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Attitudes of mothers of cerebral palsied children toward the habilitative therapies.

Frank Paul Bernarducci
University of Massachusetts Amherst

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ATTITUDES OF MOTHERS OF CEREBRAL PALSYED
CHILDREN TOWARD THE HABILITATIVE THERAPIES

A Dissertation Presented
By
FRANK PAUL BERNARUCCI, JR.

Submitted to the Graduate School of the
University of Massachusetts in partial fulfillment
of the requirements for the degree of
DOCTOR OF EDUCATION
February 1979

Education
DEDICATION

I dedicate this work to my father, who passed away August 14, 1978, three days after which I had successfully passed the oral defense of this work.

Before he was called, I shared with him my joy at the success of that day. For that moment in time I shall be eternally grateful.

He will continue to act as an inspiration to me in his new life as he did in his life on earth. As his presence surrounds me, I shall remember and love him always.
ACKNOWLEDGEMENTS

The writer wishes to express his gratitude to:

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Dr. Nancy Lamb, dissertation committee member, for her suggestions, interest, and encouragement throughout this project.

Dr. Eli Sherman whose friendship and assistance will always be remembered.

The personnel of all Cerebral Palsy agencies who assisted in sharing their case load lists for the purpose of this study.

The mothers of all the cerebral palsied children who demonstrated the interest necessary for completing and returning the questionnaire. Their cooperation was essential and is greatly appreciated.
ABSTRACT

Attitudes of Mothers of Cerebral Palsied Children Toward the Habilitative Therapies

February 1979

Frank Paul Bernarducci, Jr., B.A., University of Connecticut
Ed.M., Springfield College, Ed.D., University of Massachusetts
Directed by: Professor Arthur Eve

An investigation was conducted to study the attitudes of mothers of cerebral palsied children toward Physical, Occupational, and Speech therapy. The study concerned itself with a variety of variables thought to be related to mothers' attitudes toward these treatment modalities.

The investigation addressed questions concerning the following: mothers' age, marital status, religion, number of children in the family, prior knowledge of Cerebral Palsy, mothers' educational level, family finances, severity of child's problem, mothers' relationships with professionals and mothers' relationships with other parents of handicapped children.

A survey instrument was designed by the investigator offering a mother an average of five response sets including a range of valences. Of the 350 questionnaires originally sent to mothers of cerebral palsied persons, 170 comprised the final number of subjects.

Mothers responding were between 18 and 45 years of age and had given birth to at least one cerebral palsied child. All mothers were residents of the Commonwealth of Massachusetts at the time of
the study and represented a fair distribution geographically throughout the State.

It was found that the majority of mothers took a definite interest in their child's therapy program. They were aware of changes contemplated in the treatment program prior to these changes actually taking place. Mothers appeared very involved with professional therapists in making changes and quite active in carrying out treatment programs in the home. These same mothers indicated that Physical Therapy was the modality most needed and most beneficial to their child. However, all therapies were generally considered essential. Mothers indicated that their child was making average to good progress as a result of receiving all therapies.

Though the majority of mothers had not experienced professional counseling, those mothers who had, found the experience to be supportive in nature.

Interaction with mothers of other handicapped children by mothers of cerebral palsied children affected mothers' attitudes toward their child's treatment program in a positive manner.

Most mothers found treatment programs of little burden financially since third parties have taken over the greatest percentage of payment for services at this time.

There appears to be a direct correlation-relationship between mothers' increased involvement with all aspects of their child's treatment program and positive attitudes toward habilitative therapies.
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CHAPTER I
INTRODUCTION

Persons with Cerebral Palsy were for many years recipients of severe penalties invoked by the societies within which they were born. They were treated more often than not as a nuisance, a disgrace, or an object of mirth. Not until the early 1930s were important strides made in public understanding and rehabilitation procedures.

For many years, Cerebral Palsy was known as "Little's Disease." In 1861, Dr. William John Little, a famous English physician, described in the Lancet the spastic diplegic syndrome which he maintained was always associated with mental deficiency. Dr. Little was a brilliant physician and had considerable insight into the implications of Cerebral Palsy. For example, he was able to list many of the causative factors of the affliction. On the other hand, however, Dr. Little's mistake of attaching mental deficiency to every child with Cerebral Palsy undoubtedly impeded progress in the area for many years.

In the two decades spanning 1920 to 1940, a renewed attention focused on the child with Cerebral Palsy. The emphasis was first placed on the orthopedic handicap. This was followed by considerable attention to the "whole child." A large number of studies emerged in the period 1940 to 1945 and evaluated the intelligence as well as the social and emotional aspects of the child with Cerebral Palsy. Only in the last 30 years have studies begun to emerge which have
attempted to evaluate the parents' role in the total rehabilitation program.

Most treatment centers for Cerebral Palsy had their beginning in the mid-1940s culminating in/or as a result of the formation of the National Organization for Cerebral Palsy as well as the American Academy for Cerebral Palsy.

Parents, as members of the rehabilitation team, play an extremely important role in the rehabilitation process. The parents of cerebral palsied persons are no exception to this phenomenon. Cerebral Palsy centers throughout the world have always considered parent counseling as an integral part of the total program. Counseling, however, is oftentimes conducted by therapists themselves. The budget limitations of many small Cerebral Palsy centers present obstacles to hiring the services of professional social workers and/or psychologists to provide this service.

Staff treating cerebral palsied persons have become increasingly aware in recent years that parents are by far the most important members of the team. A question frequently asked by staff members is "How do we get parents to follow through on the recommendations we make to them?" Unfortunately, because of the limited information which now exists pertaining to parents of children with Cerebral Palsy, few answers can be given to such questions.

Too often children who have made good progress while actively participating in their early years in a treatment program cease to
make progress when they reach adolescence. The progress anticipated by professional staff does not occur when cerebral palsied individuals are released from formal treatment programs. Staff oftentimes attributes this lack of progress to parents' overprotecting the child or rejecting the child. Although the presence of a child with Cerebral Palsy in the home may cause the parents to overprotect or reject the child, or to use some other form of defense mechanism, there is insufficient research to indicate that this is always true. Actually, there is no conclusive research available which would indicate that parents of children with Cerebral Palsy differ from parents of non-handicapped children in their attitudes regarding overprotection specifically or their behavior generally. A disciplined approach by parents of handicapped children regarding the therapy programs to be carried out in the home is essential if progress of lasting duration is to be attained.

Part I: Statement of the Problem

The purpose of this study is to measure the attitudes of mothers of cerebral palsied persons toward habilitative therapies. These habilitative therapies are otherwise known as Physical Therapy, Occupational Therapy, and Speech Therapy.

The study attempts to determine just what factors influence the formation of these attitudes. In addition, as a result of the study, recommendations are anticipated, within the thesis, that would have an overall effect on the rehabilitation process, specifically
the areas of Education and Counseling for parents of cerebral palsied persons.

This study will attempt to answer the following questions:

1. Do the number of children in a family, the mother's age, marital status, and religion affect maternal attitudes toward therapy?

2. Does the mother's level of education and her knowledge of Cerebral Palsy affect her attitudes toward therapy?

3. Do family finances affect maternal attitudes toward therapy?

4. Do the medical diagnosis of the child and severity of disability affect maternal attitudes toward therapy?

5. Do the geographical area in which the family lives and the availability of treatment services affect maternal attitudes toward therapy?

6. Do the mother's relationships with physicians, therapists, and social service professionals affect her attitudes toward treatment?

7. Does the child's formal treatment program affect the formulation of maternal attitudes toward the habilitative therapies?

The seven subject categories stated above are delimited and defined in a 57 item structured questionnaire designed for measuring and correlating the degree of relationship among these specific items.

It is important to understand the limitations of the study when evaluating the results of the research. Cerebral Palsy, by definition, is multi-handicapping in nature and defies a homogeneous grouping of children or their mothers. Thus, it can be observed that mothers of mildly involved cerebral palsied children may, in fact, have different attitudes from mothers of severely involved cerebral
palsied children. The study does make provisions for pointing out the relationship of differing attitudes among these two groups of mothers. However, there does exist the potential for a vast difference in attitudes because of the lack of homogeneity in the groups tested.

The method of data collection, the mailed questionnaire, offers additional limitations to the study. Respondents may not be a representative group of the population in the sense that mothers with genuine concern for their child's welfare and positive attitudes toward treatment may be the only subjects completing and returning the survey form. The position that mothers who return the survey are "not representative" of the group to whom the surveys were sent is an important consideration and limitation when evaluating the results of the study. A second possible limitation is that the respondent answers questions without the assistance of the investigator. Questions could be misinterpreted under these circumstances.

The mailed questionnaire, however, offers itself as a more pragmatic approach to surveying a population of people residing in a widely scattered geographical area. Locating these people by mail seemed far more feasible than by other methods. This approach allows the investigator the ability to test a much larger population over a greater geographical area than could the personal interview.

In any follow-up study it must be noted that persons once interested in a particular activity either may no longer be interested or are unable to respond at the time the survey was sent. Some mothers may have moved, died, or, for any other number of reasons,
are impossible to locate.

The investigator acknowledges the limitations of the question-naire approach realizing that it would not allow for as complete a study as that which might have been realized through personal interviews.

It is believed by the investigator, however, that there is merit in assembling systematic, descriptive information about the attitudes of a large cross-section of mothers of cerebral palsied children ages birth through 21. Additionally, it is anticipated that results generated within the thesis will be useful in determining the existing and future needs of mothers of cerebral palsied children and their families respectively.

Additional limitations to the study are more appropriately described later on in the Methodology Chapter under the data processing and analysis category.

Part II: Justification of Need for the Study

There is presently a paucity of literature available in the subject area of physically handicapped brain damaged children. A review of the research completed, however, leads us to believe that there have been many studies conducted in the Cerebral Palsy subject category.

The American Academy for Cerebral Palsy and the National United Cerebral Palsy Organization are responsible for encouraging much of the research conducted in the past 30 years relative to Cerebral Palsy
(physically handicapped brain damaged). Generally, these studies have centered on medical theory and psychological perceptions of parents of cerebral palsied persons. There is not, however, a reservoir of material available on Maternal Attitudes as they relate to Cerebral Palsy. Much information has been gained. Most of the information identified, however, is pertinent to the personality characteristics of mothers of severely handicapped children and not attitudes toward therapy. In addition, one can deduce from the studies that have been performed a series of factors relating projected behavior of cerebral palsied children and their mothers' attitudes toward them. Although the results of the literature revealed some interesting parallels, little was found to be significant.

In summary, the study uncovered a large amount of data available on mother-child relationships as they relate to Cerebral Palsy but nothing appeared to address the maternal feeling toward the effectiveness of therapy and the treatment process specifically.

Limitations in the studies referred to in the review of the literature deal with subjects usually frequenting one treatment facility. In addition, many of the studies seldom deal with samples greater than 100 people. Because there is little data available that specifically relates to the tightly structured title 'Attitudes of Mothers of Cerebral Palsied Children Toward Habilitative Therapies' and the small study groups, the investigator feels an even greater commitment to the research.

The results of the research effort should provide data greatly
sought after by family social workers and professional staff in general. A better understanding of those factors which tend to shape maternal attitudes can only enhance the rehabilitation process as investigators work to understand, educate, and counsel that exceptional parent, the mother of a cerebral palsied child.
CHAPTER II

REVIEW OF THE LITERATURE

This chapter is divided into three major sections. The first part consists of general background information on the subject of Cerebral Palsy, the nature of the disabilities of persons with this condition, and the various methods of habilitation. The second section reviews a series of studies conducted throughout the years designed to prove or disprove the medical effectiveness of therapies for the defined population. The final section contains the results of related studies completed in the defined subject area that have a significant bearing on the way in which the research instrumentation design is developed.

The investigator feels that the study's ultimate findings relative to attitudes would be far more significant if a measure of the medical effectiveness of therapy could be demonstrated. For instance, the results of a survey of maternal attitudes toward habilitative therapies would be more significant if it were known that the medical effectiveness of therapy was minimal.

Part I: Background Literature

Definition and description. Cerebral Palsy, although a specific diagnosis in one sense, represents essentially a complete paradox to its definition. The diagnosis of Cerebral Palsy, in fact, describes
a multi-handicapping condition that can be defined in the following way. Cerebral Palsy comprises those motor and other symptom complexes caused by a non-progressive brain lesion or lesions. This particular definition is accepted by the American Academy for Cerebral Palsy and was found in W. L. Minear's *A Classification of Cerebral Palsy* (1956). Cruickshank (1976) pointed to the inadequacies of definitions that involve only neuromotor dysfunction:

1. Cerebral Palsy is more than merely a "motor problem," and 2. Cerebral Palsy, etiologically speaking, is not limited to birth trauma alone. Thus, the practical definition...warrants serious consideration. From such a point of view Cerebral Palsy is seen as one component of a broader brain-damage syndrome comprised of neuromotor dysfunction, psychological dysfunction, convulsions, and behavior disorders of organic origin. In some cerebral palsied individuals only a single factor may appear; other individuals may be characterized by a combination of the factors mentioned [p. 225].

Mental Retardation, a condition found in a great many cerebral palsied individuals, falls by Cruickshank's definition into the more broadly based psychological dysfunction sub-category. There is extensive literature discussing the confusion that exists in defining Cerebral Palsy. It can be said, however, that Cerebral Palsy is probably that diagnosis that best describes all the manifestations of physical and mental dysfunction that a physically handicapped brain damaged child might display.

As so defined, Cerebral Palsy technically may be applied to individuals with brain lesions which do not occur until adolescence, adulthood, or even old age. However, the neurological lesions that occur during the period of development of the brain in utero and the
early years of life are in many ways different in effect from those that occur later. In this presentation, the term Cerebral Palsy is limited to conditions resulting from damage to the growing or developing brain as so defined by Thaman (1974).

It might be noted that a relationship exists between Cerebral Palsy and the relatively new term Developmental Disabilities. This latter term has come into common usage since 1970. The term Developmental Disabilities describes a total group of disabilities generally associated with the neurological system. The term includes Mental Retardation and numerous neurological problems such as Epilepsy, Cerebral Palsy, Aphasia, and similar clinical entities. The word developmental appears to connote long term if not life-span problems and serves to call attention to the fact that the issue must be faced at all developmental stages in the human. It is just as much a problem of old age and maturity as it is one of infancy and childhood.

Birch (1964), in his book entitled Brain Damage in Children, makes the observation that there is "...not a minimally brain damaged child but rather many varieties of brain damaged children [p. 127]." All brain damaged children are not necessarily physically handicapped nor are all physically handicapped children necessarily brain damaged. The combination of terms, physically handicapped brain damaged does, however, somewhat limit the possibility of diagnoses. Most studies and texts indicate that the physically handicapped brain damaged child usually demonstrates disorders other than that of the physical handicap.
alone. For instance, learning disorders, perceptual problems, and auditory memory dysfunction are among some of the unlimited combinations of dysfunction that a physically handicapped brain damaged child may demonstrate.

**Classification of Cerebral Palsy.** Cerebral Palsy is commonly classified according to syndrome, in terms of both the physiological characteristics of the neuromuscular involvement and the location of the involvement. In recent years, the most prevalent system of classification has been that of Phelps (1952) which suggests that the physiological characteristics of the major types are: flaccid paralysis, spasticity, rigidity, tremor, athetosis, and ataxia. Crothers and Paine (1959) have preferred instead to classify cases into two large groups: spastic cases, and extrapyramidal cerebral palsies, which include the majority of the other types. They recognized that mixed types of Cerebral Palsy are not uncommon. For example, tremor is sometimes associated with ataxia, and occasionally ataxia is found with spasticity or athetosis.

The location of the involvement is described by the suffix "plegia." "Monoplegia" describes the involvement of only one limb. "Paraplegia" refers to the involvement of both lower limbs. "Hemiplegia" involves one side of the body, both the arm and the leg. "Triplegia" is the term covering damage that affects three extremities leaving the fourth unimpaired. "Quadriplegia" is the involvement of all four limbs. A study of the incidence of patterns of physical
involvement is contained in the work of Hopkins, Bice, and Colton (1954). According to their findings, hemiplegia is generally associated with spasticity. Quadriplegia is more commonly associated with athetosis. Triplegia, which is less common, is associated with spasticity, as is paraplegia. Monoplegia, a rare condition, is found about equally in cases of spasticity and athetosis.

Asher and Schonell (1950), examining 400 cases in England, found the proportion of spastics to athetoids about 8:1. According to Hopkins, Bice, and Colton (1954), the spastic to athetoid ratio is closer to 2:1. O'Reilly (1971) has offered data based on 1,513 patients seen at Saint Louis University which indicates that spastics accounted for almost 60 percent and athetoids for about 14 percent of a general cerebral palsy population. Whatever may account for the marked differences in figures, all are in agreement that these two types comprise the overwhelming majority of the cerebral palsied.

Several different classifications have been proposed by a variety of authors. The following classification, which describes the functional capacity of the patient was published by Minear (1956), who was, at that time, Chairman of the Nomenclature and Classification Committee for the American Academy for Cerebral Palsy. It has been chosen for description in this study since it assists the reader in conceptualizing four basic functional levels of physical activity as opposed to a more medical description.
Class I. Patients with Cerebral Palsy with no practical limitations of activity.

Class II. Patients with Cerebral Palsy with slight to moderate limitation of activity.

Class III. Patients with Cerebral Palsy with moderate to great limitation of activity.

Class IV. Patients with Cerebral Palsy unable to carry on any useful physical activity.

Associated disabilities. Although Cerebral Palsy is defined as a motor disturbance, a further consideration is that other types of disabilities almost inevitably arise from the underlying lesion. Robinson (1973) in reporting on 296 neurologically-handicapped children confirmed the common clinical impression of a high prevalence of multiple handicaps in children with Cerebral Palsy. Love (1970) in his study of a group of children medically diagnosed as handicapped, found cerebral palsied children to suffer significantly more mental retardation, speech disabilities, and secondary problems in general than children with other types of physical handicaps.

Cruickshank and Raus (1955) estimated the following proportion of cerebral palsied children having associated impairments:

- Speech defect: 50--75%
- Mental retardation: About 50%
- Visual defect: About 50%
- Convulsions: About 35%
- Hearing impairment: About 25%

Wishik (1954) found that the person with Cerebral Palsy may have any of the above handicaps in addition to his primary neuromuscular disability and frequently has more than one of them.
Etiology. The causes of Cerebral Palsy are many and varied. They are usually classified as prenatal, natal, or postnatal. The prenatal causes, which are either genetic or congenital in nature, include metabolic anomalies, incompatibilities of blood types, developmental defects in the basal nuclei and its tracts, defects in the cerebellum and its tracts, cerebral hemorrhage, infection, and anoxia. Common natal factors are anoxia, vascular damage, and trauma due to complications of labor or delivery. In the postnatal period, any factor affecting the brain, such as: trauma, infection, poisonings or anoxia may cause Cerebral Palsy. Denhoff and Robinault (1960) suggested that combinations of causes are not uncommon. They also estimated that in about 25% of the cases diagnosed as Cerebral Palsy the cause is undetermined.

According to Perlstein (1952), there seems to be some relationship between a few of the etiological factors and certain neurological sequelae. He observed that athetoids frequently have a history of anoxia, RH incompatibility, or breech delivery. Spasticity, on the other hand, seems to have a higher-than-chance relationship to a history of prematurity; toxemia of pregnancy; maternal rubella; precipitate, cesarean, breech delivery; or birth trauma. Rigidity often seems to follow anoxia or precipitate cesarean delivery.

Incidence and prevalence. Completely accurate reports regarding the incidence of Cerebral Palsy in the total population are not available. There are several obvious reasons for this. Many children are
incorrectly diagnosed as having Cerebral Palsy while other true cases of Cerebral Palsy are never diagnosed as such. The widely quoted and generally accepted figures of Phelps (1948) indicate an incidence rate of 4 per 1,000 births. This rate is only two-thirds of the 5.9 per 1,000 births obtained in the Schenectady County, New York survey (1949) although it is within the limits of sampling error for the two rates.

The Schenectady figures are likewise higher than those found in England. In 1950, Asher and Schonell carried out a survey of the prevalence of Cerebral Palsy in four British cities and surrounding counties. The total prevalence of Cerebral Palsy among 5 to 15 year old school children was reported to be approximately 1 per 1,000. This figure is one-fourth of that obtained from cases known to the Schenectady County agencies.

A pioneering study of Schlesinger and his associates (1959) indicated that the mortality rate for persons with Cerebral Palsy was substantially higher than that of the general population. The report was concerned with survivorship status after a period of 7½ years of 3,108 individuals with Cerebral Palsy who were under 18 years of age at the time of the initial study. The death rate of 9.6 per 1,000 person-years for males was 13 times the expected rate whereas the female death rate was 8.5 per 1,000 person-years, 17 times the expected rate. The group with severe physical limitations had a mortality rate 27 to 30 times that expected in corresponding age-sex groups of the general population. Those with mild physical
involvement had a mortality rate 4 to 5 times greater than expected.

**Therapeutic management.** For many years, largely as a result of studies conducted by Little (1861), the treatment of Cerebral Palsy was entrusted to the orthopedic surgeon almost to the exclusion of other modalities of treatment. Today it is recognized that orthopedic surgery represents merely one facet in the comprehensive treatment of Cerebral Palsy.

A review of both old and new treatment modalities indicates that the diversity of the problems involved with Cerebral Palsy is so complex that treatment involves many specialists, medical and otherwise. According to Denhoff and Robinault (1960), a most important trend in treatment is the professional team comprising professionals from a variety of disciplines working together to fulfill the physical, mental, emotional, and social needs of the cerebral palsied child. The physician appraises physical fitness and limitations. The psychologist evaluates intellectual functioning, possibilities of disturbances in visual form perception, and emotional maturity. The physical therapist appraises the child's manner of ambulation. The occupational therapist is concerned with the patient's use of his arms and hands and evaluates the degree of independence in self-care the child has achieved. The speech pathologist is interested in the speech and hearing of the child and any need for training. The social worker is interested in alleviating family stress and facilitating the family's acceptance of the child's
disability. Denhoff and Robinault determined that the treatment program is based upon the sum total of the findings and impressions of the entire team staff.

The value of orthopedic surgery to correct contractures and deformities has gained wide acceptance over the years though there are differences of opinion as to the age when surgery should be done and what procedures should be used. Many methods can be used, but primarily they comprise cutting of muscle, transference of muscle tendons, and releasing muscles to function more efficiently (Denhoff and Robinault, 1960).

Although there have been numerous methods of treatment proposed for treating cerebral palsied children, Phelps (1952) states that the basic principle of treatment, irrespective of the method used, is the physical education of the motor apparatus of the body to carry out those activities which come to the normal child through the normal learning process. Therefore, Physical Therapy is of fundamental importance in the treatment of Cerebral Palsy.

Various mechanical aids for facilitating sitting, standing, walking, and functional use of the hands are also useful. Braces are used to maintain correction after surgery, to prevent and correct deformities, and to support an essentially weak structure. The use of braces as a modality of treatment has been the subject of much controversy. Some physicians regard bracing as a most valuable adjunct in the treatment program while others feel it is contraindicated with cerebral palsy patients (McDonald and Chance, 1964).
Drug therapy, also controversial, is used in the treatment of Cerebral Palsy for controlling convulsions, promoting muscle relaxation, and alleviating disturbing behavior. No single drug is satisfactory in relieving all of the major manifestations of Cerebral Palsy. Certain drugs have been employed with considerable success in decreasing both the severity and the frequency of seizures. Drugs for behavior control and neuromuscular relaxation have also been used in recent years though at present they must be considered of limited value (Denhoff and Robinault, 1960).

A growing number of specialists involved with the treatment of Cerebral Palsy are putting increased emphasis on the importance of personality and emotional development. As an example, Denhoff and Associates (1951) commented that the recognition and treatment of emotional difficulties due to psychogenic factors should be considered as important as the correction of the motor impairment. Cooper (1954) has stated his conviction that emotional factors are more important than physical factors in the patient's rehabilitation.

Neurosurgery as a treatment modality has been used in certain selected cases to control intractable seizures or to control involuntary movements. Penfield and Jasper (1954) reported success in alleviating seizures and hemiplegia by removal of a damaged portion of the cortex. Dr. Engels at Mt. Sinai Hospital in Miami, Florida as recently as 1977 has indicated success regarding the implantation of a pacemaker in the brain to control involuntary movement. Neurosurgery for the control of involuntary movements is comparatively
new. The difficulty of conducting valid follow-up studies to these surgical procedures raises a number of major questions and controversy regarding this mode of treatment.

As recently as 11 years ago, Bax and MacKeith (1967) reported that no scientific evidence, in the sense of studies with controls, proved that any one method of treatment of Cerebral Palsy precipitated better results than any other. Crothers and Paine (1959) have indicated that a method is desperately needed by which long-term progress can be reported so that there will be some ground for comparison of different methods.

No attempt can be made here to cover all of the theories of treatment of the cerebral palsied. Wolf (1969) included summaries of the more well-known systems reprinted from the literature:

Kabat and Knott System: Kabat and Knott theorized that normal actions are produced by synergistic contractions of a group of muscles rather than by single joint movements. Treatment techniques should attempt to increase the excitation in the central nervous system by applying strong resistance to mass movement patterns.

Temple Fay System: Dr. Temple Fay's method of treating cerebral palsied children is based on eliciting primitive movement patterns. Therapy attempts to organize and co-ordinate lower level reflex activities with the undamaged portions of higher cortical centers. In this way, the basic automatic reflexes are elicited (in the order of their phylogenetic appearance) to develop muscles, to relax antagonists, and to produce better co-ordination of muscle tone.

The Rood System: Margaret Rood notes that a child must have developed the lower level reflexes before he/she can develop higher level voluntary control. In the cerebral palsied child, motor
patterns do not appear in their proper sequence because the sensory motor pathways are not intact. Rood’s philosophy indicates that techniques for treating neuromuscular dysfunction are based on activation, facilitation, and inhibition of muscle action through stimulation of sensory receptors.

The Phelps System: Dr. Phelps’ systematic program for the treatment of children with Cerebral Palsy stresses the treatment of individual muscles. The therapist must learn to identify both the disordered muscles and those muscles which are functioning normally. After the muscle examination has determined the condition of important muscles, the child is enrolled in a treatment program consisting of several modalities. These modalities are divided into various types of motion, i.e., massage, passive motion, active assisted motion, active motion, resisted motion, and conditioned motion.

Bobath System: The Bobaths note that there are four levels of integration of motor function: a spinal level, a brain stem level, a midbrain level, and a cortical level. In using the Bobath approach to treatment, it is essential that physical, speech, and occupational therapists work closely together. Each must be trained to recognize the reflex patterns which are integrated at the various levels of the Central Nervous System. Each must know the normal sequences of reflex development and know how to inhibit persistent tonic reflexes through the proper positioning of the child. By positioning the child properly, it is hypothesized that righting and equilibrium reactions can be facilitated. Proper positioning of the child makes it possible to create a different pattern of sensory inflow to the Central Nervous System.

Whatever system is employed in the treatment of the cerebral palsied patient, the treatment goal is to help the individual function optimally within the limits of the basic disability. While it may be impossible to cure the patient, it is important to help him/her achieve maximum potential—physically, psychologically, and
socially. Thus, therapeutic management requires the skills and expertise of a variety of disciplines and recognizes the importance of parental understanding of the child's disability and their ability to cope with it. These concepts are well expressed by Crothers and Paine (1959) and are strongly supported by the literature under discussion in this section.

Part II: Related Literature

In a presentation of the medical results of treatment and the effectiveness of therapy of the cerebral palsied, it was found that after 30 years of intensive treatment of Cerebral Palsy, only 11 major studies have been published. The 11 studies were conducted with various scales designed and developed by their investigators. The common factor in all, however, is the attempt to measure the effectiveness of treatment. This study does not dwell at length on all the 11 studies conducted. It is intended, however, to make a determination based on the findings of prior studies whether or not habilitative therapies are medically effective toward habilitation. This determination, although not a basic purpose of this thesis, is thought to be necessary if professionals are to properly address maternal attitudes toward treatment in the future.

From the results of this study, it could be determined that attitudes of mothers should or should not be changed based on medical findings pertinent to the results of treatment.

There is a growing concern about the variety and effectiveness
of systems of treatment. Controlled studies have not been completed. It has become apparent that there is great difficulty in accomplishing such studies due to the nature of Cerebral Palsy and the complicated problems of research design. Several studies have been published that report the results of a particular method. The results of treatment also show conflicting findings as to whether or not spastics (stiff movement) or athetoids (involuntary movement) respond better to therapy and whether or not intelligence is related to progress in treatment. Studies reporting more encouraging results indicate a need for early treatment and a central (holistic) approach to the habilitation of the patient.

Phelps (1958) used a series of skill charts, testing muscles and classifying them according to four groupings. Progress in treatment was assessed in accordance with improvement of individual muscle function.

Deaver (1956) utilized the Activities of Daily Living Test which attempted to evaluate the patient's skill in performing functional activities such as: rolling to the right side in bed, brushing teeth, and the ability to dress oneself. Hand activities were also measured and recorded on charts.

Crosland (1951) proposed skill tests similar to those designed by Phelps for assessing progress made by a child undergoing treatment for the physical defects associated with Cerebral Palsy. The first part includes tasks concerning the functional ability of the lower limbs for the purpose of measuring Physical Therapy; the
second part is designed for Occupational Therapy and comprises tasks related to the function of the upper extremities and neck. The weaknesses in the test report are that:

1. A child may be able to perform the necessary movements but the quality of the movement may not be good.

2. There is no way to record this qualitative difference in performance.

3. No age ranges are provided for the various tasks to be performed.

Johnson, Zuck, and Wingate (1951) published a Motor Age Test, resulting in a numerical score, and designed to cover the span of neuromuscular motor action from 4 months to 6 years. This test was developed because prior to 1951 an objective test of motor ability lending itself to statistical analysis was unavailable.

Drs. Karel and Berta Bobath (1952) contributed an important document to the literature on the assessment of motor handicaps with Cerebral Palsy and added a new dimension in measurement—the quality of the simple basic movements which underlie all skills. Until 1958, assessment instruments did not consider the quality of the performance but were aimed more at skills and measurement of age level of performance, speed, and number of mistakes. The Bobath Test Chart of Motor Ability assesses the quality of movement and measures the patient's ability to either control or move away from his abnormal postures in eight major positions based on normal developmental sequence.

Paine (1960) re-examined a large number of patients with
Cerebral Palsy known to Children's Hospital of Boston between 1930 and 1950. Of those re-examined, a report was made on 177 patients who had either received well-documented intensive treatment or no treatment at all. This study was unique in that it compared a totally untreated group with a group treated by various methods. The findings were divided into six areas based on the type of palsy and extent of paralysis. Essentially, the conclusions were that there are no significant differences in motor ability between those children who received treatment and those who did not.

The benefits of treatment of Cerebral Palsy are extremely difficult to measure because of the many variables involved. Several attempts have been made to devise assessment instruments for this formidable purpose. The basis for construction of these assessment schemes falls into four broad categories:

1. Those that measure skills of daily living
2. Those that are based on Gesell's Developmental schedules and convert findings into a motor score or equivalent quotient
3. Those that attempt to measure the underlying neurological deficits, and
4. Those that represent some combination of the three.

There is little agreement on a number of suggestions that have been proposed concerning the criteria that must be satisfied in the assessment program.

Discussion up to this point has related primarily to the effectiveness of treatment in the areas of Physical Therapy and
Occupational Therapy. Two additional fields, Speech Pathology and Auditory Processing, deserve attention. Tape recordings with playback to a selected audience of listeners appears to be the most favored technique for the clinical assessment of speech intelligibility. Dr. Milani-Comparetti (1964) stressed that the primary consideration was the child's ability to use speech in a functional manner not his accurate articulation of isolated phonemes.

Nober (1976) reported in the area of Auditory Processing, specifically, peripheral auditory impairments. He found that most typical cerebral palsied hearing problems fall into the category of Sensory-Neural Impairments. Mixed Hearing Impairments, signifying a combination of conductive and sensory-neural pathology, are also commonly seen in cerebral palsied children. Conductive impairment, according to Nober, is the only peripheral disorder occurring in cerebral palsied persons with the same frequency as it would in any other person. Nober summarized the effectiveness of the Auditory Rehabilitation process by pointing out that there are many facets to the auditory rehabilitation of a hearing impaired cerebral palsied or non-cerebral palsied child. Included among these are auditory training, language training, and speech and reading therapy. Psychological, vocational, and social counselling must also be integrated with the various therapies. Progress and procedure will depend on the resultant interactions of the therapy and psychoeducational programs, as well as variables such as age of onset, type or degree of hearing impairment, overall intelligence, innate language aptitude, home and social support and personality traits [p. 236-237].

In bringing to a conclusion this portion of the paper dealing
with the effectiveness of treatment, several observations can be made. Although the literature is discouraging in presenting a case for the effectiveness of therapies, certain thoughts should be kept in mind. Studies in this area do little to measure the qualitative aspects of small gains realized by children as a direct result of treatment. For example, even though children may not be able to walk after extensive Physical Therapy over a period of years or be able to feed themselves after extensive Occupational Therapy, they will probably be able to decrease their spasticity while exercising some minimal control over body functions. This will allow for increased relaxation, better positioning, more rhythmic breathing, and an overall better environment for learning. The fact that the studies have not been able to effectively measure these small gains should not be considered a valid reason for the discontinuation of therapy. At the very least, we can say that treatment assists one in maintaining a certain level of dysfunction and assists as a preventive measure to contractures and a general physical regression.

The third and final portion of study deals with a review of that literature describing studies which investigated parental or maternal attitudes toward habilitative therapies as they relate to the cerebral palsied (physically handicapped brain damaged) person.

Lord (1947) completed a study based upon examinations and follow-up of 300 cases of Cerebral Palsy. She found that parents of school age children with Cerebral Palsy tended to be more concerned about their children's mental and educational potentials than about
their physical defects.

Moore (1953) interviewed 20 parents of children with Cerebral Palsy and found that 18 of them had been unfamiliar with the condition prior to the birth of their afflicted child. Although Moore's population was limited in number, the high percentage regarding that characteristic has appeared in other studies sampling larger populations.

Attitudes toward habilitative therapies may be affected by parents' unfamiliarity with the disability prior to the birth of their child. This may have some bearing on the investigator's thesis regarding attitudes of mothers toward habilitative therapies.

Birbeck (1960) indicated that there was no conclusive research available that demonstrated parents of cerebral palsied children significantly differed from parents of non-handicapped children. Research has been completed, however, measuring differences of these two groups of parents in terms of anxiety levels. The conclusions were not significant. Birbeck's review of the literature concentrated on

1. Parent influences on the personality development in children, and

2. Characteristics of parents of children with Cerebral Palsy.

Data surfaced that appears to reflect more on the behavior of the cerebral palsied child as a result of his parents' attitudes than the reverse.

The findings stated above should be interpreted as suggestive
rather than as established principles. Birbeck's study at no point attempted to measure maternal attitudes toward therapy. There is a portion of his study, however, that measured parental attitudes toward the recommendations of professionals. In all areas, parents scored high in the belief that they were doing their best to carry out the will of the therapists. Birbeck's main objective was to determine whether or not differences existed between parents of children with Cerebral Palsy and parents of children without Cerebral Palsy in the areas of anxiety, democratic atmosphere in the home, and in attitudes toward children and family life. Experimental and control groups consisted of 99 mothers and 67 fathers. Results were analyzed separately. For fathers, no significant differences were found between the experimental and control groups on seven attitude scales. The experimental group of mothers was found to have significantly poorer attitudes than the control group of mothers on scales of marital tensions, excessive demands for striving, and the Taylor Scale of Manifest Anxiety.

Birbeck's findings regarding fathers indicated that differences in paternal attitudes would probably not be significant. This can be interpreted to give, in part, even greater validity to the need for a maternal attitude study.

Ray (1951) provided interesting, if not revealing, findings relative to the investigator's area of interest. Ray interviewed 150 parents of cerebral palsied children and obtained the following findings:
1. 50% of the parents thought they could do nothing therapeutic or educational for their children, and

2. 80% expected surgical procedures to be the most valuable form of therapy.

Boles (1956) focused on the parent in the parent-child relationship. He, like Birbeck, was concerned with the degree to which parents of cerebral palsied children might differ from parents of non-handicapped children in the areas of anxiety, marital tensions, and democratic atmosphere. It is thought by most researchers that, for the most part, many of these questions have remained unanswered. The studies that have been conducted have generally revealed findings of little significance.

The value of using a control group of parents of non-handicapped children in most studies attempting to measure parental attitudes toward handicapped children is of questionable value. The fact that one cannot change the condition of the child or the situation of the parent in the handicapped experimental group causes one to question the value of comparing this group to a control group of parents of non-handicapped children.

Boles in his study used a population of 60 mothers of non-handicapped children and 60 mothers of cerebral palsied children. He then divided the children into categories based on severity of disability and the age of the child. The religious affiliation of the mother was also hypothesized by Boles to affect his findings. Boles proceeded to establish correlations between the control group
and the experimental group with respect to religious affiliation, guilt, and anxiety. His findings indicated that Catholic and Jewish mothers were significantly more anxious than Protestant mothers. Mothers of older children were found to have significantly more guilt than mothers of younger children. Catholic mothers had significantly more guilt than Jewish mothers. Protestant mothers did not differ significantly from Catholic and Jewish mothers with respect to findings of guilt. Boles did not indicate the use of valence in his questionnaire. The degree of anxiety was not measured or discussed. He speaks of only affirmative and negative responses. The breakdown of the experimental population stated above was taken into consideration for the investigator's development of instrumentation in the study of maternal attitudes toward therapy.

Bogan (1970) has touched more closely on attitudes of mothers of cerebral palsied children toward habilitative therapies than any other study discussed thus far. Bogan stressed the work of Freud and other personality theorists in emphasizing the role parents play in determining the personality characteristics and behavior of their children. The development of the cerebral palsied child's ego would be a crucial factor in his ability to develop the personality characteristics necessary to facilitate his adjustment to habilitative therapies. Bogan has referred to Ausubel's research (1952) to outline reasons for the influence of parental attitudes upon the development of the child's ego. He also cited Thurstone (1960) who found a significant amount of emotional disturbance in parents of
severely involved cerebral palsied children many years after the birth of the child.

Bogan, in his attitude scales, found that:

1. The age of the child does not affect attitudes of parents.

2. The physical condition of the child per se does not affect the attitudes of the parents.

3. The age of the parents does not have a very important influence on their attitude.

4. As the number of children in a family increases, mothers tend to become less indulgent and more rejecting.

5. Fathers with more education tend to be less protective and more disciplinary than fathers who have less education.

Bogan was essentially measuring the child's attitude toward habilitative therapy based on staff reports. He then tested parental attitudes against those findings. Bogan found no clear-cut relationship between parental attitudes and child adjustment. The only statement significant at the .05 level in the study was that the more well-adjusted a child was toward therapy, the more disciplinary his father tended to be toward him. It was not determined in this study whether the father's affect on the child's behavior was causal in nature or coincidental.

Wortis and Cooper (1957), in their extensive study of the life experiences of 63 cerebral palsied adults, found that family attitudes and family disorganization were related to the physical health and degree of improvement of the cerebral palsied person. They related
parental attitudes of overprotection to inadequate personality development in cerebral palsied children when faced with new situations or attempting new experiences. Such personality characteristics could interfere with the child's ability to make use of habilitative therapies.

Holden (1958) indicated that professional staff ratings of the motivation and adjustment of cerebral palsied children were highly correlated with ratings of overall treatment progress. Thus, in order for habilitative therapies to have their most positive effects, the cerebral palsied child should be capable of adjusting to them.

Garfield and Helper (1952) in their research indicated that the diagnostic category of the child and the social and educational level of the parents affected their attitudes toward the habilitative process.

Hall (1953) found, while interviewing 65 families, that parents of more severely disabled children had more difficulty in maintaining good family interaction and family transaction (relationships with community) than parents of mildly involved children. Mothers of both groups tended to be involved in the community and mothers of mildly involved children were involved in the community more often.

Shere and Kastenbaum (1966) reported that the physical symptoms of the child often provide a focal point for the anxiety of the mothers. Mothers in this study did not seem to realize that the children's physical limitations had important implications for their psychological well-being. This finding may have implications
regarding mothers' attitudes toward habilitative therapies.

Lassar (1956) stated in his study that it has been recognized clinically that the attitudes of parents are different when a handicapping condition occurs sometime after birth because of illness or accident. The feelings of guilt or shame in producing an imperfect child generally do not exist when the parents can point to an acquired cause.

Lerner (1976) described some approaches that may very well prove effective for mothers of cerebral palsied children as well as mothers of learning disabled children. Essentially, these suggestions affect the areas of parent counseling and conferences.

The opportunity for parents to meet with parents of children experiencing similar problems tends to reduce the parents' feeling of isolation. According to Lerner, an additional approach is to have parents meet regularly in groups and under the guidance of a professional counselor. Many times the first step in parent counseling is helping the parents transcend initial feelings about their handicapped child. Furthermore, parental attitudes toward therapy, education, and community will be affected by the parents' ability to ventila their feelings regarding the condition of their child and how it affects them regardless of what disability their child might possess.

Harper (1972) made a well-stated observation when he quoted Bronfenbrenner (1958). Bronfenbrenner stated "a surfeit of theory and a shortage of data characterizes the field of maternal attitude
The reasons appear to be related to the varied research designs, different methodologies, numerous samples investigated, as well as the difficulties in dealing with the complex interaction effects when studying the mother-child dyad.

The investigator feels that a statement regarding the current nature of the literature review for this thesis is important at this time. Most studies relevant to the subject matter were conducted during the 20 year period from 1950 to 1970. While searching for literature from 1970 to present, Cruickshank's 1976 3rd revised edition of Cerebral Palsy: A developmental disability presents the reader with an excellent example of current book editions based on prior research. This specific text is a compilation of articles and general contributions most of which are referenced to that 20 year period previously stated.
CHAPTER III
METHODOLOGY

Part I: Research Methods Review

The various methodologies encountered examined the following:

1. Is there a standard format that can be cited pertinent to all such studies?

2. Is a particular technique employed by most of the investigators in their attempt to measure attitudes? and finally,

3. What specific instrumentation, among those described, might best be employed by the investigator to measure the attitudes of mothers of cerebral palsied children toward habilitative therapies?

A brief history of those methods used by investigators mentioned in the Review of the Literature Chapter will serve as an overview to the variety of instrumentation approaches available.

The literature appears to favor both the unstructured and structured questionnaire formats for the measurement of parental attitudes. In the structured questionnaire format, most instruments offer from four to seven response sets ranging, for example, from "strongly agree" to "strongly disagree."

Existing survey instruments demonstrate a strong tendency to measure personality characteristics of parents and children with few or no items developed to measure attitudes toward a service and the relationships that may be present in forming those attitudes.
Most existing instruments are extremely lengthy in nature, impractical to administer, and have been either extracted from or combined with an investigator's own design for measuring attitudes.

Experimental designs for this type of study are virtually non-existent because no appropriate control group can be identified. The multi-handicapping nature of the disability makes this latter task impossible. No two cerebral palsied individuals demonstrate the exact combinations of physical and mental dysfunction. Unfortunately, limitless variables preclude the use of a more sophisticated experimental design approach. None of the instruments discussed, specifically, measures attitudes of mothers of cerebral palsied children toward habilitative therapies.

One of the scales used, measured maternal behavior as viewed by children in the Child's Report of Parent Behavior Inventory (CRPBI), (Schaefer, 1965). The CRPBI has a lengthy administration time requiring the completion of 192 items.

Certain investigators adapted a variety of existing tests such as the Maryland Parent Attitude Scale (MPAS), (Pumroy, 1966) consisting of four scales: Indulgence, Discipline, Protection, and Rejection. Others devised their own survey instruments and combined them with those like the CRPBI and the MPAS.

The most popular formalized survey instrument to be mentioned is the Parent Attitude Research Instrument (PARI) developed by Schaefer and Bell (1958). Factors in the PARI include: authoritarian control, hostility, rejection, and democratic attitudes.
The majority of parent attitude instruments developed, including the PARI, have been found to be sensitive to such variables as social class, educational level, and the social desirability set. The operation of these variables tended to confound the results and limit the confidence that can be placed in them.

Certain investigators have used the interview technique to measure parental attitudes. This approach is subject to the standard advantages and criticisms of such a technique. While it can be hypothesized that the validity of a study might be greater when implementing the interview technique since the interviewee can ventilate in detail his or her true feelings without limitation, the disadvantages, however, would include the lengthy time of administration, the smaller sample, and the standard criticisms of who rates the interviewer.

Lassar (1956) combined existing instruments, his own instrument, and an interview. Parents then filled out a single combined instrument and took an interview during the administration of the survey. This technique was successful but, like the interview technique, was limited by a lengthy administration time and a small number of subjects. Other techniques for measuring attitudes, in addition to those already mentioned, include: observation, case histories, and projective techniques.

Laws (1927) is credited with being a pioneer in the study of parental attitudes. In 1927, she administered a four-part questionnaire to 50 mothers in child-study groups. She made no
attempt to do a scientific study but rather used a non-leading, indirect questionnaire of a disguised, structured type.

Most studies on maternal behavior are based upon responses to questionnaires, e.g., attitude surveys or verbal reports of child management while few have been based on systematic, reliable behavior observation under laboratory-type controls.

McNemar (1955), who surveyed the field of attitude methodology, has stated: "There would seem to be no absolute basis for determining the optimal response set-up [p. 124]." Hall commented in his study "that a rather exhaustive search of the literature uncovered no scale, yet devised, which could be used without alterations for the purpose of this particular study [p. 83]."

The best means for objectively assessing attitudes are the paper and pencil tests, surveys, and inventories of parent attitudes. Brown (1942) cited the questionnaire as one of the most practical methods available for the measurement of parental attitudes. Advantages of these methods include the elimination of observer subjectivity, ease of administration, and ease of scoring. Examples of the methods stated above include: the USC Parent Attitude Survey (Shoben, 1949), Family Problems Scale (Loevinger and Sweet, 1961), and the Parent Attitude Research Instrument (Schaefer and Bell, 1958). Some limitations of the PARI have been previously described.

As a result of this brief history and summary of research methods used in previous attitude surveys, the investigator chose to develop a structured questionnaire to administer to mothers of cerebral
palsied children in order to measure their attitudes toward habilitative therapies.

Part II: Methodology Used in Study

A need to develop a unique instrument for the measurement of maternal attitudes toward habilitative therapies became apparent as previously tried research methods were reviewed.

The survey instrument was then developed by beginning with large subject categories as defined in the Statement of the Problem section. Subject categories include headings such as: Child, Family, Education, Economics, Geography, and The Treatment Process. Intense concentration was given to those subject headings thought by the investigator to affect mothers' attitudes toward Physical, Occupational, and Speech Therapy.

Subject matter was then delimited and defined specifically in an attempt to formulate a means by which maternal attitudes could be measured. All subject items thought to be causative in nature and leading toward the formulation of an attitude are included in the survey instrument. Delimited subject matter was then refined several times in an attempt to organize the survey in a fashion that dealt with sets of like types of questions. The study offered a mother of a cerebral palsied child a choice of three to six response sets with the average number of responses in a given question approximating five.

Every attempt was made to design the instrument with factual
types of questions presented first. This approach served two purposes. It provided the study with the facts that may very definitely have a bearing on maternal attitudes when cross-tabulating these questions against attitudinal questions at a later date. Secondly, the presentation of questions to mothers had to be introduced in a manner found to be friendly and non-threatening. This latter point is essential if the greatest number of return surveys was to be obtained.

Fact finding questions such as: "In what town do you reside?"; "What is your age?"; "What is the age of your physically handicapped brain damaged child?" all served the latter purpose well because they were non-threatening.

The survey was developed with the thought in mind that attitudes toward therapy were being measured and not an entire array of psychological behaviors irrelevant to the study.

It was imperative that the survey be designed in a manner which asked the appropriate questions yet limited the difficulty and number in order that a respondent would be encouraged to complete the survey in approximately 30 minutes. It was felt by the investigator that the number of completed surveys returned by interested mothers would be seriously jeopardized if the survey consisted of more than 57 questions and took more time than 30 minutes to complete.

Before the survey instrument was professionally printed, a field test was conducted with 12 mothers of cerebral palsied children. The mothers, whose children were clients of the United Cerebral Palsy
Association of the Merrimack Valley Area, Inc., met at the agency as a group and filled out the instrument. The investigator discussed with the mothers their recommendations immediately after they had completed the survey form. Input from these 12 mothers participating in the field test was used to make several changes. For example, a question was added asking mothers if they were a foster care parent of a physically handicapped brain damaged child.

A clarification was made regarding the phrasing of question numbers 45 and 46 dealing with mothers carrying out home programs for their children. Those questions were revised to ask whether or not mothers were involved in carrying out therapies at home. The words "home program" were confusing while the revision served to more clearly delineate what was being asked.

Initially, the descriptive term "physically handicapped brain damaged" was found to be unwieldy and frequently used throughout the survey. Mothers indicated that a repetition of that term tended to cause a degree of frustration and hostility as they progressed through the survey. This condition was corrected by eliminating the term except when it was thought to be essential for the sake of clarity.

Although the instrument was designed principally with forced-choice questions, three questions remained open-ended plus one fill-in question. Questions regarding the medical diagnosis of the child (question 11), other services that might be helpful (question 39), and personal comments (question 57) represented open-ended questions.
Question number 1, "Please state the town in which you reside." remained a fill-in question. Question 57 allowed the investigator the opportunity of evaluating any comments of a personal or general nature regarding the feelings and attitudes of mothers of cerebral palsied children.

The final survey instrument, drafted with the resultant corrections after considering the input of the field-tested group, was then professionally printed and sent out with several components: an introductory letter, describing the study and explaining the need for cooperation from mothers of cerebral palsied children, plus the first page of the questionnaire which included a Title and Statement of Purpose, a prepaid postage envelope, and pencils.

Several means were used to increase the number of responses. A follow-up letter to non-respondents was sent out 15 days after the survey was mailed accompanied by phone calls to approximately 75 non-respondents seven days after the follow-up letter was mailed. In some cases, it was not possible to contact all non-respondents by phone since 200 of the 350 subjects surveyed were not known to the investigator by name.

The National United Cerebral Palsy telethon, running for 20 hours during the weekend of February 4 and 5, 1978, was broadcast by the American Broadcasting Company from Hollywood, California; New York; and Boston, Massachusetts.

Follow-up letters for the study preceded the telethon by approximately one week. Although it would not be possible to
measure the effect of the telethon on the number of returns, one could hypothesize that the 20 hour broadcast did have a positive effect on the rate of returns.

The study was conducted under the auspices of the United Cerebral Palsy Association of the Merrimack Valley Area, Inc. The investigator is the Executive Director of that organization and used stationery reflecting the letterhead of that agency when presenting the material to mothers.

Part III: The Study Sample

Subjects of the study are the mothers of cerebral palsied children residing throughout the Commonwealth of Massachusetts. Participating facilities serving the children included: The Cotting School for Handicapped Children, Boston; United Cerebral Palsy Association of Merrimack Valley, Lawrence; United Cerebral Palsy of North Shore, Salem; South Shore Cerebral Palsy, Quincy; Cerebral Palsy of Greater Boston, Newton; The I. H. Schwartz Children's Rehabilitation Center (Cerebral Palsy Clinic), New Bedford; The Rehabilitation Center of Worcester County, Inc., Worcester; and United Cerebral Palsy of Berkshire County, Pittsfield.

Agencies chose one of two ways in which to cooperate with the study. In some instances, agencies provided the investigator with the names and addresses of active case load clients. Other agencies chose to send out the survey packages themselves thereby assuring the confidentiality of their clients' cases. All surveys returned were
The study attempted to survey mothers of cerebral palsied (physically handicapped brain damaged) persons. The diagnosis of the child was written in the survey based on the mother's knowledge of the child's medical history. Some surveys returned were deleted from the study because the disability described was totally unrelated to a physically handicapping brain damaged condition. Mothers whose cerebral palsied children were 22 years of age or older were also eliminated after completing question 5 in the survey. It was felt that the responses of mothers whose children were age 22 and older when compared to responses of mothers of younger children tended only to confuse the results of the project.

Of the 350 questionnaires mailed, 185 were accounted for in the returns. One hundred seventy surveys of the 185 accounted for were used in the study. The difference between the 170 surveys used in the study and the 185 surveys returned is attributed to 15 surveys being deleted for an unrelated diagnosis.

The number of subjects used in the study is encouraging. Most studies referred to in the review of the literature rarely exceeded 100 subjects and were limited, in many instances, to one population in one specific geographical area.

Part IV: Data Processing and Analysis

The investigator coded and keypunched data from the questionnaire with assistance from the staff of the Graduate Research Center,
University of Massachusetts, Amherst, Massachusetts. The data was then analyzed and a frequency analysis of each response set in every structured question was determined. The chi square test of significance was selected as the most suitable formula for cross-tabulations and data analysis.

A complete search was implemented scanning for any and all significant relationships at the .05 level or less between 11 questions considered to be dependent variables and most other questions in the instrument. In the survey, these dependent variable questions can be identified as follows: questions 25, 29, 30, 31, 32, 34, 41, 43, 45, 53, and 54. The frequency of certain response sets to questions was cross-tabulated against each of these 11 dependent variables. The 11 dependent variables represented actual questions found in the survey. Questions selected as dependent variables did not request information of a cognitive nature solely but rather an attitudinal one. Since the nature and design of the dependent variables was attitudinal, they are subsequently described as such.

Each of 39 other questions in the survey were then designated as independent variables and cross-tabulated by computer with each of the dependent variables. Dependent variables were also cross-tabulated against each other in an effort to complete the search. A total of 429 cross-tabulated tables resulted with a chi square test of significance performed for each. Of the 429 tables produced, 115 tables initially displayed significance at the .05 or less levels.
Certain limitations to the study in relation to the data analysis must be described at this time.

The computer program available to the investigator for the computation of the chi square test of significance is published in the second edition of the Statistical Package for the Social Sciences. This program, available at the University of Massachusetts Graduate Research Center, was used in determining frequency analyses and significant relationships.

The chi square test of statistical significance chosen for use in this study assists us in determining whether a systematic relationship exists between two variables. Chi square, by itself, helps us to determine whether our variables are independent or related. It does not tell us how strongly they are related. This is due, in part, to sample size and table size having such a large influence upon the chi square formula. Several statistics, however, are available to adjust for these factors.

In this study, 429 tables were produced resulting in 115 significant relationships initially. Many of the 115 tables found to be initially significant at the .05 level or less contained a number of zero frequency cells. Zero frequency cells jeopardize mathematically the size of the chi square and the exact probability computed by the cross-tabulation.

It was then necessary to collapse low frequency response sets into other response sets at the same time not eliminating respondents nor diluting inadvertently and falsely their responses. Upon
completion of this task, tables were cross-tabulated again to determine chi square. The investigator felt that this was accomplished effectively producing 12 tables significant at the .05 level or less and containing no zero frequency cells.

Tables 17 through 28 in Appendix B present the data for those 12 significant relationships. Tables 1 through 16, also found in Appendix B, represent frequency analyses for certain questions thought by the investigator to highlight findings in the study. Many other relationships are discussed that were initially found to be significant but were eliminated from the .05 significance level or less due to the limitations previously discussed.

An alternative approach to the above description would have been to design a survey instrument with response sets that reflected many preconceptions on the part of the investigator. This approach would have minimized other observations and relationships thought to be important by offering the respondents only two or three response choices as opposed to the necessary five or six. Also, due to the large search conducted producing over 400 tables, it was not practical to begin adjusting the chi square for strength of relationship.
CHAPTER IV
RESULTS AND DISCUSSION

This Chapter presents the findings of the questionnaire study and describes the method of studying the attitudes of mothers of cerebral palsied children toward the habilitative therapies. The Chapter, with the assistance of Tables 1 through 16 in Appendix B of the study, analyzes the frequency of responses and the response sets themselves as they relate to the questions.

In addition to eliciting information concerning mothers' attitudes toward therapy and some of the variables that caused these attitudes, the questionnaire provided an opportunity for the respondents to comment on the availability and utilization of special services for the cerebral palsied and to offer suggestions for additional or improved services as they saw fit.

Properly identifying the population of the study is essential in order that a true analysis of the work be obtained. It was the purpose of the survey instrument to separate and eliminate those mothers of cerebral palsied persons 22 years of age or older. The investigator considered that the attitudes of these mothers would dilute the results of the study. The age range of the preferred mother group and their children would present too great a time lapse to make the results compatible with the results of mothers of
cerebral palsied persons over 22 years of age.

The first five questions answered deal with the entire subject population of 170 mothers. The study group drops to 144 when the 26 cases representing mothers of cerebral palsied persons 22 years of age or older are deleted from the sample. The population deleted from the study represents 15.3% of the entire 170 subjects (see Table 1).

The decision made by the investigator that the two groups of mothers should not be mixed was apparently supported by the fact that 15 mothers of the 22 years or older group did comment that they wished that these services had been available to their children and them when their children were much younger. By their own statements in the narrative portion of the study, this group of mothers did not realize the importance of these services nor were the services available then to the extent that they are today.

Fifty-nine percent of the mothers responding to the survey stated that their cerebral palsied children fell into the 4--14 year old age categories (see Table 1). Of the initial 170 mothers studied, 95.2% had only one handicapped child in the family. This percentage included mothers of cerebral palsied persons 22 years of age or older (see Table 2).

With the assistance of the agencies cooperating in providing the subject population, 350 questionnaires were initially sent. A deliberate attempt was made to contact mothers of cerebral palsied children. Since many cerebral palsy centers treat diagnoses other
than Cerebral Palsy, it was surprising to find only 15 surveys describing a diagnosis totally unrelated to Cerebral Palsy.

An interesting statistic emerged that is noteworthy in and of itself even though it is not directly related to maternal attitudes. The finding was consistent with the report of Hopkins and associates (1954) which indicates a sex distribution of 1,406 children of whom 57% were males and 43% females. In the investigator's study of 170 mothers, 59.4% of the mothers had male children and 40.6% female children.

In the 144 surveys ultimately studied, only 5% (5) of the mothers made reference to a diagnosis related to but not specifically Cerebral Palsy. The remaining 95% (139) of the mothers wrote in Cerebral Palsy in some form. In most cases, the term used was Cerebral Palsy. In an extremely small percentage of cases, mothers more knowledgeable about the medical diagnosis of their child described a specific type of Cerebral Palsy, i.e., spastic, athetoid, or used a more generic term, i.e., hemaparesis, quadraparesis.

**Description of Study Group**

Thirty percent of the respondents lived in the Northeast section of the State. The balance of the sample (70%) resided in a relatively equal distribution throughout the Northwest, Southeast, Southwest, and Central portions of the State of Massachusetts. The Commonwealth was divided for purposes of the study: northerly to southerly from Winchendon to Southbridge and westerly to easterly
from Pittsfield to Boston. An area within 25 miles radius from Leominster was considered to be the central portion of the State.

Information concerning the total number of children in the family including the cerebral palsied child was provided in all 144 cases studied. The distribution presented a greater range than might have been expected with a relatively equal distribution from two to five children in each family (see Table 3). Closely related to the total number of children in the family is the question relating to the order of birth of the cerebral palsied child. Fifty-eight percent of the mothers said that their handicapped child was first or second-born. The remaining 41.3% of the handicapped children were distributed between third, fourth, and fifth-born (see Table 4).

It has often been assumed that Cerebral Palsy is related to the first-born child because of the frequency of difficult labor in connection with first-born children. According to Hopkins, et al., (1954) there is sufficient evidence to show that cerebral palsied children may appear co-incident with any pregnancy or with any birth order, and that the smaller number of cerebral palsied children who are later-born is accounted for by the small number of families with four or more children. Even though the sample population studied demonstrated a greater average number of children in the family when compared to other studies, data based on this sample does not contradict the conclusion that Cerebral Palsy is a factor related to any or all pregnancies.
It was thought by the investigator that the degree of physical handicap could have a significant bearing on the mothers' attitudes toward habilitation. This thought, however, was not borne out by the statistics gathered from this study group (see Table 5). No significant relationships developed when the questions of degrees of handicap were cross-tabulated with attitudinal questions. Fifty-eight percent of the mothers indicated that their children were physically of the moderate involvement category defined in the survey instrument as a handicap serious enough to impair walking, communication, and self-help skills but not sufficient enough to disable a person entirely. As defined in the survey instrument, (see Appendix A, question 12), the remaining 42% of the children were equally distributed between the mildly involved and severely involved categories. Definitions regarding degrees of physical involvement were compiled as a result of other studies conducted describing those levels of physical dysfunction.

Ninety-four percent of the mothers were found to be the biological parent of the child. Only two mothers in the study group were found to be foster care mothers. Eighty-nine percent of the mothers were married and 11% divorced. Although the literature suggests that family structure, integration, and parental cohesiveness is generally adversely affected by the presence of a handicapped child, the comparatively low divorce rate reported here would not bear this out.

The distribution of mothers by age fell into a relatively wide
range with 77% of the mothers ranging from 26 to 45 years of age (see Table 6). Mothers in the age range 26 to 45 years of age represented a formally intact family structure. It was difficult to assess the cohesiveness of the younger mother group, ages 18 to 25, since only 4.2% answered the questions and returned the instrument.

Most children in the study group fell into the 4–14 year old age categories. As a result, it would appear that many mothers and physicians within the Commonwealth of Massachusetts are quite current regarding their orientation and treatment for this population of handicapped children (see Table 7).

Ninety-seven percent of the children lived with their parents at home. In previous investigations dealing with follow-up studies to the adjustment of the cerebral palsied adult, it has been noted that approximately the same percentage of cerebral palsied adults continue to live at home. The majority of these persons, at any age, live at home with their parents or ultimately with siblings when their parents are deceased.

Of 143 cases studied, 67.8% of the mothers had between 10 and 12 years of education. A relatively high percentage, 20.2%, had two years of college or more. Level of education apparently had no bearing on the finding that 76% of mothers responding had little or no knowledge of Cerebral Palsy prior to the birth of their cerebral palsied child. It was interesting to note, however, that of the mothers who had experienced two to four years of college, many of them commented on the need for respite care on weekends for their
child. Respite care was interpreted primarily as temporary relief for parents. In general, the mothers with higher levels of education availed themselves of the opportunity to respond to the two open-ended questions relating to "other services needed" and "personal comments." The results of the study indicated that mothers with education levels beyond high school ventilated their feelings in writing when presented with the opportunity.

**Social Activity and Community Services Being Used**

Forty-four percent of the 142 mothers responding indicated that they tended to remain involved in social activities to the same extent as they had prior to the birth of their cerebral palsyed child. Seventeen percent of the mothers became more active socially while 23% became less active.

It was interesting to note that 33% of the mothers responding indicated that the presence of a cerebral palsyed child had had a positive impact upon their life, 30% felt nothing had changed, and 24% felt little or no positive impact had occurred.

It was not uncommon in approximately 62% of the surveys returned to read that mothers felt that God had sent a special child to them so that they might fulfill a unique mission. The child's presence in the family had a positive impact on the mother in the sense that the mother felt closer to carrying out God's plan. The religious feelings for these mothers had obviously been strengthened.

Eighty-three percent of the mothers felt that doctors were
somewhat helpful to very helpful in treating and/or referring their child to an appropriate treatment source (see Table 7). Many mothers did indicate in narrative form that they had experienced "doctor shopping" and that there was usually one physician with whom they felt most comfortable. Generally, it was the physician who was most knowledgeable about their child's case. The other physicians were not particularly helpful at all. Mothers appeared to agree generally that an adequate number of medical specialists were involved with their child's case. In terms of mothers' relationships with professionals, 54% of the mothers indicated that they felt equally comfortable with therapists representing all modalities. Most mothers appeared satisfied generally with the agencies serving their children. Eighty-two percent of the mothers found treatment records satisfactory.

Therapy and Mothers' Involvement with Treatment

Children in the study group had been receiving substantial amounts of therapy as evidenced by their mothers' responses. Seventy-seven percent of the children received Physical Therapy one to two times per week, 55% had received Occupational Therapy one to two times per week, and 51% had received Speech Therapy one to two times per week. Sixty-eight percent of the mothers responding indicated that their child's primary problem was physical. Thirty-two percent of the mothers perceived their children to have a combination of physical and mental problems. The mental problems
were of a cognitive nature and apparently more significant to those mothers than the physical dysfunction.

Cruickshank (1976) presents us with data indicating that approximately 50% of the cerebral palsied population are mentally retarded. Statistics in this study do not refute that claim but do indicate that most mothers perceive their child's primary problem as being a physical one.

Thirty-six percent of the mothers felt that Physical Therapy was most helpful to their child. This finding contrasts sharply with only 3% of the mothers stating that Occupational Therapy was most helpful and 10% indicating that Speech Therapy was most helpful. Twenty-nine percent of the mothers stated that all three modalities were equally helpful. It becomes apparent in the first three response sets, however, that Physical Therapy is considered to be the single modality commonly perceived by mothers to be most helpful to their child (see Table 8). This finding appears to relate closely to the previously-discovered finding that most mothers consider their child to have a primarily physical problem.

Nationally there has been a movement in the past 10 years to have infants with Cerebral Palsy and other developmental disabilities referred to treatment sources at a very early age. Physicians have been encouraged to refer infants demonstrating developmental problems as early as 3 months old. Seventy-four percent of the mothers studied indicated that their child was enrolled in some therapy program prior to the child being 3 years old (see Table 9). This
relatively large percentage of children experiencing early referral and treatment could be indicative of several factors. The possibility exists that there is a greater availability of necessary services in the Commonwealth of Massachusetts than can be found in other states. Physicians are becoming more aware of the national advocacy movement which promotes early referrals for the handicapped. Mothers of handicapped infants are more aware of the need for services and seek out resources earlier while there also exists an availability of third parties to pay for the costs of treatment.

Most mothers in the study felt that generally their children received an adequate amount of therapy with an extremely small percentage indicating that their child would benefit from more Physical Therapy.

Fifty-seven percent of the mothers felt that therapy is helping their child to function better to a great or very great extent. Thirty-two percent felt that therapy has helped their child to function better to some extent (see Table 10). As the number of children increased in the family, mothers' attitude toward therapy for their cerebral palsied child did not change.

Most mothers became aware of changes made in their child's treatment program before or at the time changes were made (see Table 11). Approximately the same percentage of these mothers were very much involved or involved with professionals in making these changes in the treatment plan (see Table 12).
It was further indicated in question 41 that 53% of the mothers responding felt that it was difficult to determine if surgery was more helpful than therapy. The "balance of mothers" registered small percentages in the other response sets ranging from more helpful than therapy to not as helpful as therapy. Of the mothers whose children had actually experienced surgery, question 42, 85% were of the opinion that their child's condition was improved or very much improved as a result of the surgical procedure.

Seventy-three percent of the mothers had made requests to participate in therapy with their child. An equal percentage of mothers stated in a different question that therapists requested their presence at the treatment facility to participate in therapy.

Therapy administered by mothers at home after a home program had been described and taught by the therapists was widely considered to be the single most important factor in the therapy program. Therapy programs are of many years duration and cannot be accomplished by professionals alone. In this regard, it was interesting to note that 79% of the mothers are occasionally to actively involved in carrying out the home therapy program with their child (see Table 13).

Of 139 mothers studied, 79% felt that therapy had been effective for their child to a great or very great extent (see Table 14).

Most mothers had not had the experience of therapists in their home administering treatment to their child. This practice is becoming more popular as Early Intervention programs are funded to
identify "high risk" infants in the community. Of those mothers who did experience therapists in their homes, 87% found the arrangement effective for their child and comfortable for them.

The question placed before mothers regarding their feelings as to whether their child was making progress in therapy was purposely placed at a distance from the question regarding the effectiveness of therapy in order to test for the consistency of a mother's response in this category. As a result, the findings indicate that 76% of the mothers felt that their child was making average or good progress in therapy. Twelve percent of the mothers were uncertain as to progress and 12% felt that their child was making poor progress or no progress at all. Approximately 79% of the mothers indicated that therapy had been effective for their child to a great or a very great extent.

Sources of payment for treatment provided the investigator with some interesting insights. Private insurance and Medicaid appear to be the major sources of third party payments for most families (see Table 15). Very few families pay for services from personal finances in 1978 in the Commonwealth of Massachusetts.

It is revealing when Table 15 is compared to the findings relating to the payment of health services being a burden to families. Sixty-five percent of the mothers felt that the cost of health services was not that burdensome or no burden at all (see Table 16). Seventy-six percent of the mothers stated that if personal finances were the only source of payment for all treatment services, they
would opt to pay for Physical Therapy.

In view of the fact that the availability of transportation has traditionally played an important role in determining whether some handicapped children receive services, the investigator included two questions in the survey instrument addressing this topic. Eighty-four percent of the mothers were found to live within 20 miles of a treatment facility with 59% of the mothers using their cars as the primary source of transportation. Forty-one percent of the mothers used buses and taxis.

Questions in the survey instrument relating to psychological support for parent and child provided some interesting results. Mothers and children who had never received counseling by a professional social worker or psychologist represented 51% of the population studied. Approximately 38% of the mothers and children had received this service and found it to be helpful to very helpful in assisting them and their families in adjusting to the presence of a handicapped child in their family. Eleven percent of the mothers studied found the counseling service not to be helpful. Over 71% of the mothers felt that interaction with other parents of handicapped children was helpful and supportive to them.

Tables 1--16 represented in this section of the study have been chosen on the basis that they most clearly establish the frequency of those response sets thought to have some bearing on mothers' attitudes toward therapy. The following section of this chapter dealing with the chi square test of statistical significance and the
final chapter of the study refer to many of the response sets described in Tables 1--16.

**Significant Relationships Among Variables**

Discussion in this section of Chapter IV addresses those 12 significant relationships determined as a result of the study.

Most mothers described themselves as being greatly involved with their child's therapy program. When this result was cross-tabulated with the frequency of professional staff requests for the mothers' presence to assist in treatment at the facility, the relationship was found to be significant at $p < .01$. Professionals requested mothers' presence occasionally to frequently while mothers apparently interpreted their response to this request as being an indication of great to very great involvement with their child's program (see Table 17).

Most mothers indicated that with third party payments assuming most of the costs of treatment for their handicapped child, the financial strain on the family in this regard was reduced and described as a very small burden. This finding related closely to mothers' interpretation of their great involvement in their child's treatment program ($p < .05$). Table 18 presents data reflecting this relationship more effectively.

Of the three different treatment modalities experienced by children, most mothers felt that Physical Therapy was the modality most helpful to their child. This finding was revealed as being
significant at the $p < .05$ level when compared to the finding that most children received Physical Therapy at least one to two times per week (see Table 19).

Historically, most physicians initially refer cerebral palsied children for Physical Therapy. This tendency supports a strong motivation to correct the child's physical dysfunction with a good deal of physical therapy treatment (see Table 19). Mothers generally found doctors to be helpful in referring them to an appropriate treatment facility for their child. This finding related closely to the attitude that all therapies were interpreted by mothers to assist their child to function better physically ($p < .05$). There appears to be a strong and positive attitude between physician input and mothers' interpretation of positive results (see Table 20).

Professional staff requested mothers' presence at the facility to assist in treatment at least occasionally and many times frequently. This finding related closely to the mothers' attitude that all therapies had assisted their child to function better physically ($p < .01$). Mothers' involvement in treatment with professionals at the facility appears to have corroborated their feeling that all therapies helped their child to function better physically (see Table 21).

Most mothers felt that interaction with other parents of handicapped children was helpful to them in dealing with their child's problem. This result related closely with the mothers' attitude that their children were helped to function better
physically by all therapies generally \((p < .01)\). Positive attitudes toward the effects of therapy seem to be closely related to moral support given by parents of children with other types of handicaps (see Table 22).

Mothers generally fell into the 26 to 45 year old age category. The group of mothers in this age range felt strongly that it was very difficult to determine whether surgery was more or less helpful than therapy \((p < .05)\) (see Table 23). This relationship was reported because of the level of its significance. The investigator, however, does not consider it to be of significant importance to the conclusions or recommendations made at a later place in the study.

Approximately half of the mothers had never experienced counseling by a social worker. A slightly larger percentage indicated that they had experienced counseling and found it to be helpful. This finding related strongly to mothers' difficulty in determining whether or not surgery was more or less helpful than therapies \((p < .01)\). It could be hypothesized as a result of this relationship that mothers who had received professional counseling developed somewhat of a more mature attitude about the difficulty in choosing surgery as being more helpful than therapy for their child (see Table 24).

Occasional to frequent professional staff requests for mothers' participation also related significantly to the finding that mothers viewed themselves as being quite active in carrying out home treatment programs for their children \((p < .01)\). A mutually supportive attitude appears to exist between professional requests and mothers' behavior
(see Table 25). Additional support for the previous relationship described is found when it is noted that mothers' occasional to frequent request to participate in therapy with their child is closely related to their considering themselves active in carrying out home treatment programs ($p < .01$) (see Table 26). Mothers appear to have a positive attitude generally toward their relationships with professionals.

Most mothers felt that their child was making good progress in therapy. This finding related closely to the statement that mothers felt that all therapies assisted their child to function better physically ($p < .01$). Although mothers indicated Physical Therapy as being most important, they felt equally comfortable with therapists representing all three modalities.

The two questions related to progress in therapy and therapy assisting the child to function better physically were purposely placed at a distance from each other in the survey to test for mothers' consistency of response. It appeared that their responses in this regard were found to be consistent (see Table 27).

Mothers occasionally to frequently requested participation in therapy with their child. This finding related closely to the finding that most mothers felt their child was making good progress in therapy ($p < .05$).

Mothers apparently felt that they could see tangible evidence of their child's functional improvement when they perceived themselves as quite involved in the child's treatment program (see Table 28).
Should personal finances be the only source of payment for services, mothers would pay for Physical Therapy first. Speech Therapy rated higher than Occupational Therapy in this regard. Speech Therapy appeared in this study to be the second preferred modality; the specific physical dysfunction of a child notwithstanding.

Most mothers responding to questions in the study indicated that the age of their child fell into the 4–14 year old range and that they were aware of changes in their child's treatment program before or at the time changes were made. Both the above-stated results involving awareness of change in the child's treatment program and the child's age related closely to the mothers' strong conviction that their child should receive Physical Therapy more often.

Most children described by mothers in the study had not experienced surgery. Of those mothers whose children had experienced surgery, most felt that their child's condition had improved as a result. This finding related well to mothers' generally active involvement with professional staff.

Most mothers had never had the experience of professional staff treating their child in their own home. This result related closely to the mothers' active involvement with professional staff in making decisions and/or changes in their child's treatment plan.

Mothers who were actively carrying out therapies in the home related closely to those mothers requesting participation in
therapies with their child at the treatment facility.

Mothers indicated that in most instances their child received Physical Therapy one to two times per week. These same mothers were very active in carrying out the home treatment program. Mothers who were actively involved in home programs also felt that Physical Therapy was the individual treatment preferred most often.

Summary

This chapter has presented the findings of the questionnaire study. The data was presented in descriptive form with the exception of those areas where significant associations were found between mothers' attitudes toward habilitative therapies and various factors thought to influence those attitudes. The statistical analysis revealed 12 significant findings at the .05 level or less.

From the results of the study, it would appear that the majority of mothers were equally distributed and fairly represented a cross-section of the Commonwealth of Massachusetts. A predominant number of mothers were married at the time of the study, were between the ages of 26 and 45, and had one cerebral palsied child in the age category 4 to 14. The total number of children in any family ranged from two to five. The order of birth of the cerebral palsied child in the family fell generally into the second-born to fifth-born range. All mothers indicated that their child lived with them, with the majority of mothers stating that their child was moderately involved physically.
Mothers generally indicated 10—12 years of education for themselves with little knowledge of Cerebral Palsy or related disabilities prior to the birth of their cerebral palsied child.

The primary problem viewed by mothers was a physical problem. They were aware of mental deficits in some cases but were primarily concerned with the physical dysfunction demonstrated by their child.

Mothers appeared to be involved in outside social activities to the same extent as they were prior to the birth of their handicapped child. Forty-three percent of the mothers felt that the birth of their cerebral palsied child did affect their lifestyle in a positive way. The "balance of mothers" appeared to be equally distributed between same extent, little extent, and no extent.

Mothers had been exposed to several doctors feeling comfortable with those physicians most knowledgeable about their child's case. Searching for knowledgeable and supportive physicians was a very definite activity for mothers during their child's early years. Children were generally enrolled in therapy programs at a young age, 0—3 years. Children received different treatment modalities based on their specific areas of deficit. Not all children received all three modalities. The amount of therapy received by a child averaged one to two times per week for each modality of treatment received.

The majority of mothers felt equally comfortable with therapists representing all modalities. Attitudes toward
therapists had no apparent bearing on Physical Therapy being the preferred modality of treatment.

Areas of varying relationships appeared when the chi square formula of statistical significance was introduced.

The majority of mothers took a definite interest in their child's therapy program. They were aware of changes being made in the treatment program at the appropriate time. Mothers were involved with professional staff in making changes and quite active in carrying treatment programs out in the home. These same mothers felt that therapies were necessary but that Physical Therapy was most important. Most mothers not only took an active part in their child's program but felt that average to good progress was being made.

Most mothers had not received personal counseling nor had their cerebral palsied child. Those that had, however, found it a helpful experience.

Interaction with mothers of other handicapped children by mothers of cerebral palsied children had a positive effect in terms of attitude as it related to mothers' involvement in their child's program and their child's progress.

Most mothers live within a reasonable distance to a treatment center offering a variety of services for the handicapped. The family car and special transportation provided by some school systems seem to be the main sources of travel to the facility.

In terms of finances, most parents find treatment programs
of little financial burden presently. Third parties have taken over the greatest percentage of payment for services at this time.
CHAPTER V
SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS

The present research was a study of the attitudes of mothers of cerebral palsyed children toward the habilitative therapies.

All mothers were residents of the Commonwealth of Massachusetts at the time of the study and had at least one cerebral palsyed child to whom they had given birth. All mothers were at least 18 years of age.

The considerable body of literature related to the general category of parental attitudes toward handicapped children provided the theoretical framework and research pattern for the investigation.

The study sought to identify the attitudes of mothers toward Physical, Speech, and Occupational Therapy as well as to analyze factors and relationships resulting in the formation of those attitudes.

Information was gathered with the assistance of agencies throughout Massachusetts serving cerebral palsyed persons and through the use of a questionnaire mailed to the mother or guardian of a person thought to have Cerebral Palsy.

Study Group

Of the 330 questionnaires sent, 185 were completed and returned. Fifteen surveys were eliminated from the 185 due to an acclaimed diagnosis unrelated to Cerebral Palsy. The remaining 170 subjects
comprised the final sample.

Mothers whose cerebral palsied offspring were 22 years of age or older were asked to complete questions 1 through 5 and return the survey. Twenty-six mothers fell into this category. The results of the frequency analysis of questions 1 through 5 included these 26 cases (170). The study was then continued with the 144 remaining subjects.

Certain Tables throughout the study reflect a total population of 136 to 144 mothers responding to questions 6 through 56. These figures represent the actual number of respondents to questions 6 through 56 in any specific Table.

Of the final sample, 101 mothers had sons and 69 mothers had daughters. The overwhelming majority of mothers resided with their cerebral palsied child at home. Of the 170 mothers initially studied, 162 had only one physically handicapped brain damaged child in their family. Eight mothers had more than one multi-handicapped youngster.

The majority of children ranged in age from 4 to 14 with the total number of children in the family ranging from two to five and the order of birth of the cerebral palsied child ranging from second-born to fifth-born. No particular response set appeared outstanding regarding these two observations.

It is interesting to note that the study was conducted in the Commonwealth of Massachusetts. As a result, the total number of children in a given family does appear higher than what might be
considered the present national average of 2.3 children per family. One hundred and five mothers were married. The results also included 89 Catholic mothers, 39 Protestant mothers, and no Jewish mothers.

Most mothers responding were between the ages of 26 and 45 years old and had little knowledge of Cerebral Palsy or related disabilities prior to the birth of their cerebral palsied child. Mothers diagnosed their child for purposes of the study basing the diagnosis on knowledge of their child's medical history. Practically all mothers diagnosed their child as having Cerebral Palsy. The majority of mothers demonstrated 10 to 12 years of education for themselves with 29 respondents having received two years of college or more.

**Therapy and Mothers' Involvement with Treatment**

Most respondents described the degree of Cerebral Palsy of their child as a moderate involvement with the primary problem being a physical one.

Children experienced an active therapy program encompassing a treatment program consisting of one to two therapies per week of those modalities necessary to their particular dysfunction. The majority of children were enrolled in therapy between 0—3 years of age.

Physical Therapy was the modality of treatment thought by mothers to be needed most often by their child. Therapies, in general, were perceived by mothers to help their child function
better physically with Physical Therapy, once again, considered the modality needed more often.

Although Physical Therapy was the preferred form of treatment, mothers generally felt comfortable with therapists representing all modalities. In order of importance and preference, Speech Pathology ranked second to Physical Therapy, with Occupational Therapy being the least preferred modality of treatment.

Relationships between factual responses and attitudinal responses begin to appear as questions in the survey turned toward the mothers' behavior.

Mothers responding to the study appeared to be significantly involved in many aspects of their child's treatment program. Significant relationships developed as correlations were sought between mothers' overt actions and experiences reflecting mothers' being acted upon by outside elements. Positive attitudes appeared to surface as mothers worked closely with professionals, i.e., physicians and therapists concerned with their child's case.

An increase in treatment, coupled with an increased rapport developed with therapists, tended to affect positively mothers' attitudes toward their child's treatment program as being particularly productive.

Professional and Community Services

Community services provided an interesting array of observations
for the investigator. The majority of mothers (78) indicated that they had never received services from a social worker or psychologist in a counseling setting. However, of the mothers who had received the service, 51 stated that they had found the service to be helpful.

In addition to professional intervention by social workers and/or psychologists, most mothers interacting with mothers of children with other types of unrelated handicaps found the experience to be quite supportive. Mothers' positive attitudes toward progress and overall improvement in the physical functioning of their child appeared to be positively related to the findings reflecting social interaction with professionals and with other parents of handicapped children.

Mothers expressed in greater detail their feelings toward community services and the need for same in the open-ended question at the end of the survey in which their personal comments were requested.

An interesting observation appeared as mothers who had experienced two years of college or were four-year college graduates tended to express themselves in greater detail in this narrative option. Although only a small number of mothers fell into this category, it became readily noticeable.

Many mothers expressed a need for respite care for their child as well as their general frustration at this service not being available to them. Respite care was described as a weekend per month where parents could bring their child to a residential setting.
Mothers described this procedure as an opportunity to be with their spouses alone or to rejoin their family for one weekend per month in the absence of caring for their cerebral palsied offspring.

Mothers, although grateful for services available, vented their frustrations at a lack of specific services, i.e., socio-recreational programs, continued therapies through the summer months, and social services support.

Mothers were hopeful, noting vast improvements in the increased availability of treatment services over the past 20 years. Mothers of cerebral palsied persons 22 years of age and older indicated that they wished the services had been available when their child was much younger.

The investigation becomes of particular interest as we have come to learn and acknowledge that the medical effectiveness of treatment as viewed by physicians and other related professionals appears to be at the very least inconclusive and at times less than encouraging.

As a result of this study's findings, the investigator feels strongly that even though mothers' feelings appear ambivalent in any singular moment in time, as a group, mothers of cerebral palsied children sincerely believe in the benefit of therapy. This belief in therapy is promulgated due to perceptions of their children making progress in therapy as evidenced by an increased ability of their child to function better physically.

Certain poignant considerations arise from the results of the
study. Past emphasis on the medical aspects of Cerebral Palsy accounts, in part, for the neglect in meeting other important needs of cerebral palsied children and their parents.

Not until the passage of the Dale/Bartley bill in 1974, otherwise referred to as Chapter 766, were public schools in the Commonwealth of Massachusetts required to provide special education facilities for all handicapped children under the age of 22. Although this law is continuing to experience difficulties in its implementation, it has served to bolster the spirits of many mothers of cerebral palsied children.

Another point concerns the use of community services. Ignorant and apathetic attitudes exist on the part of many families, particularly in high poverty areas, regarding utilization of services which are presently available.

A most significant and immediate problem is the inability of the community to provide a full range and depth of services as well as an even distribution of these services making them available in non-urban as well as urban areas. Lower population in non-urban areas compared to urban areas combined with the fact that Cerebral Palsy is a low incidence disability makes planning difficult.

**Recommendations: Data Based**

Several recommendations for further research can be made on the basis of the present findings. It is suggested that programs encompass a considerable target
area in order to comprise sufficient numbers of disabled persons to justify the establishment of services.

First, it seems imperative to expose both parents to an orientation as well as supportive services soon after their multi-handicapped child has been identified as being an atypical or "high risk" infant. An appropriate approach to effectively and continuously involving both parents in the "early intervention" process could prevent unsatisfactory outcomes at a later date. Is there a demonstrable relationship between high level parental involvement, services for the cerebral palsied child and family, and lower levels of unsatisfactory outcomes?

Second, there is an absence of longitudinal studies of the families of cerebral palsied persons obtaining a sequence of behavior from the birth of their child through adulthood. Only through continued observations of parents from a developmental perspective can insights about appropriate services be derived.

The investigator feels that the results of the present study are unique. The findings were different than those found in other studies for several reasons. Other studies of parental attitudes toward a handicapped child did not measure attitudes toward tangible treatment modalities. The studies referred to were designed to measure and analyze psychological perceptions of parents toward their handicapped child and the child's perceptions of the parents.

Studies did not have a tendency to measure maternal attitudes and did not define the handicapped population as being cerebral
palsied. A combination of the mother, her cerebral palsied child, and her attitude toward a tangible effect resulted in a unique combination of relationships.

Mothers, for many years, have demonstrated a strong commitment to their cerebral palsied children by transporting them to treatment centers throughout the country and specifically throughout the Commonwealth of Massachusetts. In line with this commitment, the investigator was unable to uncover any previous studies that measured the degree of knowledge, feeling, or action of mothers pertinent to treatment services being helpful in a manner that could be interpreted as significant.

Approximately 30% of the mothers commented in the open-ended questions that schools were providing treatment and education in some cases. In other cases, private treatment centers provided treatment. There is not a centralized approach by professionals to treating cerebral palsied children. Professional Rehabilitation administrators must seek positions in the school systems as well as in private facilities if a coordinated and intelligent approach to the delivery of services is to be accomplished.

As a result of data collection in this study, in-service workshops should be conducted periodically involving therapists and teachers in both the public and private sector.

It can be concluded that mothers of cerebral palsied children have very definite and positive attitudes toward the habilitative therapies. There appears to be a direct proportion between attitudes
of mothers of cerebral palsied children who interact closely with professionals and other parents of handicapped children and their attitudes toward the modalities of treatment.

Attitudes toward a total program of service are not all positive however. Anxieties and frustrations are experienced by mothers as they were identified previously. Conclusions of this particular study indicate that mothers generally have positive attitudes because they perceive progress in their child and an overall increase in physical functioning.

A great deal more work must be completed before it will be possible to speak with assurance about the relationship between parental attitudes toward services for their multi-handicapped child and factors responsible for the development of those attitudes.

Services are oftentimes incomplete and fragmented. Only by understanding the factors most directly affecting outcomes will the efforts and direction of the entire service system be more meaningfully applied and hopefully beneficial.

General Comments and Recommendations: Investigator

The investigator has served in the capacity of Executive Director of a Cerebral Palsy treatment and education center for the past seven years. As an administrator of such a facility, his experiences have been consistent with the findings of this thesis in certain instances and, at other times, inconsistent. While many of the investigator's "hunches" correlated directly with the
results of the study (prior to it being conducted), many other
preconceptions did not.

Medical. The medical effectiveness of therapy is real and tangible
as viewed by the investigator. The fact that the results of medical
studies do not necessarily share this conviction is understandable.
Longitudinal medical studies over an extensive period of time have
not been conducted. Such studies are not very exciting by nature,
lack funding, and will not produce immediate and tangible findings.
Assuming this framework to be true, it can be understood that there
is a reluctance on the part of medical professionals to study small
gains and the improved quality of function demonstrated by handi-
capped persons who have experienced good and continuous treatment
over an extensive period of time. The investigator feels strongly
that allied health professionals, special educators, and parents
working as a team, are in a far better position to state the medical
effectiveness of treatment. The investigator's experiences indicate
that the consensus would state that treatment is in fact effective.
Short-term medical studies cannot accurately reflect short-term
results to a life-long problem.

The matter of continuously seeking an experimental design to
study the brain damaged person is disconcerting. No two physically
handicapped brain damaged persons are alike in their physical or
mental involvement. On this basis alone, the quest for a control
group and the experimental approach to study, although recognized
as being more sophisticated, is in fact impossible. Rhetoric regarding this subject should be abandoned in favor of longitudinal studies conducted periodically over an 8 to 10 year period of time from approximately 3 years of age through 10 to 12 years of age.

The investigator has experienced that the degree of physical involvement of a child does, in fact, have a direct bearing on the mother's attitude toward therapy. Although this experience was not supported by the results of the study, attitudes of mothers toward the habilitation process are more positive if their children are mildly involved physically and mentally. It stands to reason that children who are handicapped to a lesser extent have a greater chance of succeeding in the world as self-sufficient persons. This potential is reflected positively in their parents' attitudes.

One can view also the effectiveness of treatment in another manner. First, it must be acknowledged that psychological overtones do exist to some extent regarding mothers' perceptions of their child's physical and mental progress or lack of it. These psychological perceptions appear to be overshadowed however by a review of professional case records reflecting progress. In addition, it is difficult to believe that mothers would continue to sacrifice their time to the extent that they do if their child made no gains over a period of years. The investigator makes this statement knowing well that normal physical maturation and growth contribute to the progress children make naturally. The commitment of mothers to carrying out home programs for their child also lends
credibility to the observation that mothers do see physical improvement taking place.

Family. The group of mothers responding to the survey appeared to be comprised of a conservative, traditional group demonstrating a great deal of intestinal fortitude. Most mothers were represented in the 26 year old to 45 year old age bracket with a strong commitment to marriage, religion, and the family unit. The investigator has, in recent years, experienced attitudes quite different with the younger set of mothers, ages 18 years to 25 years. Marital problems appear to plague this latter group as evidenced in many cases by confusion toward the treatment process and at times a general disinterest. A continuing fragmentation of family life appears to be growing within the younger families. The reasons are believed to be socio-economic in nature. Regardless of the causes, it is imperative that support programs be developed to counteract this movement if the handicapped person and the family are to survive as a unit. More importantly, the child's chances for services are drastically reduced if the family unit disintegrates. It must also be pointed out, however, that younger mothers with younger children have not yet fully accepted their child's disability nor do they completely comprehend and are ready to accept their lifetime role in this extensive treatment process. The need for social services support is readily identifiable within this group of mothers.
The responsibility for the success of long-term treatment programs cannot be shouldered by professionals alone. The key to success lies in the family carrying out, on a continuous basis and in a disciplined manner, the home treatment program.

In recent years "early intervention programs" have developed with the target population being the culturally disadvantaged mothers of handicapped children. This approach to early identification and referral should be continued and expanded to include all families with handicapped infants irrespective of social class.

Parents of handicapped children must become more realistic regarding their approach to obtaining services for their children. They must be willing to accept a greater responsibility in working personally with their children in treatment and education areas. In addition, they must continue to form coalition groups promoting the development and implementation of legislation aimed at assisting those with low incidence disabilities. This is essential if good programming is to be developed.

The Rehabilitation concept. There may be a definite reason why parents are sometimes charged with not taking advantage of community resources. Their multi-handicapped youngster is more often than not evaluated and treated for the first 12 years of life then promptly eliminated from any serious professional attention regarding career assessment, skill training, and placement.

The Rehabilitation chain has a missing link certainly for the
multi-handicapped young adult. Our society has not yet developed support for how a multi-handicapped young adult can contribute to his/her own independence. Little formal attention is paid to developing work activities for the multi-handicapped which parallels their ability to perform. Oftentimes, handicapped persons are formally tested with non-handicapped norms. Work centers should be available throughout the country allowing the minimum wage to be paid for a full work effort irrespective of production. Emphasis should be placed on the concept equal compensation for a full work effort.

By not directing more attention to the plight of the handicapped adult, all the treatment and education accomplished in the early years becomes nothing more than "stop gap," busy work filling a fleeting moment in time.

Education and the public sector. New legislation has recently mandated that public schools take over the total responsibility of meeting the educational needs of special children. A controversial issue arises, however, when the term education is defined. Ages 3 through 8 is viewed by the investigator as the time for a formal and intense medical treatment program for the multi-handicapped child. Formal education is important during these ages also but only to the extent that its definition includes treatment as well as cognitive learning.

As an administrator, the investigator feels strongly that
private agencies should be encouraged to continue to meet the total treatment and educational needs of multi-handicapped children. Historically, public schools have been charged with an ever-increasing responsibility not only in the area of education but also child-rearing. With the advent of the two income family, schools are taking over the responsibility of the family unit. Although the investigator does not agree with this trend, it does present a stronger argument for private agencies with a professionally trained team of specialists to work skillfully with low incidence disabilities.

It is natural, however unfortunate, that the bureaucracy pushes aside the needs of those with low incidence multiple handicaps in favor of the "more likely to succeed." Furthermore, if a true financial analysis were undertaken, it would demonstrate that private agencies can do the job less expensively primarily for the reason that there is greater accountability in the private sector. Private agencies represent small, not-for-profit businesses with an excellent product by and large and a need to survive. They must run more efficiently in order to continue in existence.

It is unfair to place the medical aspects of programming for the multi-handicapped squarely on the shoulders of the public school and expect that the job can be accomplished properly. They are simply not equipped to coordinate the necessary services in a non-fragmented manner.

It is encouraging to see however that special needs children
are being treated and educated throughout the Commonwealth of Massachusetts. Although the delivery of these services is fragmented in many instances, Massachusetts is far ahead of many other states comparatively in their attempt to meet the needs of this population.

In the months and years to come, a continuous effort should be made to provide marital counseling for parents of multi-handicapped children as well as in-service training for professionals in the fields of allied health and special education. An emphasis toward centralizing all out-patient services for the individual child should be encouraged so that the treatment and education of the "whole child" can be accomplished more realistically and effectively.
REFERENCES


Birbeck, Herbert E. Parental attitudes in families where Cerebral Palsy is present (Doctoral dissertation, University of Iowa, 1960). Dissertation Abstracts International, 1960, 21, issue 7, 1840. (University Microfilms No. 60-5642)


Little, William John. On the influence of abnormal parturition, difficult labor, premature birth and asphyxia neonatorium, on the mental and physical condition of the child, especially with deformities. Lancet, 1861, 2, 378-380.


APPENDICES
APPENDIX A

LETTERS

QUESTIONNAIRE
January 1978

Dear Parent:

The study in which you are about to participate is being conducted by the United Cerebral Palsy Association of Merrimack Valley for the expressed purpose of providing better services to cerebral palsied children and their families.

Approximately five hundred questionnaires designed to measure mothers' attitudes toward Physical Therapy, Occupational Therapy, and Speech Therapy are being sent to mothers of cerebral palsied children throughout the Commonwealth of Massachusetts. It is anticipated that this large number of participants will lend statewide as well as national significance to the project. The results of the study will be shared nationally, via professional journals, with all interested parents and professionals.

With a good understanding of the causes that shape attitudes of mothers of cerebral palsied children toward the habilitative therapies, better support programs for parents and better direct services to children will result.

Hopefully, the survey gives you, the mother, the real primary provider of therapy, a chance to express your feelings about those many years of therapy for your child.

Your response to this study is essential if all of us are to be successful in treating the handicapped.

In an attempt to keep the survey current, we would ask that if your child is twenty-two years of age or older, please complete only questions one through four, and return the survey. All other mothers should complete the survey fully and return it promptly.

The questionnaire should take approximately thirty minutes to complete.
It is hoped that we have provided you with all the necessary materials to complete the study and trust that you will find it enjoyable.

Your cooperation is greatly appreciated regarding this matter.

Sincerely,

Frank P. Bernarducci, Ed. M.
Executive Director
United Cerebral Palsy Association of Merrimack Valley
A Study of the Attitudes of Mothers of Cerebral Palsied Children Toward the Habilitative Therapies (Physical Therapy, Occupational Therapy, and Speech Therapy)

The purpose of this study is to measure not only the attitudes of mothers toward the habilitative therapies as the title suggests but, more importantly, the results of the study will give professionals and mothers of cerebral palsied children a better understanding as to what causes the formation of attitudes. A more complete knowledge of those causes underlying the formation of these attitudes will assist both providers and consumers in designing programs and services that more accurately meet the needs of the multi-handicapped child and the family.

Instructions: In each question, PLEASE CIRCLE THE NUMBER BESIDE THE RESPONSE that is most appropriate. If a fill-in response is required, please comply accordingly.

1. Please state the town in which you reside ____________________________.

2. How many physically handicapped brain damaged children do you have?
   1. 1
   2. 2
   3. More than 2

   If you have more than one physically handicapped brain damaged child, please answer the questions in the survey in relation to one child only.

3. Is your child a foster care child?
   1. Yes
   2. No

4. Is your physically handicapped brain damaged child:
   1. Male
   2. Female
5. What is the age of your child?
   1. 0 - 3 years
   2. 4 - 8 years
   3. 9 - 14 years
   4. 15 - 18 years
   5. 19 - 21 years
   6. 22 - years or older *

* Mothers of a child 22 years or older, please return survey at this time. Thank you very much for your assistance in conducting this survey.

6. What is the total number of children in your family including your physically handicapped brain damaged child?
   1. 1
   2. 2
   3. 3
   4. 4
   5. 5 or more

7. What is the order of birth of your physically handicapped brain damaged child in the family?
   1. 1st born
   2. 2nd born
   3. 3rd born
   4. 4th born
   5. 5th born
8. To what extent did you have knowledge of Cerebral Palsy or physical disabilities in general prior to the birth of your physically handicapped brain damaged child?

1. Very great extent
2. Great extent
3. Some extent
4. Little extent
5. No extent

9. Does your physically handicapped brain damaged child live:

1. With you
2. In a residential facility
3. In his/her own residence
4. Elsewhere

10. Are there any children in your family with handicaps, other than physically handicapped brain damage?

1. None
2. 1
3. 2
4. 3 or more

11. Please state the medical diagnosis of your physically handicapped brain damaged child as you know it.

12. Is your child mildly handicapped, moderately handicapped, or severely handicapped?

1. Mild - Child is able to walk, use arms, and speak well enough to require no special help.
2. Moderate - Serious enough to handicap the child in walking, communication, and self-help skills but not sufficiently to
disable the child entirely.

3. Severe - Child is incapacitated to the extent that he or she is bedridden or restricted to a wheelchair.

13. What is your child's primary problem?
   1. Physical problem
   2. Mental retardation
   3. Learning disabled
   4. Developmentally delayed
   5. Other mental condition

14. How many years of schooling did you complete?
   1. Less than 6 years
   2. 7 - 9 years
   3. 10 - 12 years
   4. 2 year college graduate
   5. 4 year college graduate

15. What is your age?
   1. Less than 18 years
   2. 18 - 25 years
   3. 26 - 35 years
   4. 36 - 45 years
   5. 46 years or older

16. What is your marital status?
   1. Single
   2. Married
   3. Separated
   4. Divorced
5. Widowed

6. Re-married

17. To what extent does the presence of your physically handicapped brain damaged child allow you to be involved in outside social activities?

1. Very great extent
2. Great extent
3. Same extent
4. Little extent
5. No extent

18. To what extent has the presence of a physically handicapped brain damaged child had a positive impact upon your life style?

1. Very great extent
2. Great extent
3. Same extent
4. Little extent
5. No extent

19. What is your religious preference?

1. Catholic
2. Protestant
3. Jewish
4. Other
5. No religious preference

20. What is the father's religious preference?

1. Catholic
2. Protestant
3. Jewish
4. Other
5. No religious preference

21. How helpful has your child's doctor been in treating and/or referring your child to an appropriate treatment source?
   1. Very helpful
   2. Somewhat helpful
   3. Not that helpful
   4. Not helpful at all

22. How comfortable a professional relationship do you have with the doctor most knowledgeable about your child's case?
   1. Very comfortable
   2. Comfortable
   3. Uncomfortable
   4. Very uncomfortable

23. How do you feel about the number of professional medical specialists involved with your child?
   1. Too many
   2. Adequate number
   3. Not the right specialists
   4. Not enough specialists

24. At what age was your child enrolled in a therapy program?
   1. 0 - 3 years
   2. 4 - 6 years
   3. 7 - 10 years
   4. 11 - 15 years
   5. 16 years or older
   6. Not enrolled in a therapy program
25. To what extent are you involved with your child's therapy program?
   1. Very great extent
   2. Great extent
   3. Little extent
   4. No extent

26. How often does (or did) your child receive Physical Therapy?
   1. 1 time per week
   2. 2 times per week
   3. 1 time per month
   4. Less than 1 time per month
   5. Child never received Physical Therapy

27. How often does (or did) your child receive Occupational Therapy?
   1. 1 time per week
   2. 2 times per week
   3. 1 time per month
   4. Less than 1 time per month
   5. Child never received Occupational Therapy

28. How often does (or did) your child receive Speech Therapy?
   1. 2 times per week
   2. 1 time per week
   3. 1 time per month
   4. Less than 1 time per month
   5. Child never received Speech Therapy

29. Which therapy do you feel has been most helpful to your child?
   1. Physical Therapy
2. Occupational Therapy
3. Speech Therapy
4. Physical Therapy and Occupational Therapy
5. All equally helpful
6. None

30. What therapy, if any, do you feel your child should receive more often?
1. Physical Therapy
2. Occupational Therapy
3. Speech Therapy
4. Physical Therapy/Occupational Therapy
5. Child receives adequate therapy generally
6. Child is not in need of any therapy

31. In your experiences, do you feel more comfortable with the Physical Therapist, the Occupational Therapist, or the Speech Therapist?
1. Physical Therapist
2. Occupational Therapist
3. Speech Therapist
4. It varied equally
5. All
6. None

32. To what extent have all the different therapies your child has received helped your child to function better physically?
1. Very great extent
2. Great extent
3. Some extent
4. Little extent
5. No extent

33. When changes were made in your child's treatment program, when did you become aware of them?
   1. Before such changes were to be made
   2. At the time changes were made
   3. After changes were made
   4. Not aware that changes were ever made

34. How involved are you with professional staff in making changes or decisions in your child's treatment plan?
   1. Very much involved
   2. Involved
   3. Seldom involved
   4. Not involved at all

35. To the best of your knowledge are the treatment records kept on your child satisfactory?
   1. Very satisfactory
   2. Satisfactory
   3. Unsatisfactory
   4. Very unsatisfactory
   5. I have no knowledge of how treatment records are kept.

36. Do you feel that family counseling by a social worker was helpful to you, your physically handicapped brain damaged child, and your family?
   1. Very helpful
   2. Somewhat helpful
   3. Not helpful at all
   4. Never received the service
37. Do you feel that your child's participation in counseling by a social worker or psychologist was helpful?
   1. Very helpful
   2. Somewhat helpful
   3. Not helpful at all
   4. Never received the service

38. Do you feel that interaction with other parents of handicapped children was helpful?
   1. Very helpful
   2. Somewhat helpful
   3. Not helpful at all
   4. Never had the opportunity

39. Are there any services other than the above (questions 36, 37, 38) that you feel would be helpful to you, your child, and your family?
   Please specify _______________________________________

40. Did your attitude toward therapy for your child change as the number of children increased in your family?
   1. Became more involved with child's therapy program
   2. Became less involved with child's therapy program
   3. Remained the same
   4. Not applicable

41. Surgery, in your opinion, is:
   1. More helpful than therapies
   2. As helpful as therapies
   3. Less helpful than therapies
   4. Not helpful at all
   5. Difficult to determine
42. In your particular situation has surgery caused your child's condition to be:

1. Very much improved
2. Improved
3. Didn't change
4. Condition worsened as a result of surgery
5. Child never had surgery

43. How frequently did you make requests to participate in therapy with your child?

1. Frequently
2. Occasionally
3. Seldom
4. Not at all

44. How frequently did professional staff request your presence at this treatment center to participate in your child's therapy program?

1. Frequently
2. Occasionally
3. Seldom
4. Not at all

45. Are you involved in carrying out therapy in the home for your child?

1. Actively involved
2. Occasionally involved
3. Not involved at all
4. Home program is not currently available

46. Do you feel that you receive adequate information about how to help your child while carrying out therapies at home?

1. Information is quite adequate
2. Information is inadequate
3. Would like more information

47. In general, when you communicated by phone with representatives of the agency treating your child, how satisfactory was the communication?
   1. Very satisfactory
   2. Satisfactory
   3. Unsatisfactory
   4. Not applicable

48. To what extent do you think therapy has been effective for your child?
   1. Very great extent
   2. Great extent
   3. Little extent
   4. No extent

49. How often have therapists visited your home and given therapy?
   1. 1 time per week
   2. 2 times per month
   3. 1 time per month
   4. Less than 1 time per month
   5. Not at all

50. Do you find the experience of therapists treating your child in your home:
   1. Effective and comfortable
   2. Comfortable but ineffective
   3. Uncomfortable and ineffective
   4. Therapists never treated my child in the home
51. Which of the following pays for most treatment services for your child?

1. Private health insurance
2. Medicaid
3. Other State agency
4. Federal Government
5. Personal finances

52. How great a financial burden is the payment of health services for your child?

1. Very great burden (more than 20% of yearly income)
2. Great burden (10% - 20% of yearly income)
3. Burden (5% - 10% of yearly income)
4. Not that burdensome (less than 5% of yearly income)
5. No burden at all

53. If your personal finances were the only source of payment for therapy, which would you choose to pay for?

1. Physical Therapy only
2. Occupational Therapy only
3. Speech Therapy only
4. Physical Therapy and Occupational Therapy
5. All
6. None

54. Do you feel that your child is making:

1. Good progress in therapy generally
2. Average progress in therapy generally
3. Poor progress in therapy generally
4. Uncertain about progress in therapy
5. No progress in therapy

55. How far is the appropriate treatment facility for your child?
   1. Less than 10 miles
   2. 10 to 20 miles
   3. 21 to 40 miles
   4. Greater than 41 miles
   5. Facility not available

56. What is your main source of travel to the treatment facility?
   1. School bus
   2. Train
   3. Taxi
   4. Family car
   5. Other

57. Comment: Please feel free to make any personal comments you might feel appropriate about this study in general or the questions in the survey specifically.
January 1978

Dear Parent:

Approximately two weeks ago you received a survey in the mail requesting your support in a very important study.

A great portion of the success and national significance of this study will depend on your cooperation.

In order to continue to provide appropriate services of the highest quality to the multi-handicapped, we need to know your feelings about such matters.

If you have not yet taken the time to fill out the survey, please do so.

Your experience as a mother of a multi-handicapped person is invaluable to all the professionals who have dedicated their careers to helping you and yours.

With sincere appreciation,

Frank P. Bernarducci, Ed. M.
Executive Director
APPENDIX B

TABLES 1 TO 28
<table>
<thead>
<tr>
<th>Age categories</th>
<th>Absolute frequency</th>
<th>Adjusted frequency (PCT)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Zero to three</td>
<td>16</td>
<td>9.4</td>
</tr>
<tr>
<td>Four to eight</td>
<td>48</td>
<td>28.2</td>
</tr>
<tr>
<td>Nine to fourteen</td>
<td>53</td>
<td>31.2</td>
</tr>
<tr>
<td>Fifteen to eighteen</td>
<td>15</td>
<td>8.8</td>
</tr>
<tr>
<td>Nineteen to twenty-one</td>
<td>12</td>
<td>7.1</td>
</tr>
<tr>
<td>Over twenty-one</td>
<td>26</td>
<td>15.3</td>
</tr>
<tr>
<td>Total</td>
<td>170</td>
<td>100.0</td>
</tr>
</tbody>
</table>
### TABLE 2

Absolute Frequency and Adjusted Frequency Percentage of the Number of Cerebral Palsied Persons in One Family

<table>
<thead>
<tr>
<th>Cerebral palsied persons</th>
<th>Absolute frequency</th>
<th>Adjusted frequency (PCT)</th>
</tr>
</thead>
<tbody>
<tr>
<td>One cerebral palsied person</td>
<td>162</td>
<td>95.2</td>
</tr>
<tr>
<td>Two cerebral palsied persons</td>
<td>4</td>
<td>2.4</td>
</tr>
<tr>
<td>More than two cerebral palsied persons</td>
<td>4</td>
<td>2.4</td>
</tr>
<tr>
<td>Total</td>
<td>170</td>
<td>100.0</td>
</tr>
</tbody>
</table>
TABLE 3

Absolute Frequency and Adjusted Frequency Percentage of the Total Number of Children in Each Family Including the Cerebral Palsied Child

<table>
<thead>
<tr>
<th>Number of children</th>
<th>Absolute frequency</th>
<th>Adjusted frequency (PCT)</th>
</tr>
</thead>
<tbody>
<tr>
<td>One child</td>
<td>16</td>
<td>11.1</td>
</tr>
<tr>
<td>Two children</td>
<td>38</td>
<td>26.4</td>
</tr>
<tr>
<td>Three children</td>
<td>35</td>
<td>24.8</td>
</tr>
<tr>
<td>Four children</td>
<td>23</td>
<td>16.0</td>
</tr>
<tr>
<td>Five children</td>
<td>31</td>
<td>21.0</td>
</tr>
<tr>
<td>More than five children</td>
<td>1</td>
<td>.7</td>
</tr>
<tr>
<td>Total</td>
<td>144</td>
<td>100.0</td>
</tr>
</tbody>
</table>
TABLE 4

Absolute Frequency and Adjusted Frequency Percentage of the Order of Birth of the Cerebral Palsied Child in the Family

<table>
<thead>
<tr>
<th>Order of birth</th>
<th>Absolute frequency</th>
<th>Adjusted frequency (PCT)</th>
</tr>
</thead>
<tbody>
<tr>
<td>First-born</td>
<td>40</td>
<td>29.0</td>
</tr>
<tr>
<td>Second-born</td>
<td>41</td>
<td>29.7</td>
</tr>
<tr>
<td>Third-born</td>
<td>23</td>
<td>16.7</td>
</tr>
<tr>
<td>Fourth-born</td>
<td>12</td>
<td>8.7</td>
</tr>
<tr>
<td>Fifth-born</td>
<td>22</td>
<td>15.9</td>
</tr>
<tr>
<td>Total</td>
<td>138</td>
<td>100.0</td>
</tr>
</tbody>
</table>
TABLE 5

Absolute Frequency and Adjusted Frequency Percentage of the Degree of Physical Involvement of the Cerebral Palsied Group

<table>
<thead>
<tr>
<th>Degree of physical involvement</th>
<th>Absolute frequency</th>
<th>Adjusted frequency (PCT)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td>31</td>
<td>22.0</td>
</tr>
<tr>
<td>Moderate</td>
<td>82</td>
<td>58.1</td>
</tr>
<tr>
<td>Severe</td>
<td>28</td>
<td>19.9</td>
</tr>
<tr>
<td>Total</td>
<td>141</td>
<td>100.0</td>
</tr>
</tbody>
</table>
TABLE 6

Absolute Frequency and Adjusted Frequency Percentage
of Mothers' Age in the Study Population

<table>
<thead>
<tr>
<th>Mothers' age</th>
<th>Absolute frequency</th>
<th>Adjusted frequency (PCT)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eighteen to twenty-five</td>
<td>6</td>
<td>4.2</td>
</tr>
<tr>
<td>Twenty-six to thirty-five</td>
<td>56</td>
<td>39.2</td>
</tr>
<tr>
<td>Thirty-six to forty-five</td>
<td>54</td>
<td>37.8</td>
</tr>
<tr>
<td>More than forty-five</td>
<td>27</td>
<td>18.8</td>
</tr>
<tr>
<td>Total</td>
<td>143</td>
<td>100.0</td>
</tr>
<tr>
<td>Degree of physicians' helpfulness</td>
<td>Absolute frequency</td>
<td>Adjusted frequency (PCT)</td>
</tr>
<tr>
<td>----------------------------------</td>
<td>--------------------</td>
<td>-------------------------</td>
</tr>
<tr>
<td>Very helpful</td>
<td>68</td>
<td>48.2</td>
</tr>
<tr>
<td>Somewhat helpful</td>
<td>49</td>
<td>34.8</td>
</tr>
<tr>
<td>Not that helpful</td>
<td>18</td>
<td>12.8</td>
</tr>
<tr>
<td>Not helpful at all</td>
<td>16</td>
<td>4.2</td>
</tr>
<tr>
<td>Total</td>
<td>151</td>
<td>100.0</td>
</tr>
</tbody>
</table>
TABLE 8

Absolute Frequency and Adjusted Frequency Percentage of Those Therapy Modalities Mothers Thought to be Most Helpful to Their Cerebral Palsied Child

<table>
<thead>
<tr>
<th>Most helpful therapy modalities</th>
<th>Absolute frequency</th>
<th>Adjusted frequency (PCT)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical therapy</td>
<td>50</td>
<td>36.0</td>
</tr>
<tr>
<td>Occupational therapy</td>
<td>5</td>
<td>3.6</td>
</tr>
<tr>
<td>Speech therapy</td>
<td>14</td>
<td>10.1</td>
</tr>
<tr>
<td>Physical therapy and occupational therapy</td>
<td>22</td>
<td>15.8</td>
</tr>
<tr>
<td>All</td>
<td>41</td>
<td>29.5</td>
</tr>
<tr>
<td>None</td>
<td>7</td>
<td>5.0</td>
</tr>
<tr>
<td>Total</td>
<td>139</td>
<td>100.0</td>
</tr>
</tbody>
</table>
TABLE 9

Absolute Frequency and Adjusted Frequency Percentage
of the Age that Cerebral Palsied Children
were Enrolled in Therapy

<table>
<thead>
<tr>
<th>Commencement age of therapy</th>
<th>Absolute frequency</th>
<th>Adjusted frequency (PCT)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Zero to three years</td>
<td>105</td>
<td>73.9</td>
</tr>
<tr>
<td>Four to six years</td>
<td>21</td>
<td>14.8</td>
</tr>
<tr>
<td>Seven to ten years</td>
<td>6</td>
<td>4.2</td>
</tr>
<tr>
<td>Eleven to fifteen years</td>
<td>4</td>
<td>2.8</td>
</tr>
<tr>
<td>Sixteen years or older</td>
<td>1</td>
<td>.7</td>
</tr>
<tr>
<td>Never enrolled in a therapy program</td>
<td>5</td>
<td>3.6</td>
</tr>
<tr>
<td>Total</td>
<td>142</td>
<td>100.0</td>
</tr>
<tr>
<td>Extent of therapy helpfulness</td>
<td>Absolute frequency</td>
<td>Adjusted frequency (PCT)</td>
</tr>
<tr>
<td>-----------------------------</td>
<td>--------------------</td>
<td>-------------------------</td>
</tr>
<tr>
<td>Very great extent</td>
<td>35</td>
<td>24.8</td>
</tr>
<tr>
<td>Great extent</td>
<td>45</td>
<td>31.9</td>
</tr>
<tr>
<td>Some extent</td>
<td>45</td>
<td>31.9</td>
</tr>
<tr>
<td>Little extent</td>
<td>11</td>
<td>7.8</td>
</tr>
<tr>
<td>No extent</td>
<td>5</td>
<td>3.6</td>
</tr>
<tr>
<td>Total</td>
<td>141</td>
<td>100.0</td>
</tr>
</tbody>
</table>
### Table I

<table>
<thead>
<tr>
<th>Mothers' awareness of change</th>
<th>Absolute frequency</th>
<th>Adjusted frequency (PCT)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Before changes were made</td>
<td>65</td>
<td>47.1</td>
</tr>
<tr>
<td>At the time changes were made</td>
<td>57</td>
<td>41.3</td>
</tr>
<tr>
<td>After changes were made</td>
<td>7</td>
<td>5.1</td>
</tr>
<tr>
<td>Not aware that changes were made</td>
<td>9</td>
<td>6.5</td>
</tr>
<tr>
<td>Total</td>
<td>138</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Absolute Frequency and Adjusted Frequency Percentage of the Time that Mothers Became Aware of Changes in Their Cerebral Palsied Child's Treatment Program
TABLE 12

Absolute Frequency and Adjusted Frequency Percentage
of the Degree of Mother Involvement with Professional Staff
in Making Changes and Decisions
in their Child's Treatment Plan

<table>
<thead>
<tr>
<th>Mothers' involvement with therapy changes</th>
<th>Absolute frequency</th>
<th>Adjusted frequency (PCT)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very much involved</td>
<td>56</td>
<td>40.6</td>
</tr>
<tr>
<td>Involved</td>
<td>55</td>
<td>39.9</td>
</tr>
<tr>
<td>Seldom involved</td>
<td>18</td>
<td>13.0</td>
</tr>
<tr>
<td>Not involved at all</td>
<td>9</td>
<td>6.5</td>
</tr>
<tr>
<td>Total</td>
<td>138</td>
<td>100.0</td>
</tr>
</tbody>
</table>
TABLE 13

Absolute Frequency and Adjusted Frequency Percentage of Degree of Involvement of Mothers Carrying Out Therapy in the Home for their Child

<table>
<thead>
<tr>
<th>Mothers' home therapy involvement</th>
<th>Absolute frequency</th>
<th>Adjusted frequency (PCT)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Actively involved</td>
<td>85</td>
<td>61.2</td>
</tr>
<tr>
<td>Occasionally involved</td>
<td>24</td>
<td>17.3</td>
</tr>
<tr>
<td>Not involved at all</td>
<td>18</td>
<td>12.9</td>
</tr>
<tr>
<td>Home program not currently available</td>
<td>12</td>
<td>8.6</td>
</tr>
<tr>
<td>Total</td>
<td>139</td>
<td>100.0</td>
</tr>
</tbody>
</table>
**TABLE 14**

Absolute Frequency and Adjusted Frequency Percentage of the Extent to Which Mothers Feel that Therapy Has Been Effective for their Child

<table>
<thead>
<tr>
<th>Therapy effectiveness</th>
<th>Absolute frequency</th>
<th>Adjusted frequency (PCT)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very great extent</td>
<td>56</td>
<td>40.3</td>
</tr>
<tr>
<td>Great extent</td>
<td>54</td>
<td>38.8</td>
</tr>
<tr>
<td>Little extent</td>
<td>25</td>
<td>18.0</td>
</tr>
<tr>
<td>No extent</td>
<td>4</td>
<td>2.9</td>
</tr>
<tr>
<td>Total</td>
<td>139</td>
<td>100.0</td>
</tr>
</tbody>
</table>
TABLE 15

Absolute Frequency and Adjusted Frequency Percentage of Those Sources of Payment Responsible for Most Treatment Services for the Cerebral Palsied Child

<table>
<thead>
<tr>
<th>Sources of payment</th>
<th>Absolute frequency</th>
<th>Adjusted frequency (PCT)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Private insurance</td>
<td>68</td>
<td>48.6</td>
</tr>
<tr>
<td>Medicaid</td>
<td>39</td>
<td>27.9</td>
</tr>
<tr>
<td>Other State agency</td>
<td>20</td>
<td>14.3</td>
</tr>
<tr>
<td>Federal Government</td>
<td>4</td>
<td>2.9</td>
</tr>
<tr>
<td>Personal finances</td>
<td>9</td>
<td>6.3</td>
</tr>
<tr>
<td>Total</td>
<td>140</td>
<td>100.0</td>
</tr>
</tbody>
</table>
TABLE 16

Absolute Frequency and Adjusted Frequency Percentage of the Extent to Which the Payment of Health Services for the Cerebral Palsied Child is a Financial Burden

<table>
<thead>
<tr>
<th>Degree of financial burden</th>
<th>Absolute frequency</th>
<th>Adjusted frequency (PCT)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very great burden (&gt; 20% of yearly income)</td>
<td>8</td>
<td>5.9</td>
</tr>
<tr>
<td>Great burden (10% to 20% of yearly income)</td>
<td>14</td>
<td>10.3</td>
</tr>
<tr>
<td>Burden (5% to 10% of yearly income)</td>
<td>25</td>
<td>18.4</td>
</tr>
<tr>
<td>Not that burdensome (less than 5% of yearly income)</td>
<td>46</td>
<td>33.8</td>
</tr>
<tr>
<td>No burden at all</td>
<td>43</td>
<td>31.6</td>
</tr>
<tr>
<td>Total</td>
<td>136</td>
<td>100.0</td>
</tr>
</tbody>
</table>
TABLE 17

Observed Frequencies of Professional Staff Requests for Mothers' Presence at the Treatment Facility to Participate in Child's Treatment Program and the Extent of Mothers' Involvement with the Child's Therapy Program

<table>
<thead>
<tr>
<th>Mothers' involvement</th>
<th>Staff requests</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Frequently</td>
<td>Occasionally</td>
<td>Seldom</td>
<td>Never</td>
</tr>
<tr>
<td>Very great extent</td>
<td>22</td>
<td>11</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Great extent</td>
<td>19</td>
<td>21</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Little extent</td>
<td>4</td>
<td>14</td>
<td>5</td>
<td>11</td>
</tr>
<tr>
<td>No extent at all</td>
<td>2</td>
<td>5</td>
<td>1</td>
<td>6</td>
</tr>
</tbody>
</table>

\[ x^2 = 27.44 \quad df = 9 \quad p < .01 \]
### TABLE 18

Observed Frequencies as to the Extent to Which Mothers Viewed the Payment of Health Services For their Cerebral Palsied Child as a Financial Burden and the Extent of Mothers' Involvement in Therapy with their Child

<table>
<thead>
<tr>
<th>Mothers' involvement</th>
<th>Financial burden</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Very great burden</td>
<td>Great burden</td>
<td>Burden</td>
<td>Some burden</td>
<td>No burden</td>
</tr>
<tr>
<td>Very great extent</td>
<td>1</td>
<td>5</td>
<td>11</td>
<td>15</td>
<td>10</td>
</tr>
<tr>
<td>Great extent</td>
<td>2</td>
<td>3</td>
<td>5</td>
<td>20</td>
<td>16</td>
</tr>
<tr>
<td>Little extent</td>
<td>1</td>
<td>3</td>
<td>6</td>
<td>9</td>
<td>15</td>
</tr>
<tr>
<td>No extent at all</td>
<td>4</td>
<td>2</td>
<td>3</td>
<td>2</td>
<td>2</td>
</tr>
</tbody>
</table>

\[ x^2 = 26.06 \quad df = 12 \quad p < .05 \]
TABLE 19

Observed Frequencies of Therapy
Thought to be Most Helpful to the Child
and the Number of Times the Child Received Physical Therapy

<table>
<thead>
<tr>
<th>Times received Physical Therapy</th>
<th>Therapy most helpful</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Physical therapy</td>
</tr>
<tr>
<td>Once per week</td>
<td>17</td>
</tr>
<tr>
<td>Twice per week</td>
<td>19</td>
</tr>
<tr>
<td>Once per month</td>
<td>14</td>
</tr>
</tbody>
</table>

\[ x^2 = 16.74 \quad df = 8 \quad p < .05 \]
TABLE 20

Observed Frequencies of the Extent to Which All Therapies Helped the Child to Function Better Physically and Mothers' Attitude Toward the Helpfulness of Doctors' Treating or Referring Their Child to an Appropriate Treatment Facility

<table>
<thead>
<tr>
<th>Doctors' helpfulness</th>
<th>Function</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Great extent</td>
<td>Some extent</td>
<td></td>
</tr>
<tr>
<td>Very helpful</td>
<td>47</td>
<td>18</td>
<td></td>
</tr>
<tr>
<td>Somewhat helpful</td>
<td>23</td>
<td>23</td>
<td></td>
</tr>
<tr>
<td>Not much helpful</td>
<td>8</td>
<td>9</td>
<td></td>
</tr>
</tbody>
</table>

\[ x^2 = 7.21 \quad df = 2 \quad p < .05 \]


TABLE 21

Observed Frequencies of the Extent to Which All Therapies Helped the Child to Function Better Physically and the Frequency of Professionals Requesting Mothers' Presence at the Treatment Facility to Participate in the Child's Therapy Program

<table>
<thead>
<tr>
<th>Staff requests</th>
<th>Function</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Great extent</td>
<td>Some extent</td>
<td></td>
</tr>
<tr>
<td>Frequently</td>
<td>36</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>Occasionally</td>
<td>33</td>
<td>31</td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>7</td>
<td>14</td>
<td></td>
</tr>
</tbody>
</table>

\[ x^2 = 15.31 \quad \text{df} = 2 \quad p < .01 \]
TABLE 22

Observed Frequencies of Mothers' Attitude Toward Interacting with Parents of other Handicapped Children and the Extent to Which Mothers Felt that All Therapies Helped Their Child to Function Better Physically

<table>
<thead>
<tr>
<th>Function</th>
<th>Very helpful</th>
<th>Somewhat helpful</th>
<th>Not helpful</th>
<th>Never helpful</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very great extent</td>
<td>21</td>
<td>6</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Great extent</td>
<td>14</td>
<td>14</td>
<td>3</td>
<td>13</td>
</tr>
<tr>
<td>Some extent</td>
<td>8</td>
<td>24</td>
<td>2</td>
<td>9</td>
</tr>
<tr>
<td>Little extent</td>
<td>3</td>
<td>5</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

\[ x^2 = 23.23 \quad \text{df} = 9 \quad p < .01 \]
TABLE 23

Observed Frequencies of Mothers' Age
and Mothers' Opinion as to Whether Surgery Was
More or Less Helpful than Therapies

<table>
<thead>
<tr>
<th>Surgery helpful</th>
<th>Mothers' age</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>26--35</td>
<td>36--45</td>
</tr>
<tr>
<td>More helpful</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Same</td>
<td>6</td>
<td>13</td>
</tr>
<tr>
<td>Less helpful</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Not helpful</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Difficult to determine</td>
<td>36</td>
<td>20</td>
</tr>
</tbody>
</table>

\[ x^2 = 19.26 \quad df = 8 \quad p < .05 \]
## TABLE 24

Observed Frequencies of Mothers' Attitude Toward Surgery

**Being More or Less Helpful than Therapy**

and the Extent of Help Experienced in Family Counseling

**With a Social Worker**

<table>
<thead>
<tr>
<th>Counseling helpful</th>
<th>Surgery helpful</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>More helpful</td>
<td>Same</td>
</tr>
<tr>
<td>Very helpful</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Somewhat helpful</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Not helpful</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td>Never helpful</td>
<td>4</td>
<td>15</td>
</tr>
</tbody>
</table>

\[ x^2 = 22.35 \]  \[ df = 9 \]  \[ p < .01 \]
<table>
<thead>
<tr>
<th>Home therapy</th>
<th>Staff requests</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Frequently</td>
<td>Occasionally</td>
</tr>
<tr>
<td>Active</td>
<td>38</td>
<td>30</td>
</tr>
<tr>
<td>Occasionally</td>
<td>3</td>
<td>12</td>
</tr>
<tr>
<td>Not involved</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>Not available</td>
<td>5</td>
<td>2</td>
</tr>
</tbody>
</table>

\[ x^2 = 27.59 \quad df = 9 \quad p < .01 \]
TABLE 26

Observed Frequencies of Mothers' Involvement in Carrying Out Home Therapy Programs and the Extent of Mothers' Requests to Participate in Therapy with their Child

<table>
<thead>
<tr>
<th>Mothers' requests</th>
<th>Home therapy</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Active</td>
<td>Occasionally</td>
<td>Not involved</td>
<td>Not available</td>
</tr>
<tr>
<td>Frequently</td>
<td>45</td>
<td>4</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Occasionally</td>
<td>23</td>
<td>11</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>Seldom</td>
<td>5</td>
<td>6</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Never</td>
<td>9</td>
<td>3</td>
<td>9</td>
<td>1</td>
</tr>
</tbody>
</table>

\[ x^2 = 34.12 \quad df = 9 \quad p < .01 \]
### TABLE 27

Observed Frequency of Mothers' Attitude Toward Progress Made in Therapy and the Extent to Which All Therapies Have Helped Their Child to Function Better Physically

<table>
<thead>
<tr>
<th>Function</th>
<th>Progress</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Good</td>
</tr>
<tr>
<td>Great extent</td>
<td>45</td>
</tr>
<tr>
<td>Some extent</td>
<td>5</td>
</tr>
</tbody>
</table>

\[ x^2 = 34.21 \quad \text{df} = 3 \quad p < .01 \]
TABLE 28

Observed Frequency of Mothers' Attitudes Toward Progress Made in Therapy and the Frequency of Mothers' Requesting to Participate in Therapy with their Child

<table>
<thead>
<tr>
<th>Mothers' requests</th>
<th>Good</th>
<th>Average</th>
<th>Poor</th>
<th>Uncertain</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frequently</td>
<td>24</td>
<td>21</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Occasionally</td>
<td>12</td>
<td>19</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>Seldom</td>
<td>2</td>
<td>5</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Never</td>
<td>12</td>
<td>1</td>
<td>2</td>
<td>4</td>
</tr>
</tbody>
</table>

\[ x^2 = 20.64 \quad df = 9 \quad \frac{p}{2} < .05 \]