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The special children's center for cerebral palsied and multiply handicapped children in a rural area involving a community sponsored multidisciplinary day program is the topic of the presentation by Frances Berko. A rural outpatient program which provided services to children in a six county area previously without sufficient services is discussed. The purposes, structure, and functions of the program are reviewed. This unit of reports is available in microfiche. (WW)



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# SELECTED CONVENTION PAPERS

46th Annual International Convention New York City April 14-20, 1968

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#### EOMEBOUND AND EOSPITALIZED

THE SPECIAL CHILDREN'S CENTER—A RURAL AREA, COMMUNITY SPONSORED MULTIDISCIPLINARY DAY PROGRAM FOR THE CEREBRAL PALSIED AND MULTIPLY HANDICAPPED

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Frances G. Perko

#### Preliminary Considerations

In discussing rural area treatment and training of the cerebral palsied child, there are certain preliminary considerations. By now it must be fairly well recognized that there is a gap between psychological theory in perception and learning and textbook clinical treatment of the cerebral palsied and multiply handicapped child; there is an equally wide difference between what the books tells us to do and what is actually done in today's treatment and training of the child in the clinical and/or special education setting. If we recognize this, then we are prepared to face the reality that certain stock phrases like "treating the whole child" have virtually become meaningless when we speak of actual service to the child today. In describing any program which may be unique or different, a point is reached at which, except for these hackneyed trite phrases, our present vocabulary fails to be descriptive of what can transpire on the clinical level. Recognition of these facts is becoming increasingly widespread among the practitioners, as exemplified by Dr. Ray Barsch's (1967) latest works. He tries to establish a completely new vocabulary to express a relatively old concept within the modern framework.

It should be relatively simple to establish complete programs for the cerebral palsied in the larger urban areas where there are high population concentration of both potential caseloads and qualified professional practitioners in all the related disciplines. However, in the more rural areas which have neither the advantage of attracting trained personnel nor the concentration of caseloads, it becomes a challenge to provide an outpatient service of equal caliber to that which can be available to the child living in the metropolitan areas.

That is the challenge which we in Ithaca faced five years ago. At that point, and for at least some ten years previously, the Ithaca area had an outpatient facility serving cerebral palsied, mentally retarded, and other handicapped children who resided in a six county area. The staff consisted of a medical director who was an orthopedist, an executive director whose background was in a social case work, three therapists in physical, occupational, and speech therapy, a preschool teacher and an aide, a parttime leader for the adult program who was a freshman law student, and three bus drivers. Of the 59 names on the so called active case load, 34 were receiving some service, and information was finally gathered on five or six others. The children came from a six county area of central New York. Aside from the orthopedic evaluation on the physically handicapped children and the social case history, there was little or no information in the files. The therapists and teachers had no special training or experience with the multiply handicapped child. It was a therapeutically oriented clinic, where preschool was an unstructured waiting area for therapy. In fact, the preschool program was referred to as the "playroom." Concepts, such as childhood brain damage, specific learning disabilities,



behavioral changes through operant conditioning, the needs for the structure program learning, perceptual motor deviances, etc. were completely foreign to the staff. Thus we had situations like a child trying to learn to lace a shoe in occupational therapy for three years, or the child drilling the "S" sounds in speech when he could not comprehend as simple a question as "What is your name?"

In other words, we began with a typical rural area facility, sponsored by four United Funds and Community Chests, under the leadership of a voluntary health board of interested, well meaning community leaders, and under the directorship of a capable woman who had neither the professional training nor the clinical experience to evaluate and design programs under modern clinical standards

#### Purpose of Program

This then was the challenge: (a) to structure and gain finance to support a program commensurate with modern clinical practices, (b) to obtain the physical plan suitable to meeting the program needs, (c) to find and train a staff capable of carrying through a program to serve as many children as needed the program, and (d) to enlist the support of the professional and the lay community in support of such a program.

Before all this could become a reality, certain hypotheses had to be established. Essentially, the purpose of the Center is to obtain sufficient language learning improvement in the multiply handicapped child so that he can successfully return to the normal flow of community life. This is to say that, now and for the past five years, in so far as service to children is concerned, the Special Children's Center has disclaimed all pretense of being a day training center. While it is believed that every child, regardless of multiplicity of handicap, severity of retardation, or present level of function, deserves an opportunity to show what gains he can make under an intensive, professionally oriented clinical program, no child is sutained in the program, once it is established beyond a reasonable doubt that he cannot benefit therefrom. Essentially this means that criteria must be established and defined before programing is begun. Then, progress must be reported in accordance with the criteria. To achieve such progress, two approaches must be used concommittently: The environment must be adjusted to meet the needs of the child, while the child is taught to adjust to the environment. In this procedure, there also must be some selectivity on which needs of the child are to be served

This decision making for the Special Children's Center, in view of its basic structure, was relatively simple. Since it was programed for direct treatment of the child who resided within a 40 mile radius from its home base, it seemed obvious that little or nothing could be done by this facility to directly alter the psychological and socioeconomic condition of the home. By the same token, in view of the staffing limitations, any attempts to ameliorate preexisting parental conflicts which cause rejection of the child would at best be fragmentary. For example, finances have never permitted the Center to employ a qualified social worker who could make home visits. Therefore, the premise was established that alteration of the language learning behavior of the multiply handicapped child would have a radiating effect on the child's needs in that as the child demonstrates to the parent his increasing abilities, the parents would become more accepting of the child as an individual member of the family.



#### Structure and Functions of Programs

In programs based on this premise, the concept of "structure" was introduced. The assumption was made that if the multiply handicapped child could learn heterogeneously from free play experience, he did not need to be at the Center. However, free play learning is proceded in normal development by a certain degree of ability in behavioral control, perceptual motor development. attention span, receptive and expressive communication, and adaptive and creative play. These are the major learning deficits of the children within our program. It was therefore decided that, regardless of primary diagnosis, the group experience should concentrate on these learning areas in a strictly controlled environment, so that the trained teacher could be aware not only of what stimuli are being fed into the child, but also how the child is interpreting and acting upon the stimuli. Within this framework, it was hypothesized that no new learning could occur without a certain degree of behavioral control. To achieve sufficient behavioral modification to insure individual learning within the group of eight to ten children, simple operant conditioning was used, in which focus is upon one behavior at a time, and transference to the voiced command is made as rapidly as possible. The ultimate aim of such group programing was established at three goals: minimizing the specific learning disabilities, establishing the abilities at creative play within the free play framework and at the child's individual mental age level, and thus enabling the child to learn in the less structured group situation at that level.

#### Staff Responsibility

On another dimension, there had to be a definition of responsibility among the clinical staff of the various disciplines. In most general terms, the therapies were considered to be individual learning experiences given the child on a one to one basis, while preschool and other classrooms which were later developed taught the child to use in the group situation what was learned in therapy. This meant that most children had to be scheduled for both individual therapy and group learning experience.

# Purposes of Therapies

The therapies themselves were redefined in purpose. Physical therapy was assigned the responsibility for self locomotion. On the premise that no real learning can occur without the ability to sit upright, thus allowing the perception of the environment as it is normally perceived, locomotion was broadened beyond the concept of walking. Rolling chairs were designed so that, whenever possible, the child could sit with his feet on the floor and push himself to where he wanted to go. These chairs were specifically intended for classroom usage and eliminated the use of the wheelchair during the time the child was at the Center. The use of the rolling chair in no way impinged upon the gross motor activity or the use of the floor for certain of the group learning experiences.

Occupational therapy was charged with the responsibility of visual perceptual motor development. Here again, the broadest possible range of activities was assigned to this area of learning. Everything from eye focus and hand eye coordination to abstract learning in reading comprehension and arithmetic problem solving was included in the definition; self care, including feeding and dressing, are considered a part of this visual perceptual continuum. In other words, occupational therapy at the Center is a combination of modern traditional occupational therapy for neurologically impaired children and educational therapy.





Perhaps the greatest deviation from traditional concepts was made in the redefining of speech therapy's responsibilities. To this area was assigned the responsibilities for individual language development and auditory perceptual development. It became a relative rarity for the Center's speech therapists to concern themselves with intelligibility of sound or of speech production. The primary concern here was to develop communicative ability, including vocabulary, phrase and sentence structure, verbal comprehension, and adequate oral language for self expression. While it was felt that sound and speech intelligibility came later in the developmental cycle and could well be sound production improves in this type of child as auditory perception of sound becomes more discriminating (Johnson and Myklebust, 1967; Meecham, Berko and Berko, 1966).

### Overlapping

Naturally, there is a considerable overlap between these modalities. What is more fundamental is that no child is a series of pieces which can be fit together like a jigsaw puzzle to make a whole. With the belief that the overlap cannot be eliminated, each child's program is designed to take maximum advantage of what overlap does occur. It might be said here, parenthetically, that this approach cannot be used without a bright, well motivated, well trained staff, among whom there is a complete absence of friction, tension, and jealousy. In this respect, we at the Center have been extremely fortunate during the past four years; so much so that in periods when there has been a shortage of personnel in one discipline, the staff in the other disciplines have incorporated some of the lacking objectives for the child into their own curriculum Thus, when we are short of speech therapists, as we are now, much of the language development is included in the lesson planning for occupational therapy. This, of course, indicates a strong, continuing inservice training program, so that individuals of one discipline become fully familiar with the techniques used by the other clinicians.

More advantageous to the habilitation of the multiply handicapped child, however, is that the clinicians understand that the overlap is not detrimental or repetitious in the child's overall learning. Each therapist and teacher, by the very fact that he is a human being, differs in his approach to teaching the same concept, even when the same materials are used. This fact, rather than confusing the child as it might be theoretically hypothesized, seems to reinforce conceptual learning and overcome the rigidities and abstract learning deficits. The ongoing, instrastaff communications about the learning performance of each child eliminate whatever temporary confusion may occur.

# Diagnostic Evaluation

In order to achieve this caliber of programing approach, there initially must be a complete initial diagnostic evaluation. This entails a much larger team of diagnostic disciplines than the Center had five years ago. Gradually over the years, consultants in psychology, speech pathology, pediatrics, neurology and psychiatry were added. Today, when a child is first referred to the Center (98 percent of the referrals are made either by the family physician or some recognized agency), records of his past medical diagnostic and habilitative history are obtained. The first visit with his parents is for the purpose of complete case history taking and neuropsychological evaluation. Then the child is scheduled to be seen the same half day by the pediatrician, orthopedist, neurologist and psychiatrist, who, after they see the child and parent separately, confer with each other in the presence of the clinical staff to arrive at a diagnosis and prognosis, and to make recommendations both for

programing and additional evaluations, if necessary, particularly in audiology and opthalmology. Audiometic screening and speech and language assessments are done by the Center's speech therapists who have master's degrees in Speech Pathology; these screenings and assessments are reviewed and strengthened by the consultant in speech pathology two or three times yearly.

#### Transportation

Because of the wide rural area served, transportation often becomes "the tail that wagged the dog." For example, it took a number of years to establish relatively homogeneous groupings on the basis of developmental level because of the routing problems involved in our own transportation system. The Center operates three buses, each originating from a point 30 to 40 miles away from Ithaca. Through the purchase of the larger buses, having each route make two round trips a day, and supplementing this service through public school transportation, this problem has gradually been diminished.

#### <u>Facilities</u>

During Christmas week, 1967, the Special Children's Center moved into its long dreamed of home. At a cost of \$900,000, the Tompkins County Board of Supervisors had approved remodeling of an existing building which literally involved a complete gutting of the interior of the old structure and redesigning of floor plans to meet both the needs of the agencies housed therein and the demands of the governmental departments which support them. In this facility, the Special Children's Center occupies some 9,400 square feet, including classrooms, four speech therapy rooms, examining rooms, occupational and physical therapy departments adequate enough to house three therapists per department, a gross motor room, a workshop for the Special Adults program which is beyond the scope of this paper, and office space.

# Relationship of the Center to the Public School System

After several vain attempts to get a grant from governmental and foundation sources, the local public schools were approached to provide special education for these children at the Special Children's Center. Since the class was designed to serve the older child (five to eight years old) regardless of primary diagnosis, whose academic function was on the kindergarten or first grade level, this special class was called the "classroom for the multihandicapped." Hence began a unique wedding between a public school system and a private agency in the education of children who need to learn in a special way. By mutual agreement the public schools agreed to provide furniture, supplies and the salary of a teacher hired after joint interview by both agencies. The Center was to provide curriculum guidance, supervision of the teacher, and other supervisory services which generally fall to the school principal. The classroom teacher is considered a member of both the Center's staff and the Special Education staff of the local school system, which, since December 1966, is the Board of Cooperative Educational Services of Tompkins-Seneca Counties. These five classrooms function on the same principle as the preschool, with a single exception. Because of certain administrative restrictions pertaining to age span in groupings, there are occasional children who are placed in one group because of their chronological age when their overall level of function is more compatible with another group's curriculum. However, because of the closeness of the cooperation between the public and private agency, these rare misgroupings are usually corrected to the advantage of the child. Perhaps the most unique feature of this programing is the interrelation between the classroom group and individual therapy. Not only is there a





constant flow of children from the classroom to the various therapies, but there is an equally constant flow of communication between the teacher and the therapists, each shedding more information to the other about the child and his language learning needs. It is this dedication of staff which makes for progress; with 20 percent of the children successfully returning to the normal flow of public school placement each year, there is no need to cite other justifications for this program.

Obviously, this evolution to a relatively complete, professionally oriented center for the training and education of multihandicapped children could not have occurred without the support of the professional workers in the community. The education of the pediatricians, school psychologists, clinical psychologists, social workers, welfare and public health personnel, and school officials has reaped many benefits for all the children of our area. Beginning a continuing process, has included systematic staff, physician education, quarterly progress reports, and attendance at the monthly evening staff meetings. While there is still much to be done in this respect, the communication between the pediatricians of the area and the Center has reached the level at to discuss observations and recommendations, even those which may be medical in nature.

Inservice courses have been given to welfare and public health personnel, so that the constant communication between these agencies have become a part of the daily routine.

#### Conclusion

This then is how the challenge is met. It is far from a perfect solution. Not only are there certain handicapped children within our service area who cannot benefit from such a program, such as the autistic child or the very severely retarded child below the chronological age of five, but we do not have the room to accommodate all the children that can be benefited At no time within the past four years have we been without a waiting list in all departments; yet both our average daily attendance and our active caseload as more than tripled during that period. Each of our teachers is responsible for ten to 20 different children in the course of the day's work; while full time therapists teach a minimum of ten, but were frequently 11 or 12 different cases a day. In order to achieve an equal balance between individual and group learning, the therapy schedule is preset according to the prescribed weekly frequency of each therapy; in this manner the teacher has notice when each child will be absent from the group and can plan her curriculum accordingly. Due to perrenial shortages in trained personnel, the use of parttime therapists is frequent; this is feasible only when the therapist can work at the same time of day, two or more days a week, thus allowing the single therapist to see the same child at the prescribed frequency. Because some group learning situations are on a half day basis, it is also possible to employ parttime teachers, but experience has shown that this is not desirable in view of the amount of staff training, supervision, and general communication needed to maintain the established level of service.

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