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#### ABSTRACT

This final report discusses the outcomes of a research project that examined the nature of the relationship between 52 Navajo caregivers' perceptions of the early intervention service system and specific program, provider, and family variables. The project also investigated perceptions of 16 early intervention personnel regarding barriers to, and strategies for, providing early intervention services to eligible families in the Navajo Nation. Results found caregivers had greater satisfaction with early intervention services in programs perceived to be more family centered. Those individuals who were less educated or more traditional generally rated the program as being less family centered. Provider variables such as ethnic matching between the provider and caregiver, and the educational level of the provider, failed to relate strongly to either measure of satisfaction. Ninety-six percent of the caregivers had no preference with regard to the ethnic/racial background of the provider. The acculturation status had a strong and statistically significant positive relationship with satisfaction with family-related aspects of services. Overall, caregivers were quite positive about early intervention services and seemed to be unable to identify anything needing improvement. Service providers identified travel time issues as a significant barrier to providing services. (Contains 40 references.) (CR)

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# Parent Perceptions of Home Visitors: A Comparative Study of Parents who are American Indian and Non-Indian Parents

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H023B30006

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#### Introduction

Early intervention programs face a wide range of challenges and must make adaptations in their models of service delivery in an effort to be responsive to the resources, priorities, and concerns of families living in the Navajo Nation. The federal directive (Part H of the Individuals with Disabilities Education Act, IDEA) to bring the family to the center of the service system requires close scrutiny of what constitutes best practice for Navajo families. Families whose lives are influenced by the interaction of geographical realities, a rich and varied cultural context, and the prevailing theme of poverty demand approaches that are flexible and responsive to the uniqueness of each family.

#### Overview

The policy of assimilation imposed on the Navajo people by the United States government has resulted in a dissonance exemplifying what Festinger (1957) describes in his treatise on cognitive dissonance. He states that "dissonance could arise because of cultural mores. The dissonance exists simply because the culture defines what is consonant and what is not" (Festinger, 1957, p. 14). Policies of assimilation forced American Indians to reject their own culture and adopt the majority one. Compher (1989) could have been writing about the case of the American Indian when he wrote:

Major discord occurs as the majority culture imposes its values of competition, individualism, and productivity upon cultures, which, by and large, are more socially and expressively oriented. Dissonance is most evident for the individual or family where it relates to other necessary systems of the society which are usually controlled by the majority culture. (Compher, 1989, p. 63)



Some suggest that efforts to reduce cultural dissonance in the provision of human services be directed beyond the practice of individual professionals to the design of the service system. This was recognized in a recent forum centered upon the American Indians with developmental disabilities: "Programs designed along the dominant cultural patterns are known to be non-conducive to American Indian and Alaskan Native participation". (ADD Commissioner's Institute, 1993, p.4).

The significance of the cultural context is underscored in the developing system of services for families of infants and toddlers with special needs (Anderson, Fienchel, & Schrag, 1989). In his qualitative evaluation of early intervention programs conducted prior to the passage of Part H of the Individuals with Disabilities Education Act (IDEA), Mallory (1980) revealed that programs were most likely to serve those families who could adapt to the demands of the program regarding family form and cultural values. It is imperative that the system of services be continuously examined to determine whether it is in concert with the cultural context of the family, or if early intervention becomes a new culture imposed on the family.

Understanding the need to develop programs consonant with the culture of the American Indian led to the formation of a Blue Ribbon Panel charged with the development of guidelines for the delivery of services to Navajo children with special needs and their families (Agosta, O'Neal, & Toubben, 1987). In their report, the conceptual framework for early intervention services for Navajos is outlined. Underlying values proposed by the panel focus on the provision of services within the context of the Navajo family, recognizing the role of individual family members as well as cultural beliefs and practices of the Navajo. To understand how well these



guidelines have been followed, it is critical to assess the consonance between the family and the service system for Navajo families.

As the complex interplay of culture, family, and human services is more fully appreciated, the necessity for service systems that are responsive to the unique resources, concerns, and priorities of each and every family is imperative. The only effective measure of that responsiveness is to involve those individuals whose culture is markedly different from the dominant culture, as in the case of the Navajo, in the process of assessing the consonance between the early intervention system of services and the families it serves.

#### Statement of Purpose

The purpose of this study is to determine the nature of the relationship between caregiver perceptions of the service system and specific program, provider, and family variables, and to investigate perceptions of early intervention personnel regarding barriers to, and strategies for, providing early intervention services to eligible families on the Navajo Nation.

#### Research Questions

- 1. What is the relative contribution of program variables (family centeredness, intensity, travel time), provider variables (ethnic match between provider and caregiver, educational level of the provider), and child/caregiver variables (disability, duration in services, caregiver education, acculturation, and socioeconomic status) to caregiver satisfaction with early intervention services for Navajo families receiving services under Part H?
- 2. What are Navajo caregiver perceptions of the early intervention system of services?
- 3. What are the perceptions of service providers regarding the system of early intervention services for Navajo families?



#### A Review of the Literature

#### The Navajo People and Their Land

Approximately 148,451 Navajos reside on the Navajo reservation and trust lands (see Figure 1), 25,351.4 square miles in Arizona, New Mexico, and Utah (Rodgers, 1993). Their existence is characteristically rural with an estimated 6.37 people per square mile (Rodgers, 1993) compared to 70.3 in the entire country, 32.3 in Arizona, and 12.5 in New Mexico (U.S. Department of Commerce, 1992). Many people live in remote areas accessible only by dirt roads, which are frequently impassable during the winter months. Hence, many Navajos are far removed from marketplaces, schools, health services, and employment opportunities. This isolation plays a major role in the lives of many Navajos, and ultimately impacts the provision of human services.

During the last decade, this country has witnessed an increase in Navajo population by 38%, while the Caucasian population increased 5% (Tsosie, 1992). It is estimated that 58.8% of Navajo people over the age of 25 have not graduated from high school, 28% are unemployed (Rodgers, 1993), and 57.9% of the Navajo people live below the federal poverty line (Tsosie, 1993). The overarching theme of poverty on the Navajo Nation has considerable impact upon the people, and many of the characteristics suggested by Lewis (1966) in his classic description of the "Culture of Poverty" are played out in the Navajo Nation (e.g., higher rates of fertility, lower levels of education, and higher unemployment rates).



■ Navajo Reservation
■ Hopi Reservation

Figure 1. Map of the Navajo Nation.

#### Cultural Influences

Family structure and childrearing practices. Nuclear families are the exception rather than the rule, most families extend to include aunts, uncles, grandparents, and nieces and nephews. Historically, Navajo society has been matrilineal; in many families the aunts and grandmothers assume caregiving responsibilities of the young children.

As soon as they are able, the young child is given responsibility. Children seldom receive harsh discipline, and learn early on to be responsible for their own behavior. Caregivers generally model behavior rather than attempt to shape it. Milestones in the life of the young child include the first smile and the naming ceremony, and these are celebrated by everyone in the family.

<u>Family perceptions and attitudes</u>. Joe (1980) found that people frequently lack names for disabling conditions and consider the symptoms of



an illness or disability more important than its cause. Disease etiology is typically seen as either natural, as in the case of a broken bone, or supernatural, involving sorcery or breaking of a taboo. After the birth of a child with special needs, the family may arrange for a sing or healing ceremony for the child. Joe (1982) indicates that many families who have a ceremony feel they have hope even if little change is seen in the child.

Language and communication styles: Many individuals are bilingual, frequently using their native language in the home or community and adopting English when seeking assistance through the educational, medical or social service systems.

The communication style of the Navajo differs significantly from the Anglo. Upon meeting one another they extend a hand in greeting, showing respect by using a weak grasp. The speaker does not address one person specifically, rather communicates generally to others. They do not interrupt others or attempt to control the conversation. Longer pauses often occur, and greater silence is tolerated (Phillips, 1983).

Navajos have undergone considerable cultural conflict in recent history that has major implications for those who are providing human services to families. Each individual, and each family responds uniquely to the demands of the dominant culture. Understanding and respecting an individual's cultural identity and their degree of acculturation can serve to reduce dissonance between that individual and the individual or program providing services.

#### Early Intervention for Navajos

The Navajo Nation has been faced with a unique dilemma in its implementation of Part H services. The Nation contains lands in three different states, each having its own definitions for eligibility for services and



respective service systems. Recognizing the need to identify a plan for implementing Part H, the Navajo Nation created its own early intervention program, known as "Growing in Beauty".

The Assistant Director of Growing in Beauty reported that a total of 1,262 Navajo infants and toddlers with disabilities had been identified by April 15, 1994, and 708 of those children had Individualized Family Service Plans (Seanez, 1994).

#### Cultural Dissonance within Human Services

Harry (1992) enumerates several potential sources of dissonance which may occur between professionals and families of infants and toddlers with special needs. These include the meaning of disability, concepts of family structure and family identity, and finally, parenting style. Anderson, Fenichel and Schrag (1989) provide a similar perspective and add a very important dimension, the interaction style between the professional and the family.

Various approaches have been adopted in an attempt to reduce cultural dissonance. Out of the vast literature on cross-cultural counseling it has been learned that particular characteristics of the counselor can influence the counseling interaction and ultimately the outcome. In the case of the American Indian, it has been learned that trustworthiness is valued over ethnicity in counselors (Heinrich, Corbine, & Thomas, 1990). Dauphinais (1981) found Indians preferred more subtle, non-directive approaches where Anglos preferred more direct approaches.

The quality of the relationship between helper and client has been found to be highly correlated with overall outcome (Beck & Jones, 1973). Rouse (1989) found the temperament, values, and beliefs of the early interventionist were the best predictor of change in the maternal commitment to the mother/child interaction.



In recent years there has been much written about becoming culturally competent as a professional. Becoming culturally competent is critical to the non-Indian professional working with Navajo families, particularly with the present shortage of qualified Navajo professionals (Johnson, 1991).

In fact, it is this shortage of qualified personnel that led to the employment of paraprofessionals on the Navajo Nation. In spite of the obvious benefit of hiring paraprofessionals during personnel shortages (Savino, Kennedy, & Brady, 1968), another perhaps more important benefit is the value of employing indigenous persons to serve as liaison between professional staff and the community (Koerber, 1979).

Another approach to reducing cultural dissonance utilized by programs providing service to families on the Navajo Nation is the home visiting model. Instead of requiring families to take their children to clinical settings, the provider visits the family in their home, within their own context. Employment of the home visiting model has received support for indigenous populations (Larner, 1990), including the Navajo (Roach & Resnick, 1992).

#### **Assessing Cultural Consonance**

Utilization of services is an important indicator of satisfaction with or acceptance of services. Because utilization can be influenced by many factors, one should be cautious as to its use as the sole marker of acceptance of the services.

Weiss (1988) discusses the important role parent perceptions play in understanding the interplay between the service delivery system and the family. Slaughter (1988) suggests that in the case of racially diverse communities, parent perceptions should be sought before program goals are developed, as a formative rather than summative process.



Parents of infants and toddlers with special needs living in Arizona expressed general satisfaction with the system of services (O'Connell, et al., 1989). However, a recent statewide survey found 67% of the respondents felt that the system of care in Arizona was ineffective (Eyer, 1993). There has been little or no effort to formally investigate how Navajo families perceive the early intervention system of services in the Navajo Nation since the implementation of Part H.

#### Summary

The Navajo people live a very rural existence and many families struggle to cope with the debilitating effects of poverty. In recent years Navajos have grappled with the challenges of self governance after decades of domination by the United States government. Policies of assimilation sought to negate the importance of the cultural heritage of the Navajo people, a heritage that brings with it elements that potentially come into conflict with modern day early intervention practices. Various approaches have been adopted to reduce the dissonance including ethnic matching between providers and families, developing professional cultural competence, employing indigenous personnel, and providing services in the family's home.

Assessing cultural consonance can be accomplished by determining rates of service utilization or by providing consumers the opportunity to reflect on their experiences. From a large and broad-based literature on the construct of satisfaction there is a notable lack of consensus regarding its definition and measurement. Several factors can influence the measurement of satisfaction and are well documented in the literature.

Since the passage of Part H, leaders in the field assert that families must be an integral part of the evolving system of services. While more and more



studies have involved families, little is known with regard to cultural dissonance of early intervention practices with American Indian families in general and Navajo families in particular.



#### Method

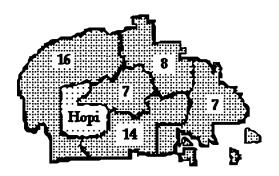
A mixed method design was used to allow the investigator to study specific variables and to explore new variables. Survey methodology using a cross-sectional cohort was used to address the questions under investigation. Face to face interviews using a standardized open-ended interview format were conducted with caregivers. Both individual and group interviews as well as written questionnaires were used to survey service providers.

#### **Subjects**

#### **Caregivers**

A total of 52 caregivers were interviewed over an eight-month period from November, 1993 to July, 1994. Seventy-one percent of the caregivers are from Arizona, and the remaining 29% are from New Mexico. Figure 2 illustrates the general distribution of caregivers across the agencies of the Navajo Nation.

Figure 2. Distribution of interviewees by agency.





Sample selection. Directors of all early intervention programs were contacted and invited to participate in the study. Because of confidentiality issues, the original plan called for subject recruitment to be conducted by program staff, and not by members of the research team. This method of recruiting subjects proved to be inadequate in obtaining a sufficient number of subjects; therefore, the original sampling plan was abandoned and a new plan was devised that would ultimately be more effective. The new plan shifted subject recruitment from the program staff to a recruiter, a Navajo woman working in early intervention, who was hired to talk with families.

In the original sampling plan, steps were taken to ensure the participation of all families, including those who were dissatisfied with services. There was little or no response to these strategies, which were designed to "cast a wide net". For these reasons and because not all families currently involved in the early intervention system were contacted by the Navajo recruiter, this is largely a sample of convenience.

#### **Providers**

Providers were included in two different phases of data collection. The first phase involved surveying each of those providers identified by caregivers as being the principle provider involved with her family. Because of this close match, providers came from the same programs and regions of the Navajo Nation as the families interviewed. This group included 16 providers, 6 from New Mexico and 10 from Arizona. Ten providers are Navajo and 6 are non-Indian, while 12 are paraprofessionals and 4 are professional.

The second phase involved individual and group interviews.

Professional and paraprofessional providers representing two of the three



states, and all of the regions of the Navajo Nation, with the exception of the southern most portion, participated in the individual and group (focus) interviews.

Two focus groups were conducted in Arizona. The first group contained four members (a female Navajo paraprofessional, a male Navajo professional, an Anglo male professional and an Anglo female professional). The second group also contained four members who were all service coordinators from Growing in Beauty; all four were Navajo, three were female and one was male.

#### Instrumentation

#### Interview Guide

The interview protocol contains items from the Client Satisfaction Questionnaire (Attkisson & Zwick, 1988), the Family version of the FOCAS (Bailey & McWilliam, 1991), and a series of questions adapted from those developed by Barber and his colleagues (1985) constructed to assess the degree of acculturation, as well as the other variables under investigation. Six openended questions were developed and included in the interview guide. Visual aids were developed to facilitate the interview process requiring two versions of the protocol (literate and non-literate).

#### Provider Ouestionnaire

Information was obtained from providers who were identified by the caregivers as having the most contact with the family. Questionnaires were developed requiring information pertaining to three of the variables in the study, acculturation, education, and the child's disability. The ABILITIES Index (Simeonsson & Bailey, 1988) was used to describe the nature and extent of each child's disability



The FOCAS (Bailey, 1991) was included in the instruments disseminated to investigate the perceptions of service providers working in the Navajo Nation. Data obtained from the FOCAS were also used to triangulate qualitative data derived from individual and group interviews.

#### **Procedures**

#### **Caregiver Interviews**

- 1. Recruiting Subjects
- 2. Development and piloting of instruments
- Hiring and training an interviewer One interviewer was selected instead of multiple interviewers to minimize interviewerrelated error.
- 5. Data analysis

Variables were measured according to the following descriptions:

<u>Family-centeredness of the program</u>. The caregiver was asked to rate typical and ideal practice on each of the 12 dimensions of the FOCAS. The typical rating on each of the dimensions was aggregated to represent the caregiver's perception of the family-centeredness of the program.

<u>Intensity</u>. The number of face-to-face contacts from all early intervention personnel was computed on a monthly basis.

<u>Travel time</u>. In an effort to assess the actual burden of travel on the family, the travel time was multiplied by the frequency of travel.

Ethnic match. Caregivers and providers were asked questions pertaining to acculturation adapted from those created by Barber et al. (1985). Two sets of data, objective and subjective, were obtained from each group.

The objective data were drawn from eight questions pertaining to language and cultural practices. Those scoring 8-12 were placed in one group while those scoring higher than 12 were placed in the other group. The same



system was used for providers with an additional group created for those providers who were non-Indian.

The subjective data were drawn from two questions involving self-ratings on a Likert scale ranging from 1-5. An average of the two scores was computed. Individuals with mean scores greater than 3 were placed in one group while those with scores of 3 or less were placed in the other group. Providers were grouped similarly with an additional group created for non-Indian providers.

The match between the caregiver and the provider was ascertained by computing the relationship between the two acculturation ratings (acculturation of the provider/acculturation of the caregiver) on both the subjective and objective portions of the acculturation questions.

Using the acculturation groupings, each dyad (caregiver and provider) was ranked according to how well matched they are. Those dyads who were perfectly matched (Navajo provider, Navajo caregiver, comparable levels of acculturation) were placed in group 1 and those who were both Navajo but scored differently on the acculturation measures were placed in group 2. Dyads having non-Indian providers were placed in group 3 (See Table 1).

Table 1. Groupings by ethnic match.

Acculturation: Provider	Acculturation	n: Caregiver
	Traditional	Acculturated
Traditional	1	2
Acculturated	2	1
Non-Indian	3	3

Education of the provider. Providers who indicated they were either a "paraprofessional" or "instructional aide" were placed in group 2 while individuals who indicated they are professional were placed in group 1.



<u>Disability</u>. Providers were asked to complete the ABILITIES Index on the child of each of the caregivers participating in the study. A method was adopted similar to the one described by Bailey, Buysse, Simeonsson, Smith, and Keyes (In press) where those children who received a rating of 1, 2 or 3 in any of the categories on the index were placed in group 1 and those who were ranked 4, 5 or 6 in any category were placed in group 2. Assignment to group 1 represents a child with a mild disability, whereas assignment to group 2 signifies a more significant disability.

<u>Duration</u>. The length of time a family had been receiving services was determined by asking the caregiver when her family began receiving services.

Education. Each caregiver was asked to indicate her educational status in a question containing four rankings from below eighth grade to completing some college-level courses.

Acculturation level of the caregiver. The data obtained from the acculturation questions described above were used to determine the objective and subjective acculturative status of the caregiver.

Socioeconomic status of the caregiver. Each caregiver was asked to indicate the range of income for their family from a selection ranging from below \$10,000 to over \$40,000.

Satisfaction. Two measures of satisfaction were used. The difference between the current and ideal scores on the FOCAS, was used to reflect caregiver satisfaction with specific family-related aspects of the program. The second measure, CSQ, contains eight questions pertaining to overall satisfaction with services. An average score on the CSQ was computed to determine overall satisfaction.



Responses to the six open-ended questions were coded and a reliability study was conducted. The interrater agreement coefficients were sorted by the six questions. Percent agreement for all codes ranged from 65% to 100% with overall percent agreement at 84%.

#### Provider Ouestionnaires

Caregivers were asked to identify the early interventionist who worked most closely with her family and a packet of materials including a description of the study, and survey questionnaires was mailed to each of the providers identified.

#### **Provider Interviews**

Sampling procedures. Personnel from the participating early intervention programs and Growing in Beauty were identified. A sample of professionals, and paraprofessionals, representing both Navajo and non-Navajo people was obtained. This sample was not random, and did not contain representation from all programs currently in operation on the Navajo Nation.

#### Data Analysis

The data were aggregated from the individual and group interviews and analyzed to determine emergent themes related to barriers and solutions to those barriers in the early intervention service system on the Navajo Nation.



#### **Results**

#### Research Ouestion 1:

#### Summary of Univariate Statistics

Each of the variables under investigation was summarized in terms of frequencies, mean scores, and ranges as presented in Table 2.

Table 2: Summary of selected univariate statistics of ordinal variables

Variable Name	Mean	Standard Deviation	Range
Family-centeredness of the Program	66.3	18.65	21-107
Intensity of Services (number of contacts in a month)	7.0	3.76	2-19
Travel Time (computed in minutes)	675.29	860.84	0-3780
Duration of Services (computed in months)	14.96	8.37	2-36
Satisfaction with family related practices (measured by a discrepancy score on the FOCAS)	17.65	14.54	0-48
Satisfaction with overall program (measured by the CSQ)	3.32	.29	2.5-3.75

#### Provider Variables

Thirty-five (67%) of the caregivers had Navajo providers and the remaining 17 (33%) had non-Indian providers. Table 3 reflects the groupings for ethnic match. Fourteen (27%) of the caregivers identified professionals as their primary provider and the remaining 38 (73%) have paraprofessional providers.

Table 3. Groupings for ethnic match.

	Group 1	Group 2	Group 3
Using Objective Acculturation Measure	16 (31%)	19 (36%)	17 (33%)
Using Subjective Acculturation Measure	19 (36%)	16 (31%)	17 (33%)



#### Child/Caregiver Variables

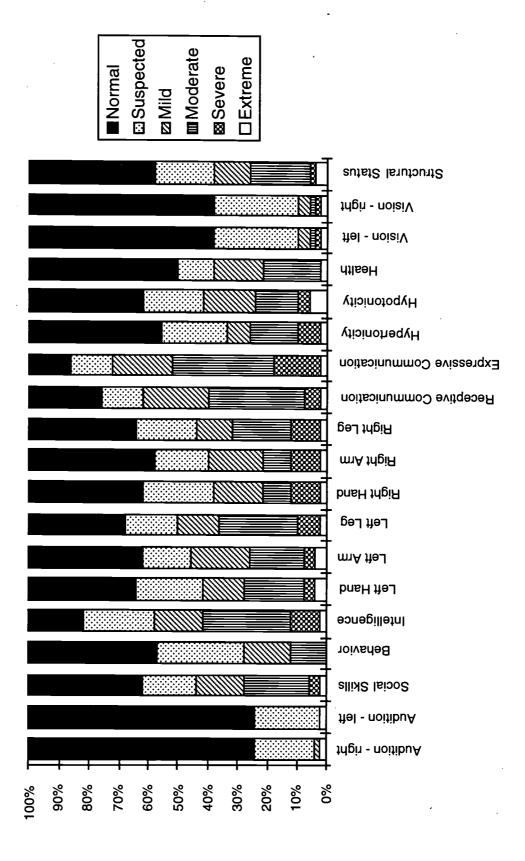
Sixteen (31%) of the children of the caregivers were judged to be mildly delayed or disabled according to ratings on the ABILITIES Index. Figure 3 reflects the rankings on the various domains of the ABILITIES index for this sample. Table 4 shows the distribution of caregivers in each of the four categories pertaining to education. Each caregiver was asked to classify her family's income into one of four categories; the percentage of caregivers within each category is shown in Figure 4. Regarding acculturation, a greater portion of the caregivers is in the more acculturated group (Group 2) on both the objective measure (67%) and subjective measure (54%) respectively. The average number of months a family had been involved in early intervention services was approximately 15 months.

<u>Table 4.</u> Education level of caregivers.

Education Level	Percent of Respondents
Less than 8th grade	7.7
Beyond 8th grade	32.7
Graduated from high school	36.5
Some education beyond high school	23.1



Figure 4. ABILITIES Index ratings of children.





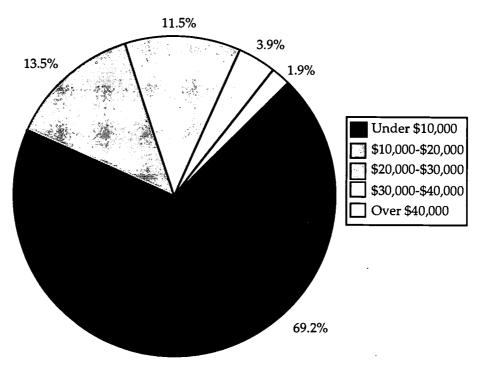


Figure 4. Income Levels of Caregiver

Satisfaction with family related practices. The first measure of satisfaction was determined by computing a discrepancy score between current and ideal practices. Table 5 reflects the mean scores of Typical and Ideal practice of the caregivers on each of the dimensions of the FOCAS.

Satisfaction with overall program. A score of 4 on each of the eight questions represents complete satisfaction with services on the CSQ. The caregiver's scores ranged from 2.5 to 3.75. These scores are skewed toward the higher ranking with 88% of the scores ranked above 3.0.

#### Summary of Bivariate and Multivariate Statistics

The correlations between the dependent variables and the independent variables were inspected next to assess their relative strength.



Table 5, Mean Typical, Ideal and Discrepancy Scores on FOCAS (Caregivers)

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	Α	<b>B</b> .	C	D	н	F	5	H	I	ſ	¥	Ţ
Typical	5.64	5.00	5.23	4.25	5.60	5.54	5.37	4.94	6.21	6.35	5.75	6.44
Ideal	7.06	6.75	6.81	6:36	68'9	7.02	6.44	6.35	7.42	7.60	7.52	7.73
Discrepancy	1.42	.1.75	1.58	2.14	1.29	1.48	1.07	1.41	1.21	1.25	1.77	1.29

Program philosophy about working with families **ж**ы С С ы н. С

Family-professional collaboration in developing a program philosophy

Parent participation in decisions about the child assessment process

Parent participation in child assessments

Identifying family needs and strengths/resources

Family participation in decisions about identifying family needs and resources

Parent participation in team meetings

Parent roles in decision-making

H

IFSP format

Family goals on the IEP/IFSP

Flow of services

Case managment

Table 6 reflects the correlations between the twelve independent variables and the two dependent variables.

<u>Table 6.</u> Correlations between the independent variables and the two dependent variables.

Independent Variables	Dependen	t Variables
Variable Name	Satisfaction with specific family-related aspects of the program	Satisfaction with the overall program
Program Variables		
Family-centeredness of the program	58**	.34*
Intensity of services	.06	.01
Travel Time	.15	.07
Provider Variables		
Match between provider and caregiver (objective measure)	07	07
Match between provider and caregiver (subjective measure)	.05	04
Educational level of the provider	20	.08
Child/caregiver Variables		
Child's disability	01	.15
Duration in early intervention	.08	.25
Education level of caregiver	05	.30*
Income level of caregiver	.04	.01
Acculturation rating of objective measure	22	.09
Acculturation rating on subjective measure	.38**	.15

<sup>\*</sup> p<.05

Note: Satisfaction with specific family-related aspects of the program is the discrepancy score on the FOCAS and Satisfaction with the overall program is the mean score on the CSQ.

#### Programmatic Variables

Family-centeredness of the program was significantly inversely correlated with the discrepancy between typical and desired practice (-.58, p<.01). In other words, the more family-centered the program was rated in terms of typical practices, the less the discrepancy between typical and desired practice. However, this correlation coefficient is quite likely to be inflated, as the measurement of family-centeredness utilized one half of the items on the FOCAS (typical scores) which were also part of the first measure of



<sup>\*\*</sup> p<.01

satisfaction. Family-centeredness of the program was also significantly and positively correlated with overall program satisfaction (.34, p<.05). This suggests that a higher level of family-centeredness is associated with with increased levels of overall program satisfaction.

#### Provider Variables

Correlation coefficients of the provider variables were low and not statistically significant. T tests and ANOVAs were conducted on each of the groups for ethnic matching using mean scores on both dependent variables. The resulting statistics revealed no statistically significant differences between the means of the groups regarding the satisfaction measures.

#### Child and Caregiver Variables

Two caregiver variables were significantly correlated with the dependent variable. The acculturation of the caregiver on the subjective measure was significantly related to satisfaction with family related aspects of the program (.38, p<.01), such that more traditional families reported greater satisfaction with family-centered aspects of service. The education level of the caregiver was significantly correlated with satisfaction of the overall program (.30, p<.05). This suggests that those caregivers who are more educated tend to be more satisfied with the overall program.

Research Question 2: Fifty-two caregivers responded to the six openended questions and each response was coded according to the coding system previously described. Total percentage of occurrence of each code was computed and is reflected in Table 7. A sample of responses follows.

Question 1: Tell me about your child with special needs.

"Jimmy has Down Syndrome. He was very small when he was born, 4 1/2 pounds. At two years old he was still too small, but he was running around. He couldn't talk. But when we started working with him, he started saying this and that. You have to work with these kids to get them to talk."



<u>Table 7.</u> Percentage of responses by category on the open-ended questions.

Question 1: Tell me about your child with special needs? (n=51)	Percent
Functional description	.51
Historical description	.49
Medical terminology	.43
Intervention description	.35
Positive statements	.25
Question 2: Would you tell a new parent about services? (n=50)	
Yes	.80
No	.20
Help received How to obtain services	.50
	.26
Description of early intervention services	.14
Activities conducted with the child	.06
Services are provided in the home	.06
Staff	.05
Question 3, part I: What is the most important thing about staff? (n=51)	
Teaching the child	.49
Helpful staff	.20
Affective characteristics of the staff	.14
Home visits	.12
Relationship between child and staff	.10
No comment Specific professional skills	.06
Informative staff	.04
	.04
Normalized treatment of the child	.02
Question 3, part II: Does it matter to you if the person is Navajo or Anglo? (n=49)  No preference	
Preference for a Navajo provider	.96
Preference for an Anglo provider	.04
	.00
Question 4: What do you like best about the services for your child from past experiences? (n=50)  Child progress	
Intervention activities	.28
Toys brought into the home	.22
Staff characteristics	.18
Home visits	.14
All services	
Therapy	.12
Consistency of programs or providers	04
Parent groups	.02
No comment or uncertain	.02
Question 5: What haven't you liked about services? (n=51)	.02
Nothing	- 06
Specific staff	.86
My child cries	.06
Frequency or duration of services	.04
Traveling to the clinic for services	.02
Respite care providers	.02
Question 6: If you had a chance to change anything about your child's services, what would you make different? (n=52)	.02
Nothing	.60
Frequency or duration of services	.10
Additional services	.04
Waiting at the clinic	.02
Scheduling appointments on the same day	.02
Opportunities for my child to play with peers	.02
Staff	.02



"She has a disease. She has her legs just bunched up together when she is laying down. She responds to your voice a little. Other than that she is usually okay, unless she is sick. I don't think of her as a disability child. From my point of view, I am just glad that she has all of the services that she has. For me, she does have a special need, all she needs is to be with her parents. When she first got sick, they told us to send her to a handicapped hospital, like Phoenix or Salt Lake. They wanted us to send her to the doctors in Phoenix. Then again, we said, we would take her home with us. She belongs with us. We just brought her home. We just take care of her, she is like a newborn infant. She is like that to us. She is not disabled, she is like a small baby, even if she is two years old."

Question 2: Would you tell a new parent about services? What would you tell them?

"No, if my child has a problem like that I don't ask anybody. I wouldn't talk to another parent."

"Yes. I would tell them that it really helps. They really teach you a lot of things, how to stimulate them, and how to handle their problems. And, they really talk to you and become like family to you."

"Yes, I probably would tell them that it really helped a lot because the way he is, he really communicates with us, and sometimes he has a hard time. But, Joanne comes over and plays with him and stuff like that. They are really a lot of help."

Question 3: What is most important to you about the people who are involved with your child and your family?

"That they know what they are doing and that they can help her the best way they can. With me, I am just learning right along with her too. That they can provide learning materials."

"I guess to come down. I am like a private person, and I see that they can help my child and they can help her more than I can because I don't know what to do. They are important to the family because they can teach us how to handle Jennifer and what we can do for her."

"They care for little kids like this one. They have a place for them in their hearts. I think of it like that because Joanne always comes over or we see Tina and she always comes to him, and talks to him and he smiles. She is really good with him, she talks with him, plays with him a lot too."

Question 4: What do you like best about the services from past experience?

"I like the service they have for my child because he has improved."



"Mainly concentrating on the baby, not with us, but what the baby needs. We try to support them too, like try to help her. We look forward to seeing her. She brings a bag and he looks forward to when she sits down on the floor and he tries to open up that bag and take out the toys. It is kind of neat."

Question 5: What haven't you liked about services?

"Nothing. The whole thing was good. There isn't anything I would change."

"There is nothing. I like them a lot; I enjoy them. It is nice to have people help my daughter out. I like to do as much as I can for her."

Question 6: If you had the chance to change anything about your child's services, what would you make different?

"Right now, I think he is getting just about everything he can, not unless there is some new program that comes up that might be able to help him a little bit more or more modern method or whatever comes up. Right now I think he is getting what he should be getting because he is developing real well right now. He is talking and he just started walking."

"I would want someone like Terry Jackson to be available every day, not only one hour a day for one hour a week."

Research Question 3: What are the perceptions of service providers regarding the system of early intervention services for Navajo families?

The following is a description of the responses to the central themes of the individual and group interviews.

Barriers, obstacles or issues facing the delivery of services to families living on the Navajo Nation:

Travel time. Distance is seen as a barrier both to traveling to see families and in coordinating with other providers who are not in the local community. The inadequacy of the roads, particularly in the winter when many roads are impassable, is also seen as a significant barrier to service delivery.



<u>Professional</u>. Professionals who have "different agendas" and who are territorial are seen as obstacles in coordinating services for families. Poor group dynamics is perceived as blocking effective team efforts.

Agency. The administrative policies and procedures were often seen as prohibitive to creating a responsive service system. The priorities of each service agency, dictating different agendas, were seen as major obstacles to effective cross-agency communication. Providers, particularly the service coordinators from Growing in Beauty, indicated their roles were unclear. Available funding from the agency as well as excessive caseloads, paperwork, and time constraints were mentioned. Some felt that the system is driven by billable hours rather than by client needs.

Family. Difficulty encountered in trying to communicate with families because of the lack of telephones, parental illiteracy, and families who do not check their mail routinely were a seen as significant barriers. Several mentioned the fact that some families fail to see the value of early intervention services as they are "just trying to survive from day to day." Families who do not follow through on recommendations or who do not show up for appointments were seen as difficult to work with. Other families are seen as being to dependent on providers to meet all their needs. Transportation was consistently mentioned, as families do not have reliable vehicles, or money to purchase gas.

General. Repeatedly, the lack of resources, including qualified personnel, day care, and housing for families was cited as a barrier. The lack of a coordinated system of services was noted, reflected in duplication of effort in some areas. One provider stressed the fact that Anglos making programmatic decisions had resulted in services that were not culturally sensitive.



#### Recommended Strategies to Overcome Obstacles or Barriers

<u>Professional</u>. One recommendation was to prepare families ahead of time for the process of early intervention (i.e. give the family a blank copy of an IFSP before planning begins). Training for families was also recommended as an approach to informing them about the early intervention service system. Professionals should schedule meetings at locations and times preferred by families. Many indicated that communication with families should be ongoing, not just when formal reviews are required, and that providers respond to problems as they occur.

Agency. Numerous individuals indicated that agencies should seek more funding for personnel, and vehicles to transport families. It was further recommended that supervisors should be more "in touch" with the issues, and the system should not drive services as in the case of billable hours.

General. Several people noted the importance of providing services to families in their homes. Others discussed the importance of using the native language; therefore requiring additional interpreters to facilitate communication. One person underscored the importance of having interventionists who speak Navajo. Related to this is the desire for professionals who are culturally competent. Lastly, the need for training, both for professionals and paraprofessionals, was stated by several people. Part 2

Sixteen providers completed the FOCAS. A description of the characteristics of this sample is previously described. A summary of the mean scores for the typical and ideal rankings on each item is shown in Table 8 for both groups. It should be noted that caregivers were responding to their



own experience while providers were rating the overall program across a number of families.

<u>Table 8.</u> Comparison of mean scores of providers and caregivers on items of the FOCAS.

	Caregivers	Providers
Program Philosophy about Working with Families	<u> </u>	
Typical	5.635	7.188
Ideal	7.058	8.000
Family-Professional Collaboration in Developing a Pro	gram Philosophy	
Typical	5.000	5.563
Ideal	6.750	7.875
Parent Participation in Decisions about the Child Asses	sment Process	
Typical	5.231	6.000
Ideal	6.808	7.625
Parent Participation in Child Assessments		
Typical	4.250	6.625
Ideal	6.385	8.000
Identifying Family Needs and Strengths/Resources		
Typical	5.596	6.813
Ideal	6.885	8.188
Family Participation in Decisions about Identifying Fam	nily Needs and Resources	7 7
Typical	5.538	6.625
Ideal	7.019	8.625
Parent Participation in Team Meetings		<del></del>
Typical	5.365	6.250
Ideal	6.442	7.938
Parent Roles in Decision-Making		
Typical	4.942	6.438
Ideal	6.346	8.250
IFSP Format		
Typical	6.212	7.125
Ideal	7.423	8.313
Family Goals on the IEP/IFSP		
Typical	6.346	7.063
Ideal	7.596	8.438
Flow of Services	`	
Typical	5.750	5.625
Ideal	7.519	8.438
Case Management		
Typical	6.442	6.750
Ideal	7.731	7.813

#### Discussion

The sample of caregivers was one of convenience as the sampling plan failed to obtain representation from all states or programs. Of particular note is the high probability that the sample was comprised of individuals who were at least minimally satisfied with services or they would have withdrawn from services and unavailable during the recruiting phase, or they would have been unwilling to participate.

The variable having the strongest association with both global satisfaction and satisfaction with family-related aspects of the early intervention program was how family-centered a program was perceived to be. The caregivers in this sample report greater satisfaction with early intervention services in programs perceived to be more family-centered.

Those individuals who were less educated or more traditional generally rated the program as being less family centered. This begs the question as to whether the program is in actuality different for individuals according to their education level or degree of acculturation.

Provider variables (ethnic matching between the provider and caregiver, and the educational level of the provider) failed to have a strong relationship with either measure of satisfaction. Both of these were of particular interest in this study, as ethnic matching and the use of indigenous staff are generally felt to produce less dissonance, and hence greater satisfaction among different cultural groups.

The low correlation between the variable pertaining to ethnic matching and program satisfaction was an important piece of information. It was further supported by qualitative data reflecting 96% of the caregivers having no preference with regard to the ethnic/racial background of the



provider. Some of the caregivers mentioned an affective characteristic of the provider when asked what was important about staff. Even more importantly, statements pertaining to the behavioral repertoire of the provider were mentioned frequently (i.e. teaching skills, and general helpfulness).

The acculturation status (measured by subjective rating) has a strong and statistically significant relationship with satisfaction with family-related aspects of services. This suggests that the those individuals who identified themselves as being more acculturated saw a greater discrepancy between typical and ideal practice in early intervention. It may be that those individuals who view themselves as less traditional have gained insights into the most effective strategies for navigating service systems designed by non-Indians. Through the process of acculturation they may feel more comfortable with taking an active role in their child's program and want the opportunity to do so.

## Question 2: What are caregiver perceptions of the early intervention system of services?

Caregivers were quite positive about early intervention services and seemed to be unable to identify anything needing improvement. Many of their statements focus on intervention with their child and not with the family.

When asked to describe what was the most important thing about staff, caregivers provided the investigator with further evidence regarding the role of ethnicity in the delivery of services. Caregivers failed to identify as important the fact that the principal service provider was ethnically or



culturally similar. Instead, responses focused on the provider's interactions with their children.

Question 3: What are the perceptions of service providers regarding the system of early intervention services for Navajo families?

Data collected through individual and group interviews were triangulated with data from other sources. Many of the same themes emerged from all three sources of data.

The travel time issues regarding distance and travel on inadequate roads will always be a significant barrier to be faced, if programs continue to provide service in the home. Professional issues identified as barriers are not new to early intervention providers who are part of a team any where else and these must be confronted to facilitate service delivery. Providers on the Navajo reservation encounter more than the usual amount of difficulty coordinating services across agencies and programs and fragmentation is likely to occur as expressed by the providers in this study.

Providers responding to questions on the FOCAS demonstrate an interesting pattern compared to caregivers. Providers clearly think that services are more family-centered than caregivers on all dimensions measured by this instrument. It is also notable that providers see a program that ranks higher on the FOCAS (ideal score) as desirable where caregivers desired a program that was not dramatically different than what they currently have.

#### Limitations of this study

This study has several limitations. The first limitation has been previously described and pertains to the composition of the sample. Because the sample was one of convenience, the findings are not generalizable to all families living on the Navajo reservation. Additionally, those who were



interviewed were more likely to be satisfied as they had not withdrawn from services, therefore inflating the rate of expressed satisfaction, a problem discussed by Kiesler (1983).

The investigator feels that the answers to the open-ended questions included in the interview protocol did not adequately reveal caregiver perceptions of the current system of services. This may be the result of caregivers not wanting to jeopardize services they are currently receiving, a problem described by Homans (1974). It could also be a cultural mismatch where caregivers have different expectations regarding early intervention services, and perceive it very differently so that the questions did not adequately address the underlying issues. Both of these are real barriers to measuring satisfaction described further by Ellmer and Olbrisch (1983). It is speculated that all of these factors contributed to the responses to the openended questions in this study.

Cultural differences further impacted this study as Navajo caregivers and providers were asked to rate the services. This is not typically a behavior encouraged among Navajo people, particularly those who are more traditional. Their responses may have been made to satisfy the interviewer, but may not accurately reflect their impression of services.

Language played a significant role in this study. Interviews conducted in Navajo did not parallel those done in English because of translation. While the interviewer was asked to remain consistent, the second individual who transcribed tapes of the open-ended questions indicated that the meaning sometimes changed from the meaning of the question in English.

#### Implications for practitioners

The overall satisfaction rate of the caregivers in this study is important to note. There are additional findings that merit further consideration.



One of the most important findings relates to how responsive the program is to the family. Programs that involve the family in the manner sensitive to the family's desires create more positive perceptions of all aspects of services. Families have a more favorable impression of services they perceive to be more family-centered.

The practice of hiring indigenous workers as a strategy to reduce cultural dissonance is not supported by the results of this study. The caregivers in this study indicated that they did not have a preference regarding the ethnicity of the provider. This was supported by the quantitative data showing a weak relationship between ethnically matched provider/caregiver dyads and satisfaction. However, caregivers paired with paraprofessional providers were somewhat more positive in their views pertaining to family-related aspects of the program.

The results suggest that programs are more family-centered for caregivers who are more acculturated and who have more education. However, the discrepancy between current and desired practice was not significantly different for these same caregivers. This may reflect different approaches with caregivers according to their education and/or acculturation, but these approaches have not resulted in less favorable views of the programs. Considering the relative importance of family-centered practices to satisfaction, this should be studied further to assess the reason for this disparity.

The barriers that prohibit service delivery on the Navajo reservation are well identified by those who are part of the system. Providers and administrators should begin a dialogue to begin working on solutions.

Agencies and programs should consider strategies to facilitate the delivery of services to families in the home. This may require allocation of



monies toward vehicles and allowances for travel expenditures. Perhaps some families should be prioritized for telephone service so that they can communicate with early intervention personnel. In some instances, families would benefit from travel allowances to access services. Individuals who are bilingual should be employed by agencies or programs for those families who are unable to communicate in English and who are illiterate.

#### Directions for future research

Other research designs should be investigated to assess the consonance between early intervention services and the families served. For example, assessing the patterns of service utilization might be considered to determine the extent of satisfaction, as Navajo caregivers who are dissatisfied with services are more likely to withdraw from services than express their dissatisfaction. It is important to study further the relationship between acculturation status of the caregiver and the service delivery approach.

The perceptions of caregivers regarding the nature of family-centered services warrants further investigation. This may be occurring at the program or staff level, and is beyond the scope of this study.

The practice of ethnic matching should be studied further with regard to other cultural and ethnic populations. While it did not have a strong relationship with satisfaction in this study, the literature contains many references supporting this approach.

Further research regarding the Navajo people and early intervention would provide important insights as to what are the most effective approaches with this particular population.



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