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# An Evaluation of Medical Services Provided to Developmentally Disabled Navajo Children

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AN EVALUATION OF MEDICAL SERVICES PROVIDED TO  
DEVELOPMENTALLY DISABLED NAVAJO CHILDREN

June, 1982

IHS Grant # 63-A-000021-01-0

Prepared by the Dine Center for Human Development  
Navajo Community College

Through a Tribal Evaluation Organization Project  
Granted to the Navajo Division of Health Improvement Services

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## Introduction

In response to specific objectives outlined in the Navajo Master Health Plan, the Dine Center for Human Development, Navajo Community College convened a multi-disciplinary, multi-agency committee in late 1979 which continued to meet through the summer of 1981, reporting on efforts being carried out to expand and coordinate services for physically and mentally handicapping conditions among Navajo children. It was also the intention of the committee to keep the need for improved developmental disability services in the forefront of Navajo leadership discussion.

In the fall of 1980 a Report by Bogin and Milligan<sup>(1)</sup> described the Navajo Area Indian Health Service's (NAIHS) capabilities and deficiencies in providing comprehensive child health services. The Report which described personnel needs, management objectives, health provider perceptions, and service component coverage is meant to be used by professionals within the health delivery system. Adjoining that is this report which further documents the need for allocating and managing medical and developmental resources for the prevention and treatment of disabling conditions among Navajo children. Not all of the service gaps identified can be met by a medical care system alone; many require related social services, and societal improvements brought about by economic development endeavors.

The compiled information is addressed to the Navajo Tribal Council, the Tribal health, education, and social welfare sectors, and to those who determine policy and the allocation of resources within the Indian Health Service.

## Methodology

### Goal

The overall goal of the Tribal Evaluation Project was to evaluate the medical services provided by or paid for by the Navajo Area Indian Health Service to Navajo developmentally disabled children. The attainment of the goal was designed in a one year program plan, carried out between July, 1981 and June, 1982, with the following objectives.

1. Select a geographically distributed sample of Navajo children with a variety of disabling conditions, who's case histories could be documented in terms of management process.
2. \*By means of a select group of developmental specialist consultants, map out a representative sampling technique and information gathering strategy in such a manner that the consultant group might perform a "peer review" of a subsample of cases.

These advisors consisted of:

- 2 developmental pediatricians
  - 1 cytogeneticist physician
  - 1 Navajo medical anthropologist
  - 1 research scientist in special education
3. Establish an audience of local health care clinicians and social and educational providers to receive, comment on, and react to the findings of the study.
  4. By means of a Navajo professional, interview the parents or caretakers of the disabled children, ascertain their perceptions and involvement in caring for them, and their perceptions of the medical care provided by the Navajo Area Indian Health Service and its referral agencies and hospitals.

\* See Appendix for Sample Selection and Peer Reviews

5. Gather data on medical care management of the sample cases by performing in-depth review of each child, their medical records, on and off the Reservation, using established review procedures which could be evaluated in terms of developmental treatment and individual case characteristics.
6. Present the parental and medical information in a manner which is useful to both the health provider and the consumer.

### Summary of Findings

In general, the primary medical care provided once the child had entered the medical care system (birth, clinic visits, hospital admissions, home health care visits) was adequate and appropriate, but the specialty intervention and care associated with developmental problems was not. These specialty interventions include:

- documentation of early childhood development, both progress and delays
- timely specialty assessments including, hearing, fine and gross motor abilities, cognitive and language skills, social and psychological development.
- treatment resources for infants and small children who are at risk of not recovering or developing as well as they might without a specially prescribed program according to educational and medical theory.
- parent training and counselling on how to accept and interact with a delayed or handicapped child.
- long term planning for disabled children

In addition, a high proportion of the families of these disabled children did not demonstrate parenting behaviors which would be considered conducive to prevention of or habilitation for developmental problems. This included a low participation in prenatal care, well child health care, and educational activities. In comparison to parents of all Navajo children, this developmental disability group appears to be atypical in some areas which leads to many implications for targeting service groups of people who are at greater risk of not being able to cope with children.

A glossary of terminology appears on the next page for clarifying some of the terms used in the evaluation report.

## GLOSSARY

delay - child not able to do or accomplish what others his/her age can do; behind in developmental milestones.

Denver Developmental Screening Test (DDST) - a relatively short test administered by trained professionals to children between 1½ and 4 years of age to identify those who are, or may be at the risk of being developmentally delayed.

cognitive skills - relating to perception, awareness, and ability to solve tasks; basic skills needed to gather more knowledge and apply that to new situations.

developmental disability - see Appendix I and handicap of childhood.

handicap of childhood - a limitation that hinders a child from learning, playing, or adapting; a limiting disability. Terms handicap and disability used almost interchangeably in this report although there are finer distinctions.

medical diagnosis - recognizing a disease or condition by identification of symptoms and/or by tests; a scientific description of a person's physical and/or emotional condition.

developmental diagnosis - technical description of a child's progress or delay in achieving stages in growth and development within expected but not rigid time frames.

developmental assessments - same as above which also may include the evaluation of specific areas of child development by members of a multi-disciplinary professional team; a systematic appraisal of a child's abilities and limitations.

developmental intervention or treatment - based on developmental assessment, the specific therapy, habilitation, educational plan for the individual child and his family.

medical treatment - the application of scientific remedies and/or therapies for a disease or condition.

early identification - determining the presence of a developmental disability or potential disability as soon as possible so that treatment or change can be made to allow maximum recovery or progress.



high-risk pregnancy - a condition of the pregnant women which threatens the life or well-being of the baby; conditions include alcoholism, infection, diabetes, hereditary condition, early teenage or greater than 35 year-old mother, placental separation, emotional distress.

infant stimulation - a program designed with the parents' participation to increase the baby's physical and cognitive abilities; encouraging and supportive adult behavior toward the infant's evolving capacity for communicating, learning, interacting, and mobilizing.

physical and occupational therapies in childhood - prescriptive treatment and habilitation relating to child's age, abilities, and limitations which promote normal development, adaptive behavior, self-esteem, and social interaction; physical therapy may include special exercises, massage, and heat treatments.

habilitation - provision of first-time learning experiences so that disabled child may develop his potentials and abilities.

## Part I

CHARACTERISTICS OF THE STUDY'S SAMPLE CHILDREN

Total number of children = 60

Ages: between  $2\frac{1}{2}$  and 11 years in January, 1982

Median Age: 6 years

Sex: 25 girls 35 boys

Geographic Area Residing in, 1981-1982,  
by IHS Service Units;

Fort Defiance	20
Chinle	6
Gallup	19
Shiprock	15

### Children's Disability Conditions

The sample children were chosen by selecting a broad variety of developmentally disabling conditions. The following are some of the medical-handicapping problems as examples:

Cerebral Palsy

Down's Syndrome

Fetal Alcohol Syndrome

Cleft Palate with Developmental Delays

Multiple Congenital Anomalies

Partial Paralysis after Motor Vehicle Accident

Neurological Damage after Meningitis

Developmental Delays with Parental Neglect

Deaf

(See Appendix III for details)

Primary Caretaker

Child's Primary Caretaker:

	<u>#</u>	<u>% of total</u>
Parent(s)	27	45%
Grandmother	8	13%
Other Relatives	7	12%
Institution	9	15%
Combination of above	7	12%
Other*	<u>2</u>	<u>3%</u>
	60	100%

\* 1 Boarding school  
1 Unknown

Forty-five percent (45%) of the children's primary caretaker(s) were the natural parents. These included parents who work and have another person care for the child during the day.

Fifteen percent (15%) reside in a special school or facility ("institution")

Of the remaining forty percent (40%) (n=24), the parents are unable or unwilling to nurture and raise the child. At least 16 of these children, or twenty-seven (27%) of the total, are being shuffled between foundling homes and relatives.

### Prenatal Care

Number of sample mothers known to have had prenatal care =  
24 of 60 or 40%

Percent of all Navajo mothers participating in prenatal care  
in 1976, 6 years ago = approx. 70%

Percent of all Navajo mothers participating in prenatal care  
in 1981 = 80 - 85%

Of the sixty children in the study all were born between 1971 and 1979, and most were born after 1975. Only 24(40%) of the mothers had had prenatal care. Not participating in pre-birth health care results in a higher negative pregnancy outcome for any group of women. Prenatal care does not prevent all birth defects or all infant problems but it greatly reduces them.

The mothers of this developmental disability group were not typical of most Navajo mothers giving birth at the same points in time. According to NAIHS records, in 1976 approximately 70% of delivering mothers had received prenatal care. That percent has been increasing each year so that recent counts show, in the same Service Units from which our sample children were born:

1979 - 80% received prenatal care

1980 - 83% received prenatal care

1981 - 85% received prenatal care

The kind of attitudinal change which takes place prior to increased participation in a health promoting concept like prenatal care is in many ways the same kind of thinking that needs to occur in order for parents to practice development-oriented child care. The child does not grow and change by some act of fate but is influenced all along the way by environmental factors, especially the people around him. Most children experience a fair number of illnesses such as colds and ear infections and part of development is coping with these illnesses. Coping and maintaining a balance in the body is what health is about. Prenatal care and child care are health activities - mostly dealing with the prevention of medical problems. Wide acceptance of the notion of using the health care system to prevent problems requires community education in prevention thinking.

Many of the mothers and grandmothers we interviewed said that they did not go to the clinic for prenatal care because "there was no need to - nothing was wrong". These women represent what is called "high risk" individuals. They take more chances and run into more complications because they don't prepare ahead - not only with pregnancy but in other aspects of living too. More

than half of the mothers who did not seek prenatal care are also not currently raising these children. (See apendices for further details) Consequently the disabled children of these women, regardless of the cause of the handicap, were not doing as well as the disabled children who came from families where the adults tended to plan ahead and to actively seek health and special education services.

Two Case  
Histories

- The 2 case histories that follow demonstrate the interaction between the medical personnel and the parents at the onset of each child's disabling problem. They also demonstrate different levels of parenting behavior and response to emotionally traumatic situations. While each child's outcome is to a large extent determined by the organic nature of their problems, the areas of potential development and habilitation rely on therapeutic intervention which requires a high degree of parental participation.

Case A: An Institutionalized Child

Summary

P. was the second child born to a twenty year old mother and a twenty-four year old father in June of 1980. The mother had sought no prenatal care and arrived at the nearby hospital in advanced labor with complications life-threatening to the baby. Due to those complications (neonatal sepsis and anemia secondary to placental abruption) the newborn infant was kept in the hospital for almost 2 weeks until he was well and steadily gaining weight.

At nine months of age P. was admitted to the hospital with a bacterial meningitis which lead to severe neurological damage including blindness, spasticity, and probable deafness. During twenty-five days of hospital treatment for this devastating infection the parents were counselled regarding the seriousness of the disease and the fact that the baby would probably not fully recover from the brain damage.

The mother began to learn special feeding techniques and rehabilitative exercises to do with the baby, however, it became quite apparent that there was a great deal of stress at home, especially regarding this baby's condition. Two social workers and a physical therapist worked with the parents in preparing a therapeutic infant development plan for P. while also attempting to counsel the family in their distress.

During the next two months P. was readmitted to the hospital twice with high fevers, seizures, and dehydration. The parents expressed anger toward the hospital staff for not being able to cure the baby. Recognizing the need for cross-cultural and psycho-social intervention, the clinicians agreed to temporarily discharge the infant for a sing during one of the admissions.

Later, at thirteen months of age with obvious neurological problems which were not quickly resolving and which were overwhelming to the parents, the mother admitted P. to a nursing home and began formal psychological counselling sessions for herself. At first P. was still in medically unstable condition, but from the Fall of 1981 until June, 1982 he has been out of medical danger - however he still remained at the nursing home.



Family Household

<u>Member</u>	<u>Birthyear</u>
Paternal grandfather	1926
Father	1956
Mother	1960
3 children by father's first marriage	1976, 1977, 1978
2 children by this marriage including P.	1979 & 1980

P. lives at the nursing home and the seven other family members live in a one-room house which belongs to the grandfather and is four miles from a paved road. There is no running water, but electricity is available. The family has one truck which P's father takes to work in town, five miles away from the house. P's mother has her hands full at home with the family, including her blind father-in-law, and P's next older sibling who is three and has developmental delays.

Child's Physical Status

Two years old in June, 1982  
 Sits in a wheel chair with supports  
 Poor head and body control  
 Responds to loud noises  
 Fed soft food with spoon

Problems/Comments

For almost a year the mother's hopes were that the child would fully recover from his illness with no major disabilities. The father compares the three healthy children from his previous marriage with the two from this current marriage and blames the mother for their problems. The father abuses alcohol and beats his wife. A Native practitioner who was consulted was unable to provide support, in fact he added to the burden of guilt by indicating that the parents were to blame for P.'s condition.

At first the mother was occasionally participating in the nursing and physical therapy of the child at the nursing home. After three or four months she visited him less frequently although he was making some slow recovery. The parents are unable to cope with or accept P's disability, or to set realistic goals within his limits, such as placing him in a special education facility where more of his recovery might be enhanced.

Case B: Intact Family; Very Involved with Developmentally  
Disabled Child's Therapeutic Program

Summary

S. was the second child born to twenty year-old parents in 1977. Her mother had started prenatal care during the fourth month of her pregnancy and had no problems during that time. S. was born with many congenital abnormalities involving her hands, feet, and joints. The medical term for her condition is Arthrogryposis. Because of the need for surgical corrections and long-term planning, S. was transferred to the children's hospital in Phoenix where she stayed for almost four months of medical workup, physical therapy, parent training, and surgery. Other pediatric specialists also consulted on long-range plans with her parents and her Indian Health Service doctors.

Until two years of age, S's mother cared for her almost entirely on her own which included extensive nursing care following surgeries for correction of severe bone and muscle deformities. Continuous attention had to be paid to special exercises of her hands and legs to prevent muscle tightening and to her normal needs as a small child encumbered by plaster casts and physical immobility. At two years old her parents enrolled in "infant stimulation" classes at a nearby program. At that time, while very limited physically, her social and psychological development was tested and found to be normal for her age.

At two and a half years of age S's parents enrolled her in a special daytime pre-school program on the Reservation where teachers and therapists trained in child occupational and physical therapy guided and assisted her through the developmental stages of early childhood. The interview and progress notes from the school records indicate that her parents were highly involved in her progress and could communicate well with the school's professionals as to their personal feelings and incremental goals for their disabled child.

At three years of age, in face-to-face planning between parents, teachers, and therapists, an Individual Educational Plan was formulated with prioritized instructional targets relating to her physical and emotional development, emphasizing self-help skills. Almost a year later a progress report indicated that this child behaved very independently, with skills at problem solving including finding ways to work around her disability, and possessed a strong, positive self concept. Her cognitive and language tests showed her to be beyond other children her age. In addition, while

the primary language in her home is English, she was learning Navajo from her classmates. Her fine motor (finger and hand skills) and walking abilities were still quite limited.

### Family Household

<u>Member</u>	<u>Birthyear</u>
Father	1957
Mother	1957
Son	1974
Daughter (S.)	1977

The family of four lives in a mobile home located in a suburban Reservation area with many relatives living nearby. The father is employed full time and the family has two cars. The parents have availed themselves of community resources in addition to those at the nearby special education school, and to a lesser degree, traditional support such as a Native Practitioner. The mother reports that S. is treated by other immediate family members as a "special child" with extra love and attention.

### Child's Status

At almost five years old (June, 1982) S. has been gaining skill at walking without her leg braces which she still uses at night to strengthen joint alignment. Because her hands are contracted, much of her current training is in finger and hand manipulation such as picking up small objects and buttoning her clothes. As already described, S's communicative, social, and cognitive abilities are considerably above average and she possesses a good deal of confidence and curiosity in her surroundings.

### Problems/Comments

In addition to the positive attitudes and therapeutic activities displayed by S's family, a number of different professional groups have been involved in her physical and emotional care. The amount of coordination of specialty appointments, distant referrals, and family assistance which has been necessary is not apparent to the casual observer. The community health nurse and social worker roles have been vital to the provision of total services, but rather typically, go relatively unnoticed in the complexity of the process. That in itself may not be a problem, but may prevent planning for or prioritizing these key positions when personnel

needs are allocated.

The school which has a highly skilled and socially sensitive staff does not actively share its specialized information and individual child plans with the medical community. The medical-hospital staff seems to have removed itself from health related activities which involve the eventual outcome of its patient treatments. In fact, the medical records would indicate that the hospital and Crippled Children's clinicians are not aware of the child's functional limitations, abilities, needs, or progress. The valuable evaluative and developmental information from the school should be in the child's medical record; for the purpose of viewing the child holistically, for team planning and support, for reference and decision-making by new clinicians, for retrospective review. What is now separate worlds of professional activities needs to become mutually beneficial in intent and overt actions for the well-being of the child and the family.

## PART II

## EVALUATION OF DEVELOPMENTAL DISABILITY HEALTH SERVICES

Section A; Medical Record Reviews

The project staff reviewed and summarized the medical records of the sixty developmentally disabled children. The physician consultants in turn reviewed the medical and community health records of the subsample children, for general medical care management and then specifically for developmental health care. The latter have been summarized in a rating of services grid, components of which are;

1. The timeliness of the developmental diagnosis (separate from the medical diagnosis)
2. The documentation of developmental assessments, including pediatric, physical therapy, speech, and hearing testing.
3. Developmental treatment as a unique set of interventions separate from or in addition to purely medical treatment.
4. Identifiable barriers to providing adequate or timely developmental treatments (the IHS medical care system, the family, available community resources)

In the total medical management of children with handicapping conditions, developmental diagnosis and treatment is assumed to be part of child health care, going hand in hand with the treatment of the child's medical problems. The consultants judged items 1 through 3 above on a numerical basis from each of the 23\* children's medical records. For simplification the scores are totalled in the following table, where it is shown that functional or developmental components of the over-all health care were lacking to a significant degree.

\* Because disability was not confirmed, 1 case was not rated

CONSULTANT RATINGS ON SERVICES PROVIDED

	Timeliness of Developmental Diagnosis	Developmental or Functional Assessments	Developmental Treatment
Potential Scores	69	69	69
Consultants' Score	40	38	35

Based on the medical records, family and clinician interviews, three major barriers to providing services were identified; the lack of adequate resources both within the health care system and the community, health care provider behavior, and the family's attitude and behavior.

In general the children's medical problems were identified early but long-term planning and early developmental treatment for the handicap were missing. When these components were carried out it was usually tied to the efforts of 1 or 2 people associated with a particular child. For example, in the case history of S. presented earlier, with the assistance and support of 2 health professionals her parents started an early treatment program - "infant stimulation" which worked to help them and their child make the next step into special education and training. But since not all parents and professionals behave this way, not all of the children were fortunate enough to receive early developmental treatment. Another case history helps to exemplify the problems;

L. was born in 1973 with multiple abnormalities of her head and neck. In addition to receiving vigorous medical treatment at the nearby Indian Health Service Hospital she was frequently sent to Phoenix for corrective/reconstructive surgery of her mouth, ear, and spine. During her first 2 years of life, she and her mother flew to Phoenix 13 times and yet it was not until she was almost 3 years old that her hearing was tested and it was not until she was  $4\frac{1}{2}$  years old that she first was treated for her deafness. No, one professional seemed to take charge of this child's management to make sure that all of the many specialty services that she needed were in fact carried out early on. She eventually ended up in a special education setting but after about a two year delay, which in early child development timing is considered disastrous. The health care system, while not totally responsible for all aspects of child rearing which are ultimately the parents' domain, nevertheless has an obligation to play an important role, and in many instances to initiate health related treatment programs. In view of the fact that before a child becomes school-aged, the only professional people he is likely to come into contact with are health workers - doctors and nurses in the clinic, those people are ethically responsible for trouble-shooting any special needs the child may have within the considerations of the family's desires and abilities.

In order to keep the summary findings of this evaluation study short, some of the technical aspects of the review have been placed in the appendices. The same strategy used by the project consultants was applied to all sixty of the cases summarized. The findings were generally the same, that is that the medical component of the child's care was adequate but the developmental components were not.

Some Documentation of Developmental or Functional Status

Contained Within Child's Medical Record - Total Sample (60)

frequency

Within 6 months of medical disability being noted or suspected

20

Between 7 and 12 months of medical disability being noted or suspected

18

Occuring later than 12 months after medical disability noted, or no documentation at all

22

(See Appendices for further details)

## Section B: Family Interviews

Quality of life areas such as child development (including developmental disabilities) become social issues if a crucial number of people within a society place a crucial amount of value on that particular area. It is very difficult and probably a mistake to make broad generalizations about Navajo families attitudes regarding developmental disabilities. Like anyone else, a Navajo's knowledge of and feeling's about the field runs the full continuum. On the other hand, the families involved in this study were people with disabled children and one would assume that the care of these children would have led to a greater knowledge and interest than that found in the general population.

Culture is not static, it is dynamic, with new information, ideas, and circumstances continually reshaping it. One frequently hears something referred to as "Navajo tradition" and what that ambiguous term is often alluding to is a repertoire or collection of valued beliefs and practices such as religious ceremonies. But not all Navajo's at all times value all the same things. A nursing research study carried out in 1980 documents these phenomena;<sup>(2)</sup> ten percent of all Navajo women who were pregnant that year were interviewed regarding their cultural beliefs and practices about pregnancy and delivery.

Among the findings of the prenatal study:

1. 95% could speak English but 31% spoke Navajo most of the time.
2. 58% of the women's husbands had a wage or salaried job.
3. 74% said they practiced "traditional Navajo religion" but those same women also practiced other religions: Native American Church 49%, Protestant or Catholic church 53%, Mormon 24%.
4. 52% said they felt it is "wrong to prepare" for the baby before it is born. (buying clothes, etc)
5. 6% were not attending prenatal clinic.
6. 81% said that they would like to have the father present at the birth.
7. 41% did not plan to have a blessingway ceremony before or after the birth.



8. 55% did not plan to give the a baby a Navajo name.

9. 75% believed in witchcraft.

This evaluation projects staff interviewed a subsample of the sixty children's families in order to determine how much they understood about their childrens' problems, how active they had been in seeking help and therapy, and what their perceptions are regarding the care provided by the Indian Health Service. These cultural or societal knowledge and attitude factors regarding health care and developmental disabilities covered three specific topics;

1. Health Promotion

A. Prenatal Care

B. Well Child Care

C. What is the Role of the M.D.?

D. What is a public health nurse's role?

2. Early Childhood Development

A. Medical and educational models of developmental milestones; Are they widely accepted?

B. Concept of people from outside of the home intervening; When is that acceptable?

3. Developmental Disabilities

A. Connotation of terms in Navajo and English

B. Why are some conditions (deafness) denied more then others (palsy)?

C. The value or acceptance of therapeutic interventions

The mothers of the children who had the most timely and thorough therapeutic interventions tended to be the same mothers who also utilized early prenatal care, could describe their child's problem using some medical terminology, had at least a partial high school education, and were married to men who had steady jobs. To put it the other way, multi-problem families had much more difficulty dealing with or even acknowledging a child with developmental delays. Certainly, the parents' ability to interact with the physicians and nurses affects the outcome of a clinic visit and the doctor's motivation to converse with parents and help them seek solutions to complex problems depends on his/her perception of the parents' skills and enthusiasm. The following are some of the attitudinal concepts which came out of the interviews, keeping in mind that not all parents had these feelings.

### Some Attitudes Expressed

1. Since the hospital is a place for sickness, the notion of a "Well Child Clinic" is contradictory and confusing as is the notion of an M.D. mentioning "wellness".
2. The physician is sought for curing, in the cultural context of that word, he must do something, give an injection for example, or else he fails.
3. Parents are interested in the cause, not the symptoms but the physicians usually talk to them about the symptoms, part of which includes development and delays.
4. Parents may not keep follow-up appointments at their Service Unit hospital because they don't associate that with what a "specialist" at an off-reservation hospital did.
5. Public health nurses visits are not always welcome. When they occur at an inconvenient time or are thought of as an intrusion, the desired result cannot be expected. The home visit system can be a tactful balancing act; ultimately those families who see it as beneficial, in turn, benefit from it.
6. The medical and educational models of developmental milestones are not commonly accepted. Traditionally, the first laugh is one of the few valued infant milestones. Achievement in childhood may even be thought of as a negative trait. Solid food consumption, weaning, and toilet training are not generally valued at as early an age as among non-Navajo families.
7. Concepts of time as reflected in the Navajo language, do not place aspects of "child development" into a collective category.
8. If a child is not sick then his status is not thought of as requiring medical care.
9. If a child is perceived of as doing well at home, then no problems exist for the family. If an M.D. sees a problem - then it becomes his problem. The same would be true with the school's attitude.
10. There are no Navajo words similar to disability, developmental delay, or handicap. When those concepts are translated or used, they may carry very negative connotations and are definitely associated with breaking taboos.
11. Physical therapy or special education do not seem to demonstrate immediate or short term results and their value is not usually appreciated.

12. If a treatment causes a child discomfort or requires a behavior change then someone else (not a family member) should do it.
13. The notion of a child specialist, a baby doctor, or a pediatric nurse, is exciting to many parents and it might be beneficial to maximize the general knowledge of that specialty within the IHS.
14. Families usually weren't able to identify the childrens' functional disabilities; instead, when asked to describe "the problem" they would identify one of the medical conditions (small baby, heart problem, etc). A few denied that any problems existed.
15. Families were usually unaware of the medical world in general and of the organizational scheme of the Indian Health Service and its interface with private medical care. For example, most seemed to think that a specialist could only exist in the private sector or if they had had an appointment with a specialist they hadn't realized it. Personnel labels confused them and interagency differences were even more bewildering. They often didn't realize that the Indian Health Service was paying for referral care at a private hospital. Consequently, responses to the interview questions were often contradictory.
16. Dissatisfaction with medical services tended to focus ultimately with not alleviating the child of all of his problems and more subtly, of not being satisfied with whatever explanations were provided.

Two More CaseHistories

The following 2 histories demonstrate, among other factors, the failure of the professionals involved with the children to provide developmental support and intervention for children who's outcomes would have been greatly enhanced by such measures.

Case C: Adoptive Family Who Are Trying  
To Cope With A Disabled Child

Summary

This 6 year old boy was the eighth child born to a 36 year old mother who drank sporadically but heavily during her pregnancy. She had sought no prenatal care and arrived at the hospital in labor complicated by extremely high blood pressure. The newborn baby was allegedly abused and neglected by his mother and when 18 months old, the maternal aunt took the baby into her home, however he was still not brought to a clinic for health care until almost 3 years old. During his second year, immunizations were given to him at home by the Community Health Nurse who also urged the adoptive aunt to have his delayed development and crossed, drooping eyes checked at the hospital clinic.

At 3 years of age a developmental evaluation showed J. to be delayed in all areas (approximately a year behind other 3 year olds) with speaking skills at only 50% of normal. At 3½ years an eye doctor asked for permission to surgically correct J's abnormal eyes but the aunt and uncle seemed unable to acknowledge any of J's problems, and would not allow the surgery until he was 5 years old, had entered kindergarten, and more people were urging them to do something.

Biological Family Household

<u>Member</u>	<u>Birth Year</u>
Father	1937
Mother	1940
Daughter	1963
Son	1967
Daughter	1969
Daughter	1971
Daughter	1972
Daughter	1973
Son (died 1975)	1974
Son	1977
Son	1979
Daughter	1981

Adoptive Family Household

<u>Member</u>	<u>Birth Year</u>
Aunt	1934
Uncle	1934
Cousin	1967
Nephew (J)	1976
(Other children grown and away)	

J. has lived with his aunt and uncle for the past 4½ years in a small, 2-room house which has electricity but no running water. The adoptive family has no transportation or employment and lives on monthly welfare payments. Their house is at least 25 miles from any health facility and as needed, they rely on other relatives for rides to the trading post or town. J's biological family lives next door but rarely has contact with this family who has adopted him.

### Child's Status

At 6 years of age in April, 1982, J. had been attending a regular kindergarten class and appeared to be quite delayed but had received no special testing in spite of that. He had made developmental progress since being in school for the previous 9 months, and since having his severely crossed eyes fixed. His head is small and oddly shaped.

### Problems/Comments

No medical diagnostic evaluation of J's total problem was performed until he was 5 years old and his medical record seems to have parts missing. He has not had a psychological, speech, or hearing assessment performed, although it was felt that his eye problems would need to be corrected first in order to do a fair evaluation of all his skills and abilities. At the same time, it appears that no one is taking responsibility for his total needs.

His medical problems have been reasonably well attended to, with the major barriers being the adoptive family's reluctance to have surgery and inability to acknowledge the importance of child health care except in a crisis situation. The adoptive parents still do not consider his developmental delays as a problem and yet they have been interested in noting his progress over the past year, while in kindergarten.

It is highly likely that, although this child has some organic problem such as Fetal Alcohol Syndrome or another complexity of physical and mental anomalies, a part of his developmental delay was due to environmental deprivation from abuse and neglect during his first year and a half.

It also appears to be likely that his adoptive family would have, in time, responded to earlier intervention if a resource were available and a crucial number of professionals had helped them to avail themselves of such a program. The first step in that direction would have been the health care system who had access to the child in his early years. As an example, his recent progress and contacts with many professionals and ancillary people seems to have stimulated his 48 year old stepmother's interest in

and concern for his continued improvement. Now and as he grows older, the negative behavior towards him from his nearby natural family will increase as a psychological problem, and needs to be dealt with.

The family's distance from any resources, lack of employment, and subsequent lack of transportation and motivation have and will continue to bear heavily on J's progress.

Case D: A Troubled Family, Not Able  
to Cope with Children

Summary

N. is a 7½ year old boy who was the ninth child born to a 37 year old mother - a known alcoholic with additional medical problems including toxemia, seizures, and active tuberculosis for which she refused to take medication. Despite a 42 day hospitalization after birth, his mother visited him only once. N. was discharged to an aunt on a cardiac drug with arrangements to have the Community Health nurse visit the home to check on his well-being and medication compliance. At 2 months of age N. was admitted to the hospital with Failure to Thrive; he had been found with his grandmother who had no milk for him and he was dirty and malnourished. His parents had been away from home on a binge for the previous 2 days. His father later came to the hospital and discharged him against medical advice.

The family had a documented background of child neglect, with 3 children allegedly dying of abuse and neglect and a fourth one having committed suicide.

N's medical record indicates that a number of times the physicians suspected that he might have Fetal Alcohol Syndrome and be retarded, but whenever arrangements would be made to have an out-of-town specialist examine him, the family would fail to show up at the clinic. Over the years the community health nurses and social workers attempted to arrange a permanent foster home for N. but the parents would not agree to it. N. and his siblings have stayed at emergency shelters a number of times. At age 6 he started school in a special education class.

Family Household

<u>Member</u>	<u>Birthyear</u>
Father	1934
Mother (sometimes)	1938
4 deceased children	1964, 65, 66, & 67
Son (boarding school)	1969
Son (boarding school)	1970
Daughter (at home)	1972
Son (boarding school)	1973
Son (N.) (boarding school)	1974



The parents live apart frequently and often when the children are home from school it is the father who takes care of them. They have an old dilapidated hogan and rely on relatives and neighbors for transportation. It is 25 miles to the nearest clinic and the boarding school which N. attends is 25 miles from the home in another direction. The father works sporadically as a laborer, usually out of state. At other times he collects unemployment compensation.

### Child's Status

In March, 1982 N. was 7½ years old and was in a special education program at a boarding school but would frequently be absent after visits home. Recent testings done found him to have normal intelligence with, however, significant delay in language and communicative skills and a record of very poor school achievement. This was felt to be a combination of learning disabilities and low personal motivation. N. visits home on weekends and holidays and returns to school telling stories of the horrors of those visits in a detached manner. His father claims to not be aware of his son having any problems.

### Problems/Comments

It seems incomprehensible that legal action was not carried out to intervene in this family's situation some years ago. From the very beginning this child and his siblings have been living in an unacceptable home environment with numerous indicators of abuse and neglect. Five separate times in his medical record it had been recommended that N. be removed from his parents' home, but no effective measures or placement were taken on a permanent basis.

The family's deviant behavior constitutes the biggest problem for this child and the greatest barrier to therapeutic intervention including educational endeavors. The lack of effective means of intervening in the area of abused and neglected children is obvious. The mother's medical record indicates that attempts had been made since 1965 to rehabilitate her, and since those failed, the situation should have been changed from a different direction.

## PART III

## CONCLUSIONS AND RECOMMENDATIONS

Section A: Significance of Developmental Disabilities

In the past twenty years, many of the medical care goals relating to the reduction of morbidity among the Navajo people have been achieved. Vital statistics show dramatic changes in the specific distribution of causes of death. From 1960 to 1980, the percentage of Navajo children's deaths under one year of age has decreased from 40% to 1% of total deaths. The infant mortality rate for 1980 is equal to that of the state of New Mexico and ranks in the lower half among the 50 states. The factors which have contributed to an improved perinatal outcome, reduction in infectious disease, and a steady decline in fertility rates, are not entirely due to the medical care system. Road improvement, sanitation, and education, to name a few, have changed behavior, health levels, and accessibility to health care.

In the field of pediatrics, the majority of health care services have shifted from in-patient to out-patient care, because children's general level of health has improved so dramatically. However, prevention, including screening and early intervention, seems to still be out-weighted by acute and high technology medical care. This is also true in private medical practice.

While this report in no way entailed research on the prevalence of mentally and physically disabling conditions within the Navajo population, the majority of these, by operational definition, (see Appendix I ), begin in early childhood when, due to medical problems or during health promotion activities such as well-baby clinics, the family and young child are accessing health professionals. It is therefore at these early encounters that an infant's and child's developmental progress or delays should be evaluated, and as necessary remediated. If a young child is disabled it is up to the medical professional to manage his total habilitative plan and oversee the development of health related therapeutic resources in the community. The pre-school aged child and the infant have no other professional to turn to, and to wait and pass off the job to the school system at some later time is irresponsible.

## Section B: Professional Societal Concerns

DAHC: Dine Association for Handicapped Citizens  
 DCHD: Dine Center for Human Development  
 DHIS: Division of Health Improvement Services  
 IHS: Indian Health Service

Problems/Issues	Recommendations	Suggested Responsible Persons
<u>I. Health Promotion</u>		
A. Pregnancy is perceived as normal so many mothers do not seek prenatal care at an early point, and do not realize its important goals	1. Self Care and health maintenance concepts should be first learned in childhood-prior to procreation, and later taught in greater detail	Parents Schools; grammar → college IHS Div. of Social Welfare "Tribe" (thru public policy)
B. Most mothers interviewed were not well informed about normal growth and development	1. Parenting skill and knowledge also are first learned in childhood and growth and development should be systematically taught to young people 2. Child development emphasized in health delivery/services	Schools IHS Tribe (thru public policy) DHIS
C. Many mothers took their children to the clinic (or emergency room) only when they were sick, and the clinic personnel's behavior seemed to reinforce this in its disease orientation	1. A good deal of community education regarding health needs to be done, including preventive care and the utilization of health and health-related services (community health nurse, PNP, CHR, well child clinics, educational programs)	IHS Tribe (thru public policy) Tribal Health & Social Welfare

Problems/Issues	Recommendations	Suggested Responsible Persons
	2. The emphasis in pediatrics should be child care and development rather than disease, and the allocation of resources should follow accordingly, including special and separate well-child clinics	a. Overall IHS Area policy b. Local pediatrician in collaboration with community health nursing.
D. Most parents seemed confused about the role and objectives of health workers regarding handicaps or prevention of handicapping conditions	1. Do parent workshops on roles of professionals in preventive and longterm care - focus on what parents should request and expect	DCHD DAHCH IHS
<u>II. Family</u>		
A. Considerable numbers of the disabled children are being cared for or are being reared by relatives other than biological parents, or combinations of people	1. A form of "case manager" for each handicapped or chronically ill child should exist for use within IHS and for working with other agencies	IHS Area-wide Pediatrics policy
B. There appears to be an increased tendency for children in multi-problem families to receive the most fragmented services and/or have the poorest follow-up	1. Same as above plus strengthen the community worker programs (CHN's, social workers) 2. Implement the Navajo Children's Code	Tribe (legal system) DHHS Div. of Social Welfare DCHD IHS

Problems/Issues	Recommendations	Suggested Responsible Persons
<p>C. Most family members were not fully informed or knew the types of resources e.g. hospitals and specialists where their child was referred or treated. Parents also complained they're constantly being subjected to same questions over and over again.</p>	<ol style="list-style-type: none"> <li>1. Develop a mini health book similar to an immunization record which would record key health info - or revamp the one formerly used, specifically for these disabled children.</li> <li>2. Improve the quality (neatness, thoroughness, and readability) of the hospital records.</li> <li>3. Provide time for M.D. to read record before seeing the patient.</li> </ol>	<p>IHS DHIS</p>
<p>D. Most families said they were not aware of other families with disabled children or who had similar problems, so tended to isolate themselves. Some were embarrassed or denying the situation.</p>	<ol style="list-style-type: none"> <li>1. Bring D.D. into the open through <u>Navajo Times</u>, human interest stories and other media. Also in the schools.</li> <li>2. Develop local support system by perhaps doing workshop or having a monthly D.D. clinic with opportunity for families to gather. Develop film, etc. on "successful" family experiences to share with others.</li> </ol>	<p>DCHD DAHC DHIS Div. of Social Welfare IHS</p>
<p>E. Most families tended to relegate medical and educational problems to the providers of these services and did not appear to see themselves as active participants.</p>	<ol style="list-style-type: none"> <li>1. Institute workshops or videotape about "joint partnership" (parent/professional) and role and expectations of parents. Carry this out in the clinic conference room.</li> </ol>	<p>IHS DAHC DCHD</p>

Problems/Issues	Recommendations	Suggested Responsible Persons
F. Many parents were confused by "numerous" explanations of etiology and treatment of their D.D. child - the more confused, the less tendency to follow through on suggested care.	1. Identify a person in the hospital/clinics to "go over" in detail about the condition - Treatment - Prognosis - various options, review resources, etc. Again the case manager approach.	IHS       Area-wide Pediatric policy
G. Many parents had trouble keeping follow-up appointments which in some cases were 6 - 8 scheduled appointments with various health workers per month.	1. Make appointment setting and coordinating less of a burden for the doctor and the parent - hire more clerical support, automate, schedule subspecialties all in one day. 2. Evaluate family's transportation situation and help out as necessary.	IHS       DHIS (CHR's)

Problems/Issues	Recommendations	Suggested Responsible Persons
III. General Societal/ Professional Concerns		
A. Despite the very young median age of the Navajo population, social services seem to emphasize the elderly.	1. The Tribe should emphasize the well-being and future of its youth and young families who comprise the majority of the people.	Tribe Social Program Policy
B. Despite the fact that women and children comprise the majority of the patient population, the services/ resources for them are not allocated accordingly within the health care system.	1. Reallocate resources and services and develop more health related community programs. 2. Develop concrete mission statements which reflect the basic health needs of the population.	IHS DHIS
C. Health and Social Services to aid D.D. families is fragmented.	1. Develop a model interagency program. 2. Promotion of consumer knowledge and advocacy.	DCHD IHS - Maternal and Child Health Tribal Social Service policy

### Section C: Conclusions & Recommendations

1. Health Consumer/Tribe
2. Society/Community
3. Navajo Area IHS policy
4. Physicians

Issue	Recommendations	Who
1. Failure to recognize developmental disability as a problem.	Utilization of: a. This report b. Bogin & Milligan report c. Demographic and epidemiologic statistics	NAIHS Health Consumer/ Tribe Physicians
2. Failure to assume/assign responsibility for addressing d.d. issues.	a. Development of mission statement b. Development of management plan c. One person in each service unit responsible for d.d. issues d. Definition of community oriented role for M.D. and emphasis on prevention	NAIHS Physicians
3. Lack of M.D. awareness and opportunities (look beyond seeing 60 children a day and include role in community program development, updating skill, apportioning time)	a. Information at periodic pediatrics meetings b. Resource booklet for distribution to M.D.'s and others c. Increased interaction between IHS and non IHS staff c. Structured orientation for M.D.'s new to Navajo Area (include role of technology) d. Look for ways to save M.D.'s time and analyze how time now spent	NAIHS Physicians



Issue	Recommendations	Who
4. Failure to understand and support process necessary for early identification, evaluation, management and follow along specific to d.d. (including allied health and need for functional diagnosis)	<ul style="list-style-type: none"> <li>a. Need coordinated system involving M.D.'s, CHN's and others for early ID, and follow up. Must be jointly developed, written with clear responsibilities</li> <li>b. Improved consumer education (prenatal, developmental milestones, well child care, role of IHS and role of family)</li> <li>c. Utilization of developmental diagnosis training for doctors and nurses</li> <li>d. Infant awareness training for mothers, fathers, <u>and</u> grandmothers as appropriate</li> </ul>	<p>Health Consumer/ Tribe</p> <p>Society/ Community</p> <p>NAIHS</p> <p>Physicians</p>
5. Inadequate coordination of services and people	<ul style="list-style-type: none"> <li>a. Better administrative/clerical support for M.D.'s</li> <li>b. Sharing of scarce resources in and with community</li> <li>c. Establish handicapped child case manager system</li> <li>d. Develop more treatment programs (infant stimulation, physical and occupational therapy)</li> <li>e. Enhance information transfer between M.D.'s, hospitals and special programs</li> </ul>	<p>Health Consumer/ Tribe</p> <p>Society/ Community</p> <p>NAIHS</p>
6. Inadequate allied health support	<ul style="list-style-type: none"> <li>a. Better sharing of scarce resources with community</li> <li>b. Use M.D. extenders as much as possible</li> <li>c. More IHS financial support for allied health</li> <li>d. Involve allied health with diagnosis and treatment - "staffing" on each d.d. child</li> </ul>	<p>Society/ Community</p> <p>NAIHS</p> <p>Physicians</p>

Issue	Recommendations	Who
7. Lack of modern hospital technology and management ranging from simple to sophisticated.	<p>With attention to basics first, depending on facility and feasibility, examples:</p> <ul style="list-style-type: none"> <li>a. Automate appointment desk and record retrieval</li> <li>b. Audiometric screening at all clinics</li> <li>c. Poloroid camera for dysmorphology</li> <li>d. Teaching equipment (such as bilingual audiovisual aids)</li> </ul>	NAIHS
8. Inadequate communication and coordination between IHS health delivery personnel, Tribal support services, and the family.	<ul style="list-style-type: none"> <li>a. Make Tribal support services known to consumers</li> <li>b. Promote better use of Navajo consumer advisory councils</li> <li>c. Encourage assertiveness and active participation of health consumer</li> <li>d. Make available simple explanations regarding the IHS delivery system</li> </ul>	<p>Health Consumer/ Tribe</p> <p>Society/ Community</p> <p>NAIHS</p> <p>Physicians</p>

## REFERENCES TO FOOTNOTES IN NARRATIVE SECTION

1. Bogin, Frederick, Milligan, Carol; "Report on a Comprehensive Child Health Program - Including Early Monitoring and Screening For The Navajo Area Indian Health Service: Present Status and Outlook for the Future", Navajo Area Indian Health Service, Window Rock, Arizona, September, 1980.
2. Milligan, Carol, Wilson, Ursula, et al; compiled from a study in progress on contemporary attitudes regarding pregnancy and childbirth; Grant from Division of Nursing Research, U.S. Public Health Service, 1980-1983.

## Appendix I

Developmental Disability

Title V of the Comprehensive Rehabilitation Amendments of 1978 (P.L. 95-602) defines a "developmental disability" as a "severe, chronic disability of a person which;

- a) is attributable to a mental or physical impairment or combination of mental or physical impairments;
- b) is manifested before the person attains age 22;
- c) is likely to continue indefinitely;
- d) results in substantial functional limitations in three or more of the following areas of major life activity:
  - 1) self care,
  - 2) receptive and expressive language,
  - 3) learning,
  - 4) mobility,
  - 5) self-direction,
  - 6) capacity for independent living, and
  - 7) economic sufficiency;
- e) reflects the need for a combination and sequence of special, interdisciplinary, or generic care, treatment or other services which are of life-long or extended duration and are individually planned or coordinated."

## Appendix II

SAMPLE SELECTION and INFORMATION GATHERING METHODS

1. Operational definition of d.d. (Appendix I, P.L. 95-602), born between 1971 and 1979, and having entered the NAIHS system.
2. A minimum of 25 names obtained from community health staff, chronic disease registries, and pediatric referrals in each of the 4 Service Units. (n= 100)
3. A subsample of 24 children drawn from a total list of over 100 - representing a variety of medico-functional problems, a  $2\frac{1}{2}$  - 10 year-old age distribution, not greater than 15% institutionalized, with 6 children from each Service Unit.
  - a. Each medical record reviewed to confirm existence of developmental disability
  - b. Written informed consent obtained in person from 26 parents/guardians
  - c. Family interviews field tested on 3 families and revised
  - d. Record abstraction forms field tested on 10 records and revised
4. Over 100 medical and special education records transcribed on 24 subsample children including all IHS and referral hospitals.
5. Twenty-three parents or guardians interviewed (one family declined)
6. An additional sampling of 50 children drawn from list in #2.
  - a. Medical records abstracted
  - b. 14 eliminated from study - did not meet operational definition
  - c. Final yield = 36 additional cases; 60 total cases
7. Subsample cases analyzed by Project Consultants, on-site in 4 Service Units, following the developmental components listed in Part II of the Narrative.
  - a. abstracted and actual medical records
  - b. review of family interviews
  - c. meetings with local clinicians, therapists, and educators
8. Utilizing same techniques and components as in #6, the additional 36 cases summarized and analyzed by Project staff.

### Appendix III

#### Characteristics of the Study's Sample Children

Some of the factors which contribute to the existence of a child's disability in the first place, and the likelihood of "successful" intervention in the second place are implied in the following pages of selected characteristics and family attitudes. Ideal goals set in providing developmental disabilities services, even if more resources were available, would be difficult to achieve for many of these children without raising the respective families standard of living and subsequent ability to then prioritize finer quality of life issues. How the health care system has interfaced with these demographic characteristics is partially described in the 4 case histories included in the narrative section of the report.

Total SampleMedical-Functional Problem

<u>CHINLE</u>	n=6	<u>FT. DEFIANCE</u>	n=20
#		#	
1 - Chronic Renal Disease with Sensori Motor Delays		6 - Cerebral Palsy	
1 - Mild Delay		3 - Multiple Congenital Anomalies (1 w/ retardation) (2 w/o retardation)	
1 - Psychomotor Retardation		1 - Accident (motor & speech loss)	
1 - Cleft Palate and Developmental Delays		3 - Mild FAS (2 are brothers)	
1 - Mild Cerebral Palsy		4 - Neglect with Developmental Delay (3 are brothers)	
1 - Renal Disease with Painful Rickets		1 - Hypoxia Aspiration, CNS damage	
		1 - Arthrogryposis Multiplex Congenita	
		1 - S/P Meningitis	
<u>GALLUP</u>	n=19	<u>SHIPROCK</u>	n=15
#		#	
2 - Fetal Alcohol Syndrome(FAS)		2 - Down's Syndrome	
1 - FAS with abuse		2 - Juvenile Paget's Disease	
2 - Down's Syndrome		1 - S/P Meningitis	
3 - S/P Meningitis		1 - FAS	
2 - Developmental Delays		1 - DD from FAS or Noonan's Syndrome	
1 - S/P Encephalitis		1 - Mild Retardation with Neglect	
1 - Congenital Deafness		1 - Craniosynostosis	
1 - ? Hypothyroid, ? Retardation		1 - Bilateral Retinoblastoma	
1 - Cerebral Palsy		1 - Myelomeningocele with Gross Motor Delays	
1 - Environmental Deprivation		1 - Esophageal Achalasia with Developmental Delays	
1 - Multiple Congenital Anomalies		1 - Hypothyroid with Delays	
1 - Moderate to Mild Delays		2 - Cerebral Palsy with Retardation	
1 - Neonatal CNS Bleed; Hydrocephalus			
1 - Achondroplasia			

Total # Sample Children = 60

<u>24 Subsample</u>		<u>Ages</u>		<u>36 Others</u>
6	-	2	- 3½	10
7	-	3½	- 5	10
3	-	5½	- 6	2
<u>8</u>	-	6½	- 10	<u>14</u>
24				36

SEX

Female - 12

Male - 12

SEX

Female - 13

Male - 23

PRENATAL CARE

24 Subsample

Yes = 8

No = 14

Unk = 2\*

36 Others

Yes = 16

No = 11

Unk = 9\*

Of the "yes", which Trimester

4 - 1 - 4

4 - 2 - 6

0 - 3 - 6

\* Not recorded in delivery hospital, or only child's current chart reviewed



Index Child's Primary Caretaker (Sixty Cases)

<u>24 Subsample</u>		<u>36 Others</u>
8	Biological Mother & Father <sup>o</sup>	14
1	Mother only	2
1	Father only	1
6	Grandmother*	2
3	Other relatives	4
3	Institution	6
2	Combination of above	5
0	Unknown	1
0	Boarding School	1

<sup>o</sup> May include one step parent

\* In 2 cases child documented as without caretaker most of early years

Siblings Residence Same as Index (Sixty Cases)

<u>24 Subsample<sup>o</sup></u>		<u>36 Others</u>
12	- Yes -	11
7	- No -	13
4	- Combination* -	1
1	- Unk -	9
0	- N/A - (no sibs living)	2

\* Usually with different relatives

<sup>o</sup> Eleven of the 24 subsample children have more than two siblings and of those, seven have more than 4 siblings. Two families have nine surviving children.

## 24 Subsample Cases

Average # of people in family household and general conditions

The number of people living in a household and the living conditions relate to socio-economic factors such as employment and are indicative of a family's ability to care for a child with a disability. In some cases, for example, when there are five or six people per room, the family's primary concern may be day to day subsistence and the notion of infant stimulation or prescribed therapeutic follow-up is superceded by the attempt to meet the basic necessities for the entire household.

CHINLE

1. 10 - 2 rooms, poor
2. 4 - hogan, dirt floor
3. 5 - trailer, small
4. 5 - 2 rooms, poor
5. 5 - did not see home
6. 5 - low rent housing,  
2 bedrooms

GALLUP

1. 6 - small trailer
2. 7 - did not see house
3. 5 - 2 bedrooms, good
4. 7 - 1 room, poor  
condition
5. 6 - 2 bedrooms, good
6. 6 - small house, poor  
condition

FT. DEFIANCE

1. 4 - 1 room, small house
2. 6 - 2 room house
3. 4 - trailer, good condition
4. 10 - low rent housing,  
overcrowded
5. 7 - trailer, good
6. 8 - housing project, good

SHIPROCK

1. 10 - 2 bedrooms, fair  
condition
2. 5 - 2 bedroom trailer
3. 9 - 3 bedrooms, very poor  
condition
4. 7 - 2 rooms, clean
5. 4 - 1 room small house
6. 12 - low rent, 2 bedrooms,  
poor condition

24 Subsample Cases  
Parents' Median Age

At the time of the index child's birth, the median age of the twenty-four mothers was about 30 years old. In the extremes, one woman was below 18 years old (she was eleven) and five women were 36 or older. Because the sample selection was not random to begin with, the maternal age of these 24 subsample cases is not a statistically significant variable. However, when paired with total number of children, economics, and coping skills, the mother's age maybe very significant in terms of therapeutic outcome for the index child.

When not raised by the biological mother, the "surrogate mothers'" ages (six grandmothers, three aunts, and four others) range from young, preteenage sibling to late seventies.

The average ages of the biological fathers correspond with those of the mothers' except in two cases; one where the father is 10 years older than the mother and one where the biological father is at least 30 years older than the mother. In view of the fact that 2 fathers are deceased, 4 are unknown to the family and at least 3 more are estranged from the mothers/families, the father's chronological age seems less important than whether or not he participates in rearing the child.

Subsample  
Education of Parents, Employment, and Transportation

Four of the twenty-four mothers or stepmothers have finished high school, and seven more are known to have had some ninth to tenth grade education. In other words, more than half of the mothers (13) have had less than an eighth grade education.

One father is a college graduate, and four more have finished high school. The number of known employed fathers or step-fathers is ten (42%) which is not dissimilar from the unemployment rates found generally which run between 40 and 60% (Navajo Tribe, Labor Relations Office, 2/82)

In twelve of the twenty-four families there is no wage earner.

Six of the 24 subsample families do not own a car or truck, of these one lives 5 miles from a health facility, two at 15 miles, two at 25 miles and one at 45 miles from a health center.