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A study of the physical, psychosocial, and vocational needs of adults with spastic or athetoid cerebral palsy

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A STUDY OF THE PHYSICAL, PSYCHO-SOCIAL, AND VOCATIONAL NEEDS OF ADULTS WITH SPASTIC OR ATHETOID CEREBRAL PALSY

BY

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1957

A field study
submitted in partial fulfillment of the requirements
for the Degree of Master of Science
in the School of Nursing
Boston University
August, 1961

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ACKNOWLEDGEMENT

This study was supported in part by a training grant from the Office of Vocational Rehabilitation of the Department of Health, Education, and Welfare, Washington, D.C.

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CHAPTER I

INTRODUCTION

There are 600,000 persons in the United States with cerebral palsy and 10,000 babies born with cerebral palsy each year.[1] Seven persons in a 100,000 population are born with cerebral palsy and of these seven, one will die prior to reaching the sixth birthday.[2] On the other hand, Berenberg states that the vast majority of individuals with cerebral palsy who die because of the condition will not live to the age of twenty years.[3] However, the life expectancy of those who live is the same as that for the general population. As pointed out by Perlstein, children born with cerebral palsy are afflicted by a motor dysfunction which may or may not be accompanied by other handicaps of cerebral origin which may later produce learning difficulties, psychological problems,

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[1]William McCahill, "Vocational Rehabilitation," Paper read at Eighth Annual Cerebral Palsy Institute at Boston University, June 13, 1960.

[2]Winthrop M. Phelps, "Cerebral Palsy," ed. W. E. Nelson, Textbook of Pediatrics (Philadelphia: W. B. Saunders Co., 1954), p. 1211.

[3]William Berenberg, "Long Term Follow-up Studies," Paper read at Eighth Annual Cerebral Palsy Institute at Boston University, June 17, 1960.

sensory defects, and convulsive and behavioral disorders.[4] Therefore, it would appear that adults with cerebral palsy have not only the same needs as any adult but have additional needs because of the physical limitations imposed on them as a result of cerebral palsy.

Over the span of years many private and public agencies have been concerned with the care and treatment of children with cerebral palsy. In 1946, the National Society for Crippled Children and Adults organized a cerebral palsy division and in that same year, the American Academy for Cerebral Palsy was established. In March, 1947, the Children's Bureau held a conference in Washington, D.C. to formulate principles and policies for the further development of services for individuals with cerebral palsy. Title V of the Social Security Act authorized the Children's Bureau to make grants for the extension and improvement of existing services to crippled children which includes those with cerebral palsy.[5] The United Cerebral Palsy Associations, Inc. was formed in 1949 by parents of children with cerebral palsy and $800,000 was allotted for research.[6]

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[4]Meyer A. Perlstein, The Problem of Cerebral Palsy Today (New York: Association for the Aid of Crippled Children, 1947), p. 8.

[5]Sherwood Messner, Cerebral Palsy Voluntary and Tax-supported Services in the United States (Boston: Little, Brown and Co., 1958), p. 3.

[6]United Cerebral Palsy Associations, Inc. United Cerebral Palsy Research and Educational Foundation Program for Calendar Year 1959, p. 3.

This association, now eleven years old, has 350 chapters in the United States and grew out of the need for more services to children with cerebral palsy.[7] Although some chapters have selected services for adults, little emphasis has been placed on the adult with cerebral palsy until very recently. It was not until 1955 that the Cerebral Palsy Work Classification and Evaluation project was established in New York City.

Statement of Problem

What are the physical, psycho-social, and vocational needs of adults with spastic or athetoid cerebral palsy?

Justification of Problem

The writer, a public health nurse, acting as a case-finder, counselor, and coordinator in a cerebral palsy clinic, observed that there were many services available for children with cerebral palsy but many of these services were no longer available to patients after they became twenty-one years of age. This experience led to an increased interest in exploring the nature of the needs of adults with cerebral palsy. Continued work and study in rehabilitation has convinced the writer that adults with cerebral palsy could lead happier and more useful lives if their needs, as adults,

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[7]Sherwood Messner, "Community Planning for the Cerebral Palsied," Paper read at Eighth Annual Cerebral Palsy Institute at Boston University, June 7, 1960.

were better understood by community workers and if community services provided for them were based on the needs as identified by the adults with cerebral palsy. The rehabilitation nurse and the public health nurse have to guide, counsel, and advise individuals with cerebral palsy in many instances during the course of their treatment. The findings of this study should be of value to nursing as well as to other professional personnel involved in rehabilitation.

Scope and Limitations

This study is limited to the physical, psycho-social, and vocational needs identified as problems by sixteen adults with a diagnosis of spastic or athetoid cerebral palsy of congenital origin. All participants were at least eighteen years of age, were within the educable range of intelligence, were residents in the Greater Boston area, had received medical supervision at the Children's Medical Center between the years 1930 and 1960, and were participating in the program of the United Cerebral Palsy of Greater Boston, Inc. The findings are applicable only to the group studied and cannot justifiably be generalized to other persons with cerebral palsy.

Definition of Terms

For the purpose of this study, the terms as used, are defined as follows:

1. Cerebral Palsy -- "Any abnormal alteration of movement or motor function arising from defect, injury, or disease of the nervous tissues contained in the cranial cavity present at birth."[8]

2. Athetoid -- A type of cerebral palsy "characterized by involuntary, purposeless movements."[9]

3. Spastic -- A type of cerebral palsy involving "the pyramidal tracts, and manifested by an exaggerated stretch reflex, increased tendon jerks, and an extensor plantar response."[10]

Preview of Methodology

Clinical records of persons with cerebral palsy were studied to detect the problems as reported by the patients or members of their families; the physical findings of the doctors, including their recommendations; the psycho-social and emotional aspects and the suggestions for vocational training which might have been recorded by the members of the rehabilitation team. An interview schedule was developed from information obtained from a review of literature and from the writer's experience.[11] The questions pertained to the physical, psycho-social, and vocational problems that individuals with cerebral palsy might be expected to encounter. The respondents were interviewed by the writer. In order to rate

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[8]Temple Fay, "Desperately Needed - Research in Cerebral Palsy," Cerebral Palsy Review, XIV (March-April, 1953), 11.

[9]Perlstein, op. cit., p. 7.

[10]R. S. Illingworth, Recent Advances in Cerebral Palsy (Boston: Little, Brown and Co., 1958), p. 1.

[11]Appendix A.

the respondents in relation to the physical, psycho-social, and vocational adjustments based on the problems presented, a physical profile and educational-vocational guide which had been developed for a similar study were utilized.[12]

Sequence of Presentation

Chapter II includes a review of the literature and the statement of the hypothesis. The details of the methodology are presented in Chapter III. In Chapter IV, the data are presented and analyzed. Chapter V presents the summary, conclusions, and recommendations.

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[12]Appendix C.

CHAPTER II

THEORETICAL FRAMEWORK OF STUDY

Review of Literature

A review of the available literature indicated that among agencies working with individuals with cerebral palsy there appeared to be a tendency to concentrate on helping children to the exclusion of adults. Perlstein referred to the adult who had cerebral palsy as "the forgotten of the forgotten."[1] In 1957, Crothers said: "our experience leads us to believe that one of the great gaps in our knowledge [of cerebral palsy] is due to the fact that most of us have studied our patients as children and have not been sufficiently aware of end results."[2]

As pointed out by Phelps, "cerebral palsy includes not only the problems of infancy and early childhood, but as their problems continue throughout the life span of the brain injured child they stretch from pediatrics to geriatrics."[3]

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[1]Richard D. Burk and James P. Zimmerman, "Serving the Cerebral Palsied Adult," Journal of Rehabilitation, XXVI (January-February, 1960), 7.

[2]Helen Wortis and William Cooper, "The Life Experience of Persons with Cerebral Palsy," American Journal of Physical Medicine, XXXVI (December, 1957), 328.

[3]Temple Fay, "Cerebral Palsy: Medical Considerations and Classification," American Journal of Psychiatry, CVII (September, 1950), 181.

Since the problems associated with cerebral palsy continue from infancy throughout the life span, the attitudes of parents and their management of such a child will influence the child's adjustment to life. Evidence of emotional disturbance secondary to having a child with cerebral palsy has been observed in parents of these children. Wortis and Cooper reported that

> family members saw their role as serving the handicapped child. They showed marked anxiety in relation to the child's falling, hurting himself, or having convulsions. Overprotection, in some cases, was due to the fact that the mother was anxious, overwhelmed by her problem, and unable to handle it. Overprotective patterns of care, when established in infancy, often continued beyond childhood into adolescence and adulthood.[4]

Thirteen studies related to the problems of adults with cerebral palsy were reviewed in order to compare the findings to the data collected in this study. The findings of nine of these studies are reported in detail.

The Joint Legislative Committee to Study the Problem of Cerebral Palsy was appointed by the New York Legislature in 1946 to study the physical, education, and social problems of individuals with cerebral palsy, to determine what responsibilities the State of New York had toward these patients and to make recommendations on how the responsibilities might be met. One hundred families, in which a member had cerebral palsy,

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[4] Wortis and Cooper, op. cit., 335.

were interviewed by a social worker, and a medical examination of ninety-nine persons was done to determine the medical needs and to make a diagnostic evaluation in doubtful cases.[5]

The significant findings were as follows:

> . . . twenty-two per cent had attended regular school, thirty-four per cent had attended special classes, and twenty-seven per cent attended no school. Regarding employment of those twenty-one years of age and over, twenty-one per cent were fully employed, seventeen per cent partially employed, and sixty-two per cent unemployed. The results of the survey brought about mandatory reporting of cerebral palsy in New York in 1950.[6]

A study of cerebral palsy services, facilities, and needs was conducted in the Boston area, in 1950, by a committee of one hundred people representing various disciplines, with members of the United Cerebral Palsy Association, Inc. staff serving as consultants. Special report forms regarding available services and facilities were used for gathering information from all agencies serving individuals with cerebral palsy. The findings emphasized the need for adequate support of existing diagnostic and therapy programs. The study emphasized the need for leisure time activities for children and adults, group work, informal education, socialization, pre-vocational exploration and testing, job

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[5]William J. Butler, Report of the New York State Joint Legislative Commission to Study the Problems of Cerebral Palsy, Legislature Document #55 (Albany: 1949), p. 11.

[6]Ibid., p. 17.

training, sheltered employment, and job placement as goals.[7]

Osborn conducted a study of cerebral palsy in Connecticut, in 1951, to locate all individuals with cerebral palsy under the age of twenty-one years of age, and to determine the nature and amount of medical and related services needed. Significant findings reported by Osborn were:

> . . . thirty to forty per cent required no restorative services. Twenty-five per cent had a mild, thirty-five per cent moderate, and forty per cent severe degree of involvement. Thirty per cent had visual defects. Thirty per cent had hearing defects. Eighty-two per cent had speech defects. Twenty-four per cent were complicated by epilepsy. Thirty-three per cent had marked dental caries. The study indicated a need for more restorative services, occupational therapy, physical therapy, and speech therapy.[8]

Also, in 1951, Glick made a survey of one hundred and fifty adults with cerebral palsy in New York City regarding the extent of disability and vocational training skills. One hundred and fifty ambulatory adults were interviewed in their homes. Significant findings of the Glick study were:

> Eighty per cent had speech involvement of moderate to severe degree. Seventy-five per cent had multiple physical involvement. Twenty-five per cent used braces, crutches, canes, or wheel-chairs. Seven individuals had hearing difficulties and three of these were severe. Educationally, none of the twenty-three college graduates in the group were using their education. College education appeared to add to their frustration and dissatisfaction and indicated a lack of vocational

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[7]Anon. Boston Area Study of Cerebral Palsy Services, Facilities, and Needs (New York: United Cerebral Palsy Associations, Inc., 1950), pp. 2-3.

[8]Stanley H. Osborn, The Study of Cerebral Palsy in Connecticut (Hartford: Connecticut State Department of Health, 1951), pp. 16, 98.

> guidance. Only seventeen per cent had received vocational guidance after graduation. One service requested most by the respondents was vocational guidance and many expressed a desire to continue their education.
>
> Regarding employment, thirty-seven were employed, ninety-one were unemployed, and twenty-two needed extensive work training. The services requested were speech therapy, occupational therapy, physical therapy, and a few wanted psychotherapy. The respondents placed much stress on recreational activities and expressed a desire to belong to social clubs with non-handicapped people.
>
> From the psycho-social point of view, it was evident that social pathology in the home was a serious problem and might well be responsible for emotional maladjustment which was evident in three-quarters of the respondents. The parental attitudes observed were depression, guilt, overprotection, severe rejection, and denial which affected the individuals with cerebral palsy by causing feelings of inferiority, worthlessness, and an inability to cope with reality which was intensified in the adults with cerebral palsy. A need for more research was indicated.[9]

Another study by Glick was conducted in 1953, in New York City. Two hundred adults with cerebral palsy, eighteen and a half to forty-five years of age, were interviewed in their homes to learn about their adjustment problems, about their family backgrounds, and about the attitudes of the parents. Glick observed:

> . . . that in three-quarters of the cases emotional maladjustment was found involving unrealistic attitudes, inability to make decisions, intense feelings of insecurity and inferiority, and a low frustration tolerance. Eighty per cent of the mildly disabled had difficulty adjusting to their handicaps, in

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[9]Selma J. Glick, "Survey of the Adult Cerebral Palsied Population," Cerebral Palsy Review, XIV (January-February, 1953), 9-10.

> accepting their limitations, and in planning realistically for the future. The parental attitudes of the subjects indicated rejection in twenty per cent of the cases, overprotection in fifty-four per cent, and denial of the existence of cerebral palsy in their offspring in seven per cent. Nineteen per cent of the parents adjusted well to the condition of their children. Seventy per cent showed a lack of motivation which was related to parental overprotection. Forty-two per cent of the cases showed an inability to face reality and had difficulty making meaningful decisions in relation to school programs and vocational choices. Fifty-one per cent displayed excessive fears and three quarters of the cases studied indicated a need for help with their emotional problems.[10]

Berko and Berko conducted a four year occupational inventory survey of adults with cerebral palsy over the age of sixteen years, in New York City. A questionnaire was used. The questions concerned the education, social living, motor skills, work history, medical and non-medical guidance which had been received by the participants. Significant findings reported by the Berkos were as follows:

> . . . 11.3 per cent had never attended school and 6.6 per cent never completed any academic grades. 25.8 per cent attended regular classes in public schools, and 26.9 per cent had received home instruction. Forty-seven per cent had complete speech intelligibility. Vocationally, 66.5 per cent were unemployed when surveyed and 8.2 per cent were unskilled. 12.7 per cent received on-the-job training and twenty-six per cent received aid from the State Division of Vocational Rehabilitation. 70.05 per cent never received educational guidance and 69.3 per cent never received vocational guidance.[11]

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[10]Selma J. Glick, "Emotional Problems of 200 Cerebral Palsied Adults," Cerebral Palsy Review, XIV (December, 1953) 3-5.

[11]Frances G. Berko and Martin J. Berko, "An Abstract of the Adult Occupational Inventory," Cerebral Palsy Review, XVII (September-October, 1956), 119, 142.

In 1954, Hopkins, Bice, and Colton summarized the physical, educational, and psychological findings of 1,505 cases of cerebral palsy under twenty-one years of age in New Jersey. They reviewed the clinical records of the Crippled Children's Division and made the results available to all persons interested in developing a comprehensive program to meet the needs of individuals with cerebral palsy. The findings showed a need for counseling parents concerning guilt, frustration, and fear in relation to cerebral palsy.[12]

In 1954, another survey was done in New York City of adults over forty years of age with cerebral palsy. The names and addresses of 165 individuals with cerebral palsy were obtained from agencies serving adults with cerebral palsy. Seventy-eight of these individuals were interviewed for information about family status, living conditions, financial status, education, and employment experience. Significant findings were:

> . . . fourteen were employed when surveyed. Thirteen were supported by parents or relatives and thirty-six were on public assistance. Twenty-two had never been employed. Forty-eight had at one time been employed in remunerative occupations. Educationally, eleven had no education; twenty had completed elementary school; eight were high school graduates; eleven had had some high school; and fifteen had graduated from college. Thirty had hobbies. The recreational

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[12]Thomas W. Hopkins, Harry V. Bice, and Kathryn C. Colton, Evaluation and Education of the Cerebral Palsied Child - New Jersey Study (Washington: International Council for Exceptional Children, 1954), 114 pp.

> activities of the group were limited to organizations for the handicapped or in-patient social activities.[13]

In 1955, the Cerebral Palsy Work Classification and Evaluation Project was started by five community agencies to determine the work capacities of individuals with cerebral palsy over sixteen years of age. The work sample technique was used as a method of assessing vocational performance and predicting successful achievement. A work evaluation system was established and close follow-up of the clients was done for three years to prove or validate the system of evaluation. Significant findings revealed by the Fourth Annual Report were:

> . . . that at least fifty per cent of those born with cerebral palsy will need the services offered by sheltered workshops to be habilitated adequately. Associated defects revealed by the clients included speech involvement, hearing loss, gross perceptual loss, personal maladjustment and behavior which hindered vocational performance. Thirty-four per cent proved unable to perform in competitive employment. Seventy-three per cent of the clients could benefit from personal adjustment services, according to psychological and psychiatric examinations. The findings indicated a need for professional help in the interpretation of how a disability will affect employment opportunities.[14]

A pilot study was conducted in the State of Vermont in 1957 to determine the needs of individuals in the age group of

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[13]Edward F. Kilbane and Morris Klapper, "The Older Individual Who Has Cerebral Palsy," Cerebral Palsy Review, XVII (May-June, 1956), 59, 71.

[14]Fourth Annual Report: Cerebral Palsy Work Classification and Evaluation Project (New York: Institute for the Crippled and Disabled, 1959), pp. 32-33.

fifteen to thirty years who could be located and were known to have cerebral palsy. One hundred and three individuals with cerebral palsy and their families were interviewed. The significant findings were as follows:

> . . . twenty-nine needed medical, dental, or other health services. A large number appeared to require eye care. The field workers emphasized the need for psycho-social service. Fourteen of the individuals studied had a variety of needs which interfered with complete independence. There were many financial problems. A need was indicated to acquire and analyze medical, social, educational, and vocational data related to the medical status, treatment, and training of the individuals with cerebral palsy. An evaluation was needed of the status and rehabilitation achievement and potential of the individuals.[15]

Wolfe and Reid conducted a study in 1958 of all the cerebral palsy cases of all age groups in Texas. They used questionnaires and personal interviews with 2,303 individuals and their families. Significant findings were as follows:

> . . . 42.78 per cent at one time had convulsions. 31.77 per cent had defective teeth. Speech defects, inability to walk, mental retardation, convulsions, and lack of community educational programsprevented 35.38 per cent from attending school. More than half of the cases studied needed speech therapy, occupational therapy, or physical therapy. Ninety-four persons were reported by their parents as working for wages and seventy-four of these had obtained work on their own initiative.[16]

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[15] Anon. "Interim Report of 1957 Vermont Survey," Twin State Cerebral Palsy Study, pp. 2-3.

[16] William G. Wolfe and L. Leon Reid, A Survey of Cerebral Palsy in Texas (Austin: United Cerebral Palsy of Texas, 1958), pp. 277-298.

The United Cerebral Palsy of Miami Rehabilitation Center in Miami, Florida began a research project in 1958 for the assessment and rehabilitation of severely handicapped brain damaged people. Each individual was to be evaluated intensively for vocational strengths and weaknesses by a complete rehabilitation team. Training and supervised employment was to follow the evaluation. Each year sixty to seventy-five clients were to be assessed, trained, and followed up in the project. It is expected that the study will be supported over a period of years and that it will yield pertinent results which will subsequently be applied to habilitation and rehabilitation programs. The study is still going on and no reports have been published to date.[17]

At the present time, a survey is being done in North Carolina to determine an accurate estimate of the magnitude of the cerebral palsy problem, to learn the number of cases, their degree of incapacitation and their geographical location. When the survey is concluded, a registry of cerebral palsy cases will be established in order to lead to improved organization within the state. The final report will be made available to all voluntary organizations and state institutions interested in the mentally and physically handicapped child. The group in North Carolina believe that the hope and future of

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[17]Anon., "Research," Cerebral Palsy Review, XVIX (November-December, 1958), 7.

cerebral palsy lies in research.[18]

A review of the birth histories of individuals with cerebral palsy has indicated that there are specific causes relating to the etiology of the condition. Perlstein reported that 60 per cent of the cases of cerebral palsy are due to anoxia, prior to, during, or shortly after birth and that not more than 5 per cent of the cases of cerebral palsy are caused by the injudicious application of forceps, holding the head back, or inducing labor by drugs. Perlstein also has reported that kernicterus due to Rh factor is responsible for less than 3 per cent of the cases of cerebral palsy; that when anoxia is the etiological factor, extrapyramidal or athetoid cerebral palsy results; and that when traumm or vascular disturbances are responsible, pyramidal or spastic cerebral palsy occurs.[19]

Denhoff reported a genetic factor which results in spastic paraplegia, atonic diplegia, and familial athetosis. He further reported that maternal infections which involve the fetal brain may cause prematurity.

> The varied causes of prematurity are maternal diabetes, toxemia of pregnancy, nutritional deficiency, Rh factor, and infectious and chronic maternal diseases are

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[18]Charles E. Flowers, Jr., "Increasing the Horizon of Cerebral Palsy," Cerebral Palsy Review, XXI (July-August, 1960), 8-9.

[19]Meyer A. Perlstein, "Infantile Cerebral Palsy: Classification and Clinical Correlations," Journal of American Medical Association, CXLIX (May 3, 1952), 30-34.

> outstanding. Prematurity is more likely to be precipitated by maternal infectious diseases and nutritional and metabolic deficiencies.[20]

The literature revealed some interesting data concerning vision, hearing, and speech in cerebral palsy. Many individuals with cerebral palsy have eye defects which interfere with many activities. Guibor reported:

> Motor defects of the eyes occurred in 75 per cent of the patients. Subnormal vision existed in 25 per cent. Eyes turned toward the nose in 51 per cent. The most frequent combination was horizontal conjugate deviation of the eyes with one eye turning nasally. Some patients display an improvement in walking, talking, and writing after an improvement in the ocular stability.[21]

Perlstein observed that:

> . . . children with athetosis frequently have an associated deafness, generally of the inner ear type or of high frequencies and in the athetoid type, 16 per cent had decreased hearing.[22]

Christman noted that the visual and auditory senses are defective in at least 50 per cent of the cases of cerebral palsy and sensory defects may be present in the sense organ, or perception may be inaccurate in the brain center. Aphasia, which may affect the sense perceptions of one's expressive

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[20]Eric Denhoff, Victor N. Smirnoff, and Raymond H. Holden, "Medical Progress: Cerebral Palsy," New England Journal of Medicine, CCXLV (November, 1951), 728-729.

[21]George P. Guibor, "Some Eye Defects Seen in Cerebral Palsy, With Some Statistics," American Journal of Physical Medicine, XXXII (December, 1953), 347.

[22]Meyer A. Perlstein, Erna L. Gibbs, and Frederic A. Gibbs, "The Electroencephalogram in Infantile Cerebral Palsy," American Journal of Physical Medicine, XXXIV (August, 1955), 479.

abilities is a problem in itself.[23] Christman added:

> The effect of visual-perceptual defects in the learning and language of the individuals with cerebral palsy cannot be minimized. Reading, through which a great deal of one's knowledge of the world about him is gained, often remains a slow and tortuous process, even for the adult.[24]

The review of the literature revealed that adults with cerebral palsy have many problems which originated in infancy or childhood, and that studies which have been done indicate that there is still a lag in the knowledge and facilities for the treatment of adults with cerebral palsy compared to those offered to children with cerebral palsy. Even though the adults may be participating in cerebral palsy programs, it appears that they still have needs which are not being met. Much more can be done to solve the problems of adults with cerebral palsy by arousing awareness of the problems in the individuals concerned, their families, existing agencies, and the general public.

Statement of Hypothesis

Even though participating in the activities of a cerebral palsy program, adults with cerebral palsy have many physical, psycho-social, and vocational needs which are not being met.

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[23]Dan Christman, "Problems of Communication of Individuals with Cerebral Palsy," Cerebral Palsy Review, XVII, No. 6 (November-December, 1956), 157.

[24]Ibid., 157.

CHAPTER III

METHODOLOGY

Description of Sample

The sample selected for this study consisted of sixteen adults with a diagnosis of cerebral palsy of congenital origin. Nine had a diagnosis of spastic cerebral palsy and seven had athetoid cerebral palsy. Ten were males and six were females. The intelligence quotient of the group varied between 60 and 110. The participants ranged in age from 18 to 39 years. The average age was 25.4 years. All had received medical treatment at the Children's Medical Center between the years 1930 and 1960 and were also receiving the services of the United Cerebral Palsy of Greater Boston, Inc. The services included rehabilitation referrals for evaluation and therapy, speech training, group psychotherapy, office training, typing and shorthand classes, sewing lessons, and occupational therapy. The social and recreational activities consisted of social meetings, roller skating, swimming, bowling, Arthur Murray dancing, and attending events at the Boston Garden. In the summer, camping was available for those who were interested.

Selection of Sample

The writer reviewed, with the social worker, the list of clients who were receiving service from the United Cerebral Palsy of Greater Boston, Inc. All were eliminated who were under the age of eighteen, who had been classified as being below the educable range of intelligence, and whose diagnosis was other than spastic or athetoid cerebral palsy. The list was then reviewed to obtain the names of clients who had received medical treatment at the Children's Medical Center. The final list consisted of twenty-six names.

Written permission was obtained from the Assistant Administrator of the Children's Medical Center to review the clinical records of the twenty-six listed. The records revealed that three on the list had an acquired type of cerebral palsy which eliminated them as participants. The first sixteen records which were reviewed were selected as the sample for this study. The records were reviewed to detect the problems as reported by the patients or members of their families; the physical findings of the doctors, including their recommendations; the psycho-social and emotional aspects and the suggestions for vocational training which might have been recorded by members of the rehabilitation team.

Tool Used to Collect Data

With information from available literature and from the writer's experience with adults with cerebral palsy, an

interview schedule was developed.[1] The interview schedule was divided into three sections: physical, psycho-social, and vocational problems that individuals with cerebral palsy might be expected to encounter. The section on physical problems consisted of sixteen questions constructed to obtain data regarding vision, hearing, coordination, equilibrium, speech, dentition, convulsive disorders, and/or bladder and bowel dysfunction.

The section on psycho-social problems consisted of fifteen questions designed to elicit responses from the participants as to how they felt about their diagnosis, treatments, future activities, and the effect of their limitations on family and social relationships. The final section, pertaining to the vocational aspects, had twenty-three questions so structured as to obtain information about the education and work status of the participants and their relationships in the school and work environment.

The interview schedule was tried out with one adult with cerebral palsy who met the same criteria as the respondents but who was not a participant in the study. As a result, some of the questions were revised for clarity. The interview schedule was so arranged as to permit the writer to make notes of the participants' responses to each question.

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[1] Appendix A.

Method of Data Collection

A letter was sent to each of the sixteen individuals selected from the records asking for their participation in the study.[2] Self-addressed stamped envelopes were enclosed to insure prompt replies. Eleven replied and agreed to participate. The five who did not reply were contacted by telephone and consented to participate.

The respondents were then contacted by telephone and arrangements were made for the time and place of the interviews which were conducted during January and February, 1961. Twelve interviews were conducted at the respondents' homes; one was conducted at a school the respondent attended; and three were conducted at the respondents' places of employment. The time required to conduct each interview ranged from one and a half to two hours. Many of the interviews in the homes were interrupted by family members, by visitors, or by the presence of children. The three interviews conducted at the places of employment of the respondents involved some distraction by people entering and leaving the room and by noise in the environment. However, all of the families and respondents appeared to be hospitable and interested in the interviews.

The participants' responses were recorded verbatim and observations were made by the writer of parents' comments,

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[2]Appendix B.

family relationships and the effect they had on the respondents. As soon as the interviews were completed, the responses were checked against information from the clinical records. A physical profile and educational vocational rating scale, developed for use in a similar study conducted in Vermont, was applied to portions of the data. This rating scale was feasible for this study and had been developed by a panel of consultants from orthopedics, general medicine, psychiatry, physical therapy, social work, vocational and psychological counseling.[3]

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[3] Appendix C.

CHAPTER IV

FINDINGS

Presentation and Analysis of Data

The data of the study are presented and analyzed in three sections: physical, psycho-social, and vocational problem areas.

Physical Problem Area

The degree of physical and mental involvement varied among the individuals studied. The various degrees of involvement were categorized under specific headings and are illustrated in Table 1.

TABLE 1

SEVERITY OF PHYSICAL AND MENTAL PROBLEMS OF SIXTEEN ADULTS WITH CEREBRAL PALSY

Category	Normal	Slight Involvement	Moderate Involvement	Severe Involvement
Vision	8	5	3	0
Hearing	12	2	2	0
Speech	6	6	3	1
Dentition	12	3	0	1
Coordination	5	3	4	0
Equilibrium	7	5	4	0
Bladder & bowel dysfunction	13	2	1	0
Mentation	8	6	1	1
Emotional status . .	6	8	2	0

*Rating scale from Twin State Cerebral Palsy Study - Appendix C

In only three instances were the problems rated as severe and those were in the areas of speech, dentition, and mentation. Although mobility was a problem to many of the respondents, only five used appliances for ambulation; one used crutches, two walked with a cane, and two wore braces.

The responses were further categorized under specific headings and are listed in Table 2.

TABLE 2

OUTSTANDING PHYSICAL PROBLEMS OF SIXTEEN ADULTS WITH CEREBRAL PALSY

Speech defects	10
Visual defects	8
Incoordination of hands	5
Dental defects	4
Mental retardation	4
Hearing defects	4
Scissors gait	2
Hyperactive reflexes	2
Disequilibrium	2
Equinus deformity	2
Obvious emotional disturbance	2
Deformity of right leg	1
Tight muscles left arm and leg	1
Convulsive disorder	1
Tight heel cords	1
Weak dorsiflexors and peroneals	1
Little control of spine	1
Stiff knees and hips	1
Weak right hand	1

Ten of the respondents (62.5 per cent) had speech defects as compared to 82 per cent found in the Connecticut study,[1] 80 per cent found by Glick,[2] and 50 per cent found in

[1] Osborn, op. cit., p. 16.

[2] Glick, op. cit., 9-10.

the Texas study.[3] However, the speech defects were not statistically significant to those in the Connecticut study, as shown in item 1 of Appendix D, and not statistically significant when compared to Glick's study, as shown in item 2 of Appendix D.[4] One respondent realized that he needed more speech therapy but did not want any. Another was interested in obtaining more speech therapy "if it would help." One who stuttered said that she had given up speech therapy as she felt resigned to her condition. One, whose speech was almost incomprehensible, was not interested in more speech therapy as he felt that he had enough in the past. Another, who was receiving speech therapy twice a week, said he would like to have speech therapy more often. One, who had slow athetoid speech, felt that speech therapy might help him.

Eight (50 per cent) were found to have visual defects. These findings may be compared to Osborn's findings of 30 per cent, and agree with the findings of Guibor[5] and Christman.[6] When compared with the Connecticut study, the visual defects were not statistically significant, as shown in item 3 of Appendix D.[7]

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[3]Wolfe and Reid, op. cit., p. 279.

[4]Appendix D.

[5]Guibor, op. cit., 347.

[6]Christman, op. cit., 157.

[7]Appendix D, op. cit.

Five respondents complained of incoordination of the hands which is characteristic of athetosis. One of these felt that her hand incoordination was related to a visual defect. No studies of hand incoordination were available for a comparison of data.

Four (25 per cent) had dental defects which are similar to the findings of 33 per cent found in the Connecticut study,[8] 28 per cent in the Vermont study,[9] and 31.77 per cent in the Texas study.[10] A chi square could not be used to test the significance of these figures as the number of respondents was less than five. Two of the respondents in need of dental care stated that financial problems prevented them from obtaining it.

Four of the respondents (25 per cent) were limited by mental retardation which handicapped them educationally. This was similar to 35.8 per cent found in the Texas study.[11]

Four (25 per cent) had hearing defects which interfered with their performance. These findings were similar to 30 per cent found in the Connecticut study,[12] 28.1 per cent in

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[8] Osborn, op. cit., p. 98.

[9] "Interim Report," Twin State Cerebral Palsy Study, loc. cit.

[10] Wolfe and Reid, op. cit., p. 280.

[11] Ibid., p. 280.

[12] Osborn, loc. cit.

the Vermont study,[13] 31.77 per cent in the Texas study.[14] They agreed with Perlstein's findings,[15] and differed from the findings of Christman.[16] One respondent appeared to need a hearing evaluation in connection with a speech difficulty. Another, who wore a hearing aid, said that his hearing problem affected his speech. One, who talked with a lisp, had not had his hearing evaluated for twenty years. His "S's" sounded like "th" when he talked. Another, who had a high frequency hearing loss caused by athetosis, was currently receiving lip reading and speech therapy. She stated that her hearing loss affected her speech, and complained that the pitch of certain voices bothered her.

Two of the respondents had hyperactive reflexes, disequilibrium, and equinus deformities. Two exhibited obvious emotional disturbances and were receiving some form of psychotherapy. Other physical problems which were mentioned once were tight heel cords, tight muscles of the left arm and leg, a convulsive disorder, weak dorsiflexors and peroneals, little control of the spine, stiff knees and hips, and a weak right hand. These problems were residual in nature and had

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[13] "Interim Report," Twin State Cerebral Palsy Study, loc. cit.

[14] Wolfe and Reid, loc. cit.

[15] Perlstein, op. cit., 479.

[16] Christman, loc. cit.

been minimized by treatment. Three complained of urinary frequency but none had a loss of control of bladder or bowel.

When asked how old they were when they realized that they had cerebral palsy, the respondents' answers ranged between the age when they began school up to adulthood. The feelings aroused by becoming aware of cerebral palsy varied. Four said that they "felt different." Seven said that they were not upset. One thought that the cerebral palsy was poliomyelitis as she also had poliomyelitis. One said that he stopped doing things because he thought that he might get hurt. Three stated that they just accepted their conditions.

The respondents were asked what they thought had caused the cerebral palsy. Three said that they had been premature babies; one said that he had been given too much oxygen at birth; another said that he had not had enough oxygen at birth; and three blamed the condition on the use of instruments at the time of delivery. The other eight gave answers such as: "I was born with it," "injury at birth," or "brain injury." A comparison of these responses with information from the clinical records indicated that the respondents were not too well informed about the specific causes of cerebral palsy. The records revealed that the causes included prematurity in four cases, anoxia in three cases, precipitate birth in two cases, prenatal maternal infections in two cases, icterus neonatorum in one case, and the causes in the other four cases were

unknown. The causes as found in the group studied corresponded to those observed by Perlstein[17] and Denhoff.[18]

When asked if the cerebral palsy could have been prevented, seven felt that it was preventable, three were not sure, and six thought it was not preventable. Three who felt that it was preventable thought that a Caesarian section might have prevented the condition.

When asked what more they thought could have been done in their medical treatment, all the respondents agreed that everything possible had been done for them. Regarding their present treatment, eleven were not receiving medical treatment of any kind. The other five were receiving the following medical treatment: psychotherapy, evaluations at the Children's Medical Center Adolescent Clinic, occupational therapy at United Cerebral Palsy of Greater Boston, Inc., speech therapy, physical therapy, and periodic check-ups at the Children's Medical Center, check-ups at the Robert Brigham Hospital, and speech and lip reading at Emerson College.

The respondents were asked if they would like to have more speech therapy, physical therapy, occupational therapy, or any other kind of therapy. Eleven said that they were not interested in any kind of therapy. Three requested more speech

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[17]Perlstein, op. cit.,pp. 30-34.

[18]Denhoff et al., op. cit., 728-729.

therapy, two wanted more physical therapy, and one asked for occupational therapy. Two of those requesting more therapy said that transportation and financial problems interfered with their obtaining the needed therapy. One requested vocational training and public speaking. Another expressed a desire for typing lessons. Speech therapy and typing lessons were available at the United Cerebral Palsy of Greater Boston, Inc., but the respondents apparently were not taking advantage of the available services.

Nine of the respondents were receiving medications at the time of the interviews and seven were not. The drugs used by the respondents were butysal grs 1/4 "once in awhile for nerves," thorazine, phelantin for the control of seizures, multivitamins, Carter's liver pills, "pills to relax the arm muscles," and "soma," a relaxing drug.

The respondents felt that cerebral palsy prevented them from participating in the following physical activities: mountain climbing, expanding basketball activities, walking, baseball, basketball, ice skating, roller skating, participating in sports, and dating. The chief complaint was an inability to engage in athletic activities while going to school.

When asked if they thought that treatment had improved their conditions and the reasons for their answers, the respondents said that treatment had improved their conditions in several ways. Six felt that they could walk better because

of the physical therapy they had received. Four felt that they could talk better since receiving speech therapy. One reported that surgery stopped her right leg from jumping. Six felt that surgery had helped to improve their walking. A hearing aid and lip reading helped the hearing and speech of one respondent. One stated that surgery had enabled him to ride a bicycle. One remarked, "If I hadn't had the treatment, I don't think I'd be where I am today. I was carried into Children's Hospital and I walked out." One had surgery five times, one had surgery three times, and four had surgery once to correct deformities, lengthen muscles, or to correct eye defects.

The responses to the question as to how cerebral palsy had affected the activities of their families were quite varied. Seven felt that there was no adverse affect. One remarked, "I had to be watched more carefully when I was younger." Another commented, "Sometimes I would like to be brighter than I am but it doesn't always work." One felt that the fact that she had cerebral palsy upset her father but that he never said much about it. Another felt that he had been neglected as a small child because of having cerebral palsy. Two felt that their mothers had to spend more time with them when they were younger. One felt that he held his family back from doing things. One felt that the family had to plan activities around him. Another felt that it was because of his condition that the family did not own a car.

When asked if they had any suggestions for improving their conditions, two suggested more physical therapy. One wanted speech therapy and penmanship lessons. Another mentioned that surgery on his hip was needed. Another mentioned gaining confidence by traveling alone. Suggestions other than physical measures included part-time work, typing, and sewing. Eight offered no suggestions.

Suggestions offered by the respondents for helping others with similar conditions were quite varied. Self-acceptance, which is the first step in rehabilitation, was mentioned as being of great importance. This appeared to be a reflection of the training which had been received at hospital schools. Physical therapy was emphasized. Educating the public as to when to help and when not to help was mentioned. Encouragement was stressed and it was suggested that talking to people with cerebral palsy would give them confidence. Taking things as they come and conditioning the strong part of the body to overcome the weak was advised. Increased attention to work rehabilitation was stressed as an important aspect of treatment. Trying to avoid becoming too dependent on mothers was emphasized. Most of the comments appeared to be ways of adjusting which had been utilized by the respondents.

The respondents were asked what services for cerebral palsy were available where they lived. Table 3 illustrates the services for individuals with cerebral palsy which were known to the respondents.

TABLE 3

CEREBRAL PALSY SERVICES KNOWN TO SIXTEEN ADULTS WITH CEREBRAL PALSY

Services	Respondents
Medical treatment at Children's Medical Center	16
Adult program of United Cerebral Palsy of Greater Boston, Inc.	16
Home teachers	8
Speech therapy in schools	7
Vocational rehabilitation	5
Occupational therapy in schools	3
Clinics for physical therapy	3
Physical therapy from Visiting Nurse Association	3
Red Cross transportation	2

All were familiar with the Children's Medical Center and the United Cerebral Palsy of Greater Boston and had used the services of these two agencies. Only half knew about the availability of home teachers and less than half had obtained speech therapy, physical therapy or occupational therapy in schools or clinics, and a few knew about the services offered by visiting nurse associations and the transportation services provided by the Red Cross. It would appear that the participants had a need for more knowledge about the cerebral palsy services available to them. As only five had contact with the

vocational rehabilitation services offered by the state, it would appear that the other eleven respondents might profit by a vocational evaluation.

The respondents were asked for suggestions for adding to or changing the program at the United Cerebral Palsy of Greater Boston, Inc. Five suggested better organization of the program. Four suggested a need for improved methods of transportation, and questioned the possibility of the agency acquiring a Volkswagen bus such as that owned by the Western Massachusetts group. Four suggested adding more social groups and felt that more variety was needed in the program. Three expressed an interest in a photography course and in starting a camera club. Three wanted to start a reading group and three wanted to improve the educational set-up of the program. Two suggested putting on musical productions for audiences to increase the confidence of the members. Two stated that more cooperation and interest was needed from the group members. Two suggested resuming the adult bowling group which had been discontinued. Two wanted ice skating classes started and two wanted to start a driver's course for individuals with cerebral palsy. Two suggested increasing the length of the sewing classes to two hour sessions. Two suggested adding painting and drawing groups. Two suggested that remedial reading be added to the program and two suggested adding arithmetic for every day use. There was one suggestion offered

for each of the following: notify people more promptly when activities were cancelled, vocational job training, and public speaking. The individuals who suggested the painting, drawing, and photography activities stated a willingness to lead the groups if they could be organized.

Psycho-Social Problem Area

Data pertaining to the psycho-social problem area are presented in relation to family and community relationships, and leisure time activities in the home and community. The respondents were rated by the writer as to their social adjustment in the family and community. Table 4 summarizes the degree of adjustment in family and community relationships.

TABLE 4

DEGREE OF ADJUSTMENT IN SOCIAL RELATIONS OF SIXTEEN ADULTS WITH CEREBRAL PALSY

Category	Normal	Fairly Well	Moderate Difficulty	Unknown
Family relations	2	10	0	4
Community relations	5	7	3	1

*Rating scale from Twin State Cerebral Palsy Study - Appendix C

The three rated as having moderate difficulty in community relations, were homebound because of the severity of their physical disabilities. The four classified as unknown,

under family relations, were interviewed at school or at work and the investigator did not have an opportunity to observe the conditions and relationships in the home. Although more than half showed evidence of being overly dependent on their families, they were rated as fairly well adjusted. The parents of six of these verbalized non-acceptance of cerebral palsy. Only two were determined as totally independent by the rating scale used. The findings of overdependency were not statistically significant when compared to the Glick study, as shown in item 4 of Appendix D.[18] The findings on family rejection were not statistically significant when compared with the Glick study, as shown in item 5 of Appendix D.[19]

Although none of the respondents admitted that they were easily upset emotionally, five (31.2 per cent) admitted that they were self-conscious of their conditions. One admitted that he was very reserved and had difficulty in making friends. When asked what things upset them emotionally, one mentioned teasing by a younger sister and three mentioned teasing by co-workers. Three (18.7 per cent) stated that not having a job was disturbing to them and four

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[18] Appendix D, op. cit.

[19] Ibid.

(25 per cent) complained that consciousness of their limitations was a source of frustration. Another complained that his speech defect was a source of frustration. These findings may be compared to those of the Glick study[20] and with those of the Cerebral Palsy Work Classification and Evaluation Project.[21] The findings on personal maladjustment were statistically significant at the five per cent level when compared with the Glick study, as shown in item 6 of Appendix D.[22] They were not statistically significant when compared to the Cerebral Palsy Work Classification and Work Evaluation Project, as shown in item 7 of Appendix D.[23]

The respondents were asked how they spent their leisure time at home. Their responses are illustrated in descending rank order in Table 5. Most of the home activities were of a sedentary nature. Three were having a difficult time trying to read because of visual defects. All stated a preference for spending time with other people but did not always have an opportunity to do so. Those who owned pets found them to be a source of companionship.

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[20]Glick, op. cit., 4-5.

[21]Fourth Annual Report: Cerebral Palsy Work Classification and Evaluation Project, op. cit., pp. 32-33.

[22]Appendix D, op. cit.

[23]Ibid.

TABLE 5

USE OF LEISURE TIME IN THE HOME BY SIXTEEN ADULTS WITH CEREBRAL PALSY

Activity	Number
Watch television	12
Read	9
Photography	3
Care for pets	3
Play records	2
Play piano	2
Clean the house	2
Play cards	2
Collect coins	1
Knit	1
Sew	1
Write	1
Paint by number	1
Homework	1
Visit	1

Nine community activities were mentioned as leisure time pursuits. Table 6 lists the community activities in which the respondents participated.

TABLE 6

COMMUNITY ACTIVITIES PARTICIPATED IN BY SIXTEEN ADULTS WITH CEREBRAL PALSY

Activity	Number of Respondents
Attend church regularly	6
Church social groups	6
Indoor sports club	4
Bowling	2
Movies	2
Volunteer work	2
Church choir	1
Veterans of Foreign Wars	1
Grange	1
None	3

The Indoor Sports Club, in which 25 per cent of the group participated, is an organization for handicapped people. The volunteer work mentioned consisted of group activities with psychiatric patients at a mental health center and making collections on drives for community organizations. The three who did not participate in any community activities were unable to go out because of using orthopedic appliances. They expressed a desire to participate in community activities and believed they could if transportation were made available to them.

Concerning feelings about the home and community activities, five (31.3 per cent) commented on boredom and of being tired of staying at home. Eight (50 per cent) expressed dissatisfaction with the lack of activities and limited social contacts. One respondent commented that she did not feel smart enough to keep up with all the activities. Four (25 per cent) complained of restlessness and of having too much free time. Three who were unable to work admitted that they would rather be working.

All of the respondents said that they got along well with their families and with people outside of their families. All preferred being with other people but did not always feel accepted in social groups as others made them feel conscious of their handicaps. Four commented that there were arguments between the parents over finances. Two stated that adolescence was frustrating.

When asked if much time had been spent away from home while growing up, many said that they had been away from home while attending hospital schools, summer camps, or while hospitalized for surgery. Six (37.5 per cent) spent from one to eleven years in hospital schools. Eleven (68 per cent) attended summer camps ranging from a one two week period to part of four summers. The time spent in hospitals for surgery varied with the participant from one week to six months. One respondent thought that he had undergone "too much surgery." Nine commented that they had been homesick while away from home. Five complained of the regimentation of camp life and of schedules being too restricted.

The thirteen unmarried respondents were asked their opinions regarding dating and marriage. A variety of interesting opinions were expressed. Four stated that they did not date very often but were interested in the opposite sex. Two said that they dated fairly often. Six (36 per cent) said they had never dated but would like to. One went out on bowling dates only. Two complained that a lack of finances prevented them from dating girls. Two families put a stop to the dating of their offspring with handicapped individuals of the opposite sex. Four (36.3 per cent) of the single respondents expressed a desire for marriage. One commented, "I need security and a job first. It might be difficult." Another said, "I'd like to get married if I could." A third

remarked, "I want to finish school first, get a job, and see what develops later." Seven (43.7 per cent) stated that they had not thought about marriage.

The three married respondents, when questioned concerning the effect of cerebral palsy on marital adjustment, said that they were happier since marriage. All were interested in raising children. The spouses of two were also handicapped; one because of cerebral palsy, the other because of poliomyelitis. One had two children and the wives of two others were pregnant. The respondent who was the mother of two children, had both by Caesarian section. She had been told by her doctor not to have any more children. This family also had many financial problems.

Because of the limited sample, it was not possible to statistically compare these data with those of other studies in relation to the psycho-social problems of adults with cerebral palsy. However, the psycho-social problems areas were similar to those revealed by other studies.

Vocational Problem Area

Data about the vocational problem area are presented first in relation to education and second in relation to vocation. Both are presented as to current status as well as to relationships at school and in the work situation. The respondents had attended a variety of schools and most had experienced several types of school situations. The types of

schools attended by the sixteen individuals are listed in Table 7.

TABLE 7

TYPES OF SCHOOLS ATTENDED BY SIXTEEN ADULTS WITH CEREBRAL PALSY

School	Number of Respondents
Public school	7
Industrial School for Crippled Children . . .	7
Home teachers	5
Massachusetts Hospital School	5
Special class - public school	3
Parochial school	3
Trade school	2
Other hospital school . .	1
School for deaf	1
University	1
Technical institute . . .	1

The ones who had attended public schools not requiring special classes were minimally involved physically and were of average or above average intelligence. As illustrated by Table 7, more than half spent some time in special schools or special classes, because of physical or intellectual limitations which required special attention. Only two had received an education beyond high school. Two others were still attending high school.

When asked how many years of schooling they were able to complete despite their handicaps, the answers covered a wide range. The amount of education received by the group

studied is listed in Table 8.

TABLE 8

NUMBER OF YEARS OF EDUCATION COMPLETED BY SIXTEEN ADULTS WITH CEREBRAL PALSY

Education Completed	Number
High school graduates	5
Special ungraded classes	3
Seventh grade	3
Two years of high school	2
Ninth grade	2
Two years of college	1

Three of the high school graduates had completed general courses and two had completed commercial courses. All had remained in some type of school until age sixteen years, or had received an equivalent number of years of education with home teachers as required by Massachusetts law. The educational findings of this study differed from the data obtained in the New York,[24] Berko and Berko,[25] and Texas[26] studies, as all the respondents had attended school at some time. However, it must be borne in mind that the participants were a select group as one of the criteria for participation was an educable range of intelligence.

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[24]Butler, op. cit., p. 17.

[25]Berko and Berko, op. cit., 119.

[26]Wolfe and Reid, op. cit., p. 279.

When the respondents were asked which subject they liked best in school and the reasons, sixteen subjects were mentioned. Two or more preferred English, science, bookkeeping, history, literature, mathematics, and typing. Those who showed an interest in mathematics said that they liked to work with figures. An interest in reading influenced a preference for English, literature, geography, and history. Seven disliked mathematics because they had trouble counting the numbers. Half disliked having to read too much. One disliked printing because he had difficulty seeing the print. Another disliked bookeeping because she could not write small enough to fit between the lines. The learning problems related to reading difficulties and abstract thinking agreed with the findings of Guibor[27] and Christman.[28]

When the respondents were questioned about membership in school clubs and extracurricular activities, eight (50 per cent) said that they did not participate in any school activities outside of the classroom. Four (twenty-five per cent) were members of the Beacon Club at the Industrial School for Crippled Children. Two played on a basketball team for handicapped students. One was the high school representative to the alumni association. One belonged to a coin club, stamp club, and camera club. The inability to join in athletic

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[27]Guibor, op. cit., 347.

[28]Christman, op. cit., 157.

activities was mentioned by all the male respondents as a source of frustration to them during adolescence.

Several respondents verbalized their feelings toward school activities. One was unable to do linotyping because of the uselessness of his left hand. One, whose education ended at the fifth grade, commented that he would like to have finished his education. Three were disappointed because they could not participate in gym classes. One, who enjoyed working on the school newspaper remarked, "Usually, if I really wanted to do something, I would put my mind to it and do it." The remark indicated the importance of motivation to this individual. Following graduation, this respondent succeeded in finding employment without help from any agency. One, who attended a school for the deaf, remarked that the grades should go higher and that art classes should be added to the curriculum. Another, who held leadership positions in several school activities, was attending a university and preparing to enter a professional field. The reactions appeared to show the uniqueness of the individuals in the group studied.

When questioned about employment experience, the respondents offered equally unique answers. The employment experience of the sixteen individuals studied is listed in Table 9.

TABLE 9

EMPLOYMENT EXPERIENCE OF SIXTEEN ADULTS WITH CEREBRAL PALSY

Type	Number of Respondents
Full-time employment	7
Never employed	5
Part-time vacation jobs . . .	3
Day work and night school . .	2
Part-time after school	1
Housewife	1

Only seven were employed full-time when interviewed. The five who had never been employed received their education from home teachers. The extent of their physical disabilities kept them confined to their homes and prevented them from traveling independently by public transportation. Those who were working and going to school at the same time seemed to indicate a high degree of motivation. One, a housewife, had been employed full-time prior to marriage. Of those who were working, three expressed fear of losing their jobs because of low productivity. Positions held as either part or full-time employment were: inspector, binder, upholsterer, conveyer operator, appliance maker, door to door salesman, drafting, clerical work, and cleaning. The findings in relation to

employment differed from the New York study,[29] Glick's study,[30] Berko and Berko's study,[31] Kilbane and Klapper's study,[32] and the Texas study.[33] The findings were statistically significant at the five per cent level when compared to the Cerebral Palsy Work Classification and Evaluation Project, as shown in item 8 of Appendix D.[34]

All helped with chores at home. The male respondents spent some time raking leaves, shoveling snow, and mowing lawns. All the female respondents helped with housework as much as they were able to. Several mothers commented, while the interviews were being conducted, that they preferred not to have help washing and drying dishes because the individuals with cerebral palsy dropped too many or took too long a time to perform the task.

The respondents were asked what kind of special work training they had received. Table 10 lists the special work training received by the sixteen individuals studied.

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[29]Butler, op. cit., p. 17.

[30]Glick, op. cit., 10.

[31]Berko and Berko, op. cit., 142.

[32]Kilbane and Klapper, op. cit., 59.

[33]Wolfe and Reid, op. cit., 298.

[34]Appendix D, op. cit.

TABLE 10

SPECIAL WORK TRAINING RECEIVED BY SIXTEEN ADULTS WITH CEREBRAL PALSY

Work Training	Number of Respondents
None	6
Wood-working	3
On-the-job training	3
Commercial course	1
Drafting	1
Linotyping	1
Teaching	1

The special training in wood-working had been received as part of the school curriculum and none of the three who received it had applied their training after leaving school. In contrast, all who had received on-the-job training were applying it in their present work situations. Seven said that the special training they had received was of insufficient quality and quantity. These data point to the need for further vocational exploration and guidance for the group studied.

The respondents were asked if they were able to support others besides themselves and if they felt that their incomes were adequate. The various degrees of economic independence are listed in Table 11.

TABLE 11

DEGREE OF ECONOMIC INDEPENDENCE OF SIXTEEN ADULTS WITH CEREBRAL PALSY

Degree of Independence	Number
Supports self and dependents	0
Supports self	4
Partially supports self	5
Dependent	7
Total	16

*Rating scale from Twin State Cerebral Palsy Study - Appendix C.

None were able to support others besides themselves. One quarter were self-supporting and paid board to their families. Almost half were entirely supported by their families and two of these were receiving disability compensation under Social Security. The findings, concerning the number of individuals who were financially dependent on their families, were not statistically significant when compared to the Cerebral Palsy Work Classification and Evaluation Project, as shown in item 9 of Appendix D.[35] They were not statistically significant when compared to the Glick study, as shown in item 10 of Appendix D.[36]

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[35]Appendix D, op. cit.

[36]Ibid.

When asked about interpersonal relationships at work, many comments indicated a strain in interpersonal relations. For example, one respondent stated: "I never liked any job I had and the competition bothered me with other people." Another remarked, "The boss bawls me out sometimes. They blame me for things that go wrong." One respondent stated that she liked her co-workers, the company, being on her own, but felt that she had no chance for advancement. One respondent's only complaint was that he preferred working indoors. Another remarked, "The whole organization is just wonderful to work with." Two, who worked on production jobs, admitted being too slow. Two others said that they would be slow if they were working on production and another said that he could work fast if he had to.

A variety of preferences were offered when the respondents were asked about a choice of work. The responses included work in a publishing house or library, office work, commentating sports on the radio, television repair work, factory work, accounting, office machine work, operating a camera store, clinical psychologist, assembly line work, operating a steam roller or steam shovel, lens grinding, and electronics. Only one respondent expressed satisfaction with present employment and two were undecided about vocational preference.

The respondents were asked if they thought that cerebral palsy was a handicap in finding a job. Examples of comments were as follows:

> "I made out many applications. They say they will call you but they don't."
>
> "It took me a long time to find a job. People put you off. They say they will call you but they don't."
>
> "Three years ago I went to the rehabilitation office and they put my name on file. It's a pretty long wait."
>
> "I filled out one application and started work that week."
>
> "I guess it is the public's lack of understanding."
>
> "I can't work because of cerebral palsy."
>
> "People feel that you have it [cerebral palsy] and you can't do as good a job as the person who hasn't."
>
> "You have to know somebody to get them to hire the handicapped."
>
> "All you had to do was mention it [cerebral palsy] and they would tell you to fill out forms. That's all you would hear from them."

Only one respondent, who was minimally involved, did not find cerebral palsy a handicap in finding work. The responses indicated a need for further vocational guidance.

When asked if they had received enough help in finding the right job, only two respondents answered affirmatively. Three said that they did not receive any help. Two felt that they had received enough help from the Cerebral Palsy office and friends. Two did not ask for any help and one obtained employment through a vocational guidance office but was unable to remain on the job because of slowness.

When asked if they would be interested in more education or vocational training if it were available, all said they were interested. Two expressed a desire for typing, reading, and photography courses. Two were interested in penmanship classes. The others mentioned an interest in printing, wood-working, finishing high school, business school, running office machines, art classes, lens grinding, television repair work, nursery school teacher training, and journalism. The responses pointed out a need for more vocational training for the sixteen individuals studied.

These data supported the hypothesis that, even though participating in a cerebral palsy program, adults with spastic or athetoid cerebral palsy have many physical, psycho-social, and vocational needs which are not being met.

CHAPTER V

SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS

Summary

The purpose of the study was to determine what the physical, psycho-social, and vocational needs of adults with spastic or athetoid cerebral palsy were. The participants were sixteen adults with spastic or athetoid cerebral palsy who had been followed by the Children's Medical Center between 1930 and 1960, who were of the educable range of intelligence, who were residents of the Greater Boston area, and who were participating in the program of the United Cerebral Palsy of Greater Boston, Inc. The data for the study were collected by reviewing the clinical records and interviewing the participants in their homes, at school, or at work. An interview schedule was developed from information obtained from a review of literature and from the writer's experience. A physical profile and educational-vocational guide which had been developed for a similar study were utilized to rate the respondents in relation to the physical, psycho-social, and vocational adjustments based on the problems presented.

Only two of the items studied, personal maladjustment and the number of individuals who were fully employed, were

statistically significant when compared to the studies reviewed in the literature. However, the physical problem areas were similar to those found to be problems of adults with cerebral palsy as indicated in other studies. Ten of the respondents had speech defects, half had eye defects, and half offered suggestions for improving their own conditions, which indicated that their physical needs were not being fully met.

The following data indicated that the psycho-social needs of the respondents were not being met adequately. Half expressed dissatisfaction with their limited social contacts. A quarter complained of boredom and of being tired of staying at home. A quarter complained of restlessness and of having too much free time. In only two instances were the family relationships considered to be completely normal.

The following facts point out that the vocational needs of the sixteen individuals studied were not being met. All expressed an interest in more education or vocational training. Seven were entirely supported by their families. Only a quarter were self-supporting. Only one was satisfied with present work. None were able to support others besides themselves.

Conclusions

The conclusions were as follows:

1. All the physical needs of the respondents were not being met because ten had speech defects, eight had eye defects, four had dental defects, and four had hearing defects.
2. All of the psycho-social needs were not being met as half expressed dissatisfaction with limited social contacts, a quarter complained of boredom and of being tired of staying at home, and a quarter complained of restlessness and of having too much free time.
3. The vocational needs of the sixteen adults studied were being met in only two instances.
4. Families in which there was a member with cerebral palsy had an inadequate knowledge of the facilities available to them and there was a lack of knowledge among the general public regarding cerebral palsy.

The findings of the study proved the hypothesis that even though participating in a cerebral palsy program, adults with cerebral palsy still have many physical, psycho-social, and vocational needs which are not being met.

Recommendations

As a result of this study, the following recommendations are made:

1. That an investigation be conducted to determine the needs of homebound individuals with cerebral palsy.
2. That more research be conducted to determine the need for prevocational and vocational guidance during and following the education of individuals with cerebral palsy.
3. That similar studies be conducted using a larger sample.
4. That the United Cerebral Palsy of Greater Boston, Inc. utilize the findings of this study for reevaluating their service program for adults.

APPENDICES

APPENDIX A

INTERVIEW SCHEDULE - PHYSICAL

Code # _____

1. What do you consider to be your main physical problem?

   a) Do you have trouble with your eyes?

   b) How long ago did you have your eyes examined?

   c) Do you have a hearing problem?

   d) How long ago did you have your ears checked by a doctor?

   e) Do you have trouble using your hands?

   f) Do you have any trouble walking?

   g) Do you have trouble with balance?

   h) Do you have trouble trying to talk?

   i) Do you have many tooth-aches?

   j) Do you think that you need any fillings in your teeth right now?

   k) How long ago did you have your teeth checked by a dentist?

   l) Do you have spells or black-outs (convulsions, seizures)?

   m) Do you have to go to the bathroom frequently?

   n) Do you ever have constipation or other trouble with your bowels?

   o) If yes, what?

2. How old were you when you realized that you had cerebral palsy?

3. What were your feelings when you first became aware that you had cerebral palsy?

4. Do you know what caused your cerebral palsy?

5. Do you think it could have been prevented?

6. What more do you think could have been done in your medical treatment than was done?

7. What treatment are you receiving now?

8. Do you think you would like to have more therapy in:

   a) Speech?

   b) Training in walking better (P.T.)?

   c) Occupational therapy?

   d) Other?

9. What medicine are you taking now?

10. What physical activities would you like to do now that you cannot do because of your handicap?

11. Do you think treatment has improved your condition (surgery, exercises, etc.)?

    a) Why or why not?

12. How has the fact that you have cerebral palsy affected the activities of your family?

13. Do you have any suggestions for improving your condition now?

14. Do you have any suggestions for helping others with similar conditions?

15. Do you know what services are available in your home town for people with cerebral palsy?

    a) Do you use any of them?

    b) Why?

16. What suggestions do you have for adding to or changing the program at the Boston United Cerebral Palsy?

INTERVIEW SCHEDULE - PSYCHO-SOCIAL

Code # _____

1. What kinds of things do you do in your spare time at home (read, TV, etc.)?

2. What kinds of community activities do you engage in (church, social, etc.)?

3. How do you feel about the things you do at home and in the community?

4. How do you think you get along with your family?

5. How do you think you get along with people outside of your family?

6. Do you like to be with other people?

7. How do you think people feel about you (having you around, appearance, etc.)?

8. Do you think you get upset easily?

9. What things seem to bother you?

10. While growing up, did you spend much time away from home?

    a) Hospital?

    b) Camp?

    c) School?

    d) Other?

11. How did you feel about being away from home?

<u>For single people only</u>:

12. Do you go out on dates?

13. Would you like to go out with girls, boys, if you could?

14. What do you think about marriage for you?

<u>For married people only</u>:

15. In what ways has your adjustment to marriage been affected by the fact that you have cerebral palsy?

INTERVIEW SCHEDULE - VOCATIONAL

Code # _____

1. Where did you go to school?
2. How far were you able to go in school in spite of your handicap?
3. What subjects did you like best in school? Why?
4. What subjects did you like least in school? Why?
5. What clubs, if any, did you belong to in school?
6. Was there something in school you would like to have done that you could not do because of your handicap?
   a) Sports?
   b) Clubs?
   c) Anything else?
7. Do you work?
8. Have you ever had a job?
   a) Steady?
   b) Part time?
   c) Work at home?
9. Have you had any special work training? If so, what kind?
10. Do you support others besides yourself?
11. Do you feel that your income is adequate?
12. Are you receiving any financial help because of your disability?

13. Do you like the people you work with?

14. Do you think they like you?

15. Do you have any problems associated with your work situation because of transportation, climbing stairs, toilet facilities? Anything else?

16. How do you think you are getting along in your job right now?

17. What do you like best about your job? Why?

18. What do you like least about your job? Why?

19. How do you think your production compares with the other workers?

20. If you had a choice, what kind of work would you like to do?

21. Do you think that having cerebral palsy was a handicap in finding a job?

22. Do you think you had enough help in finding the right job for you?

23. Would you be interested in more education or vocational training if it were available? If so, what kind?

APPENDIX B

126 Warren Street
Brighton 35, Mass.
December 27, 1960

Mrs. _____ _____

Street address
City, Mass.

Dear _____:

You have been chosen to become a member of a group to help in a study of the needs of adults who were born with cerebral palsy. The study is part of the master's degree program at Boston University School of Nursing. I received your name from the Boston Cerebral Palsy office.

If you agree to take part in the study, I shall contact you in January to arrange to see you, probably at your home, during the last two weeks in January to ask you a few questions about the problems you now have in connection with cerebral palsy. I am a former cerebral palsy clinic nurse and also work with the Massachusetts Cerebral Palsy Association.

Please sign the enclosed form and return it to me by mail as soon as possible. If you have any questions to ask me about the study, you may reach me by telephone at AL 4-3473.

Sincerely yours,

Carolyn V. Furness, R.N.

December 28, 1960

I agree to be interviewed by Miss Carolyn V. Furness as part of the Boston University study on cerebral palsy.

Signed _____

APPENDIX C

PHYSICAL PROFILE GUIDE SHEET

Code: 0 Normal 1 Mild 2 Moderate 3 Severe

5 Warrants evaluation and treatment, if indicated

Vision

0 No difficulty in reading or identifying objects.

1 Visual defect correctable with glasses, or so slight as to offer little handicap.

2 Significant visual defect.

3 Severe visual defect, or totally blind.

Hearing

0 No difficulty in hearing and following conversation.

1 Misses some words, and word endings, some tone levels.

2 Significant difficulty in following ordinary conversation or direct speech.

3 Almost completely or totally deaf.

Speech

0 No involvement in following:

a) Breathing patterns normal during speech.
b) All words pronounced clearly and correctly.
c) No extraneous movements of head, face, or body during speech.
d) Pitch of voice normal for age and sex.

1 Slight involvement

a) Breathing patterns change only slightly. Runs out of breath at ends of sentences. Takes deeper breath when beginning to speak.
b) Four or five words mispronounced, such as omitting sounds or substituting sounds.
c) Minor extraneous movements of head, face, or body.
d) Pitch of voice slightly too high, nasal, or hoarse.

2 Moderate involvement

a) Breathing patterns definitely interrupt speech and call attention to itself.
b) Most words pronounced incorrectly.
c) Heavy spasms, grimaces, and body movements during speech.
d) All speech hard to understand because of high pitch, hoarseness or extreme nasality.

3 Severe

a) Breathing so totally different speech is hard to understand, or speech totally absent.
b) All words mispronounced or not words understandable.
c) Spasms of face and body making speech impossible to understand.
d) No understandable speech because of extreme voice quality.

Dentition

0 Teeth in good condition; no caries or discoloration

1 Few caries, some discoloration, few missing, little cosmetic disadvantage.

2 Moderate amount dental work needed; could be improved from cosmetic viewpoint.

3 Major dentistry required.

Bladder and Bowel

0 Complete control of both bladder and bowel.

2 Loss of control of one or both at infrequent intervals. Frequent micturition.

3 Complete lack of control of either or both bladder and bowel.

Mentation

0 Has graduated from high school or shows average grasp of general information and comprehension; appears bright and alert; reads newspapers, books, magazines, etc., performs skilled work.

1 Has graduated from 8th grade or shows limited grasp of general information and comprehension; shows some dullness and slowness; can assume responsibility for general care of self; reads only simple material; performs semi-skilled or unskilled work.

2 Limited or no schooling, or has little information or comprehension of what goes on around him; had mentality for only a few matters of care of self; no reading ability; no work capacity except simple chores.

3 Comprehends very little and is mentally incapable of doing anything for self; shows little awareness of what goes on around him; cannot do even simple shores.

Emotional Status

0 Lives comfortably with self and others; handles problems of daily living without showing symptoms of upset and tension; is rarely appreciably upset; gets along well with others;is self-assured.

1 Ordinarily gets along without symptoms of tension and anxiety; occasionally is visably upset and angry; shows some nervousness in dealing with others; tends to be dependent and has difficulty in making decisions.

2 Is easily upset by trifles; very ill at ease with others; unable to accept responsibility or make decisions; difficult to get along with; frequent temper tantrums; cries easily.

3 A problem to manage; strong mood swings; rages if thwarted; must be treated as a small child.

Physical (plus Communication and Eating) use following Code:

0 Normal

1 Fairly well

2 Moderate difficulty

3 Severe disorder

Economic - Check applicable sentence.

Educational and Vocational - Encircle applicable words by number.

A. Schooling

0	1	2	3	5
College or Vocational	High or Trade	Grade	None	▱

Regular or special school Where?

If grade school only, name last grade attended

B. Training

0	1	2	3	5
Professional or technical	Skilled or Semi-skilled	Unskilled	No training	▱

C. Experience

0	1	2	3	5
Steady employment	Occasional jobs	Only home chores	No work experience	

From, Anon., "Interim Report of 1957 Vermont Survey," Twin State Cerebral Palsy Study.

APPENDIX D

COMPARISON OF INVESTIGATOR'S STUDY WITH OTHER SIMILAR STUDIES USING CHI SQUARE WITH YATES' CORRECTION

Item No.	Classification	X^{2*}	P**
1	Speech	5.0	.08
2	Speech	1.25	.60
3	Visual	3.0	.22
4	Overdependency	1.0	.60
5	Family rejection	2.8	.22
6	Personal maladjustment	6.2	.05
7	Personal maladjustment	2.0	.36
8	Full time employment	6.0	.05
9	Financially dependent	2.9	.22
10	Financially dependent	3.7	.13

*X^2 = Chi square

**P = Probability

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