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ABSTRACT

The report covers the first 2 years of operation of the Summer Family Conference, a 5-day program designed to provide intensive educational and counseling services to families with young (2-6 years) cerebral palsied children. Families involved were those considered hard to reach due to poverty or other factors by United Cerebral Palsy of New York City, Inc., the conference sponsor. The report of the first and second conferences covers purposes of the conference, a description of the problems of cerebral palsy (medical, learning, psychological, and social problems), planning information (conference format, criteria for selecting families and site, parent preparation, transportation), the daily program and activities, and evaluation findings. Appended are detailed conference schedules and various forms, questionnaires, and letters related to conference planning and evaluation. (KW)

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The Summer Family Conference of the Early Education Program

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A report of a project carried on by United Cerebral Palsy of New York City, Inc. in cooperation with the Bureau of Education for the Handicapped, Handicapped Children's Early Education Assistance Act, P.L. 90-538

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Summer Family Conference Report

Table of Contents

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Summer Family Conference Year One

I. Background and Intent of the Summer Family Conference

Families of handicapped children are faced with many difficult problems. United Cerebral Palsy of New York City, Inc., hereinafter referred to as UCP, has been a prime mover in the initiation and development of educational, recreational and counseling services for handicapped children and their parents. It is within this context that United Cerebral Palsy developed the Summer Family Conference described in this paper.

The Summer Family Conference was conceived as part of the Early Education Project, a demonstration project to develop early educational procedures and curricula for very young handicapped children, age 2 to 6 years.

The Early Education Project is partially funded by a grant from the U. S. Department of Health, Education, and Welfare, Bureau of Education for the Handicapped, under the Handicapped Children's Early Education Assistance Act of 1968 (P.L. 90-538).

The First Summer Family Conference took place from August 30, 1970 to September 3, 1970 at Monmouth College, West Long Branch, New Jersey. The immediate objective was to provide intensive educational and counseling services for families* which in the past had been considered "hard to reach" due to poverty and the many difficulties inherent in living in a large city with a handicapped child. The broad long-term goal of the conference was to help parents living in the four boroughs of New York City serviced by UCP, to cope more successfully with some of the difficulties confronting them and their handicapped children.

It was hoped that this could be accomplished by providing educational and counseling services in an environment removed from the daily cares of keeping house and looking after children. It was our further intention that intensive exposure to psychologists, social workers, and teachers in a relaxed atmosphere and pleasant surroundings might accomplish this where past procedures had failed.

The specific objectives of the program were as follows:

1. to experiment with a new program setting and overall procedure as a new way of providing counseling and information to families with young handicapped children;
2. to provide intensive education on the nature of the handicapping condition (CP) which affects at least one of the children in the family;
3. to provide counseling opportunities in a formal and informal manner;
4. to provide recreation and relaxation to parents without the concomitant guilt of leaving their handicapped child behind;
5. to give parents a holiday from daily routines.

**For the purpose of the paper, the term "family" means all those people who constituted the immediate household in which the handicapped child lived.*

In the past it was not easy to involve families that had many difficulties in daily living with which to contend. Many of these difficulties were related to inner city problems, to poverty and to different cultural and ethnic backgrounds; these burdens often outweighed the problem of care for the handicapped child in the household. It was hoped that an intimate environment away from the daily problems would enable families to participate in intensive education and counseling and open avenues of communication between staff members of UCP and the families served.

It was also hoped that as a result of intensive client-staff contact, a subsequent closer relationship between agency personnel and parents would develop and continue after the Summer Family Conference ended. Recreational opportunities for parents also had to be provided. In order to develop trust and confidence in those with whom the parents would meet in educational and counseling situations, it was decided that the professional staff of the agency would provide most of these services.

II. The Problem of Cerebral Palsy

a. Definition *

Cerebral Palsy presents a problem or series of problems far more complicated than those found in most other groups of physically disabled individuals. Because of the intimate relation of cerebral palsy to the central and peripheral nervous system, it is relatively commonplace in people with this condition to find physical and mental anomalies other than just the neuromuscular involvement. Associated disabilities may take the form of visual, auditory and speech impairments, mental retardation, seizures, disturbances of perceptual-motor function, and others.

This complexity is compounded by the fact that authorities do not entirely agree on a definition of cerebral

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**For detailed definitions see the literature on Cerebral Palsy.*

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palsy. In some instances it is viewed as an orthopedic problem, while others see it from a pediatric, neurological or psychological point of view. One definition says that "Cerebral palsy is a condition characterized by paralysis, weakness, incoordination or other aberration of motor function due to pathology of the motor control centers of the brain." In this definition, cerebral palsy is viewed solely in terms of its physical components.

A still more limited definition is one where cerebral palsy is viewed as a condition in which interferences with the control of the motor system arise as a result of lesions occurring from birth trauma (only one of the causes of cerebral palsy.)

As these definitions seem much too limited for the purpose of this study; a more practical definition which views cerebral palsy as one component of a broader brain-damage syndrome will be elaborated and proposed. The definition which we will accept and use is that cerebral palsy is a result of a brain insult which leads to neuromuscular dysfunction with probable associated organic, psychological, intellectual and other impairments. Accompanying or secondary impairments may be evidenced in perceptual difficulties and/or retardation. They invariably involve social implications and may cause educational problems affecting the impaired child and his entire family.

b. Medical Problem

There is no known cure for cerebral palsy at this time, however medical intervention may reduce some of its effects. Physical therapy can help persons with cerebal palsy to make better use of their existing physical abilities. Occupational therapy can train the palsied to use their limited bodies in activities of daily living. Proper medical management can help an afflicted person avoid later complications and secondary physical problems. Speech therapy can improve communication skills.

c. Learning Problem

Inherent in the concept of brain dysfunction is the probability of learning disorders. Visual, auditory and tactile perception may be impaired. This requires intensive retraining before academic learning can be attempted.

d. Psychological and Social Problems

Being handicapped and viewed as "different" from others has a profound effect on the emotional development of a person. Handicapped individuals are often not accepted by the non-handicapped. Social attitudes toward deviant appearance and behavior are generally expressed in suspicion, rejection, fear of contagion and at times just plain curiosity. These attitudes all too often comprise the daily experiences of the handicapped child and his family. They often enhance the family's feeling of worthlessness, shame and guilt and create familial as well as individual emotional conflicts.

As a result of these emotional and social components of cerebral palsy, parents are generally in a state of confusion and look for concrete "prescriptions" as to the "what," "when," "why," and "how". Extremes of parental attitudes are often noticed in the child's early life. Some parents expect quick cures for their handicapped children, while others appear to have given up all hope. Eventually, most parents reach the point where they see the lack of physical and mental development in their child and a physician's advice is sought.

What parents do after the first visit to the doctor varies greatly and depends on the doctor. A parent may have the good fortune of being directed to a medical authority in the field of cerebral palsy (Appendix #1).

During their search for help, with its mounting costs and repeated disappointments, parents develop various attitudes. In general, these vary from an aggressive bitterness to submissive sentimentality. Parents often report their first emotional response upon learning that they have a child with cerebral palsy as disappointment or guilt. Many consider such terms inadequate to describe how they really feel. No question is more frequently uttered than, "Why did it happen to me?". Heredity and pre-natal environmental causes are commonly discussed. Any abnormality or variation from the usual course of development observed in a member of the families concerned may be accepted as evidence of inheritance of the condition: "People tell you cerebral palsy is inherited. When that happened to me, I wanted to throw it up to my husband and blame him. I also thought 'Am I guilty?'" unjustified feelings of guilt are common: "My own neglect has caused this; there is something I did or failed to do". Familial conflicts sometimes arise. Often parents find it difficult to put their true feelings into words.

Parents encounter much difficulty in attempting to carry out professional recommendations for their child. There are many things that a person with cerebral palsy cannot do for himself and may even be unable to do with assistance. Responsibility then falls to the parents for day-to-day care. The cerebral palsied person must be fed, dressed, bathed and toileted. While a child is young and easy to handle, this is a small problem. But as he grows and continues to be incapable of performing these acts for himself, conflicts arise. The problem is obviously more serious than just how to manage the handicapped child and how much to require of him. The total organization of the home is involved. Uncertainty creeps in and contributes to increased tensions. The uncertainty of the *outcome* of all the efforts on behalf of the child also enters the thinking of parents.

All parents have plans for their children. Some or all of the following attainments rank high in parental estimation: acceptance in the school system and success in it; admission to the preferred religious community; success in industry, business or a profession; and the establishment of a home. A few cerebral palsied children will attain all major goals; many will attain none. For the majority there will be much failure and some limited success. The basic motives of all parents and growing children meet some measure of frustration but this is greatly increased for the handicapped. Increasing disappointments may in some cases draw a father and a mother together, more often, the opposite effect is reported. Parents blame one another as well as themselves.

Overprotection and infantilization of the cerebral palsied child often interfere with his progress. Without the parent being fully aware of what is happening, the undue attention given a child masks growing parentive resentment. All the things that are done to the rejected child are too well known to repeat here. What happens to any child who is not wanted in the home, happens to the cerebral palsied child.

Counseling and education of the parents by teachers, psychologists, and social workers are designed to clarify and help parents cope with some of the above problems. Many of the recommendations professional people make involve added responsibilities for parents who already have too much to do. Some lose confidence in the doctor or psychologist because the results of treatment or counseling are meager. Parents need confidence in the doctor, psychologist, teacher and others involved in the rehabilitation of their child. This confidence can only come through a sustained relationship, and a "learning and helping together".

III. Preparations

a. Format of the Summer Family Conference

The following questions were posed:

1. Can enough parents, especially the inner-city parents, be interested in this program?
2. Can the Conference be timed so that most of the qualified agency staff will be available?
3. Can children successfully spend parts of each day away from their parents?
4. Can meals become social, communal and unifying opportunities?
5. Can education and counseling components be developed so as to aid handicapped children through their parents?

The following program outline attempted to provide an opportunity to answer these questions.

Each day of the Conference would be divided into three parts. The morning would be allocated for an educational component, the afternoon for a counseling component and the late afternoon and evening would be set aside for recreation. This recreation component, in addition to affording clients an opportunity for relaxation, would attempt to bring families and staff together in a congenial, informal and personal manner to meet others with similar problems. Pervading the entire program would be the availability of staff members. These members would include the administrative staff, psychologists, teachers, social workers, speech therapists and several persons who could speak Spanish to converse with and translate for the Spanish-speaking families.

All these staff members were to make themselves available during the formal session and during recreation and relaxation periods. The intent of this exposure was to enable parents and older siblings to think of the staff as people to whom they could turn for counsel and information concerning their problems. In order to counsel and inform parents in a short intensive residential session they had to be free from worry about their children. Therefore, arrangements were made to place all children, handicapped and non-handicapped, in a day camp situation within the context of the Summer Family Conference. This day camp was to become the responsibility of the education and recreation staff of UCP (Appendix #3.)

b. Criteria for Selecting Families

Criteria for selecting families which would be invited to participate in the Summer Family Conference were the following:

1. The family must have had a pre-school age child in one of the programs sponsored by UCP at the time of the Conference.
2. This child had to be accompanied by one or more of

his parents. If either parent was not available, the child had to be accompanied by someone appointed by the parents.

3. If the child had lived with a guardian or in a foster home, someone from the place where the child resided was acceptable.

Prior to the actual occurrence of the Summer Family Conference, it was hoped that every contacted family would attend. It was anticipated that some resistance would be encountered from inner city multi-problem families. Each family was encouraged to bring all of the members residing in the household; i.e., all siblings and where applicable, grandparents. Much effort was spent on encouraging families to participate.

c. Conference Site

Early in January of 1970, a systematic search was initiated for a suitable location for the Summer Family Conference. Thanks to the diligent efforts of the agency's camp staff, Monmouth College was suggested, visited and approved as an excellent location.

The college was chosen for its park-like surroundings, smooth, even walks, spacious living arrangements, friendly, cooperative staff, many meeting rooms and several auditoriums, excellent recreation facilities, and beautiful main house (which had, at one time, been the summer White House of President Wilson). The facilities included an Olympic size pool and fine New Jersey beaches within a few miles of campus.

d. Preparation with Parents

Preparing parents for their involvement in this experience consisted of the following:

1. personally contacting each of the parents
2. making arrangements for family living quarters
3. establishing transportation schedules
4. arranging babysitting facilities and staff.

After deciding upon Monmouth College as a suitable site for the Summer Family Conference, letters of invitation were sent to the families of handicapped pre-school children involved in the agency programs (Appendices #4,4a).

The response from this initial contact was sparse. In a casual conversation with one of the client families, it was discovered that the date on which families were expected to reply came too early for families to make decisions concerning their vacation plans. Therefore, a second invitation was sent and in a relatively short time many replies were received (Appendix #5). A great many of the enrollment forms were inadequately filled out and it was decided that follow-ups should be done by phone and visits to the homes by members of the social work department. Each family was, therefore, visited individually and advised on the details of the camp.

Out of 36 eligible families, 24 anticipated coming at one time during the spring of 1970. Of these 24, 18 families eventually attended. (It should be noted that all correspondence was translated into Spanish for Spanish speaking families.) As soon as acceptance replies were received, acknowledgements were mailed thanking each family for its reply and assuring it that it would hear from the agency again shortly (Appendix #6). At the end of July, "family information meetings" were conducted in each of the four boroughs (Appendix #7).

At these meetings, the Project Director described the intent of the program, the components of the program (education, counseling and recreation) and the practical details such as housing, clothes, safety measures, babysitting, etc. About two thirds of the families attended these meetings. Those who did not attend were contacted individually. A final letter explaining procedures was sent shortly before the start of the conference (Appendix #8).

e. Transportation

Transportation to Monmouth College would be provided, on a group basis, for all families by the agency's transportation department. United Cerebral Palsy buses would pick up families at their homes and drive them directly to West Long Branch, New Jersey. Large families would be accompanied by a United Cerebral Palsy staff member. In an attempt to mitigate against unforeseen difficulties, one staff member would be selected to remain at the central office and to facilitate communication between families, bus drivers, and the staff at Monmouth College. (Fortunately, no "hitch" occurred and the precaution proved unnecessary.)

f. Preparation with UCP Staff

Several visits were made by selected agency staff members to make sure the location was suitable for our needs prior to finalizing the arrangements. At United Cerebral Palsy, meetings were held to plan for the content and practical arrangements of this new and rather complex undertaking. As a result of these meetings, at which various disciplines contributed their thinking, the total plan for the conference program was devised and made operational. This plan was

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then presented to the Early Education Advisory Committee. The suggestions and comments of this Committee were iincorporated into the final plan. Letters were sent to members of the Board of Directors of United Cerebral Palsy of New York City, Inc. and to other interested parties (Appendix #9), inviting them to visit the Summer Family Conference while it was in session. An invitation was also sent to the staff of the Bureau of Education for the Handicapped, Department of Health, Education, and Welfare in Washington, D. C.

At the staff meetings, the roles and responsibilities of the various staff participants and specific assignments were made. The Director of Recreation was given the task of organizing the day camp activities for older children (over 6 years of age), while the teachers of the Early Education Project planned the day camp activities for the younger children.

g. Planning with Monmouth College Staff

During the preliminary visits to the college, arrangements were made with the officials of that institution for the buildings that would be available for use. The meeting rooms were chosen, arrangements were made for the use of the pool, and lifeguard attendance at the pool was insured. Mealtime schedules were prepared and menus selected. The gymnasium hours were agreed upon and the indoor and outdoor athletic areas assigned.

Audio-visual equipment was graciously loaned to the Conference, as were loudspeakers for our outdoor activities. Arrangements were made for a coffee hour each evening to provide an evening snack for children and parents and to enhance the social portion of the program. It was decided that meals would be served cafeteria style in the student dining room.

Prior to the actual conference, key staff members were given a detailed tour of the campus, so that they would, at a later date, be able to familiarize other staff personnel with the facilities.

A nurse was to be in attendance on the campus from 9:00 A.M. to 5:00 P.M. daily and a doctor was to be available. The local medical center would be made aware of our stay and of the special needs of the conference members. Security guards patrolled the campus day and night. The agency expanded its insurance coverage to include the Summer Family Conference. Street-crossing guards would be assigned to assist families to move against heavy highway traffic.

IV. The Daily Program

a. Overview

Each family would breakfast together as a unit and then take its children to a designated place to meet the camp counselors. Some staff members would be assigned to help large families during breakfast. While all children would be in the care of "camp counselors" (composed of the agency's teaching and recreational staff), the adults would be invited to attend the morning education sessions. The topics chosen were, "A Medical Examination," "Education of Children with Cerebral Palsy," "Home Management," and "Life-long Planning with and for Cerebral Palsied People." It was decided that each of these topics would be presented in the form of a demonstration with as much audience participation as possible. These meetings were planned to terminate at approximately 11:30 A.M. so time would be available to prepare for lunch. Lunch would not be a family meal. The children would eat with their counselors, and the parents with the rest of the staff.

The afternoon sessions entitled, "What's Your Problem and Who to See" were planned to be group discussions focusing on some of the questions generally asked by parents, and the topics to be raised from a questionnaire which the parents would be asked to complete. These sessions would be led by a team consisting of a social worker, a psychologist and a teacher. During this part of the program, parents would be grouped according to the location of the United Cerebral Palsy center their child attended. Staff members were to be assigned on the same basis in the hope that what would be initiated here would carry over and continue beyond the end of the conference.

The late afternoon and evening were allocated for recreation and relaxation. This part of the day parents and children would spend together. Families could use the pool, go to the beach, rest, chat, walk in the beautiful gardens around the college, or amuse themselves as they desired.

b Living arrangements

Families would live in the dormitory buildings of the college, which were ideally suited for the purpose. Each family would have a small suite consisting of 2 or 4 small bedrooms, a bathroom and a sitting area. Bedding and linens would be provided by Monmouth College, cribs and rubber sheets by UCP. In the two student buildings, used by the families, a key staff member would be designated as "housemother" and assigned a first floor room in case of emergency. There was a refrigerator in each building, which would be filled with milk and snacks each day. Washing machines and dryers were also standard equipment. The majority of the agency staff would live in a third building with similar accommodations The college was nearly empty of students during the time of the Conference so that there was plenty of space available.

During the planning stages, the following decisions concerning living arrangements and daily programs were arrived at: the living accommodations should be so assigned that families from different boroughs and of different social and economic backgrounds could mingle. For the counseling sessions, however, families should be grouped according to the UCP centers in which their children spent their school year. Families which would need wheelchairs should be given ground floor suites, while families with many older children were given top floor suites (two flights up).

Children of staff members would be invited to join their parents and integrate with the day camp program. It was also decided to mix the handicapped children with non-handicapped brothers and sisters of similar age groups during the day.

Dinner would be, once again, a family time with staff assisting the larger family units. After dinner, programs were planned for adults. They would include small social gatherings, film presentations, swimming at the pool, and live entertainment.

c. Babysitting arrangements

Babysitting would be provided each evening so that parents could feel free to enjoy the social activities of the program as well as each other's company. They could meet with counseling staff if they wished or they could participate in the planned evening entertainment without worrying about their young children. All agency staff members were to participate, on a rotating schedule, so that each building would have several "sitters" and even the smallest child could be left without parental fears.

d. Work schedule for staff

The work schedule for the staff was planned as follows:

1. The children's staff was to work from breakfast at 8:00 A.M. until 3:30 P.M. and resume their duties at 7:00 P.M. until 9:00 P.M. One evening of babysitting from 9 – 11 P.M. and an occasional staff meeting before breakfast would be included.
2. The adult's staff was to be on duty from breakfast until 1:30 P.M., except for those leading the small group discussions, who were to work until 3:30 P.M. This staff would then be with the families as needed until 7:00 P.M. and occasionally spend a whole evening with a particular person. This group would also spend one evening from 9:00 P.M. to 11:00 P.M. as babysitters.

e. Day camp schedules

Day camp schedules for the younger children were developed by the Early Education Project teachers. Day camp programs for the older children were developed by the agency recreation division. In both program segments, plans providing for rainy days (indoor sports and games for ages 5 weeks to 16 years) were included. Some of the materials and equipment, such as films, wading pools, arts and crafts materials, books, and games were sent to the camp site before the opening day and stored until needed.

f. Evaluation Procedures

As a final preparation, an evaluation interview form was developed. This form (Appendix #10), was to be administered on an individual basis during the last day of the Conference. Its aim was to supply information to determine whether, and to what extent the conference objectives were achieved, and what value the Conference did have for the parents of the handicapped pre-school population. In addition to this long questionnaire, we also developed two short questionnaires (Appendix #11), which were to be used for content development of the afternoon counseling sessions. Preparations were also made to film and tape some of the spontaneous reactions of parents and older siblings to the Conference. Verbatim samples of the tapings are attached (Appendix #12).

V. The Conference

a. The First Day

The first day began with the early arrival of agency personnel. They checked the facilities, made final preparations and put the name of each family on their assigned quarters (Appendix #13).

Parents and children began arriving in the early afternoon. Most of the families came by United Cerebral Palsy transportation, but several families came in their own cars. The first afternoon and evening was primarily devoted to the following:

1. assignment of rooms
2. a tour of the college grounds and facilities
3. an introductory meeting during dinner
4. a coffee hour with agency personnel and invited guests.

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Assignment of rooms

The room arrangements were assigned in family units as described earlier. Each family was put into the care of a staff member, whose assignment was to help it find its accommodation, unpack, and see to its comfort and immediate needs. These arrangements, planned in detail well in advance, went smoothly and families settled in quickly and with a minimum of discomfort.

Tour of the campus

Tours of the college and its grounds were included to familiarize clients and families with the campus facilities. Each family was shown the meeting areas, the dining room, the swimming pool and gymnasium, the nurse's office and the staff (emergency) accommodations in its building. They were familiarized with the locations of the appliances in their area and the use of these appliances. These tours were conducted individually by a staff member for each family.

Introductory meeting and first dinner

At the introductory meeting and dinner, families were officially welcomed to the Summer Family Conference by the Executive Director of United Cerebral Palsy of New York City, Inc. and staff members were introduced. The daily schedule was presented and explained. A question and answer period followed during which further details were discussed.

Coffee Hour

After the younger children had been put to bed by their parents and the babysitting schedule put into effect, adults met for coffee and a get-acquainted session. At this informal session, they were able to meet and talk with members of the Board of Directors of United Cerebral Palsy of New York City, Inc. During this time, the older children were afforded the opportunity of meeting the recreation staff as well as each other. Toward the close of the evening, a film was shown for those who were interested.

Through the courtesy of ABC-TV, the Conference received the loan of several films and was able to show a film every evening. As most clients are accustomed to spending recreation time around their TV-sets, and as no commercial entertainment was available at Monmouth College, it was decided that movies would serve the purpose. It was discovered that they had a double advantage. On the one hand, they were the form of entertainment most similar to TV, while on the other hand, they constituted a group activity which brough clients closer together. Coffee and cake were served prior to each movie in order to enhance and personalize the atmosphere, and to create a congenial social situation.

b. Subsequent Days

Each of the next four days was basically divided into the following parts:

1. morning educational session
2. afternoon counseling session
3. evening recreational session.

These sessions comprised the core of the Summer Family Conference.

The Morning Session

The time between 9:30 A.M. and 11:30 A.M. was devoted to parent education. Each of the four meetings planned addressed itself to a different aspect of the cerebral palsy problem. These meetings always took the form of a demonstration rather than a lecture. The sequence was from medical evaluation to educational methods and materials to home management and closed with a session on planning.

Demonstration of Medical Evaluation

In order to give parents more *practical insight* into the problems of cerebral palsy, a pediatric neurologist presented a demonstration of a typical physical examination of a cerebral palsied child. The immediate purpose of this was to provide a visual illustration of the actual procedures and medical equipment used in the diagnosis and treatment of the cerebral palsied child. Its long-range goal was to show that the doctor's role is not limited to an initial contact, but instead must be continuous and ongoing. Cerebral palsy is primarily a medical condition which can deteriorate if medical supervision is not included on a regular basis in the life of an individual with cerebral palsy.

Demonstration of Education of the Cerebral Palsied Child

In order to enable parents to have a clearer understanding of the learning problems that often accompany a brain dysfunction, educational methods and materials were demonstrated by an educational specialist from UCP. It was explained during this presentation how parents can modify and apply some of the very same methods and materials for home use and thereby reinforce the learning that is initiated in the educational centers. Stress was placed on all the things parents can do at home, or from home, to broaden and enrich the learning experiences of their children. The presentation was followed by a discussion period, during which time was set aside for parents to handle the demonstrated materials and to examine them more closely.

Home Management Demonstration

This presentation was designed to impart to parents safe, simple and inexpensive ways of managing children with severe physical problems at home. Devices for carrying and feeding and bathing children were discussed and demonstrated. Methods of positioning children to enable them to use their available facilities to their best advantage were explored. Many self help devices were shown with instructions on how these could be made at home. Improvements of commercial wheelchairs were also shown. Following the presentation, time was set aside for parents to ask specific questions and to handle the demonstrated materials. This session was led by the Director of Program Services of the New York State office of the Cerebral Palsy Associations.

Life-long Planning for the Cerebral Palsied Person

The final morning session was devoted to the problem of life-long planning for the cerebral palsied person. In order to inform parents and reassure them that agency services would be available on an on-going basis for as long as their needs persist, the long range goals and plans as well as the philosophy of the agency were discussed. A series of slides showing adult cerebral palsied people in various phases of training and employment was shown, as well as slides on how adult cerebral palsied people function in various situations. One additional goal of this program segment was to show parents of young cerebral palsied children the possibilities of physical, educational and social improvement, which continuous work with their children might achieve.

The medical problems, the learning problems and the management problems of the handicapped child were presented as being closely related and as constituting the core of the problem of life-long planning for the cerebral palsied. This presentation was made by the Executive Director of United Cerebral Palsy of New York City, Inc.

The Afternoon Sessions

The time from 1:30 to 3:30 P.M. was devoted to group sessions. Three groups were established with each being led by a team composed of a psychologist, a social worker, and an educator.

The pre-conference questionnaire completed by the parents was designed to find a focus for these sessions. It was surprising to discover that each group quickly found topics which members could address themselves to. They became very involved in these topics as well as with each other. While each group developed differently, all the groups were quickly able to discuss problems without relying on guidance of the group leaders. The topics discussed ranged over a broad terrain, to include frustration over medical information [illegible] the hurt experienced through insensitive [illegible] question of how to explain to the child [illegible] different from most others.

The title, "What's your problem, who to see" was originally chosen because it was thought that the term "counseling" might be misinterpreted by clients. The procedures and content varied according to the participants of each group.

Two other sessions that were held in the early evening hours appeared to have an important impact on the parents. The first was a session with the "normal" siblings of the handicapped children. It was called, "Brothers and Sisters – How Do They Feel?" During this session, led by a psychologist, the youngsters were invited to discuss some of the difficulties they encountered in living in a household with a handicapped child. The following evening, a meeting was held with parents to bring to them some of the feelings of the non-handicapped children in their family and to discuss with them their own emotions and actions regarding their non-handicapped children.

The evening session

Aside from the described evening recreation facilities and films, there were two delightful evening entertainments. One was a performance by a Boy Scout troop from Monmouth County of authentic Indian dances in authentic Indian costumes, and the other, a talent show arranged by a group of well known singers in which the older children participated.

Late in the evening an unplanned activity seemed to spontaneously arise. Families and staff mixed over pizzas, and talked until all hours of the morning. New friendships were formed and new ideas exchanged in an informal, parent-sponsored activity.

VI. Evaluation

a. The Questionnaires

The techniques selected to evaluate the conference objectives took the form of an interview of each parent based on a questionnaire. This supplied information from those who might have had difficulties in expressing themselves in writing and yet provide consistency in the questions.

The questions were:

1. Did intensive counseling away from the cares of

home and in a relaxed atmosphere help parents face some of their feelings and help them cope with them?

2. Did the environment chosen allow parents to relax?
3. Had the "educational" component helped them understand better the problems they were now experiencing and those they would be expecting later?
4. Had meetings between parents and Social Workers — Psychologists in an informal contact built a relationship which might continue?
5. Had meeting others with similar problems made a difference?
6. Had the conference met the expectations of those who participated?

In consultation with the Advisory Committee and the Psychological Consultant to this agency, a questionnaire was developed which was hoped to give some answers. Parents were told that an interview to find out how they felt about the Conference would take place. Staff was given a verbal explanation and written instructions. (See Appendix #10.)

b. General Findings

OVERALL FEELING ABOUT THE CONFERENCE

To the question, "Did you like this vacation?" every answer but one was positive. For many of the families this was the *only* chance to get away from the city all summer. When asked what they liked the most about the vacation, many replied that they enjoyed the comradeship of the other families and found this interaction was educational. One father mentioned that the experience had helped him to discover how his other two children really felt toward their handicapped brother. A majority of the parents said that they liked the demonstrations or the afternoon group sessions.

The major objection about the vacation as a whole was to the tight schedule. Most people (including the staff) felt that there were not enough breaks and that the morning and afternoon meetings were too close together.

Sleeping Arrangements

Except for someone who complained about "the lack of a television," everyone was extremely pleased with the accommodations. Many commented that they were quite pleased with the family-style arrangement of the sleeping quarters. Separate rooms for parents and children were a bonus to those who live in more cramped quarters at home. The major (and justifiable) complaint was that the air conditioning was too cold. Some families also mentioned that they needed more information on how to obtain towels and other supplies.

Food

On the whole, those attending the conference thought the food was good. The only objections were to certain dishes that were served. One mother reflected the sentiments of all the women present. When asked what she liked best about the food, she replied, "I didn't have to cook it."

Entertainment

The most popular feature of the entertainment was the children's talent show. The movies and the coffee hour were also favorites. Several parents were grateful for the pool for their children. The only complaints concerned the movies. Some parents felt they were too juvenile. Others had to leave before the movies were over since they lasted past 11 P.M., when the children were released from the babysitters. On the whole, however, reactions to the entertainment were extremely favorable.

Demonstrations

Reactions to the demonstrations were mixed, according to the particular needs of the parent being interviewed. Almost all parents found the "Education" and "Home Management" demonstrations useful because they contained concrete information on how to care for their child's physical and intellectual needs. For instance, one mother who had desired to teach her child at home commented, "I learned a lot about things I didn't understand before — how to teach language, numbers, letters." The demonstrations had more than just practical value for some parents. A few parents received a certain sense of confidence through knowing how to handle certain problems: "I felt I wasn't alone in that the problem of my child wasn't so unusual." On the other hand, some parents complained that the demonstrations were too long or that certain ones were not useful for them.

Children's Activities

All parents interviewed were very pleased with the children's activities. There were almost no complaints. One mother said her children had such a good time that they didn't want to go home. One of the fathers was especially glad that his child who was not handicapped had a chance to meet with other normal children with handicapped brothers and sisters.

Afternoon Group Sessions

The afternoon group sessions were very well accepted. Most parents felt they were a valuable learning experience. Many of the parents had never been able to discuss their family problems with anyone else because they did not know anyone else in their situation. As one parent expressed it: "I found out how much we have in common. It also brought out some feelings you never really discuss with other people." Another mother said, "I like to talk about my child because I do not understand her sometime." The parents also benefited from tips on child care that other parents had to offer. There were very few complaints about these meetings. Some felt that they were too close to the morning meetings and that they should be held inside rather than outside.

Did the Vacation Help?

All parents agreed that the vacation helped them in some way. Most of the parents appreciated being relieved of responsibility for their children for a short time each day. Many parents said they benefited from just knowing that other people had the same problems. Two comments by the parents best express the two major themes of the answer to this question: "I relaxed – no cooking, no washing, no cleaning the house." "I saw how other families love their handicapped children just as much as I love my child."

Did Feelings about the Child Change?

Over half of the parents interviewed said their feelings about their handicapped child did not change. Even though almost all of them had previously said that they had learned from the demonstrations, group sessions, and interaction with similar families, no one saw this learning as a change in *feelings*. Perhaps they felt that saying their feelings had changed would indicate that they were unsure about their children. One parent quite honestly said that his feelings hadn't changed because "the problem hasn't changed." Those who said their feelings had changed gave varied reasons, such as the information from the demonstrations, new insights from the group sessions, and encouragement from other parents handling similar problems.

Suggested Changes

The only suggestion found consistently in all of the interviews was that the program be changed, mainly to allow for more free time and longer breaks. Most people were satisfied with the actual content of the program.

c. Tape Recordings

In addition to the formal evaluation instrument, informal interviews were taped by one of the social workers. On tape some parents remarked that the summer conference was the most practical and helpful way of learning about their child and his needs. Others reported that the result was not so much of a practical nature; they gained the knowledge that there were others to whom they could talk and who understood. Many parents noticed that they were reassured by the education and counseling sessions. Others reported that they felt something akin to relief in meeting other families with similar problems. They felt less alone than before. All described, as a most pleasant part, the fact that for long periods of each day their children were cared for by others whom they could trust, thus leaving them free to attend the sessions without this responsibility. Some parents expressed a wish to have some periods without sessions and without children.

One of the tangible results was the formation of a Women's Division on Staten Island. This was one of the boroughs in which no Women's Division had existed prior to the Summer Family Conference.

d. Staff Evaluation

Although the staff worked long and strenuous hours, each member felt excited and elated about the congenial atmosphere of the Conference. They were pleased with their contact and communication (dialogue) with the client participants. One staff member brought her husband along who worked as hard as any paid staff member.

Staff also expressed appreciation of some unexpected benefits: they met and got to know members from other boroughs. They came to know members from other disciplines better than they usually do during the working year. Psychologists and social workers, teachers and therapists learned to appreciate each other's skills. Typical of the genial atmosphere of the evening babysitting periods was the sight of the Executive Director of the agency giving a 5-week old baby his bottle while the mother enjoyed a movie in another building. All staff members expressed satisfaction about the way the day camp had functioned and how easily all staff members had cooperated with each other.

It was felt that living together provided much more intimate and personal interaction between all participants than any groups or meetings had done heretofore.

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e. Post Conference Data

In January 1971, the Project Director asked for feedback from Social Workers in each borough. Here are the comments:

> One family has cooperated with the Social Worker in regular counseling sessions since the Conference. This family refused to cooperate before, because the father expressed his discomfort in knowing that the Social Worker knew intimate details of his life. He saw the Social Worker as an intrusive person, while the mother saw her as a supportive person. Yet this same family has asked for information on family summer camps. The mother now meets with the Social Worker for regular counseling.
>
> One mother reported that she has become much more aware of her role as a mother. She takes care to express love for her children more overtly. She takes care that the food she provides is more balanced and has asked for information about nutrition. She meets her school children with a friendly welcome (something she had not done before), cuddles the toddler, and for the first time in seven pregnancies goes to a pre-natal clinic. She herself attributes these changes to the Conference, even though she was one of those who felt there had been "too much sittin".
>
> One of the staff members at camp has taken a nine year old boy out every three weeks ever since the boy was in his group at the day camp. There is no father in that family and the "big brother" relationship gives much satisfaction to both.

VII. Some Unexpected Highlights

There were 18 families, comprising 54 children and adults, as well as 35 staff members at Monmouth College. There was not one key available to any of the bedroom suites, yet nothing was taken or even touched.

A seven year old boy announced proudly that he liked it so much at the college that he would "work hard at school" and return as a student.

Children of one family were reported to have cried for several days after they had returned to their tenement lodgings. Many new friendships developed among mothers of each center.

VIII. The Cost

The total cost of the conference was for food and transportation and an honorarium for speakers. Staff on a yearly salary were paid only for transportation cost. Use of all the college facilities was included in the overall fee. Other expenses included a lifeguard at hours not scheduled by the college, rental of cribs, supplementary food for snacks in mornings and evenings, and an entrance fee to the beach for adults. The total cost was about $5000.

Summer Family Conference, 1970 – Statistics

TOTAL: 129 people
Families of handicapped – 13
Handicapped children under 6 years – 18
Brothers and sisters under 15 years – 41
Brothers and sisters over 15 years – 4
Grandmothers – 2
Mothers – 17
Fathers – 11 Families from Manhattan – 0
(All 5 Manhattan families cancelled for *most* valid reasons.)
Families from Bronx – 4
Families from Brooklyn – 5
Families from Staten Island – 9
Negro Families – 7
Spanish–American Family – 1
Italian Families – 3
Staff Members – 35

X. Recommendations For Future Conferences

At the beginning of September, a staff meeting was held and the following recommendations were made.

1. That the Summer Family Conference be an annual event of United Cerebral Palsy.
2. That more staff be provided for the children's program at subsequent conferences so as to allow parents more time without their children and yet not put greater burden on staff.
3. That all the materials used during the demonstrations over the 5 days be exhibited so that parents could view and handle these at their leisure.
4. That the long and cumbersome meal service through family style eating (bowls of food at each table), be improved.
5. That the New York City Board of Education, through its Bureau for the Handicapped, be involved in the Conference so that bureau staff can become familiar with this form of parent education and counseling.
6. That a reunion be held of all those who attend the Conference in order to better evaluate what lasting effect the conference may have had on attitudes and behaviors. (This reunion did not take place due to difficulties of living in a large city.)

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Summer Family Conference Year Two

I. Preparations

After the last goodbyes had been waved to departing families following the First Summer Family Conference last year, there was no doubt in the minds of those who had participated that there would be a Second Conference the following year. Thus, when UCP staff members convened for the first of several meeting on the Second Conference, the initial item of discussion was the number of families that would participate. The general feeling, tinged with some uncertainty, was that we should have about 40 families. Some of the staff, including the Director of Early Education, had concern about the large number of children this would entail and about the resulting lack of intimacy among participating families. However it was decided to give it a try. The place chosen was the same as in the previous year – Monmouth College, West Long Branch, New Jersey. By now, within the agency, staff were talking about the "Monmouth Conference" rather than the Summer Family Conference, anyway. Letters were sent out to all families who fell within the following guidelines of eligibility. 1) The family has a child in the center aged 6 years or under. 2) The child is eligible for return for at least part of the following school year. 3) If a family had participated in the first conference and was still eligible, this would be acceptable (Appendix #14). 4) If there were openings after the centers within the agency had offered participation to their eligible families, other sources could be approached, such as the Board of Education, Center for Multihandicapped Children. It was also decided that the social workers of each center, that is Manhattan, Bronx, Brooklyn and Staten Island, would be responsible for contacting and enrolling families (Appendix #14). The Parent Activity Coordinator would then coordinate the information about each family and make all necessary arrangements. One of the assistant directors of the agency would become the Dean of the Conference, responsible for running the Conference it its second year, with the Director of Early Education as resource person and consultant.

To everyone's delight and apprehension, enrollments came in very fast, so that within a few weeks 56 families had made application. By the week prior to the actual conference date this had dwindled to 42 families, with 39 eventually actually participating. All who had to withdraw had valid reasons, such as hospitalization of a child, moving, etc. The Evaluator of the Early Education Project, the Project Director and the psychological consultant arranged for a new kind of evaluation. (The form is enclosed as Appendix #15.) The objective was to discover if an intensive five day conference would make an impact on the family of the handicapped child with respect to its realistic appraisal of the child's potential.

A letter inviting parents to a preparatory meeting in each center was mailed (Appendix #16). All centers were visited to explain that the conference would not just be a free holiday but an opportunity for parents to participate in the educational and counseling sessions offered through UCP and that their children would be well taken care of during these periods set aside for parents. It was also explained how families would live, what their day would be like and who would be participating beside the families (social workers, teachers, psychologists, etc.).

The forms for evaluating the Conference (Appendix #15), were filled out as a pre-conference paper and would be filled out again at the end of the Conference. All this was carefully explained. Furthermore an elaborate method of anonymity had been developed, which was also explained. (Each family was to put its address on the inside flap of an envelope. After the post evaluation form had been filled out, this flap with the address on it was to be removed.)

The Parent Activity Coordinator, Evaluator and the consultants to the Conference visited all centers, explained all procedures, and answered questions. Other preparatory procedures followed format of the first year's Conference. Finally, each family received a printed list of reminders and a phone number to call for pick-up time (Appendix #17). Families were transported from their homes to the Manhattan Center of United Cerebral Palsy and from there by air-conditioned buses to Monmouth College. Wheelchairs, and cribs as well as the play materials, films, cameras and video taping equipment were sent to Monmouth by UCP transportation. Staff either traveled on their own, accompanied the families, or shared transportation with each other. In addition to staff employed by the agency in its year around programs, there were SWEAT* students and several staff husband volunteers.

A few program changes from the year before were made. Even more stress was put on demonstration rather than presentation. The Education Demonstration was changed to teaching devices and methods. The speech therapists presented many ways in which parents could stimulate language and learning at home. More free time was provided

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for parents *after* the counseling group sessions, so that they could "unwind" from the often highly emotional impact of these sessions. Due to the large number of Spanish-speaking families, one of the counseling sessions was conducted in Spanish by a Spanish-speaking caseworker under the supervision of a social worker. As it turned out, the social worker spoke no Spanish and families made a great effort to speak in English to accommodate her! (A full program is attached as Appendix #18.)

Finally it was decided to have a pizza party as a "warming up" on the first evening. Later, as during the first year, a movie would be shown. The Director of Recreation of this agency was in charge of all day camp arrangements for all children. Teachers were in charge of groups which were intergrated as to handicapped and non-handicapped children. Babysitting was also arranged through the Director of Recreation, with nearly everyone participating. Video tapes were to be made of significant parts of the conference.

Invitations were sent to the various advisory councils, committees and boards of UCP, and to all those members of the community who might be interested in this conference. Many visited and some of their comments are attached (Appendices #19, 20, 21).

II. The Conference

The weather was most clement. A heavy and very destructive hurricane had passed the region two days before the Conference, but most fortunately there was sunshine more or less all the time the Conference was in session. It can well be said that the Second Conference was a great success. All those participating felt they had spent time learning, sharing, and enjoying themselves.

There were, however, marked differences over the First Conference due to the larger numbers of children and adults. For example, babysitting became very complex because so many more floors had to be used in the college dormitories. Families did not all get to know each other and tended to congregate in dormitories. Staff did not develop the same intimacy that had been characteristic of the First Conference. On the other hand, many more families were reached. The ones that had been at the First Conference acted as guides and helpers for the new ones. Speakers felt much closer to staff than during the first year. For example, the physician who presented the Medical Demonstration brought his whole family for an extra day so that they could participate and enjoy themselves.

III. THE EVALUATION summarized by Miss Peggy Crull, Evaluator

The Evaluation of the second year of the Summer Family Conference was planned differently from that of the first year.

Through various channels of information, several conclusions were reached about the effects of the Conference on the families. While all of the staff who attended *felt* the Conference was a great success, the Early Education Project's role as a model and demonstration program compelled UCP to try to show objectively the effect of the experience on the families which attended. UCP collected several kinds of data.

Every parent answered a set of questions concerning what he felt were his child's present abilities and what he felt his child would be able to accomplish in the future. The parent filled out two similar questionnaires, one before and one after the Conference. The child's teacher also filled out the questionnaire, once for each child. Her estimation of the child's abilities were compared to the parents' estimation to see where discrepancies occurred. It was hoped that as a result of the Summer Family Conference, the discrepancies would decrease.

Some trends did appear. Although it was not statistically significant, the parents who answered differently after the Conference had changed their perceptions of their childrens' self-help skills. Before the Conference they saw their children as *less* capable of feeding and dressing themselves than did the teachers. After the Conference, their judgements were more like the teachers'. We think the change came about because at the Conference the parents saw their children with their teachers in a situation where they were expected to be independent. It seems that both teachers and parents had a great deal of trouble judging whether or not a child's motor skills (particularly in ambulation) would improve in time. The Conference experience seemed to clarify the problem for a few of the parents, but, on the whole, it was still difficult for them to predict future improvements. This difficulty is present in a somewhat modified form even for their teachers and therapists. Finally, the parents were most unrealistic or inaccurate in their judgement of their childrens' present and predicted intelligence. Their estimate of the child's intelligence was usually higher than the teacher's. This unrealism did not show any change as a result of the Conference.

While it was found that the statistical results of the pre- and post-questionnaires were inconclusive, this is not believed to be an indication that the Conference had no impact on the parents. It *is* believed, however, that the measure was not precise enough to measure the changes in perception of the children that it was felt occurred. A measure that will pick up such changes is still being sought. In addition, it was not felt that such changes are the *only* benefits that the Summer Family Conference might provide. Other evaluation procedures were attempts at illustrating those additional benefits.

On the same questionnaire, we asked the parents to comment on what they liked best about the Summer Family Conference, and what they liked least about it. Most of the negative comments were in relation to the accommodations and the schedule. Since we had many more families this year and because of difficulties within the Monmouth College Office of Community Relations, some of the families were inconvenienced in housing and dining facilities.

Comments on the *content* of the Conference were mostly positive, and criticisms were constructive and intelligent. The morning lectures were praised by almost everyone. A few modifications were suggested. For example, several parents mentioned that some of the information presented was not relevant to their *own* child's handicapping condition. To remedy this, they suggested that parents attend only the morning lectures which were relevant to their child. Or, perhaps, having different conferences for parents of different kinds of children would be more feasible. Another desire expressed by the parents was that they have more time with the specialists who lectured so that they could ask advice about their child's particular problems. Without time for questions and answers, they felt that information in the lectures was too general. Finally, some parents expressed regret that they had not had access to the kind of information and support provided by the Conference at an earlier time in their child's life. They suggested that such conferences be available for all parents of newly diagnosed cerebral palsied children.

All parents responded very positively to the discussion groups in the afternoon. Over half of them mentioned that this was one of the high points of the Conference. No one suggested any changes in the format or timing of the groups.

In general most people expressed genuine delight over the quality of interaction of families with other families and staff with families. They found that getting together with other families in such an "ideal' setting and talking about common problems gave them new insights and helped them to realize that others "cared". They described the staff as approachable, dedicated, and warm, and were pleased to meet them in an informal setting. However, a few people commented that they felt the staff responsibilities were unevenly divided, and therefore, some staff "worked too hard." A few others felt that staff integration with families was poor. This opinion was probably an exception, but it helped to alert us to the need for more individual attention.

Another type of Evaluation of the Summer Family Conference came from the social workers at each center, who were asked in December to send follow-up reports on the families who went to Monmouth. They were asked to focus on six questions:

1) What has the Summer Family Conference done to make families in your Center better acquainted with each other?
2) What has it done for better understanding of cerebral palsy?
3) What difference has the Conference made for any one family you may choose to report on?
4) Do parents show evidence of better acquaintance with the agency and use of services?
5) Does the staff find parents more cooperative?
6) Do you have evidence of better parent participation?

All of the social workers answered that they had seen some of the long term effects mentioned in the questionnaire. They reported that all families became better acquainted as a result of the Conference, especially within centers. Everyone made plans to continue the friendships after the Conference. Some mothers have successfully carried out their plans by having lunch together periodically; others have found it difficult to find the free time to meet together socially, but have continued warm relationships within center activities. They also seem to feel more comfortable with the staff and some have shown renewed interest in working with and for the Agency. In three of the centers, the social workers felt that the information on cerebral palsy which was provided at the Conference helped in the parent's understanding of their childrens' disabilities. In one center, the social worker felt that the parents had already become familiar with cerebral palsy in other contacts with the Agency. Every social worker reported that parents seemed somewhat more cooperative with the staff after the Conference, especially in requesting conferences with the teachers and in attempting to continue discussion groups similar to the ones at the Conference. They have become more aware of agency services and more willing to seek them out, although all centers have tried to create such an awareness as a part of the ongoing programs.

Another way in which the effectiveness of the Conference was evaluated to ask people from the professional community outside the Agency to submit opinions of what they had seen at the Conference. Several of those who received letters requesting opinions sent back their comments. All were impressed by the "vivacious" participation of the parents and the warmth of interaction between staff and families. One of the experts felt that this week of intensive counseling was perhaps one of the best vehicles for involving the family unit in the education of the handicapped. As with the parents, all were especially pleased with the discussion groups and felt that they were the highlight of the Conference.

The four kinds of data we collected were invaluable sources of ideas for planning, both of future conferences and of parent participation in the day to day activities of the agency. We have found that such data can help us in improving our services and others in planning similar services.

IV. Statistics AUGUST 29 – SEPTEMBER 2, 1971

TOTAL NUMBER OF FAMILIES ATTENDED		38
	# of mothers	37
	# of fathers	23
		60
TOTAL NUMBER OF CHILDREN		105
	# of handicapped clients	38
	# of siblings	67
		105
OTHER RELATIVES:	grandmothers	4
	grandfather	1
		5

TOTAL NUMBER OF FAMILY MEMBERS	170
NUMBER OF SPANISH SPEAKING FAMILIES	9 (14 adults)

BREAKDOWN OF FAMILIES BY BOROUGH

Manhattan – 7
Bronx –16
Brooklyn – 6
Staten Island – 9

Manhattan (27)

# of Families – 7
# of Handicapped Clients – 7
# of Mothers – 7
# of Fathers – 2
of Siblings – 8
of Grandparents – 3

Brooklyn (29)

# of Families – 6
# of Handicapped Clients – 6
# of Mothers – 6
# of Fathers – 4
# of Siblings – 13

TOTAL # OF CLIENTS – 38
TOTAL # OF MOTHERS – 37
TOTAL # OF FATHERS – 23
TOTAL # OF SIBLINGS – 67
TOTAL # OF GRANDPARENTS – 5
170

V. Recommendations

It was recommended at a post conference meeting of participating staff members that week end conferences similar to the Summer Family Conference should be offered to all families of pre-school children entering a program of this agency.

It was recommended that the number of participating families should be limited to not more than 25 families at any one time. Staff members found that the actual number of persons at the second year's conference was too large for the close personal contact established at the first year's conference.

Appendix No. 1

EXCERPT FROM TAPED INTERVIEW

Interviewer:
How old is your child?

Father:
Three. She was three in March.

Interviewer:
How handicapped is she?

Father:
On the right side. We really don't know too much because the doctors don't tell you anything.

Interviewer:
What do you mean?

Father:
Well, when we go from doctor to doctor, they tell you they don't know how bad she is. I really don't get any satisfaction, at least from the doctors.

Interviewer:
Have you gone to a Cerebral Palsy Clinic?

Father:
Yes. They had one session where we live. They had three doctors come in the hospital but as far at that goes, there is no clinic for cerebral palsy children.

Interviewer:
Were they more helpful than doctors have been in the past as far as imparting information to you?

Father:
Well, I don't know. It seemed like one didn't agree with the other about her condition. It was sort of confusing. And you don't know who to listen to. . . .whose word to take.

Interviewer:
What kind of medical treatment had your child gotten in the past? Was it a matter of going from doctor to doctor?

Father:
Well, we were going. . . . When we first found out she had cerebral palsy was when she wouldn't crawl. The right side — her leg was stiff and we took her to the pediatrician and he didn't know anything about it except that he sent us to another doctor and then they sent us to an orthopedic surgeon. Then the doctors told us she had cerebral palsy and that was the end of it. We didn't know where to go from there or who to go to so we went home and about three or four weeks later, a woman came by from the Elks Club. She told my wife what to do for the child and then about six months later they opened the UCP pre-school in our borough.

Appendix No. 2

United Cerebral Palsy Summer Parent Conference Sunday, August 29—Thursday, September 2,1971

SUNDAY
AUGUST 30

1:00 P.M. – Staff Arrival

2:00 – Buses leave Bronx, Brooklyn, Manhattan & Staten Island

4:00 – Arrive at Monmouth College
Assignment of rooms by staff & students from college

4:15-5:15 – Tour of campus (individually for each family with students and staff members)

5:30 – Dinner – Welcome by Mr. Leslie D. Park – Dining Hall
General meeting of parents and children
Go over weekly schedule
Introduce children's group leaders – Mr. Park
Introduce major staff
Question period
– Exhibits at Woodrow Wilson Hall
Self-halp devices assembled by Mrs. Lois Ratalsky
Literature assembled by Mr. Edward Kilbane
Films of children in program
– Children in their own program

7:30 – Coffee hour for all adults with Board of Directors at Woodrow Wilson Hall

9:00 – Recreation facilities available
Film
Pool

MONDAY
AUGUST 31
Staff Meeting & Breakfast – Dining Hall

8:00 A.M. Family Breakfast – Dining Hall

8:30 Adult Meeting:

9:30 - Adult Meeting: *Demonstration of Medical Evaluation)* at Woodrow Wilson Hall
– Children's Program (see separate schedule)

12:00 Noon – Luncheon - (Children under supervision of camp staff) Dining Hall

1:30 P.M. – Small Group Meetings: *"What is Your Problem, Who to See?"* (See page 6)
– Childrens Program (see separate schedule)

3:30 – Recreation Period: Family style - pool, hikes, beach, etc. Life guards on duty: 2:00 – 4:00 Parents responsible for their children Staff Off Duty

5:30 – Dinner – Families will eat together – Dining Hall

7:30-11:00 – Recreation:
Pool
Film – Title to be announced
Coffee hour each evening, exact time to be announced daily

Mental Health Staff Available for Construction and Discussion

TUESDAY
SEPTEMBER 1

8:00 A.M. – Staff Meeting & Breakfast

8:30 – Family Breakfast

9:30 – Adult Meeting: *Learning Problems of Children With Cerebral Palsy*
Mrs. Marilyn Orgel, Director Brooklyn Center

11:00 – Woodrow Wilson Hall
– Children's Program (see separate schedule)

12:00 Noon – Luncheon

1:30 P.M. – Small Group Meetings (see page 6)
– Children's Program (see separate schedule)

3:30 – Recreation Period

5:30 – Dinner: Cook-out with games, food provided by Monmouth College

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8·00-9:00 – Meeting with brothers and sisters led by Mr Robert Schonhorn,
Mrs. Dorothy Nelson, Mr Mark Weiler and group leaders.
No sitters for older children until 9 pm

9.00-11:00 – Recreation:
Pool
Film – Title to be announced
Coffee hour

Mental Health Staff Available for Consultation and Discussion

WEDNESDAY
SEPTEMBER 2

8 00 A M. – Staff Meeting & Breakfast

8:30 – Family Breakfast

9·30 – Adult Meeting: *Demonstration of Home Management*

to Mrs. Lois Rafalsky and Mr. Robert Bartlett demonstration of devices, techniques for lifting and carrying Woodrow Wilson Hall

11·00 – Children's Program (see separate schedule)

12:00 Noon – Luncheon

1:30 P.M. Small Group Meetings (see page 6)
– Children's program (see separate schedule)

3:30 – Recreation Period

5:30 – Dinner

7:00-8:00 – Parents Only (optional) *Brothers and Sisters – How Do They Feel? Mr Robert Schonhorn – Woodrow Wilson Hall*

8·30 – Recreation: *Talent Show* for Parents & Children with Mr. Baron Keith Stewart, writer, lyricist & singer Coffee Hour

Mental Health Staff Available for Consultation and Discussion

THURSDAY
SEPTEMBER 3

8:00 A.M. – Breakfast for everyone

9.30 – Adult Meeting. *Understanding Lifelong Planning For and With the Cerebral Palsied, led by Mr. Leslie D. Park*
– Slides of Adult Program
– Children's Program (see separate schedule)

11:00 – Packing

12:00 Noon – Luncheon

1:00 P.M. – Conference Evaluation: Questions to be answered by individual families to individual staff members

2:00 – Buses leave for return trip.

SMALL GROUP MEETINGS

BROOKLYN Meeting with Mental Health Team
Daily at 1:30 pm
A Psychologist
A Social Worker
A Teacher

MANHATTAN & BRONX Meeting with Mental Health Team
Daily at 1:30 pm
A Pyschologist
A Social Worker
A Teacher

STATEN ISLAND Meeting with Mental Health Team
Daily at 1:30 pm
A Psychologist
A Social Worker
A Teacher

Appendix No. 3

CHILDREN'S SCHEDULE

SUNDAY – Same as Parents

MONDAY – 8:30 – Breakfast with family

9:30 – Meeting Unit leaders
Pre-schoolers – Match colored name tags to balloons on trees. (In case of rain – meet in the dormitory lobbies).
School Children – At the picnic tables.
(In case of rain meet at the Student Union)
Music, Dramatics, Crafts, Games

11:30 – Pre-schoolers – Clean up at the Dining Hall for LUNCH
School Children – return to dorms to clean up for LUNCH and put on swim suits

12:00 – All Children – LUNCH with leaders in the Dining Hall

12:45 – Pre-Schoolers – In the Student Union
Nap time, movies, stories
School Children – In Edison Hall – Room E-1
Movies, Song Fest

1:45 – Pre-Schoolers – In Front of Student Union
(In case of Rain meet in Dorm lobbies and Student Union).
Wading, and out-door activities
School Children – In the Pool Area
(In case of rain use the Gym).
Boys: 2:00 – 3:00 – Swimming
3:00 – 4:00 – Sports or Hiking
Girls: 2:00 – 3:00 – Sports or Hiking
3:00 – 4:00 – Swimming

4:00 – Parents pick up their children

5:30 – DINNER with family

7:30 – Babies Sleep (Baby sitter on duty on all floors)
3-7 Year olds – Dormitory lobbies – Bedtime Stories
8-12 year olds – Wilson Hall – Talk Session
13-19 year olds – Wilson Hall – Talk Session

9:00 – 3-7 year olds – Sleep (Baby sitters on duty on all floors)
8 and UP (At the discretion of parents)
Edison Hall – Movies

11:00 – BEDTIME

TUESDAY – Same as Monday, except Dinner will be a COOK-OUT at 6:30 P.M.

WEDNESDAY – Same as Monday, except evening program
No Talk Session tonight

7:00 – Rehearse for show

8:00 – TALENT SHOW

THURSDAY – Same as Monday until noon

12:00 – LUNCH with families

1:30 – Depart for home.

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Appendix No. 4

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UNITED CEREBRAL PALSY OF NEW YORK CITY, INC. 339 EAST 44th ST. NEW YORK, N.Y. 10017 (212) MO 1-0300

NATIONAL OFFICERS
LEONARD H GOLDENSON
Chairman of the Board
JACK HAUSMAN
PALMER TURNHEIM
Vice Chairmen of the Board
GEORGE SCHWEIZER JR ESQ
President
WARREN F BEER
Exec Vice President

OFFICERS
JACK HAUSMAN
Honorary Chairman of the Board
ROBERT I ROGIN
Chairman of the Board
LEO HAUSMAN
President
CHARLES E McCARTHY
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Secretary

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SIDNEY CARTER, M D
MRS THOMAS L J CORCORAN
HARRY J DELANEY
ERNEST FLEISCHER
NORMAN FOX
MRS JACK GODDARD
MRS JACK HAUSMAN
MARTIN HAUSMAN
MRS CHARLES D HERBERT
MRS WILLIAM C LANGLEY
MISS IDA LEVINE
ALAN LICHTENBERG
SAMUEL R MILLER
MRS ALAN MOSS
MRS LOUIS J ROBBINS
[illegible]NCES C ROONEY JR
MARTIN RUBENSTEIN
MRS PAUL N SAULT
LEON R SPEAR
MRS HAROLD STORCH
MILTON UNGER
[illegible]DERICK D WILKINSON
MRS. ELLIS WINER

MRS MORTON I DAVIDSON
President, Women's Division

PROFESSIONAL ADVISORY COUNCIL
SIDNEY CARTER, M D
Chairman
DONA[illegible] CONWELL, M D
LEONARD DILLER, PH D
S[illegible] G DIMICHAEL, PH D
[illegible] GOLDSTEIN, PH D
DA[illegible]D HARRIS M D
STANLEY S LAMM M D
RICHARD M LUBELL
[illegible]ARTIN E [illegible] Ed D
MISS [illegible] McGUIRE
MISS [illegible] MARTIN
MISS [illegible] MOSHER
MISS [illegible] PINNER
LAWRENCE B [illegible], M D

[illegible] D PARK
Executive Director
NORA [illegible] KIMBALL
Director of Fund Raising and Public Relations

April 20, 1970

Summer will soon be upon us and United Cerebral Palsy of New York City, Inc., cordially invite you and your children to spend five of those hot days as our guests at Monmouth College in Red Bank, New Jersey, from August 30, through September 3, 1970.

During these five days special programs of a recreational and educational nature will be presented in the hope of making your stay with us as enjoyable and profitable as possible. During your stay, you will not only have an enjoyable vacation, but will be able to spend some time in meetings with our staff. We hope we can discuss the problems of raising a handicapped child and how to plan for his future.

Each family attending will be provided with a spacious family unit, consisting of bedrooms, a living room, toilets and showers, a snack kitchen with a refrigerator, and a laundry room. All meals will be provided in a central dining hall.

Your children, both handicapped and non-handicapped, will be able to spend several hours each day with our leaders and counselors in day camp activities suitable for their age and interests.

This summer program is provided free of charge. Transportation, if necessary, will also be provided. Fathers who cannot get away from work during this time can stay at the College for the evening programs and go to their jobs during the day.

In the hope that you can spend this time with us, we are enclosing a form for you to complete, together with a return stamped, addressed envelope. Please return this form by May 4, 1970. If you have any questions, please do not hesitate to call me at 661-0900.

We look forward to seeing you at the pool or in the dining hall at Monmouth College.

Sincerely yours,

Mrs. Berta Rafael
Program Director
BR/dm

UCP

Appendix No. 4a

UNITED CEREBRAL PALSY OF NEW YORK CITY, INC.
460 West 42nd Street, New York, N.Y. 10036

FAMILY VACATION ENROLLMENT FORM

The following members of my family will go to Monmouth College at Red Bank, N.J. Family Summer Camp from August 30 to September 3 1970 and will bring:

NAME of mother or guardian ____________

NAME of handicapped child ____________

NAME of other family members ____________

Father ____________

Sister: Name ____________ Age ______

Brothers: Name ____________ Age ______

Other: Name ____________

Relationship ____________

Age ____________

Signature of applicant ____________

Address: ____________

Phone: ____________

Center in which child is enrolled:

Staten Island ☐

Manhattan (in Carver Hall) ☐

Brooklyn ☐

Bronx ☐

Appendix No. 5

UNITED CEREBRAL PALSY OF NEW YORK CITY, INC.
460 West 42nd Street, New York, N.Y. 10036

June 1, 1970

Dear

At the end of April you received a letter with an invitation for a 5 day summer holiday for you and your family at Monmouth College, New Jersey.

We are still waiting for your reply and would like to hear from you soon.

We are enclosing a new application form and a self-addressed envelope.

Please reply as soon as possible. If you have any problem contact me at 868-0250.

Yours truly,

Berta Rafael
Program Director

BR:mh
enclosure

UCP

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Appendix No. 6

UNITED CEREBRAL PALSY OF NEW YORK CITY, INC.
460 West 42nd Street, New York N.Y. 10036

June 11, 1970

Mr. and Mrs.

Dear Mr. and Mrs.

We are very pleased that you and your family can join us for the family vacation on August 30th through September 3rd.

We shall let you have details closer to that date and shall set up a meeting with you in July for that purpose.

Sincerely yours,

Berta Rafael
Program Director

BR:mh

Appendix No. 7

UNITED CEREBRAL PALSY OF NEW YORK CITY, INC.
460 West 42nd Street, New York, N.Y. 10036

July 21, 1970

Mr. and Mrs.

Dear Mr. and Mrs.

A meeting concerning your stay at Monmouth College will be held on Tuesday, July 28, 11:00 am at the UNITED CEREBRAL PALSY CENTER, 297 Bard Avenue, Staten Island. Questions you have about the Monmouth College Summer Holiday will be answered at this time. Please make sure to be there. If transportation is needed contact Mrs. Hanshaft at 981-0483.

Sincerely,

Berta Rafael
Program Director

BR:mh

UCP

Appendix No. 8

UNITED CEREBRAL PALSY OF NEW YORK CITY, INC.
339 East 44th Street, New York, N.Y. 10017

August 14, 1970

Dear ________________ :

Just in case you were not at the parent meeting and to remind you, we are giving you more detailed information about the UNITED CEREBRAL PALSY vacation camp at Monmouth College. We are writing to you in order to share with you what we discussed at the meeting.

1.) Please bring wheelchair, baby carriage, stroller, playpen, bed rails or any other special equipment used regularly by one of your children.

2.) Dress will be casual. Children should bring playclothes. Bring something for rainy weather and for cool days also. Washer and dryer are available in each dormitory building.

3.) If you need any special clothing like swimsuits and are reluctant to buy these for the four days, contact us and we shall try to help. Bring swimsuits and towels for the beach.

4.) Three meals will be served daily: breakfast, lunch and dinner. Coffee or milk and cookies will be served later in the evening for adults and older children.

5.) You will live in a small unit with bedrooms, toilets and lounge.

6.) You will be picked up, where your child is usually picked up, between 1:30 and 2:00 pm on Sunday, August 30th so please be ready at 1:30 with your luggage for the trop to Monmouth College. You will return to your home Thursday, September 3rd around 3 - 4 pm.

7. If your children like to sleep with or are attached to a special toy or blanket, bring it along so that they are comfortable in the new bed.

8.) If any member of your family plays a musical instrument please bring it along.

9.) Your children will be in day camp, on the grounds, run by staff members of UNITED CEREBRAL PALSY from 9:30 - 3:30 daily. Then you have them until 7:30 pm. There will be sitters in the evening and activities for older children.

A program telling about the educational and re reational events will be given to you on arrival at Monmouth.

If you have any questions, etc. call 661-0900 X 812 and we will be glad to answer them.

UCP

Appendix No. 9

UNITED CEREBRAL PALSY OF NEW YORK CITY, INC.
330 East 44th Street New York, N.Y. 10017

MEMORANDUM

August 3, 1970

TO: Board of Directors
Professional Advisory Council
Early Education Advisory Committee
Others

FROM: Leslie D. Park, Executive Director

RE: SUMMER FAMILY CONFERENCE, MONMOUTH COLLEGE, WEST LONG BRANCH, N.J.
RECEPTION AND SOCIAL HOUR, SUNDAY, AUGUST 30, 1970, WOODROW WILSON HALL, 7:30 P.M.

One of our most exciting enterprises related to family counseling and parent education will be held at Monmouth College, West Long Branch, N.J., (a comfortable hour's drive from New York City) this summer from Sunday, August 30 through September 3, 1970.

More than 30 families, representing over 130 mothers, fathers, sisters and brothers of handicapped children, will be attending this conference as a part of the Early Education Project being carried on by our agency. In addition, more than 45 members of our staff will be in attendance for the four days and will be working with the parents and children in an educational program which we hope will provide a useful and new experience for all concerned. The objective is to see if we can provide parents with a concentrated period of education concerning what they are facing with a young handicapped child in the family and to help them plan for the future. Much time and thought has gone into the program and it promises to be an exciting experience for all of us.

You and your husband or wife are cordially invited to join us on Sunday evening, August 30th at 7:30 P.M., in Woodrow Wilson Hall, Monmouth College, for a reception for the parents and staff members who will be participating in this conference. Coffee, punch and light refreshments will be served and we will all have an opportunity to see the makeup of the conference participants.

Many of the parents who will be attending will have had very limited experiences of this sort. Your presence is both to help them feel more comfortable, as well as to get a personal view of this program.

I sincerely hope you will be able to join us for this evening. A return card is enclosed for your convenience. Also enclosed, is a map which you may use to help you find Monmouth College.

LDP:bm
Encl.

UCP

Appendix No. 10

UNITED CEREBRAL PALSY OF NEW YORK CITY, INC.
339 East 44th Street, New York, N.Y. 10017

UNITED CEREBRAL PALSY SUMMER PARENT CONFERENCE

GUIDE TO INTERVIEWERS

1. See each parent separately. Solicit names and ages of other children and fill in blanks.
2. Please put as much information as possible into mother's or father's *own words.*
3. Comments from you go into box.
4. Where there is a line: NO ________________ YES, let parent make own mark.

NAME OF CHILD IN PROGRAM:

____

AGE OF CHILD IN PROGRAM: __________

NAME OF PARENT OR GUARDIAN·

____

How many years of schooling? ________________

What job do you have (mother or housewife considered as a job)? ________________

NAMES OF OTHER CHILDREN HERE WITH YOU: AGE

______________________________ ____

______________________________ ____

______________________________ ____

______________________________ ____

OTHER CHILDREN AT HOME: (Names & Ages)

______________________________ ____

______________________________ ____

______________________________ ____

______________________________ ____

5. Wherever possible try to solicit examples for replies (items marked as a, b, c).
6. Where reply is unclear probe by saying: "Tell me more about it", "Can you explain further"?, "Try and give me an example."
7. Try not to pose "leading question(s).
8. Accept parents refusal to answer question(s).
9. Please rate the following at the end of interview:
   Was parent cooperative?
   NO ________________ YES ________________
   Did parents understand questions?
   NO ________________ YES ________________

COMMENTS BY INTERVIEWER

UCP

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DID YOU LIKE THIS VACATION?

Check:

1. ☐ YES – WITHOUT ANY DOUBT OR RESERVATION
2. ☐ YES – BUT I AM NOT SURE ABOUT SOME THINGS.
3. ☐ NO – THERE WAS A LOT I DID NOT LIKE.
4. ☐ NO – NOT AT ALL.

IF ANSWER CHECKED IS 1, 2, or 3:

1. WHAT DID YOU LIKE THE MOST?:
   a. ______
   b. ______
   c. ______
2. WHAT DID YOU LIKE THE LEAST?:
   a. ______
   b. ______
   c. ______

DID YOU LIKE THE SLEEPING ARRANGEMENTS?

NO ______ YES

1. WHAT DID YOU LIKE?
   a. ______
   b. ______
   c. ______
2. WHAT DID YOU NOT LIKE?
   a. ______
   b. ______
   c. ______

(Try to get three answers for items 1 and 2)

DID YOU LIKE THE FOOD?:

NO ______ YES

1. WHAT DID YOU LIKE THE MOST?
   a. ______
   b. ______
   c. ______
2. WHAT DID YOU LIKE THE LEAST?:
   a. ______
   b. ______
   c. ______

DID YOU LIKE THE ENTERTAINMENT?:

NO YES

1. WHAT DID YOU LIKE THE MOST?:
   a. ______
   b. ______
   c. ______

COMMENTS BY INTERVIEWER

2 WHAT DID YOU LIKE THE LEAST?:
a. ____________________
b ____________________
c ____________________

DID YOU LIKE THE FREE TIME ARRANGEMENTS?
NO ____________________ YES
DID YOU HAVE ENOUGH TIME TO DO WHAT YOU LIKED?
NO ____________________ YES
DID YOU HAVE TOO MUCH UNORGANIZED TIME?
NO ____________________ YES
DID YOU LIKE THE DEMONSTRATIONS IN THE MORNING?
1. MEDICAL EVALUATION
NO ____________________ YES
2. EDUCATION
NO ____________________ YES
3. HOME MANAGEMENT
NO ____________________ YES
4. LIFELONG PLANNING
NO ____________________ YES
COULD YOU TELL ME THE ORDER IN WHICH YOU LIKED THEM AND WHY?:
____
____
____
____

WHY DID YOU LIKE THEM?

WHY DID YOU NOT LIKE THEM? (As appropriate from previous answer)

WERE YOU SATISFIED WITH THE CHILDREN'S ACTIVITIES?
NO ____________________ YES
1. WHAT DID YOU LIKE THE MOST?
2. WHAT DID YOU LIKE THE LEAST?
DID ____________ ENJOY THE SUMMER FAMILY
(handicapped child)
VACATION?
NO ____________________ YES
DID ____________________ ENJOY THE
(names of other children)
VACATION?
NO ____________________ YES

COMMENTS BY INTERVIEWER

UCP

DID YOU TALK TO?:
Name of Psychologist ____________________
Name of Social Worker ____________________

DID YOU LIKE THE MEETINGS IN THE AFTERNOON?
NO ____________________ YES

1. WHAT DID YOU LIKE THE MOST?
   a. ____________________
   b. ____________________
   c. ____________________
2. WHAT DID YOU LIKE THE LEAST?
   a. ____________________
   b. ____________________
   c. ____________________

DID THE VACATION HELP YOU IN ANY WAY?
NO ____________________ YES
DESCRIBE HOW: (Try to elicit reasons)

DID __________ BEHAVE AS HE/SHE DOES AT HOME?
(handicapped child)
NO ____________________ YES
DID __________ BEHAVE AS HE/SHE DOES AT HOME?
(names of other children)
NO ____________________ YES
HOW WAS __________ THE SAME?
(handicapped child)
HOW WAS __________ DIFFERENT?
(handicapped child)
HOW WERE __________ THE SAME?
(names of other children)
HOW WERE __________ DIFFERENT?
(names of other children)
IF DIFFERENT, WHY DO YOU THINK THIS HAPPENED?

COMMENTS BY INTERVIEWER

DID KNOWING OTHER FAMILIES WITH SIMILAR PROBLEMS CHANGE HOW YOU FEEL ABOUT YOUR CHILD?

NO ______________________ YES

WHY DID YOU PLACE YOUR MARK WHERE YOU DID?

NAME TWO FAMILIES WHO YOU THINK ARE DOING A GOOD JOB.

1. ______________________

2. ______________________

WHY OR HOW?:

IF WE REPEATED THE SUMMER FAMILY VACATION NEXT YEAR

(a) WHAT WOULD CHANGE? (b) WHAT WOULD YOU KEEP?

1. ACCOMMODATIONS
2. FOOD
2. PROGRAM
4. CHILDREN'S PROGRAM

COMMENT:

COMMENTS BY INTERVIEWER

____

SIGNATURE OF INTERVIEWER

Appendix No. 11

QUESTIONNAIRE

I. [illegible]:

A. What kind of things are you interested in learning about your child?
  1. Medical condition
  2. Causes of medical condition
  3. Treatment of medical condition
  4. Prognosis (explain term as needed)
  5. Others:

B. Ways of living with the problem:
  1. Self-help: feeding
     walking
     toileting
     dressing
     Through special devices
     Through special training
  2. Schooling and future placement

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3. Ways of running a household with a handicapped child in it.
4. Ways of dealing with behavior problems.
5. Ways of dealing with brothers and sisters, relatives, neighbors.

WHICH ARE THE THREE MOST IMPORTANT OF THE ABOVE?

QUESTIONNAIRE

II. POST:

A. Which of the topics listed below would you like to discuss further during the school year?
   1. Medical condition
   2. Causes of medical condition
   3. Treatment of medical condition
   4. Prognosis (explain term as needed)
   5. Others:

B. Ways of living with the problem:
   1. Self-help: feeding
      walking
      toileting
      dressing
      Through special devices
      Through special training
   2. Schooling and future placement
   3. Ways of running a household with a handicapped child in it.
   4. Ways of dealing with behavior problems.
   5. Ways of dealing with brothers, and sisters, relatives, neighbors.

WHICH ARE THE THREE MOST IMPORTANT OF THE ABOVE?

Appendix No. 12

Interviewer: When you got the invitation Mrs. H and you did not know what this place looked like . . .

Mother: I sure didn't. But when I did arrive here Sunday and I saw all the accommodations and all, I said this is really something. This is really beautiful. It's like living in a hotel or motel. And the cribs. The baby liked it in his crib. Sleeps good—I hope. Poor kid is not used to it yet and that's what it is. And my kids. No sooner than they hit the bed from playing all day long, they're knocked out. They said – Joan, my daughter Joan, she is the one who had brought up the subject. She said, "Mama I would love to come to this college. This is a beautiful college." I said, you learn hard enough and study and all, you can come to this college. I said, well that's up to you. All I want from you is just to finish high school. Do, that then you can do what you want to do after that. But my daughter, Joan, if she keeps it up like she is now and she wants to go to college, maybe she'll make it.

Interviewer: Great!

Mother: I hope she does make it. And A. said. Well, he's young yet, he really don't know too much about it, he said "I like it Mommy. It's beautiful Mommy." I said, "It is baby." But, the first night he wanted to go back home. I said, "Why?" And he said, "Too many trees out here."

Interviewer: That's funny. Tell me, Mrs. H., what would you do different other than what we have done? How would you improve what we've done?

Mother: To tell you the truth, I could not improve it no more than you have done. To me everything was arranged nicely and is beautiful and is set up nice for the kids and for the adults.

Interviewer: I noticed you are very friendly and talk with a lot of the other women.

Mother: I do. They like it here. They really like it here. They said—how do you say—you call this a vacation. This is really a vacation.

They say it's beautiful for one thing and the kids enjoy themselves. All of the mothers feel like I feel too. We got the kids out of our hair for a while. That's the most important thing.

Interviewer: How about the things that you learned?

Mother: Well, I learned quite a few things, like I said, about how to handle a child.

Interviewer: What made you accept the invitation in the beginning?

Mother: Well, I'll tell you. It's because I said it must be interesting for my son. It must be a lot to learn about him and what I could do for him or more than what I'm doing for him now. And I figure this way, well, you never learn too much. There is always something new to learn about a child who has cerebral palsy. And then I found out there is a lot to learn from the meetings and all. There is a lot to learn about what you can do for your child, how to make him comfortable, how to make him happy, about his dislikes, likes and so on.

Interviewer: How do your other children like it here?

Mother: My kids love it here. My kids don't want to go home.

Interviewer: Your oldest daughter is 14 and she is the one with the heart condition?

Mother: Right, right. So really, I have more than one child sick, I have two kids sick.

Interviewer: That's true. It's hard.

Mother: I've got my share. I have my share of problems, I got my share of sickness and I got my share of doctors and all.

Interviewer: Well, one of the things that we tried to do was to make things easier for you so that you could take it easy.

Mother: You all have. It has helped me out a lot, because from 9:30 to 3:30 I could see myself doing a whole lot that I can't do at home. You're relaxing, resting a little bit, listening to the lectures and all and if I have something very important to do, I tell them I can't make it and I do what I have to do and get my kids straightened out and don't have to worry about them at night time. This way I can relax more. I feel 100% better and I feel more rested. Since I had my baby, he is six weeks old, I feel 100% better. I'll tell you the honest truth, when I go home now I can say *I have been somewhere* and I have rested for four days.

Interviewer: That's wonderful. You sound as though you are quite busy right now and I am not going to keep you very long. How have these meetings been different from what you had in school and have you found them more interesting?

Mother: They are more interesting. They are longer but they are more interesting because I have learned a lot more and I have met different people with my same problems that feel the same way that I do. Because a lot of times at home and when I have these meetings once a month, there are so many people involved I never have the chance to talk to someone.

Interviewer: Personally?

Mother: Personally. Right. But this way everyone is really, you know, helping out. Doctors are coming, you know, speaking on different things and a lot of questions are being answered that I don't even have to ask So that part of it is very educational and it makes me feel that we are talking about the parents and things, that I am not by myself with this type of thing. I am not the only one that sometimes feels that everything is against me. And this I really feel better about.

Interviewer: Will you see any of these people again in the city? Will you talk to them? Will you be in touch with them?

Mother: Yes. There are quite a few I did not know before coming here that live in Brooklyn and other places. There is one lady that lives in my unit that I have become very fond of and I'm pretty sure we will keep in touch with each other.

Interviewer: I see. And you think that will be helpful.

Mother: Yes. If no more than just to get on the phone and talk about 10 minutes. And, always this helps me any way.

Interviewer: I think it helps almost any body to have a shoulder to lean on, which I know you don't have. Tell me, if we had another one of these would you come?

Mother: Now that I'm prepared I believe that I would because I know that it isn't one thing.

Appendix No. 13

MEMORANDUM

August 14, 1970

FROM: Mrs. Berta Rafael
Director, Early Education Project

TO: ALL STAFF ATTENDING SUMMER PARENT CONFERENCE,
MONMOUTH COLLEGE, WEST LONG BRANCH, N.J.
SUNDAY, AUGUST 30, to THURSDAY, SEPTEMBER 3, 1970

GENERAL INSTRUCTIONS

1. Reminder: Staff meeting for all attending the Summer Parent Conference, on Wednesday, August 26th, 10 to 12 Noon, Board Room, 2d floor, 339 E. 44th St.
2. Staff members should be at the College by 1 P.M., on Sunday, August 30th, before the families arrive, to settle into their quarters and familiarize themselves with the campus as much as possible.
3. A map showing routes and driving instructions to the College is attached. It is suggested that you allow from 1 1/2 to 2 hrs. traveling time.
4. For those commuting daily to the College, an agency bus will pick up passengers at 339 E. 44th St., daily, except Sunday, August 30th. The exact time will be announced at a later date. Staff members will also return in the evening by bus.
5. Staff members requesting transportation for Sunday, August 30th, will be informed of pickup time.
6. Dress will be casual and should include rainwear.
7. Staff will be served breakfast at 8 A.M., and parents and children will breakfast at 8:30 A.M.
8. Work assignments will be arranged by Division heads, who will advise you of your responsibilities.

If you have any questions, please contact me or Belle Miller.

DIRECTIONS TO MONMOUTH COLLEGE FOR THOSE WHO ARE DRIVING DOWN BY THEMSELVES

Driving out of New York City take the Lincoln or Holland Tunnels to connect with the New Jersey Turnpike South. (The Holland Tunnel and Turnpike has less traffic than the Lincoln Tunnel and Turnpike.) From Staten Island the Goethals Bridge connects with the New Jersey Turnpike.

Get off the New Jersey Turnpike at Exit 10 to connect with the Garden State Parkway, South.#105 Parkway Exit is the best shore route to Long Branch because the road from the Parkway runs right into the Eatontown traffic circle pictured on the enclosed map to Monmouth College.

Tolls will be about $2.00 each trip.

Appendix No. 14

TO PARENTS OF PRE-SCHOOL CHILDREN IN UCP PROGRAMS

UNITED CEREBRAL PALSY OF NEW YORK CITY, INC.
IS PLEASED TO ANNOUNCE ITS
SUMMER FAMILY CONFERENCE
SUNDAY TO THURSDAY
AUGUST 29 TO SEPTEMBER 2, 1971
AT
MONMOUTH COLLEGE
WEST LONG BRANCH, NEW JERSEY

You and your family are cordially invited to be the guests of United Cerebral Palsy at a beautiful college campus located on the New Jersey shore. Meetings and group sessions are planned at which it is hoped we can help each other with the day-to-day problems we face in bringing up a handicapped child. Comfortable sleeping arrangements and deliciously prepared meals have been arranged. Day camp activities will be provided for all children, handicapped and non-handicapped. There will be opportunities for adult social and recreational activities.

If you are interested and would like to know more about the summer family conference from August 29th to September 2nd, please telephone me at the center or return the attached slip below as quickly as possible.

Sincerely Yours,

SOCIAL WORKER

PLEASE FILL OUT AND RETURN

☐ I am interested in knowing more about the Summer Family Conference at Monmouth College, August 29th to September 2, 1971.

____
Signature

UCP

ERIC Full Text Provided by ERIC

Appendix No. 15

PARENT'S QUESTIONNAIRE

SECTION 1

1. Please write your street address and borough in the blank below.
   You do not need to write your name.
   Street Address ___________ Borough ______
2. Sex of your handicapped child in our program.
   Boy ____ Girl ____ (Check one)
3. Birthdate (or age) of the handicapped child. ______
4. List age and sex of other children in your family.

	Age	Sex		Age	Sex
1)	____	____	4)	____	____
2)	____	____	5)	____	____
3)	____	____	6)	____	____

5. Are you the
   father __ mother ___ grandfather __ grandmother ___
   other __ (Check one)
6. If you are working at present, what is your job? (Mother or housewife is considered a job.)

   ____
7. What language is spoken in your home?

SECTION 2

Please answer the following questions to the best of your ability.

DO YOU THINK YOUR CHILD:

1. Has normal intelligence (that is, average or above)? (Check one)
   Yes__Maybe yes ___ I'm not sure__No ___
2. Will he or she be able to attend regular school some day? (Check one)
   Yes__Maybe yes ___ I'm not sure__No ___
3. Will he/she be able to learn to read a newspaper? (Check one)
   Yes__Maybe yes ___ I'm not sure__No ___
4. Will he/she be able to graduate from high school if he/she works hard? (Check one)
   Yes__Maybe yes ___ I'm not sure __ No ___
5. Will he/she be able to attend a college some day if interested and money is available? (Check one)
   Yes__Maybe yes ___ I'm not sure__No ___
6. Will he/she be able to attend a trade or vocational school some day, if interested? (Check one)
   Yes__Maybe yes ___ I'm not sure__No ___
7. Will he/she need to attend a special class for slow learners when he/she becomes of school age? (Check one)
   Yes__Maybe yes ___ I'm not sure__No ___
8. (a) Has he lower than normal intelligence? (Check one)
   Yes__Maybe yes ___ I'm not sure__No ___
   (b) Is he functioning like a: (Check one)
   __ one year old
   __ two year old
   __ three year old
   __ four year old
   __ five year old
   __ six year old
   __ seven year old
   __ eight year old
   (c) If he is slow, do you think he will make up in time for that slowness? (Check one)
   Yes ___ Maybe Yes___ I'm not sure__No ___
   (d) If so, how much will he make up? (Check one)
   All __ About half __ A little _____ None ___
   (e) Do you think your child may require care in an institution some day? (Check one)
   Yes__Maybe Yes ___ I'm not sure__No ___
   (f) If so, why? (Check any that apply)
   __ To help him learn
   __ To make him happier
   __ To help you with his care
9. Will he be able to learn to play the piano or a musical instrument some day if he has the interest? (Check one)
   Yes__Maybe yes ___ I'm not sure__No ___
10. Will he be able to keep up with the other children of his age in:
    (Check any that apply)
    __ Regular play?
    __ In gymnasium?
    __ In competitive sports?
11. Will he be able to join and participate in a regular or special Boy or Girl Scout group if he is interested? (Check one)
    Yes ___ Maybe Yes ___ I'm not sure__No ___
12. As an adult, will he be able to travel alone to distant cities? (check one)
    Yes ___ Maybe Yes ___ I'm not sure __ No ___
13. Will he be able to choose suitable friends? (Check one)
    Yes__Maybe yes ___ I'm not sure__No ___
14. Will he be able to go on social dates when he is in the older teens? (Check one)
    Yes__Maybe yes ___ I'm not sure__No ___

15. Will he be able to manage a family of his own, as an adult? (Check one)
Yes ___ Maybe yes ___ I'm not sure No ___

16. Will he, as an adult, be able to manage his own household? (Check one)
Yes ___ Maybe yes ___ I'm not sure ___ No ___

17. In adulthood, will he be able to do his own meal planning and shopping for food? (Check one)
Yes ___ Maybe yes ___ I'm not sure ___ No ___

18. As an adult, will he be able to manage his own budget? (Check one)
Yes ___ Maybe yes ___ I'm not sure ___ No ___

19. (a) As an adult, will he be able to have a regular paying job and be self-supporting? (Check one)
Yes ___ Maybe yes ___ I'm not sure ___ No ___
(b) If yes, how much will he be able to support himself? (Check one)
___ Partially
___ Fully

20. In adulthood, will he be able to plan for and buy his own clothes? (Check one)
Yes, ___ Maybe Yes ___ I'm not sure ___ No ___

21. Will he, as an adult, be able to obtain a driver's license and drive a car? (Check one)
Yes ___ Maybe yes ___ I'm not sure ___ No ___

22. Will he overcome his muscle handicap so that most people will not notice it when he is of adult age? (Check one)
Yes ___ Maybe yes ___ I'm not sure ___ No ___

23. Will he some day be able to speak well enough to be understood by most persons? (Check one)
Yes ___ Maybe yes ___ I'm not sure ___ No ___

SECTION 3

DOES YOUR CHILD HAVE A PROBLEM IN ANY OF THESE AREAS? (Check any that apply)

1. Walking
___ No problem at all
___ A little problem
Can walk with help of braces, crutches,
___ a walker, another person
___ Cannot walk at all

2. Dressing himself
___ No problem at all
___ A little problem
___ Has a lot of trouble and needs help
___ Cannot dress himself at all

3. Feeding himself
___ No problem at all
___ A little problem
___ Has a lot of trouble and needs help
___ Cannot feed himself at all

4. Toileting himself
___ No problem (is completely toilet trained)
A little problem (has trouble at night, sometimes forgets
___ during the day)
___ Has a lot of trouble, both day and night, but is learning
___ Is not toilet trained

5. Playing with other children
___ Plays well with other children
___ Has a little trouble getting along with other children
___ Cannot get along with other children
___ Never plays with other children

6. Talking
___ No problem at all
___ A little problem
___ Has trouble and needs help
___ Has a lot of trouble

7. Learning
___ No problem at all
___ A little problem
___ Has trouble and needs help
___ Has a lot of trouble

SECTION 4 QUESTIONS ABOUT THE MONMOUTH CONFERENCE

1. List ages and sex of your children who are attending this conference.

	Age	Sex		Age	Sex
1)	___	___	4)	___	___
2)	___	___	5)	___	___
3)	___	___	6)	___	___

2. Who else in your family is here?
1) ___
2) ___
3) ___

3. What did you like the most about the Conference?
1) ___
2) ___
3) ___

4. What did you not like about the Conference?
1) ___
2) ___
3) ___

5. Any suggestions for next year?

6. Any comments?

Appendix No. 16

UCP

UNITED CEREBRAL PALSY OF NEW YORK CITY, INC. 339 EAST 44th ST. NEW YORK, N.Y. 10017 (212) MO 1-0900

NATIONAL OFFICERS
Leonard H Goldenson
Chairman of the Board
Jack Hausman
Palmer Turnheim
Vice Chairmen of the Board
George Schweizer, Jr., Esq
President
Warren F Beer
Exec Vice President

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Martin Hausman
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Mrs William C Langley
Miss Ida Levine
Alan Lichtenberg
Samuel R Miller
Mrs Alan Moss
Mrs Louis J Robbins
Frances C Rooney, Jr
Martin Rubenstein
Mrs Paul N Sault
Leon R. Spear
Mrs Harold Storch
Milton [illegible]
Frederick D Wilkinson
Mrs Ellis Wilner

Mrs Morton I Davidson
President, Women's Division

PROFESSIONAL ADVISORY COUNCIL
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David Harris, M D
Stanley S Lamm, M D.
Richard M Lubell
Martin E McCavitt, Ed D
Miss Rita McGuire
Miss Marion Martin
Miss Florence Mosher
Miss Janet Pinner
Lawrence B Slobody, M D

Leslie D Park
Executive Director
Norman H Kimball
Director, Fund Raising and Public Relations

July 21, 1971

Dear

Some time ago you expressed an interest in attending our Summer Family Conference at Monmouth College from August 29 to September 2, 1971.

We are now asking the parents of the Early Education Project who are planning to go to the Conference to meet with us so that we can tell you about the Conference, the facilities at Monmouth College and answer any questions you have. The meeting will be held on Thursday, July 29th at 10:30 a.m. in the Board Room.

This is a very important meeting and I strongly urge you to make every effort to come. If for any reason you cannot attend this meeting, please call me to let me know.

Please make a note of the date - Thursday, July 29th, 10:30 a.m. at 339 East 44th Street.

Sincerely yours,

Elsie Thompson
Coordinator, Parent Activities

UCP

Appendix No. 17

In preparation for your coming to the Summer Family Conference at Monmouth College, the following are a few things you like to know and a list of items you should bring with you:

1. Bring equipment your child or children uses or will need such as crib, crib sheets, wheelchair, baby carriage, stroller, playpen, bed rails, pampers, baby food, special diet foods or any other special equipment they use regularly. IF YOUR CHILD IS ON MEDICATION, BE SURE TO BRING IT WITH YOU.
2. Dress will be casual; shorts, slacks, sun dresses, play shoes, etc. Bring swimsuits bathing caps, towels for the beach and clothes for cool and rainy weather for the children and yourself. Bring personal toilet articles such as soap, toothbrush, toothpaste, wash cloth, shower cap, medications, etc. Bring a camera—the scenery is beautiful.
3. If your children like to sleep with or are attached to a special toy or blanket, bring it along so that they will be comfortable in the new bed.
4. You and your family will be housed in a small unit consisting of bedrooms, toilets and lounge. You will be expected to make your own beds and keep your area neat. The college will do the general cleaning. There are refrigerators in each dormitory building for storing milk, baby food, etc. Washing machines and dryers are also available in each dorm so bring soap powder for the washing machine.
5. Three meals will be served daily; breakfast, lunch and dinner. Coffee and milk and cookies will be served in the evening for adults and older children.
6. Your children will be in a day camp program, on the campus, run by staff members of United Cerebral Palsy of New York City from 9:30 A.M. to 4:00 P.M. daily. Babysitters will be provided each evening from 7:30 to 11:00. There will be evening activities and entertainment for older children adults.
7. If you or any member of your family plays a musical instrument, bring it along (no pianos, please).
8. Families using United Cerebral Palsy transportation, you will be picked up where your child is usually picked up during the year between 1:30 and 2:00. Please be ready with your luggage to leave for Monmouth promptly at 1:30 on Sunday, August 29th. You will be notified of your pick-up time, the week of August 23rd. The Conference ends on Thursday, September 2nd and the buses are scheduled to leave between 1:30 and 2:00. Driving directions will be given to families providing their own transportation.
9. A detailed program telling you about the educational and recreational events will be given to you on your arrival at Monmouth College.

IF YOU HAVE ANY QUESTIONS ABOUT THE CONFERENCE OR IF YOU FIND THAT YOU WILL NOT BE ABLE TO ATTEND, PLEASE CALL MISS THOMPSON AT 661-0900, EXTENSION 813.

Appendix No. 18

SUMMER FAMILY CONFERENCE
SUNDAY, AUGUST 29–THURSDAY, SEPTEMBER 2, 1971
MONMOUTH COLLEGE, WEST LONG BRANCH, N.J.

SPONSORED
BY

UNITED CEREBRAL PALSY OF NEW YORK CITY, INC.

Mr. Leo Meyer, Assistant Executive Director and Conference Dean
Mrs. Berta Rafael *Director of Early Education*
Mrs. Dorothy Nelson *Director of Counseling and Direct Services*
Miss Joanne Nigro, *Director of Recreation*
Miss Elsie Thompson *Coordinator of Parent Activities*

UCP

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Summer Family Conference
United Cerebral Palsy of New York City, Inc.
Sunday, August 29 — Thursday, September 2, 1971

1:00 P.M.	Staff Arrival Dining Hall — Lunch
2:00	Buses Leave Manhattan, Bronx, Brooklyn and Staten Island
3:00 – 4:00	Families Arrive at Monmouth College and Unpack
5:00 – 5:15	Meeting and Briefing with Parents (Ground Floor Lobby in Each Dorm)
5:30	Dining Hall — Dinner Greetings — Mr. Leslie D. Park, Executive Director United Cerebral Palsy of New York City, Inc. Mr. Paul Zigo, Assistant Director Community Relations, Monmouth College
8:00 – 9:00	"Get Acquainted" Pizza Party (On lawn in front of Student Union or in building depending on weather)
9:00 – 11:00	Thomas A. Edison Hall — Movie "Family Band" (Optional to adults and children age 8 to up at discretion of parents)

Babysitters Will be Available Every Evening From 7:30 – 11:00 P.M.

MONDAY
AUGUST 30

8:00 A.M.	Dining Hall — Staff Breakfast
8:30 – 9:15	Dining Hall — Family Breakfast
9:30 – 4:00	Children's Schedule — See separate schedule
9:30 – 11:00	Thomas A. Edison Hall, E-1 Medical Evaluation Demonstration Dr. Ralph Cobrinik, Associate Medical Director Comprehensive Child Care Program Brookdale Hospital Center, Brooklyn, N.Y.
11:00 – 12:45	Free Time for Parents
12:00 – 12:45	Dining Hall — Lunch for Children and Day Camp Staff
12:45 – 1:15	Dining Hall — Lunch for Parents, Other Staff and Guests
1:30 – 3:00	Woodrow Wilson Hall — Small Group Meetings by Borough Manhattan — Room 102 Bronx — Room 103 Brooklyn — Room 104 Staten Island - Room 106 Spanish Speaking Parents — Room 201
3:00 – 4:00	Free Time for Parents
4:00	Parents Pick Up Children From Day Camp Staff
5:30	Dining Hall — Dinner
7:00 – 8:30	Woodrow Wilson Hall - Group Meetings with Brothers and Sisters Group I — Brothers and Sisters ages 8 – 12 Group II — Brothers and Sisters ages 13 and up
9:00 – 11:00	Thomas A. Edison Hall - Movie "Lillies of the Field"

Social Workers and Psychologists are Available For Consultation During Free Time
Coffee will be Available in Student Union Every Evening
Babysitters will be available from 7:20 – 11:00 P.M.

TUESDAY
AUGUST 31

8:00 A.M.	Dining Hall — Staff Breakfast
8:30 – 9:15	Dining Hall — Family Breakfast
9:30 – 4:00	Children's Program — See separate schedule
9:30 – 11:00	Thomas A. Edison Hall, E-1 Home Management and Adaptive Equipment Demonstration Mr. Robert Bartlett,

UCP

	Associate Professor and Chairman Program In Physical Therapy State University Downstate Medical Center, Brooklyn, N.Y. Mrs. Marion Marx, Physical Therapist Mrs. Jean Held, Physical Therapist United Cerebral Palsy of New York City, Inc.
11:00 – 12:45	Free Time for Parents
12:00 – 12:45	Dining Hall – Lunch for Children and Day Camp Staff
12:45 – 1:15	Dining Hall – Lunch for Parents, Other Staff and Guests
1:30 – 3:00	Woodrow Wilson Hall – Small Group Meetings by Borough Manhattan · Room 102 Bronx – Room 103 Brooklyn – Room 104 Staten Island – Room 106 Spanish Speaking Parents – Room 201
3:00 – 4:00	Free Time for Parents
4:00	Parents Pick Up Children From Day Camp Staff
4:00 – 5:30	Beach or Pool – Optional
6:30	Cook-Out – On Lawn Near Dining Hall
7:30 – 8:45	Woodrow Wilson Hall – Group Meetings with Brothers and Sisters Group I – Brothers and Sisters 8 – 12 Group II – Brothers and Sisters ages 13 and up
9:00 – 11:00	Thomas A. Edison Hall – Movie "Boatnik"

Social Workers and Psychologists are Available For Consultation During Free Time
Coffee will be Available in Student Union Every Evening
Babysitters will be available from 7:30 – 11:00 P.M.

WEDNESDAY
SEPTEMBER 1

8:00 A.M.	Dining Hall – Staff Breakfast
8:30 – 9:15	Dining Hall – Family Breakfast
9:30 – 4:00	Children's Program – See separate schedule
9:30 – 11:00	Thomas A. Edison Hall, E-1 Carry-Over of School Program Into Home Activities Mrs. Berta Rafael, Director of Early Education Mrs. Dorothy Nelson, Director of Counseling and Direct Services Mrs. Mary Budraitis, Speech Therapist, Brooklyn Center Miss Barbara Progebin, Speech Therapist, Manhattan and Bronx Centers Mrs. Shelia Russo, Speech Therapist, Staten Island Center
11:00 – 12:45	Free Time for Parents
12:00 – 12:45	Dining Hall – Lunch for Children and Day Camp Staff
12:45 – 1:15	Dining Hall – Lunch for Parents, Other Staff and Guests
1:30 – 3:00	Woodrow Wilson Hall – Small Group Meetings by Borough Manhattan · Room 102 Bronx – Room 103 Brooklyn – Room 104 Staten Island – Room 106 Spanish Speaking Parents – Room 201
3:00 – 4:00	Free Time for Parents
4:00	Parents Pick Up Children From Day Camp Staff
5:30	Dining Hall – Dinner
8:00 – 10:00	Pollak Auditorium, Woodrow Wilson Hall Talent Show by Children

Social Workers and Psychologists are Available for Consultation During Free Time
Coffee Will be Available in Student Union in the Evening
Babysitters will be Available from 7:30 – 11:00 P.M.

THURSDAY
SEPTEMBER 2

8:00 A.M.	Dining Hall – Breakfast for Families and Staff
9:30 – 12:00	Children's Program – See separate schedule
9:30 – 10:30	Thomas A. Edison Hall, E-1 Services Offered by United Cerebral Palsy of New York City Mr. Leslie D. Park, Executive Director

10:30 – 11:00	Parents Fill Out Questionnaire
11:00 – 12:00	Packing
12:00	Dining Hall – Lunch for Families and Staff
1:30	Departure

SMALL GROUP LEADERS

MANHATTAN:	Mrs. Joan Farkas, *Social Worker*
	Mrs. Berta Rafael, *Director of Early Education*
BRONX:	Mrs. Dorothy Nelson, *Director of Counseling and Direct Services (Psychologist)*
	Mrs. Roza Alexander, *Social Worker Supervisor*
	Miss Mary Bryant, *Social Worker*
BROOKLYN:	Mrs. Ruth Berman, *Social Worker*
	Mrs. Roslyn Eagle, *Psychologist*
STATEN ISLAND:	Mr. Jerry Hanshaft *Social Worker*
	Mrs. Eileen Kadonoff, *Psychologist*
SPANISH:	Mrs. Eleanor Younker, *Director of Social Service*
	Mrs. Cecilia Baldao, *Case Aide*
BROTHERS AND SISTERS:	Miss Peggy Crull, *Psychologist*
	Mr. Peter Deri, *Psychologist*
	Mrs. Dorothy Nelson, *Psychologist*
	Mr. Robert Schonhorn, *Executive Director, United Cerebral Palsy Associations of New York State (Psychologist)*

CHILDREN'S SCHEDULE

SUNDAY – Same as Parents

MONDAY – 8:30 – Breakfast with family

9:30 – Meet Unit leaders

Pre-Schoolers – Match colored name tags to balloons on trees. (In case of rain – meet in the dormitory lobbies).

School Children – At the picnic tables.
(In case of rain meet at the Student Union)

Music, Dramatics, Crafts, Games

11:30 – Pre-schoolers – Clean up at the Dining Hall for LUNCH

School Children – return to dorms to clean up for LUNCH and put on swim suits

12:00 – All Children – LUNCH with leaders in the Dining Hall

12:45 – Pre-Schoolers – In the Student Union
Nap time, movies, stories
School Children – In Edison Hall – Room E-1 Movies, Song Fest

1:45 – Pre-Schoolers – In front of Student Union
(In case of Rain meet in Dorm lobbies and Student Union).
Wading, and out-door activities
School Children – In the Pool Area (In case of rain use the Gym).
Boys: 2:00 – 3:00 – Swimming
3:00 – 4:00 – Sports or Hiking
Girls: 2:00 - 3:00 – Sports or Hiking
3:00 – 4:00 – Swimming

4:00 – Parents pick up their children

5:30 – DINNER with family

7:30 – Babies Sleep (Baby sitter on duty on all floors)
3-7 year olds – Dormitory lobbies – Bedtime Stories
8-12 years old – Wilson Hall – Talk Session
13-19 year old – Wilson Hall – Talk Session

9:00 – 3-7 year olds – Sleep (Baby sitters on duty on all floors)
8 and UP (At the discretion of parents)
Edison Hall – Movies

11:00 – BED TIME

TUESDAY - Same as Monday, except Dinner will be a COOK-OUT at 6:30 P.M.

WEDNESDAY - Same as Monday, except evening program
No Talk Session tonight
7:00 - Rehearse for show
8:00 - TALENT SHOW

THURSDAY Same as Monday until noon
12:00 - LUNCH with families
1:30 - Depart for home

Appendix No. 19

Mr. Leslie D. Park, Executive Director
United Cerebral Palsy of New York City, Inc.
339 East 44th Street
New York, New York 10017

Dear Mr. Park,

Since the first family conference at Monmouth College both Gloria and I have had numerous occasions to appreciate the remarkable quality of dedicated service provided by UCP for the entire family at so many different levels. Paul has been attending school at the Brownsville center during the past year. The devotion of his teachers has brought him to achievements which fill our hearts with hope.

It is difficult to describe the great emotional impact last year's conference had on the entire family. For the first time Gloria and I were really able to see ourselves as part of a larger group with similar problems. Seeing and talking with these other parents was in itself a revelation. The success of these talks and meetings was in no small way dependent upon being made to feel comfortable and relaxed, and free of worrying about the children. Similarly, Paul's sister and brother had the opportunity to see many other handicapped children of all kinds, and to meet their brothers and sisters in a relaxed setting with beautiful surroundings. Where else in the world could such an experience be had?

For us, this year's conference was certainly interesting, there is always something new to learn and the children loved it. On the other hand there is nothing like the first time, and probably one time is enough. Clearly, a number of first-time attendees were as affected by the conference this year as we were last year. Mrs. Rafael's extraordinary sensitivity, organizational ability, and enthusiasm, shone throughout both conferences.

We realize now, more than ever, the many ongoings programs UCP sponsors. As a small token of our appreciation please accept the enclosed contribution of $100 to be used by the organization as you see fit.

Sincerely,

Appendix No. 20

SEP 10 1971

Form—6A

file
Monmouth -1971

The City of New York

DEPARTMENT OF HEALTH
125 WORTH ST., NEW YORK, N. Y. 10013
Telephone: 566—6150
DIVISION OF DAY CARE,
DAY CAMPS AND INSTITUTIO.
BUREAU OF CHILD HEALTH
350 Broadway
New York, N. Y. 10013

September 8, 1971

Mr. Leslie D. Park, Executive Director
United Cerebral Palsy of New York City, Inc.
339 East 44th Street
New York, N. Y. 10017

Dear Mr. Park:

May we express our gratitude for the opportunity of visiting the Summer Family Conference at Monmouth College. The transportation arrangements and the hospitality extended to us contributed to a memorable day.

The skill and enthusiasm of the staff created an atmosphere in which the needs of each of the participants (the children, the program, their siblings and their parents) were met.

The agency is to be commended for its ability to provide this unique service to its families.

Sincerely yours,

Mildred Price
Mildred Price
Ruth Lehr
Ruth Lehr, Consultants
Early Childhood Education
Division of Day Care, Day Camps
and Institutions
Bureau of Child Health

MP:RL/eb

cc: Mrs. Joseph Rothenberg, Vice Pres.
Mrs. Berta Rafael, Dir. Early Educ. Proj.

ERIC
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Appendix No. 21

30X(10/67)

The City of New York
DEPARTMENT OF HEALTH
OFFICE OF ASSISTANT COMMISSIONER
125 WORTH ST., NEW YORK 10013
Telephone: 566-8130

SEP 14 1971

September 10, 1971

Mr. Leslie D. Park
Executive Director
United Cerebral Palsy of
New York, Inc.
339 East 44th Street
New York, N.Y. 10017

Dear Mr. ~~Park~~ Les:

We want to thank you and your staff for the most gracious visit to the Monmouth College Cerebral Palsy Camp. Mrs. Jacobson and I were both very impressed with the general atmosphere and attitude of both the parents and the children. I feel the area of social support and environmental support for these parents is as important as the pure medical aspects, and this has long been a neglected area. It was extremely rewarding to both of us to see the genuine interest and enthusiasm of your staff with these families.

We enjoyed the small portion of Mr. Bartlett's lecture to the parents, and were glad to see him using materials made by one of our therapists.

If there is anything we can do to further this experience for these families and any way that we could be of help, please do not hesitate to call on us. Again we would like to commend you and your staff at United Cerebral Palsy for this excellent step forward.

Sincerely yours,

Donna O'Hare
Donna O'Hare, M.D.
Assistant Commissioner

Jetta H. Jacobson (I)
Jetta H. Jacobson, Coordinator
Special School Programs

UCP

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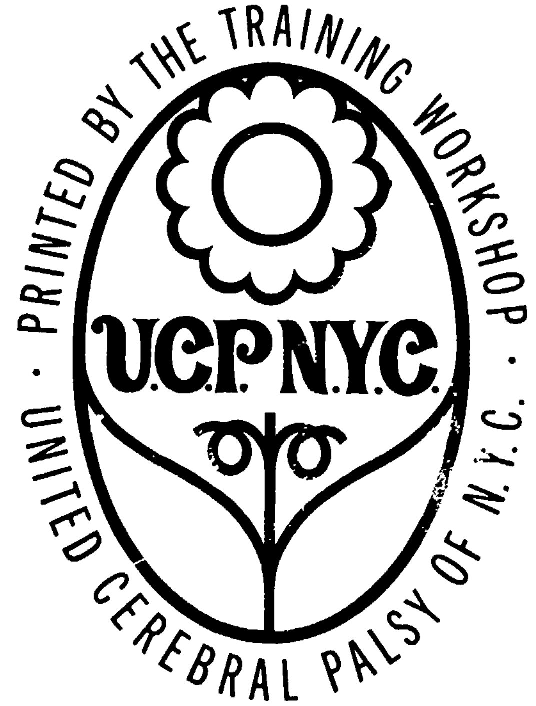

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