

Comprehensive Health Services for Developmentally Disabled Navajo Children

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ABSTRACT. A retrospective study of 60 Navajo children with developmental disabilities was conducted to evaluate the quality and comprehensiveness of health services provided. Descriptive analysis by a multidisciplinary panel included medical record reviews, family interviews, and site visits to local health, educational, and family support services. Findings included timely and appropriate management of "medical" problems but a general neglect of "developmental" issues, such as hearing, speech/language, cognitive, and behavioral functioning, and attention to family understanding and adjustment toward caring for a handicapped child. Primary prevention and screening efforts were judged generally adequate, although not utilized by the majority of mothers of disabled children. Diagnostic assessments, family counseling, and referrals for treatment were incomplete, fragmented, and poorly coordinated. These problems resulted in potentially harmful delays in making referrals to available treatment programs. The majority of families interviewed tended to focus on the "medical" problems, had a poor understanding of the "developmental" components, and rarely participated actively in treatment.

INTRODUCTION

A 1980 report on the comprehensiveness of child health services on the Navajo reservation concluded that "programs for screening, evaluation, medical follow-up and remediation of developmental disabilities are perhaps the greatest area of deficiency."¹ The following descriptive study was conducted in 1981 to 1982 in order to investigate the specific concerns cited.

Approximately 150,000 Navajos live on and near the Navajo reservation in northwestern New Mexico, northeastern Arizona, and southern Utah. They constitute the largest Indian tribe and occupy the largest reservation, an area covering 16 million acres, the majority of which is sparsely inhabited, due to the arid high desert conditions. The median age is 18 years.²

The economics of this region are severely depressed. Per capita median income was \$2,000 in 1980.^{3,4} Unemployment is estimated to be 70%.³ The traditional pastoral livelihood has been impossible for the majority

of Navajo people since the 1920s, and the leading employers are now federal and tribal governments.³ However, the reservation is not homogeneous, and socioeconomic determinants of health as well as living conditions vary considerably. Household surveys conducted in the mid-1970s revealed that nearly half of the adults had less than a 4th grade education, while 7% had attended college (May P, Broudy D, et al: Comparative Health Service Evaluation Project. Window Rock, AZ, Navajo Health Authority, 1977). More than 35% of homes are without plumbing, and few have telephones; many lack electricity; 26% of families are maintained by a female householder with no husband present.^{2,5} The majority of Navajos under 40 speak English either as a secondary or primary language; older people speak primarily Navajo.

An active network of traditional healers is utilized by a substantial portion of the population. Traditional Navajos believe that disease or handicap results when the harmony of nature is disrupted because of the transgression of taboos by the patient or his family. Restitution of harmony may occur through the intervention of a medicine man.⁶ Adherence to traditional beliefs varies considerably today. In a 1980 study of Navajo mothers, 74% believed in traditional medicine and witchcraft, 55% did not plan to give their infant a Navajo name, and 41% did not plan a ceremony at birth.⁷ Acceptance of western medicine, primarily to cure or prevent certain physical symptoms, is widespread, although not universal.

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As established by Congress, free medical care is provided to tribally enrolled Indian people by the Indian Health Service, established under the United States Public Health Service in 1955. In addition to providing direct health services through an organized network of primary care clinics and regional secondary care hospitals, Indian Health Service also conducts preventative, environmental, and community health and outreach programs, staffed principally by young non-Indian physicians and nurses, most of whom serve 2-year tours of duty.

Since 1955 there have been major changes in the morbidity and mortality of Navajo children. Infant mortality has declined three-fold to levels now approximating the United States average.^{8-10,13} Inpatient pediatric admissions have decreased markedly over the past 20 years.¹⁰ While acute diarrheal and respiratory illnesses still contribute a substantial portion of the inpatient and outpatient pediatric work load, chronic diseases and handicapping conditions, accidents, injuries, and disorders related to life-style, such as child abuse and neglect, substance abuse, suicide, and homicide, have emerged as a "new pediatric morbidity." Despite barriers imposed by cultural belief systems and geographical distance, utilization of health services is high. Approximately 97% of Navajo mothers deliver their babies in-hospital; 80 to 85% receive prenatal and well child care; and childhood immunization rates are over 90%.⁸

The Navajo Area Indian Health Service (NAIHS) encompasses eight geographically defined "service units," five of which contain primary and secondary care hospitals. While it is not encouraged, patients often visit more than one service unit. Due to extreme geographic distances within the reservation, this study was limited to four of the central and eastern service units, which could be reached by car within 2½ hours from Gallup. These four service units contain 69% of the total population and are representative of the broad array of living conditions. Services for handicapped children in the four service units studied included health services provided by 15 pediatricians, 2 pediatric nurse practitioners, 4 physical therapists, 6 medical social workers, 2 clinical psychologists, 1 orthopedist, 1 audiologist, and 17 community health nurses (registered nurses). Social and educational services are provided by the Bureau of Indian Affairs, the states of Arizona, Utah, and New Mexico, the Navajo Tribe, and churches. Regional boarding schools and institutional care settings are gradually being replaced by local day programs. University-based regional multidisciplinary developmental evaluation centers and the Indian Children's Program conduct outreach clinics on the Navajo reservation, as do consultants in certain medical subspecialties under state Crippled Children's Programs.

Within this geographic area, five preschool intervention programs served a total of 90 children in 1981.¹¹ In addition, the Navajo Headstart Program served 3 thousand children, 3% of whom were handicapped.¹¹

Such programs are staffed by individuals who have had limited training. The availability of consultants in special education, psychology, speech pathology, and occupational/physical therapy is limited. Other special services available to this population include three local residential facilities for the handicapped and special programs for blind and deaf infants and children in state facilities in Arizona and New Mexico several hundred miles from the reservation.

METHODS

Panel of Experts

At the outset of this study, a "panel of experts" was convened by the principal investigator (C.F.) to help design the study, develop evaluation instruments, and later analyze results. The panel consisted of three developmental pediatricians, two of whom had spent 3 years with Indian Health Service (IHS), and a pediatric geneticist, who also serves as director of a university-affiliated facility; a Navajo anthropologist, whose special research interest is handicapped Navajo children; and an educational researcher from a university-affiliated facility, with previous experience in program evaluation on the Navajo reservation.

Selection of Subjects

The sample of children to be studied was selected from lists provided by Community Health Nurses and pediatricians. From the initial lists of approximately 25 children provided by each of four service units, 15 were chosen to assure a broad array of conditions, severity, etiologies, and age range. Time and funding precluded interviewing 60 families; therefore, from each group of 15, six were selected from each service unit, again distributing ages and conditions. Family interviews were conducted on these 24. Thus, the sample was broad but not randomly chosen. Born between 1971 and 1978, all met the federal operational definition for developmental disability.¹² The ages of the children ranged from 2½ to 10 years at review. There were 25 girls and 35 boys; the median age was 6 years. The children's diagnoses are listed in Table 1.

Characteristics of families in the subsample of 24 children included limited education: 4 of the 24 mothers were high school graduates, while 7 completed 10th grade. Thus, over half had less than an 8th grade

TABLE 1. Children's Diagnoses (N = 60)

Cerebral palsy (5 with mental retardation)	10
Down syndrome	4
Fetal alcohol syndrome	7
Congenital hypothyroidism	2
Child abuse or neglect with developmental delays	5
Congenital deafness	1
Posttraumatic neurologic injuries	2
Postinfectious delays (meningitis/encephalitis)	6
Congenital anomalies with developmental delays	14
Mental retardation of unknown etiology	6
Chronic illness (cardiac, renal, GI) with delays	3

education. In 35% of families, there was no father or stepfather present. Forty-two percent of fathers or stepfathers who were present were employed. Twenty-four percent reported no car or truck available to the household.

Evaluation Criteria: Components of Health Care Evaluated

Four principal components of child health care were evaluated relative to developmental disabilities: (1) primary prevention; (2) developmental screening; (3) developmental diagnosis and parent counseling; and (4) referral for treatment.

Data Collection and Analysis

After obtaining written informed consent, the principal investigator and Navajo research assistant summarized the medical records for each child. These included pregnancy and birth records, all clinic visits, hospital admissions, referrals (to IHS and other consultants), public health nurse home visits, social service reports, and other professional communications with schools. Each child had an average of three to four separate medical records and the transcription process took place on site at each facility. Reliability of abstracts was verified by the developmental pediatricians who reviewed selected records.

In the subsample of 24 children, the biological parent(s) or legal guardians were interviewed. Their perceptions and involvement in caring for their child, the medical care provided, and their understanding of their child's condition were recorded. The Navajo anthropologist designed the interview format, with input from the clinicians on the "expert" panel. This was field-tested and administered by a Navajo research assistant in the Navajo language and verified by selected interviews by the panelists on site.

All of the available information was reviewed in detail by each panel member. Using a four point scale, the clinical health services provided were rated in each of the four major component categories of developmental health services for each child. Site visits to health facilities, early intervention programs, public and BIA schools and residential programs were conducted to interview staff and record observations.

RESULTS

Primary Prevention of Developmental Disabilities

Medical record reviews revealed that, in general, appropriate medical services were provided to reduce the risk of developmental disabilities. Such services included prenatal care, perinatal care with appropriate designation of high risk pregnancies, transfers to specialized high risk centers, and screening for metabolic disease. These results are gratifying and are reflected by an impressive fall in maternal and neonatal mortality rates over the past 20 years.⁸⁻¹⁰

While the majority of Navajo mothers were using preventative services, most mothers of sampled chil-

TABLE 2. Prenatal Care Utilization by Families of Subsample of Developmentally Disabled Children Compared with Other Characteristics (n = 24)

	No Prenatal Care (%) ^a	Three or More Antepartum Visits (%) ^b
Child raised by biological parents	38	100
Regular attendance at Well Child Clinics	6	75
Known alcohol abuse by one or both parents	56	0
Wage earner in household	25	100
Actively involved in child's education	13	63

^a n = 16, and 14 of 16 had no prenatal encounters.

^b n = 8 and 7 of 8 had >6 visits.

dren with developmental disabilities did not utilize them. Only 40% of mothers in the study sample had three or more prenatal visits, compared to over 70% for Navajo mothers during 1976.^{7,8} Mothers who did not make use of prenatal care were also unlikely to use well-child care or participate actively in their children's education (Table 2). These differences were not related to distance from health or educational facilities.

Family interviews indicate that mothers not using preventative health services reported certain negative beliefs: "It is bad luck to prepare for a new baby." Nonusers of preventative health care appear to represent a high risk group for having children with developmental disabilities. When children with fetal alcohol syndrome and child abuse and neglect were considered, only 33% of their mothers utilized prenatal care.

Interviews with physicians and public health nurses indicate that while outreach efforts are made to mothers suspected of being pregnant, there is no organized approach to help with the adjustment to pregnancy or to encourage a supportive companion during labor, and no formal programs to facilitate mother-infant bonding.

Developmental Screening

Interviews with health providers indicate that routine developmental screening is recognized as an important component of well-child care and is regularly practiced, using the DDST in most cases. Record reviews indicate that, in general, children with developmental disabilities were detected early by a combination of clinical impressions and the use of screening instruments. However, family interviews suggest a general lack of understanding of what is meant by "child development" and the role of screening for developmental problems in the context of well-child care.

Developmental Diagnosis and Family Counseling

When a child was suspected of having a developmental problem based on clinical impression or screening there was marked variability in the health system's response. Four components were evaluated:

1. Timeliness of developmental diagnosis after developmental problems suspected.
2. Use of appropriate medical and nonmedical consultants to establish medical and functional diagnosis and to determine an appropriate treatment plan.
3. Informing and counseling families concerning their child's developmental problems and necessary treatment.
4. Referral for early intervention services to community agencies.

Analysis of timeliness of developmental diagnosis revealed that approximately one-third of the sample received diagnostic services within 6 months of the first suspicion of disability, one-third between 7 and 12 months, and one-third more than 12 months later (usually upon school entry). Such delays in diagnostic services were not always related to the severity of the condition. While a number of medical and nonmedical consultants were utilized to accomplish a developmental diagnosis, their impressions appeared to be fragmented, occurring at different times and in different places without evidence of coordination or integration of findings. The following case report exemplifies this problem:

L. was born in 1973 with Goldenhar's syndrome which included multiple congenital 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 reconstructive surgery of her mouth, ear, and spine. During her first 2 years of life, she and her mother flew to Phoenix 13 times, yet it was not until she was over 2 years old and not speaking that a developmental problem was suspected. At age 3 years her hearing was first tested and found to be profoundly abnormal. Four additional audiologic exams later and three visits to ENT clinics (which were located at different sites and times from audiology), a diagnosis of profound deafness was confirmed. At age 4½ years, she was first referred to an intervention program, although such services had been available sooner. At 6½, she is cognitively normal, but essentially nonverbal, making use of some signs. Her family denies the severity of hearing loss and does not encourage the use of her hearing aid or sign language at home.

No one professional appeared to take charge of this child's management. While she eventually arrived in an appropriate setting, this occurred only after a 2-year delay, which significantly reduced her chance to develop oral language.

These data suggest that efforts to inform and counsel parents concerning their children's disabilities are ineffective. Analysis of family interviews of the subsample of 24 children revealed an astounding number of families who misunderstood or denied their children's developmental disabilities (15 of 24). Even obvious problems such as a profound hearing loss were denied by many families.

Analysis of individual responses revealed interesting results. Families tended to focus on the medical problems and denied that their children had "special needs."

Some demonstrated anger towards the health care or educational system for not curing their child. Many reported confusion about how the system works. Factors associated with families who appeared to misunderstand or deny their children's problems include: overwhelming family-social problems, poverty, alcoholism, and distrust. A number of families could not relate to "developmental milestones." Some appeared to have the attitude that if a doctor or teacher noted a problem, it was *their* responsibility to fix it. By acknowledging that a problem existed for their child, some families would take this to mean that they were not accepting of their child and so would deny "that problems exist." Some families said that children should not be made to do things that make them uncomfortable (such as wearing a hearing aid or having physical therapy). Of particular interest, there are no Navajo words similar to "disability," "developmental delay," or "handicap." Literal translation carries negative connotations such as "being out of one's mind."

Information on the children's primary caretakers was significant. Forty-five percent of the children were being raised by their parents, 15% were in institutions, and 13% were in stable placements in the care of grandparents or other relatives. Twenty-seven percent were being shuffled between founding homes and relatives.

Referral for Treatment

The panelists' ratings indicated that appropriate referrals for early intervention services were made in only 50% of cases. Visits by the panelists to several local programs indicated that communication between health providers and educational programs was rare. Interviews with health providers revealed that they were frequently not aware of locally available community intervention programs.

How Aware and Skilled Are Health Providers in Caring for Children with Developmental Disabilities?

Interviews of pediatricians and community health nurses revealed a marked variability in previous training and experience in working with handicapped children. Most felt overwhelmed by the clinical demands on their time, although they readily acknowledged that perhaps 50% of their clinical encounters were "unnecessary," involving minor acute illnesses and conditions which parents could be trained to handle on their own or could be handled by paraprofessionals. Most pediatricians interviewed would welcome training in developmental screening, diagnosis, and family counseling if it were made available.

DISCUSSION AND CONCLUSIONS

The major findings in this descriptive study are that health services directed at specific medical problems for this sample of Navajo children with developmental disabilities were both timely and appropriate. However,

the developmental disability, while suspected early, was unlikely to be properly evaluated or the child referred for appropriate and available intervention services.

The current approach to developmental diagnosis is grossly inadequate. When developmental problems are suspected, the current system of referrals is fragmented and lacks an integrated approach. Comprehensive developmental diagnostic teams are available, but have not been widely utilized, and no one seems to be playing the primary role of case coordinator. Families move from specialist to specialist without receiving synthesis of diagnostic findings and recommendations. It is not surprising that families are bewildered, angry, and non-compliant with later treatment recommendations. While cultural factors may play a role in the lack of parental understanding demonstrated, the haphazard diagnostic system gets a family off to a bad start. These findings are not unique to Indian disabled children. Surveys elsewhere attest to a lack of coordinated, comprehensive, and sensitive care for developmentally disabled children.^{14, 15}

Who should assume the role of coordinator? Given the nature of the current system, the pediatrician is one logical choice; however, training gaps must be corrected and workload and priorities restructured. The high rate of turnover of physicians and their non-Indian background suggests that others who are part of the community would make a better choice. Navajo public health nurses, physician assistants, mental health technicians, or social workers could be trained to assume this role. Support must also come from above, as the regional coordination of medical and nonmedical specialist-consultants and modifications in record systems must be addressed. Greater use of itinerant diagnostic teams seems feasible, both to provide diagnostic services and to provide technical assistance to local intervention programs on how to carry out treatment recommendations.

How significant are developmental disabilities anyway? Are they a legitimate concern of health providers? In a developing society with a scarcity of resources and severe underemployment, what priority should be placed on helping those with the least potential to become productive citizens? These questions are difficult to resolve.¹⁶ While severely disabled children constitute a small minority, the Tribe has stated that such children and their families deserve health services, social supportive services, and educational interventions on a par with such services elsewhere.¹⁷

Besides the relatively small number of children with severe disabilities, many more Navajo children with normal potential have milder disabilities and constitute a growing concern. Rates of school failure, language delays, learning disability, and behavior problems, including substance abuse, juvenile delinquency, and adolescent pregnancy and suicide, are major problems of Indian youth.^{8, 19-22} In addition, this study suggests that nonutilizers of preventative health services may constitute a high risk group for disability. Fetal alcohol syndrome and child abuse and neglect have recently

emerged as significant and common causes of developmental disability that are potentially preventable (May P: Fetal Alcohol Research Project, University of New Mexico, personal communication, July 1982).¹⁸

Beyond these suggested modifications of the health care delivery system, what should be done to deal with perceived "cultural barriers" to the active utilization of early intervention services? It is important to recognize the limitations of the present study to adequately separate "systems" from "cultural" barriers when denial, confusion, and nonadherence with recommended treatment were observed. The children studied were not randomly selected; it is probable that multiproblem families may have been overrepresented in cases brought to the researchers' attention by local clinicians.

Certain modifications for counseling Navajo families of disabled children can be offered based on our current observations. The counselor should be familiar with Navajo beliefs and common emotional reactions; aware of local treatment resources; and patient, allowing ample time to gain rapport and understanding. It may be beneficial to include a Navajo nurse or social worker or health aide to interpret during counseling sessions. The first hurdle to be crossed is explaining the concept of "developmental delay," as milestones may not be generally understood, although Navajo parents are sensitive observers of their children's growth and development (Joe J: Disabled Children in Navajo Society, doctoral dissertation, Department of Anthropology, University of California, Berkeley, 1980).²³ The parents will usually recall the predisposing disease (such as asphyxia, trauma, or meningitis) but will need help to understand that their child now has survived the disease but is left with residual deficits.

The difficult issue for Navajo parents at this time is often *why*. This may lead to questions of incompetency on the part of physicians who are unable to cure the child; or it may lead to a search for traditional explanations (Joe J: Disabled Children in Navajo Society, 1980). Despite what they are told by physicians, some Navajos will continue to search for explanations and receive relief only when a medicine man confirms the breaking of a specific taboo and offers a mechanism for restoring harmony. For less traditional Navajos, the medicine man may only accentuate guilt, and peer support may be more appropriate.

Certain disabilities may be more culturally acceptable than others. For example, congenital hip dysplasia occurs with some regularity and may not be seen as abnormally disfiguring, which may lead some families away from surgical treatment.²⁴ Epilepsy may be viewed as the result of incest and lead to shame and social withdrawal.²⁵ Mental retardation may be confused with "being out of one's mind" and rejected (Joe J: Disabled Children in Navajo Society, 1980).

In general, treatment should be presented from the standpoint of how it will help the child fit into the community (Joe J: Disabled Children in Navajo Society, 1980). The counselor should strive to make treatment goals and components explicit. This may involve

visiting an early intervention program or showing pictures of expected surgical results. Particularly when the benefits of treatment are not immediately obvious, it can be anticipated that adherence to such treatments will be more difficult.

Finally, the counselor needs to be familiar with and tolerant of the range and expression of emotional reactions displayed by Navajo families and knowledgeable about local support systems. Some families can be expected to withdraw and react principally with silence; others may express and project anger onto the physician or school who detect the problem but don't offer a cure. In some families, overwhelming social problems of poverty, alcoholism, depression, and social isolation may lower the priority for dealing with the handicapped child. In such families, referral to appropriate social agencies to assist in obtaining adequate housing, for example, may be seen as a more immediate goal than special education (Joe J: *Disabled Children in Navajo Society*, 1980).

In serving Navajo children with disabilities and their families, non-Indian clinicians must confront the inherent frustrations and limitations of their roles. They generally do not offer cures, nor should they attempt to usurp families as knowing what is best for their children. Instead they educate and facilitate family understanding and acceptance in order that Navajo families can obtain and utilize appropriate treatment for their handicapped child. Sometimes the counselor will act primarily as child advocate (and on occasion may even recommend out of home placement or invoke child protective service intervention). More frequently, he or she will advocate for the family and for local community rehabilitation efforts. Such efforts include helping to build community awareness on the cause, consequences, treatment, and prevention of childhood disability. Such participatory efforts should be consistent with current federal policies of self-determination, whereby Indian people are given the assistance to gain control over their own services.

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depicted in Figure 1 and indicate significantly higher scores on the Aggression, Inhibition, Activity Level, and Somatization scales and lower scores on the Sociability scale than the control group.

Study 2. The next step was to determine whether the MCBC could discriminate between subgroups of referred children differing in presumed etiology and presumed severity of behavioral disorder. Children referred to developmental disabilities clinics are suspected of having primary medical, developmental, or handicapping problems. Emotional or behavioral problems, if present, are presumed secondary to or additional to these developmental problems. On the other hand, children referred to psychiatric clinics are suspected of having primary emotional or behavior problems. Thus, it was predicted that children referred to a psychiatric clinic would be rated higher on the MCBC behavioral problem scales than children referred to a developmental disabilities clinic and that both clinic samples would be rated higher than nonreferred controls. Thirty male and 20 female subjects were obtained from the Duke Developmental Evaluation Center (DEC), an outpatient clinic of the Department of Pediatrics, the Community Guidance Clinic (CGC), and outpatient psychiatric clinic of Duke Medical Center, and from children having routine physical examinations at several local pediatric clinics and offices.⁴⁴ The subjects in each of these three samples were individually matched on sex, age, and SES.

The results, depicted in Figure 2, show that children referred to the psychiatric clinic (CGC) were rated significantly higher in problems related to aggression, activity level, and sleep disturbance than were children referred to the developmental disabilities clinic (DEC). Both clinical groups also were related higher in these problem areas than were control children. The children referred to the psychiatric clinic were also rated as

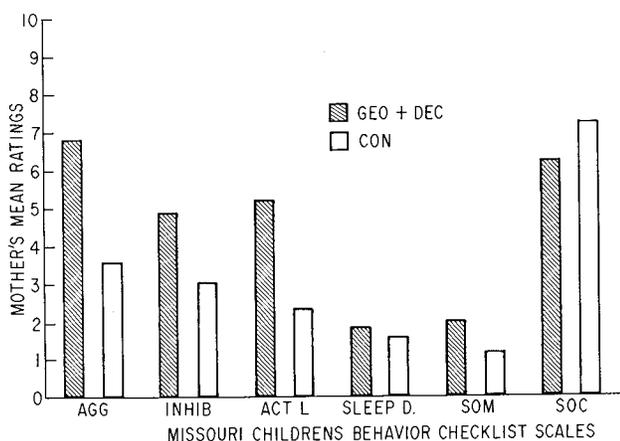


FIGURE 1. Mothers' ratings of developmentally disabled children from the Georgetown University Affiliated Program in Child Development and Duke University Developmental Evaluation Center (GEO + DEC), and control (Con) children on the Missouri Children's Behavior Checklist Scales of Aggression (Agg), Inhibition (Inhib), Activity Level (Act L), Sleep Disturbance (Sleep D), Somatization (Som) and Sociability (Soc).

having significantly more somatic complaints and sex-related problems than the children referred to the Developmental Evaluation Center. The sociability scale did not discriminate between the psychiatric and control group children, but both were rated higher on sociability than the developmentally disabled children. Only the inhibition scale failed to discriminate between the two clinic groups, but both clinic groups were rated as significantly more inhibited than the control group.

Study 3. The findings achieved in these first two studies were based on group differences in raw scores on one or more of the MCBC scales or dimensions. To increase the clinical utility of the MCBC, it was necessary to cease relying solely upon global group differences along single scales or dimensions and to develop a method of pattern identification and analysis based on constellations or profiles of scores across several scales. The next study utilized cluster analysis of the MCBC to differentiate subgroups of children within the developmentally disabled population on the basis of patterns of behavioral problems.⁴⁵ Pattern analysis provides information with respect to the prevalence of broad band syndromes, such as externalizing and internalizing, and narrow band syndromes, such as somatic complaints and sleep disturbance. It also had been unclear whether the previous findings of elevated group means across scales are attributable to generalized mild to moderate levels of behavioral disturbance in most children with developmental disabilities or to a small subgroup with high levels of behavioral disturbance. Finally, pattern analysis based on empirically derived clusters would provide information regarding whether differences between developmentally disabled and other populations are a function of different behavior patterns being demonstrated by different subgroups or are a function of different frequencies of the same behavior patterns.

A total of 257 children 2 to 12 years of age referred to the DEC were split into two subsamples for the first phase of the study. Utilization of cluster analysis resulted in four behavior profiles that replicated across both subsamples. The Aggressive-Active cluster is characterized by high scores on both the Aggression and Activity Level scales. The Inhibited cluster was char-

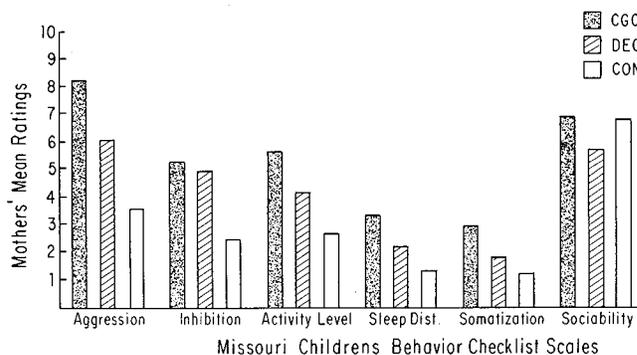


FIGURE 2. Mothers' ratings of children referred to psychiatric (CGC) and developmental disabilities (DEC) clinics and nonreferred controls (CON) on the Missouri Children's Behavior Checklist Scales.

TABLE 1. The 12 Clinical Entities, by Category, Which Were Presented to Residents

Physical	Behavioral	Mixed
Meningitis	School phobia	Failure to thrive
Beta-hemolytic <i>Streptococcus</i> pharyngitis	Childhood psychosis	Down's syndrome
Chronic glomerulonephritis	Conversion reactions	Well-child care
	Suicidal behavior	Enuresis
		Terminal illness

funding by the W. T. Grant Foundation (thus evidencing an interest in developing behavioral programs). The remaining list of 198 schools was then reviewed independently by four individuals familiar with pediatric residency programs, who deleted from the list any schools which they believed had a significant component of training addressed to behavioral and/or developmental issues. From the final list of 166 schools, 15 were selected so as to parallel the distribution of schools within the Funded group, with regard to geographic location and size of the residency program. Of the 15 schools invited to participate in the evaluation study, 13 accepted.

During the first year of the evaluation study, all "comparison" programs were contacted to ensure that they had not introduced mandatory training in behavioral pediatrics subsequent to their inclusion in the study. This survey, however, revealed that seven schools had, in fact, done so. The 13 schools were thus subdivided into two groups. One group of seven schools, while not funded to do so, had instituted either a "block" rotation or continuous training in behavioral pediatrics which was required for all residents; these schools were designated as the *Not Funded* group. In the remaining six schools, such training was either elective or was not formally offered; these schools were designated as the *Control* group.

Instruments

To assess attitudes and knowledge, an Inventory* was administered to residents in all 24 schools, both at the beginning and at the end of the 1980-1981 academic year. Of the 802 residents enrolled in all programs, 569 (71%) completed the Inventory at both test points. The PL-1 residents generally demonstrated a higher response rate than did more senior residents. However, chi-square analyses revealed that there were no significant differences in the response rate among the three school groups for any PL year. The rates were 72, 69, and 71%, respectively, for the Funded, Not Funded, and Control programs.

The Inventory consisted of three sections; the first two sections assessed attitudes, and the third assessed knowledge.

Attitudes. Section 1 was a single rating of "current interest" in behavioral pediatrics, using a five-point scale ranging from 1 ("no interest") to 5 ("extreme interest").

Using a "critical incident" approach, Section 2 as-

sessed attitudes towards 12 clinical "entities" which would be representative of different patient ages and degree of illness/problem severity (see Table 1). These entities were grouped into three categories shown in Table 1 prior to any data analysis. The categorization was performed by six professionals knowledgeable about behavioral pediatrics (the two senior authors and four behavioral pediatricians). Each judge was asked, independently, to place the 12 entities into the appropriate group. "Physical" entities were defined as those which, for diagnosis and/or management, require attention primarily to physical issues. "Mixed" entities were defined as those which, for diagnosis and/or management, require approximately equal attention to behavioral and physical aspects. "Behavioral" entities were defined as those which, for diagnosis and/or management, require attention primarily to behavioral issues. With regard to the judges' categorization, all of the six agreed regarding the appropriate grouping for 11 of the entities, and five of the six agreed with regard to the remaining entity (enuresis).

Section 2 of the Inventory presented residents with each of these clinical entities and asked them to respond to each entity by completing a 5-point rating scale to indicate their current self-perception of, for example, overall competence in diagnosing this entity. The rating scale ranged from "None" (1) to "Extreme" (5). Each resident completed nine ratings for each clinical entity. These included: (1) competence in *diagnosis*; (2) competence in *management*; (3) competence in *referral*; (4) ability to *counsel and advise parents*; (5) knowledge of hospital and community *resources* which could assist with diagnosis and/or management; (6) the *interest of the pediatric faculty* in this clinical entity; (7) the resident's perceived *need to learn more* about this entity; (8) the *future relevance* to their career of the ability to *manage* this entity; and (9) the *future relevance* to their career of the ability to *identify and refer* this entity.

Knowledge. Section 3 of the Inventory consisted of 60 multiple-choice questions designed to assess *knowledge* of behavioral pediatrics. All used the "one best answer" format with five alternatives presented. These questions were selected to incorporate knowledge previously designated as important by the directors of the behavioral training programs and covered three age groups (infancy, school age, and adolescence), as well as general issues (such as interviewing and statistics).

Statistical Analysis

All measures, regarding both attitudes and knowledge, were assessed by analysis of variance to compare

* Available upon request.

difference scores (end of year minus beginning of year performance) to detect significant differences in the amount of change between the three types of programs.† For those measures where the *F* ratio was statistically significant at the 0.05 level or better, Scheffe post-hoc analysis was employed. All results reported as statistically significant achieved the 0.05 level or better, unless otherwise indicated.

RESULTS

Section 1: Interest

Examining ratings of “current interest in behavioral pediatrics” revealed mean scores which ranged from 3.29 to 3.80 at the beginning of the year and 3.21 to 3.71 at the end of the year. These indicated “moderate” to “definite” interest on the part of the residents. PL-1 residents entering the Funded programs displayed the highest mean score (3.80). This suggests a self-selection factor, with residents who are more interested in behavioral issues tending to enroll in programs which emphasize behavioral pediatrics. However, there were no significant differences among the three program groups in the amount of change observed over the year, for any PL year.

Section 2: Attitudes

PL-1 Residents. Section 2 of the Inventory, assessing the residents’ attitudes regarding the clinical entities, revealed only one significant effect related to program type for PL-1 residents. The results of self-rated ability to counsel and advise parents are shown in Table 2. While all residents displayed some improvement during the first year, residents in Funded and Control programs demonstrated significantly greater change over all entity groups than did Not Funded residents. There was also a significant overall effect of entity group, for all programs, with significantly greater improvement found for mixed and for physical entities than for behavioral entities. This suggests that PL-1 residents are largely oriented towards learning related to physical (or more “medical”) issues and may best learn about those behavioral topics which represent a “mixture” of physical and behavioral issues, rather than those which are more “purely” behavioral.

PL-2 Residents. Ratings of PL-2 residents demonstrated significant differences related to program type for five measures. The amount of change found for self-reported competence in management is shown in the top section of Table 3. There was a significant interaction of program type and entity group. The relevant comparisons are shown in the top section of Table 4, presenting a summary of significant findings by type of

TABLE 2. PL-1 Residents’ Ratings of “Ability to Counsel and Advise Parents”: Mean Amount of Change during the Academic Year (End of Year Score Minus Beginning of Year Score), by Program Type and Entity Group

	Funded Programs	Not Funded Programs	Control Programs
Physical entities	0.36	0.32	0.59
Mixed entities	0.46	0.27	0.52
Behavioral entities	0.24	0.06	0.28

TABLE 3. PL-2 Residents’ Ratings of “Competence in Management,” “Ability to Counsel and Advise Parents,” and “Future Relevance—Ability to Manage”: Mean Amount of Change During the Academic Year (End of Year Score Minus Beginning of Year Score), by Program Type and Entity Group

	Funded Programs	Not Funded Programs	Control Programs
Measure: Competence in Management			
Physical entities	0.07	0.28	0.16
Mixed entities	0.22	0.22	0.22
Behavioral entities	0.27	0.20	0.03
Measure: Ability to Counsel and Advise Parents			
Physical entities	0.10	0.29	0.20
Mixed entities	0.20	0.17	0.24
Behavioral entities	0.30	0.33	0.03
Measure: Future Relevance—Ability to Manage			
Physical entities	−0.24	0.04	−0.09
Mixed entities	0.02	−0.16	−0.04
Behavioral entities	−0.09	−0.06	−0.23

entity. The top section of Table 5 presents a summary of significant findings by type of program.

Similar results were found for changes in the PL-2 residents’ reported ability to counsel and advise parents (see the middle section of Table 3). Significant findings are summarized in the middle section of Table 4 by type of entity and in the middle section of Table 5 by type of program.

PL-2 residents’ prediction of the future relevance of their ability to manage these entities generally showed either no change or a decrease over time (see the bottom section of Table 3). This finding of a decline over time in ratings of “future relevance” replicated the results of an earlier study.³ The statistical findings are summarized in the bottom section of Tables 4 and 5.

The pattern of results was thus similar for PL-2 residents for three measures: competence in management, ability to advise parents, and prediction of future relevance. Funded and Not Funded residents demonstrated significantly greater improvement, or less decrease, for behavioral entities than did Control residents. Also, relative to their ratings for physical disorders, Funded residents consistently displayed greater improvement, or less decrease, for both behavioral and mixed disorders. It should be noted, however, that the

† The analysis reported in this paper grouped all residents within the same program type (e.g., all residents in Funded programs were treated as a group). To ensure that these results were not distorted, a second analysis was performed whereby residents were grouped within their own school, and the schools, in turn, were “nested” within a program type. Comparable results were obtained by these two approaches.

TABLE 4. A Summary of Significant Findings for the Amount of Change in PL-2 Residents' Ratings of "Competence in Management," "Ability to Counsel and Advise Parents," and "Future Relevance—Ability to Manage": Results by Type of Entity^a

Measure: Competence in Management	
Physical entities	Not Funded programs greater than Controls; Controls equivalent to Funded
Mixed entities	No significant differences
Behavioral entities	Funded and Not Funded programs equivalent; both greater than Controls
Measure: Ability to Counsel and Advise Parents	
Physical entities	Not Funded programs greater than Controls; Controls were equivalent to Funded
Mixed entities	No significant differences
Behavioral entities	Funded and Not Funded programs equivalent; both greater than Controls
Measure: Future Relevance—Ability to Manage	
Physical entities	Funded equivalent to Controls and Controls equivalent to Not Funded, although Funded decreased more than Not Funded
Mixed entities	Not Funded equivalent to Controls and Controls equivalent to Funded, although Not Funded decreased more than Funded
Behavioral entities	Control programs decreased more than Funded; Funded equivalent to Not Funded programs

^a "Equivalent" indicates that no significant differences were found between groups.

TABLE 5. A Summary of Significant Findings for the Amount of Change in PL-2 Residents' Ratings of "Competence in Management," "Ability to Counsel and Advise Parents," and "Future Relevance—Ability to Manage": Results by Type of Program^a

Measure: Competence in Management	
Funded programs	Behavioral entities equivalent to Mixed, both greater than Physical
Not Funded programs	Physical entities equivalent to Mixed and Mixed equivalent to Behavioral, although Physical greater than Behavior
Control programs	Mixed entities equivalent to Physical, with both greater than Behavioral
Measure: Ability to Counsel and Advise Parents	
Funded programs	Behavioral entities greater than Mixed, Mixed greater than Physical
Not Funded programs	Behavioral entities equivalent to Physical, both greater than Mixed
Control programs	Mixed entities equivalent to Physical, both greater than Behavioral
Measure: Future Relevance—Ability to Manage	
Funded programs	Physical entities decreased more than Behavioral; Behavioral decreased more than Mixed
Not Funded programs	Mixed entities decreased more than Behavioral; Behavioral decreased more than Physical
Control programs	Behavioral entities decreased more than Physical; Physical decreased more than Mixed

^a Equivalent indicates that no significant differences were found between groups.

Funded group showed less improvement (or greater decrease) for physical disorders than did the Not Funded group.

A different pattern of results was found for two other measures for PL-2 residents. With regard to *knowledge of resources*, Not Funded residents improved significantly more than Funded residents, who in turn improved significantly more than Control residents (see

the top section of Table 6). This was the case over all entity groups. Since the absolute ratings of Funded residents were the highest of all three groups at the beginning of the year, these changes resulted in the absolute ratings of Not Funded residents becoming nearly as high as those of Funded residents by the end of the academic year.

Similar effects were found for PL-2 residents' ratings

of *faculty interest* (see the bottom section of Table 6). With regard to behavioral disorders, Not Funded residents demonstrated significantly greater improvement than did Funded residents, whose ratings decreased but who, in turn, decreased marginally less than did Control residents. This yielded absolute ratings by Not Funded residents which were almost as high as those of Funded residents by the end of the academic year.

Results were thus similar for PL-2 residents for two measures: residents' knowledge of resources and their perception of faculty interest. Absolute ratings at the beginning of the year were highest for the Funded group but, by the end of the year, the Funded and Not Funded residents were equivalent, and both had higher ratings than did the Control group, at least with regard to behavioral entities.

PL-3 Residents. Third year residents did not demonstrate any significant effects related to program type for Section 2 of the Inventory.

Section 3: Knowledge

The results of Section 3, assessment of changes in *knowledge* related to behavioral pediatrics, are shown in Table 7. There was a trend in all three residency years for Funded and Not Funded residents to demonstrate greater improvement during the academic year than did Control residents. This effect was significant in the PL-2 year and marginal in the PL-3 year. The resultant end of year performance was consistently superior for the Funded and Not Funded groups, compared to the Control group. This difference was mar-

TABLE 7. Mean Scores (Percent Correct) at the Beginning and End of the Academic Year, and Mean Difference Scores, on Section 3 of the Inventory (Knowledge of Behavioral Pediatrics), by PL Year and Program Type

	Funded Programs	Not Funded Programs	Control Programs
PL-1 residents			
Begin year	59.53	60.15	58.99
End year	63.67	63.90	60.93
Difference score	04.14	03.75	01.93
PL-2 residents			
Begin year	63.23	62.78	62.15
End year	67.55	67.26	62.82
Difference score	04.33	04.48	00.67
PL-3 residents			
Begin year	67.05	66.23	61.07
End year	68.89	70.09	61.15
Difference score	01.84	03.86	00.09

ginal in the PL-1 year and significant in the PL-2 and PL-3 years.

DISCUSSION

Self-reported attitudes, which focused upon specific clinical entities, demonstrated only one effect of program type in the first year and none in the third year. It thus appears that virtually all significant change *related to the type of program* occurred during the PL-2 year. Three measures demonstrated a clear advantage of training: self-reported competence in management, reported ability to advise parents, and prediction of the future relevance of residents' ability to manage behavioral and mixed entities. The fact that Funded and Not Funded residents' ratings of behavioral entities revealed significantly greater improvement, or less decrease, than did those of Control residents presumably reflects the impact of mandatory training in behavioral pediatrics—whether or not such training is externally funded. The more consistent effects of training for both behavioral *and* mixed disorders shown by Funded residents may be a function of a broader focus on a variety of topics made possible by external funding.

A different pattern of results emerged for two other attitudinal measures: knowledge of resources and perceived faculty interest. The fact that Funded residents displayed higher absolute ratings for behavioral entities at the beginning of the year may reflect higher expectations and the impact of training during the PL-1 year. Training in Not Funded programs, however, produced the greatest change over the course of the second residency year, resulting in both "mandatory training" groups being equivalent by the end of the year, and both superior to the Control programs. These data suggest that the presence of required training in behavioral pediatrics, whether externally funded or not, will assist PL-2 residents to locate relevant resources in their environment to assist them with diagnosis and/or management of *all* types of clinical entities. Such mandatory training also appears to enhance the degree to which

TABLE 6. PL-2 Residents' Ratings of "Knowledge of Resources" and "Faculty Interest": Mean Amount of Change During the Academic Year (End of Year Score Minus Beginning of Year Score) and Resultant Mean Scores at the End of the Year, by Program Type and Entity Group

	Funded Programs	Not Funded Programs	Control Programs
Measure: Knowledge of Resources			
Physical entities			
Difference score	0.32	0.59	0.18
End year score	3.91	4.02	3.90
Mixed entities			
Difference score	0.36	0.43	0.29
End year score	3.56	3.46	3.53
Behavioral entities			
Difference score	0.39	0.54	0.14
End year score	3.20	3.17	2.98
Measure: Faculty Interest			
Physical entities			
Difference score	-0.04	0.03	-0.05
End year score	3.82	4.20	3.78
Mixed entities			
Difference score	0.00	-0.03	-0.11
End year score	3.48	3.32	3.36
Behavioral entities			
Difference score	-0.09	0.28	-0.20
End year score	2.78	2.70	2.44

residents perceive the pediatric faculty as being interested in behavioral issues; this effect seems especially pronounced in the Not Funded programs, whose behavioral focus may be less salient than it is in programs whose external funding often enhances the "visibility" of behavioral pediatrics.² Residents in Not Funded programs may thus not become fully aware of the behavioral interests of the faculty until they have had mandatory training in behavioral pediatrics in their second year.

The effects of training shown in the attitudinal measures were paralleled by the results of the knowledge measure, based upon 60 multiple-choice questions. The Funded and the Not Funded residents consistently showed greater, though modest, improvement in their knowledge of behavioral and developmental issues during the academic year than did the Control residents, and this effect was most pronounced in the PL-2 year.

Several limitations of this study should be noted. The attitudinal data are based upon self-report, with no objective corroboration that residents' competence has actually increased. Also, these results represent relatively short-term changes. Ideally, we should assess the impact of training for these residents some years later and determine whether their patients' health has improved as a consequence of the specific training received regarding behavioral pediatrics. Finally, although the effects reported are statistically significant, the absolute magnitudes of change observed are not dramatic. While it is encouraging to find evidence of attitudinal change, and of increased knowledge, it is hoped that residents have been affected more than is shown by these results.

One obstacle to documenting the effects of training is the large variance between programs—even within the same program "group." It seems reasonable to suppose that some of the "mandated training" schools were better able than others to impact upon their residents. For example, a previous evaluation of residency training at the University of Maryland (one of the Funded programs), using a very similar assessment instrument, revealed attitudinal changes which were from three to five times greater than those reported in this paper. The present results represent a composite of *all* schools in a given group.

A second challenge which confronts the program evaluator is the relative homogeneity of pediatric residents. Those of us who teach residents generally view them as a highly varied group, overlooking the fact that they are a highly selected population of intelligent, "test-wise" individuals. As an example, consider the percentile rankings provided by the American Board of Pediatrics for their In Training Exam: in 1981, scores of 67% correct and 55% correct translated to percentile ranks of 56 and 14, respectively. This illustrates the fact that residents whose relative rankings are very different actually score quite similarly when we consider the absolute magnitude of performance. This homogeneity among pediatric residents makes it difficult to demon-

strate striking differences in performance as a function of different training experiences.

While our findings are in the expected direction, the order of magnitude of the changes observed are disappointing. It would certainly be of interest to evaluate other areas of residency education (e.g., cardiology, neonatology, infectious disease) to determine whether our results reflect problems unique to the behavioral area, or whether all areas of pediatric training experience common difficulties in documenting attitudinal and educational change. We would hypothesize that similar problems will be observed across content areas in pediatric education.

Since our findings do not represent dramatic differences in the amount of change in attitudes or knowledge attributable to training in behavioral pediatrics, we are hesitant to make dogmatic statements regarding the most appropriate approach to residency training in this area. Nevertheless, our data strongly suggest that *mandated* training in behavioral pediatrics will produce desired changes in attitudes towards the psychosocial aspects of pediatric care, in residents' perceived competence in this area and in their knowledge base. External funding for such training in a residency program appears to add only a few advantages, such as attracting those residents who are particularly interested in behavioral pediatrics and providing an opportunity to address a greater variety of topics. It should be noted, however, that there are additional advantages of external funding with regard to faculty development and the training of fellows.²

We have argued in a previous paper that the teaching of behavioral pediatrics should begin in the PL-1 year.³ However, data presented in this paper indicate that the second year of residency may be the more critical year with regard to residents' receptivity to behavioral issues. Clearly, those changes in attitudes, perceived competence, and knowledge which were a function of required training were seen predominantly in the PL-2 year.‡ The effects which were observed in the PL-1 year suggest that residents will be more receptive to learning about "mixed" entities, those which require attention to both behavioral and physical aspects, in contrast to those entities which are more "purely" behavioral (see Table 1 for examples).

In summary, the present study represents one approach to assessing the short-term impact of training in behavioral pediatrics. Three conclusions may be drawn from these results. First, these data demonstrate that changes in residents' attitudes and knowledge with regard to behavioral pediatrics are related to the presence of *required* training during the residency years: residents who have had mandatory training show greater change than control residents. Second, programs which are funded to provide such training appear to generate the

‡ We examined the data for a hypothesized "cumulative impact" for those PL-2 residents who had had mandatory training during their PL-1 year as well, and were unable to document such an effect.

most consistent attitudinal effects with regard to *both* behavioral and "mixed" disorders. Third, these results suggest that the impact of behavioral pediatric training is most apparent in the PL-2 year.

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Behavioral and Developmental Pediatrics

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