

1963

A study of six preschool children with cerebral palsy

<https://hdl.handle.net/2144/30853>

"Downloaded from OpenBU. Boston University's institutional repository."

A STUDY OF SIX PRE-SCHOOL CHILDREN WITH CEREBRAL PALSY

How these children were helped to solve some of their problems in individual growth and development in a nursery school adapted to their capabilities.

By

Eleanor Hunt Rahn

(B.S.N., Medical College of Georgia, 1959)

A field study submitted in partial fulfillment of the requirement for the Degree of Master of Science in the School of Nursing
Boston University
August, 1963

Reader:

Elizabeth J. Hall
Elizabeth J. Hall

MS
1963
no
copy 2

251

ACKNOWLEDGMENTS

This study was supported (in part) by a graduate training program in Maternal Child Health Nursing from the Department of Health, Education and Welfare, Children's Bureau.

The writer appreciates the support and help given her by the members of the United Cerebral Palsy Association team of the South Shore Area and the Staff of the Nursery School for children with Cerebral Palsy.

TABLE OF CONTENTS

CHAPTER	PAGE
I. INTRODUCTION	1
II. REVIEW OF LITERATURE	4
III. METHODOLOGY	9
IV. FINDINGS	12
V. SUMMARY AND CONCLUSIONS	27
Summary	27
Conclusions	27
Recommendations	28
BIBLIOGRAPHY	30
APPENDIX A	32
APPENDIX B	50
APPENDIX C	57

CHAPTER I

INTRODUCTION

Children with handicaps are numerous and their handicaps often create a feeling of helplessness or of revulsion in some nurses unless they have developed an attitude which can help them to look at the person behind the handicap.

Because of a long standing interest in neurological problems in nursing the writer developed her field experience, which is a required part of the program in Maternal Child Health Nursing, in the area of Cerebral Palsy. This experience was gained at a Nursery School for children with Cerebral Palsy which was designed to meet the needs of families in the South Shore Area of Massachusetts. This community experience was particularly valuable because the nurse who works in the hospital is limited in her contacts with the child who has cerebral palsy because these children are not patients frequently seen in the pediatric units of general hospitals. There is also very little information available about the problems of care which the families of these children experience; therefore, the following is presented as a field study about the problems of these children in the nursery school setting.

The specific purpose of the study is to study the problems of six children who attended the Nursery School for The South Shore Area and to determine how these children were being helped by the program as provided.

It is hoped that the study will be important to people who are

just beginning to understand that the child with cerebral palsy is not necessarily a mentally retarded child and therefore should have the benefit of some type of education. Since the deformities of children with cerebral palsy make them appear so different the possibility of average or above average intelligence is hard for many people to comprehend. Even the parents of these children need help to be able to accept the child's needs in his strivings for individuality in growth and development.

This study may also help student nurses, graduate nurses, and others involved in the care of children with cerebral palsy to look beyond the cerebral palsied exterior to the child who has the same, "...basic human needs for acceptance, for love from his parents, his peers and others, for exploration of his environment, for learning as other children do and for the feeling of status which comes through gradually increasing independence..."¹

Six children were selected for the study. The data was collected by use of anecdotal records and a guided interview with the parents and the children in the home.

Anecdotal records on all of the children were kept from October 1962 until May 1963. From the first week in April until the end of the first week in May the homes of the selected children were visited to discuss the child and his problems with the parents.

The literature was reviewed to formulate a plan of approach to the study and to determine in what ways these children differed from the

¹D. Marlow and G. Sellew, Textbook of Pediatric Nursing (Philadelphia and London: W.B. Saunders Company, 1961), p. 477.

normal in their needs.

Data listed in the medical records of the children were studied to clarify and affirm any physical or mental references made from observations or from parental interviews.

The study was limited by the small number of children in the school and the limited number of interviews with the parents. As the homes of these parents were widespread in the geographic area represented, more than one visit to each home was not attempted.

Chapter II contains a review of the literature pertinent to the study.

Chapter III consists of the methodology used.

Chapter IV presents the data and its analysis.

Chapter V is a summary, and the conclusions and recommendations drawn from the data presented.

CHAPTER II
REVIEW OF THE LITERATURE

Cerebral palsy has existed for hundreds of years. Findings in historical writings give evidence of the problem and medieval mosaics, pictures, and monuments are lasting evidence of the condition as we know it today.

The story of the cerebral palsied is that of children who were felt to be a "curse on the family" so were hidden away from the public view.¹ "... the spastic has come out of the closet." was part of a statement made at a symposium in 1952.² After all the many years this problem has existed, it was not until about 1930 that people began to try to learn something about the numbers of cerebral palsied and give them a chance to prove themselves.

Dr. Bronson Crothers of Boston was the first to describe the true neurological basis for cerebral palsy. Dr. Earl Carlson, who is a victim of cerebral palsy, has added much to our knowledge of the condition and has given us a view of the feelings of the person in his autobiography, "Born That Way." Dr. Winthrop Phelps of Baltimore has provided much valuable information on the diagnosis and treatment.³

¹G.G. Deaver, Cerebral Palsy, Methods of Evaluation and Treatment, Rehabilitation Monography IX (The Institute of Physical Medicine and Rehabilitation: New York University - Bellevue Medical Center, 1955) p.2.

²Psychological Problems of Cerebral Palsy (Chicago: The Easter Seal Society, 1952) p. 3.

³Deaver, op. cit. p.2.

"Of course, the first need of a child is to be an adequate child. He needs to feel secure, wanted, loved. He needs to be able to relate successfully to other children, to do what they do, look as they look, speak as they speak, play as they play, and live as they live. The child who is disabled -- physically, emotionally, intellectually, socially -- faces a great variety of special hazards in his quest of being an adequate child."⁴

Dr. Oberman's statement makes one aware of the need of the cerebral palsied child to have close peer relationships as it is through these that he learns to relate to others successfully. If he is unable to be among his peers in an unrestricted neighborly way a place must be provided for him where he can have these valuable experiences. The nursery school for children with Cerebral Palsy provides a beginning learning experience for the child in an atmosphere which he can understand because he has others around him like himself. His rate of achievement is more comparable to that of the other children so he does not become as discouraged in his attempts.

This summary of a section of the Mid-century White House Conference report gives a good overview of the basic need of children whether normal or handicapped.

In children, development of personality represents the most complicated function of the human organism but does not consist of parts in the organic sense. The development of locomotion, sensory, and social capacities and individual modes of dealing with experiences have a proper rate and sequence which is important in physical growth and functional harmony. These can develop only if development proceeds according to the ground plans. The pre-

⁴C. Esco Oberman, Editorial, Rehabilitation (March-April, 1962), p. 2.

school years are a period of enterprise and imagination. Phantasy substitutes for literal execution of desires and the meagerest equipment provides material for great imagining. The child is no longer guided by outsiders but is beginning to form a set of ideals for himself. He must be given leeway and encouragement to help him develop to his greatest potential ability. He needs to have a feeling of achievement, a sense of identity, a sense of intimacy and, greatest of all, a sense of integrity.

The influence of congenital characteristics plays a great part in how he develops. From their differences in sensitivity, tempo and rhythm, bodily resistance and vulnerability, intellectual endowment, speed and rhythm of growth, they will build their own lives and goals.

His parents feelings may be markedly affected and they differ in their relations to their handicapped child, so may push him away. The child is likely to be affected by his feelings about himself.⁵

Since there are so many ways in which children may differ, is it any wonder that the cerebral palsied child or any other handicapped child is treated as "different"? Every cerebral palsied child is different from the other from the beginning because of the way in which his brain is damaged. He needs help from the beginning or as soon as the difficulty is diagnosed.

In his book, My Left Foot, Christy Brown who is a severely physically affected cerebral palsied person says he feels that confidence and friendliness are far more important than medical treatment in helping the cerebral palsied child to grow and develop soundly.

⁵Mid-century White House Conference, A Healthy Personality for Every Child, (Washington, D.C.; Health Publications Institute, Inc., 1951) pp. 3-39.

He thinks that the minds of the cerebral palsied become as twisted as their bodies unless they are helped to understand their own problems.⁶ By association with others like himself the person with cerebral palsy stands a better chance of achieving at his own level instead of needing to compete with non-handicapped persons. By doing this he gains both a feeling of belonging and a sense of status. The multiplicity of the handicaps may make education an extremely complex situation but every physically handicapped child has a right to an education even though he may never be gainfully employed.⁷

The cerebral palsied child with his circumscribed limitations of movement lacks breadth in experience. He especially needs the stimulating experiences in a nursery school to develop his intellectual curiosity as soon as he is ready for a group situation. He must learn to live and take part in group activities to become familiar with the world outside his home for optimal growth and development. The nursery class will also help the evaluation team to determine what the child might achieve. As he begins to expand his knowledge and activities at the nursery school the observations should become more meaningful.⁸

The cerebral palsied child has an even greater problem in be-

⁶Christy Brown, My Left Foot (New York: Simon and Schuster) 1955, p. 146.

⁷Denver, op. cit p. 55.

⁸"Seven Essentials in Educational Planning for Children with Cerebral Palsy" Program Bulletin No. 5, (New York: The Cerebral Palsy Association, Inc.) p. 2.

coming an adequate child for he has his own apparent handicaps to remind him that he is different. In the home where he must compete with non-handicapped siblings or in the community where he is looked at as a creature for curious scrutiny or something repulsive because of his bizarre movements, he frequently becomes withdrawn. As he grows from childhood where he realizes he is different but does not worry about it, into adolescence where he begins to know he can never be as his peers are, he cannot be expected to compete. He tends to give up and withdraw unless stimulated. If the child is exposed to early education with other children like himself he at least doesn't have to try to make himself like those around him and can concentrate on experiences which will help him to develop a personality of his own.

The experiences and achievements of the children in the nursery school help many of the parents to realize the depth of the problems their children have.

CHAPTER III

ETHNOLOGY

This study was begun in October 1962 and ended in May 1963 at the Nursery School of the United Cerebral Palsy Association of the South Shore Area. The school was located in three rooms of the Second Universalist Church in Columbus Square, South Weymouth, Massachusetts.

The main room of the school was equipped with the usual pieces of nursery school furniture plus some special tables and chairs for children with cerebral palsy. This room was usually the scene of such activity as none of the children liked to remain quiet for very long periods of time. Their play activities were guided toward meaningful activity to supplement the physical therapy which the children received. The second room had a large table for meals, the teacher's desk, and a table for changing the children's clothes. A third room contained cots upon which the children rested immediately after lunch period.

The personnel of the program included the head teacher who was prepared by way of a Master's Degree in Education. This was her first year in nursery education so that, besides learning something about handling children with cerebral palsy, she had to learn how to work with young children as well. The assistant teacher was an athetoid cerebral palsied person who attends Boston State Teachers College and plans to become a qualified teacher for handicapped children. A volunteer also assisted daily. She was a mildly retarded young adult with cerebral palsy who was capable of caring for some of the physical needs of the

children under guidance and supervision.

On Wednesday the physical therapist, the occupational therapist, and the speech therapist visited the school. A visiting nurse also made a weekly visit to check the children for possible infectious diseases or other problems which might need medical attention.

The offices of the Director and the Cerebral Palsy Treatment Center were in Quincy, Massachusetts. All of these people involved in the care of the children were paid by the United Cerebral Palsy Association of the South Shore Area.

The Director of the local association signed the request permitting the study to be done because he felt this study could help the association to determine the effectiveness of the program to the children and their parents.

Eleven children were enrolled in the school when the study began. Six of these children were selected for study.

The anecdotal notes which had been made regarding the six children from October until February were studied and a list of the problems of the children made. Next the notes from February to May were scrutinized for signs of improvement or other change.

Several of the children's parents appeared so interested in discussing the problems of their children at a parent-teacher meeting it was felt all of them might be interested in participating in the study.

During the first week in April the writer started visiting the parents of the children selected for the study. Telephone calls or short notes sent home by the children secured immediate response and the time for the visits were made at the convenience of the parents. All of

the visits were made in the afternoon and in four of the homes both parents were available.

As soon as possible after each visit the information obtained was recorded. This was usually done upon arriving home at night or early the next morning.

The parents were asked the following questions:

1. How did you learn about the nursery school?
2. Why did you send your child there?
3. What changes have you seen as a result of his participation in the school?
4. How have you profitted by having him there?
5. Do you think having a nurse in the school is of value?

The interviews were planned to last approximately two hours, instead they lasted from one to six. After the questions were answered the mothers found pretexts to keep the interviewer with her. During these interviews the chief topics of conversation centered around the child with cerebral palsy and his siblings. The children were in and out of the room for various reasons so that the interaction between them could be observed.

When the interviews were completed additional information was gained from the children's records which were available at the treatment center. This information clarified the information provided by the parents and gave a comprehensive view of the physical and mental capabilities of each child.

CHAPTER IV

FINDINGS

The data was first collected on the problems of the children which were evident in their daily care in the school program. This was followed by one interview with a parent or parents of each child in the home setting.

When the parents were contacted by telephone or by a note sent home with the child the proposed visit was warmly welcomed. The parents knew that the interviewer was a nurse who was interested in their children's problems.

The mother of one little boy had had several psychotic episodes. When visited she was a pleasant soft spoken person. The interview was terminated at the end of one hour because this mother was becoming increasingly vague with nervous hand movements. She, however, completed her responses to the five specific questions.

In all of the other homes the interviewer was asked to stay until the fathers came home as the mothers thought the fathers would want to talk with her too. This proved profitable in every case as the fathers brought out thoughts and feelings which had not previously been expressed.

Most of the children were excited when they found the nurse was going home with them. As she had no car at her disposal she went home with the children in the school taxis. The ways in which the different children showed their excitement was interesting. Kelly cried and acted

shy, Billy wore a big grin all the way home and went immediately to show off his new little brother, Frankie could not be quiet but because of the excitement expressed himself verbally by squealing. Paul asked every so often for several days before, "Are you coming to my house today?"

With only one exception the children came and asked to be allowed to sit in the writer's lap during the visit. In the school one of the little girls had sat in her lap and another of the children was held to quiet her fears during the visit of a stranger. One of the mothers said she thought the children wanted to be held because they felt that this was their particular friend so used this way to show their brothers and sisters they had a friend they could bring home too.

The problems that were noted and the information that was gained during the parent interviews will be discussed in the following paragraphs.

The responses to the questions were as follows:

1. How did you learn about the nursery school?

"The doctor in the clinic in Quincy thought it was time for her to start nursery school so he suggested the cerebral palsy school." This is the general answer given by the parents of all except one child. This child was enrolled because the parents thought it was time to send him to school.

2. Why did you send the child there?

"Because I thought she might become less dependent on me as I couldn't leave her at all."

"I think it helps children in a family to be away from home and their families some."

"To learn how to get along with other people."

"So she would have some experience at being away from home; then, the doctor said she should go too."

If she doesn't learn anything but does have a place where she can enjoy being, I'll be satisfied."

"They told us our son was a retarded child. This disappointed us so because to us he seemed so bright. We sent him because they told us to but I don't know what to expect."

"Around the neighborhood the kids never play with him unless he has a new toy they like and as soon as that is gone they quit playing with him again. He gets so lonesome if he has to play by himself that he wants to sit around the house all the time. At least at the school he has someone to play with."

3. What do you feel that he has gained there?

"He has learned a lot. He talks more than he did and I believe his attention span is longer now. I can't remember nearly as many of the T.V. programs as he can and he knows when to turn the set on for the ones he likes."

"He has learned to know so many more people since he has been there. He talks about the others and it sounds just like any other four year old."

"She has made progress in some ways but has forgotten some of the things she knew. She won't even try to use her crutches now and we had her where she would use them with very little help before she went there."

"He isn't as clinging as he was and he takes care of himself more. He knows most of the letters of the alphabet and I didn't teach them to him so he must have learned them there somehow. He likes to draw and color now too."

"Frankie talks more clearly and knows more people than he has ever known before. He calls the names of the children there and likes to tell tales of what has happened and to whom. He is happier since he is going to school as his brothers and sister are."

"She talks more and is interested in other children, especially those in the school. She will stay with a "sitter" now but I have to tell her well in advance

that I'm going to be away as she still gets so upset when anything new is introduced into her life."

4. How have you profited by having him there?

"When he's in school I can do my shopping. Then too, I can do my house work faster when I don't have to stop so often."

"While he's at school I can leave the baby with my mother and take the girls with me to do my shopping. I put the littlest one in the stroller and the oldest one likes to walk. I couldn't do this when he was at home as he got upset if I forced him to use his crutches and he is too heavy to carry. If he'd ride in the stroller it would be O.K., but he won't."

"The taxi picks her up so late in the morning that I have to wait until she leaves before I can start my work. That makes me so late getting started that I'm never finished before they bring her home again. I never seem to get my house work done."

"It gives me time to do my housework. Since I've been sick I haven't had a chance to catch up and he does need entertaining."

"He is easier to care for at home now as he at least has outside interests which help to make him happier at home."

5. Do you think having a nurse in the school is of value?

"I have felt much more comfortable about sending him to school every day. If he had a sniffle but no fever I sent him on because I knew the nurse who was there would let me know if anything developed. I think a nurse is a big help because she knows about well children as well as sick ones."

"Having more exercise must have helped because his back is stronger. He sits up much straighter at the table now."

"I think the main value of a nurse in the school is that she does understand the behavior of handicapped children."

"Maybe having a nurse in the school might have made

him less scared of people in white than he used to be. He used to have a tantrum every time I took him to the clinic and now he doesn't."

"A nurse would be of help in looking after the general health of the children."

Summary of Interviews

All but one of the children were in the nursery school as a result of referrals from the doctors in the clinic or treatment center. The other mother decided that her son who was mentally retarded along with his cerebral palsy must start to school when the other six year olds did but was wise enough to seek aid in her selection of a school.

Most of the parents expressed the need for their children to have playmates who are of similar age and physical development since the children could not get out in their own communities to play. They felt the children would become less dependent on their parents.

All of the parents expressed the thought that their children had learned something new and thought it a worthwhile experience. Some of the areas in which the children had improved according to the parents were in speech, lengthened attention span, had become more like other children their own ages in the way they reacted to conditions outside the school, had some gain in emotional maturity, and in having outside contacts as their siblings had.

Shopping was easier for the mothers when they didn't have to take their dependent children with them and the housekeeping went more smoothly when so many stops were not required.

The problems which were evident in the anecdotal notes regarding the children in the nursery school are classified according to the

following categories: punctuality, peer relationships, toilet training, dressing and undressing, mobility, and emotional instability. These problems of the children will be discussed in relation to management and final results in the nursery school setting.

Punctuality

The nursery school hours were from 9 a.m. to 2 p.m.. The children arrived in the school between 9:30 and 10 a.m. The taxi drivers were back to take them home by 1:30 p.m. so the children never spent the full time in the school. This same taxi service provided transportation for school children. It appears that the school period for the children with cerebral palsy was not recognized as important because there were no formal classes to be attended.

What does lack of punctuality do to the growing child when it continues day after day? Many of these children will be expected to be on time for regular classes in the public school system and later if they are able to work. Being taught punctuality now is important for later development of the sense of being where one is supposed to be at the time designated. A consultation was held with the owner of the taxi service. Some improvement was noted but no real correction of the situation was achieved.

Peer Relationships

Only one of the six children could play out of doors alone; the others could not walk unless assistance was given. None of the children had peers in their own communities so that their most frequent contact with other children was in the home. Other children discussed by these six were usually siblings or an occasional cousin.

Each of the children in the school learned the names of all of the other children and, though one child had little speech she knew the name of each child. She showed that she knew by turning to look and sometimes to point toward the child being spoken to. Peer relationships are important for the establishment of self-esteem. In the nursery school setting where everyone else had similar problems the children did not appear different and they could progress at their own rate in the task of growth and development.

Toilet Training

Every child in the group selected for the study had some problem with toilet training. The only child who could go to the bathroom by himself was a hemiplegic. He had to have help as he could not fasten his pants. Two of the children were still wearing diapers and plastic pants at the beginning of the year but they never wet their diapers if toileted at two to two and one half hour intervals.

During an orthopedic check-up at the Cerebral Palsy Treatment Center the doctor suggested to Paul's father that he might try the child in training pants instead of diapers. Soon after, Paul came to school in training pants. He immediately took responsibility for asking to go to the bathroom and the two hour toilet trips were suspended. A short time after Paul started wearing pants an occasion arose necessitating a phone call to his home. As the mother was ill, the father answered and at this time he was commended for carrying through on the doctor's suggestion. He seemed pleased when told how well Paul had reacted to the change at the school.

While talking with the second child's mother it was learned that

she had been told the year before to dress her little girl in slacks. This mother was using diapers and plastic pants as a precautionary measure. She immediately responded to the simple suggestion that she try her daughter in dresses and panties. Although this little girl can say very few words, she had learned to say "bathroom" when she wanted to go.

Dressing and Undressing

An effort was made to help the children gain some independence in dressing and undressing themselves by letting them remove and put on their own outdoor clothing with minimal assistance.

Two children could remove their own outdoor clothing alone, only one could put them back on again. One could hang up his coat. The others were helped to hang up their coats to try to create an awareness of the need for taking care of their own clothes.

One mother used some zippers with large ringed pulls and sewed them to strips of cloth which she attached to a piece of board so that the children might practice. The zippers were obtained from old jackets so they were the same as those which were on the children's jackets. Button strips with large buttons and buttonholes were also made which were easy for small fingers to manipulate and wooden shoes with large holes were used to teach the children how to lace their own. These seemed to help since the children were encouraged to play with them and they were available in the play area at all times.

Only one child failed to show improvement in removing her own jacket even though help was also provided by the occupational therapist.

Mobility

At the beginning of the year the children were placed in chairs

when they were brought in by the taxi drivers in the morning. A puzzle, beads, picture book, or some other toy was given to them and they played with these toys until juice time except for short periods when they were encouraged to walk under close supervision or to go to the bathroom. After juice, roll call was taken and the pledge of allegiance was said, then some type of group activity was employed until lunch time.

One morning when part of the staff did not arrive before the children there was not enough time to take off coats, make bathroom trips, and provide toys individually. The toys were placed in the middle of the table for those interested in sitting in chairs. The other children were put down on the floor near a large box of blocks. When the rest of the staff arrived two of the children with long leg braces were flat on their abdomens busily digging in the box of blocks and did not want to stop even when juice time was announced.

Two of the mediums which normal children use in their play are pretty well out of the reach of these youngsters. These two things are snow and dirt. One morning the teacher brought some snow to make a small snowman. All of the children aided in it's construction then watched as it melted. While they were building the snowman, they felt the texture of the snow, smelled it, tasted it, rubbed it on their clothes and on the table. For several days they watched the snow on the ground as it melted. Some of their questions were, "Where does it come from?" "Why is it cold?" "Who made it?" "Why is it white."

As soon as the weather permitted, the children were taken into the yard to play. Some walked up and down on their crutches and did not seem as afraid of falling as they had indoors. Others were put on a

blanket on the grass. One little girl who is usually afraid of new experiences crawled from the blanket to play with the grass and in the dirt.

Another day when the children were playing in the yard the teacher decided to go to the store next door for a large ball. Some of the boys asked to go along. As a result plans were made to take all of the children. There were four adults and eight children so that the trip was made without incidence. The sales people in the store and the other customers treated the youngsters just as they would have any other child who might have been shopping with their parents. This was a good learning experience for some of these children. They were consulted about the size and color of the ball and were allowed to hold it and look it over before it was paid for so that each child could feel that he had had a part in the purchase.

Fear of Falling

All except two children were afraid of falling. One child walked with a limp but his balance was good, so if he did fall he was relaxed and never hurt himself. Another child would slide from his chair with a thump, turn over on his abdomen and take off in the direction in which he wanted to go.

The assistant teacher suggested holding the child's hands in helping him to walk. If the child was steady enough someone walked beside him and allowed him to hold her hand. If the child still seemed afraid the person assisting walked backward and had the child hold both of her hands. The children were encouraged to look where they were going instead of depending upon their assistants to lead them.

Kelly's parents bought her a helmet to protect her head as they were afraid she would fall also. The helmet was presented to her for her birthday and for days after she would let no one remove it even for nap time. This seemed to make her feel much more secure.

All of the children were put on the floor to play for part of the time. They were encouraged to go to the toy cupboards for the toy they wanted instead of waiting for someone to bring it to them. They soon started to go from one room to the other if others were going who could walk.

By the end of the study all of the children had gained some feeling of security and the two boys who could move about without support were moving about on their braces and crutches undaunted; if they felt they were going down they learned to throw their crutches away from them and go down relaxed. The two girls relaxed enough so that they could walk with one hand on anything that would give them a sense of balancing stability. Many times the things the girls reached out too were not stable but at least they gave them emotional support. One of these girls learned to go up and down the stairs by holding the banister on one side.

Emotional Instability

There were two children in the group who cried frequently. One had a tendency to cry each time a new adult came near her but later was able to be around a group of fourteen Girl Scouts without a whimper and to play happily with some of the girls. She cried each time the physical therapist approached her although she had the same exercises at home daily. By the end of the eight months this crying could be controlled to

a certain degree and the crying periods were not as frequent.

No one could determine what made Billy cry so much. On some days he could play a game but on other days the same game brought on a crying jag if it was even mentioned. On some days he could handle his own clothes when he went to the bathroom then on other days he would stand and cry until someone pulled his pants up for him. There was no apparent improvement in this condition, in fact, it even seemed to grow worse. He also started wetting his pants again at intervals even though he had been trained for more than a year. Further information about this child is presented in Appendix A.

Summary of Observations in the Nursery School

Physically all of the children had pretty well established bladder and bowel control because the training that had been initiated in the home had been consistent by extending the training into the school. Muscles were strengthened by allowing the children to use their bodies at their own level of ability and by encouraging good posture.

Socially friends had been made with whom the children could relate and there were experiences which they could share with those at home on a more equal base. The children began to seek ways in which they might gain parent approval. Articles that were made were carried home to show to "Mamma" or to sister or brother.

The attention spans of all of the children increased in length with the exception of one. This child continued to jump from one thing to another during the entire study and, if not allowed to leave the group when he became restless, he would begin to distract the attention of the

others. Interaction as a group or with one other child could be observed. All of the children learned to say "me too" or "wait for me" if they were being left out or were afraid they would be.

Only one child failed to gain some measure of self help in dressing and undressing. The other children learned to remove their own coats and hats and to try to put them on again. They could only hang their clothes up with assistance but were eager to try.

Mobility was increased by allowing the children to move about as they desired. By introducing excursions into the nursery curriculum the horizons of the children were broadened.

The fears of falling which were displayed by four of the children were partially allayed by helping them to relax. With relaxation came the desire to move about with the less affected children.

Emotional stability was improved in all of the children except one. He in turn seemed to grow worse.

Some of the problems of the children are not directly applicable to the handicaps of the children. They come with the inability of others to realize the importance of helping the children set up realistic goals and to work with them in their efforts to achieve the goals.

Characteristics of the children are described in Appendix A.

Other phases of concern in care of the children as expressed by the parents are included in Appendix B.

A resume of the meetings held during the year concerning the children and their families are given in Appendix C.

Excerpt of Interviews and Observations

The parents expressed the needs for their children to have play-

mates. It was noted in the school that none of the six children selected for the study ever mentioned peers with whom they played outside of the school. The observer also noticed in two of the homes that the siblings of the children played with the child with cerebral palsy until some of their peers came to visit then the handicapped child was ignored. The handicapped child was not deliberately ignored but could not keep pace with the non-handicapped children.

Gradual development of personality traits were evident in the anecdotal records kept through the eight month period. The parents also mentioned some changes.

A need for the children to be with others of similar mental age and physical ability or disability was stressed by all of the mothers. All of the parents cited changes in their children which they thought the children had gained by being with others of like conditions.

Two of the children were observed to gain some maturity in emotional growth. The parents confirmed this during the interviews.

Development and improvement of health habits were evident in better posture, fewer bladder and bowel accidents, growing appetites as the children became more active, and the desire to become more independent in dressing and undressing and in caring for their own clothes. The parents mentioned these accomplishments and seemed pleased with their children's growth and development.

In October when the writer first entered the building where the school was located she could hardly believe there were children present as the atmosphere was so quiet. By May the children had developed into individuals each with ideas of their own. At times it became hard to

hear anything but children! They were well on their way toward becoming adequate children within their own rights and capabilities.

In January and again in May 1963 meetings were held with all of the members of the team for care of the children with cerebral palsy, including those in the treatment center and the school present. Each child's problems and improvements or regressions were discussed. The Psychologist and the Pediatrician acted as guides for the discussions. These meetings helped to clarify the problems and provided the team with a better understanding of ways in which they might help the children.

CHAPTER V

SUMMARY AND CONCLUSIONS

This study was conducted at the Nursery School of the United Cerebral Palsy Association in South Weymouth, Massachusetts. The purpose was to determine which of the problems of six children who attended the Nursery School were being helped by the program.

The information was derived by using two methods. These were:

1. Observations and anecdotal records of the children included in the study.
2. A guided interview with the parents in the homes.

Conclusions

The data revealed that the selected children did have problems which could be helped in a nursery school program where all the staff worked together to provide an opportunity for the children to experience activities within their individual capabilities.

The growth and development problems of the six children with cerebral palsy selected from this nursery school were partially solved in several areas.

1. Peer relationships were improved by allowing the children to have more free play time to explore and develop their curiosity and imagination. A longer observation period with the children would be required to determine how much help the children actually need.

2. By placing the mentally and/or physically disabled child with others of similar mental age or physical disability he may develop to

the fullest extent of his potential capabilities.

3. Attendance in a nursery school helps to relieve over-dependency on the parents.

4. Development of good health habits such as posture, toilet training, and dressing can be improved in a situation where others are having the same problems without embarrassment or inhibitions.

5. It would appear that the child with cerebral palsy learns best how to be an "adequate child" by being allowed to explore in a non-structured atmosphere with his peers.

6. A more accurate picture of children with cerebral palsy can be obtained by meetings of the entire school staff (a team approach). All of the pertinent points of the observations of those in the immediate care of the children in the school can be discussed with the psychologist present to clarify the material which is presented. Interviews with the parents also contribute to the total picture.

Recommendations

1. A similar study with a larger group of children to increase the validity of the findings in this study.

2. Programs in nursing education to include information about the family who experiences a child with cerebral palsy so that all nurses are able to help parents in this area.

3. An organized parent group in the South Shore Area especially for parents of children with cerebral palsy.

4. A nurse included in the team of the United Cerebral Palsy Association of the South Shore Area to help in coordinating the work of the Treatment Center, the school, and the homes of the children.

5. A study to determine whether children with cerebral palsy might not eventually develop a mode of ambulation of their own in the nursery school by being put on the floor where they can follow their peers with the means at their disposal.

BIBLIOGRAPHY

BIBLIOGRAPHY

Books

- Brown, Christy, My Left Foot, New York: Simon and Schuster, 1955
- Carlson, Earl R., Born That Way, New York: Van Nostrand Press, 1941.
- Cohen, Dorothy and Stern, Virginia, Observing and Recording the Behavior of Young Children, New York: Bureau of Publications, Teachers College, Columbia University, 1958
- Deaver, George G., Cerebral Palsy, Methods of Evaluation and Treatment Rehabilitation Monography IX. (The Institute of Physical Medicine and Rehabilitation), New York University - Bellevue Medical Center, 1955.
- Gruenberg, Sidone M., The Parents Guide to Everyday Problems of Boys and Girls, New York: Random House, 1958
- Marlow, Dorothy K. and Sellev, Gladys, Textbook of Pediatric Nursing, Philadelphia and London: W. B. Saunders Company, 1961.
- Psychological Problems of Cerebral Palsy, Chicago: The Easter Seal Society, 1952.

Articles and Periodicals

- Barckley, V. and Campbell, E. I., "Helping the Handicapped Child Achieve Emotional Maturity", The American Journal of Nursing, 59: 376-379, 1959
- Carlisle, Verne, "The Pre-school Exceptional Child", The Crippled Child, 28: 20-22, August 1950.
- Miller, Elsa A., "Cerebral Palsied Children and Their Parents," Exceptional Children, Vol. 24, No. 7: 298-302, 305, March 1958.
- Oberman, C. Esco, Editorial, Rehabilitation, March - April, 1962.
- Reid, Eleanor S., "Helping Parents of Handicapped Children". Children, 5: 15-19, January - February 1958.

Public Documents

- Association for Aid of Crippled Children, Inc.
- _____. Cerebral Palsy Institute Proceedings: New York, 1950

The Cerebral Palsy Association, Inc.

"Seven Essentials in Educational Planning for Children with Cerebral Palsy," Program Bulletin No. 5.

United Cerebral Palsy Association, Inc.

Stevens, Godfrey D. and Birch, Jack W., "Guidelines for the Future," A Parent Education Series, 1959.

_____. "Some Thoughts on Planning Parent Programs," Program Bulletin No. 8.

United States Government Printing Office, Washington, D.C.

Your Child from One to Six, Children's Bureau Publication No. 324

Mid-century White House Conference, A Healthy Personality for Every Child, Washington, D.C.; Health Publications Institute Inc., 1951.

APPENDIX A

APPENDIX A

TONI

Toni was born a normal little girl except she was small weighing only six pounds and a half. When she was eight hours old she began to run a temperature and to have convulsions. The doctors thought at first she might have sustained some injury at birth as she was also showing symptoms of a brain hemorrhage.

Not long after she started having the first trouble they noticed that her liver was enlarged and she started vomiting blood. She was a very sick little girl they said and they didn't know whether she would make it through those first three days. When five days old she became jaundiced and her bilirubin was elevated so a replacement transfusion was done. Following this she began to improve a little.

When she was one month old, the parents were told they might take her home but the doctors at that time had very little hope that she would survive for more than three months. At three months they still gave the parents no hope that she would live.

At this time the parents were also told that the cause of the illness was a viral infection and the reason they didn't learn what it was sooner was because it was the first time they had seen this in so small an infant.

This family lived in a fairly new suburban community in South Braintree. All of the homes in the area are of similar construction on nice large lots where there is plenty of room for the children to play.

There are many children in the area and Toni is accepted by them and they come to play with her in her yard or push her up and down the walk in her wheelchair.

The father works in construction so makes a good income while he is working but at times when he is out of work the family has to draw on savings or seek unemployment compensation. At times they have to "rob Peter to pay Paul" then scramble to straighten the mess out later. This makes paying for nursery school attendance for Toni quite an expense when they have four other children and another baby on the way.

The mother is a pleasant friendly person who can talk pretty freely about her feelings. She was quite upset over the taxi situation. She said, "The children are supposed to go to school from nine to three but they never do as it is about ten o'clock some mornings when the driver comes for her and this is a problem for me. I get her ready then dress the boys and put them out in the yard to play and she's still waiting. By this time she is getting restless and begins to get fussy so I have to entertain her until they come. It's so late when she leaves that I've just gotten my work started when she's back again."

"I wonder if the other mothers wish the same thing I do? If they would just make the hours nine to twelve or twelve to three and stick to them I would know how to arrange. I think she is happy there and that's the most important thing but it sure does wear on me. It would be easier for me to keep her at home than to deal with this."

Neither of these parents felt that the child created any problems. Their other children are younger than Toni with the exception of one, so there is always someone for her to play with.

They do not appear to be looking forward to see what will happen in the future but are living with their problem child on a day to day basis.

PAUL

Paul was a premature baby as were all of Mrs. G.'s children. He was the third in a line of four. At birth one of his lungs did not expand properly so he remained in an incubator for about a month.

His birth weight was four pounds and five ounces and he was born by cesarian section. The effects of his cerebral palsy were evident very early. He was diagnosed as a spastic paraplegic.

Paul was in a treatment center for about six months when he was two years old for surgery and training. During this time the mother was delivered of her fourth child and developed a post-partal psychosis. She was hospitalized in a mental hospital.

The father was making a good salary but the strain of the child's hospital bills plus the mother's and the housekeeper who had to be hired to care for the other children was too much for the best of salaries. Paul was taken home with a referral to the Cerebral Palsy Clinic in Quincy for physical therapy and nursery school. At the school he was the youngest child so he received much attention, especially since he had a very well developed personality and a big grin.

The parents were led to believe the child was mentally retarded. Of this, the mother said, "We were so disappointed because he seemed so bright to us."

"Since he has been there for two years he has learned to know so many people. He talks just like any other four year old and acts like his older brother and sister did when they were his age." The mother did not know the writer before but evidently knew she had been doing the

child's exercises at the school twice a week because she commented on how much straighter the child sat.

The father commented, "He has learned to take up for himself. He doesn't let the other kids put anything over on him and even sometimes starts the fight. He has learned to use his crutches better than some of the older children at the school."

"You should see him do tricks. He likes to slide off of the sofa and turn a flip."

The first encounter with this father was at a Christmas Play presented by the Adult Cerebral Palsied Young Peoples Club in the South Shore area. The children were included in this program so the father had taken Paul and his sister. The father was rather abrupt and seemed reluctant to talk at this meeting. Later when the child was seen in the Cerebral Palsy Clinic by the Orthopedist for evaluation the writer was present in uniform. This must have given him a more relaxed feeling with her because since then he has been more friendly.

He gives the impression of being hard but since he has had to assume the responsibility as both mother and father at times and direct the running of the home even with the mother there it is suspected the exterior was assumed to cover his anxieties at having a handicapped child and a wife who was unable to take full responsibility.

The family was Catholic and must have attended church fairly regularly as the little boy talked about going and always named off the whole family as attendants.

JACK

At seven months of age Jack was a healthy thriving little boy who was sitting alone, beginning to pull himself to a standing position, and beginning to try to form simple words. He became ill with a staphylococcal pneumonia and from this developed a generalized infection. When he recovered from this spell of illness five weeks later he no longer did any of the things he had been trying to do before he became ill.

He was eighteen months old before he tried to sit up again and the only way he could move about was by sitting on the floor and by using his right hand and foot he could propel himself about. During this time the doctors explained to the parents that their child had cerebral palsy. A satisfactory explanation for the cause has never been given. The parents were told that during the height of his illness the child had a ten minute respiratory arrest but the doctors were not sure whether this was responsible or not.

The nurse met Jack's parents a few weeks after she started field work at the nursery school. At a parent-teacher meeting the parents offered to drive her to the bus. During the ride the subject of children and their problems arose. This led to a discussion of personal feelings and the mother brought up the subject of Jack and his education. He was already seven years old and she was trying to think ahead for a solution of what to do next. "He's mentally retarded you know, so we can't get him into the school system. I'd like to keep him in the nursery school for another year but I don't know whether they will

let me or not."

When the interviewer went to the home later for a visit the mother was expecting her so they had a nice long chat before the mother brought up the subject of possibly keeping the boy in the nursery school again. She explained how much she felt he had learned and that he did have someone to play with where at home he was alone too much.

The parents are looking ahead to the time when the boy will no longer be a child and are trying to find some occupation he can learn which will not be above his mental and physical capacity. The mother had mentioned possibly helping to run a filling station but the father immediately helped her to see that this would not do.

There are two other children in this family. The daughter is nine and the son two and a half. They own their own home at Wollaston Beach and are in the middle income group.

One of the problems the parents are having right now is trying to help Jack attain the knowledge he needs for his first Communion in the Catholic church. He recognizes the pictures they are using and can explain but this explanation is so simple that the priest is not sure the boy understands what he should be getting from them.

The mother was quite upset over the attitude of the priest and was determined to go to someone else if Jack was not accepted the next time he tried.

According to the mother, the father of the child is not too disturbed over the child's physical and mental condition. She said she thought her husband did not see the child in a worse light because he had a brother who was born with multiple deformities who is now in a state

institution. The children in the father's family were brought up with the belief that their brother was intended to be that way so the parents had not tried to have anything done for him.

This mother's health is not too good but she keeps putting off having anything done about it until she has to go to the hospital.

KELLY

Kelly was such a pretty little girl. Her hair was light brown and turned up around her face in soft ringlets. Her eyes were large and blue with long silky lashes and well shaped brows. Her complexion was fair with rosy cheeks and lips but she had a rash around her mouth from time to time as she drooled almost continuously.

She smiled readily but bursts into tears almost as easily. Her speech was clear and distinct most of the time but when she became excited she couldn't talk.

Kelly's mother dressed her in pretty bright colored dresses which always looked so fresh and starchy. During the winter she wore leotards to keep her well shaped legs warm. Her leotards always matched her dresses and her shoes were freshly polished.

This little girl with cerebral palsy was the second of three children born to the M's. She showed signs of her brain damage early so the parents were alerted for possible problems. The cause of her cerebral palsy was never determined. The father said, "If it had been the oldest one we could have understood it better because she was a sight. She looked like she'd been beaten and she didn't breathe for a couple of minutes."

The oldest girl was eight years old and in the second grade. She was also a very beautiful child. The baby of the family was a boy. He was a round roly-poly little guy whose coloring was exactly the opposite of that of his sisters. He was three years old and all boy.

The M. family owned a big rambling two family house in Brockton.

Mrs. M. made almost all of the children's clothes plus keeping her house and working occasionally as a practical nurse in a hospital near home.

Mr. M. was an electrician who made an adequate living for the support of his family. The main reason Mrs. M. worked outside of the home was because of Kelly's dependency.

Kelly had become so dependent on her mother that the mother could not be out of sight without the child having an emotional outburst. The mother decided that if she were not there Kelly would have to go to someone else.

Both of the parents realized Kelly's limitations physically and mentally. Mr. M. said of her mental disability, "The doctor said that she was about four years old mentally but I don't think she's more than three." Both of Kelly's parents discussed the problems and possibilities freely and had begun to think ahead to what may happen in the future.

Kelly was a well-developed appearing five year old girl. She did not stand or walk without support but could hold onto objects about her to go from one place to another. She had such a fear of falling that she may never walk alone.

Her sister and brother accepted her and did not appear affected by her defects. When they were playing in their own home with or without their friends they included Kelly but when they went away Kelly played alone. She seemed satisfied to sit and play alone but enjoyed being with them when they were around.

Mrs. M. exercised Kelly regularly each day but didn't seem to get very far toward helping the child gain muscular coordination and

balance.

Kelly was toilet trained and could feed herself but these were her total self help accomplishments.

BILLY

Billy also lived in Brockton. He had a left hemiplegia and an alternating strabismus.

He was the oldest of four children of a twenty-one year old mother. He would be five years old in October. One of his sisters was three years old, the other was eighteen months old. The baby brother was two months old.

This little boy had an emotional problem as part of his cerebral palsy but so many other things had happened in the months of the study which could affect a little boy that it was impossible to tell which was causing his crying and his regression in toilet training.

The father was an alcoholic who had left home several times then returned but he was out of the home at the time of the study.

Just before the new baby was born in the Spring the orthopedist had prescribed a brace for Billy and started him on crutch walking. Billy liked the brace and soon learned he could walk without the crutches but the doctor didn't want him to do this.

At the school he used the crutches readily but at home burst into tears if his mother tried to get him to use them. At home he had been going to the toilet alone for some time and could manage his clothes quite well; in school he became very disturbed if someone didn't take him to the bathroom and wait for him to pull his pants up.

In March the doctor prescribed glasses for him because he was near sighted and because of his strabismus. Later the doctor planned to change to a frosted lens over his best eye to try to help him to use the

poor eye.

After he received the glasses, he started wetting his pants again. One might ask, what will happen when Billy is forced to use the eye from which he cannot see quite as well.

As young as Mrs. R. was, she seemed to have a good knowledge of growth and development. Her house was neat and clean and all of the children seemed healthy sound little tots except for Billy.

She really had a lot of responsibility, but she was apparently capable of handling her young growing family with the help of her mother who lived in the upper part of the two family house.

The income in this family was rather limited and she was receiving Aid to Dependent Children to supplement.

FRANKIE

Frankie was not in the nursery school until the last of November. He is a seven-year-old Jewish boy with quadriplegia due to cerebral palsy. His mental age is below average so he could not enter public school in the Fall when his twin Sammy did.

Frankie and Sammy have thick shiny black hair, hazel eyes, with black eyebrows and eyelashes, and healthy rosy complexions. They were identical twins but the only evidence of this fact was to be found in their coloring and facial appearances.

The day Frankie first came to nursery school he sat slumped in his chair with his head drooping and said only an occasional word. He had cried in the taxi on the way but stopped by the time he reached school. He has just become toilet trained so had a few accidents before he learned he had to tell someone when he wanted to go to the bathroom.

A puzzle was just that to him! He would stack the pieces up on top of the frame then announce "I'm through." He soon began to watch the other children and try to follow what they did. He could be led into activities and, with help, learned to finish short tasks without losing interest.

By February Frankie's vocabulary had increased and the things he said were easier to understand. He learned to pull himself up in his chair to an erect position but had to be reminded to do so frequently. About this time he was put down on the floor to play with blocks.

Block play didn't last long as he loved to crawl about, especially up and down the corridor. He couldn't walk but when down flat

on the floor moved about quite rapidly on his forearms and knees.

Frankie enjoyed having a part in what the other children were doing such as working with dough, paints (most of which he put on himself), valentines, Easter baskets, and in going out of doors to play.

He learned he could wriggle down out of his wheelchair by himself so when he was out of doors he got himself down on the ground so he could follow the other children as they moved about.

After a few weeks Frankie knew the names of all of the children in the school plus those of the personnel. His taxi driver talked with him while they were traveling as he lived so far from the school; she started singing to him one day so after that he tried to sing too. His favorite song was, "Oh, Johnny". Frankie couldn't sing nor could he learn all of the words but he tried hard enough for two little boys.

His mother said he came home every day with some tale about what happened at the school. One day a child fell from a table and received a mild concussion, Frankie went home with this tale and the mother was quite worried, When she saw the writer the next night she asked about the condition of the other child as her son had made it sound as if the child had been seriously injured.

Frankie and Sammy were born January 11, 1956. Frankie came first then Sammy followed seven minutes later. Frankie weighed three pounds twelve ounces, Sammy three pounds five ounces.

Both boys ate and grew but Frankie was always harder to feed than his brother and by a year of age Sammy was larger and more active than Frankie. Since the parents had had experience with premature babies before they sort of knew what to look for in caring for these two.

When Frankie had reached this age and was slower in growth and development the parents were sure something was wrong with him so a visit was made to their pediatrician. Frankie was diagnosed as a cerebral palsy then. Sammy did not appear to have any brain damage until he started to try to walk and his heel cords were so tight he couldn't put his feet down flat. Frankie had remained slower than Sammy in every way.

Sammy's mental age was apparently normal or a little above average but Frankie had been placed at about the four year old level.

The parents of these boys have two other children. Noel was thirteen months older than the twins and Jeanne was ten years old. They lived in an eight room house in Milton, Massachusetts. The house was in a clean friendly neighborhood among others of middle income families.

A hedge surrounded the small neat lawn which separated the house from the street. The house was painted pale green with white trim and crisp fresh curtains peeped out through the windows. Inside the house was furnished neatly and was always clean.

Mr. and Mrs. H. were interested in the welfare of their children. They kept them neatly dressed and took an interest in the children's outside activities. Each child entered nursery school when he was old enough except Frankie who was not ready for it at three years. All of the children except Frankie attended Hebrew School besides going to Public School.

According to Marlow and Sellew Sammy's description fit that

¹D. Marlow and G. Sellew, op. cit., p. 596

of the average seven year old. He was a co-operative member of the family and wanted approval by his parents so tried hard to meet their standards. His posture was erect and his muscular coordination good except for his short Achilles tendons. Socially he was friendly and outgoing with everyone including his brothers and sister. He dressed and undressed himself but liked to have someone help him with his braces and shoes. When he had on sneakers he put on and took off his own.

Frankie on the other hand, had none of the attributes of the seven year old except size. He was usually co-operative and wanted to do but could not. His muscular co-ordination was very poor. He couldn't stand or walk without braces and support and only moved from one place to another by crawling. He couldn't dress or undress himself nor could he speak distinctly.

Mr. H. drove a special cab during the school year then picked up regular taxi service after school was out. During the school year he took regular fares from the time the school children were home until six at night. Mrs. H. said he usually left home about six thirty in the morning and was never back before six at night. By long hours and a determination to do his best he supported his family comfortably.

The twins had been a pretty heavy expense for this family. Their shoes alone cost about fifteen dollars a pair then there were adaptors that had to be added because of the braces which both boys wore. Frankie's braces cost \$275.00 but they could be used for several years as new bands could be added and the braces extended at knees and ankles as he grew. Besides the braces Frankie had crutches, a walker, a wheelchair, parallel bars for walking, and recently the father had had a

standing table made for him.

In addition to the twias with their cerebral palsey, Noel had a speech defect. He had attended a speech clinic in Quincy twice a week for two years so there was the expense of his therapy and two way transportation for two people to Quincy and back.

One morning the daughter who is ten years old said to her mother, "You always help the boys dress but you never help me. Frankie gets all of the attention around here."

Realizing the reason for the outburst the mother started asking Jeanne to share with her in giving the others attention so she would have more free time. Jeanne became an active member of the team and began to do more things in the home. This gave her mother more free time so she started taking the girl out for an occassional walk or trip into town and the little girl settled down to loving her brothers again and stopped complaining so much.

This was the best adjusted family found among the six homes visited. Both parents showed so much interest and pride in their accomplishments instead of complaining of what they didn't have that the nurse developed a desire to see more of them and enjoyed going back later.

APPENDIX B

APPENDIX B

OTHER CONCERNS OF THE PARENTS AND FAMILIES

Kelly's parents realized the impact she might have on the other children when they grew older. Both Mr. and Mrs. M. told the interviewer that they had agreed as soon as they found Kelly was palsied that if a time ever came when the others lives would be affected too much by her that they would institutionalize her.

Mr. M. said, "We, Mary and I, are sorry she is like she is; but, you know she is kind of cute and she gets an arm around you and she holds on so tight."

"I guess God knows who He's giving handicapped children to. He knows which one's can stand it."

Frankie's parents both talked freely of his mental and physical problems. The father said he had tried for a month to teach Frankie the three main colors but gave up because he realized he was not getting anywhere and the child was only becoming frustrated.

Mrs. H. says of Mr. H. "He exercises Frankie every night and anything that anybody mentions which they think might help Frankie he either buys or makes for him."

Mr. H. commented on the problem of Frankie having to be lifted so much and what a job it was getting to be for his wife to do. He (Mr. H.) came by each afternoon about the time Frankie got home from school to carry him to the bathroom and remove his braces so Mrs. H. would be spared some of the back breaking work.

Frankie's twin, Sammy, was to have his Achilles tendons

lengthened in June. During the visits the interviewer made in this home she was asked several questions by the child. He wanted to know about the injections he would have to have and about what was to be done to his feet.

The coming surgery was discussed by Sammy, his parents and the nurse. Sammy was apparently satisfied by the explanations of why it was necessary to use injectable drugs when anyone had an operation and about where the parts of his feet which needed fixing were. He wanted to know whether the surgery would hurt or not. He was told that this was the reason people were helped to go to sleep as they would not feel the hurt then.

Sammy was not too happy at the idea of the "shots" but decided it would be better to have them than to be uncomfortable. He talked freely about the hospital, how long his casts would be and how long they would stay on, and about using Frankie's wheelchair while he couldn't walk.

His desire to use the wheelchair was the only indication this child ever gave which would make one aware he felt he was not getting the same treatment his twin was. In other things he treated Frankie just as the other members of the family did. If Frankie slipped down in his chair and no one else was there to pull him up Sammy would grab him by his shoulders and give him a tug to help him up.

Mrs. R., Billy's mother, had a few questions concerning growth and development of all of her children but was especially concerned about the need for both of her daughters to wear corrective shoes to prevent them from toeing in. The youngest girl tumbled over her own feet

frequently.

The type of shoes these little girls need plus Billy's special shoes make quite a large shoe bill for any family. Added to this cost there are the frequent changes necessitated by the rapid growth of the feet of children under two years old and the youngest of these little girls was only eighteen months old.

Toni's mother was more disturbed by the tardiness of the taxi service than any of the others, although several of the children's mothers mentioned it. She said she did not think it fair to the child to have her ready at nine o'clock then expect her to sit and wait until ten before the taxi came.

Mrs. L. said when Toni and her brothers were playing in the house Toni would lie in wait for the boys to trip them if they aggravated her. Her means of retaliation were apparently to bring them down to her level.

Though Toni seemed so vague and uncommunicative she did many things for herself that none of the other children in the nursery school could do. She took her own bath and was very unhappy if anyone insisted on bathing her. She could take off and put on her own clothes if there were not too many buttons. Her shoes were high laced ones which she could remove but had not learned to put back on yet.

Toni could ride a tricycle and manipulate her wheelchair but she was afraid of falling to try to walk alone. Since she has shown so much initiative in other things she may find some way to walk for herself.

Neither of Toni's parents seemed to realize the importance of the future for the child and, in a way, this is probably natural as they were

never given any hope that the child would live this long. At first the doctors would say "perhaps three months, a year, another six months" but since she outlived all predictions the parents had apparently adopted the attitude of "wait and see."

Paul's mother is not physically or emotionally capable of giving him other than the essential early mothering. When he was two years old she had another child and developed a post-partal psychosis.

Mrs. G. had had some problems with psychoses before her marriage then was married for seven years before her first child, a girl, was born. All of her children are premature and had to be delivered by cesarean section.

Paul was in a Treatment Center during part of the mother's hospitalization so did not feel the result of her absence from the home so much. Evidently after she returned from the hospital the mother continued to treat Paul as she did the young baby so he began his second year in the nursery school as a rather immature four year old.

In February 1963 Mrs. G. returned to the mental hospital for a six weeks treatment as she was having some trouble again. Just before she had to go back to the hospital she ran out of diapers one morning so had to substitute training pants for Paul. (It was really by accident that he came out of the diapers so soon after the doctor had seen him.) By the time his mother returned home Paul was pretty well settled in his toilet training and rarely had an accident.

The nurse had planned to visit this family as part of a study program. When the first phone call was made the mother talked with her and seemed pleased that her family had been selected. Another call made

a few days later found the father trying to keep up with his job and the home as the mother was in the hospital.

Mr. G. frankly told what had happened about the pants then laughingly said, "He's back in diapers today, I've run out of training pants now." He also asked if anyone knew where he might find a permanent housekeeper.

An older woman was sent to him by a family homemaking program so he got relief. This woman continued the party habit plus caring for the home and all the children.

While the mother was in the hospital Paul moved ahead rapidly. Since Paul did need exercise so badly his braces were removed daily at the nursery school so he could crawl plus having his three days of exercise there. He was put on the floor on his hands and knees and encouraged to move about freely. The crawling became a game with several of the children trying to race from one room to the other or up and down the corridor.

Paul soon learned he could pull himself up at the side of the table and to climb up on the table and chairs to show off to the other children. About this time he began to talk more loudly, hold his head higher, and scrap for what he wanted.

By the time his mother came out of the hospital Paul was more like a four year old boy than the infantile acting one she had left. Apparently Mrs. G. could accept him as he had grown during her absence but was unable to help him grow over the hump from infancy to boyhood.

Paul should be able to grow into a more normal adulthood with exercise to strengthen his muscles and education should not be so much

of a problem if his body grows as it should.

Mrs. G. had a problem on her hands that had not arisen in any of the other homes.

This family of Italian descent was quite a closely knit one and Jack was the first grandson. In his first few months of life he grew and developed so rapidly the whole family watched and became so proud of him. When the child developed his illness the whole family came even closer together and to him.

After Jack recovered he was treated as one who could do no wrong. The mother's efforts to train him were at many intervals interrupted by the father and the other members of the family. The mother worked for hours to teach Jack how to put on his shirt only to have one of the others come along and do it for him when they saw him struggling with it.

Eventually Mrs. G. became very frustrated and angry when she saw her hard work being destroyed. She made a rule that no one was to help Jack in his attempts to learn to care for himself. The family including the father must have realized how desperate she had become so only helped him in doing things which are absolutely impossible to do with only one hand such as bringing the belt together on his pants or put on his left shoe with its brace.

The mother's sister was visiting in the home the day of this interview. She furnished the information related in the last three paragraphs. As a child the aunt had rheumatic fever so seemed to recognise the necessity for a child with a handicap to be encouraged to

develop independence. She said she had been as bad as the rest about waiting on Jack but, after Mrs. C. made her ultimatum, she could see how important it was for all of them to go along with the mother's decision.

APPENDIX C

APPENDIX C

At parent-teacher meetings problems of transportation were discussed. All of the parents seemed to feel that their children had to stay dressed in outdoor clothes too long while waiting so they'd be ready when the taxis came.

The special shoes that all of the children must wear are sometimes hard to find and are quite expensive. This was another of the areas of conversation. They exchanged ideas and prices so helped each other in this way.

These meetings gave the parents a chance to meet as most of them lived so far apart they didn't know each other or anyone else with children with cerebral palsy. The only organization for the parents of handicapped children in the South Shore Area is an organization that is made up of parents of children with all types of disabilities.

The parents of the handicapped children with cerebral palsy felt this did not give them the type of help they needed as their problems were different. If they had a club of their own with a councilor they thought they would be able to help each other more.

In the Spring the parents, teachers, and others who were interested in cerebral palsy were invited to attend a meeting at the Public Health Center in Quincy, Massachusetts. The complete team was present consisting of: the Director of the program of the United Cerebral Palsy Association of the South Shore Area, the Pediatrician, Orthopedist, Psychologist, Coordinator of the Treatment Center, the Physical,

Occupational and Speech Therapists, and the Teachers.

The Director acted as master of ceremonies. He introduced each of the members of the team and asked them to explain what their parts in the program for the care of the children was.

A general but simple explanation of cerebral palsy was given by the Pediatrician. He had a large drawing of the brain and spinal cord with its structures on the blackboard so that he could show the various areas that were usually affected in this disorder. His explanations were geared to the understanding of the public and were apparently grasped by all as evinced by the questions which were asked later.

After his talk each of the others explained their types of education, what part they played in the treatment of the children, and the outcome they would hope to see.

Each of these people expressed the importance of the team approach to such problems. The parents parts in the team were stressed and the point made that without the help of the parents and the public, nothing could be accomplished.

After the completion of the program the meeting was thrown open for questions and discussion. Many questions concerning causes and effects were broached and answers were given to the fullest extent possible.

At the close of the meeting a social hour was held. All of the members of the team were present during this hour to meet and talk with those interested in any of the problems.

All seemed to feel this had been a most educational evening and asked that it be repeated from time to time. The parents of the children with cerebral palsy welcomed this chance to meet and discuss their children's problems with others concerned in the children's care.