, and Czarnecki, illustrates the feasibility of training tribal health care staff -- specifically, Community Health Representatives -- to detect and refer community members who possibly suffer from panic disorder. The authors further demonstrate that, despite the sparse
literature on this psychiatric illness among Indians, symptoms of panic disorder are discemable. Furthermore, as is rapidly becoming evident in the general population, these symptoms frequently co-occur with those of depression and alcoholism, indicating the need for increased attention to questions of co-morbidity in diagnosis, treatment, and prevention.

"An Ethnographic View: Positive Consequences of the War on Poverty," by Miller, highlights the capacity-building effects of ICAP and CETA funds among individuals, family networks, as well as tribes during the 1960's and 1970's. Through historical analysis and case examples, the author argues that these programs enabled individuals, especially women, to acquire technical expertise that was necessary to the successful transitions then underway at the community level. Concomitantly, many of these women developed a sense of competence and mastery that carried over into their personal lives and those of their families. Miller also maintains that the funds in question provided additional means for supporting expensive cultural practices that experienced a resurgence during the same period. Finally, the availability of such funds are linked to the development of inter-tribal administrative and social services organizations that form the foundation for present-day collaboration among Northwest reservation communities.

Spero M. Manson, Ph.D.
Editor-in-Chief
Abstract: Due to a growing consensus of the inadequacy of the current mental health system in rural Alaska, an assessment of mental health strengths and needs was conducted in two Eskimo villages. Respondents were 216 Eskimos who completed a structured interview. Results document perceptions of problems and strengths unique to the village cultures and settings. To increase effectiveness, programs must take into account the perspectives expressed by village people.

Two Eskimo Villages Assess Mental Health Strengths and Needs

The literature on rural mental health has documented several unique characteristics of rural settings that impact the effectiveness of community mental health services. One of these characteristics is large geographic catchment areas (Bloom & Richards, 1976; Dolan, 1975; Clayton, 1977). To reach their clients, mental health workers in rural settings spend more money on transportation and more time traveling than their urban counterparts (Flax, Ivens, Wagenfeld, & Weiss, 1978). A second characteristic is the harsh physical environment found in many rural areas. The profound effect of weather on everyday life presents a special challenge to those from urban areas who take jobs in rural settings (Keller & Murray, 1982). In addition to these physical challenges, mental health workers are often not prepared for the different attitudes and value systems of those living in rural areas (President's Commission on Mental Health, 1978). The resulting "culture shock" has been one explanation given for the short length of stay of many mental health workers in their rural jobs (Keller et al., 1982). Alaska epitomizes the characteristics which make rural mental health delivery unique. The state has a small population that is widely dispersed over a vast land mass (U.S. Bureau of the Census, 1989). The state's physical terrain, while breathtaking, impedes transportation. Extreme weather conditions are common. Eight native cultural groups have been identified in the state, each with its own language, values, and cultural
Barbara A. Minton and Susan Soule

heritage. These groups include Inupiaq and Yupik Eskimos; Athabaskan, Tlingit, Haida, Tsimshian, and other Indians; and Aleuts (Alaska Blue Book, 1989).

These characteristics suggest the need for a service system that is culturally sensitive and accessible to small groups of people in remote areas. However, Alaska's first mental health centers were established using national guidelines developed for urban and suburban areas outside the state. Catchment areas were defined on the basis of population, and professionals were hired to perform a variety of services including education, prevention, and treatment.

The system of mental health care which resulted from adopting this national model has not been optimal for people living in rural areas of Alaska. Mental health workers frequently spend more time travelling to an area than they spend in actual consultation or treatment. This excessive travel time results in workers presence in villages only one or two days every few months. Establishing rapport and maintaining ongoing treatment plans is extremely difficult under these constraints. In emergency situations, the mental health worker may be hundreds of miles away, powerless to help resolve a crisis.

In Alaska, the challenges of rural mental health delivery are often combined with that of cross-cultural work. A rural mental health worker discovers the difficulties of working in settings in which the culture and lifestyle are neither shared nor understood. Local hire is an obvious solution to this difficulty, but lack of higher education has excluded many Alaska natives from clinical positions. Professionals from outside the state have generally be recruited to fill clinical vacancies. These professionals, who are unfamiliar with the cultures and rural lifestyles, stay in their jobs an average of one year (State of Alaska, 1985). This short length of stay has led to disrupted and inefficient service delivery.

In one of the first formal statements of such problems in Alaska, a group of rural mental health center directors argued that the dominant culture service model was not working (Scott, Soule, Bill, Friendman, Collier, Walluk, Wiscinckkas, & Graf, 1982). They stated that to be effective, professionals must disregard the model of services emphasized in most American graduate programs. Instead, clinicians must allow community members time to get to know them as individuals, work at a slower pace, provide services in informal settings, and view the community rather than the individual as the target for intervention.

In the early 1980s, some communities began their own experiments to address mental health problems. In one of the most innovative approaches to service delivery, the Four Worlds Project in Canada (Bopp, 1987) began promoting self-determination and healing, with decreased dependence on professionals found outside local communities. Their approach emphasized local initiatives, integration of native traditions with self-help programs, and use of indigenous service providers with consultation from other sources as necessary. In Alaska, Inupiaq Eskimos
began a program called Inupiaq Ilitqusiat, which called on local villages to reemphasize traditional Inupiaq values and to define their own solutions to the problems of suicide, alcohol and drug abuse, and violence (Inupiaq Ilitqusat, 1982). These programs shared common themes of reliance on traditional wisdom and use of local talent as part of the healing process. Advanced degrees were not required and help was made available within the local area.

The inadequacies of the mental health system in rural Alaska and the new emphasis on local determination formed the context for the current study. If mental health care is to be improved, system changes must be consistent with cultural norms and practices. The current study had as its major purpose the documentation of local thinking about mental health problems, strengths, and sources of help. The purpose of the study was not to design a specific system of intervention for the villages. Rather, it was to begin to identify important factors that must be addressed in a culturally relevant system. To maximize cultural relevance, local participation and control was emphasized in all stages of research design, data collection, and analysis.

Method

Respondents

The State of Alaska (which provided partial support for this project) selected the geographic area in which the study was located. Their decision was based on a desire to locate the project in an area of the state that was not receiving other special project monies, as a way of helping to assure fiscal equity in local communities.

Respondents were 216 Eskimos living in two villages in rural Alaska. The villages were similar in ethnic composition and lifestyles. Respondents were randomly selected within four age groups using lists of village residents supplied by each local government. Age groups sampled were 7-18, 19-29, 30-54, and 55+. These age groups were selected by the village people in a village meeting run by an elder. The village participants labeled the age groups "young people," "young adults," "middle aged people," and "elders."

Initial sampling was 40 people within each age group. However, sample size was exceeded in most groups, resulting in a total of 216 people participating in the project. Overall response rate to requests for interviews was 92%. Approximately 30% of the respondents chose to be interviewed in their native language; the remainder were interviewed in English. Those who chose to be interviewed in their native language were exclusively in the "middle aged people" and "elders" categories. (Effects of age and language spoken are, therefore, confounded.)
Procedure

Individual meetings were arranged with regional and village leaders to discuss project participation. Once village leaders became interested, they called a community meeting to discuss the project. At this meeting, research hypotheses and design were discussed. An approach derived from Manson, Shore, and Bloom (1985) was used to determine interview questions. This approach used the community meeting to derive the initial set of interview questions. During this meeting, community members stated that the concept of "mental health" had no equivalent in their native language and was not an appropriate construct to use. Questions considered more meaningful to local people were discussed in small groups at the initial meeting. These small groups reconvened and the larger group reviewed and selected a set of questions for further refinement. Approximately 135 people attended this initial community meeting and all age groups were represented.

After the initial meeting, eight bilingual community members were chosen by village leadership to be interviewers. The first author and the interviewers discussed the questions further and refined wording. Once interview questions were finalized, interviewers were trained in standard interview techniques. Interviewers then contacted respondents, explained the purpose of the interviews, and requested respondent participation. Interview questions were presented in either English or the native language, according to respondent preference. All interviews were taped and transcribed in the villages. Interviews were then sent to the first author for analysis.

Standard content analysis was completed on all interviews. Thematic categories were derived from analysis of the first 50 interviews, and the next 50 interviews were coded into these categories by two trained raters. Resulting interrater reliabilities were .94 using the pi method (Scott, 1969) which corrects both for the number of categories in the category set and for the probable frequency with which each is used. The remaining interviews were then scored. Respondents received a score in each thematic category. Data were coded dichotomously; a one was assigned if the category was mentioned and a zero was assigned if the category was not mentioned.

Results

Three questions from the structured interview were chosen for analysis. These are "What makes you sad?" "What makes you happy?" and "Where do you go when you're sad?" These questions were viewed by the interviewers as those which would be most helpful in understanding the problems, strengths, and resources of village people and were chosen for initial analysis on that basis. The other interview questions provided elaborations on these major questions (see Appendix I). The content
analysis resulted in 22 categories for the questions assessing sources of sadness, 31 categories for the question assessing sources of happiness, and 11 categories for the question assessing resources used when sad (see table 1). Sources of sadness include those documenting the impact of other people (Other People, Victim, Communication), those which are focused on self (Transgressions, Personal Inadequacy), and those which describe negative events of habits (Death, Alcohol, Sickness). Similar types of categories were discovered for answers relating to happiness. Categories mentioning other people (Interaction with People, Doing for Others, Family), self (Accomplishment, Time Alone), and specific events causing happiness (Outdoor Activities, Sports) were discovered. The question asking for resources used by respondents when sad elicited responses primarily about other people (Friends, Pastor, Parents). Definitions of each categories are provided in Appendix II.

Because some respondents gave multiple responses for a category, data were scored with two systems. In one system, multiple responses were counted and recorded. In the second system, multiple responses were counted as a single response. all analyses were performed on both sets of data. Findings were not significantly different for these two coding systems.

| Table 1
| Categories Derived from Content Analysis and Percent of People Whose Responses Fell in Each Category (n=216) |
|---------------------------------|---------------------------------|
| Questions: What makes you sad?  |                                  |
| Response Categories              | Death                           |
|                                 | Alcohol                         |
|                                 | Other People                    |
|                                 | Kids                            |
|                                 | Miscellaneous                  |
|                                 | Negative Personal Emotion       |
|                                 | Victim                          |
|                                 | Relatives                      |
|                                 | Communication                  |
|                                 | Sickness                        |
|                                 | Boredom                         |
|                                 | School                          |
|                                 | Drugs                           |
|                                 | Religion                        |
|                                 | Losing a Friend                 |
|                                 | Lack of Contact with Friends    |
|                                 | Basic Needs                     |
|                                 | Transgressions                  |
|                                 | Finances                        |
|                                 | Suicide                         |
|                                 | Personal Inadequacy             |

| Death                                      | 31.5% |
| Alcohol                                    | 22.9% |
| Other People                               | 22.6% |
| Kids                                       | 20.3% |
| Miscellaneous                              | 18.5% |
| Negative Personal Emotion                  | 16.1% |
| Victim                                     | 13.0% |
| Relatives                                  | 12.1% |
| Communication                              | 8.7%  |
| Sickness                                   | 7.0%  |
| Boredom                                    | 6.1%  |
| School                                     | 6.1%  |
| Drugs                                      | 6.0%  |
| Religion                                   | 5.7%  |
| Losing a Friend                            | 4.8%  |
| Lack of Contact with Friends               | 4.8%  |
| Basic Needs                                | 3.4%  |
| Transgressions                             | 3.0%  |
| Finances                                   | 2.2%  |
| Suicide                                    | 2.2%  |
| Personal Inadequacy                        | 1.7%  |
Table 1 (Continued)

<table>
<thead>
<tr>
<th>Question: What makes you happy?</th>
<th>Response Categories</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Outdoor Activities</td>
<td>25.6%</td>
<td></td>
</tr>
<tr>
<td>Miscellaneous</td>
<td>18.1%</td>
<td></td>
</tr>
<tr>
<td>Kids</td>
<td>17.8%</td>
<td></td>
</tr>
<tr>
<td>Sports</td>
<td>17.8%</td>
<td></td>
</tr>
<tr>
<td>Relatives</td>
<td>16.9%</td>
<td></td>
</tr>
<tr>
<td>Getting Along or Being with Friends</td>
<td>16.8%</td>
<td></td>
</tr>
<tr>
<td>Work</td>
<td>15.6%</td>
<td></td>
</tr>
<tr>
<td>Interaction with People</td>
<td>14.8%</td>
<td></td>
</tr>
<tr>
<td>Religion</td>
<td>10.9%</td>
<td></td>
</tr>
<tr>
<td>Doing for Others</td>
<td>9.0%</td>
<td></td>
</tr>
<tr>
<td>Inside Entertainment</td>
<td>9.0%</td>
<td></td>
</tr>
<tr>
<td>Travel</td>
<td>8.6%</td>
<td></td>
</tr>
<tr>
<td>Other's Happy</td>
<td>7.8%</td>
<td></td>
</tr>
<tr>
<td>Gifts</td>
<td>6.5%</td>
<td></td>
</tr>
<tr>
<td>Anything</td>
<td>6.0%</td>
<td></td>
</tr>
<tr>
<td>Good Daily Living</td>
<td>6.0%</td>
<td></td>
</tr>
<tr>
<td>Escaping Bad Things</td>
<td>5.6%</td>
<td></td>
</tr>
<tr>
<td>Doing with Others</td>
<td>4.8%</td>
<td></td>
</tr>
<tr>
<td>Walking Around</td>
<td>4.7%</td>
<td></td>
</tr>
<tr>
<td>Control of Drinking/Drugs</td>
<td>4.4%</td>
<td></td>
</tr>
<tr>
<td>Good Health</td>
<td>3.9%</td>
<td></td>
</tr>
<tr>
<td>Going to School</td>
<td>3.9%</td>
<td></td>
</tr>
<tr>
<td>Accomplishment in School</td>
<td>3.9%</td>
<td></td>
</tr>
<tr>
<td>Finances</td>
<td>3.9%</td>
<td></td>
</tr>
<tr>
<td>Food</td>
<td>3.0%</td>
<td></td>
</tr>
<tr>
<td>Nice Weather</td>
<td>2.2%</td>
<td></td>
</tr>
<tr>
<td>Doing for Family</td>
<td>2.1%</td>
<td></td>
</tr>
<tr>
<td>Time Alone</td>
<td>1.7%</td>
<td></td>
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<tr>
<td>Positive Feedback</td>
<td>1.7%</td>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>Question: Where do you go when you're sad?</th>
<th>Response Categories</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Friends</td>
<td>59.8%</td>
<td></td>
</tr>
<tr>
<td>Religion</td>
<td>29.6%</td>
<td></td>
</tr>
<tr>
<td>Parents</td>
<td>27.5%</td>
<td></td>
</tr>
<tr>
<td>Others (Nonspecific)</td>
<td>17.6%</td>
<td></td>
</tr>
<tr>
<td>Relatives</td>
<td>16.2%</td>
<td></td>
</tr>
<tr>
<td>Miscellaneous</td>
<td>14.8%</td>
<td></td>
</tr>
<tr>
<td>Teachers</td>
<td>8.5%</td>
<td></td>
</tr>
<tr>
<td>Elder</td>
<td>6.3%</td>
<td></td>
</tr>
<tr>
<td>Counselor</td>
<td>4.9%</td>
<td></td>
</tr>
<tr>
<td>Yourself</td>
<td>2.8%</td>
<td></td>
</tr>
<tr>
<td>City Officials</td>
<td>2.1%</td>
<td></td>
</tr>
</tbody>
</table>

The percent of people whose responses were scored in each category give an indication of consensus about sources of sadness, happiness, and help. Sources of sadness most often mentioned are Death...
(31.5%), Alcohol (22.9%), Other People (22.6%), Kids (20.3%), Miscellaneous (18.5%), Negative Personal Emotions (16.1%), Victim (13%), and Relatives (12.1%). Sources of happiness most frequently mentioned are Outdoor Activities (25.6%), Miscellaneous (18.1%), Sports (17.8%), Kids (17.8%), Relatives (16.9%), Friends (16.8%), Work (15.8%), Interactions with People (14.8%), and Religion (10.9%). Sources of help when people feel sad are Friends (59.8%), Religion (29.6%), Parents (27.5%), Others who have Positive Personal Traits (17.6%), Relatives (16.2%), and Miscellaneous (14.8%). Percentages of all response categories can be found in Table 1 above.

Multivariate analysis of variance (MANOVA) was performed to test for effects of village, gender, and age for response categories of all three questions. For the sources of both sadness and happiness there are main effects of age and gender. For the question assessing sources of sadness, age effects are significant at p<0.05 (F=1.41). Gender effects are significant at p=0.01 (F=2.01). For the question assessing sources of happiness, both age and gender effects are significant at p<0.01 (F_{age}=2.17, F_{gender}=2.07). MANOVA performed on the question assessing sources of help shows only a significant age main effect (F=1.87, p<0.01). Univariate tests after MANOVA were examined for clues to the categories that might have contributed to the significant main effects (Harris, 1975). For the question assessing sadness, age effects may be related to the categories of School, Victim, and Alcohol. More young people (ages 7-18) that other age groups endorsed school and victimization as sources of sadness. Alcohol use was cited less often by the young adult group (ages 19-29) than by the other age groups (see Table 2). Categories most likely related to gender effects are Death, Relatives, and Boredom (see Table 3). More females than males cited Death and Relatives as causing sadness. Males cited Boredom more often than did females as a source of sadness.

### Table 2

<table>
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<tr>
<th>Category</th>
<th>School</th>
<th>Victim</th>
<th>Alcohol</th>
</tr>
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<tbody>
<tr>
<td>7-18</td>
<td>12.4</td>
<td>24.4</td>
<td>18.5</td>
</tr>
<tr>
<td>19-29</td>
<td>3.8</td>
<td>5.7</td>
<td>5.7</td>
</tr>
<tr>
<td>30-54</td>
<td>0</td>
<td>2.3</td>
<td>25.0</td>
</tr>
<tr>
<td>55+</td>
<td>3.7</td>
<td>11.1</td>
<td>44.5</td>
</tr>
</tbody>
</table>
Table 3

Sad Question
Percent of People in Categories with Significant
Univariate F-tests for Gender (p<.05)

<table>
<thead>
<tr>
<th>Category</th>
<th>Death</th>
<th>Relatives</th>
<th>Boredom</th>
</tr>
</thead>
<tbody>
<tr>
<td>Females (n=122)</td>
<td>36.1</td>
<td>20.5</td>
<td>2.5</td>
</tr>
<tr>
<td>Males (n=94)</td>
<td>26.6</td>
<td>2.2</td>
<td>11.7</td>
</tr>
</tbody>
</table>

Significant univariate F tests were also examined for the question assessing sources of happiness to provide clues as to categories that may have contributed to main effects for age and gender. For age effects, categories with significant univariate tests as presented in Table 4.

Table 4

Happy Question
Percent of People in Categories with Significant
Univariate F-tests for Age (p<.05)

<table>
<thead>
<tr>
<th>Category</th>
<th>Good Daily Living</th>
<th>Other People Happy</th>
<th>Kids</th>
<th>Sports</th>
<th>Family</th>
</tr>
</thead>
<tbody>
<tr>
<td>7-18</td>
<td>0</td>
<td>5.8</td>
<td>1.4</td>
<td>40.5</td>
<td>21.7</td>
</tr>
<tr>
<td>19-29</td>
<td>0</td>
<td>0</td>
<td>22.4</td>
<td>20.4</td>
<td>20.4</td>
</tr>
<tr>
<td>30-54</td>
<td>6.5</td>
<td>8.7</td>
<td>26.1</td>
<td>2.2</td>
<td>17.4</td>
</tr>
<tr>
<td>55+</td>
<td>18.9</td>
<td>18.9</td>
<td>28.3</td>
<td>3.8</td>
<td>7.6</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Category</th>
<th>Religion</th>
<th>Walking Around</th>
<th>Money</th>
<th>Friends</th>
<th>Going to School</th>
</tr>
</thead>
<tbody>
<tr>
<td>7-18</td>
<td>1.4</td>
<td>10.1</td>
<td>2.9</td>
<td>30.3</td>
<td>13.0</td>
</tr>
<tr>
<td>19-29</td>
<td>2.0</td>
<td>8.1</td>
<td>2.0</td>
<td>22.4</td>
<td>0</td>
</tr>
<tr>
<td>30-54</td>
<td>8.7</td>
<td>0</td>
<td>0.9</td>
<td>8.7</td>
<td>0</td>
</tr>
<tr>
<td>55+</td>
<td>35.9</td>
<td>0</td>
<td>3.8</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Categories that increased with age include Good Daily Living, Kids, and Religion. Categories for which responses decreased with age are Sports, Family, Walking Around, Friends, and Going to School. Two categories had more complex patterns with reference to age: Other People Happy and Money. Other People Happy showed the highest response percentage from elders (ages 55+), no mention in the young adult group (ages 19-29), and intermediate values in the other two age groups. Money was mentioned most often by the middle aged group, by smaller percentages of young people and young adults, and not at all by elders. Gender effects on the question asking for sources of happiness are significant for five categories: Kids, Good Health, Religion, Family and Relatives, and Doing Things with Others. Females had a higher number of responses to all categories except “Doing Things with Others,” in which males were higher (see Table 5).
Univariate tests after MANOVA for the questions assessing possible sources of help when people are sad indicate three categories that might be related to the significant main effect of age. These are Friends, parents, and Miscellaneous. With age, there was less mention of friends and parents as sources of help. The category Miscellaneous, which contains one-of-a-kind responses, had more items generated by the young adult and middle aged groups than by either the young people or the elders (see Table 6).

The interview data revealed several important community characteristics that should influence the design of new local mental health programs. These are: 1) long-standing, intimate human relationships, 2) developmental differences, 3) sex differences, 4) perceived areas of need and strength, and 5) acceptable sources of help. Each of these findings and its implications for program design will be discussed.

The emphasis on long-standing, intimate relationships can be seen in many of the interview responses. The respondents in this study perceive themselves as living within a web of human relationships that includes nuclear family, extended family, and friends. Most people in villages grow up with each other, live and work together as adults, and grow old together. Village families often intermarry, creating multiple extended family relationships. The resulting close relationships seem to have both positive and negative consequences. On the positive side, respondents report gaining a great deal of happiness from their children, relatives, and friends. On the negative side, children and other people were often cited as sources of sadness. Perhaps it was this high degree of social connectedness that
Scott et al. (1982) sensed when they called for community oriented strategies that mobilize this strong social network to create the context within which the problems of the individual can be solved. Effective mental health programs must take these relationships into account and work within this network of relationships to ensure lasting, positive change. Focusing therapeutic work solely on an individual may be ineffective due to the impact of the larger social network on all areas of functioning.

Another important community characteristic that should affect mental health program design involves developmental differences in values and activities. Age effects show that older people derive more happiness from religion and everyday pleasures and less from physical activities, school, and kids. These responses may reflect elders' current life situations, as they may be less involved in child-rearing, school, and activities that require physical strength and stamina. It is also possible that their emphasis on religion and everyday pleasures reflects developmental shifts as aging brings a focus on the present rather than the future and an emphasis on religion as a source of meaning.

However, a more compelling explanation for elders' emphasis on religion and everyday pleasures may be a cohort effect. Those who are elders in the 1980s grew up when there were no schools in villages and sports had not been widely introduced. Instead, the focus was on traditional Eskimo games and skills such as hunting, fishing, and skin sewing. This was also when missionaries targeted village people for Christian conversion. Therefore, elders' sources of current happiness may be an expression of the activities they learned to value when they were younger instead of developmental change associated with aging.

While it is impossible to resolve the question of whether each finding reflects true developmental change or a cohort effect, the implication is clear. Mental health programs must be designed to approach elders in a manner consistent with their values regarding religion and meaningful life activities. Programs must also take into account younger people's emphasis on sports, school, and their own children.

Developmental change in responses to the sad questions indicate several interesting patterns. First, with age there is less emphasis on school as a source of sadness. The percentage of respondents who mention this category drops dramatically at age 19. Since few villagers attend college, it is reasonable to assume that school-related problems decrease once people leave the school setting. A second developmental pattern shows both young people and elders victimized more than other age groups. These responses may reflect feelings of powerlessness and lack of control over the environment by those who are not yet given adult status and by those who are facing the consequences of aging.

A third developmental difference shows alcohol abuse cited most frequently as a source of sadness by elders and least frequently by young adults. The high frequency of responses from elders may reflect beliefs related to personal experiences of life during times when less alcohol was
available, strong religious sanctions existed against its misuse, and the fact that during their lifetimes survival often depended upon having a clear mind to cope with a harsh, unforgiving environment. It is also possible that condemnation of alcohol use could be a reaction to guilt over behavior now discontinued. The young adult group, on the other hand, did not report this category with great frequency though it is this age group, statewide, for which alcohol abuse is the highest (State of Alaska, 1989). These findings lend credence to the argument that denial of the negative impact of alcohol is highest among those most involved in its abuse. It should be noted that responses in this category included a broad definition of alcohol-related concerns and were not limited solely to one’s own use.

The developmental differences related to sadness suggest several important variables for program design. Programs must take into account the importance of school for young people and their relatively high feelings of victimization. Interventions might be oriented to learning practical ways of coping with school-related problems as well as increasing respondents’ sense of power and control in personal and social relationships. Programs should also explore age-related difference in attitudes about whether or not alcohol is a major problem in the village, and should design interventions that take into account these varying perceptions.

Significant sex differences also have program implications. In this study, women focused more on family concerns, health, and religion, while men emphasized outdoor activities with other people. These emphases appear similar to those found in western culture, with women traditionally focused on home and families and men oriented outside the home (Henslin, 1988; Huber, 1988). This finding may show socialization received from the white culture. It may also be related to the traditional Eskimo male role of hunter and the traditional Eskimo female role of family caretaker. Interventions must take into account the different role demands and preferences of the sexes.

Sadness and “bad” feelings were different than those a mental health practitioner might assume. The areas of sadness most often mentioned in all age and gender groups were death and alcohol. Most dominant culture mental health interventions do not focus on the problem of death. This finding may be related to several factors. First, the many intimate involvements reported by respondents suggests that the number of deaths of loved ones is higher in Eskimo communities than it is in communities with more diffuse social relationships. Many respondents reported that deaths of cousins, aunts, and friends were as emotionally devastating as deaths of spouses or children. Second, respondents reported often being called upon to provide support for bereaved friends and family members, even when the death was of someone not well known to them. Third, contributing to the impact of death may be the fact that Alaska natives have a high death rate in general; death rates for accidents, sudden infant death, homicide, and suicide are significantly higher than the national average (Alaska Federation of Natives, 1989).
It should be noted that suicide was mentioned rarely as a source of sadness. This is in contrast to assumptions made on the basis of statistics that point to the high suicide rate of Alaska natives compared to other groups (State of Alaska, 1988). Several explanations may account for this phenomenon. The first is that the base rate of suicide remains very low for Alaska natives even though their rate compared to other ethnic groups is high. Therefore, suicide remains a rare occurrence and does not frequently impact a village population. Second, it is possible that respondents were reluctant to mention suicide in the interviews due to feelings of embarrassment or shame. Third, it is possible that suicides were not directly identified as suicides but were mentioned as deaths. Anecdotal data from the interviewers suggests that several instances of this did occur. Therefore, it is likely that some of the responses coded within the death category were suicides. However, interviewers (most of whom knew how deaths had occurred) did not feel that a significant number of suicides were miscoded into the death category. Thus, it seems reasonable to conclude that death itself is a source of concern for a large percentage of the village population regardless of its specific cause. While suicide is a problem, the data indicate mental health programs need to become aware of all deaths among village people and help them develop healthy ways of dealing with the associated stressors.

Alcohol use was cited second most frequently as a source of sadness. Currently, the State of Alaska differentiates between alcohol and mental health programs and provides independent funding and monitoring of programs. These data strongly suggest that villagers do not make a distinction between alcohol and mental health problems. Instead, they view all these problems as part of a general class that creates sadness in the village. A mental health or alcohol worker must understand that programs designed to separate the two areas may not be easily understood or appropriate in these village contexts. The high concern overall about alcohol abuse suggests that programs must address this concern and that age-related differences in attitudes must be taken into account.

The categories documenting sources of happiness reveal a community oriented toward the outdoors and other people. The happiness category mentioned most frequently, "Outdoor Activities," included responses such as going hunting, picking berries, and riding snow machines. These responses indicate that outdoor activities, both traditional and nontraditional, are important as a way of improving mood. Participation in sports was the second most frequently mentioned source of happiness. Within this category, there were many references to basketball, one of the few indoor sports available in these villages in the winter. Other categories mentioned frequently as causing happiness involved maintaining positive relationships with other people and observing as others maintain positive relationships. The importance of living in a harmonious community is supported by these responses.
The findings documenting sources of happiness provide two valuable pieces of information. First, they provide a menu of pleasurable activities and experiences that can be used to increase positive feelings in both prevention and treatment programs. Second, this information gives clues about the types of experiences that might be missing for those who have problems. Rather than relying on majority culture definitions of pathology, one could examine the aspects of "happy" functioning that are missing and use these as guidelines in devising a treatment program for an individual or group.

When feeling sad, subjects placed great emphasis on other people and religion as sources of help. The finding that people in these villages do not perceive counselors as sources of help is not surprising, given their lack of access to mental health workers. Additionally, several negative experiences with professionals were cited in the interviews and were apparently discussed widely among village residents. Interestingly, use of other people as sources of help decreased with age. While it is possible that older people chose more dependence on religion and less on other people, it is more likely that their opportunities to rely on others diminish as cohort members die. The fact that the young adults and middle aged groups used a variety of strategies coded under miscellaneous indicates more individualized solutions to finding sources of help then in the other two age groups. A typical response in this category was "going to the city and driving around." These types of responses indicate more exposure to opportunities than younger and older age groups and the means to pursue them.

Overall, the patterns of data in this study suggest that it is a mistake to look at village people as homogeneous groups with the same stressors and supports. Rather, this study suggests that village people have a multiplicity of concerns, pleasures, and sources of supports. These dimensions also vary in complex ways according to age and gender. To be effective, any comprehensive mental health program will have to take into account the patterns of differences among people. For example, a program to address concerns about death might involve separate approaches for women and men. While both approaches might emphasize use of outdoor activities and religion, the women may benefit from family visits while men may benefit from going hunting with friends. These types of interventions are more holistic and community-based than the standard solution of individual counseling sessions one or two hours per month. They also rely on organizing the community to create interventions rather than asking an outside agency to visit the community and solve the problem.

One of the most intriguing findings of this study came to light during the design of the interview questions and was serendipitous in nature. In the initial community meeting to discuss the project, village people rejected the concept of "mental health" as having meaning in their culture. "Mental health" was viewed as a concept invented and promoted by "white people." Discussion focused on the fact that many terms used by the dominant culture to describe emotional problems (such as "depression") do not have
an equivalent in their native language. While no formal data were collected on these issues, an important message was given regarding the cultural relativity of diagnostic labels and concepts. Thus, the involvement of local people in the initial phases of the study caused the design of the interview questions to be radically different than they would have been otherwise. For interview questions, villagers preferred the use of the terms "happy" and "sad" because they were matched in meaning with Eskimo terms relating to emotional difficulties and emotional health. It appears that labels learned by professionals in most graduate schools are inadequate to conceptualize and communicate about emotional problems in these villages. More careful research is needed to systematically document the conceptual differences in terms used to describe emotional states.

The importance of looking at local conceptualizations of mental and emotional difficulties has been emphasized in this study. The outcomes support alternative ways of thinking about problems, strengths, and sources of support for Eskimo people. Because of the differences in through between these villages and a typical dominant culture mental health professional, it is likely that the professional will have great difficulty providing effective services at the village level. Village people themselves, who understand the cultural conceptualizations, will be more effective at designing services. In addition, village people will more likely be effective at mobilizing the social network that appears to be a strong determinant of health. Looking at local conceptualizations and involving local people will allow programs to be more sensitive to cultural variation, and will thus, enable them to more effectively serve those who need help.

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References


Appendix 1
Interview Questions

- What are the things that make you happy? What else makes you happy? (Repeated until respondent has no more responses).
- What do you do when you feel happy?
- How do you tell when a person is happy?
- What are the things that make you sad? What else makes you sad? (Repeated until respondent has no more responses).
- What do you do when you feel sad?
- How can you tell when a person is sad?
- Where do you go for help when you feel sad?
- Would you be willing to help someone that is sad?

Appendix 2
Response Category Definitions

Happy Definitions

- Outdoor Activities - activities that take place outside such as hunting, fishing, berry picking, riding sno-go.
- Kids - any mention of children, including having kids, being with kids, when kids are happy, healthy.
- Sports - includes playing sports as well as watching sports; includes swimming and dog racing as well as basketball, football, baseball, etc.
- Family - having a family, being with family. Does not include doing things for family or getting along with family, which is a separate category.
- Interaction with People - being with people, talking, visiting.
- Work - includes household work as well as paid employment. Does not include school work (homework).
- Religion - religious beliefs (God, Jesus, the Bible, etc.) and religious activities (going to church, praying).
- Travel - self-explanatory.
- Doing for Others - does not include doing things for family, but for people outside the family.
• Inside Entertainment - indoor activities such as listening to music, singing, sewing, knitting, playing video games.
• Other People Happy - when other people are happy and/or living happily.
• Anything & Everything - includes vague answers such as, "Anything makes me happy."
• Good Everyday Life - when everyday living goes smoothly.
• Gifts/Getting Things I want - self-explanatory.
• Good Health - includes others as well as self.
• Accomplishment - attaining goals, getting done what needs to be done, doing a good job. Does not include accomplishment in school, which is a separate category.
• Controlling Drinking and/or Drugs - when one stops or moderates intake of alcohol/drugs. Includes self as well as others.
• Going to School - self-explanatory.
• Food - includes any mention of food (having it, preparing it, eating it).
• Doing Things With Others - self-explanatory.
• Accomplishment in School - doing homework, getting good grades, etc.
• Escaping Bad Things - includes answers such as "coming out of surgery well," avoiding arguments with friends, etc.
• Money/No Financial Worries - having money, having no bills to pay, etc.
• Nice Weather - self-explanatory.
• Time Alone - self-explanatory.
• Positive Feedback - receiving sympathy, understanding, and compliments from others.
• Getting Along With Others - does not include family.

Sad Definitions
• Religious and Spiritual Concerns and Interpretations - active evil spiritual religious forces working in the village, lack of fulfillment of Christian beliefs, or "being in the last days."
• Negative Personal Emotions - negative emotions in reference to self such as "when I feel I'm a bad person."
• Personal Inadequacy - not living up to self-expectations.
• Basic Needs - lack of food, heat, or other basic physical needs.
• Kids - problems with one's own children of any age.
- Other People - when something negative happens to others or others are doing something negative (including conflict among others).
- Relatives - negative things happening to or experienced by relatives (excluding death, which is scored under Death).
- School - doing poorly academically or in sports or not liking school (including homework).
- Lack of Contact With Friends - self-explanatory.
- Victim - someone else doing something bad to you - first-hand experiences.
- Own Transgressions - person themselves does something wrong to others or breaks a rule.
- Communication - rumors, miscommunication.
- Lack of Direction From Adults - self-explanatory.
- Misc. - miscellaneous.
- Drugs - self-explanatory.
- Alcohol - self-explanatory.
TEWA CHILDREN WHO HAVE EPILEPSY:
A HEALTH CARE DILEMMA

LEMYRA M. DEBRUYN, Ph.D.

Abstract: This paper explores the part ethnicity may play in utilization of available western health care methods by Tewa families who have a child with epilepsy. Suggestions are made for appropriate responses by non-Indian health care providers to Tewa patients with epilepsy and their families. Findings indicate that, on the surface, Tewa families behave much like other Americans generally in utilization of western health care services. However, the Tewa are extremely reluctant to discuss with non-Indian health care providers traditional healing practices that may be used simultaneously. Such reluctance is well-documented in literature on the Tewa Pueblos and is substantiated in the present research. Suggestions are made for health care providers who wish to be "culturally aware" about the appropriateness of routinely asking a patient about his or her perception of the traditional etiology of the disease. The roles of the family and the western health care system are challenged. The response of Tewa extended families to children who have epilepsy is complex and not necessarily supportive. Often considered the primary health care provider for Native Americans, the Indian Health Service is based on an acute care model and lacks the ability to serve chronically disabled American Indian children. Finally, the paper argues that epilepsy is varied enough to complicate the development of a single model of chronic illness that is appropriate for those who suffer from the disability.

Much research has been done on the importance of ethnicity in health care response (Adair, Deuschle, & McDermott, 1969; Ahern, 1975; Guilmet & Whited, 1989; Joe, 1980; Leslie, 1976; Rubel, 1960; Saunders, 1954; Spicer, 1977; Vogel, 1970). This is because ethnicity, in part, implies that people who recognize themselves as being part of a particular group share at least some common experiences that influence their basic concepts and attitudes toward health and illness (Harwood, 1982). In a more applied vein, it has been widely accepted that modern health care providers' awareness of non-mainstream therapies and belief systems may help them communicate more effectively with their patients and thus provide the most appropriate interventions (Guilmet & Whited, 1989; Harwood, 1982).

This research is concerned with how Indian parents of the Tewa Pueblos in New Mexico cope with problems of epilepsy among their...
The focus of the study was to determine: first, if and how ethnicity plays a part in the response of Tewa families to epileptic children; second, what information medical providers need about Tewa healing practices to enhance the quality of available modern medical care; and third, what behavioral characteristics epileptic patients in a cross-cultural setting share that can contribute to the development of chronic illness models more comprehensive than those that presently exist.

**Epilepsy Described**

Epilepsy represents a range of seizure disorders. It is not a specific or single chronic disease of the brain, but a symptom and manifestation of abnormal cerebral function that may be due to any one of a large number of causes (Lagos, 1974). These include birth injuries, post-traumatic seizures following a blow to the head, chronic alcohol use (seizures that are not delirium tremens), vascular problems, brain tumors, or inflammatory diseases. In many cases, no cause can be detected.

Epileptic seizures occur more frequently in children than in adults. In approximately 80% of all cases the initial seizure occurs during the first two decades of life. Three age ranges mark the most common occurrence of seizures: the first two years of life, between four and eight years of age, and the years of adolescence. Due to risk of injury at birth, the incidence of seizures is highest among newborns (Lagos, 1974).

Western treatment of epilepsy usually consists of the use of anticonvulsant drugs and, depending on the physician, varying amounts of educational counseling for the patient and family about management of the disorder. The object of drug therapy is to make the epileptic person seizure-free, although this goal is not possible in many cases. Estimates vary, but with drug therapy seizures are controlled in about 50% of the epileptic population, partially controlled in an additional 20 to 25%, and poorly controlled in the remaining 25 to 30%.

Levy's research on epilepsy and hysterical seizures among Indian tribes is the most pertinent literature available for this specific population group (Levy, 1979; 1981; Levy, Neutra, & Parker, 1979; 1987; Levy & DeBruyn, 1980). The tribes studied include the Navajo, known for their cultural discernment of seizure syndromes, and three Pueblo groups: the Zuni, Hopi, and Tewa tribes. These studies are epidemiological, and also explore sociocultural components of response to epileptic persons. The prevalence of epilepsy in all four tribes was found to be higher than in the "control" population in Rochester, Minnesota (Hauser & Kurland, 1975). Rochester's rate was 5.7 per 1,000 population as compared to 8.2 among the Navajo, 9.1 among the Zuni, and 7.5 among the Tewa.

The pueblo populations have common features in their belief systems that are different from those of the Navajo. Levy observed that none of the Pueblos have singled out the signs of epileptic seizures for special attention in their own healing systems in the same way the Navajos...
have. Since Navajos believe that signs of grand mal seizures are direct consequences of sibling incest, epilepsy is a major stigma both for the patient and the family. In contrast, Pueblos do not place such negative connotations on the illness, do not see convulsions as the symptom of a single disease process, and do not always believe that their appearance stigmatizes the patient or the family. However, members of the community may suspect, especially if the seizures are chronic and uncontrolled, that something is wrong with the child and his or her family. What that "something" is is vague and undefined, usually implying some emotional disturbance (Levy, 1981).

The Tewa Pueblos

The Native American villages located along the Rio Grande River in New Mexico, 16 in all, comprise the Eastern Pueblos. Six of these represent the population on which this study is based: San Juan, Santa Clara, San Ildefonso, Tesuque, Nambe, and Pojoaque, where the Tewa dialect of the Tanoan linguistic family is spoken. The Tewa Pueblos range in distance between 12 to 25 miles from Santa Fe, New Mexico. In comparison with other American Indian tribes, few details are known about the Eastern Pueblos. This is a result of pueblo history, where traditional ceremonies and beliefs were banned - usually violently - by Spain and later the United States (Ortiz, 1979), and Pueblo peoples became reticent to discuss themselves or allow outside research (Bodine, 1972). Anthropological studies of the 1930s and 1940s among the Eastern Pueblos helped influence this attitude, when Pueblo people were shocked to find their jealously guarded secrets in print (Ortiz, 1979). To be accepted at all, research must have some applied focus that will potentially benefit pueblo residents.

Among the Tewa, breach of tabu was the most frequent explanation for disease, followed by object intrusion and contagious magic. Witchcraft was often used to explain illnesses where it was difficult to determine specific responsibility. Illness and death from natural causes were recognized, but their role was incidental in the overall theory of disease. Breach of tabu encompassed any type of either non-sanctioned or antisocial behavior, or any digression from the ideally conceived way of life, that is, mutual cooperation and sharing with other pueblo members (Ortiz, 1969; 1972). When misfortune, accident, illness or death could not be readily explained in terms of a religious breach of tabu, witchcraft was usually used as the causal explanation. The theory of witchcraft stemmed from a belief in the ability of individuals to acquire supernatural power and control it for their own uses as well as to transfer it to others. Anyone suspected of witchcraft was feared or shunned. Witchcraft served as an indirect social control against aggressive and individualistic actions (Hill, 1972).

Whether or not the Tewa people continue to believe strongly in witchcraft cannot be easily determined, for they do not talk about it to
outsiders. Any discussion of witchcraft in the presence of a non-Tewa was and is accompanied by obvious uneasiness. Although witchcraft may have been an explanation for epilepsy among the Tewa in the past (Naranjo, 1980), Tewa people today are unwilling to discuss the subject or to say whether the traditional healing system is utilized in regard to seizure disorders.

Methodology

The present research was an outgrowth of the Tewa Epilepsy Project, sponsored by the Indian Children's Program of the United States Public Health Service and Bureau of Indian Affairs. The purpose of the project was to determine the prevalence and causes of epilepsy in the Tewa population and compare these findings with similar data on the Navajo, Hopi, and Zuni Indians. The "control" group from Rochester, Minnesota, comprised an epidemiological sample of the prevalence of epilepsy in a medically sophisticated midwestern community; it also provided comparison of the utilization of western health care facilities and of compliance with the use of prescribed medication across all population samples. During the two years of data collection (September 1979-September 1981), family interviews and ongoing counseling and education were provided about epilepsy by the author to the families in both the Tewa Epilepsy Project and the sample of children chosen for the present research.

The sample of children for the present study was selected both through the use of the computerized data retrieval system of the Albuquerque Area Indian Health Service (IHS) from entries covering July 1, 1971 through June 30, 1978, and by referrals from health workers and community residents. A computer search was made for all Tewa children with diagnostic codes for seizures of any type, including febrile seizures, syncope (fainting spells), headaches, and medication that is usually given for epilepsy. Medical records of individuals seen during the period who had seizures at some time in their lives were abstracted and all families of children were interviewed, where possible. Up to three separate interviews were conducted per family.

Nine persons in the Tewa Epilepsy Project were included in the present study because they were less than 19 years of age during the time period. Twenty-two additional children were included in the present research, making a total of 31 children and 28 households (since there are three sets of siblings) in the research sample.

Direct inquiries about traditional beliefs and practices regarding epilepsy or other health matters were not made. The present study was acceptable to Pueblo officials largely because of the promise that questions about traditional medicine and religious beliefs would not be asked.
The Children and Their Families

Of the 31 children, 13 suffered only from some form of epilepsy, six had epilepsy along with other handicaps, and 12 had experienced febrile seizures. The seizures of the majority of children were controlled by anticonvulsant medication. Twenty children had some history of seizures in the immediate or extended family: in six cases there was a family history of epilepsy, in nine cases there was a family history of febrile seizures, and in five cases both epilepsy and febrile seizures were represented in the family. The remaining 11 children had no family history of either epilepsy or febrile seizures. Two children are deceased, one eight years prior to 1979 when the research began; the other died in an accident during the two-year period in which the research was conducted.

Of the 28 households, 22 included nuclear families; two had extended relatives, either grandparents or parents' siblings; and four households were headed by single parents. Adults living in the same household as the child were usually the most important caretakers, both emotionally and economically. Some non-resident grandmothers cared for the child during the day and some children were placed in day care facilities.

The majority of children had one non-Tewa parent. In only 10 families were both parents full-blood Tewa, although not necessarily from the same Tewa pueblo. It must be noted, however, that children living in the pueblos followed the dictates of the Tewa village, and the non-Tewa parent's ethnicity was most often not emphasized by the family and community when referring to the child. Most of the children (26) lived in pueblo communities; five older children had moved away.

Tewa Response to Epilepsy in Children

When the first seizure occurred, Tewa parents commonly reacted with fear for the child's life. This was followed by denial of the child's epilepsy, self-blame for the development of the disorder, and social isolation of the mother. Long-term family reactions varied depending on the child's behavior, visibility of the disorder, and whether or not development was otherwise normal. If a child had poorly controlled seizures, over-protection was a common reaction.

Mothers and fathers differed in their willingness to talk about a child's disorder. Mothers would attend a parent support group started during the course of the research to discuss their concerns about their children with epilepsy; although invited, fathers did not attend. It was explained by the mothers that men had more difficulty discussing these issues, and that the women were the primarily caretakers for their children.

Relatives appeared to be less willing to help care for the child if one parent - especially the mother - was not a member of the pueblo. Relatives were particularly unwilling to take responsibility for care in the case of an epileptic child with poorly controlled seizures. Many children therefore...
suffered some social isolation, especially since schoolmates increased their teasing as children with poorly controlled seizures grew older.

Familial response to a child’s first severe seizure, usually grand mal, included dismay and fear. In every case, the child was rushed to the emergency room at the nearest hospital. Families also responded with great concern at the first awareness of petit mal seizures, taking the child to a nearby hospital or clinic as soon as they recognized that the seizures were something other than daydreaming or inattention. Parents with professional medical training or previous experience with epilepsy were as frightened as those who knew nothing about the disorder. They differed only in that parents who had no information about epilepsy thought the child was dying.

Response to the diagnosis of epilepsy was usually denial, most frequently by the father. Both parents blamed themselves for the child’s disorder. A mother frequently began to isolate herself from others. Parental anxieties were not easily dispelled either by health workers or other members of the family.

The extent of self-blame was unexpected. Women reported that their husbands shared the sense of blame but would not talk about it. How much parents suffered became apparent during informal gatherings on a one-to-one basis or in group situations where mothers talked together. During the talks, women often wept. They said again and again that a bad thought or action during pregnancy or early in the child’s life may have caused the illness. This reference to self-blame that may be related to traditional Tewa beliefs was unsolicited. However, self-blame by parents for the illness or death of a child is a nearly universal phenomenon and should not be relegated necessarily to a single cultural belief system. Furthermore, many of the mothers at group sessions expressing these feelings were non-Tewa and non-Indian.

Mothers would ask, "Was it a bad thought I had when I was carrying my child? I can’t help but think it was something I thought or did that caused my child’s seizures." Sometimes women asked, "Why me?" but then returned to asking what they had done to cause the epilepsy. Mothers also said they wished they could take the child’s disorder upon themselves: "I often think, if only I could take on my child’s problems. He’s just a baby and I am so much stronger. If only it were me instead of my baby who had the seizures."

Variation of Family Response with Control Over Seizures

When seizures can be controlled, epilepsy can accurately be described as an "invisible handicap" (Freeman 1979). Tewa families who had children with medically controlled seizures usually treated them "normally," encouraging them to play with their siblings and other children, and to participate in the general life of the society. Only a few families with such children tried to overprotect them - sometimes even when the child
had not had convulsions for years and was no longer on medication - saying, for example, "Don't upset her, she might have a seizure."

It is easier to deny the existence of epilepsy when seizures are controlled. Periodic seizures are a constant reminder of the disability. Interview data from 17 mothers with children whose seizures were controlled show that they both treated their children normally and denied the presence of the disorder. Health care workers encouraged them to treat the children normally, but the parents also wanted to forget about the disorder altogether. Consequently, they were unlikely to talk to the child about his or her epilepsy, and the children knew little or nothing about their disability. Their siblings knew only that a brother or sister "has to take pills all the time." Those children who were aware that they had epilepsy did not want their peers at school to know. They also were growing up with little understanding of their disability, and were not aware that the environment outside the family was likely to be less nurturing and less oblivious than the family setting.

Six children in the sample had poorly controlled seizures. They and their families faced constant frustrations, continual adjustment of medication, curtailed social activities, and family disruption. Parents lived in fear that the child would have a seizure when away from them. They were strongly tempted to be overprotective even if they were opposed to over-protecting the child. While children with controlled seizures participated in the normal run of social activities, seizure-prone children were restricted.

Parents of seizure-prone children also tended to direct much of their attention toward the disability, neglecting other children. They did not have the extra emotional strength needed to meet the demands of their “normal” children. Siblings close in age to the epileptic child displayed many attention-getting behaviors, especially when young, but such attempts usually met with little response from overburdened parents. Mothers said they could not help but be more concerned about the child who was developing differently, even if additional caretakers were available.

Six children suffered from other disabilities in addition to epilepsy. Families preferred to keep multiply handicapped children at home. In two instances, however, the burden became too great and the children were institutionalized. In another case, one mother told of her child who had had epilepsy and an additional handicap, whom the father had institutionalized. Although the child died eight years before this study began, his mother still regretted having sent him away, stating he died of loneliness. Despite the strain on the family, Tewa parents usually preferred to keep their disabled children at home. The two who had placed their children in institutions visited them frequently and brought them home for weeks at a time, especially for holidays.
Employment and Caretaking

Employed women were likely to give up their jobs when they had to care for an epileptic child, especially if the child had uncontrolled seizures or multiple handicaps. Five of the 18 women who were consistently or sporadically employed between 1979 and 1981 faced serious crises with their epileptic children. All five either quit work, changed to half-time work, or took time off.

A lack of caretaking on the part of extended kin was surprising given the general belief that the Tewa extended family provides a strong support system for its members. Parents of children with multiple handicaps or poorly controlled seizures had a difficult time in obtaining and keeping caretakers. In most cases it was the mother who bore the brunt of the caretaking tasks. Relatives who would have helped care for normal children usually needed special instruction in dealing with an epileptic child. If a child had a seizure, a caretaker was often reluctant to continue caring for the child. Visible seizure activity was frightening and much more difficult to cope with than making certain that a child had its medication at appropriate times. A few caretakers who had learned what to do if a seizure occurred were willing to continue to help, but in most cases, extended kin helped only sporadically. This added to the mother’s sense of isolation, and made it almost impossible for a woman with such a child to continue to work at a regular job.

Societal Behavior Toward the Children

Older children whose seizures were poorly controlled faced constant teasing by peers. Teasing was clearly evident for one child approaching adolescence whose seizures had begun to shift from petit mal to psychomotor and grand mal epilepsy. The child was labelled in school as a "monster" and considered "contagious" by classmates.

Five children in the sample were reported by their mothers and health personnel to have emotional problems. All were between ages 10 and 19. Two had controlled seizures, and three had seizures that were uncontrolled. Studies of epilepsy among the Zuni, Hopi, and Tewa people indicate that emotional problems begin just prior to or during adolescence (Levy, 1981), probably due to the parents' denial of the disorder.

Pueblo parents who try to treat an epileptic child as normally as possible fail to answer the child's questions or to address what the child is about to face both socially and emotionally. The child then has "few means to adjust to the illness when he becomes more independent during adolescence" (Levy, 1981, p. 48).

It is probable that as they mature, Tewa children who have epilepsy will face continuing problems. The experience of adults included in the Tewa Epilepsy Project sample indicates that epileptics face a high degree of social isolation. It is not possible to determine cause-effect relationships...
between seizures and other emotional problems, but all those Tewa who had suffered from epilepsy for a long time also experienced alcoholism and other emotional and somatic problems. Seven adults included in the project sample had experienced seizures since childhood. Two had severe alcohol problems at the time of the study, while two more had a history of chronic alcoholism and may still have been abusing alcohol. Two had serious emotional problems, and one refused any medical or psychological treatment. One, whose brother also suffered from epilepsy, had suffered from severe gastroenteritis for years, a common complaint in his family.

These data lend credence to the hypothesis that even epileptic children whose seizures are controlled eventually have problems in part because of their parents' refusal to face the implications of the disorder, i.e., they become adults who do not know how to cope either with their epilepsy or their social environment. However, family attitudes may not be the crucial variable. Regardless of family treatment of epileptic children (e.g., nurturing among the Tewa and alienating among the Navajo), adults with seizures face serious social problems. It has been suggested that Navajos who have epilepsy are more likely to develop severe alcohol problems and suffer violent deaths, while Tewa people who have epilepsy temper social isolation with alcoholism. Nevertheless, Tewa people with epilepsy also may come to violent ends; in recent years, two Tewa adults with epilepsy died violently and three were reported as having died violent deaths in earlier years.

The Search for Treatment

Unlike more isolated American Indian groups, the Tewa have access to a wide variety of health care services, including the United States Public Health Service (IHS), state programs that focus on disabled children, physicians in private practice, local hospitals in addition to the Santa Fe Indian Hospital, home remedies, traditional curers, acupuncturists, and herbalists. In fact, the whole Santa Fe, New Mexico, area is noted for its variety and interest in different healing traditions from all parts of the world.

Within the range of medical services, the most important factor in choice of agency was the complexity of the child’s disorder. When children could be maintained on anticonvulsant medication and otherwise needed only periodic check-ups, families used the IHS exclusively. In contrast, families of children with poorly controlled seizures and/or multiple handicaps most often sought help outside the IHS system. Fourteen of the 31 children in the sample used IHS primarily while 11 most often used non-IHS help. Data were not available for six of the children. Of the 14 users of IHS, 13 had controlled seizures. Of the 11 taken to non-IHS practitioners, seven had poorly controlled seizures and/or multiple handicaps.

Although some families utilized non-IHS facilities because they thought they could receive more consistent care, most children with poorly...
controlled seizures or multiple handicaps were in need of on-going therapeutic services such as occupational, speech, or physical therapy that the IHS could not provide. Moreover, multiply handicapped children faced a variety of tests and screenings wherever they were taken. Due to poor coordination among service agencies, the children often had the same work-up several times. The situation improved, however, during the course of the research. When the research began in 1979, the problem was to find services that would provide follow-up and on-going care. However, in 1981, through outreach efforts on the part of the IHS and the New Mexico Department of Disabilities, new state programs specializing in the care of handicapped children became aware that Indian children needed more consistent services than the IHS could provide. As a result, there was greater coordination between IHS and these state programs, at least during the remaining course of the research period.

Lack of On-going Treatment by the IHS

For reasons that are outlined here, the IHS could not consistently provide the necessary services for chronically ill or disabled children. This was especially noticeable in the treatment of the more severely handicapped epileptic children in the sample, those most in need of continuity of care.

There are various factors that affect the ability of the IHS to serve the Tewa people. First of all, the Tewa population is mobile. Some families in the sample left the area for a time during the two years of they study, taking their children with them (at least four families moved out of the community and back within the research period). The children then received treatment outside the area, creating a gap in their medical records. When they returned, it took time and effort to send for records, and this sometimes was never done.

The high turnover of professional staff, particularly doctors, within the IHS also affected continuity of care. During 1979-1981, many physicians left after only two or three years of service, moving on to private practice or to another Public Health Service position. Physicians commented to me that they left not because of the people they served, but in reaction to the government restrictions on treatment and the heavy burden of paperwork that kept them from "doing real medicine." Often, the physicians had repaid the two-year service period they owed from accepting government loans during their schooling and were anxious to move into private practice. Since consistent care is best obtained from a physician familiar with a child's history and family situation, the practice of rotating IHS physicians caused some Tewa families to turn to private physicians. They used the IHS only for medication refills and periodic check-ups. The more severe the child's handicaps, the more likely Tewa families were to use a private physician.

Lack of funding also affects continuity. The IHS has been plagued by insufficient funding since it was established in 1955 and, with the cuts of
the early 1980s, auxiliary services became even more limited. Like the rest of the medical system in the United States, the IHS developed with an emphasis on acute care. Even though in the early days widespread sanitary efforts were made to improve reservation environments, the acute care focus has prevailed. It has become even more prevalent in response to budget cuts.

The severely disabled children in the sample needed many resources not provided by the IHS. Private health insurance, Medicare and Medicaid, or Social Security Income met the cost of some of the treatment for some of the children, but not for all. Frequently IHS doctors, community health nurses, social workers, and mental health personnel found themselves desperately searching for appropriate treatment facilities outside the IHS system. They did so at some personal risk. IHS physicians were reprimanded on occasion for referring a child to a non-IHS facility when funding was not specifically contracted for such care.

Willingness of Parents to Use Medical Services

The evident willingness of Tewa families to discuss their children with medical personnel and to seek their help is a relatively new phenomenon. This may be related to families' knowledge that medication regimens developed since 1938 (Freedman et al., 1975), which became more consistently available to Native Americans after the Public Health Service takeover of Indian health services in 1955, are likely to be effective in controlling the disorder.

One set of parents said that as recently as the 1960s, families were secretive about such matters. Tribal leaders and community members repeatedly spoke of a change in village attitudes during the 10 to 15 years prior to 1980. They said that in the past such children were "never seen outside the home," and that people needed "to know about these problems." When asked why pueblo parents were unwilling to talk about their disabled children in the past, staff members responded: "Relatives do not give constructive advice about disabled children. They give pity, which parents do not need. Professionals (trained in the developmental disabilities area) are more helpful." In other words, with more services available since the mid-1960s, parents are bringing their disabled children "out of the closet."

Although most Tewa are now prepared to consult medical staff about their children, this does not mean that they are prepared to talk about all aspects of the child's treatment. As in many ethnomedical systems, traditional Tewa beliefs about causation and healing are contained within the religious and spiritual sphere. Any discussion of Tewa religion with non-Tewa in specific terms is considered tabu. To be asked directly about those beliefs by a non-Tewa person is considered rude and discourteous. Contacts during the during the research period (1980-1983) and continued contact through 1991 made it evident that many Tewa respect different kinds of healing knowledge - both modern medicine and their own - and will
utilize them according to proved effectiveness. However, Tewa have no problem in keeping these medical paradigms separate from each other. Medical personnel, particularly physicians and nurses, are highly thought of because of their knowledge about how to stop seizures. The Tewa appreciate the sensitivity shown by those physicians and nurses who do not thoughtlessly ask questions about traditional healing practices that Tewa are not supposed to discuss with outsiders.

Discussion Of Research Findings

On the surface, the health care-seeking behavior of the Tewa regarding their children who have epilepsy could be descriptive of any population in the United States that has access to modern western medical care and appreciates its efficacy. As expected, however, indicators of ethnicity were present, in both medical and non-medical interactions with non-Tewa persons. First, traditional healing practices are kept distinctly separate from modern western medicine. And second, the Tewa are extremely reluctant to discuss traditional healing and religious practices with outsiders. The fact that Tewa families utilize the western health care system with such efficiency does not alter their sense of being Tewa. They utilize an easily available form of modern medical intervention that often demonstrates positive results. It is very likely that they are also responding differently at another level, utilizing their own medicine. This the outsider does not see.

One example of numerous conversations regarding this issue is noted here. A tribal elder, asked what western health providers needed to know to counsel and work with Tewa families, said they need to know nothing: "You have your area of expertise and our pueblo medicine people have theirs. Our families know the difference and can choose according to what each of you has to offer."

Implications For Health Care Policy

What do the research findings mean with respect to health care policy for the Tewa and, by extension, for patients from other traditional societies with indigenous medical systems? Probably most important is the fact that Tewa people do not talk about traditional healing practices with non-Tewa outsiders. One of Harwood's main points in his discussion on guidelines for culturally appropriate health care is that clinicians should take care to elicit the patient's concept of his or her problem and its cause (1982). This concept is far too simplistic for use with people across different ethnic groups. Rather, if health professionals wish to be culturally sensitive to their Tewa patients, they need to do their homework. First, they must read about Tewa history and culture, and learn why the pueblos have needed to keep cultural information secret (Schepers-Hughes, 1987). Second, physicians and other service providers need to "learn how to ask"
Briggs, 1986). Listening to patients and letting their cues guide questions can make all the difference as to how that patient interacts with the service provider. If a physician or service provider is not willing to take the time to learn Tewa culture history and find appropriate ways of asking delicate questions (and asking those questions only when the answers are necessary for appropriate treatment), it seems clear that the professional should not ask about traditional Tewa beliefs. The Tewa are usually well versed in modern medical symptomatology and can answer questions about cause and problems of illness without reference to tabu topics. Specifically, Tewa parents with children who have epilepsy easily give information on family history of the condition and possible environmental determinants of seizures without having to reference their traditional paradigm of disease etiology and cure.

Like other non-western groups (Foster & Anderson, 1978), Tewa parents gladly use modern medicine when they can see that it helps their children. Hence, where non-IHS care is available and the IHS itself cannot provide sufficiently for children who have epilepsy, every effort must be made to assure coordination among agencies that can provide the needed care.

Implications Of Research For Chronic Illness Models

Research findings point to a number of factors to be considered when developing models of chronic illness behavior in any group. One of the most widely criticized models of illness behavior is Parsons' (1951), in which the sick person is neither expected to carry out normal role responsibilities nor is blamed for the illness. However, the sick person is expected to get well and must seek technically competent help in order to do so (Parsons, 1951).

Most researchers have criticized the Parsonian model as addressing only acute illness. They call for models that account for the effects of chronic illness on the behavior of patients and physicians (Stewart & Sullivan, 1982). They ask for a definition of sociocultural determinants of behavior during illness (Stewart & Sullivan, 1982; Hopper, 1981), and for discussion of the social and psychological problems faced by the chronically ill (Kassebaum & Baumann, 1965; Strauss, 1975).

In contrast to Parsons, Strauss (1975) outlines a framework for thinking systematically about the experiences of those suffering from chronic illness, noting that any given chronic disease potentially causes multiple problems in daily living both for patient and family. These include the prevention of medical crises and their management once they occur, control of symptoms, carrying out prescribed regimens, prevention of or living with the social isolation caused by lessened contact with others, adjustment to changes in the course of the disease, attempts at normalizing both interactions with others and style of life, and finding the necessary financial resources to pay for treatments. Strauss also recognizes that the
importance of medical personnel is secondary to a patient's day to day "carrying on" in the face of the disease.

Strauss' generalizations about chronic illness help elucidate the first factor that must be considered in developing models of chronic illness, i.e., how patients and families adapt to everyday life in response to the disease. For epileptic persons, the control of symptoms is particularly important because of the range of visibility of seizure disorders. As was demonstrated in the Tewa family response data, when epilepsy is not apparent to the outside world, patient and family can function with relative normalcy, denying the reality of the affliction to self and others. However, when evidence of the disorder is visible because of seizure activity, the patient assumes the overt behavior attributed to the classic Parsonian patient role. During an epileptic crisis, the patient role fits Parsons' model. It is in the daily role of the person who has epilepsy - especially among those whose next seizure is imminent but unpredictable - that the classic patient role breaks down. Rather, the patient must become "committed to the meaning and implications of the disability" (Gussow, 1964), facing multiple problems of day-to-day life as posed by Strauss. The disability, in fact, becomes part of the patient's self-identity. The patient, then, falls in and out of the classic sick role, and adapts to the inevitability of recurrent seizures. Consequently, there is a continuum between the non-visibility and visibility of epilepsy that gives rise to different behavioral responses at different times.

Conclusions

The research findings about how Tewa families respond to epilepsy in children question broad generalizations about the response of non-western peoples to modern medicine and the definition of illness behavior. That physicians should learn how to ask questions and not assume the appropriateness of asking about traditional medicine behavior among the Tewa challenge Harwood's simplistic statement that clinicians should always elicit the patient's concept of the problem and its cause. Further, ethnic identity as a Tewa person is strong. Overt health-seeking behavior can overshadow nuances that well-meaning health professionals may overlook, thereby making for communication difficulties.

The research also demonstrates that epilepsy is varied enough in character as a chronic illness to complicate the development of a single chronic illness model appropriate to its victims. The fact that response to epilepsy varies depending on its degree of visibility underlines the importance of considering each patient's situation individually as well as in cultural context before predicting what his or her behavior will be.

Finally, the research shows that Tewa families who have a child with epilepsy face a large number of problems. They are plagued by social isolation and the lack of adequate care. They are faced with the consequences of their denial of the disorder as it affects the children, and
in the cases of children whose seizures are poorly controlled, a future that drains emotional and financial resources. Nor is the world outside the Tewa community very supportive. The Age of Enlightenment is an idle dream for the person who has epilepsy. Other than the usefulness of modern medicine when it can control seizure activity, the western world has little compassion or comfort to offer when it comes to understanding the effects of a very complex chronic illness.

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Notes

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References


PANIC DISORDER AMONG AMERICAN INDIANS:
A DESCRIPTIVE STUDY

Gordon Neligh, M.D., Anna. E. Barón, Ph.D.,
Patricia Braun, M.D., and Michael Czarnecki, M.D.

Little is know about panic disorder among American Indians. In
a pilot project involving two Northwest Coast Indian villages,
community health representatives screened the population for
panic disorder, substance abuse, and major depression using
DSM-III criteria. Accompanying the screening were subsequent
patient education and further evaluation by a psychiatrist, a social
worker, and primary care physicians. Of fifty community resi-
dents who agreed to take the screening examination, seven were
found who met diagnostic criteria for panic disorder. Four of the
seven had symptoms of alcohol abuse which complicated the
course and diagnosis of panic disorder, and individuals with panic
disorder reported more than twice the lifetime prevalence of
depression in comparison with other community members.
Limitations of the study and refinements of study design are
needed in future study discussions.

Relatively little is known about major mental illnesses among
American Indians because of difficulties in diagnosis across cultural
boundaries, artifacts of the service delivery system, and the reluctance of
many American Indian communities to participate in research (Neligh,
1988a). Mental health programs operated by the Indian Health Service
(IHS) and individual tribes in the past have tended to avoid diagnostic
"labeling" and to be oriented toward a non-diagnostic counseling approach
to the mental health problems of Indian people. Although some Indian
mental health programs are making the transition to the use of formal
diagnostic systems such as the ICD-9-CM (Commission on Professional
and Hospital Activities, 1978) and the DSM-III-R (American Psychiatric
Association, 1987), the historic avoidance of formal diagnostics has
linger ed in many programs. Furthermore, the avoidance of formal
diagnostics by many Indian mental health programs may have left
undetected patterns of major mental illness among American Indians which,
if known, could have stimulated the delivery of effective treatment to Indian
people suffering from these illnesses.

In addition to the reluctance of the service delivery system to use
formal diagnostic procedures, the diagnosis of major mental illnesses

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across cultural boundaries is complicated by differences in reported symptoms of these illnesses among people from different cultures. For example, investigations of depression in non-majority cultures have demonstrated different symptom groupings in comparison with symptom clusters reported for depression among members of the majority culture (Kinzie, Manson, Do, Nguyen, Bui, & Than, 1982). The exploration of depressive illness among American Indians has been similarly informative (Manson & Shore, 1981; Manson, Shore, & Bloom, 1985).

Studies on panic disorder and its associated symptoms in cultures other than the American majority culture have received comparatively little attention. Prior to 1980, there was only one report of agoraphobia, a symptom usually associated with panic disorder, among Alaska Eskimos (Hudson, 1982) and none among American Indians. In 1988, Neligh (1988a) reported panic disorder among Plains Indian people in the service utilization data from the Billings Area of the IHS. A program for diagnosing and treating panic disorder among Plains Indians was started by Catherine Eder on a northern Plains reservation with a high level of utilization and at least anecdotal success (Neligh, 1990). In spite of the reports of panic disorder among Plains Indian people, some doubt remained about whether this disorder was unique to Plains Indian people. If it were in view of the hereditary nature of panic disorder in some populations, this pattern of distribution would have major implications at least for research on the genetics of mental illness (Cloninger, 1987).

If panic disorder were not limited to Plains Indian groups, the health implications of the wider distribution among Indian people could be substantial. Patients with panic disorder have a higher-than-normal co-morbidity from cardiac abnormalities, particularly mitral valve prolapse, than the general population (Liberthson, Sheehan, King, & Weymen, 1986; Dager, Comess, & Dunner, 1986). Individuals with panic disorder experience a higher than expected rate of premature death (Johnson, Weissman, & Klerman, 1990; Weissman, Klerman, Markowitz, & Ouellette, 1989) and may experience a substantial morbidity from the symptoms of generalized anxiety and agoraphobia (Markowitz, Weissman, Ouellette, Liah, & Klerman, 1989), which are frequent complications of panic disorder (Klein, Zitrin, & Woerner, 1978). Furthermore, if effectively diagnosed and treated in accord with the literature panic disorder is relatively easily treated (Rickels & Schweizer, 1987). If this disorder were widespread among Indian populations, unnecessary death and disability might be prevented with effective detection and treatment through the use of "secondary prevention" programs (Neligh, 1988b).

A Study of Panic Disorder in the Portland Area

Given this background, the tribes and IHS programs in the Portland Area undertook a project to determine whether panic disorder existed among the Indian people in the Pacific Northwest, as well as among Indian
people of the Plains groups. As a result of training programs for Community Health Representatives (local community members trained as paraprofessional health care providers) in the Portland Area, several tribes expressed interest in hosting initial trials for panic disorder detection and treatment programs. From among the groups volunteering to be initial sites, two reservations were chosen on the basis of: 1) their small population size, which would permit a large portion of the adult population to be screened, 2) support by the tribal leadership for the project, and 3) a history of an active Community Health Representative program.

The goals of the project were conceptualized along several dimensions. The first goal of the study was to screen the population for symptoms of panic disorder. Second, issues of comorbidity would be explored. Third, when patients with panic disorder were identified, the project would initiate a secondary prevention strategy by trying to connect them with the health care delivery system so that they would receive effective treatment. Finally, the project was designed to test the role of the Community Health Representative in outreach and screening, which had been proposed for these paraprofessionals (Neligh & Manson, 1984). This outreach and screening role was to be patterned after strategies developed by the World Health Organization for extending mental health care to populations in the developing world through paraprofessional workers (Sartorius & Harding, 1983; Harding, Climent, Diop, Giel, Ibrahim, Murthy, Suleiman, & Wig, 1983; Murthy & Wig, 1983).

Methods

Because the goals of the study mixed both research and service-delivery objectives, a system was designed so that a high percentage of the adult community members would be screened for panic disorders by Community Health Representatives. If a screening showed a patient to be positive, he or she would be referred to both a mental health professional and a primary care physician for further diagnosis and treatment.

The study developed an instrument to be administered to community members by the Community Health Representatives. It contained diagnostic criteria for panic disorder used in the DSM-III (the current DSM at the time of the study), and questions designed to screen for major depression (also using DSM-III criteria) and substance abuse. An initial version of the screening instrument was shared with the Area Community Health Representatives as a "focus group" for checking the wording of the questions for comprehensibility, and to determine whether all the significant information about panic disorder had been covered. The group suggested several minor changes in wording, and asked for the inclusion of a question about loss of educational opportunities as a result of symptoms of panic disorder. The original, DSM III-based instrument was otherwise unchanged. Screening questions for psychotic disorders and
mania were not included because it was felt by the Community Health Representatives that they would be offensive to community members.

The instrument incorporated DSM-III criteria for panic disorder, agoraphobia, and major depression, except for certain exclusionary criteria, as noted above. Additional questions were incorporated to screen for alcohol and drug abuse, as were questions designed to produce an estimate of the degree of impairment from depression or panic disorder.1

The panic disorder screening instrument was designed in a logical tree structure patterned after the Schedule for Affective Disorders and Schizophrenia-Lifetime Version (SADS-L)(Endicott & Spitzer, 1978), using the diagnostic criteria of the DSM-III. Probe questions asked by the paraprofessional interviewer, if answered in the positive, would lead to a series of additional questions that would establish whether the patient met the full criteria for the diagnosis. If the probe question were answered in the negative, the interviewer would move to the next probe question.

The service-delivery portions of the project began with the actions of the Community Health Representatives at the time of the screening. Educational materials, written in lay terms, were developed for each possible outcome of the screening process. For persons who met the screening criteria for panic disorder for depression, the brochure explained the condition the person was suspected of having, the need for further evaluations, and the types of treatment available if the diagnosis were confirmed. Positive expectations for good outcomes for the treatment of panic disorder, agoraphobia, and depression were stressed in the educational materials. Persons who had no evidence of major mental disorders according to the screening instrument received a short educational talk and materials about the screening project, in the hope that they would refer friends and relatives suffering from the disorders who did not live on the reservation itself.

When the study was originally designed, it was anticipated that patients who answered the questions from the screening instrument in a pattern suggestive of panic disorder would be given the SADS-LA by a consulting psychiatrist trained in the use of the instrument. Although administration of the SADS-LA to the entire study population was thought to be desirable for accurate validation of the screening instrument in its administration by paraprofessionals, funding was unavailable for this expanded study design.

Prior to implementation, the project was reviewed by the tribal councils of the participating tribes. The project was carried out over the course of one summer, with the screening instrument administered to all consenting adult members of the two tribes (i.e. those living on the reservations) by two local Community Health Representatives and one medical student acting as a Community Health Representative. Additional evaluations were carried out by a Masters-level psychologist and the consulting psychiatrist. Staff of the project met with local primary care physicians in order that they be able to recognize and treat panic disorder
effectively, should any of the subjects choose to use their services rather than IHS and the tribes.

Results

Through the efforts of the Community Health Representatives, it was possible to approach all individuals in the two communities. Of the approximately 100 adults who were approached to take the screening examination, 50 agreed to participate in the screening. Seven were found to have symptoms that met DSM-III criteria for panic disorder. However, of the seven, only four would agree to sit for the SADS-LA interview.

Table 1 shows the frequency distribution for sex and age in this sample. The sample was composed predominantly of females (n = 39), and the median age was 31 years. Table 2 shows the cross-tabulation of sex and number of panic disorder symptoms, indicating that females reported panic disorder with twice the frequency of males in this sample ($p = 1.00$). A total of seven individuals reported four or more panic symptoms, thus exceeding the threshold for panic disorder according to the screening DSM-III symptoms used in the instrument.

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<td>39</td>
<td>78</td>
</tr>
<tr>
<td>Age:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤ 20</td>
<td>9</td>
<td>18</td>
</tr>
<tr>
<td>21-30</td>
<td>15</td>
<td>30</td>
</tr>
<tr>
<td>31-40</td>
<td>8</td>
<td>16</td>
</tr>
<tr>
<td>41-50</td>
<td>12</td>
<td>24</td>
</tr>
<tr>
<td>51+</td>
<td>6</td>
<td>12</td>
</tr>
<tr>
<td>TOTAL</td>
<td>50</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Number of Symptoms</th>
<th>Sex</th>
<th>0</th>
<th>Percent</th>
<th>1-3</th>
<th>Percent</th>
<th>4+</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Males</td>
<td>10</td>
<td>91%</td>
<td>0</td>
<td>0%</td>
<td>1</td>
<td>9%</td>
<td></td>
</tr>
<tr>
<td>Females</td>
<td>32</td>
<td>82%</td>
<td>1</td>
<td>2.6%</td>
<td>6</td>
<td>15.4%</td>
<td></td>
</tr>
</tbody>
</table>

Fisher's exact test: $p = 1.00$

Table 3 presents the frequency with which panic symptoms and depressive symptoms were reported together. Among the seven individuals with panic disorder determined by the screening instrument, six reported one or more depressive symptoms, and of the forty-two individuals
who did not meet the panic disorder screening threshold, 13 reported one or more depressive symptoms (p = .0027).

Table 3
Frequency of Depressive Symptoms with Panic Disorder Symptoms

<table>
<thead>
<tr>
<th>Number of Panic Disorder Symptoms</th>
<th>0</th>
<th>Percent</th>
<th>1-4</th>
<th>Percent</th>
<th>5+</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td></td>
<td>n</td>
<td></td>
<td>n</td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>29</td>
<td>69%</td>
<td>6</td>
<td>14%</td>
<td>7</td>
<td>17%</td>
</tr>
<tr>
<td>1-3</td>
<td>1</td>
<td>100%</td>
<td>0</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4+</td>
<td>1</td>
<td>14%</td>
<td>0</td>
<td>0</td>
<td>6</td>
<td>86%</td>
</tr>
</tbody>
</table>

Fisher's exact test: p = .0027

Table 4 shows the patterns of response of the seven panic disorder positive individuals to questions about their behavior with respect to panic attacks. None of these individuals reported a physical illness that might be the cause of the panic attacks, one of the exclusionary criteria for the disorder. Three subjects reported experiencing lifestyle changes as a result of having panic attacks; none reported the loss of an educational opportunity because of panic attacks. The use of alcohol to deal with panic attacks was reported by four of the seven positive subjects, and the use of substances other than alcohol to try to control the panic attacks was reported by two of the seven. When asked if family members thought that the subjects drank too much as the result of panic attacks, three responded affirmatively. Three reported that panic attacks occurred at a time when they had not been drinking for at least two weeks.

Table 4
Responses by Individuals with Four or More Panic Symptoms

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>%</th>
<th>No</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical illness that might</td>
<td>0</td>
<td>0</td>
<td>7</td>
<td>100%</td>
</tr>
<tr>
<td>cause panic attacks</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Change in lifestyle as a</td>
<td>3</td>
<td>43%</td>
<td>4</td>
<td>57%</td>
</tr>
<tr>
<td>result of panic attacks</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Panic attacks have resulted</td>
<td>0</td>
<td>0</td>
<td>7</td>
<td>100%</td>
</tr>
<tr>
<td>in lost job or educational</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>opportunity</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drink alcohol to deal with</td>
<td>4</td>
<td>57%</td>
<td>3</td>
<td>43%</td>
</tr>
<tr>
<td>panic attacks</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family members think you</td>
<td>3</td>
<td>43%</td>
<td>4</td>
<td>57%</td>
</tr>
<tr>
<td>drink too much as a result</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>of panic attacks</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Panic attacks occur even</td>
<td>3</td>
<td>43%</td>
<td>4</td>
<td>57%</td>
</tr>
<tr>
<td>when not drinking for at</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>least two weeks</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Use of other substances to</td>
<td>2</td>
<td>29%</td>
<td>5</td>
<td>71%</td>
</tr>
<tr>
<td>deal with panic attacks</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 5 shows the prevalence of lifetime depression in the overall sample and by number of panic disorder symptoms. The overall number of people in the community sample of 50 who reported having had symptoms of major depression in their lives was 21, and the seven individuals who exceeded the threshold on panic symptoms had more than twice the prevalence of lifetime depression compared to those who did not exceed the threshold \( (p = .0325) \).

<table>
<thead>
<tr>
<th>Depression Symptoms of Two Weeks or Longer</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall</td>
<td>21</td>
<td>29</td>
</tr>
<tr>
<td>Panic Symptoms</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-3</td>
<td>15</td>
<td>28</td>
</tr>
<tr>
<td>4+</td>
<td>6</td>
<td>1</td>
</tr>
</tbody>
</table>

Fisher's exact test: \( p = .0325 \)

Current depressive symptomatology is shown in Table 6. The overall sample showed that six people of the overall sample had current symptoms of depression, with the panic disorder individuals reporting three times the frequency of current depressive symptoms as the remainder of the sample \( (p = .192) \).

<table>
<thead>
<tr>
<th>Current Symptomatology</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall</td>
<td>6</td>
<td>44</td>
</tr>
<tr>
<td>Panic Symptoms</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-3</td>
<td>4</td>
<td>39</td>
</tr>
<tr>
<td>4+</td>
<td>2</td>
<td>5</td>
</tr>
</tbody>
</table>

Fisher's exact test: \( p = .192 \)

Discussion

As a result of this project, as well as previously reported work in Montana, it appears that panic disorder exists in some American Indian cultural groups and gene pools. Other reports (Biemoff, 1989) suggest that panic disorder may exist in Southwestern Indian cultural groups as well. From the 50 people who agreed to participate in the screening examination, seven reported symptoms of panic disorder. However, of these subjects, only three had panic symptoms in a two week or greater period in which
they had not been drinking. This study does not answer the questions of whether alcohol withdrawal symptoms may have been reported as panic symptoms in four of the seven subjects, whether alcohol was used as a form of self-treatment, or whether patients with panic attacks as a primary symptom used alcohol, which then precipitated further panic attacks. Recent work suggests that, using intravenous lactate infusion, it may be possible to determine which patients with panic disorder/alcoholism comorbidity suffer from panic disorder or alcoholism as the "primary" disorder. This technique has yet to be widely tested for this purpose, but recent work (Baron, Sands, Ciraulo, & Shader, 1990) suggests that alcohol should not be an exclusionary criterion for panic disorder; further investigations would be required to differentiate the primary alcoholics from primary panic disorder patients in samples such as that reported here.

In broader applications of this screening method, some means for separating the chronology of the development of drinking behavior from panic disorder and depression should be considered. Whether the use of alcohol in some Indian groups represents a primary disorder or is a non-specific response to stress, including the stress of other major mental illnesses, may be a fruitful area for future studies.

Four major limitations of this project were: 1) the 50% participation rate by community members in the study, 2) the small number of people in the study, 3) the lack of SADS-LA validation of the responses to the survey, and 4) the inability of our group to convince all of the subjects who screened positive on the screening instrument to sit for the SADS-LA. Further studies, with sufficient funding to pay subjects for their time, may help to increase compliance with the complete evaluation protocol and increase participation levels. On the other hand, it may be that research instruments such as the SADS-LA are so daunting to subjects that their widespread use in Indian communities may not be practical, in contrast to the SADS-L and other more abbreviated instruments that have been used in other studies in Indian country.

In contrast to the limited success in achieving the epidemiologic goals of this study, the willingness of Indian community leaders to cooperate with a program that identifies and treats a mental health problem as a public health problem, and the ability of an isolated rural health system to recognize and treat a novel disorder as an organized team, were more successful. We believe that this project demonstrates that indigenous paraprofessional workers, the Community Health Representatives, can play a major role in screening Indian communities for major mental disorders. In this project, these workers were far more successful than the professionals in gaining cooperation from Indian community members. We would urge Indian health organizations to consider these expanded screening roles for indigenous paraprofessionals in secondary prevention efforts in the future. In spite of the limitations of this initial project, the methods used in the project hold promise for use in Indian communities,
both for large projects to screen other Indian populations for panic disorder, and for screening for other major mental disorders.

The observations that panic disorder appears to exist in several populations of American Indians, that it may carry high rates of mortality and morbidity, and that it can be treated effectively and easily suggest that Indian mental health programs can perform a valuable public health service by adopting systematic screening and diagnostic procedures, and by performing modern, effective treatment for those cases identified.

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Notes

1Copies of the screening instrument and the patient referral information packet are available upon request from the senior author.

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References


Biernoff, M. (Mental Health Branch Chief of the Albuquerque Area Indian Health Service) 1989, personal communication.


An Ethnographic View: Positive Consequences of the War on Poverty

Bruce G. Miller, Ph.D.

Abstract: Life history data from Coast Salish tribes of Washington state reveal that federal War on Poverty programs produced important results that routine analysis has failed to uncover. The Comprehensive Training and Employment Act and the Indian Community Action Project provided income that enabled family networks to serve as centers of moral and financial support for members engaged in therapeutic work and provided training opportunities for a generation of leaders who are now instrumental in attracting funding for mental health programs.

Hidden among the ruins of the federal War on Poverty of the 1960s and 1970s are important contributions to the mental health of Indian people. These contributions are largely unrecognized because they were not anticipated in the writing of the legislation that established the War on Poverty and therefore are not considered in program analysis. I argue that specific federal War on Poverty programs have created conditions encouraging the mental health of the membership of Indian communities in two main ways. The programs have provided vital income that has been distributed through family networks, thereby helping these networks to continue to function as centers of financial, practical, and moral support for members engaged in therapeutic ceremonial work. In addition, a generation of tribal leaders received training and opportunities through War on Poverty programs. Today these leaders are instrumental in attracting funding for a range of programs that help Indian people and communities dealing with the stress of biculturalism and the accompanying high death rate caused by suicide, alcoholism, accidents, substance abuse, and violence (Guilmet & Whited, 1989).

Coast Salish Indian people live in a particularly stressful environment and experience high levels of stress, distress, and anxiety. There is a certain irony in this as Guilmet et al. (1989) point out. While the Indian Health Service (IHS) and other medical services have gained control of easily managed health conditions, mental health services for chronic, debilitating problems continue to be underfunded and are actually losing ground. This makes programs that promote Indian traditional institutions with a therapeutic role and new tribal institutions that provide mental health care services all the more important.

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It is not the intent here to make the case that Indian communities have important mental health needs, or even that traditional curers and ceremonial leaders have a significant role in promoting tribal mental health. These points are documented adequately elsewhere. Guilmet et al. (1989), Jilek (1982), Amoss (1978), and Slagle and Weibel-Orlando (1986) have written about the Coast Salish of Washington State, and the IHS itself has documented the seriousness of mental health issues and the role of traditional people (Report of Portland Area Office, 1986), as have the tribes themselves (for example, Crume, 1988).

Rather, this paper focuses on the contributions of federally funded programs and the ramifications they have in Indian communities. Life history data from leaders of a Coast Salish Tribe (identified as "A") and from other small Puget Sound tribes are used in order to clarify the implications of the federal funding for the leaders and their tribes. My own fieldwork, 1986-1988, and interviews with leaders from other tribes, help place the life histories in the context of the tribal social organization and the events of that period. A brief discussion of the federal War on Poverty and the subsequent analyses of two of the constituent programs, Comprehensive Employment and Training Act (CETA) and Indian Community Action Projects (ICAP) suggests why the important contributions of these programs are overlooked.

War on Poverty Programs

The positive consequences of otherwise poorly regarded federal programs have gone unnoticed because they are not easily quantifiable (Levitan & Taggart, 1977), because program assessments have relied on macroeconomic analyses, and because evaluation of programs over a life cycle has been too expensive (Levin, 1977). Furthermore, because politicians, the public, and professional researchers have generally written off the War on Poverty programs as at best of marginal benefit given the costs (Bullock, Anderson, & Brady, 1983) the benefits to Indian communities are unexpected. A detailed ethnographic examination is necessary to uncover the results of these federal programs; enough time has now elapsed to clearly show the results.

The picture of federal War on Poverty programs on Indian reservations is muddied for reasons in addition to the ones mentioned. In some cases, internal struggles on reservations over the hiring of personnel and use of funds, and competition and distrust between tribes have clouded the record of CETA (which lasted from 1973-1982), and the ICAP (1964-1970). One American Indian newspaper, *Wassaja* (1979) reported that "Applicants for CETA jobs are often accepted on a 'political basis,'... and power struggles occur within tribal CETA administrations, and such is the case among the Navajo."

A detailed study of the Fort Yuma Reservation (Bee, 1969) documented the difficulties in implementing War on Poverty programs,
including ICAP, because of internal authority struggles and the concentration of authority in too few hands. In addition, several tribes in the Northwest and perhaps elsewhere failed to participate in programs such as ICAP because of distrust of the federal government and other tribes with whom they would have to cooperate (Jefferson, personal communication, see Note 1). In addition, the American Indian Policy Review Commission (1976) reported that “Training under CETA has, according to many prime sponsors, been hampered by the lack of technical assistance provided by the Department of Labor and by limitations on the consulting services which may be contracted for by prime sponsors.”

However, War on Poverty funds, especially those provided by CETA and ICAP, have contributed significantly to the ability of several small tribes of western Washington State to enhance tribal sovereignty by providing training opportunities to people who eventually became the tribal leaders of the 1980s. The skills these leaders gained have helped their tribes develop the sophistication necessary to compete for grants, to operate successful health clinics, to manage natural resources, and to protect tribal interests through difficult periods of "soft" grant money in the middle and late 1980s (Robbins, 1986). Simply put, the leaders produced by these programs take primary responsibility for the delivery of health care and other services in the 1980s and in the present. It is notable that most of these leaders are women, and indeed CETA funds provided an "opportunity structure" for Indian women that has had a significant impact on tribal social organization. It is perhaps worth speculating, as several of these leaders have done, that the ending of these programs has eliminated an important source of leaders for the future.

The CETA and ICAP programs have been selected for special examination, but this is not to suggest that other programs did not have important impact in the Indian communities. These two programs have been selected for examination in part because they are unusual in that tribes and Indian organizations developed their own programs that helped promote tribal sovereignty. Jones (1982) noted "For the first time in the history of Federal employment and training programs, Native Americans have their own set of regulations, i.e., designed with their input and with their special problems in mind." The American Indian Policy Review Commission (1976) held that "The two major programs in which Indian Control is significant are the Indian Action Teams and programs under the Comprehensive Employment and Training Act of 1973."

Barsh and Diaz-Knauf (1984) wrote, "Indian CETA, which in FY-1980 accounted for one-fourth of all subsidized reservation jobs, was structured on the assumption that there would be no reservation economic growth, and therefore no point in providing Indians with marketable skills." While this may well have been the perspective of the federal government, the skills gained by men and women in the CETA program have proven to be useful as seed money and not just as income transfer. Furthermore, the training programs helped open the vision of these women to the possibilities...
for their own careers, and many moved into vocational institutes, community colleges, and universities for job training following these periods of employment.

War on Poverty Programs and Assessment

Haveman (1987) wrote that the early 1960s were marked by a concern for problems of poverty and disparities between the health, income, and opportunities of Anglos and minorities. Presidents Kennedy and Johnson proposed and attempted to carry out the creation of a "Great Society," and Johnson clearly intended Indians to be part of this social initiative (Prucha, 1984). A flood of new programs aimed at the poor were developed to supplement or replace older programs. "These efforts were undertaken with optimism that poverty could be reduced, racial inequalities diminished, and efficient investments in human productivity made" (p. 65).

The new programs attempted to address social problems from a variety of angles so that a wide range of needy would benefit. Some programs, such as the Youth Conservation Corps, provided little structured training and simply placed workers in entry-level, low-paying jobs. A second sort of program included the Manpower Development and Training Act (MDTA), which was aimed primarily at the poor and provided classroom and on-the-job training. Another program of the second sort, Job Opportunities in the Business Sector (JOBS), reimbursed businesses that trained disadvantaged workers. A third type of program allowed the poor to participate in developing programs for themselves. The Indian Community Action Program, administered under the Office of Economic Opportunity (OEO), although initially designed to coordinate public and private efforts aimed at benefitting the poor, came to be a community directed program, and was oriented to increasing the political participation of minorities previously excluded from political life (Bullock et al., 1983). The MDTA, JOBS, the Neighborhood Youth Corps, and Operation Mainstream all were superseded in 1973 by CETA and were substantially reduced in funding under President Reagan before being eliminated or replaced.

Education, training, and employment programs were not new to Indian reservations in the 1960s, and War on Poverty programs, in some cases, merged with older federal programs. In 1956, Public Law 959, the Indian Vocational Training Act, provided vocational training and employment opportunities for Indians ages 18 to 35. Three and one-half million dollars were provided to fund the program in 1956, and the figure increased to $25 million by 1968 (Tyler, 1973). The Industrial and Commercial Development Program (ICDP) established in 1955 allowed the Bureau of Indian Affairs (BIA) to provide tribes with grants for public works and facility development to improve opportunities for long-term employment. The OEO, established in 1964 during the War on Poverty, provided funding for ICDP loans and grants for community development
and employment. Altogether, from 1961 to 1971 the BIA had four types of programs aimed at Indian unemployment: adult vocational training; voluntary relocation for employment; public works projects on reservations; "force accounts" construction projects; and industrial development projects on or near reservations (Fay, 1976).

The effects of the various programs on Indian communities are disputed. One macroeconomic analysis (Sorkin, 1971) examined three aspects of manpower development: direct relocation, on the job training, and adult vocational training programs. Sorkin concluded that "...measured by benefit-cost ratios at current programs levels, all three of the employment programs for Indians are relatively efficient compared with similar programs for non-Indians; apparently on the job training is somewhat more efficient than the other two. However, because present programs may have skimmed off the most promising trainees...the analysis should not be used to establish priorities for program expansion" (p. 115). Sorkin showed that from 1963 to 1967, the unemployment rates for those entering MDTA, the predecessor to CETA, dropped from 85.2% to 20% two to three years after leaving the program.

However, Sorkin (1971) also noted that, "For the on-the-job training programs, the most fundamental criticism is that a high proportion of women are enrolled, while males and nominal heads of households remain unemployed." For Sorkin, the advantage of decreasing the enrollment of single women in vocational training would be that it would increase the benefit-cost ratio. My own work (Miller, 1989a) suggests this is not a disadvantage in that the employment of women has a community-wide benefit, including providing children and youth with stable households and positive female role models.

Sorkin's findings on Indian reservations during the heyday of the War on Poverty, 1971, are in sharp contrast to both the findings of Barsh et al. (1984) 13 years later and the findings of other analysts concerning similar War on Poverty programs for non-Indians. Concerning the decade of the 1970s, Barsh et al. wrote:

*Federal taxpayers may spend more, nominally, on each Indian than they do on other Americans, but the permanent benefits to reservation communities have been smaller. One fifth of all spending maintains federal agencies, and local aid is often channelled through State agencies. Much federal 'Indian' spending therefore supports non-Indian administration away from the reservations, and poor Indian communities have been a financial windfall for some State and State subdivisions. Funds that do reach the reservations tend to be absorbed by tribal administration and unproductive public employment, with little or no stimulus to private-sector activities (p. 1).*
Barsh et al. further noted that federal investments in Indian programs are unproductive because they emphasize temporary employment, bureaucracy, paperwork, and poor economic development strategies. As an example of the unproductivity of federal programs, the authors point to Indian CETA funding: “Although the Department of Labor proudly boasted about the low (0.7%) federal overhead of Indian CETA funding a few years ago, sixteen percent of Indian CETA paid for tribal administrators” (p. 14). Overall, the authors found the government programs directed at Indians to be incompetent and ineffective.

Morris (1988), taking a different view, complained about Reagan administration Indian policy, which he described as “termination by accountants,” and decried what he felt was an abrogation of the federal trust responsibility. In 1982 the Reagan administration proposed the total elimination of Title II and Title VI, the public service employment portions of CETA, which would have meant the loss of an estimated 10,000 on-reservation Indian jobs (ibid.). Instead, Congress created the Job Training Partnership Act of 1982 (JTPA) to replace CETA, with 25% of funds allocated on the basis of the number of unemployed Indians in the area and the remainder allocated on the basis of the number of Indians who meet the poverty criteria. In addition, the Administration for Native Americans (ANA) was established in part to promote economic and social self-sufficiency. There was an over-all net loss of funding for training programs.

Analysts of non-Indian War on Poverty programs generally take a different view of the federal programs than did Sorkin. Haveman (1977) wrote that as a result of both planned and unplanned developments, the decade of 1965-75 saw improvements in the economic status of the poor, but that this was overbalanced by negative results of the programs. The programs discouraged work efforts on the part of recipients, encouraged family break-ups, and promoted migration from low- to high-benefit areas. Haveman found that by the end of the period, poverty diminished but income inequality persisted. In sum, Haveman (1977, p. 14) wrote: “When held to generally accepted principles of efficiency and equity, the social policy legacy of the 1965-75 decade does not score well.”

Levin (1977) found that on the basis of both investment efficiency and poverty reduction, the Job Corps, MDTA, and JOBS made only slight impact in providing specific job skills and increasing employability.

Almost a decade later, and with the benefit of additional data, Danziger and Weinberg (1986), like Haveman, found that antipoverty programs of the Great Society came to increasingly rely on income transfer, not training, and that “disincentive effects” derive from income transfer in general. They found overall limited gains from education and employment programs.

Bassi and Ashenfelter (1977) reported that CETA programs had greater benefit to minority women, especially young ones. Further, of the four types of CETA programs, work experience was the least effective. The
other three types included classroom training, on-the-job training, and public service and produced positive benefits for women, averaging $600-1,200 gains and no loss of income after the program.

The ICAP programs operated from a very different premise than CETA. ICAP centers were established at four universities to provide technical support, and tribes adopted resolutions to authorize CAP agencies to be designated as Community Action Agencies. Within three years of the establishment of the program in 1964, there were 67 ICAP programs on 170 reservations serving 300,000 people (Levitan & Hetrick, 1971). The innovative feature was that Indians themselves designed the programs and allocated the funds (Bullock et al., 1983).

CETA and the Indian Communities

CETA was a small part of the federal budget for Indian communities, and by no means the most important. The program was administered nationally by the Department of Labor, Employment and Training Administration, Office of Indian and Native American Programs. In 1978, about 193 Native American organizations received grants (Jones, 1982), and in 1978 the Department of Labor claimed CETA programs reached "...virtually all reservation tribes, most of the non-reservation tribes, the recognized tribes of Oklahoma, the Alaskan Natives, Hawaiian Natives, and the majority of viable urban Indian organizations" (Indian Program Evaluation 1978, p. 130). The Indian CETA program worked directly with American Indian entities with a governing body, a service population of at least 1,000, and the capability to administer a program (Jones, 1982). Smaller tribes formed consortia.

A 1977 report found 14.6% of participants in classroom training, 7.2% in on-the-job training, 5% in public service employment, 50% in work experience, and 24.4% "other," totalling 50,600 people. The report concluded, "What is important is the stress shown by these figures on employment and subsidization rather than formal training" (American Indian Policy Review Commission, 1977, p. 353).

In 1977, expenditures nationwide in Indian communities were budgeted at $52.56 million (Ceta Allocation, 1976); these rose to $113 million by 1981. Of this, $2,317,466 was for the State of Washington (Barsh et al., 1984). By 1980, federal expenditures for CETA in Indian country amounted to $258 per capita (Barsh et al., 1984). Despite the low levels of outlays, the program was important to several small tribes of Washington State, and many others elsewhere (Beckham, personal communication, see note 2).

There were several important implications of the CETA programs in Indian country. First, even though the income gains derived from CETA were small, they were essential to very poor Indian communities with high unemployment rates, and the impact of the new income ramified through the community. Mooney (1976), Miller (1989a), Robbins (1986) and others
have demonstrated the significance of inter-household exchange networks in Coast Salish communities, and the role these play in the well-being of family network members. Guilmet et al. (1989) noted that:

The extended family support system is of ultimate importance to most American Indian...clients. Since informal resources such as the extended family are known to provide emotional support, material assistance, physical care, information referral, and mediation in times of emotional need, a client...who perceives him/herself as being isolated and without "family" to depend upon and interact with may experience much more difficulty in coping with acute episodes and chronic illness (p. 70).

Families frequently are structured around and actively depend on leadership from members with relatively large and stable incomes who can provide aid to family members. This aid frequently takes the form of balanced reciprocity. For example, small sums of money are provided to family members for important purposes such as keeping a car operating. The favor may be returned by chopping wood or carrying out other useful tasks. Also, family members make loans at strategic times that are returned when the crisis is weathered and can be repaid. In Coast Salish communities this movement of capital through gift or loan may be enough to enable family members to meet the expenses of operating fishing boats or to keep homes heated in the winter. Tribal members who are not members of family networks are often unable to meet emergency or even routine financial needs (Miller, 1989a).

Second, CETA funds in the Indian communities have indirectly served to promote family cohesion, not family break-up, as was found to be a common result of federal assistance programs. In Coast Salish communities with an ethos of communalism (Mooney, 1976), the exchange of goods and services is the glue that binds people together. Coast Salish communities can be viewed as collectivities of family networks, and as will be seen, leaders who trained under the provisions of CETA and other programs have been able to provide benefits to their family network through their membership on the tribal council. Expertise is necessary in order for families to compete effectively with others in the tribe, a success that binds families more closely together. Furthermore, technically able leaders trained under such programs who are members of families too small to run their own candidate are able to mitigate the potential for factionalism in the community by drawing electoral support across family lines, a topic I have treated in detail elsewhere (Miller, 1989a, 1989b).

Third, the income and the skills developed from CETA and other programs have served both directly and indirectly to support family and tribal cohesion through providing the finances necessary for traditional cultural activities, including funerals and winter ceremonials. Mutual support and
participation in ceremonial life is essential to family life among Coast Salish people and quite costly (see Amoss, 1978, for a thorough discussion of ceremonial life among the Nooksack, a Coast Salish tribe, and Suttles, 1987, for a discussion of the importance of ceremonial life to tribal cohesion). Sending a family member through the Seowyrt winter society initiation requires that family members cook sporadically all through the winter for hundreds of guests; money be available to thank trainers, visitors, and guests; and that the families purchase items to give away to guests. The operation of the Indian Shaker Church also creates a significant financial demand on otherwise poor people. CETA employment and subsequent spin-off employment has helped Indian people meet these demands.

Fourth, tribal councilors from tribes all over Puget Sound have commented on the subtle influence of CETA in their communities. Anne Pavel, Skokomish, said of CETA that “Women were ready to take advantage of it, to be trained, and to see it as upward mobility steps. People became more qualified because of the experience” (personal communication, see Note 3). She noted that inter-tribal cooperation was fostered because CETA administrators were required to deal with multi-tribal groups. In response, the small western Washington tribes, varying from several hundred to several thousand in membership, created joint programs to meet the program terms. Experience gained in the inter-tribal ventures was useful in later successfully competing to fund multi-tribal mental health programs, such as, for example, three programs established in 1988; the Bloc grants under the provisions of the 1988 Omnibus Drug and Alcohol Abuse legislation, the Intertribal Displaced Homemaker Program, and the Intertribal Early Childhood Handicap Program. Inter-tribal experience enabled leaders to present an effective, unified position in negotiations with the state and federal government.

Juanita Jefferson, Lummi, remarked that “The War on Poverty programs produced many present tribal leaders” (personal communication, see Note 1). Jefferson refers here to both elective officials who serve on the tribal council and an array of administrators serving tribal needs. Jefferson said further that the critical system of mentoring that has helped advance the careers of tribal leaders of the 1960s crossed tribal lines in part because of the multi-tribal nature of the War on Poverty Programs. Jefferson recalled the help given her in launching an administrative career, started in a ICAP program established at Swinomish, by Laura Wilbur, a Swinomish elder. Help provided in the early days was a hallmark of the careers of many leaders of the 1980s, and has been an important element at several reservations according to leaders such as Maureen Fisher, Upper Skagit, Nancy Wilbur, Swinomish, and Lois Dodson, Nooksack (personal communications, see Note 4). All affirmed that federal money positively influenced the mentoring system.
Case Studies

Three examples illustrate the importance of the War on Poverty programs and the way in which benefits to individual women ramify throughout the community. The case of Jane Jones (a pseudonym), former Health Services Director at Coast Salish Tribe A, illustrates the relationship between tribal leadership and federal funding. Mrs. Jones is a former Tribal Council member and an active participant in Tribe A cultural affairs. Her story is of interest in part because her early upbringing did not prepare her for leadership either in skills or inclination. In fact, she recalled:

*My thoughts when growing up were not to go out and work, just stay in the household and the husband would work at a regular job and provide for the family.... My thoughts have changed over the years.... I never thought about women in the work world or involved in anything (personal communication).*

Mrs. Jones' first full-time job, at Coast Salish Tribe B tribal fish plant, lasted two years; it started in 1970 and was funded by federal money through the Northwest Opportunity Council. Later, she served for 18 months as a clerk-typist at the Tribe A offices under CETA funding. Following this, she used Northwest Opportunity Council funds again to work at the Coast Salish Tribe C Education Center and Community Services. She also served two and a half years in the secretarial pool at Tribe C, again under CETA funding. This particular employment had an important effect on her. While working with tribal social services, she realized that she could make a greater contribution. "This was the starting point in my mind to do more than secretarial" (Miller, personal communication).

After service in the Tribe C Health Services Department, she took a post as executive secretary for the Health Services Department, her first full-time, non-trainee position. Later, 1983-85, after an interruption for child-rearing, and after a BIA funded stint in the Northwest Intertribal Court System, Mrs. Jones began work for the Tribal Health Clinic at Tribe A. This was another turning point, for here she received the advice of her supervisor who was also a Tribal Council member. The supervisor encouraged Mrs. Jones to receive more training and schooling, and subsequently she received an A.A. degree. In 1985 Mrs. Jones was appointed Director of the Tribal Health Clinic.

It was during this period that Mrs. Jones was appointed and then elected to the Tribal Council. It is important to note that while this woman had the talent and initiative to advance, federal funding played a critical role, and enabled her to act on the suggestions of her mentor. Mrs. Jones subsequently oversaw the creation of a series of programs aimed at improving tribal mental health, including the tribal program under provisions of the Omnibus Drug and Alcohol Bill and an Inter-tribal Displaced...
Homemaker program. Furthermore, she contributed to the delivery of health care, including mental health services, in an inter-tribal context through service on the advisory board of the Northwest Service Unit of the IHS. Tribal election data show that Mrs. Jones drew support from her family network and non-family members alike, in large measure due to her ability to bridge the gulf between tribal members and outside agencies responsible for the delivery of services (Miller, 1989b).

A second case is that of Agnes Peters (a pseudonym), Tribe A Council member and tribal administrator. Mrs. Peters comes from a rather different background than Mrs. Jones, but the two are alike in that they provide critical technical skills to the tribe as a whole and have developed an expanded view of the ability of tribal services to affect community mental health. Mrs. Peters grew up in a farming family in the Kent Valley of western Washington. She had significant contact with the non-Indian world early in life, and sold family produce in the Seattle public market at Pike Place. She also lived out of the state while doing factory work in a multi-ethnic environment. After the Boldt decision (U.S. vs. Washington, 1974) gave half the salmon catch to the Indians of Washington State and Tribe A received federal recognition, Mrs. Peters returned to the traditional area of Tribe A to help organize a three-tribe Cooperative Court and then the Northwest Intertribal Court System. Although she had no previous experience in the law, she received legal training provided under federal funding.

In subsequent years Mrs. Peters has served as General Manager of the tribe and has managed the tribal industries, including a fire crew and a box manufacturing operation. Mrs. Peters specialized in the creation of tribal code dealing with the establishment of parenting standards, alcohol and drug abuse prevention, and the provision of mental health services. She has also served as a delegate to the highly successful inter-tribal fisheries management scheme developed following the Boldt decision. Mrs. Peters arranged for mental health counselling for fire crew workers and their families after a traumatic episode in which the crew narrowly avoided death.

Taken as a whole, women who have served on the Tribe A council since its recreation in 1974 as an acknowledged tribe have provided most of the technical expertise available to the tribe through its own membership. While four female leaders have had careers as traditional leaders, that is, as representatives of their own family network and as experts in coalescing and representing public opinion, six others have become technocrats who receive tribal wide support in council elections (Miller, 1989a). All of this second group, the technocrats, have developed their careers in the following pattern: CETA and BIA funding was obtained for training in clerical and technical work; subsequent training and experience gained in the initial employment served as preparation for higher level administrative work; and the experience gave the individual the ability to make important contributions to the community as a whole.
These women have subsequently headed virtually every important division of tribal operations, including the health clinic, tribal enterprises, social services, fisheries, planning, court, housing, and elders programs. Collectively they represent a resource that is of vital importance to the well-being of Tribe A people. None would have been able to make their contribution without the availability of outside funding.

Barbara Johnson (also a pseudonym), a member of Tribe C, got her start in tribal management through War on Poverty funding, especially ICAP. Unlike Jane Jones, she had previous work experience, but Mrs. Johnson's story shows another important dimension of the impact of the federal programs: they served to draw back to the reservation people whose talent could be developed and put to use for the benefit of the tribe. In her own words:

*It made all the difference to be in a program and have job experience and all that training. A lot of us would have melted into society's mainstream, into clerical work or work at a big company. A lot of our people would have been drained off. A lot of today's leaders would have been drained off into the white world without these programs, and there are more jobs in Seattle. Lots of [Tribe C] moved home before the Boldt Decision. They were hearing there was action here, that something was changing. They wanted to get involved (personal communication).*

Johnson was hired in 1964 as the first paid staff member of the Tribe B CAP program. She received her initial training through a consultant provided by the University of Utah, one of five universities providing technical assistance to Indian CAP programs. The Tribe B CAP program was initially awarded $65,000 to provide service to a community of about 400 people. Under the terms of the CAP programs, Indian communities could assign staff to a wide range of tasks of community benefit. Johnson began by carrying out a housing survey and a home improvement program. Later, the CAP staff put a new community facility to use and provided recreation, counseling for school children, an alcohol program, and a community outreach worker. A total of five CAP positions were funded.

In the two-and-a-half years she worked at Tribe B, Johnson benefitted from the exposure to the federal funding system and from contacts with state-level leaders. She next moved to a job at Lummi as an instructor under the Manpower Development and Training Program (MDTP), where she worked for another two-and-a-half years, until 1969. In 1970 she went to work under CETA funding for a three-tribe (Coast Salish Tribes A, C and D) program. Later, she was one of the co-founders of a Community College at Tribe C.

An important consequence of the CAP programs was that a philosophic approach to governance developed, called by Johnson the
"community action approach." A generation of young leaders who began their careers in the CAP program and who were imbued with its approach emerged at Tribe C. As at Tribe A, these leaders have provided important services in community as grant writers, tribal managers, finance directors, members of the education planning board, and book-keepers.

Conclusion

A close examination of the impact of federal War on Poverty funding on Indian reservations of western Washington shows important unintended consequences at the tribal, family network, and personal levels. These programs, especially CETA, have prepared a generation of tribal leaders during an important period of growth of tribal operations. As Hansen (1979) noted: "Since 1964, the Civil Rights Act has provided legal basis for an array of federal programs based on race and ethnicity..." (p. 78). The timing of the federal War on Poverty corresponded with the shift of federal policy from the allocation of money in a manner blind to race and ethnicity to the recognition of race and ethnicity in the funding process. Indians were being asked to reorganize their tribal governments to receive federal funds, and this entailed a long process of developing technical expertise. Simultaneously, young men and women, but especially young women, gained this technical ability through training and work experience funded by the federal government. Roberts (1975) wrote:

*In 1964 Congress passed the Equal Opportunity Act. This was a momentous breakthrough in Indian affairs because the act included Indians as its beneficiaries.... For the first time Indians were asked to propose and work out plans for programs.... The Swinomish decided to take advantage of it. In order to qualify for funding they had to generate an administrative superstructure* (p. 358).

In later years, the skills these women developed have helped tribes stay competitive for the diminished federal funds. Expertise has become all the more important to small tribes as staffs have shrunk and responsibilities grown (Robbins, 1986; Miller, 1989b). Salaries received during training periods under CETA and other federal programs helped maintain and foster expensive cultural practices that are essential to family cohesion, individual well-being, ceremonial life, and the work of traditional curers. Traditional practices, such as giving children Indian names and conducting potlatches, and conducting traditional funerals, and winter Smokehouse dances, while never dormant, received a major boost following a quiet period. The revival of Coast Salish culture in the 1960s has been widely noted (Amoss, 1978; Dewhirst, 1976; Miller, 1989b).
The availability of funds on an inter-tribal basis allowed the skills to spread through a mentoring process that crossed tribal boundaries. Eventually this proved helpful in the development of important inter-tribal administrative and social service organizations.

In addition, the federal programs led to the development of technocrats who are able to skillfully mediate between the tribe and outside agencies. Again, the timing of the development of these leaders has been helpful because their ascent in the 1960s corresponds with the federal policy of recognition of tribal sovereignty. CETA funding has been useful in helping terminated tribes of southern Washington state and Oregon to establish tribal operations and to regain recognition (Stephen Beckham, personal communication, see Note 2).

ICAP funding played a role in leadership development as well, although this was intended; in fact, OEO administrators claimed that the program was attracting tribal members back to the reservation, an idea substantiated by Johnson. OEO administrators hoped that the leaders produced would play a role in tribal politics and administration, and with private corporations operating on the reservations (Levitan et al., 1971).

At the individual level, federal funding has helped allowing individual tribal members develop skills to their own advantage and satisfaction and to that of their families.

A final note: at present, several tribes mentioned here, including Tribes A and C, are considering directly administering tribal programs without BIA intervention, under the provisions of PL 93-638. In fact, in mid-1990, one Coast Salish tribe received permission to begin direct administration of its own programs. Tribal leaders are hopeful that this will enable federal dollars to go farther and that tribal programs will serve the community more efficiently. Such a development directly depends on the generation of leaders produced in the 1960s and 1970s.

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Notes

1. Interview with Juanita Jefferson, Lummi, Spring 1990. Juanita Jefferson is a former ICAP employee and member of the Board of Northwest Indian College.

2. Personal communication, Spring 1990, Steven Beckham, Department of History, Lewis and Clark State College. Beckham noted that a former Council Chair of the All Pueblo Council in New Mexico described himself as a “CETA Baby” who learned his skills through the training offered in that program.
3. Interview with Anne Pavel, Skokomish, former Tribal Council member, Summer 1985.


References


